

Wat nu?

Designing a layered support system for naasten
navigating uncertainty during palliative sedation at home

IDE Master Graduation Project

Graduation project information

Project title:

The needs of naasten during palliative sedation at home in the Netherlands

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IDE Master Graduation Project
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Preface

When I began this graduation project, I was drawn to the topic by curiosity, but I could not yet have anticipated how deeply it would come to matter to me. Throughout the project, I often found myself opening my laptop with renewed energy, writing down ideas at unexpected moments and having conversations with people for whom the subject was not abstract, but deeply personal.

At the same time, this project has never felt like something I carried alone. Therefore, I would like to thank my supervisors, Marieke Sonneveld and Laura Barendregt. Marieke introduced me to this assignment, and her intuition that this topic would fit me turned out to be completely right.

Laura supported me in every little detail. I am very grateful for the guidance I received throughout the process. The many conversations with my supervisors helped me move from broad questions to concrete next steps. After each meeting, I left with clearer direction, renewed confidence and the feeling that my questions had been heard. Their involvement, critical reflections and enthusiasm have played an important role in shaping this project. Because of that, this half year of hard work has also been a period of genuine engagement and meaning.

Before this project, I knew that I wanted to contribute to something meaningful for others. During this project, I felt for the first time that I was able to do that in a concrete way. Working on the experiences of naasten during palliative sedation at home showed me how design can enter a deeply sensitive context, not by trying to solve grief or death, but by making moments of uncertainty, care and farewell more bearable.

Last but certainly not least, I would like to thank all participants who shared their experiences with me. This includes the naasten who spoke about intimate and sometimes painful memories, the healthcare professionals who shared their expertise and reflections, and the participants who contributed to the evaluation sessions. Their openness, honesty and trust shaped this project in many ways, and I am sincerely grateful to everyone who helped this report take shape.

Abstract

Palliative sedation is a medical intervention used in the final phase of life to relieve suffering caused by refractory symptoms. It involves proportionately lowering a patient's level of consciousness. In the Netherlands, palliative sedation increasingly takes place at home, where much of the process unfolds in the presence of *naasten*: partners, relatives, friends and others closely involved with the patient. They may provide practical and emotional support, observe changes in the patient and communicate with healthcare professionals, while facing uncertainty about what to expect, how to interpret what they observe and what is expected of them.

This graduation project explored how *naasten* experience palliative sedation at home in the Dutch context and what support needs emerge during this process. It also examined how these insights could be translated into support before, during and after palliative sedation. The project combined a literature review, semi-structured interviews with seven *naasten* and six healthcare professionals, a hospice visit, co-creation and scenario-based evaluation. Rituals and meaningful moments around dying initially provided a lens for the design process, but the findings redirected the focus towards more fundamental needs concerning understanding, uncertainty and support.

The findings indicate that *naasten* experience palliative sedation at home as an unfolding and partly unpredictable process. Uncertainty may arise before sedation begins, during the waiting period and around the patient's death. *Naasten* may have questions about how the process will unfold, whether the patient is comfortable, how bodily changes should be interpreted, when professional support is needed and what role they are expected to take. At the same time, they may remain present, provide care and seek to create calm, closeness and space for farewell. The infusion

pump and the possibility of administering a bolus provided one example of how uncertainty could become intertwined with responsibility. More broadly, the findings pointed to a need for timely preparation, understandable information, repeated reassurance and clear access to professional guidance throughout the process.

These findings informed the *Wat nu?* portfolio, consisting of death education, the *Wat nu?* booklet, the *Wat nu?* app and a 24/7 support line. Together, the interventions provide complementary support at different moments: early familiarisation before palliative sedation becomes personally relevant, an accessible first orientation when palliative sedation is introduced, more detailed situation-based guidance during the process and direct professional reassurance when self-guided information is insufficient. Rather than prescribing a fixed pathway, the interventions can be accessed and revisited according to timing, preference and need.

The portfolio does not aim to eliminate uncertainty from an inherently unpredictable and emotionally demanding process. Instead, it aims to make uncertainty more manageable through preparation, accessible guidance and human reassurance. The project provides a research-informed design direction for supporting *naasten* before, during and after palliative sedation at home. Further medical validation, organisational development and evaluation in real care settings are required before implementation.

Glossary

Bolus: An additional dose of medication that can be administered through the infusion pump. In some home situations, naasten may be asked or allowed to press the bolus button when the patient appears restless or uncomfortable.

Cheyne-Stokes breathing: An irregular breathing pattern that can occur near the end of life. Breathing may become deeper and faster, then slower, followed by pauses.

Co-creation: A collaborative design method in which participants contribute their experiences, perspectives and ideas.

Continuous palliative sedation: A form of palliative sedation in which the patient's consciousness is continuously lowered until death. In the Dutch context, this may be considered when the patient is expected to die within 14 days and suffers from refractory symptoms.

Delirium: A state of confusion that can occur in the final phase of life. The patient may seem restless, agitated, confused or may perceive things differently from reality.

GP: General practitioner.

Naaste / naasten: The Dutch term 'naasten' refers to people who are closely involved with the patient. This may include partners, children, relatives, friends or other significant others. The singular form is naaste and the plural form is naasten. The term is kept in Dutch because it captures a broader relational meaning than the English terms relatives, family members or informal carers.

Palliative sedation: A medical intervention used in the final phase of life to relieve unbearable suffering caused by refractory symptoms. Medication is used to lower the patient's level of consciousness when symptoms can no longer be adequately relieved in another way.

Patient: The person receiving medical care and palliative sedation. The word patient is used in this report for clarity and consistency. However, it is important to recognise that the person receiving palliative sedation is more than a patient; they are also a loved one, family member or friend to the naasten involved.

Praatplaat: A visual conversation tool used to support reflection and discussion. Direct English translation is 'talking picture'.

Rattling breathing: A breathing sound that may occur in the dying phase when fluid or mucus collects in the throat or airways. Dutch translation is 'reutelen'.

Refractory symptoms: Symptoms that cannot be adequately relieved within an acceptable time frame and without unacceptable side effects. When suffering is caused by refractory symptoms, palliative sedation may be considered.

Scenario-based evaluation: An evaluation method in which participants respond to situational prompts that describe possible moments in a process.

AI statement

Generative artificial intelligence was used as a supporting tool during the development of this graduation project. ChatGPT was mainly used to refine text written by me, including improving clarity, academic tone, grammar and structure. It also supported the refinement of headings, transitions, research descriptions and the presentation of design and methodological choices.

ChatGPT was occasionally used to suggest search terms, relevant literature directions and possible sources. These sources were subsequently accessed and assessed by me, and only publications that I consulted directly are referenced in this report. Generative AI was also used to create or adapt several illustrative visual elements, as indicated in the corresponding figure notes.

All AI-generated suggestions were reviewed and adjusted before being incorporated into the report. The final interpretations, design choices and conclusions reflect my own judgement.

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1 Introduction

1.1 Project context

Palliative sedation is a medical intervention used in the final phase of life to relieve severe suffering caused by refractory symptoms by proportionately lowering a patient's consciousness (Palliaweb, 2022a; Surges et al., 2024b). Its use in the home setting has increased in the Netherlands, making it an increasingly relevant part of home-based end-of-life care (SFK, 2023). Many people in the Netherlands express a preference to die at home. Realising this preference depends not only on the availability of professional care, but also on the support available within the patient's social network (Visser et al., 2020). In this report, the term *naasten* refers to partners, relatives, friends and others who are closely involved with the patient. During palliative sedation at home, they may provide emotional and practical support, observe changes in the patient's condition and communicate with healthcare professionals (Garcia et al., 2023). This close involvement can be meaningful, but may also be emotionally demanding. *Naasten* may be confronted with unfamiliar bodily changes (Palliaweb, 2023b), uncertainty about the patient's comfort and the course of sedation (Van der Elst et al., 2025; Bäcklund et al., 2026), and questions about their own role and responsibility (Garcia et al., 2023).

This creates a design challenge that extends beyond the medical procedure itself. Supporting *naasten* requires not only medically accurate information, but also preparation, accessible guidance and reassurance throughout an uncertain and emotionally demanding process at home.

1.2 Project aim and research question

This graduation project aimed to understand how *naasten* experience palliative sedation at home and to translate their needs into a supportive design direction. At the start of the project, rituals and meaningful moments around dying provided an initial lens for exploring presence,

connection and farewell. However, the research gradually revealed that more fundamental needs concerning understanding, uncertainty and responsibility first required attention.

The central research question was:

How do naasten experience palliative sedation at home, and what needs emerge during this process?

The design objective was to translate the resulting insights into appropriate forms of support that respond to the needs of *naasten* before, during and after palliative sedation at home.

1.3 Target group and scope

The primary target group consists of *naasten* involved in palliative sedation at home in the Dutch healthcare context. Healthcare professionals, including general practitioners and nurses, were included as important stakeholders because they organise medical care, provide information and support *naasten* throughout the process.

The project focuses on the experiential, informational, and emotional support surrounding palliative sedation at home. It does not aim to change the medical procedure or professional responsibilities. The project delivers an integrated design direction for supporting *naasten* before, during and after palliative sedation at home. Developed through interviews, co-creation and prototype evaluation with *naasten* and healthcare professionals, the intervention portfolio provides a research-informed foundation for further development and implementation planning. Medical validation, broader user evaluation, organisational development, and real-life piloting remain necessary before the support system can be introduced into practice.

1.4 Overall design approach

The project followed an iterative design approach structured into three connected cycles, visualised as three diamonds in Figure 1. The three cycles each had a different emphasis: Cycle 1 focused on research and synthesis, Cycle 2 on concept development, evaluation and refinement, and Cycle 3 on positioning the refined interventions within the final portfolio, articulating their expected value and exploring preliminary implementation conditions. The outcome of each cycle informed the focus and activities of the next, allowing the design direction to develop in response to emerging insights.

The first cycle, **Grounding the design challenge**, focused on understanding the context and lived experiences of naasten. Literature review, interviews, a hospice visit and co-creation were used to identify difficult moments, support needs and opportunities for design. The findings shifted the initial focus on rituals towards the practical and emotional uncertainties experienced by naasten. The infusion pump, and particularly bolus administration, emerged as a concrete moment in which questions about interpretation, responsibility and reassurance became visible.

The second cycle, **Developing and evaluating the support system**, translated these findings into a portfolio of possible interventions. A systemic design perspective was used to explore how different forms of support could respond to needs arising at different moments. The concepts were prototyped, evaluated through scenario-based sessions and refined using participant feedback and supporting research. This resulted in the selection and refinement of four connected interventions.

The third cycle, **Positioning and preparing the final portfolio**, presented the four refined interventions as the final *Wat nu?* portfolio and positioned them within the broader experience of palliative sedation at home. The revised experience timeline and systemic value overview visualised when the interventions could provide support and how the portfolio was expected to create value at individual and system level. Preliminary implementation planning explored the stakeholders, activities and organisational conditions required for further development. Together, these activities provided a final articulation of the intervention portfolio and a preliminary direction for further development, validation and implementation planning.

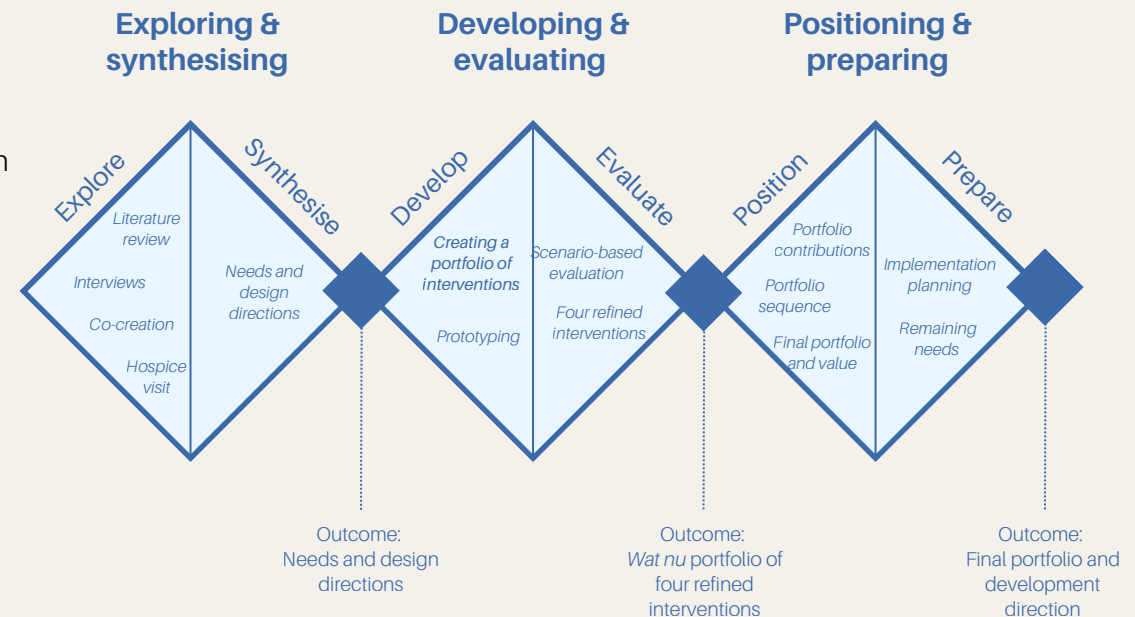


Figure 1. Overview of the three-cycle design process and outcomes

Cycle 1: Grounding the design challenge

Cycle 1 focused on developing a grounded understanding of palliative sedation at home and the experiences of naasten. A literature review established the contextual foundation, while interviews, a hospice visit and co-creation identified difficult moments, support needs and initial design directions. Together, these activities grounded the design challenge and generated the input taken forward into Cycle 2. As visualised in Figure 2, this cycle centred on exploring and synthesising the context and lived experiences of naasten.

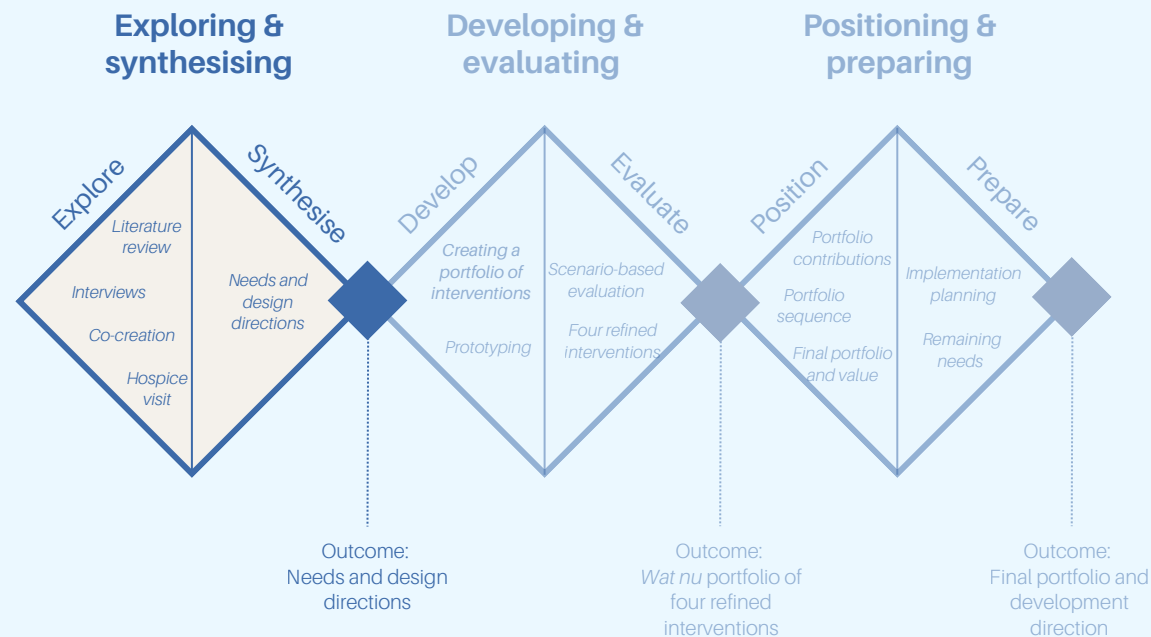


Figure 2. Focus of Cycle 1 within the three-cycle design process

2 Literature review

This chapter establishes the theoretical foundation for understanding the experiences of naasten during palliative sedation at home. It first outlines the medical and societal context, followed by existing knowledge on decision-making, the role and experiences of naasten, and their support needs. These insights provide the basis for the interview study and the subsequent design process.

2.1 Medical and societal context

2.1.1 Palliative sedation

What is palliative sedation

Palliative sedation is a medical intervention used in the final phase of life to relieve severe suffering caused by refractory symptoms. It involves the monitored use of medication to reduce a patient's level of consciousness when symptoms can no longer be adequately controlled through standard treatment. Near the end of life, symptoms such as pain, delirium and dyspnea may become severe and distressing (Bhyan et al., 2024). Symptoms are considered refractory when suffering cannot be adequately relieved through other available methods within an acceptable time frame and without unacceptable adverse effects. In such situations, palliative sedation may be considered to relieve otherwise unmanageable suffering (Surges et al., 2024b).

Guidelines for palliative sedation

The European Association for Palliative Care (EAPC) developed a framework to guide the use of palliative sedation in palliative care (Cherny et al., 2009). It is not intended as a rigid protocol, but as a flexible framework that can be adapted to different legal, cultural, and care settings, including home care. The framework is based on existing

guidelines, published literature, clinical experience, and extensive peer review. It supports healthcare professionals in making careful decisions and promotes the ethical use of palliative sedation.

The revised EAPC framework states that “palliative sedation aims to relieve refractory suffering through the monitored proportional use of medications intended to reduce consciousness in patients with life-limiting disease” (Surges et al., 2024b, p. 221). It further explains that suffering is considered refractory when the patient experiences it as intolerable and no methods are available that are likely to provide appropriate relief within an acceptable time frame and without unacceptable adverse effects (Surges et al., 2024b).

The revised EAPC framework emphasises that sedation should be proportionate to the patient's suffering. This means that the depth and duration of sedation should not be greater than necessary to relieve the suffering. The framework also recognises that refractory suffering may involve physical symptoms, psychological symptoms, existential suffering or a combination of these (Surges et al., 2024b).

Arantzamendi et al. (2021) describe that palliative sedation may be administered intermittently or continuously until death, depending on the patient's condition and care goals. In addition, Surges et al. (2024b) explain that the depth of sedation may range from light to deep. Together, these distinctions show that palliative sedation can differ in both duration and depth.

Continuous palliative sedation

Jonker et al. (2024) describe continuous deep sedation as a form of palliative sedation in which the patient remains deeply sedated until death. They further state that, according to the Dutch guideline, continuous deep sedation may be considered when persistent refractory symptoms cause unbearable suffering during the final days or weeks of life.

The Government of the Netherlands (n.d.) specifies that continuous palliative sedation may be used when the patient's estimated remaining life expectancy is no more than two weeks. It is regarded as a normal medical procedure rather than as termination of life, because the medication is intended to relieve suffering and not to cause death. Consequently, physicians are not required to report cases of palliative sedation or submit them for formal review.

Rietjens et al. (2019) found that the use of continuous deep sedation in the Netherlands increased from 8.2% of all deaths in 2005 to 18.3% in 2015.

Distinguishing palliative sedation from euthanasia

Although palliative sedation and euthanasia are both associated with end-of-life care, they differ fundamentally in their intention and intended outcome (Olsen et al., 2010; Bhyan et al., 2024). As described earlier, palliative sedation aims to relieve refractory suffering by proportionately lowering the patient's consciousness, without intending to cause death (Palliaweb, 2022a; Bhyan et al., 2024). Euthanasia, by contrast, is intended to end the patient's life and requires a voluntary and well-considered request from the patient (Bhyan et al., 2024; Regional Euthanasia Review Committees, 2026).

2.1.2 Palliative sedation at home on the rise

Increasing use of palliative sedation at home

Palliative sedation is increasingly relevant in the home context. SFK (2023) shows that the number of patients receiving palliative sedation at home rose to 44,000 patients in 2022. This means that palliative sedation at home was used in 26% of deaths in the Netherlands, an increase from 15.5% in 2013. More recent data from SFK (2025)* show that this number rose further to more than 47,000 patients in 2024, with an average age of approximately 79 years.

Preference to die at home

Visser et al. (2020) show that the wish to die at home is an important value in the Netherlands. 68% of Dutch people aged 35 and older prefer to die at home, while in practice this happens in 33% of cases. This shows a gap between preference and reality. Home is a broad concept as it refers to either the person's own house or a place where the patient feels at home. Preferences regarding the place of death can shift during the illness process, depending on the course of the disease and the capacity of the surrounding network. This surrounding network refers to the people close to the patient who need to be able to share and sustain the care responsibilities.

Role of death in society

The broader context in which dying takes place in the Netherlands has changed significantly over time. Visser et al. (2020) describe how, until the middle of the twentieth century, death was more accepted as part of everyday life. Most people died at home, within their own community and religious tradition. Since then, dying has increasingly become a medicalised process, and death and mortality have moved further away from everyday life. At the same time, growing medical possibilities have contributed to a social ideal in which illness, suffering and dying are

increasingly approached as something that can be controlled or managed. According to Visser et al. (2020), this makes dealing with vulnerability, suffering and death complicated for both healthcare professionals and care recipients.

Although attention to end-of-life issues in Dutch society has increased, many people still do not actively discuss or prepare for dying. Visser et al. (2020) describe how conversations about death with partners or family are often avoided, practical preparations are limited, and knowledge of palliative care remains low. This lack of preparation and awareness may contribute to uncertainty and misconceptions about palliative sedation.

SFK (2025) = Although the 2025 article does not explicitly mention the home setting in the same way as the 2023 article, SFK confirmed that both articles are based on pharmacy dispensing data and are used to estimate how often palliative sedation takes place in the home situation, as SFK has no insight into palliative sedation in hospitals or hospices (SFK, personal communication, June 2026).*

2.2 Organisation and decision-making

2.2.1 Roles and responsibilities

Stakeholders

The guidelines for palliative sedation on Palliaweb (2022a) state that, when palliative sedation is provided at home, various stakeholders must work together to ensure that both the patient and their naasten receive the appropriate care and support. The main stakeholders involved in home-based palliative sedation are visualised in Figure 3.

The physician, **the GP** in home-based palliative sedation, holds ultimate responsibility for determining the indication for palliative sedation. They must evaluate whether the patient has refractory symptoms and confirm that all criteria for sedation are met.

The primary care coordinator, such as **the GP, nurse practitioner, or physician assistant**, ensures continuity and coherence of care. They serve as the primary point of contact for the patient and family, coordinating communication between all involved parties.

Nurses and care staff play a central role in patient observation and monitoring. They are often the first to recognize the need for sedation and provide evidence to support the physician's indication. During sedation, they monitor comfort and symptom control continuously.

Nurse specialist and physician assistants may independently perform reserved medical tasks and can act as the primary care coordinator when necessary.

The Palliative care consultation team is 24/7 accessible. This team can be consulted by the treating physician or nurse for advice in complex cases, such as questions regarding medication dosing or ethical dilemmas.

According to the Dutch guideline for palliative sedation, naasten may support care by sharing information and helping assess the patient's discomfort. The guideline recommends clarifying in advance which roles they are willing and able to take during sedation.

Home-care considerations

Palliaweb (2022a) shows some specific considerations for home-based palliative care:

- Individual care plan: A written care plan should be left at the patient's home so that visiting nurses and on-call physicians (e.g., at the general practitioner's out-of-hours service) are immediately aware of the agreed arrangements.
- Availability: Clear agreements must be in place regarding 24/7 accessibility of the involved healthcare professionals for both the patient and naasten.
- Home care technology: When infusion pumps or other equipment are used, responsibilities for technical support must be clearly defined.
- Medication and supplies: The primary care coordinator ensures that all necessary medications and administration materials (e.g., pumps, butterfly needles) are available in the home in a timely manner.

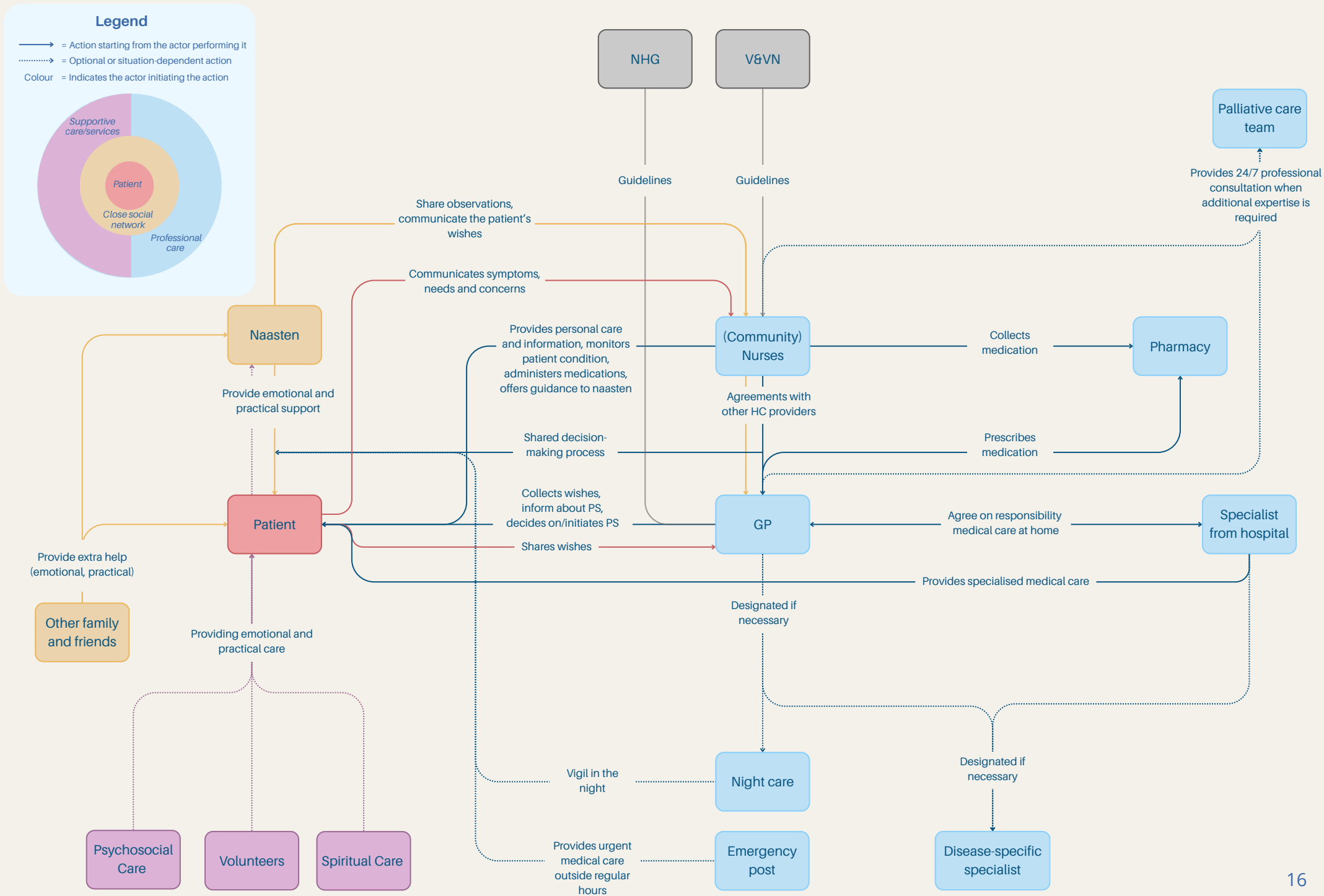


Figure 3. Stakeholder map

Challenges for stakeholders

Garcia et al. (2023) reviewed multiple studies on palliative sedation at home and identified challenges experienced by three main stakeholder groups: patients, family members and healthcare professionals. First, for patients, key challenges concern whether their preferences are known, respected and followed by relatives and healthcare professionals. This is particularly important because palliative sedation involves complex judgements about unbearable suffering and the moment at which symptoms are considered refractory. Second, family members may face increased autonomy and responsibility during home-based palliative sedation. They are often closely present at the bedside, involved in direct care, and responsible for coordinating with healthcare professionals as the care situation intensifies. At the same time, they may experience caregiver burden, family disagreements and the emotional difficulty of honouring the patient's wish to remain at home, even when this becomes demanding for the family. Third, healthcare professionals face challenges related to emotional burden, cultural and ethical tensions, symptom management at the very end of life, and uncertainty about when and how palliative sedation should be initiated, especially when the situation is acute rather than planned. Together, these challenges show that palliative sedation at home requires careful coordination between patient preferences, family capacity and professional responsibility.

2.2.2 Decision-making

Responsibility lies with the physician

A decision to start palliative sedation should be the outcome of a palliative care trajectory that the patient and the involved care team have gone through together. Before deciding on palliative sedation, the causes of the symptoms should be assessed, and it should be clear that no other treatment options are available. Multidisciplinary collaboration forms the starting point for decision-making, although the physician remains ultimately responsible for establishing the indication. In complex situations, consultation with an expert or consultation team is recommended (Palliaweb, 2022a). Although the responsibility generally lies with the physician, the KNMG (2021) adds that an important principle in medical care is that patient consent is always required for medical treatment or examinations.

Patient wishes

Van der Elst et al. (2024) describe decision-making about palliative sedation as a complex, iterative and dynamic process, rather than as a single moment or isolated decision. This process generally develops through repeated information exchange, observation, deliberation and shared decision-making. Palliative sedation is often addressed proactively. Discussions could start before the actual dying phase, and some patients formulated a conditional decision, meaning that they expressed a wish to receive palliative sedation if their condition worsened and suffering became intolerable. The final decision to start sedation was often triggered by deterioration in the patient's condition and the presence of refractory suffering. At that point, earlier conversations and preferences were often revisited with the patient, healthcare professionals and relatives.

The revised EAPC framework states that the patient, and with the patient's consent their significant others or legal representative, should be involved

wherever possible (Surges et al., 2024b). The framework also emphasises that palliative sedation requires careful assessment of suffering: healthcare professionals assess whether suffering is refractory, while the patient's own experience of suffering remains central. If the patient is no longer competent and no advance directive is available, the patient's presumed preferences should be explored through a legal representative or significant others where possible (Surges et al., 2024b).

Surges et al. (2024a) indicate that direct patient involvement is often limited in practice. This is particularly important when the patient's condition deteriorates and their ability to express preferences becomes restricted, increasing the importance of loved ones in communicating known wishes and preferences. Once sedation has begun, the patient's capacity to participate in decision-making may be reduced or lost.

Role of naasten

Van der Elst et al. (2024) found that relatives were generally involved in the decision-making process, although their role was usually supportive rather than formally decisive. Their involvement could become more prominent when the patient was no longer able to communicate. In such situations, relatives sometimes communicated or defended the patient's presumed wishes. At the same time, their own emotional difficulty with saying goodbye could lead them to postpone the start of sedation. The decision to initiate palliative sedation was therefore experienced as emotionally challenging by all those involved.

Similar tensions were identified by Guité-Verret et al. (2024). Family members sometimes requested continuous sedation because they perceived the patient's suffering as unbearable, while others preferred to delay it in order to keep the patient conscious for longer. Consequently,

relatives' perceptions of the patient's suffering and their emotional readiness could become important factors in clinicians' assessment of the situation.

Decision-making can strongly shape how naasten experience palliative sedation (Bäcklund et al., 2026). At the same time, their involvement, perceptions and emotional responses may influence how decisions are made, particularly when the patient is no longer able to communicate (Van der Elst et al., 2024; Guité-Verret et al., 2024). Taken together, these findings point to a reciprocal relationship between decision-making and the experiences of naasten. Bäcklund et al. (2026) therefore emphasise the importance of discussing palliative sedation earlier in the process, while the patient is still able to express their wishes and preferences. Once sedation has started, the patient's ability to participate in further decision-making may be reduced or lost, which can increase the emotional burden experienced by loved ones.

2.3 Experience and needs of naasten

2.3.1 naasten in the home context

Informal carers in dying at home context

Although the involvement of naasten becomes particularly visible during decision-making and communication around palliative sedation, their role is part of a broader shift towards home-based care in the Netherlands. Since the 2015 long-term care reforms, Dutch policy has aimed to support older people in living independently at home for longer (Verkooijen, 2020). According to Visser et al. (2020), this development increases the importance of informal carers and social networks. They describe informal care as indispensable, while also pointing to risks of overburdening and limited availability. Visser et al. (2020) anticipate that fewer informal carers will be available in the future, further increasing pressure on informal care. VZinfo (2024) shows that approximately 13% of adults provided regular informal care in 2024. This care was most commonly provided by people aged 50–59 and more often by women.

Emotional burden and farewell

Surges et al. (2024a) show that the process of palliative sedation can have a considerable impact on naasten. On the one hand, they may want to delay the loss of the patient and preserve the possibility of contact for as long as possible. On the other hand, they may also recognise that death is approaching and wish for the patient's suffering to be relieved. Surges et al. (2024a) describe how patients and families often value the opportunity to communicate, say goodbye and share meaningful moments during the final days of life. For some, palliative sedation may feel as if it takes away this possibility, because the patient's consciousness is lowered and communication becomes limited or impossible. Surges et al. (2024a) also note that little attention has been paid to differing views within families and how these can be reconciled.

For family members, palliative sedation can bring both relief and emotional burden. Bäcklund et al. (2026) describe how relatives may feel reassured when the patient's suffering appears to be relieved, while at the same time experiencing anxiety, uncertainty and grief. This burden can be related to questions about whether the patient is still experiencing discomfort, whether they might wake up, and how long the sedation will last. The duration of sedation can be especially difficult. Longer sedation may increase distress for relatives, while starting sedation at an appropriate moment may provide reassurance that the patient's suffering is being addressed (Bäcklund et al., 2026)

Bäcklund et al. (2026) also describe how palliative sedation can offer family members an opportunity to be present during the final phase of life. Some relatives find it emotionally difficult to remain at the bedside, as the remaining time may be experienced as merely waiting for death. Van der Elst et al. (2025) show that loved ones want to be present at the bedside towards the end of life, and this can be an intense and intimate experience. The final goodbye is important for the loved ones to ensure they experience the farewell as a positive experience.

Physical changes of patient

Palliaweb (2023) describes how the dying process may involve changes in both bodily functioning and behaviour. Patients may gradually lose the need for food and drink, become less conscious or responsive, and show confusion, restlessness, movements or signs of delirium. Breathing may also become irregular, laboured or rattling, and patterns such as Cheyne-Stokes breathing may occur. These signs are part of the dying process and are not necessarily caused by palliative sedation itself. For naasten, such changes can be difficult to interpret, especially when they are uncertain whether the patient is still aware or experiencing discomfort.

Palliaweb (2022b) therefore advises healthcare professionals to prepare naasten for possible changes during the dying phase, including altered breathing, movements, groaning and rattling sounds. Clear and timely explanation may help naasten understand what they are witnessing and reduce uncertainty about what is happening. This is particularly relevant in the home setting, where naasten may remain close to the patient for long periods without a healthcare professional being continuously present.

2.3.2 Clear communication

Clarity during uncertainty

Van der Elst et al. (2025) show that palliative sedation is accompanied by uncertainty about eligibility, timing and effectiveness, which can cause distress for both relatives and healthcare professionals. Their study also describes palliative sedation as a period of intense family communication, collaboration and caregiving, with mixed emotions. These findings suggest that naasten need clear and repeated explanations about the purpose of sedation, the timing of the decision and the possible course of the process.

Interpretation of palliative sedation

Clear communication is important not only for explaining the medical procedure, but also for helping naasten understand what is happening and what their role may be. Bäcklund et al. (2026) describe how naasten may hold different beliefs about the effect of palliative sedation on the timing of death: some believe that it hastens or causes death, while others believe that it has no effect on lifespan or may prolong the dying process. Bhyan et al. (2024) emphasise the importance of clearly distinguishing palliative sedation from euthanasia and assisted suicide in communication with patients and naasten.

The Dutch guideline on communication

This careful and process-based understanding of palliative sedation is also reflected in the Dutch guideline on palliative sedation. The guideline recommends offering patients and their naasten a conversation about palliative care, including palliative sedation, when the palliative phase is marked, during the palliative phase and when refractory symptoms are expected in the final weeks of life. These conversations should address the values, wishes, needs, fears and concerns of both the patient and their naasten regarding the final phase of life and the dying phase. If desired, written patient information can be used to support this conversation (Palliaweb, 2022a).

2.4 Mourning, rituals and meaning-making

Changes in mourning culture

Dutch mourning culture has become more diverse and individualised. According to Visser et al. (2020), this is related to secularisation, depillarisation and immigration. Mourning rituals have become more personal, informal and individually shaped. People increasingly search for forms and rituals that appeal to them, and social media also contributes to new mourning practices. Within palliative care itself, more attention has been given to grief and aftercare. However, aftercare for relatives can still be improved, as more than half of relatives reported that no farewell or evaluation conversation had taken place and that they had not been informed about aftercare options (Visser et al., 2020).

Rituals surrounding the end-of-life

According to the Raad voor Volksgezondheid & Samenleving (RVS, 2021), societal developments such as secularisation and individualisation have contributed to the decline of fixed rituals around death and grief. As a result, people may feel unsure about how to respond to death, loss and mourning in their environment. At the same time, the disappearance of fixed rituals creates space for more personal and situation-specific forms of saying goodbye, remembering and grieving. According to RVS (2021), rituals can give form to emotions and experiences that are difficult to express in words. They may offer support and create a sense of togetherness, dignity and symbolism.

The meaning-making function of rituals can also be understood in relation to the spiritual dimension of palliative care. Van der Weegen et al. (2019) argue that spirituality should not be treated as a separate domain of care, but as embedded in the physical, emotional and relational dimensions of the patient's experience. Because spirituality is personal and difficult to translate into standardised care practices, rituals and ritual-like actions may offer a tangible way of supporting meaning and connection.

Van der Weegen et al. (2019) further illustrate this through everyday care practices, which may acquire ritual significance when they are performed with particular attention and take on symbolic meaning. For instance, fluffing a patient's pillow can go beyond physical comfort by expressing care and recognition. Similarly, post-mortem care can be understood as a therapeutic ritual: rather than being merely a standardised task, it can become a compassionate act that acknowledges the body as worthy of care and the significance of a peaceful death.

This understanding also relates to the broader view of death as an embodied and ritualised life transition. Wojtkowiak and Mathijssen (2022) describe death, like birth, as a liminal and ambiguous experience shaped by personal, cultural and spiritual meanings. Rituals and ritual-like practices may help people navigate this transition by creating space for reflection, connection and meaning-making. They do not have to follow established religious traditions, but may also take personal, interreligious or post-secular forms.

2.5 Diversity and inclusivity

Cultural, religious and spiritual considerations

Suffering is experienced differently by each individual and is influenced by personal background, culture and religion (Barry et al., 2025). Many religious traditions, including Islam, Christianity, Judaism, Hinduism and Buddhism, view suffering as meaningful or temporary and may associate it with spiritual growth or the afterlife (Barry et al., 2025). Consequently, some patients may consider palliative sedation incompatible with their beliefs, while others accept it when its primary aim is symptom relief rather than hastening death (Choukat et al., 2013; Islam, 2022; Boer, 2013).

Religion continues to play a role in the Netherlands, where 43% of the population identifies with a religious or philosophical group (CBS, 2023b). Religious beliefs can influence preferences regarding end-of-life care and rituals surrounding dying and death (Zadorožny, 2020). In contrast, non-religious individuals may lack comparable cultural rituals and support surrounding death (MacMurray & Fazzino, 2017). Therefore, healthcare professionals should explore each patient's individual values, beliefs and preferences rather than make assumptions based on religious affiliation alone (Kröger et al., 2025).

Aker et al. (2024) add that many ethnic minority groups have specific preferences regarding family involvement, end-of-life care, and religious practices. Religion and spirituality play an important role in end-of-life decisions. A range of cultural, social, religious and psychological needs must be considered when planning palliative care, by involving these different identities and gathering information from various perspectives.

Inclusivity in end-of-life care

Davies et al. (2019) describe how structural inequalities continue to influence access to end-of-life care. They show that people with a lower socioeconomic status are more likely to die in hospital and have less access to specialised palliative care, highlighting persistent disparities in both access and quality of care. Building on this, Koffman et al. (2023) argue that addressing these inequities requires attention to structural, social and intersectional factors within palliative care provision.

2.6 Research gap and target group

Research gap

Existing literature shows that palliative sedation can involve uncertainty and emotional burden for naasten. Van der Elst et al. (2025) describe uncertainty surrounding its eligibility, timing and effectiveness, while Bäcklund et al. (2026) highlight concerns about the patient's comfort and the emotional burden experienced by relatives. Garcia et al. (2023) further identify increased responsibility and difficult family dynamics in home-based palliative sedation. Together, these studies show that the experience of naasten involves multiple interrelated medical, emotional and relational factors. To remain close to the lived experiences and needs of naasten, these broader insights were explored in greater depth through interviews.

The aim was to understand how the identified issues unfolded in specific moments, which needs participants themselves considered most pressing and where opportunities for design support might emerge. This allowed potential design directions to develop from participants' accounts rather than from a predefined intervention.

Rituals and ritual-like actions initially formed an explicit design direction within the project and were therefore used as a sensitising lens during the interviews. This focus guided attention towards experiences of presence, farewell, connection and meaning, alongside the practical, emotional and informational needs of naasten. As the project developed, however, the research findings led to a reconsideration of this initial direction, and rituals became less central in the later design phases.

Target group and research scope

The intended target group of this project consists of naasten involved in palliative sedation at home in the Netherlands. The term naasten includes partners, relatives, friends and other people who are closely involved with the patient during the final phase of life. The project focuses on their experience because they may be present for long periods, take on practical or coordinating responsibilities and simultaneously prepare for the loss of someone close to them.

During the initial research phase, participant recruitment focused primarily on non-religious naasten. This scope was connected to the project's initial exploration of rituals and ritual-like actions. Focusing on participants without an established religious ritual framework made it possible to explore how meaning and meaningful practices emerged from their personal experiences rather than from predefined religious traditions.

This research scope does not mean that the resulting design direction is intended exclusively for non-religious naasten. However, the limited cultural, spiritual and religious diversity of the participants should be considered when interpreting the findings. Naasten from other backgrounds may have different practices, interpretations and support needs.

3 Exploring experiences and needs

To move from the broader context to the lived experience of palliative sedation at home, interviews were conducted with naasten and healthcare professionals. This chapter explores how naasten experience the process and identifies the needs that informed the subsequent design phase.

3.1 Interview method

This study used semi-structured interviews to explore the current experiences and needs of naasten during palliative sedation at home. During the interviews, a simple journey map was used as a supportive tool to reflect on different moments in the process. The aim was to use these insights to inform a design that responds to these needs. The insights from the interviews form the basis for the design that meets the needs of naasten during palliative sedation at home. Therefore, the central research question guiding this study is:

How do naasten experience palliative sedation at home, and what needs emerge during this process?

The interview questions were informed by the initial aim of exploring whether rituals could provide support. This led to the sub-question:

Which of these needs could be supported through rituals or ritual-like actions?

Qualitative research explores how individuals perceive and experience the world around them. It is particularly useful for examining people's thoughts, feelings, and interpretations of meanings and processes in real-life, natural settings. Palliative sedation at home is a complex and sensitive context with many different dimensions and layers. Therefore, a qualitative

approach, such as semi-structured interviews, is appropriate because it allows for an in-depth exploration of the experiences and needs of naasten involved in this process (Muratovski, 2016).

An interview guide was developed and explored using the interview guide approach. This guide ensured that the same lines of inquiry are pursued with each participant. At the same time, I remained responsive to the answers given by the interviewee and asked follow-up questions when relevant. The prepared questions therefore served as a foundation for the interview, while allowing space for a more open conversation around these topics. This approach enables participants to share their personal experiences and allows for deeper insights into their needs and perspectives (Patton, 2002).

The interview study focused on two stakeholder groups, the naasten and the healthcare professionals:

Naasten were interviewed to capture the firsthand experiences and emotional realities of those directly affected by palliative sedation. Their perspectives complement the professional viewpoint, ensuring that the research reflects both experiential and systemic understandings of needs, rituals, and coping mechanisms in home-based palliative sedation.

Healthcare professionals involved in palliative care at home were interviewed because they can provide a broader perspective on the needs of naasten during palliative sedation. General practitioners often engage with patients and their naasten at multiple touchpoints throughout the process, providing them with a comprehensive understanding of the practical and emotional dynamics involved. Nurses witness these experiences closely and in detail, offering insights into the challenges faced by naasten.

Journey mapping

A simple journey map was used as a visual support tool during the semi-structured interviews. Because palliative sedation at home is a process that unfolds over time, the journey map helped participants structure their experiences chronologically and reflect on important moments, transitions and interactions with healthcare professionals. Rather than serving as a data collection method on its own, the journey map functioned as a conversational aid that supported participants in recalling and discussing their experiences (Ly et al., 2021; Simonse et al., 2019). This approach is supported by Hurtubise and Joslin (2023), who describe participant-generated timelines as flexible, person-centred tools that help structure experiences chronologically and support reflection on needs during a process.

Interview guide

An interview guide was developed to structure the semi-structured interviews (see Appendix 1). The guide was informed by the research focus on the experiences and meaning-related needs of naasten during palliative sedation at home. In addition, the formulation of several questions was inspired by Post's understanding of ritual, as discussed by Van der Weegen et al. (2019):

- Ritual is a more or less repeatable sequence of action units which take on a symbolic dimension through formalization, stylization, and their situation in place and time. On the one hand, individuals and groups express their ideas and ideals, their mentalities and identities through these rituals, on the other hand the ritual actions shape, foster, and transform these ideas, mentalities and identities (as cited in Van der Weegen et al., 2019, p. 2040).

The definition of ritual was used as a sensitising concept to guide the interview questions towards meaning-related needs, rather than only practical care needs.

The interview guide was refined during the research process. After the first interview with a naaste and a healthcare professional, notes were made about clarity and relevance of the questions. These reflections were discussed with the supervisors, after which a revised interview guide was created for the remaining interviews. During the following interviews, small adjustments were still made, when necessary, while keeping the main structure consistent. The final interview guide included questions about the context of palliative sedation, unmet needs and meaningful moments.

Ethics

Palliative sedation is a sensitive subject; therefore, participants are approached with the necessary caution. Attention was paid to the voluntary character of participation. The study was submitted to the Human Research Ethics Committee (HREC) for ethical review. Individuals were informed that participation is entirely optional, that declining participation is always possible, and that they may withdraw at any stage of the study without consequences. This information was provided through an information sheet and informed consent form approved as part of the HREC procedure. After the interview, the naasten were contacted to see how they were doing.

Approach Sensitive topic

The interviews were face-to-face. Westland et al. (2025) note that such interviews help create a comfortable and safe atmosphere. This ensures that it is easier to respond to distressing emotions that can be evoked during or immediately after the interview. Participants chose a time and location where they felt most comfortable.

In interviews on sensitive topics, the primary aim is to generate knowledge and understanding rather than to provide a therapeutic intervention. At the same time, sharing personal experiences with a non-judgemental interviewer may still be experienced as meaningful or relieving for participants. Therefore, it was important to maintain focus during the interview, respond carefully to emotions, and document sensitive moments to recognize potential bias. It was acknowledged that participants might experience discomfort or distress. However, participation could also be perceived as valuable, as it allowed them to share their story and contribute to improving care for others (Westland et al., 2025). Therefore, the purpose of the research and the value of contributions were clearly stated.

Sampling

This study applied purposive sampling to recruit participants by selecting individuals with specific experience of palliative sedation, to generate detailed and contextually grounded insights into this complex phenomenon. Tajik et al. (2024) argue that purposive sampling is useful for identifying information-rich cases as it allows for the deliberate selection of participants with experience in palliative sedation.

Furthermore, it offers recruitment flexibility, enabling the sampling strategy to be adjusted as understanding of the research context evolves. However, it is limited by its reduced generalizability, as the sample is not representative of the broader population (Tajik et al., 2024). However, the data from the interviews are not used for generalization, but as input for the design phase.

In addition, purposive sampling may introduce researcher bias because participant selection is partly based on the researcher's judgement (Tajik et al., 2024). In this study, recruitment through personal and professional networks may additionally have limited the diversity of the sample. However, every person identified through these networks as having relevant experience with palliative sedation was invited to participate, and no one was excluded based on their views or experiences.

The initial aim was to recruit naasten whose experience of palliative sedation had occurred within the previous five years, to ensure that the experience was still sufficiently recent while allowing enough emotional distance for participation. However, this criterion could not be fully maintained within the timeframe and recruitment constraints of the project. The study also aimed to include naasten who had experienced palliative sedation at home. One participant with experience in a hospice setting was nevertheless included because their account still provided

relevant insights into the needs of naasten during palliative sedation. The difference in care setting was taken into account when interpreting the findings.

For the healthcare professionals, two general practitioners and four palliative care nurses specialized in palliative sedation were included. It was important that these professionals have been closely involved in cases of palliative sedation at home within the past five years, ensuring that their experiences are still recent and meaningful to reflect upon. However, one nurse mainly had experience in hospice care but was still included because her perspective offered valuable insights into the needs of naasten during palliative sedation.

The initial context of this project focused on non-religious Dutch participants, which means that the sample is not highly diverse in terms of cultural or religious background. Participants are considered part of the Dutch context when their experience of palliative sedation took place in the Netherlands and was shaped by Dutch healthcare practices, home-care structures and norms around dying and mourning. Additionally, participants are recruited from the researcher's nearby network. This should be considered when interpreting the results. Nevertheless, the study sought diversity in terms of gender and age to achieve a broader range of perspectives within the purposive sampling.

Recruiting participants

Naasten were recruited through my personal network and contacts made through my studies. I asked people within these networks whether they knew individuals who had closely experienced palliative sedation and might be willing to participate. Potential participants were approached carefully and received clear information about the aim and nature of the study.

Healthcare professionals were purposively recruited through both personal contacts and publicly available contact details identified through online searches. They were approached by email or telephone and received information about the purpose of the study, the interview procedure and the voluntary nature of participation. Participants were informed that they could withdraw at any time without negative consequences.

The naasten and healthcare professionals who participated in the interviews are presented in Table 1. Several participants subsequently contributed to additional research and design activities. An overview of their involvement across the project is provided in Appendix 2.

Planning and interview set-up

Preparing the interview required a recording device, the interview guide and a safe environment for the participants. The interview was recorded with the participant's consent. Additional notes were taken, but the interview was mainly about having a good conversation with eye contact. After the interview, the data were coded and recurring themes were identified.

To conduct the journey map sessions, the necessary materials were collected and brought along in advance. These included stickers, sticky notes, pens, and large sheets of paper. These materials supported participants in visually mapping their experiences during the interview.

Participants

Naasten

Naaste 1	Female participant, in her 50s. She experienced palliative sedation at home with a close family member. Sedation was administered through an infusion pump.
Naaste 2	Female participant, in her 40s. She experienced palliative sedation at home with a close family member. Sedation was administered through an infusion pump. She was closely involved during the illness process and visited regularly.
Naaste 3	Male participant, in his 20s. He experienced palliative sedation at home with a close family member. Sedation was administered through an infusion pump. He was closely involved in the care process.
Naaste 4	Male participant, in his 70s. He experienced palliative sedation at home with a close family member after a long illness trajectory. Sedation was administered through an infusion pump.
Naaste 5	Female participant, in her 50s. She experienced palliative sedation at home with a close family member. The illness trajectory was relatively short. Sedation was administered by injection.
Naaste 6	Male participant, in his 50s. He experienced palliative sedation in a hospice setting with a close family member. The illness trajectory was relatively short. Sedation was administered by injection.
Naaste 7	Female participant, in her late 50s. She experienced palliative sedation at home with a close family member after a planned end-of-life trajectory. Sedation was administered through an infusion pump.

Healthcare professionals

Nurse 1	Female healthcare professional working as a terminal care nurse in a hospice. She has a background in psychiatric nursing.
Nurse 2	Female healthcare professional in her 60s, with extensive experience in terminal care at home.
Nurse 3	Male care professional in his 30s, with long-term bedside care experience and currently training further in nursing.
Nurse 4	Female oncology nurse working in home care, with extensive previous hospital experience in oncology.
GP 1	Female general practitioner with experience in both hospital and general practice settings.
GP 2	Female general practitioner and practice owner, also working as a locum GP.

Table 1. Recruited participants

Data processing and analysis

Before the analysis, the audio recordings were transcribed, checked for accuracy and pseudonymised. Identifying details, such as names and specific locations, were removed or generalised where possible. Each participant was assigned a participant code. The link between participant codes and real names was stored separately and securely outside the analysis database. Journey maps, photographs of research materials and field notes were also documented and linked to the relevant participant code where needed.

The main analytical focus was on the interview transcripts. The journey maps were used as contextual material to support interpretation, rather than as separate datasets for thematic analysis. Because the study included multiple interviews and supporting visual material, the qualitative material was organised in ATLAS.ti. This was informed by Sanders and Stappers' (2012) suggestion to use database-supported analysis when working with larger qualitative datasets in design research. In this study, ATLAS.ti was used as an organisational tool to store transcripts, code data and document analytical decisions. Working with a database can create some distance from the richness of the original data. In this study, that limitation was mitigated because I conducted and transcribed all interviews myself. This resulted in strong familiarity with the data, which supported the interpretation process (Sanders & Stappers, 2012).

The interview data were analysed using thematic analysis, following Braun and Clarke (2006). This approach was suitable because it offers a systematic yet flexible way to identify, analyse and interpret patterns of meaning within qualitative data. The analysis followed a semantic and mainly inductive approach. A semantic approach means that coding stayed close to the explicit meanings of the interview accounts, rather than focusing on underlying assumptions or latent meanings. A mainly

inductive approach was used at the beginning of the analysis, so that the initial codes and themes were strongly grounded in the data rather than derived from a pre-existing coding framework.

A limitation of thematic analysis is that it primarily focuses on recurring patterns in the data, which may cause the unique course of individual experiences to be partly lost (Braun and Clarke, 2006). This was especially relevant in this study, because the personal story of each naaste and healthcare professional was important for understanding the experience of palliative sedation at home. Therefore, the analysis remained attentive to the context and distinctiveness of individual experiences. At the same time, the analysis did not remain merely descriptive but also interpreted what the identified patterns meant in relation to the research question. To support a systematic and transparent analytical process, the six phases of Braun and Clarke (2006) were followed. These phases included familiarisation with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report. Through this process, the initial codes were gradually clustered, refined and developed into themes that reflected the experiences and needs of naasten during palliative sedation at home. A more detailed overview of how these phases were applied in this study can be found in Appendix 3.

Because the research concerned a sensitive topic, reflexivity was important throughout the analysis. Following Stahlke (2018), ethical risks were considered not only for the people taking part in the study, but also for the researcher. Reflective notes were kept during and after interviews and during analysis to document emotional responses, sensitive moments and possible influences on interpretation. Regular debriefing with supervisors supported careful interpretation of the data and helped address the emotional impact of working with sensitive narratives.

3.2 Interview results

This section presents the findings from the interviews with naasten and healthcare professionals. The results are organised around recurring themes that describe how palliative sedation at home is experienced, which moments create uncertainty and what support needs emerge throughout the process. Where relevant, similarities and differences between the perspectives of naasten and healthcare professionals are highlighted.

3.2.1 Course of the dying process

Becoming irreversibly ill

Naasten described the period before palliative sedation as a phase of marked deterioration. This was consistently framed as the moment at which life was no longer bearable. In all cases, patients were already receiving pain medication at this stage. The naasten referred to a range of signs that indicated this progression, including severe pain, becoming bedridden, loss of appetite, confusion, delirium, epileptic fits and a reduced level of consciousness. Some described how the patient would drift away or was no longer able to form complete sentences. In one case, the progression of illness was also visibly reflected in the patient's appearance, as the body became yellow. Another recurring marker was the move to a different bed, particularly the transition to a high-low bed. For some naasten, this made the approaching death suddenly tangible, as naaste 1 described:

Naaste 1: Uiteindelijk ging ze naar het hoog laag bed in de woonkamer. Dat vond ik ook een heel raar moment. Zeg maar van hier naar daar, dan weet je gewoon dat je leven voorbij is.

(English: Naaste 1: Eventually, she moved to the high-low bed in the living room. I also found that a very strange moment. Like, from here to there, then you just know that your life is over.)

Healthcare professionals similarly described this deterioration as a recognisable turning point within the dying process. They referred to a gradual loss of function, increasing dependence, becoming bedridden, and no longer being able to eat. GP 2 additionally identified nausea and severe breathlessness as important clinical indicators. These bodily changes were not only used to assess the patient's condition, but also to estimate whether death was likely to occur within a relatively short time frame. Professionals further emphasised that witnessing this decline can

be distressing for naasten, particularly because it may feel as though the patient is being abandoned by their own body. GP 2 added that before considering palliative sedation other interventions should first have been attempted, such as increasing morphine or adjusting symptom management. This is consistent with the naasten who stated that their loved one was already on pain medication.

Another significant moment concerned the recognition that the patient was no longer eligible for curative treatment. All naasten referred to a point at which it became clear that no further treatment was possible. However, GP 2 explicitly problematised the idea that a patient is ever truly out of treatment. In her view, while disease-directed treatment may have come to an end, symptom-directed care continues. She described this transition as a shift from disease-oriented palliation to symptom-oriented palliation. Nurse 3 confirms this, adding that, towards the end, care is focused solely on alleviating symptoms such as pain, restlessness and fear of death. GP 2 positioned this shift as a meaningful marker within the process and suggested that this transition might deserve more explicit recognition in practice.

The decision to administer palliative sedation

Almost all healthcare professionals indicated that the decision to start palliative sedation is closely linked to the moment at which the patient expresses that things have become unbearable or are no longer manageable. This is sometimes related to a loss of autonomy and dignity, for example when patients became fully dependent on others for basic care such as being washed in bed. Healthcare professionals emphasised that the patient's own wishes are of crucial importance. It is therefore reassuring if the patient is still able to express these clearly. In some cases, however, the patient is no longer able to express such a wish. This can be

either because their consciousness had already begun to fade or because communication had become too difficult. Naaste 2 described how the decision was made when her father could hardly speak anymore:

Naaste 2: Toen is hij op een gegeven moment beneden in bed terechtgekomen en toen daar heeft hij, denk ik 6 weken gelegen, toen op een gegeven moment begon hij zich te verslikken in zijn eten en het leek ook wat epileptisch te worden en toen is er gekozen van nou, We gaan palliatieve sedatie starten, maar hij vond de gezelligheid en zo, daar genoot hij van. Hij kon bijna niet meer praten en dus hij weet het ook niet dat hij. We hebben niet met hem besproken, zeg maar dat dat kon niet meer.

(English: Naaste 2: Then at a certain point he ended up in a bed downstairs, and then he lay there, I think, for six weeks. Then at some point he started choking on his food, and it also seemed to become a bit epileptic, and then the decision was made; well, we are going to start palliative sedation. But he enjoyed the cosiness and such. He could hardly speak anymore, and so he also did not know that he, We did not discuss it with him, so to speak, that was no longer possible.)

Another difficulty is when naasten don't respect the wishes of the patient. For example, GP 2 described it as a difficult situation when the patient was ready to be sedated, while family members still wanted to wait for additional relatives to arrive.

In many cases in the interviews, the patient was still able to express the wish for palliative sedation themselves, which was described as making the process easier for those involved. Naasten indicated that they did not want to feel responsible for making such decisions. Naaste 7 even stated that she did not want to be present during the conversation about

palliative sedation, because she did not want to feel as though she had the death on her conscience. As long as the patient's communication remained clear, relatives and professionals generally did not question their decision.

Final decision lies with the GP

Although palliative sedation may be in line with the patient's wishes, following the healthcare professionals, in the home setting the final decision to initiate palliative sedation lies with the general practitioner. Both GPs acknowledged that this decision involves a degree of tension, because it can be difficult to assess the patient's condition. GP 1 explained that she bases her decision on the comparison between what she had previously observed and what she saw in the present situation. Based on that, she estimates the patient's life expectancy. She explained that according to the guideline it should be less than two weeks. Frequent contact helps her recognise the trajectory of decline and determine whether the situation has clearly changed:

GP 1: Doordat je dagelijks of heel frequent contact hebt zie je wat achteruitgang is en wat de trend is en dan kan je ook wat makkelijker inschatten van nou, dit is iemand die zeer waarschijnlijk toch echt wel op kortere termijn gaat overlijden.

(English: GP 1: Because you have daily or very frequent contact, you see what the decline is and what the trend is, and then you can also estimate a bit more easily: well, this is someone who is very likely to die in the shorter term.)

GP 2 added that she would only initiate palliative sedation when refractory symptoms could no longer be treated in any other way. This aligns with the account of Naaste 3, who described that palliative sedation was only started once morphine was no longer effective for his mother. Although wishes, fears and possible scenarios can be discussed beforehand, GP 2 emphasised that the actual start cannot be planned in advance, as it depends on the patient's symptoms at that moment:

GP 2: En en eerlijk gezegd, ja, ik waak er ook een beetje voor om om om sedatie te plannen. Dat vind ik ook niks. Weet je wel? Dan denk ik van ja, maar Als je een refractair symptoom vaststelt, Dan wil je gewoon handelen.

(English: GP 2: And, honestly, yes, I am also a bit careful about planning sedation. I do not like that either, you know? Then I think, yes, but if you establish a refractory symptom, then you just want to act.)

This shows that advance discussions may prepare those involved, but cannot determine when palliative sedation should begin.

GP 2 also described the tension that could arise when naasten repeatedly requested sedation because the care situation had become overwhelming. In such cases, she could feel pressured to act rather than making the decision solely on medical grounds:

GP 2: Want je bent in dat soort situaties ook wel vaak in In palliatieve sedatie een beetje geduwd, weet je wel. Eindeloos aandringen van de familie van, zo kan het toch niet Dokter, weet je wel en dat je dan heb je toch al een beetje het gevoel dat je gezwicht bent, Omdat het de zorg allemaal te veel wordt en Ja dan is er ook nog haast geboden bij wijze van spreken, dat dat zijn vervelende situaties.

(English: GP 2: Because in those kinds of situations you are also often pushed a bit into palliative sedation, you know. Endless insistence from the family, like, it cannot go on like this, doctor, you know, and then you do already have a bit of the feeling that you have given in, because the care is all becoming too much, and yes, then there is also some urgency, so to speak. Those are unpleasant situations.)

This illustrates the tension between the burden experienced by naasten and the physician's responsibility to base the decision on the patient's medical condition. GP 2 also stated that sedation would not be postponed solely to wait for other naasten to arrive.

Shared decision-making

In two cases of naasten, the patient was no longer able to make the decision themselves, meaning that the decision was primarily shaped by the GP and the naasten. In both situations, it was also clear to those involved that the patient's condition had deteriorated to the point where continuing in the same way was no longer possible. One of the cases was from Naaste 6, where euthanasia had already been planned, which made the decision to start the palliative sedation easier. Because the patient had already clearly expressed a wish to die, palliative sedation was not experienced as deciding about the end of life, but as responding to suffering within an already acknowledged dying process.

Almost all healthcare professionals described the decision-making process as a shared one, involving naasten, a GP, and other care professionals. Within this process, the views of naasten were taken seriously and were explicitly considered. Several professionals indicated that it is preferable when everyone agrees. In many cases, this was also

reported to be the case, as naasten often did not want their naaste to continue suffering and therefore supported the decision to relieve that suffering.

Consideration of euthanasia

Euthanasia also emerged as a consideration within the decision-making process. GP 2 emphasised that euthanasia and palliative sedation have fundamentally different aims: euthanasia ends suffering by bringing about death, whereas palliative sedation aims to make suffering bearable without intending to end life. For most naasten, however, it was not regarded as a feasible or appropriate option at that stage. Some felt that it was already too late because the patient had become too ill or was deteriorating too rapidly. In the case of Naaste 6, euthanasia had already been scheduled, but the patient died before the planned date. Others described euthanasia as too drastic because deliberately choosing the moment of death made the transition feel more abrupt for both the patient and their naasten. Nurse 1 similarly linked the eventual choice for palliative sedation to both the emotional intensity of euthanasia and the time required for the procedure:

Nurse 1: Ik denk mensen met een euthanasie wens, dat acht van de tien Mensen uiteindelijk palliatieve sedatie krijgen. Omdat het toch te heftig is. Vaak voor de familie, euthanasie en en of om de tijd hen inhaalt, want voor euthanasie heb je weer een onafhankelijke, het is een ander proces. Dan heb je de onafhankelijke arts nodig. De SCEN-arts.

(English: Nurse 1: I think that, of people who have a wish for euthanasia, eight out of ten eventually receive palliative sedation. Because euthanasia is too intense after all, often for the family, or because time catches up with them. For euthanasia, you need an independent physician; it is a different process. You need the independent physician, the SCEN physician.)

This illustrates that the feasibility of euthanasia was influenced not only by the patient's condition, but also by the procedural time involved and its emotional impact on naasten.

Palliative sedation as a relief from suffering

Almost all naasten stated that their main concern was that the patient should be relieved from suffering. Some used striking and hyperbolic language to convey how unbearable it was to witness this suffering. Naaste 4 described the desperation he experienced while watching the patient remain in severe distress:

Naaste 4: Terwijl je in bed ligt, dagen lang, je gaat dat dat Ik heb gedacht Als ik een kussen op der mond druk, dan is ze er vanaf. In zo'n staat. Zo Erg.

(English: Naaste 4: While you are lying in bed, for days, you go... I thought, if I press a pillow over her mouth, then she is free from it. In such a state. So awful.)

Naaste 5 expressed the same wish for relief more directly:

Naaste 5: Hij heeft zoveel pijn en je gunt dat Niemand. Om zoveel pijn te hebben, je wil dat dat meteen in werking gezet werd en die die pijnmedicatie die werd wel meteen ingezet.

(English: Naaste 5: He was in so much pain, and you do not wish that on anyone. To be in so much pain, you want that to be started immediately, and that pain medication was started immediately.)

Naaste 6 similarly used extreme language to express that almost any intervention would have seemed acceptable if it had relieved the patient's suffering, while clarifying that this was not meant literally:

Naaste 6: Al hadden we er benzine ingestopt om hem rustig te krijgen. Had ook goed geweest bij wijze van spreken, nah je wil hem niet vergiftigen.

(English: Naaste 6: If we had put gasoline in him to calm him down, that would also have been fine, so to speak. Well, you do not want to poison him.)

This emphasis on relieving suffering was also reflected in the accounts of healthcare professionals, who described it as the central aim of palliative sedation.

Initiation of palliative sedation

The initiation of palliative sedation was described as a medically organised process in which the GP played a central role. In most cases, the GP prescribed the medication and returned later that day to start the sedation. Depending on the situation, either the GP or a nurse administered the first dose and connected the pump. They were also responsible for arranging or collecting the required medication and equipment, such as a pump and needle to administer the medicine.

The administration of medication was described as something that required careful adjustment to the individual patient. Across the interviews, morphine and Dormicum were consistently mentioned as the main medications involved, but the required dose differed per patient. For instance, patients who had already been using opioids for pain control often required higher doses, as did patients with a history of prolonged alcohol or drug use. By contrast, some patients appeared to slip into a deep sleep relatively quickly. In this sense, the response to sedation was repeatedly described as highly individual and difficult to predict in advance.

Administration of palliative sedation

In most accounts, medication was administered through a pump. Both naasten and healthcare professionals referred to this as the standard way in which palliative sedation took place in the home context. In two interviews with naasten, however, sedation was administered through injections rather than a pump. Two healthcare professionals explained that a pump was generally preferred, not only because it allowed continuous administration, but also because repeated injections into a sleeping patient were experienced as unpleasant. This was described as burdensome both for the patient and for the professionals involved, who would otherwise need to return multiple times a day. The pump was connected through a small subcutaneous needle, usually placed in an area with sufficient fatty tissue, such as the abdomen, upper arm, near the clavicle, or upper leg. Once connected, it delivered medication continuously over a 24-hour period.

Both naasten and healthcare professionals described the start of palliative sedation as a process of finding the right dosage rather than an immediate state of deep sleep. Several healthcare professionals explained that the medication often has to be adjusted gradually before the patient reaches a sufficiently calm and stable level of sedation. When the initial dose is too low, this may lead to restlessness or repeated waking, while naasten may already expect peace to follow after saying goodbye.

Nurse 4 and GP 1 mentioned that continuous sedation is not always used. In such cases, intermittent sedation is applied to relieve distress and restlessness during the night, while still allowing the patient to regain consciousness during the day. Nurse 4 explained that the pump would then be turned off early in the morning, so that the patient could wake a few hours later and still spend time with family or experience some quality of life. Nurse 1 added that, as long as the suffering remained manageable

during these waking hours, intermittent sedation could also create space for continued interaction and moments of farewell. Several healthcare professionals further described intermittent sedation as a possible precursor to continuous palliative sedation, particularly when suffering during the day was still considered bearable but the nights had become too distressing.

Calm and unsettled courses of sedation

Both naasten and healthcare professionals generally described a calm course of sedation as one in which the patient gradually entered a deep and peaceful sleep, with little or no further response. In such cases, palliative sedation was often experienced as a relief, as the patient no longer appeared to suffer and a sense of calm could return to the room. Some nurses also described how patients were placed in a comfortable position, sometimes even in their favourite sleeping position, before they drifted away. Several professionals emphasised that the beginning of sedation ideally marked the beginning of rest, both for the patient and for the naasten. When the process unfolded calmly, this sometimes created space for family members to remain present in a peaceful way.

At the same time, naasten and healthcare professionals repeatedly stressed that this was not always how sedation was experienced in practice. The first phase of sedation could be difficult and unpredictable, particularly when the patient did not immediately enter a deep sleep. In such cases, patients could wake up again, mumble, or show signs of distress such as irregular breathing, groaning, or visible unrest. Nurse 2 explained that these signs could indicate, for example, pain, a full bladder, or insufficient sedation, whilst another nurse explained that this did not necessarily mean that the patient was in pain or discomfort. In some cases, visible unrest or possible discomfort also led to additional care, such as repositioning, washing, or catheterisation.

Duration and waiting

Duration also shaped how palliative sedation was experienced. Some naasten described a short sedation of only several hours as peaceful and fitting, while others valued having somewhat more time before death occurred. However, longer trajectories were often experienced as burdensome, especially when family members remained in a state of uncertainty or exhaustion while continuing to watch and wait. Professionals noted that families would sometimes ask whether “something extra” could be given when the process seemed to last too long but also stressed that palliative sedation does not work by simply accelerating death. Taken together, participants described their experience of palliative sedation as being influenced by the patient’s apparent comfort and calm, as well as by whether the duration felt bearable for the naasten involved.

Insecurity around the expectations

Palliative sedation was often approached with limited prior understanding and expectations that did not match the reality of the process. Both naasten and healthcare professionals described how it was sometimes confused with euthanasia, creating the expectation that it would be quick, calm and predictable.

Healthcare professionals also noted that naasten sometimes expected the physician to resolve the situation quickly through medication, while in practice the process could be prolonged, uncertain and emotionally difficult. This mismatch was also reflected in the experiences of naasten. Naaste 1 had heard of palliative sedation but had never witnessed it at close range. Naaste 3 experienced the patient’s unrest as inconsistent with the calm process he had expected based on the information provided beforehand. Others questioned whether increasing the medication might hasten death. Healthcare professionals therefore

considered it particularly important to explain the natural dying process and clarify the role of the medication. Nurse 3 explained why death shortly after administering medication did not mean that the medication had caused it:

Nurse 3: Iemand kan, op het moment dat wij deze gif toedienen. Sneller of snel overlijden. En Dat is niet Omdat wij actief een leven verkorten, maar Omdat het lijf in rust komt en je dan merkt dat iemand niet meer actief aan het vechten is tegen ik moet overleven, En ja dan kan iemand in een heel rap tempo Komen te overlijden niet door het middel, maar gewoon puur en Alleen Omdat het lijf dan rust heeft en dat je ziet dat het steeds verder uit begint te vallen. Dat, Dat is een stuk waarin naasten heel belangrijk vinden of wat wij voor naasten heel belangrijk vinden.

(English: Nurse 3: Someone can, at the moment we administer this dose, die sooner or quickly. And that is not because we are actively shortening a life, but because the body comes to rest and then you notice that someone is no longer actively fighting against, I have to survive. And yes, then someone can come to die very rapidly, not because of the medication, but purely and only because the body then has rest and you see that it starts

Nurse 4 described how she combined this explanation with information about the physical changes that naasten might observe during the dying phase:

Nurse 4: En dan vertel ik ook altijd vaak aan de familie nog weer rustig van. Wat kunnen ze verwachten? Dus hè? De processen in de stervensfase ook hè? Het aanzien van de ademhaling, de kleur, de ja ik benadruk ook altijd van iemand gaat niet dood ter gevolgen van de medicatie. Maar Omdat het lichaam op is, dus dat benadruk ik ook altijd wel 3 keer.

(English: Nurse 4: And then I also always often calmly tell the family again: what can they expect? So, you know, the processes in the dying phase as well, right? The appearance of the breathing, the colour, yes, I also always emphasise, someone does not die as a result of the medication, but because the body is worn out. So I always emphasise that three times.)

These accounts show that expectation management was not limited to a single explanation before palliative sedation began. Healthcare professionals repeatedly prepared naasten for what they might observe during the dying phase and clarified that the medication was intended to relieve suffering rather than cause death.

Uncertainty about the experience of the patient

The interviews revealed uncertainty about what patients might still experience while under palliative sedation. Healthcare professionals did not speak with one voice on this matter. Nevertheless, most encouraged naasten to maintain contact with the patient, for example by holding a hand or saying things that still needed to be said. Some professionals were convinced that patients may still experience something, for instance because some degree of brain activity remains. Nurse 2 assumed that the patient no longer experienced anything, yet even they generally continued to encourage contact. In some cases, naasten did not naturally think to do this themselves or did not feel able to, which meant that professionals sometimes actively prompted them by saying things such as take their hand. Because of this uncertainty, naasten were also strongly encouraged to say anything important before the start of palliative sedation.

Many naasten similarly had the sense that their presence was still being felt, which made being physically present important to them. For some, this was mainly meaningful for themselves, while for others it was also experienced as a way of supporting the patient. Naasten described how holding the patient's hand appeared to calm them. Healthcare professionals also recognised this, noting that some relatives hardly dared to leave the patient's side.

At the same time, uncertainty about what the patient could still perceive could become a source of distress. Although Naaste 3 had been told that his mother was no longer aware of what was happening, he interpreted her reactions as signs that she could still hear and understand those around her. This made it difficult for him to accept the explanation he had received:

Naaste 3: Hele nare ervaring, was dat ja, Dat is echt verschrikkelijk. En ik had ook het gevoel dat ze alles meekreeg van wat we zeiden. Mijn opa en oma, die waren er ook en hadden we gesprekken met hun. En je, ik merkte gewoon aan alles dat mijn moeder het meekreeg. De artsen zeiden van niet, Maar dat Dat is niet waar. Ze heb het gewoon meegekregen.

(English: Naaste 3: A very unpleasant experience, yes, that was really terrible. And I also had the feeling that she took in everything we said. My grandfather and grandmother were also there, and we had conversations with them. And you, I just noticed from everything that my mother took it in. The doctors said she did not, but that is not true. She simply took it in.)

The moment of dying

Following a period of illness and palliative sedation, the final stage was the moment of dying itself. Several physical changes were described in relation to this phase such as changes in skin colour. Multiple naasten described a change in breathing shortly before death, including irregular or interrupted breathing. Nurse 3 explained this in more physiological terms, noting that when oxygen levels in the blood fall, the respiratory centre triggers another breath as the reason why there is still breathing at the end. Healthcare professionals described recognising that death was near through changes in breathing and appearance. They mentioned rattling or irregular breathing, pauses that became longer between breaths, and Cheyne-Stokes-like patterns. They also referred to facial changes, such as a sunken face or pointed nose, and broader bodily changes such as altered skin colour and decreasing energy. This was echoed by Naaste 7, who described how the nurse could already see that death was imminent, while the family themselves had not yet recognised it. Naaste 6 similarly described noticing this moment, explaining that the patient suddenly opened his eyes after having kept them closed for a long time and then took a distinct final breath. Although he had never seen anyone die before, he immediately felt that this must be the moment of death.

For some naasten, the moment of death itself remained a profound shock because of its finality. It confronted them with the irreversibility of the loss and, in some cases, with the sudden realisation of now having to lie alone in bed. At the same time, death also marked the end of a prolonged period of illness and caregiving. Although palliative sedation already carried a sense of finality, because it initiated the last phase of dying, the actual moment of death was experienced as fundamentally irreversible in a different way.

Several nurses similarly reflected that people often die in a way that resembles how they lived. According to them, people who had held tightly to control in life often continued to seek control at the end of life. Those who had lived with a great deal of anxiety could also remain anxious in relation to dying. Likewise, people who had spent their lives fighting often continued to struggle until the very end, which did not always result in what both naasten and healthcare professionals would describe as a peaceful death. Both Nurse 1 and Naaste 7 shared striking stories of patients who had survived war camps and who, at the end of life, seemed to keep fighting intensely, as if survival had become such a deeply ingrained response that it shaped the dying process itself.

Dying at home

Dying at home was associated with the familiarity of one's own environment. Naasten and healthcare professionals linked this to being surrounded by one's own garden, home, pets, sounds, smells, and photographs. Being in a familiar environment was described as calming and as something that made it easier both for the patient to remain at ease and for naasten to say goodbye. In the case of Naaste 4, the patient had initially been in the hospital but returned home specifically to die there.

3.2.2 The needs of naasten while providing care

Caring for the patient

Many naasten described their role during palliative sedation primarily as being present for the patient. In addition to this emotional presence, several also took on practical caregiving tasks, such as helping the patient to the toilet, repositioning them in bed, or assisting with comfort measures. Some found it meaningful to contribute to this care, and professionals also noted that it could be helpful when family members were willing to assist with simple tasks, such as turning the patient onto their side. Others described their role less in terms of direct physical care and more as coordinating what happened around the bed, including managing children, visitors, and the general atmosphere. Across these accounts, a shared aim was visible: many naasten saw it as their task to help the patient die as peacefully as possible.

Previous experience in healthcare or with death appeared to shape how naasten experienced and handled this role. Those with professional care experience generally found it easier to assist with the practical aspects of care and often felt more able to understand what was happening. Healthcare professionals also confirmed that naasten with a background in care, or with previous experiences of death, were more likely to take initiative, for example in maintaining contact with the patient or supporting the process more actively. Nurse 2 similarly reflected that her own experience of working with death had helped her to cope better with the dying phase of her father.

At the same time, such experience could also heighten awareness of what was not going well. Naaste 2 described how her own background in paediatric palliative care made her more critical of the nursing care around her father, particularly when professional standards such as checking the dosage or washing hands were not followed. At the same time, she felt that her experience made the process easier to understand, as she knew

what to expect and could better interpret what was happening. This also helped her to act quickly, which she believed reduced unrest and contributed to a calmer sedation. Naaste 5 described something similar: because of her hospice experience and earlier encounters with death, she was able to coordinate effectively, answer questions, and translate the patient's wishes clearly to the doctor. In her case, this helped to create calm and ensured that the patient's preferences were taken seriously.

Similarly, both naasten and healthcare professionals noted that the process could be much more difficult for those who had never witnessed death at close range before. Not knowing what to expect often made the period around palliative sedation more uncertain and emotionally overwhelming.

The pump is morally charged

Healthcare professionals described the option for naasten to administer an extra bolus as a technically controlled way of responding when the patient appeared to wake up or showed signs of discomfort. Nevertheless, the first use of the button could feel tense. Nurse 4 explained that she sometimes administered the first bolus together with naasten and addressed their fear that the patient might die shortly afterwards:

Nurse 4: In begin is het spannend, vaak voor ze, want van oh, maar wat als iemand dan overlijdt? En dan zeg ik ook van ja, maar iemand overlijdt niet ter gevolgen van die extra druk op de knoop. Iemand overlijdt Omdat het lichaam zo ziek is, hè? Omdat dit hè, Het gaat een sterfproces in, dus dan hè, dus schrik niet als 5 minuten na het extra knop extra druk of het extra dosis dat iemand komt te overlijden, want Het is niet de gevolgen van die extra dosis, dus dat leg ik ook altijd goed uit.

(English: Nurse 4: In the beginning it is often tense for them, because, oh, but what if someone then dies? And then I also say, yes, but someone does not die as a result of that extra press on the button. Someone dies because the body is so ill, right? Because this, right, it enters a dying process, so then, right, do not be startled if five minutes after the extra press on the button or the extra dose someone comes to die, because it is not the result of that extra dose. So I always explain that well.)

Professionals also described how fear of the patient experiencing pain could lead some naasten to consider pressing the button repeatedly. Nurse 4 explained:

Nurse 4: Maar soms hebben de Mensen zo iets ook een beetje van. Ja, ik, Ik ga ieder uur maar drukken, want hè, dan weet ik zeker dat iemand geen pijn heeft. Maar ja, Dat is Natuurlijk eigenlijk de bedoeling niet, hè? Van het pompje en de extra dosis geven.

(English: Nurse 4: But sometimes people also have a bit of a feeling like, yes, I will just press every hour, because then I know for sure that someone is not in pain. But yes, that is of course not really the intention, right, of the pump and giving the extra dose.)

Despite these safeguards and explanations, pressing the button could carry considerable emotional weight. Naaste 3 would have preferred the home-care professionals to administer the bolus, as doing it himself felt like poisoning his mother:

Naaste 3: Ik had, Ja je je moest natuurlijk die bolus geven. Als het dan, Als ze dan wakker, wakker zou worden. Maar dat vond ik ook niet fijn. Dat Vond ik ook helemaal niks. Ik had liever gehad dat, dat de thuiszorg dat zou

doen. Je dan ja, het voelde voor mij alsof ik mijn moeder aan het vergiftigen was, heel gewoon heel raar.

(English: Naaste 3: I had, yes, you of course had to give the bolus. If she then, if she would wake up, wake up. But I did not like that either. I really did not like that at all. I would have preferred it if the home care had done that. Then yes, it felt to me as if I was poisoning my mother, just very strange.)

Naaste 7 similarly avoided the button because she feared being personally responsible for her father's death:

Naaste 7: Het voelde ook een beetje als papa doodmaken en het voelde als een beetje gevaarlijk, want Het is echt wel onwijs Heftig spul, dus. Nou ja, Als ik er nou gewoon 20 ml teveel in gooi of zo CC of wat Het is, ja dan. Dan is ie opeens dood, en dan heb ik het gedaan, want ik geloof dat dat dat vooral was. Ik had echt geen zin om aan de knop te zitten, waardoor die dood ging ofzo.

(English: Naaste 7: It also felt a bit like killing dad, and it felt a bit dangerous, because it really is incredibly intense stuff. So, well, if I just put in 20 ml too much or something, cc or whatever it is, yes then, then he is suddenly dead, and I have done it. Because I believe that that was mainly it. I really did not feel like touching the button, causing him to die or something.)

Naaste 4 described the same action differently, framing his daughter's decision to administer the medication as an act of love for her mother:

Naaste 4: Ja. Het enige wat Ik kan zeggen uit liefde voor de moeder Ja [naam dochter], en die was dus toen even kijken, want [naam dochter] was dus 14 Toen ik begon, dus die was toen 27 en die gaf de morfine.

(English: Naaste 4: Yes. The only thing I can say is out of love for the mother, yes [daughter's name], and she was, let me see, because [daughter's name] was 14 when I started, so she was 27 then, and she gave the morphine.)

These accounts show that administering a bolus was not experienced merely as a practical care task. For some naasten, pressing the button created a strong sense of personal and moral responsibility for what might happen afterwards.

The need for rest

As the dying process progressed, several participants described an increasing need for rest, space, and slowness. Both naasten and healthcare professionals noted that naasten often became physically and emotionally exhausted over time. Nurse 1 described how the atmosphere around dying often slows down, and some healthcare professionals explicitly encouraged naasten to step away from the bedside from time to time or to accept support such as night care. Several naasten also described this exhaustion very concretely, for example by emphasising how tired they had become during the final phase and how necessary it was to continue caring for themselves as well.

The role of food and drink

Food and drink played an important role throughout the process. Several healthcare professionals explained that continuing to eat or drink could prolong the dying process, while reduced intake was often part of the natural progression towards death. GP 2 explicitly noted that patients do not die because they stop eating but rather stop eating because they are dying.

For naasten, however, this was not always easy to accept. Naaste 3 recalled that his mother woke up and asked for custard. Although he had been told that she should no longer eat, he still gave it to her because he felt it would be too cruel to deny her food and let her starve.

Some variation was also visible in professional perspectives. While several professionals emphasised that food and drink could slow the process or complicate sedation, Nurse 4 described encouraging small amounts of drinking in certain situations. This suggests that food and drink were not experienced as purely medical issues, but as practices shaped by emotion, interpretation, and the specific stage of the dying process.

Voluntarily stopping eating and drinking was described as a distinct way of dying. Naaste 7 described this process in detail in relation to her father, who had consciously decided to stop eating and drinking as part of his dying process. This required a long-term care process for naaste 7 and her siblings. Palliative sedation followed later within a longer trajectory of decline.

3.2.3 Support from healthcare professionals

The role of healthcare professionals

Across the interviews, healthcare professionals described their role as both practical and supportive. Although participants came from different professional backgrounds, including a terminal care nurse, district nurse, oncology nurse, student nurse, and general practitioners, the care they described overlapped strongly. Their shared aim was to make the patient as comfortable as possible and to guide both patient and naasten through the final phase.

This practical role included positioning the patient comfortably, placing cushions, washing and refreshing the body, emptying catheters, arranging medication, collecting and connecting pumps, coordinating night care, and contacting the GP when palliative sedation needed to be considered. Nurses also described themselves as closely involved in the practical organisation of the process, including maintaining contact between the patient, the GP, and the wider care team. Night care was described as particularly valuable because it allowed naasten to rest while someone continued to watch over the patient.

The role of the GP was described as more explicitly medical and coordinating. This included prescribing medication, deciding whether the criteria for palliative sedation had been met, estimating life expectancy, identifying refractory symptoms, determining the starting dose, and ensuring good handover to both the nursing team and the out-of-hours GP service. In this sense, the GP emerged as the central medical decision-maker within the process.

At the same time, both nurses and GPs described an important emotional and communicative role. This included being available to naasten, explaining what palliative sedation entails, preparing them for what may happen during the dying process, stimulating them to say goodbye, and

supporting them in difficult family situations. Some also described visiting after the death to offer condolences, reflect on how the process had gone, and provide a form of closure, not only for the family, but also in relation to the bond that had developed between the naasten and the care professionals.

Naasten's experience of healthcare professionals

Naasten described both supportive and difficult experiences with healthcare professionals. Positive experiences were mainly associated with trust, continuity and accessibility. Naaste 1 felt reassured by the GP's involvement and trusted the healthcare professionals to determine when the medication needed to be increased. Several naasten also valued the personal involvement of professionals and appreciated some form of contact or closure after the patient had died.

Difficult experiences could weaken this sense of trust. For Naaste 3, the discrepancy between the calm process he had expected and the distressing course he witnessed affected his relationship with the GP. Naaste 7 questioned whether the medication and medical support surrounding her father's sedation had been adequate and felt that greater expertise in palliative sedation might have changed the experience. Organisational disruptions also affected naasten, such as the temporary withdrawal of night care due to staff shortages, which caused considerable distress for a family that felt unable to manage without it.

Explanation and expectation management

Explanation and expectation management emerged as a central aspect of care. Both nurses and GPs described repeated conversations with patients and naasten about the end of life, the possibility of palliative sedation, and what could be expected during the process. Early conversations happened more informally, for example during washing or other routine care moments. Several healthcare professionals stressed that, as these conversations became more serious, it was important to involve naasten.

A recurring theme was that explanation often needed to be repeated several times. Professionals emphasised that explanations often had to be repeated, particularly regarding the purpose of the medication and the physical changes that may occur during dying.

Therefore, if death occurs shortly after the first dose or an increase in dosage, this should not automatically be interpreted as having been caused by the medication. Nurse 1 noted that her communication style was very direct. While this could be helpful for some families, it did not work equally well for everyone, suggesting that communication needs differed between naasten. Additionally, naaste 5 emphasised the importance of having one clear contact person. The involvement of many naasten, all wanting information, could easily complicate communication.

Healthcare professionals also felt it was important to emphasise that palliative sedation can be both a deeply precious and a difficult time for naasten, particularly because some expect a period of peace from the moment sedation begins, even though this cannot be assumed.

Additionally, professionals emphasised the importance of preparing naasten for bodily signs that may occur during the dying phase, as these may also become visible while palliative sedation is taking place. These included rattling breathing, altered breathing patterns and delirium. According to several care providers, good explanation could make a clear difference in how naasten interpreted these signs and whether they experienced them as manageable or frightening. Nurse 4 explicitly noted that there is still much to gain in this area, particularly in explaining delirium and the dying phase more clearly.

Naaste 1 would have appreciated a written leaflet, because the verbal explanation she received felt very clinical and left her with questions. The use of written information appeared to vary between professionals: some regularly gave leaflets, particularly when not everyone had been present during the conversation. Others knew such materials existed but rarely used them, relying instead on repeated verbal explanation.

3.2.4 Farewell as a process

The importance of saying goodbye

Both naasten and healthcare professionals described farewell as something that could involve different layers of the patient's social circle. In several accounts, family and friends were actively gathered so that they could still say goodbye before death or how friends and family came by while the patient was already sleeping. Nurse 1 noted that the social circle often becomes smaller towards the end of life, as visits cost energy and some people ultimately spend the final phase only with a partner, or even alone.

Several nurses and naasten emphasised the importance of having enough time and space to say goodbye. Meaningful moments could consist of lying in bed together, talking, or simply remaining present at the bedside. Participants also described how grief could begin before the patient died, particularly after a long and demanding illness trajectory. Naaste 7 described how leaving her father after spending time with him brought both sadness and a sense of gratitude:

Naaste 7: bijna elke avond Als ik, want ik fietste door het bos, want we hebben een parkje tussen in ons en zijn huis. Natuurlijk janken janken iedere avond te janken Als ik daar weer wegfietste om 11 uur's avonds. Ik had heel vaak de laatste shift en vroeg shift. Maar dat was ook wel helend ofzo. Snap je, dat je gewoon kan huilen en ook van blijdschap dat die verhalen nog verteld zijn en dat dat het dat het zo mooi afgerond leven was.

(English: Naaste 7: Almost every evening when I, because I cycled through the woods, because there is a little park between our house and his house. Of course, crying, crying, crying every evening when I cycled away from there again at 11 o'clock in the evening. I very often had the last shift and the early shift. But that was also healing or something. Do you understand,

that you can just cry, and also out of happiness that those stories had still been told and that it, that it was such a beautifully completed life.)

Beyond being physically present, farewell was also linked to the opportunity to say what had previously remained unspoken. Both naasten and healthcare professionals described these conversations as important for finding a sense of peace afterwards. Nurse 1 reflected that, when dying followed a longer illness trajectory, there could still be time to address difficult or unresolved matters. This was reflected in Naaste 7's final conversations with her father:

Naaste 7: Hij was gewoon toch aan het doodgaan. Bij hem vielen alle grenzen ook wel weg op een bepaalde manier en hij kon dus ook heel makkelijk praten over dingen waar hij vroeger niet over kon praten. Dus hij ging ook dingen uitleggen die ik nooit geweten heb. Waarom hij bepaalde besluiten had genomen. Dat ging ie allemaal vertellen. Ja, daardoor vielen er heel veel kwartjes en er was een puzzelstuk van een leven dat op zijn plek viel. Nou, Dat is echt wel chill, hoor.

(English: Naaste 7: He was simply dying after all. With him, all boundaries also disappeared in a certain way, and so he could also talk very easily about things he could not talk about before. So he also started explaining things I had never known. Why he had made certain decisions. He started telling all of that. Yes, because of that a lot of things fell into place, and there was a puzzle piece of a life that fell into place. Well, that was really quite nice, you know.)

For several naasten, farewell therefore involved not only being present before death, but also having time for conversations that contributed to a sense of closure afterwards.

Different moments of saying goodbye

Farewell was not always experienced as one single moment. Some naasten described how each family member took a private moment alone with the patient before sedation started, while others felt that the entire final phase had already become a gradual form of farewell through ongoing conversations and shared time together. Both naasten and healthcare professionals also described how small everyday moments gained greater meaning in this period, such as holding hands, listening to music, sharing a cup of tea, watching television together, or giving a final bath. Reminiscing was mentioned frequently and was often experienced as meaningful and comforting, for example by talking about enjoyable moments that had been shared or by looking through photo albums together.

Both naasten and healthcare professionals described the period before palliative sedation as an important time for farewell and for creating meaningful final moments. Some naasten consciously undertook one last activity together with the family, such as going on an outing or sharing a final meal, because they knew it might be the last time this was still possible.

Healthcare professionals emphasised the importance of saying goodbye before sedation began, as the patient would generally no longer be expected to remain communicative afterwards. Family members were therefore often encouraged to take time, share memories, express affection, and say what still needed to be said. GP 2 explicitly stated that farewell should not take place during the medical act of starting palliative sedation, as this leads to unrest.

For some naasten, the final and most definitive moment of farewell did take place at the moment of death itself. Several healthcare professionals

also described this as the point at which naasten often say goodbye once more, for example by touching, kissing, or speaking to the deceased. Some naasten described this moment as very clear and unforgettable. Naaste 4, for example, said he remembered his partner's actual moment of death with complete clarity.

Being present at the moment of death

Being present at the moment of death was highly important to several naasten, although their reasons differed. Some feared that they would feel guilty if they were absent, while others primarily did not want their loved one to die alone. Naaste 6 described briefly considering calling the hospice staff when his father appeared to be dying, but immediately returning to his side when no one answered because he wanted to be present for the final breath. Naaste 4 similarly described remaining close and avoiding going far away:

Naaste 4: Je bent blij dat je erbij bent, want Daarom ga je ook, want ik wandel er ook wel eens. Ging ook wel even In de tuin staan, maar je gaat niet ver weg. Want want ja, dan je wil erbij zijn bij. Dat is ook ook altijd bijzonder. We willen ook altijd erbij zijn.

(English: Naaste 4: You are glad that you are there, because that is also why you go, because I also sometimes go for a walk there. I also went to stand in the garden for a bit, but you do not go far away. Because, because yes, then you want to be there for it. That is also always special. We also always want to be there.)

These accounts illustrate how important it was for several naasten to remain close during the final phase and, where possible, be present at the moment of death.

The unpredictable course of palliative sedation could also make farewell feel repetitive. Naaste 3 described having to say goodbye each time his mother appeared to settle, only for her to wake again:

Naaste 3: Nou ja gewoon, Je moet afscheid nemen, het moet gewoon klaar zijn. En dan zit ze er weer en dan neem je weer afscheid. Dan zeg je; mam, ga lekker slapen. Het is goed zo, en dan een uur later zit ze er weer.

(English: Naaste 3: Well yes, just, you have to say goodbye, it just has to be finished. And then she is there again, and then you say goodbye again. Then you say: mum, go to sleep nicely. It is okay like this, and then an hour later she is there again.)

GP 2 described a different approach to this uncertainty. One patient consciously marked a moment of farewell earlier in the trajectory because she did not want every subsequent meeting to become another goodbye. Encounters after that moment could instead be experienced as additional time together. GP 2 therefore questioned why farewell is often postponed until the final moment, when meaningful conversations may also take place earlier.

Different awareness of farewell

Naasten described that not everyone was equally aware that death was approaching, which shaped how farewell was experienced. In some cases, children or other family members did not fully realise that they were saying goodbye. Naaste 1, for example, described how her son later said that he had not understood that he had been saying goodbye to his grandmother.

Several naasten also described differences in awareness within the family itself. In the case of Naaste 5, her mother-in-law had not attended the medical conversations and therefore did not realise how close her husband was to death, while others had understood this much earlier. She found it difficult to prepare her for this, especially because the necessary awareness then had to come very quickly. According to her, this difference also affected grieving: those who had understood the situation earlier had already begun grieving in advance, whereas her mother-in-law experienced the death as a much later shock. Naaste 6 described the moment of hearing that his father would not survive as an important marker, because it brought clarity and made it easier to start making decisions, while his father himself still held on to hope for some time. Before this, he found it very difficult to act given the differing perceptions of the seriousness of the situation. Nurse 2 similarly noted that some people remain in denial about how ill someone really is, and that a clear conversation with a physician is sometimes needed to make the situation more real.

Naaste 5: Zij wist niet wat er allemaal besproken was en Dat was niet naar haar, dusdanig gecommuniceerd dat het nog een korte tijd. Dat er nog een korte tijd was. Dus die heb achteraf die rouw heel erg moeten doormaken.

(English: Naaste 5: She did not know what had all been discussed, and it had not been communicated to her in such a way that there was only a short time left. That there was only a short time left. So afterwards she really had to go through that grief.)

After the death

Several naasten described how the deceased remained present in everyday life after death. This could take different forms, such as thinking back to meaningful moments together, visiting places associated with the deceased, or continuing to speak to them in some way. In some cases, memories became attached to specific moments surrounding the death itself, for example to flowers that happened to bloom during that period.

For Naaste 3, talking about the deceased was experienced as both valuable and difficult. He explained that he found it helpful to speak with someone who had gone through a similar experience, and that he often thought about his mother in moments when he was alone. At the same time, he avoided talking about it with his father and grandparents because he did not want to make them more upset. Even so, he also felt that speaking about it might be better for the grieving process. In this sense, the interview itself became meaningful to him, because it gave him a reason to talk about the experience again. It even prompted him to have a conversation with his father that same evening, which he later described as valuable.

Views on death and talking about dying

Participants also reflected more broadly on how death is understood and talked about. Several naasten and healthcare professionals noted that patients sometimes found it difficult to speak openly about dying, especially as long as there was still hope for recovery. Some naasten and healthcare professionals suggested that, if death is not spoken about, it can be kept at a distance. Others noted that people sometimes avoided such conversations because they did not want to burden their loved ones with sadness. Nurse 2 linked this partly to generational differences, arguing that older people often come from a context in which emotions were discussed less openly. More broadly, several healthcare professionals reflected that death has increasingly disappeared from everyday life and has been moved out of the home into hospitals, hospices, and institutions. In their view, this has made dying less familiar and less visible. Professionals and naasten also shared personal or spiritual views on death, ranging from very pragmatic statements such as 'when you are dead, you are dead,' to more reflective ideas about dying as an intimate or meaningful life phase, in which, for example, death and birth are seen as the most intimate moments.

3.2.5 Mutual influence between patient and naasten

Rest and unrest

Across the interviews, rest and unrest were described as having a reciprocal influence on both the patient and the naasten. Several healthcare professionals and naasten suggested that when the patient was calm, this often created calmness in the room as well. A peaceful atmosphere was associated with being able to stay present, share meaningful moments, and focus on the patient rather than on the practical or medical aspects of the situation. Some professionals therefore saw it as part of their role to manage the technical side of care, so that naasten could give their full attention to the patient. In these calmer situations, there was more space for forms of closeness such as holding hands, keeping watch, telling stories, or carrying out small caring gestures. Some professionals also felt that a quiet and familiar environment supported the patient in gradually letting go of life.

At the same time, unrest was described as deeply distressing for both the patient and the naasten. When a patient became restless, for example through irregular breathing, plucking movements, confusion, or visible struggle, this often generated feelings of panic, helplessness, and emotional overload in the people around them. Several healthcare professionals and naasten suggested that unrest could also be reinforced by the environment itself, such as by noise, conflict, crowded rooms, or differing opinions among family members. In those situations, the focus tended to shift away from presence and farewell towards controlling symptoms and managing tension. Healthcare professionals noted that such unrest could colour the dying process in a negative way, not only for the patient but also for the naasten, who might continue to carry these moments with them afterwards. Nurse 3 linked the patient's level of unrest to the activity surrounding the bedside:

Nurse 3: Dus hoe drukker het appartement of de de kamer waar iemand in ligt te sterven, hoe meer medicijn ik nodig heb om iemand plat te houden en plat te houden, betekent te te Laten slapen.

(English: Nurse 3: So the busier the apartment or the room where someone is lying dying, the more medication I need to keep someone down, and keeping someone down means letting them sleep.)

Vulnerability and changing family relationships at the end of life

Family dynamics emerged as an important source of difficulty during the dying process. Naasten described how family members did not always move through the situation at the same pace or share the same needs. Differences arose around the organisation of care, the role of rituals, caregiving responsibilities, and the time and space needed after death. In the case of Naaste 4, conflict arose over whether the dying process should be approached primarily as a medical process or organised in a more ritualised way. While a close family member wanted to proceed without medical support, Naaste 4 felt responsible for ensuring that the medical care was properly arranged. He did not reject rituals, but wanted to keep them separate from the medical procedure:

Naaste 4: Dat zei ze tegen die medische Mensen die allemaal binnen kwamen: Nee, zo doen we dat niet, wij doen dat zelf zonder de medische hulp daarbij. En toen zei ik: nee. Zo, dit heb ik zo geregeld toen zei zij, ja, maar zo wil ik het niet. En toen zei ik nou, Dat is dan jammer voor je, maar het is mijn vrouw. Dan zal jij daar toch naar moeten aanpassen, en jij mag eromheen allemaal prachtige dingen doen met met klankschalen en met met allemaal en maar niet dit.

(English: Naaste 4: She said to those medical people who all came in: No, we do not do it like that, we do it ourselves, without the medical help there. And then I said: no. I arranged it this way, and then she said, yes, but I do not want it like this. And then I said, well, that is too bad for you, but it is my wife. Then you will have to adapt to that, and you may do all kinds of beautiful things around it with singing bowls and with all kinds of, but not this.)

The disagreement also affected the children who were present. Naaste 4 recalled that they panicked when the family member left following the conflict, after which he had to explain why he believed the medical part of the process needed to be organised responsibly. The tension therefore affected both the practical organisation of care and the emotional atmosphere surrounding the patient.

Family tensions could also arise from differences in involvement and caregiving responsibilities. Naaste 7 described how the intensity of caregiving created tension between siblings who had not all approached or participated in the process in the same way.

Differences between family members continued after death. Naaste 1 described how her father wanted everyone to leave the house because he needed peace and quiet. Her brother immediately moved into a practical mode, while she wanted time to remain quietly beside her mother:

Naaste 1: Mijn broer ging in de regelfase of regelstand en ik had dat helemaal niet. Ik dacht ik, ik wil gewoon nu. Gewoon, gewoon bij mijn moeder zitten. Ja, en niet dat er al iemand langs kwam dat dat de dood werd geconstateerd en gelukkig was die mevrouw heel druk die arts. Dat duurde ook nog 3 uur ofzo voordat ze langs kwam.

(English: Naaste 1: My brother went into the arranging phase, or arranging mode, and I did not have that at all. I thought, I just want to now. Just, just sit with my mother. Yes, and not that someone already came by, that the death was confirmed, and fortunately that lady, the doctor, was very busy. It also took another three hours or so before she came by.)

Healthcare professionals similarly emphasised the importance of clear communication and role clarification, as differences within families could complicate both the organisation of care and the experience of the final phase.

Shifts in relationships

As death approached, several participants described changes in family relationships, often connected to the patient's increasing vulnerability and dependence. Nurse 1 observed that everyday concerns could become less important towards the end of life, allowing people to show themselves more openly while also becoming increasingly reliant on others.

This was reflected in the accounts of several naasten. Naaste 3 described how his family became much closer during his mother's illness. At the same time, he found this closeness difficult because it was continuously shaped by the awareness that these might be their final moments together.

In other cases, the final phase created forms of trust that had not previously existed. Although Naaste 5 had not had a particularly close relationship with her father-in-law, he entrusted her with his wishes during his final days:

Naaste 5: Nou meest waardevolle vond ik dat hij me in andere halve dag zoveel vertrouwen heb gegeven. Ik vind dat het leven dus twee meest intieme momenten hebben die je zelf beleef, dat is het geboren worden, dus dat is met je moeder en het sterven, en dat is meestal met je kinderen. En dat moment heeft ie met mij gedeeld, zijn wensen heeft ie met mij gedeeld. Het meest kostbare moment, dat meer dat ik dus ja betrouwbaar ben genoeg ben om dat wel te delen, of in ieder geval de vertaler te mogen zijn.

(English: Naaste 5: Well, what I found most valuable was that he gave me so much trust in one and a half days. I think life has two most intimate moments that you experience yourself, that is being born, so that is with your mother, and dying, and that is usually with your children. And he shared that moment with me, he shared his wishes with me. The most precious moment, that more that I am therefore, yes, trustworthy enough to share that, or at least to be allowed to be the translator.)

Naaste 6 similarly described how meaningful it was that his father ultimately placed his trust in him, particularly because he had rarely experienced that level of trust within their relationship before:

Naaste 6: Als iemand over zoiets, zo'n bijzonder stuk in je leven zeg maar zo'n belang zo'n bijzonder stukje fase van je leven, je totaal zeg maar de vertrouwen krijgt. Dat is best wel bijzonder als je dat zeg maar de rest van je leven niet zo vaak ervaren hebt.

(English: Naaste 6: When someone, about something like this, such a special part in your life, so to speak, such an important, such a special little phase of your life, gives you complete trust, so to speak. That is quite special if, so to speak, you have not experienced that very often for the rest of your life.)

The final phase could also create greater emotional and physical intimacy. Naaste 7 described how her father became more open, affectionate and emotionally available than he had previously been. Across these accounts, increasing vulnerability could strengthen existing relationships or create new forms of trust and closeness during the final phase.

Permission, acceptance and recognition

Across the interviews, letting go and acceptance were described as important but complex parts of the dying process. Both healthcare professionals and naasten referred to situations in which patients struggled to accept that death was approaching. Professionals associated this with fear of death, concern for those left behind, or difficulty accepting that no further treatment was possible. Naasten similarly described relatives who continued to hold on despite being visibly very ill. This could also make it more difficult for those around them to prepare for farewell.

Acceptance was not described as a single moment, but as something that could develop gradually. Naaste 6 described how his father moved between hope and acceptance before eventually appearing ready for the final phase:

Naaste 6: Ik had die overtuiging al eerder weet je, die uitslag was ook voor mij nul verassing, zeg maar. En ook niet een bevestiging ofzo, want ik ja, dat alles wees er gewoon op en en en dokter toe die bij hem was geweest, Die was daar ook volslagen duidelijk over en wat ik ook wel heel prettig vond. En maar goed, toen was hij er zelf ook, weet je hij heb daartussen heb ie nog sprankjes van hoop gehad, zeg maar ook wel eens niet, maar ook wel eens wel en. Toen was hij er voor mijn gevoel klaar voor, van Van dit, dit was hem dan en en alles wat er daarna nog nog kwam, was op weg naar het eind.

(English: Naaste 6: I had that conviction earlier already, you know, that result was also zero surprise to me, so to speak. And also not a confirmation or anything, because yes, everything just pointed to it, and the doctor who had been with him was also completely clear about it, which I also found very pleasant. But anyway, then he was also there himself, you know, in between he still had sparks of hope, so to speak, sometimes not, but sometimes also yes. And then, for me, he was ready, like, this, this was it then, and everything that came after that was on the way to the end.)

For Naaste 3, his mother's acceptance also affected the family's experience:

Naaste 3: Een maand voordat ze kwam te overlijden, toen ja. Ze had zoveel pijn. Toen had ze er gewoon, toen had ze er echt vrede mee. Toen had ze er echt vrede mee en dat deed ons ook gewoon goed.

(English: Naaste 3: A month before she came to die, then yes. She was in so much pain. Then she just had, then she really had peace with it. Then she really had peace with it, and that also just did us good.)

Naasten could also struggle to let go. Healthcare professionals described situations in which relatives continued offering food, resisted acknowledging that death was near, or remained emotionally unprepared for the end. Nurse 1 felt that this could influence the atmosphere and duration of the dying process:

Nurse 1: Soms zie je echt dat de familie nog iemand hier houdt, Omdat zij nog niet bereid zijn om los te Laten, dat zij daar nog niet zijn. En dan zie je echt Dat het langer duurt, ja, Dus ja, dat dat heeft zeker effect.

(English: Nurse 1: Sometimes you really see that the family is still keeping someone here, because they are not yet ready to let go, that they are not there yet. And then you really see that it takes longer, yes. So yes, that definitely has an effect.)

Several naasten described eventually expressing what they understood as emotional permission to die. They said things such as 'it is okay' or 'you can let go now.' This was not described as the patient passively waiting for permission, but as a shared recognition that the end had come. Naaste 3 recalled such a moment with his family:

Naaste 3: Op een gegeven moment stonden wij dus om ik mijn zusje en mijn vader die stonden om mijn moeder heen en toen zeiden we nog van, weet je, laat het gaan. De strijd is gestreden, Het is goed zo.

(English: Naaste 3: And at a certain point we were standing, so me, my sister and my father, we were standing around my mother, and then we still said: you know, let it go. The battle has been fought. It is okay.)

Across these accounts, acceptance developed relationally: the patient's readiness could help naasten let go, while naasten also sought ways to communicate that the patient no longer needed to continue fighting.

Dying in the presence or absence of naasten

Two recurring observations emerged around the circumstances of the moment of death. Several healthcare professionals described situations in which patients died shortly after family members or professionals had briefly left the room. They interpreted this as suggesting that some patients may need quiet or privacy during their final moments. In other accounts, naasten experienced the timing of death as closely connected to who was present. Naaste 7 felt that her father had waited until all his children had gathered around his bed:

Naaste 7: Hij voelde dat wij allemaal bij hem waren en hem vasthielden. Ik denk dat hij dat wel heel belangrijk vond, want anders had hij nooit. Het was gewoon bizar dat hij. Ik ben de hele dag en de dag daarvoor met mijn zus bij hem geweest. Dus hoezo is die toen niet vertrokken? Nee, Hij heeft echt gewacht tot iedereen er was, echt bizar.

(English: Naaste 7: He felt that we were all with him and holding him. I think he found that very important, because otherwise he never would have. It was just bizarre that he... I was with him the whole day and the day before with my sister. So how come he did not leave then? No, he really waited until everyone was there, really bizarre.)

Similar meanings were attached to the moment of death by other naasten. Naaste 1 described her parents being together when her mother died, while Naaste 6 felt that being alone with his father at that moment reflected the closeness they had shared throughout the illness trajectory.

3.2.6 Rituals and meaning-making

Rituals and meaningful acts before and around death

When asked, some participants referred to rituals as intentional acts that gave meaning to the dying process. These could be explicitly symbolic, such as lighting a candle, using singing bowls, playing meaningful music, or consciously saying goodbye. Rituals could also consist of ordinary habits that became ritual-like in the final phase because they were performed with greater awareness. Nurse 1 argued that terminal care would benefit from more ritual, while GP 2 cautioned that rituals should not interfere with the medical purpose of palliative sedation itself. In her view, rituals were more appropriately placed earlier in the process, for example around the moment when curative treatment ends. This broader understanding of ritual was reflected in Naaste 7's account, in which ordinary shared moments gained a heightened significance because she knew they would be among the last:

Naaste 7: Alles staat in een ander daglicht. Het is net alsof je zwanger bent, dan is ook de wereld nooit meer hetzelfde als je niet zwanger bent. En het had voor mij een hele ja, een hele bijzondere glans, want ik wist gewoon dat dat ik dat nooit meer ging meemaken met hem en dat ik er echt de rust en de tijd voor moest nemen om alles samen mee te maken wat we nog niet af hadden.

(English: Naaste 7: Everything is in a different light. It is just like when you are pregnant, then the world is also never the same again as when you are not pregnant. And for me it had a very, yes, a very special glow, because I just knew that I was never going to experience that with him again and that I really had to take the peace and the time to experience everything together that we had not yet finished.)

Rituals and meaningful acts after death

After death, naasten described a range of practices that were experienced as meaningful. These included giving the last rites, writing messages on the coffin, scattering ashes, commemorating the date of death, observing All Souls' Day (NL: Allerzielen), lighting candles in a chapel, or listening to music and eating foods that had been meaningful to the deceased. For some, the funeral itself was described as beautiful, especially when the wishes of the deceased had been discussed in advance and were clearly reflected in the ceremony. Naaste 2 found it meaningful to create something for others to take home from the crematorium, or to remain actively involved in shaping the farewell. At the same time, the period immediately after death also involved many practical tasks, such as contacting others, arranging the undertaker, clearing away belongings, and deciding what to keep. Several naasten described these days as exhausting, particularly after an already demanding caregiving process, while others experienced them as valuable.

Absence of rituals and differing needs

Not all naasten experienced rituals as important or necessary. Some stated that there had been no rituals around the death, either because the patient had no need for them or because the naasten themselves did not. Nurse 1 described participating in the last care after death as potentially healing, because it allowed family members to ensure that the deceased was laid out with dignity and care. Several naasten had indeed experienced this as valuable, while both naasten and professionals also stressed that this is not something everyone wants. So, the need for rituals is personal. However, participants did not always seem to use the term "ritual" in the same way. Some indicated that they did not want rituals, while still describing meaningful practices that may be interpreted as ritual-like. Religious traditions were sometimes mentioned as a source of inspiration, because they offer clearer rituals and markers around death and farewell.

3.3 Interview discussion

The interview findings show that naasten do not experience palliative sedation at home as a single medical intervention, but as an uncertain, relational and emotionally intense process shaped by the progression towards death, the patient's response to sedation, the duration of the process, communication with healthcare professionals, family dynamics, responsibility and farewell. To interpret these findings in relation to the literature and translate them into design implications, the discussion is structured around five themes: palliative sedation as an uncertain process; naasten between caregiving and farewell; administering a bolus; expectation management and support; and farewell and meaning-making.

Although the project initially explored rituals and meaningful moments around dying, the interviews showed that more fundamental needs first required attention. Before there can be space for calm, presence and meaningful farewell, naasten need to understand what is happening, know what to expect and feel supported during moments of uncertainty and responsibility.

3.3.1 Palliative sedation as an uncertain process

The findings support the understanding of palliative sedation as a complex and uncertain process rather than a clearly bounded medical moment. Van der Elst et al. (2025) describe palliative sedation as a process marked by uncertainty about eligibility, timing and effectiveness. This was also visible in the interviews, where uncertainty appeared across different moments: before sedation, during the start of sedation, throughout the vigil and around the moment of death.

Naasten described several moments that made the approaching death more visible. These included physical decline, increasing dependence, becoming bedridden, changes in consciousness and the transition to a high-low bed. Such moments were not only practical transitions but also made the end of life emotionally and symbolically more present. This suggests that support may be needed before palliative sedation itself starts, because uncertainty already begins during the broader dying process.

A central source of uncertainty was the difference between a calm and a difficult sedation trajectory. A calm sedation was associated with deep sleep, little visible response and a sense of peace in the room. A difficult sedation, in contrast, could involve waking, mumbling, irregular breathing, groaning, plucking movements or visible restlessness. These signs were especially distressing when naasten had expected that the patient would simply fall asleep and no longer wake. In such moments, the gap between expectation and reality became emotionally difficult to carry.

Duration of the sedation

The duration of sedation also shaped the experience. When sedation lasted longer than expected, naasten could become exhausted by waiting and watching. At the same time, several naasten did not necessarily want the process to be very short, because time could also provide space for presence, farewell and gradual acceptance. This shows that the experience of duration was subjective and depended on what felt bearable. This is consistent with Bäcklund et al. (2026), who describe that relatives may experience burden when they wonder whether the patient is comfortable and how long sedation will last.

Experience of the patient

Another uncertainty concerned what the patient still experiences during sedation. This was important for naasten because it shaped whether they kept talking, touching and staying physically close to the patient. Some naasten believed that the patient could still sense their presence, while others struggled when what they observed did not match what they had been told. Six et al. (2021) state that it is difficult to know with certainty what a patient still experiences during palliative sedation. Although the patient may appear asleep and may no longer respond, their actual level of awareness cannot always be reliably assessed. This supports the need for careful communication by healthcare professionals. Rather than making overly certain statements about what the patient does or does not experience, it may be more helpful to acknowledge uncertainty while still encouraging naasten to do what feels meaningful, such as speaking to the patient or holding their hand.

Limited understanding

The uncertainty surrounding palliative sedation was intensified by limited understanding of what the process entails. Several healthcare professionals described how palliative sedation was sometimes understood through comparison with euthanasia, contributing to expectations of a rapid, calm and medically straightforward process. This aligns with Van der Kallen et al. (2013), who found confusion about palliative sedation among the Dutch public. When sedation instead progressed gradually, required medication adjustments or involved periods of unrest, the mismatch between expectation and reality could contribute to fear, doubt and frustration. This highlights the importance of preparing naasten not only for the purpose of palliative sedation, but also for the possible variability of its course.

Decision-making

Decision-making added another layer of uncertainty. When patients were still able to express their wishes, naasten and healthcare professionals seemed to experience more clarity about whether sedation matched what the patient wanted. When the patient could no longer communicate clearly, the decision became more emotionally loaded, because naasten had to rely on earlier conversations or their own understanding of the patient's values. Belar et al. (2022) argue that conversations about palliative sedation should take place earlier in the process, before the patient loses the ability to participate in decision-making. The Dutch guideline also recommends discussing palliative sedation during the palliative phase and when refractory symptoms can be anticipated (Palliaweb, 2022a). However, the findings also show that palliative sedation cannot simply be planned as a fixed moment in advance. Advance care planning can therefore not remove uncertainty completely, but it can help clarify wishes, fears and possible scenarios before the situation becomes acute.

3.3.2 Naasten between caregiving and farewell

The role of naasten

The interviews show that naasten occupy a complex position during palliative sedation at home. They are not only observers of a medical process but are closely present in a personal environment and may become emotionally, practically and organisationally involved in care. For some, their role was mainly to be present with the patient. For others, it included practical care, coordinating visitors, supporting children, communicating with professionals or helping to create a calm atmosphere around the bed. This position could be meaningful, but also burdensome. Many naasten wanted to contribute to a peaceful dying process, while at the same time preparing to lose someone close to them. This placed them in a difficult position between caring and grieving. Garcia et al. (2023) show that, in home-based palliative sedation, family members may experience increased autonomy and responsibility because they are often closely involved in direct care and coordination with healthcare professionals. More broadly, Visser et al. (2020) describe informal care as indispensable in dying at home, while also warning that this reliance can increase the risk of overburdening.

The role of healthcare professionals

Healthcare professionals played an important role in shaping how manageable this responsibility felt. The GP remained the final medical decision-maker in relation to the indication for palliative sedation, which is consistent with Palliaweb (2022a), where the physician is responsible for determining whether the criteria for palliative sedation are met. At the same time, nurses and GPs also had emotional and communicative roles: explaining the process, preparing naasten for what may happen, encouraging farewell and supporting families in difficult situations. Although formal medical responsibility lies with the physician, naasten may still experience a sense of responsibility when interpreting the patient's comfort, deciding whether to call for help, staying close to the patient or responding to visible distress.

3.3.3 Administering a bolus

The pump as a morally charged object

A particularly striking finding concerned the use of the pump by naasten. Although healthcare professionals presented the pump as a safe and controlled way of giving extra medication when needed, naasten did not always experience it as a technical object. For one naaste, pressing the button felt like helping the patient or acting out of love. For others, it felt morally loaded, as if they were actively contributing to death or poisoning the patient. This shows that pressing the bolus button was experienced as an emotionally and morally charged action.

This tension between technical explanation and emotional meaning is important. It shows that practical involvement in care can also create feelings of guilt, fear and responsibility. Even when healthcare professionals explained that the pump was medically controlled and that pressing the button would not be the cause of death, some naasten still experienced the act as frightening or too responsible. Existing research appears to have paid limited attention to the specific experience of relatives who operate a bolus button during palliative sedation. This makes the pump a relevant and underexplored aspect of palliative sedation at home, which is further explored in the following design phase.

3.3.4 Expectation management and support

Explanation and expectation management

Explanation and expectation management emerged as central needs. Healthcare professionals repeatedly described that information often had to be repeated several times, because emotionally intense situations make it difficult for naasten to process and remember new information. This was also visible in the interviews with naasten, where unclear or overly simplified explanations contributed to distress when the process unfolded differently than expected.

Explanation was especially important when it helped naasten interpret bodily signs such as altered breathing, rattling breathing, groaning, gasping, restlessness or delirium. When these signs had been explained beforehand, they could be interpreted as part of the dying process or as something to monitor. When they had not been explained, naasten were more likely to interpret them as signs that something was wrong or that the patient was suffering. This suggests that information needs to be concrete and connected to what naasten may actually witness at the bedside.

The findings also show that the form of information matters. Verbal explanation is important, but it may not be enough in emotionally charged moments. Some naasten would have appreciated written information, particularly when verbal explanations felt clinical, vague or difficult to remember. Although existing Dutch information materials about palliative sedation are available, such as the Palliaweb folder (Palliaweb, 2024), they were not always handed out. This suggests a gap between available information and information that is actually accessible and usable in the home context.

Trust in healthcare professionals

Trust in healthcare professionals also shaped how supported naasten felt. Positive experiences were linked to reachability, continuity, clarity and the feeling that professionals were genuinely involved. Negative experiences were often linked to insufficient explanation, doubts about expertise, conflicting expectations or organisational issues such as staff shortages. This suggests that support is not only about providing information, but also about creating relational trust.

Previous experience may reduce uncertainty

Previous experience with healthcare or death also influenced how naasten interpreted the process. Naasten with such experience often felt more able to understand what was happening and take initiative. At the same time, this knowledge could make them more critical of the care they received. Naasten without prior experience were more likely to describe the process as overwhelming or confusing, especially when expectations did not match reality. This suggests that support should not assume prior familiarity with dying. Instead, it should make tacit professional knowledge more accessible to people who may be witnessing death from close by for the first time.

3.3.5 Farewell and meaning-making

Farewell was not experienced as one clearly bounded moment, but as a process that could unfold before sedation, during sedation, at the moment of death and after death. The period before palliative sedation was often particularly important, because conscious contact was still possible. Scheinfeld et al. (2024) show that meaningful final conversations can shape experiences of grief and bereavement. In the context of palliative sedation, this suggests that naasten may need time and guidance to say goodbye before sedation is started. This was reflected in the interviews, where healthcare professionals often encouraged naasten to say what still needed to be said before the patient was expected to become less communicative.

However, the uncertainty of palliative sedation could complicate farewell. Some naasten had already said goodbye, only for the patient to wake again or show signs of response. This could make farewell feel repeated. Many naasten also wanted to be present at the moment of death, which sometimes led them to stay close to the patient for long periods of time. Van der Elst et al. (2025) describe that relatives often want to remain close towards the end of life, while Bäcklund et al. (2026) note that being constantly at the bedside can be emotionally exhausting, especially when combined with sleep deprivation and uncertainty about when death will occur.

Reciprocal influence between patient and naasten

The interviews also showed a reciprocal influence between the patient and naasten. Calm in the patient often created calm in the room, while unrest in the patient could generate panic, helplessness and emotional overload in those around them. In calm situations, there was more room for closeness, silence, touch, stories or other meaningful acts. In unsettled situations, attention shifted towards symptom control and managing

tension. Van Dooren et al. (2009) similarly found that relatives' concerns during continuous palliative sedation were often related to the perceived well-being of the patient. This supports the idea that naasten's experience is strongly shaped by how they interpret the patient's comfort.

Family dynamics

Family dynamics further influenced the experience. Family members did not always have the same level of awareness, readiness or need for information. Differences in pace, interpretation and expectations could create tension around care, rituals, decision-making or practical arrangements after death. Lokker et al. (2012) show that awareness of dying is associated with acceptance of dying, and that perceptions of awareness can differ between those involved. This suggests that communication should not only focus on one primary caregiver but should also consider how information is shared within the wider family system.

The role of rituals and meaning-making

Rituals and meaning-making remained relevant, although not in the way initially expected at the start of the project. Some naasten described explicit rituals, such as lighting a candle, playing music or consciously saying goodbye. Others did not identify their actions as rituals, but still described meaningful practices such as holding a hand, washing the body, sitting in silence or staying close. Van der Weegen et al. (2019) describe how rituals can help create meaning, connection and recognition in palliative care. In this project, however, the findings suggest that rituals require a foundation of understanding and support. When uncertainty and responsibility dominate the experience, there may be less emotional space for calm, presence and meaning-making.

4 Exploring the pump in context

The interview findings suggest that the main design opportunity does not lie in creating ritual-based interventions alone. Rituals and meaningful moments remained relevant, but the interviews showed that naasten first needed support in understanding what is happening, feeling reassured in their role and navigating uncertainty during palliative sedation at home.

A key insight was that this uncertainty became especially visible around the infusion pump. The pump was medically used to provide comfort, but for naasten it could also become a visible symbol of transition, responsibility and doubt. Therefore, the design phase did not focus on changing the medical function of the pump, but on supporting the moments surrounding its use.

The aim of the design phase is to develop supportive interventions for naasten around the infusion pump during palliative sedation at home. These interventions aim to help naasten better understand what is happening, feel supported in moments of uncertainty and deal with the emotional and practical questions that arise around the pump.

4.1 Role and context of the infusion pump

Because the pump emerged as a key point of uncertainty and responsibility, additional research was conducted into how it is used in continuous palliative sedation and how responsibilities are organised in home-based care.

For continuous palliative sedation, the Dutch guideline on Palliaweb (2022a) describes a stepwise medication approach. Medication is adjusted gradually until sufficient patient comfort is reached, and additional boluses or dosage increases may be needed when comfort is not yet achieved. This shows that sedation is not always immediate or predictable but can involve careful titration over time.

To complement the national guideline with a more practical view of pump use at home, a regional guideline from the Oss–Meerijstad–Uden area was consulted (Van der Ven & Verhoeven, 2020). While this is not a national protocol, it shows how responsibilities around pump use can be organised in home-based palliative care. The GP initiates treatment, informs the patient and family, coordinates medication availability and contacts the technical home-care nursing team. The nurses are responsible for preparing, installing and checking the pump according to protocol and GP prescription.

This additional research shows that pump use is embedded in a coordinated system of medical decision-making, technical execution and follow-up care. For naasten, trust in the pump is therefore not only related to the device itself, but also to trust in healthcare professionals, coordination processes and clarity about their own role.

4.2 Hospice visit

Understanding the pump in practice

To better understand the role of the infusion pump, I visited a hospice where the pump was demonstrated by a hospice employee. The infusion pump is shown in Figure 4. The visit helped me understand the pump's appearance, set-up, practical use and position within a care environment.

In the hospice, the pump was placed close to the patient, often near the bedside, without physically interfering with care. However, the employee explained that certain signals from the pump, such as beeping when there is air in the tube, may still create concern for naasten. Even when the alarm has a clear technical function, naasten may interpret it as a sign that something is wrong.

Hospice employee: Ze denken vaak, als het toch ga piepen of zo van; nou gaat het wel goed? Dat ze toch wel een beetje nerveus van worden.

(English: Hospice employee: They often think, if it starts beeping or something, like: is it still going well? That they do become a bit nervous about it.)

The hospice employee also emphasised that the home setting differs from the hospice context. At home, the environment is more personal and the situation can feel closer to naasten. This suggests that a pump that is manageable within a professional care setting may still feel emotionally significant in the home.

Overall, the hospice visit confirmed that the pump itself is not necessarily the main design problem. The device can function well within care practice, but its signals and the moments surrounding its use may raise uncertainty for naasten, especially in the more personal home context. This strengthened the design focus on supporting how the pump is understood, explained and experienced, rather than redesigning the medical device itself.

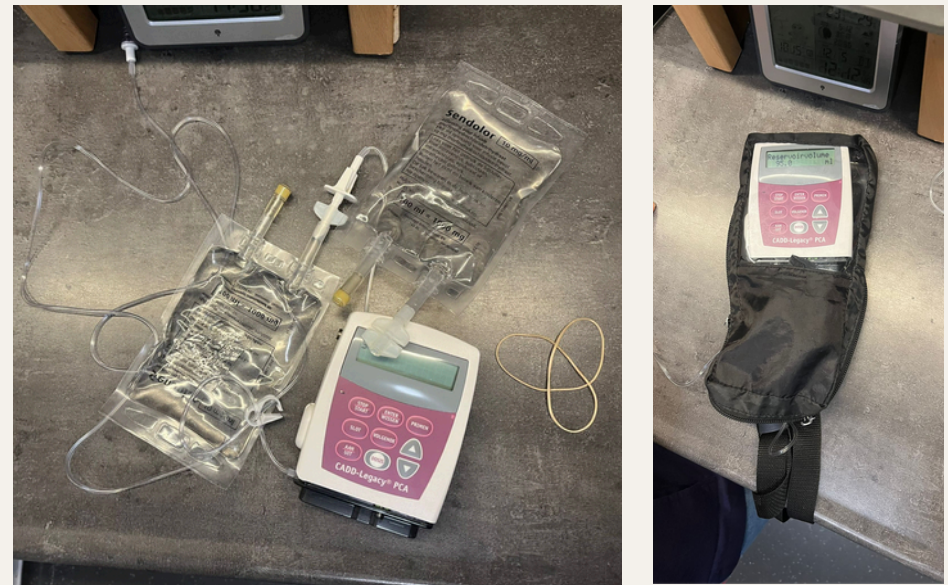


Figure 4. Infusion pump demonstrated during the hospice visit

5 Deepening needs and shaping design directions

The preceding research established the main design focus and identified several needs surrounding palliative sedation and the use of the infusion pump. The interviews provided individual accounts of these needs, while the hospice visit added insight into the practical context in which the pump is prepared and used.

Further exploration was needed to understand how these experiences relate to one another, which moments require most attention and what forms of support would feel meaningful in practice. The co-creation session was therefore used to deepen and prioritise the identified needs and to explore initial directions for support.

5.1 Co-creation method

Rationale

In complex and context-specific healthcare situations, creative problem-solving can support improvements in practice and the implementation of evidence-based strategies. Since these challenges are strongly shaped by local conditions and knowledge that may be difficult to transfer, the involvement of people directly affected by or involved in the situation is particularly valuable for understanding what is needed and developing appropriate responses (Brewster et al., 2021).

Co-creation was selected as a participatory approach within Creative Problem Solving. Following Michalik (2023), co-creation is a collaborative method in which participants jointly explore and address complex challenges. It enabled naasten to contribute experiential knowledge that may be difficult to access through individual interviews alone. By sharing and comparing their experiences, participants could recognise similarities and differences, respond to one another's perspectives and develop a more collective understanding of the situation.

The session aimed to deepen and specify the needs identified during the preceding research, explore which moments of uncertainty appeared to require further attention and generate initial directions for supporting naasten. This resulted in the following design statement:

How to improve the experience of naasten during palliative sedation by helping them feel more at ease and confident when using the pump.

Participants and recruitment

Three naasten participated in the co-creation session: Naaste 3, Naaste 5 and Naaste 6. All had previously participated in the interview study and were therefore already familiar with the research topic.

Naaste 3 and Naaste 5 had experienced continuous palliative sedation at home, including the use of an infusion pump. Naaste 6 had experienced palliative sedation in a hospice setting. Although this experience did not involve the same use of the pump at home, it remained relevant because the session also addressed broader experiences such as uncertainty, communication, professional support, responsibility and saying goodbye. This perspective also helped distinguish needs related specifically to the pump from needs connected to the wider process of palliative sedation.

Participants were selected based on the relevance and recency of their experience. Their availability was subsequently considered when forming the group. Additional naasten were approached through the researcher's wider network, but no further participants were available within the timeframe of the study.

The small group size allowed each participant sufficient space to share personal experiences and respond to the perspectives of others.

Roles during the session

Following the principles of Creative problem solving, three roles were distinguished during the session (Heijne & van der Meer, 2019):

The **problem owner** introduces the design focus and provides relevant context. Within this study, I fulfilled this role by presenting the findings from the interviews and explaining the focus on uncertainty and support around the infusion pump.

As the **facilitator**, I structured the activities, monitored the available time, supported a safe atmosphere and encouraged equal participation. To prevent my existing knowledge and assumptions from directing the outcomes, I used open questions, allowed participants to first reflect individually and avoided judging ideas during the session.

The participating naasten formed the **resource group** and contributed their experiences, interpretations and ideas. They were not expected to formally analyse the material, assess practical feasibility or make final design decisions. These tasks remained part of my responsibility as the designer.

The resource group was given freedom to make meaningful choices during the session, supporting a sense of ownership over the outcomes (Michalik, 2023). When members of the resource group found it difficult to connect or further develop their contributions, I also took on a limited role as co-designer. I reflected ideas back to the group and made possible connections visible, while ensuring that these connections remained based on the participants' input.

Planning and set-up

Preparing the session required materials for both documentation and participation. A recording device was used to capture the conversation, and consent forms were prepared in advance. Large sheets, markers and individually coloured sticky notes were provided to make each participant's contributions traceable. Each participant was assigned one colour and wrote their name on a sticky note that remained visible in the room.

A visual conversation tool, referred to as the *praatplaat*, was developed based on the preceding desk research and interview findings. The tool consisted of ten separate illustrated cards that together represented key moments in the palliative sedation process. A *praatplaat* supports dialogue and shared understanding by helping participants reflect on complex experiences in a structured but accessible way (Zorgakkoorden, 2024; De Nederlandse GGZ, n.d.). The set-up at the beginning of the first diamond is shown in Figure 5, while the ten illustrated cards forming the *praatplaat* are presented in Figure 6.



Figure 5. Set-up at the beginning of the first diamond

Because the session addressed personal and potentially emotional experiences, attention was paid to creating a safe and comfortable environment. The session took place in a quiet coaching room where participants could sit together, move around the materials and step outside when needed. Water, tea, snacks and tissues were available. Following the facilitation principles described by Heijne and Van der Meer (2019), an icebreaker, informal break and energizer were included to support group connection and maintain energy throughout the session. Michalik (2023) emphasises the importance of physical presence and an appropriate environment. Therefore, the space was arranged to facilitate face-to-face interaction and collaboration, as shown in Figure 7 on the next page.



Figure 6. Ten illustrated cards forming the *praatplaat*

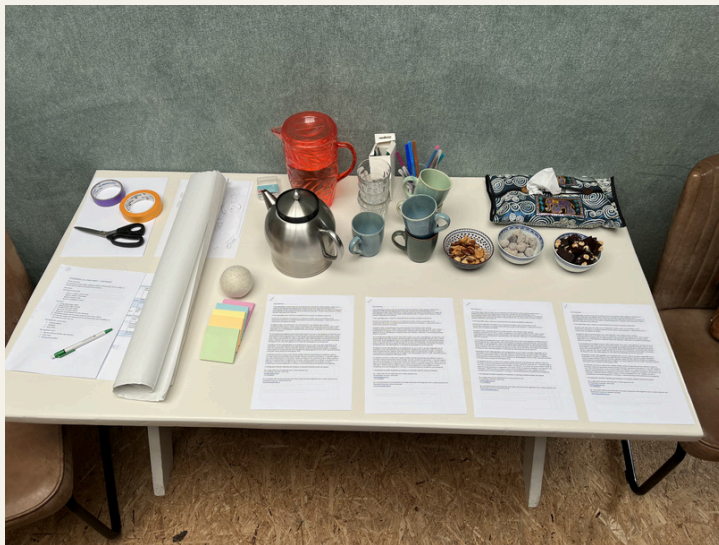


Figure 7. Materials and set-up for co-creation session

Session structure

The session was structured according to the Creative Problem Solving approach described by Heijne and Van der Meer (2019). Within this approach, each diamond consists of three phases:

- **Diverging** involves generating a broad range of experiences, perspectives or ideas without immediate evaluation.
- **Reverging** involves revisiting, arranging and discussing the generated material to identify relationships and develop a shared understanding.
- **Converging** involves selecting and prioritising the most relevant themes or options to take forward.

Heijne and Van der Meer (2019) distinguish three diamonds for problem finding, idea finding and solution finding. This session used the first two as a guiding structure.

The first diamond focused on deepening and organising the experiences and needs identified in the preceding research. No formal converging exercise was included; instead, differences in emphasis emerged through the depth of the discussion.

The second diamond was initially planned to include divergence, reverging and informal convergence through group discussion. However, as the preceding discussion took more time than anticipated, the remaining session time was deliberately used to further elaborate the generated ideas rather than rush their clustering and prioritisation. The second diamond therefore remained focused on idea generation, during which members of the resource group naturally responded to, connected and further developed one another's suggestions.

A third diamond, focused on developing and selecting a final solution, was not included in the session design. Given the limited available time, the session prioritised the activities in which the experiential knowledge of naasten was most valuable: deepening their needs and generating possible directions for support. Further synthesis, evaluation and selection required the outcomes to be considered alongside the interview findings, literature and wider healthcare context. These activities therefore remained my responsibility as the designer and were conducted after the co-creation session.

A detailed session guide, including the sequence of activities, timing, facilitation questions and ground rules, can be found in Appendix 4.

5.2 Co-creation execution

Introduction, icebreaker and briefing

The session began with a short welcome in which I introduced myself, explained the general purpose and structure of the session, and asked the participants to sign the consent forms.

This was followed by an icebreaker to allow participants to become familiar with one another and lower the threshold for participation. The participants stated their names and passed a ball to another person to indicate whose turn it was. This simple interaction supported early engagement and encouraged open communication (Heijne & van der Meer, 2019).

After the icebreaker, I provided a short briefing on the research context and the focus of the session. I explained that the preceding research had identified uncertainty and the infusion pump as important elements within the experience of palliative sedation. The resource group was informed that the session would focus on deepening the needs of naasten and exploring how the moments surrounding the pump could be better supported. It was emphasised that the aim was not to change the medical functioning of the pump itself.

First diamond: deepening the needs

Diverging

The diverging phase focused on collecting a broad range of experiences, emotions, uncertainties and needs related to palliative sedation. The resource group first reflected individually on the situations shown on the praatplaat and placed sticky notes on the relevant illustrations. This allowed them to formulate their own experiences before hearing the responses of others.

The illustrations and sticky notes were then discussed one by one. Members of the resource group were invited to explain what had happened in each situation and what they had understood or found unclear. As facilitator, I used open follow-up questions to further explore moments of uncertainty, tension, responsibility and emotional burden.

Reverging

During the reverging phase, the resource group and I revisited the experiences and needs collected during the first activity. Sticky notes that appeared to concern similar moments or needs were placed together on the large sheets.

I first demonstrated the clustering activity by grouping a small number of sticky notes as an example. The members of the resource group then organised the remaining notes themselves, creating clusters based on similarities and differences they identified in their experiences. They could move notes, separate experiences with different meanings and add explanations where needed. This resulted in a shared overview of recurring and contrasting experiences, which informed the themes taken forward into the idea-generation phase.

Converging

No separate converging activity was conducted. However, differences in emphasis emerged naturally during the discussion, as members of the resource group spent more time elaborating on and responding to certain themes. Together, the resource group and I formulated short thematic headings for the identified clusters. These headings summarised the discussion and provided direction for the idea-generation phase. The depth of discussion was interpreted as an indication of relevance, rather than as an explicit prioritisation by the resource group.

Break and energizer

After the first diamond, a short break was introduced. The jointly formulated thematic headings were retained as the starting points for the second diamond. This was followed by an energizer activity designed to re-activate creativity and group engagement. The energizer consisted of a rapid idea-generation exercise in which members of the resource group were asked to generate alternative uses for a common object (a sock), passing a ball to indicate turns.

Second diamond: idea generation

Diverging

The second diamond focused on generating possible directions for supporting naasten during palliative sedation. The themes identified during the first diamond were presented as starting points for idea generation.

Members of the resource group first wrote down their initial ideas individually on sticky notes. This activity followed the principles of brainwriting described by Heijne and Van der Meer (2019), allowing them to formulate and externalise their thoughts before a collective discussion. It also reduced the likelihood that more vocal members would dominate the idea-generation process.

During the individual activity, members already began sharing and discussing their ideas with one another. As facilitator, I used this emerging interaction to guide the group into a more in-depth discussion. Since it had become clear that there would not be sufficient time for separate reverging and converging activities, the remaining time was used to further explore the generated ideas.

Members were encouraged to respond to one another's suggestions and to combine, adapt or further develop them. The group discussion therefore served not only to share ideas, but also to explore the experiences and reasoning behind them. The planned reverging and informal converging activities were therefore not conducted as separate phases. Further clustering and evaluation were completed by me after the session as part of the design synthesis.

Reflecting and closing

The session ended with a short reflection to check whether the generated material accurately represented the participants' experiences and ideas. Participants were given space to describe how they felt after the session and were reminded that they could contact the researcher afterwards if they wished to add or clarify anything. To support further analysis, all sticky notes and large sheets were collected and photographed. The audio recording was retained for transcription, and additional notes were made about explanations and connections expressed during the discussion that were not fully visible in the written material. This documentation allowed the outcomes of both diamonds to be reviewed and further synthesised after the session, as recommended by Heijne and Van der Meer (2019).

Participants were thanked for their contribution and informed about how the results would be used in the following design phases. Arrangements were also made to share the outcomes with them afterwards.

A reflection on the execution of the session, including the facilitator role, time management and adaptations made during the second diamond, can be found in Appendix 5. Photographs and an overview of the generated materials are included in Appendix 6.

Two complementary outputs

The co-creation session produced two related forms of output. The first diamond deepened the understanding of the experiences, uncertainties and needs of naasten. The second diamond generated and further developed possible directions for support.

The following two sections present the outcomes of both diamonds: Section 5.3 describes the needs that were further clarified, while Section 5.4 presents the ideas that emerged in response to them.

5.3 Results diamond 1 - deepening the needs

The first diamond focused on further understanding the experiences and needs of naasten during palliative sedation. By discussing and clustering the situations shown on the praatplaat, the resource group identified recurring moments of uncertainty, responsibility and emotional burden. The following section presents the themes that emerged from these discussions. The findings added to the praatplaat during the first diamond are shown in Figure 8.

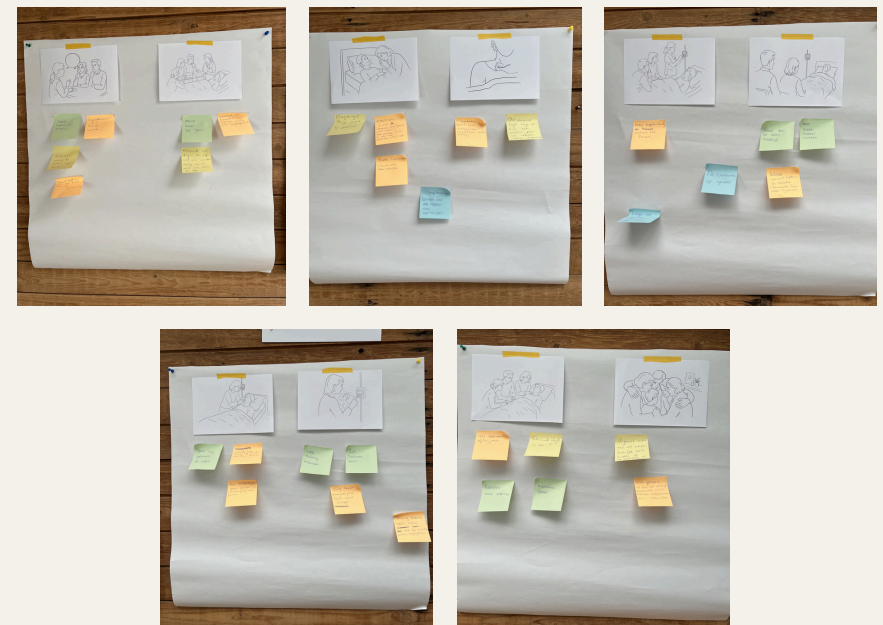


Figure 8. Findings added to the praatplaat during the first diamond

5.3.1 Uncertainty shapes the experience

Uncertainty and lack of knowledge shape the experience

Participants consistently described the period of palliative sedation as an intensive and emotionally demanding phase of care. This intensity was related to the constant alertness, sleep deprivation, and ongoing responsibility experienced by naasten. The intensity of the process was described as unexpected for naaste 3, without prior experience in end-of-life care.

Knowledge and prior experience were repeatedly described as key factors influencing how the situation was experienced. Naaste 5, who had professional care experience, described feeling certain due to her background knowledge, while Naaste 3 described the process as highly confusing due to a lack of prior exposure to death. He explained how the uncertainty was reinforced within his family, as his anxiety led to visible physical stress reactions, which in turn increased his father's concern. Naaste 3 reported that he did not receive any mental or emotional support during the process, nor was he informed about where such support could be accessed.

Uncertainty after death

After the moment of death, participants described uncertainty about what would happen next. This 'now what?' moment became visible in a short exchange between Naaste 6 and Naaste 5:

Naaste 6: Dat je onderweg naar het sterven, maar dan ben je dan dan dan is de de stervende gestorven. En dan?

Naaste 5: Ja. Dan komen ze de medicijnen ophalen en dan komen ze de pomp ophalen en echt.

(English: Naaste 6: That you are on the way to dying, but then you are, then, then the dying person has died. And then?)

Naaste 5: Yes. Then they come to pick up the medication, and then they come to pick up the pump, and really.)

Although participants could identify some immediate practical steps, the exchange reflected a lack of clear guidance about the wider process following death.

Advantage of experience

Naaste 5 reflected that her prior experience with death and healthcare background helped her understand what was happening at the bedside. Naaste 6 similarly described how previous experiences shaped his response. After being kept at a distance during a loss at age 16, he was more involved when experiencing another sudden death at age 29. He experienced this involvement as meaningful and felt that it helped him process the loss by providing greater familiarity with death and the processes surrounding it.

5.3.2 Communication as the underlying factor

Bad experience due to lack of explanation

Communication before the start of sedation again emerged as a concern during the co-creation session. Building on his earlier interview, Naaste 3 reiterated that he had been prepared for a peaceful process, while possibilities such as delirium, agitation and fluctuating awareness had not been discussed. This made it difficult for him and his father to determine whether what they observed was expected or whether additional support was needed:

Naaste 3: Ja, tegen ons is gezegd, van, uh, ze gaat lekker slapen. En ja, dan heb ze geen pijn en dan zo wordt het tegen ons gezegd, Maar het is helemaal niet lekker slapen.

(English: Naaste 3: Yes, we were told, like, uh, she is going to sleep nicely. And yes, then she will have no pain, and that is how it was said to us. But it is not sleeping nicely at all.)

The co-creation discussion added a further dimension to this earlier finding. When Naaste 5 mentioned hospice-at-home services and volunteer end-of-life support, Naaste 3 indicated that he had not known these options existed and would have used them if they had been communicated. The issue was therefore not only a lack of preparation for possible symptoms, but also limited awareness of where additional support could be found.

Participants jointly reflected that communication gaps become particularly consequential when sedation does not progress as expected. Naaste 6 described how an unpredictable course can leave naasten unsure of how to interpret what is happening:

Naaste 6: Ja en, en hoe loopt het proces dan specifiek bij jullie, weet je wel van voor hetzelfde geld, glijdt je moeder Mooi regelmatig weg en dan denk je nou, dat hebben we netjes gefixt met elkaar.....Nu krijg je allemaal tussen fases van; wat heb ik nou aan mijn broek hangen?

(English: Naaste 6: Yes, and, and how does the process then specifically go with you, you know, because for all you know, your mother slips away nicely and steadily, and then you think, well, we fixed that neatly together... Now you get all kinds of intermediate phases of: what have I got myself into now?)

Traumatic experience

For Naaste 3, the distress was not limited to one specific moment, but resulted from the combination of an unpredictable sedation process, insufficient preparation and the absence of accessible support. During one night, his mother became restless while neither he nor his father understood what was happening or knew whether additional help was needed. Afterwards, they continued to question whether they had responded appropriately. Naaste 3 described the sedation process as the most traumatic part of his mother's illness and explained that this made it difficult for him to imagine that it could also be experienced as meaningful:

Naaste 3: Vooral dit proces is wel het meest traumatisch geweest, van de 2,5 jaar dat ze ziek is geweest, vond ik dit wel wat het meest heftige eigenlijk en Daarom kan ik me niet voorstellen dat dit ook mooi kan zijn.

(English: Naaste 3: Especially this process has been the most traumatic, of the 2.5 years that she was ill, I actually found this the most intense, and that is why I cannot imagine that this can also be beautiful.)

Most helpful communication

When discussing what form of communication would have been most helpful, the group compared advance explanation with support during the process. The discussion then broadened towards the need to prepare naasten not only for the course of palliative sedation, but also for the dying process and what follows after death:

Naaste 6: Al zou je het maar een van de twee mogen kiezen. Wat had je het meest geholpen? Is het dan, zeg maar; uitleg vooraf, van pas op, ik bedoel, ze kan in een delier belanden en dat ziet er ongeveer zo uit of ondersteuning gedurende het hele proces, zeg Maar dat je; Oh, wat gebeurt er nu dat je dan gelijk kan vragen wat er aan de hand is? Wat wat Als je zou mogelijk kijk, alletwee is ideaal, denk ik.

Naaste 3: Ik denk dan toch het eerste, dat je goed ingelicht wordt, wat er wat er kan gebeuren, zodat je erop kan anticiperen, want nu heb je Geen uitleg gekregen en je. Je hebt geen zorgen gedurende het proces Als de vraag zich op doe, zou doen, kan je het niet stellen, maar goeie uitleg over hoe het proces allemaal in elkaar zit. Dat dat had ik liever gehad.

Naaste 6: Dus Je moet eigenlijk in in een spoedcursus sedatie krijgen.

Naaste 5: En overlijden.

Naaste 6: En overlijden. Ja, heel goed, ja, want Dat is inderdaad ook nog, de patiënt sterft en dan? Daarom had ik hem ook opgeschreven want Dat is eigenlijk waar Niemand het erover hebt. En op een gegeven moment ben je ook nog een keer dood.

Naaste 5: Die heb ik ook opgeschreven: en weer door.

EN: Naaste 6: What would have helped you the most? Is it then, so to speak, explanation beforehand, like, watch out, I mean, she can end up in a delirium and that looks something like this, or support throughout the whole process, so to speak, that you: oh, what is happening now, that you can immediately ask what is going on? What, what if you could possibly, look, both would be ideal, I think.

Naaste 3: I think then still the first, that you are well informed about what can happen, so that you can anticipate it, because now you received no explanation and you. You have no support during the process, if the question arises, would arise, you cannot ask it, but good explanation about how the whole process works. I would have preferred that.

Naaste 6: So you actually need to get a crash course in sedation.

Naaste 5: And dying.

Naaste 6: And dying. Yes, very good, yes, because that is indeed also still, the patient dies and then? That is why I had also written it down, because that is actually what nobody talks about. And at a certain point you are also dead.

Naaste 5: I had also written that down: and then move on.

Need for more attention

Naaste 3 and 5 jointly reflected that it was striking that communication itself emerged as a central issue in the co-creation session, as they felt this should ideally not be a problematic aspect of care. Naaste 6 responded that, in reality, communication is often a key factor influencing whether processes succeed or fail in practice.

Participants discussed possible reasons for these communication gaps. Naaste 5 suggested that expectations regarding what family members already know may be too high, resulting in insufficient explanation from healthcare professionals. Naaste 6 added that the variability and unpredictability of palliative situations may make it difficult for professionals to consistently provide more detailed guidance, as each case differs significantly. He suggested that broader system constraints, including staff shortages, may contribute to limited communication. Naaste 5 emphasised that a core issue is the lack of knowledge and especially time among healthcare professionals. Naaste 6 further elaborated that even small amounts of additional explanation, sometimes only a few minutes, can have a significant impact on understanding and reassurance, and should therefore not be omitted. He suggested that, in practice, healthcare professionals should, as it were, tick off the most important information.

Despite this, participants all agreed that the time healthcare professionals do have is generally used with care and attention, but that it is often insufficient to fully meet the informational needs of families.

5.3.3 Uncertainty surrounding the pump

The pump itself was not experienced as disruptive

Naaste 3 and 5 reported that the infusion pump itself was not disturbing. They described the device as clearly constructed, with an intuitive button interface, and stated that its appearance and sound did not cause discomfort:

Naaste 5: Maar die pomp die stond bij ons niet Als, die lag gewoon bij het kussen. Dat viel eigenlijk niet eens op.

(English: Naaste 5: But that pump, with us, it was not standing there as, it was just lying by the pillow. It actually did not even stand out.)

Both participants noted that the pump produces audible and visible cues approximately every five minutes when delivering medication. The administration of an additional bolus also produces noticeable sounds and fluid movement. While these signals did not cause concern, they increased awareness of ongoing activity and provided reassurance that an action had been successfully completed:

Naaste 5: En, Dat is dan ook weer een bevestiging dat je iets gedaan hebt. Ja, en je wilt toch weten of het Daadwerkelijk iets doet, wat je gedaan hebt.

(English: Naaste 5: And that is then also another confirmation that you have done something. Yes, and you still want to know whether what you have done actually does something.)

A practical challenge was identified by Naaste 3, who described how his mother received an earlier morphine pump that did not have a support rod, while she was still mobile. This forced his father to resort to an improvised solution: he made a rod with wheels underneath himself.

Disruptive actions surrounding the pump

While the pump itself was not disruptive, the actions surrounding its use were reported to create considerable uncertainty and require Naaste to act independently. Naaste 3 described a moment when a nurse asked him to verify the dosage while the palliative sedation was being administered. He had no prior experience or knowledge to determine whether the dose was correct, which left him feeling confused. For Naaste 5, the experience was confusing because the nurse placed the pump very quickly and then immediately left, leaving her with a sense of uncertainty about what to do next:

Naaste 5: Die verpleegkundige kwam binnen, plaatste die pomp en was weer weg. Dat ging ook heel snel, dat je denkt van ja, en nu en nu, maar wat gaat er nu? Wat gaat er nu gebeuren?

(English: Naaste 5: That nurse came in, placed the pump and was gone again. That also went very quickly, that you think, yes, and now, and now, but what is going to, what is going to happen now?)

Bolus administration and the need for support

A moment that strongly illustrates several of the identified issues is the administration of an additional bolus. In this situation, uncertainty, lack of communication, and the need for additional support became particularly visible. Administering a bolus was an especially difficult moment for Naaste 3, during which he felt unsupported and expressed a strong need for additional guidance. He and his father were alone, without any professional care present, and he would have preferred that someone else had administered the bolus on his behalf.

Naaste 3: En toen werd ze zo onrustig en dan moet jij zelf moet jij die bolus toedienen, dat vond ik helemaal niks. Het voelde echt alsof ik mijn eigen moeder aan het vergiften was. Dat deed wel pijn.

(English: Naaste 3: And then she became so restless, and then you yourself have to administer that bolus, I did not like that at all. It really felt as if I was poisoning my own mother. That did hurt.

In the case of Naaste 3, the decision to administer palliative sedation was a shared decision, including his mother, his father and himself. Yet, during the palliative sedation, he doubted whether his mother really wanted it. This was mainly because he had not been prepared for the possibility of delirium or fluctuating awareness. That is why he also did not know what to do in this situation. He had initially expected that his mother would simply fall into a calm and continuous sleep, as communicated by both the general practitioner and home care services. The discrepancy between this expectation and the actual course of events contributed to confusion and emotional burden during the decision-making moment.

Naaste 6 explained that it is precisely during moments when the patient shows signs of returning consciousness or increased agitation that an extra bolus is expected to be administered. This made it particularly difficult for Naaste 3 to administer the bolus.

Naaste 6 identified two factors that made decision-making around palliative sedation less difficult. First, he explained that when a decision regarding end-of-life had already been made while the patient was still cognitively stable, it became easier to act on this decision later, even when the patient was no longer in that state of clarity. Second, Naaste 6 described how his father's delirium occurred while he was still in the

hospital, where healthcare professionals were present and accessible. This created continuous access to nurses for consultation, which gave him the feeling that he could not make a wrong decision:

Naaste 6: Mijn vader die die begon ook aardig wild te worden, zeg maar, Maar dat was nog in het ziekenhuis en Dat is dan zo anders Als je dat nu kan, over kan sparren met met met ook al is dat op dat moment een een verpleegster die Misschien ook wel helemaal niet zoveel ervaring hebt met met stervende Mensen. Maar je hebt gewoon het gevoel dat. Je hebt nooit het idee dat je iets verkeerd doet.

(English: Naaste 6: My father, he also started to become quite wild, so to speak, but that was still in the hospital, and that is so different. If you can then, can discuss it with, with, even if at that moment it is a nurse who maybe also does not have that much experience with dying people. But you just have the feeling that. You never have the idea that you are doing something wrong.)

This contrasted with the experience of Naaste 3, who was at home without a healthcare professional present and felt alone in deciding how to respond to his mother's unrest.

Slow titration process

participants emphasised the importance of appropriate initial dosing of sedative medication. In the case of Naaste 3, it was perceived that the sedation started at a relatively low dose given the patient's long-term medication use, which resulted in a slow titration process and prolonged uncertainty before adequate comfort was achieved. This led to a broader discussion on the rigidity of dosing protocols and the need for more responsive adjustment in practice.

5.3.4 Information comes when it is happening

Information was often described as being provided reactively rather than in advance. Participants explained that many questions only emerged once unfamiliar symptoms or situations occurred, when immediate support was not always available. This created a need for both earlier preparation and accessible guidance during the sedation process. Naaste 6 explained that some questions cannot be anticipated before they are encountered in practice:

Naaste 6: De vragen die je kan bedenken die kan je stellen, maar ja, de vraag die je nog niet hebt, want delier nog nooit meegemaakt. Ja, die die komt pas op op het moment dat je het aan de hand hebt. Op dat moment is er Niemand om hem te beantwoorden.

(English: Naaste 6: The questions you can think of, you can ask, but yes, the question you do not yet have, because you have never experienced delirium before. Yes, that only comes up at the moment you are dealing with it. At that moment there is nobody to answer it.)

Together with the other needs and tensions identified throughout the first diamond, these insights formed the starting point for the second diamond, in which participants explored possible forms of support.

5.4 Results diamond 2 – Idea generation

The second diamond built on the themes identified during the first diamond. The resource group generated and discussed possible forms of support that could respond to these needs. The resulting ideas and intervention directions are summarised in Figure 9, while a more detailed photographic overview of the generated material is provided in Appendix 6.



Figure 9. Outcomes of the idea-generation process during the second diamond

5.4.1 Doula

Doula as practical support

The idea of a doula repeatedly emerged throughout the co-creation session as a potential form of support for family members during the end-of-life process. Naaste 5 was the first to introduce the concept of a doula and explained its role, emphasizing that the doula is not emotionally involved like family members, but provides practical and supportive guidance. This support could include small but meaningful tasks, such as asking which scent the patient prefers and gradually introducing it into the environment to create a comforting atmosphere.

Comparison with funeral services

Participants compared the role of a Doula with the guidance they had received from funeral directors after death. Naaste 3 described how DELA provided a clear step-by-step process, managed practical arrangements and reminded him of tasks he would not otherwise have anticipated. The participants reflected that similar guidance could have supported him before death, when uncertainty and emotional pressure were already present.

All three naasten described positive experiences with funeral directors, particularly because they provided structure and took responsibility for practical arrangements during a chaotic period. This led Naaste 6 to question why professional guidance is considered normal after death, but not while someone is still dying:

Naaste 6: Want dat is natuurlijk ook best Wel gek, dat je ook, Als je we het er nu zo over hebben, zeg Maar, dat je dan wel totaal volslagen normaal vindt dat je [naam uitvaartbegeleidster] inhuurt voor Als je gestorven bent. Maar we vinden het helemaal niet zo normaal om iemand in te huren terwijl je nog stervende bent.

(English: Naaste 6: Because that is of course also quite strange, that also, when we talk about it like this now, so to speak, you then find it totally, completely normal that you hire [name of funeral director] for when you have died. But we do not find it normal at all to hire someone while you are still dying.)

Naaste 6 noted that it is unfortunate that access to such support is often dependent on insurance coverage or personal arrangement, meaning families who have not made prior arrangements or are unaware of the service may have no access to it. At the same time, he acknowledged that it is positive that the service can exist in this form, providing families with structured support when it is available.

Healthcare professionals should introduce doulas

Naaste 5 expressed the wish that healthcare professionals should introduce support options such as a doula while the patient is still alive, allowing families to discuss and plan for these resources in advance. Although doulas exist, not all family members are aware of them. Similarly, hospice services can provide care at home without requiring inpatient admission. Naaste 3 noted that his mother did not want to go to the hospice and was unaware of the option for additional home-based support, which she would have benefited from. This support could also have helped the patient, who faced the dilemma of wanting to die at home while also recognizing how burdensome the situation was for her husband and son.

According to Naaste 5, general practitioners often hesitate to offer these alternative forms of support. She emphasized, however, that such options are important, given healthcare staff shortages and the potential for trauma resulting from a lack of guidance or information.

Participants also raised concerns regarding hospital care. Naaste 5 reported that hospitals often seek to minimize family involvement in the dying process and aim for rapid discharge. Naaste 6 confirmed this observation, describing that his father was effectively at the end of life but had to leave the hospital before dying. He speculated that this was influenced by institutional performance indicators (KPIs). Naaste 3 reported hearing similar experiences from others.

Telephone doula

Naaste 5 proposed the idea of a designated care coordinator responsible for a kit. When the kit is delivered, this coordinator would proactively contact the family members associated with it several times. In cases where the coordinator manages multiple kits, they could also arrange additional physical support when needed, functioning as a kind of telephone doula. However, Naaste 5 acknowledged potential limitations, including staff shortages and small support networks. Naaste 3 added that proactive contact from such a support person would have been helpful.

5.4.2 Information and communication criteria

Receive information earlier

Several ideas were proposed regarding the provision of information. A central theme was the need for earlier and more complete information. Participants agreed that receiving information in advance would be beneficial. For example, Naaste 6 expressed a desire for earlier clarity regarding the criteria for initiating palliative sedation:

Naaste 6: Over het algemeen weet je toch wel, Ja, het kan jaren zijn, het kan maanden zijn of weken zijn, Maar weet je wel dat het einde verhaal is, Zeg maar, een beetje lullig gezegd en maar al zou je dan op tijd zeggen van nou, weet je, Als het straks echt de medicijn kist leeg raakt om nog levenskwaliteit te hebben ja, dan volgt die stap. Dat hangt daar en daar van af, dat je langer daar meer op voorbereid. Mentaal ook.

(English: Naaste 6: In general you do know, yes, it can be years, it can be months or weeks, but you do know that it is the end of the story, so to speak, to put it a bit bluntly. But if you would then say in time, like, well, you know, when the medicine chest eventually runs empty in terms of still having quality of life, yes, then that step follows. That depends on this and that, so that you are more prepared for it for longer. Mentally too.)

More information through photos

Naaste 3 indicated that if everything had been clearly explained in advance, he would have approached the situation differently and might have been better able to regulate his emotions. The experience was overwhelming because so much occurred unexpectedly. For this reason, he suggested using images or videos of the sedation process, particularly highlighting the moments that may go poorly.

More information through a guide

The need for more comprehensive information also emerged in discussions surrounding the infusion pump. Naaste 3 reported receiving only a brief verbal explanation when the pump was installed, which contributed to feelings of uncertainty. Naaste 6 described bolus administration as a small physical action with significant consequences and a psychological threshold for Naaste 3. He suggested that a quick guide could provide a useful reference. He also emphasized that nothing could be done incorrectly, as the patient was terminal; at most, the timing could be slightly advanced, but always with good intentions. Building on this idea, Naaste 5 proposed creating a 'dummy' guide, such as palliative sedation for dummies or even dying for dummies, to provide structured and accessible guidance for family members navigating these critical moments.

Naaste 6 suggested that a comprehensive information package covering existing standard care, volunteer support, and additional services that can be hired would be valuable. He proposed the idea of a checklist, which could be included with the kit to verify completeness and to prompt consideration of any additional needs, similar to how checklists are used when moving. Naaste 6 noted that such a service could even develop into a market comparable to DELA. Despite its somewhat commercial nature, he emphasized that the presence of the service is still highly valuable when it is used.

5.4.3 Palliative sedation hotline

Participants jointly discussed several possible solutions involving continuously accessible support via a dedicated phone number. Naaste 6 suggested the idea of a 24/7 hotline where family members can ask questions at any time. This could initially be supported by AI-based responses, with the option to escalate to a human professional such as healthcare staff, a trusted care coordinator or even someone else without such a profession. The aim would be to provide immediate reassurance when uncertainty arises, allowing family members to check whether they are making the right decisions at any time of day.

Naaste 5 proposed a similar idea, comparing it to services such as the out-of-hours general practitioner service or 113, but specifically tailored to end-of-life guidance and support. Naaste 3 responded that such a system would have helped him significantly, as it would have allowed him to ask questions whenever uncertainty arose.

5.4.4 Education

Naaste 5 raised the question of how information about end-of-life processes reaches individuals such as Naaste 3, who have little prior knowledge or experience with death and dying. This led to the idea of introducing education about death in schools. She compared this to other topics taught in education, such as photosynthesis, where even basic exposure can leave a lasting impression.

Naaste 3 noted that while he had learned about birth in school, he had never received any education about death. Naaste 5 suggested that group 7/8 (approximately ages 10–12) could be an appropriate moment to introduce such topics, similar to how historical events such as the Second World War are discussed. She added that many children at that age are likely to have already experienced some form of loss. However, Naaste 3 explained that this was not the case for him, as his first experience with death was the passing of his mother.

5.4.5 Dose

Naaste 6 suggested introducing a “settling-in period” for dosing, noting that the effects of medication cannot be properly evaluated within a very short time frame. He emphasized that the first hours of palliative sedation are particularly important and require additional attention regarding the initial dosage.

Participants agreed that dosing is inherently complex, as the process never unfolds in the same way and each patient responds differently. Within this context, naaste 3 expressed difficulty understanding why treatment is often initiated at very low doses, questioning the rationale behind such a cautious approach. He suggested that starting slightly higher might sometimes be more appropriate, as the purpose of palliative sedation is to allow the patient to pass away.

Naaste 6 speculated that healthcare professionals may tend to start cautiously in order to avoid risks and protect themselves professionally. However, he proposed that clearer guidelines for initial dosing could help prevent underdosing and reduce uncertainty in the early phase of sedation.

Naaste 5 reflected that, in the past, additional doses were sometimes administered more readily, and shared an example of a peaceful experience in her grandfather’s case. Naaste 3 noted that a similar approach might have been beneficial in his mother’s situation. Finally, Naaste 5 questioned how uncertainty at the level of general practitioners could be reduced, as she considered this to be the starting point of the decision-making process.

5.5 Co-creation discussion

Palliative sedation is sometimes presented as a process aimed at creating calm, comfort and sleep. However, the findings showed that naasten may experience its course as uncertain and difficult to predict. Figure 10 synthesises the key moments identified throughout the research, including receiving explanations, saying goodbye, the installation and use of the infusion pump, administering an additional bolus and the period after death. The highlighted points indicate recurring ‘What now?’ moments, in which naasten may question what is happening, what they can expect, what they can do and where they can turn for support. Throughout the remainder of this report, these moments are referred to using the Dutch term ‘Wat nu?’ moments.

To interpret these findings and translate them into design implications, the discussion is structured around two themes: uncertainty and the needs of naasten. This is followed by a consideration of healthcare capacity constraints, which influence how additional support could be organised in practice.

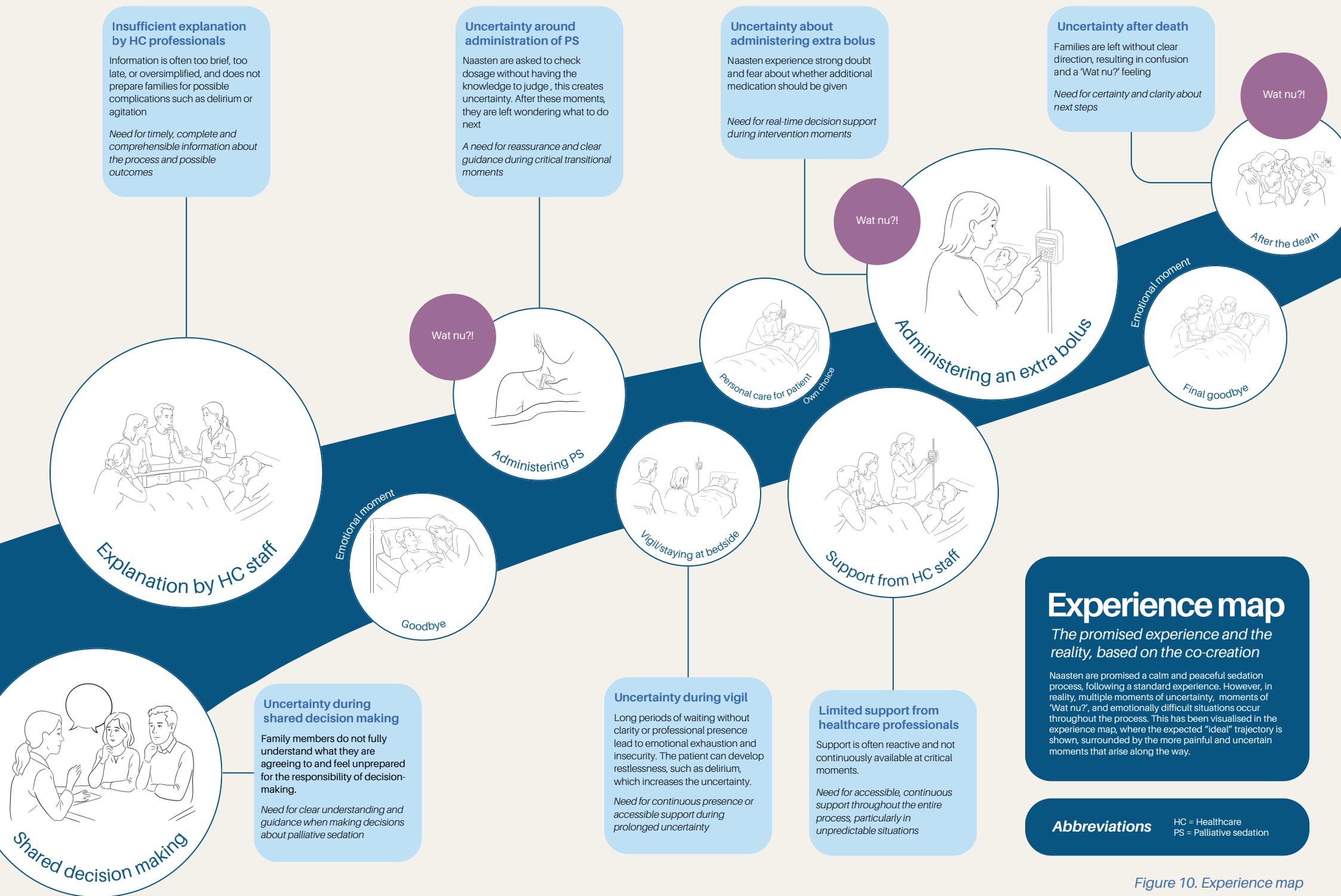


Figure 10. Experience map

5.5.1 Uncertainty

Uncertainty as a central driver of experience

The findings show that uncertainty is a central factor shaping the experience of family members during palliative sedation. This uncertainty is not only related to medical decisions, but also to understanding what is happening and what is expected from them in the process. Uncertainty was often intensified by a lack of accessible and timely information. Participants consistently emphasized that essential information is often missing at the moment it is needed, resulting in uncertainty about what actions to take and whether decisions are correct. This lack of preparedness is linked to three factors: limited prior education about end-of-life processes, insufficient communication from healthcare professionals, and lack of personal experience with death.

The level of experienced uncertainty varied between participants. Naaste 3 reported high levels of distress, which he attributed to limited prior knowledge of palliative sedation and insufficient information during the process. In contrast, Naaste 5 experienced less uncertainty, which she linked to her professional background and familiarity with end-of-life care. Naaste 6 also described lower levels of distress, explaining that his more analytical coping style allowed him to remain relatively calm in uncertain situations. These differences suggest that uncertainty is not only situational but also shaped by prior exposure and personal coping strategies.

The findings suggest that uncertainty is shaped by several factors that may occur simultaneously and reinforce one another. For example, limited information or support may make it more difficult for naasten to interpret patient unrest or make decisions at critical moments. Together, these factors can heighten stress and emotional burden.

Based on the interview and co-creation findings, six recurring and interrelated factors were identified (see Figure 11).

1. The situation is new for naasten: Naasten are sometimes unfamiliar with palliative sedation. Entering an unfamiliar situation induces uncertainty, as they must interpret events without prior personal experience.
2. Lack of information: When essential information about the process is missing, naasten are left unsure of what to expect or how to respond. This gap can amplify stress and reduce confidence in their own observations and decisions.
3. Lack of support: Limited access to healthcare professionals or insufficient emotional guidance during critical moments exacerbates uncertainty. Naasten may feel isolated, unsure of whom to consult, and unable to confirm whether their actions are appropriate.
4. Unrest by the patient: Observable changes in the patient, such as agitation, restlessness, or signs of delirium, trigger uncertainty for naasten.
5. Decision-making at critical moments: Moments requiring immediate choices, such as considering a bolus, place additional responsibility on naasten. The pressure to make the 'right' decision can heighten uncertainty and emotional burden.
6. Uncertainty by other naasten: Observing differing reactions or interpretations from other naasten can amplify personal uncertainty. Conflicting perceptions or disagreements about how to act further challenge the ability to make confident, informed decisions.

Addressing the potentially supportable factors may help reduce uncertainty and improve the experience of naasten during palliative sedation at home.

Factors contributing to uncertainty

Experience of naasten during palliative sedation at home

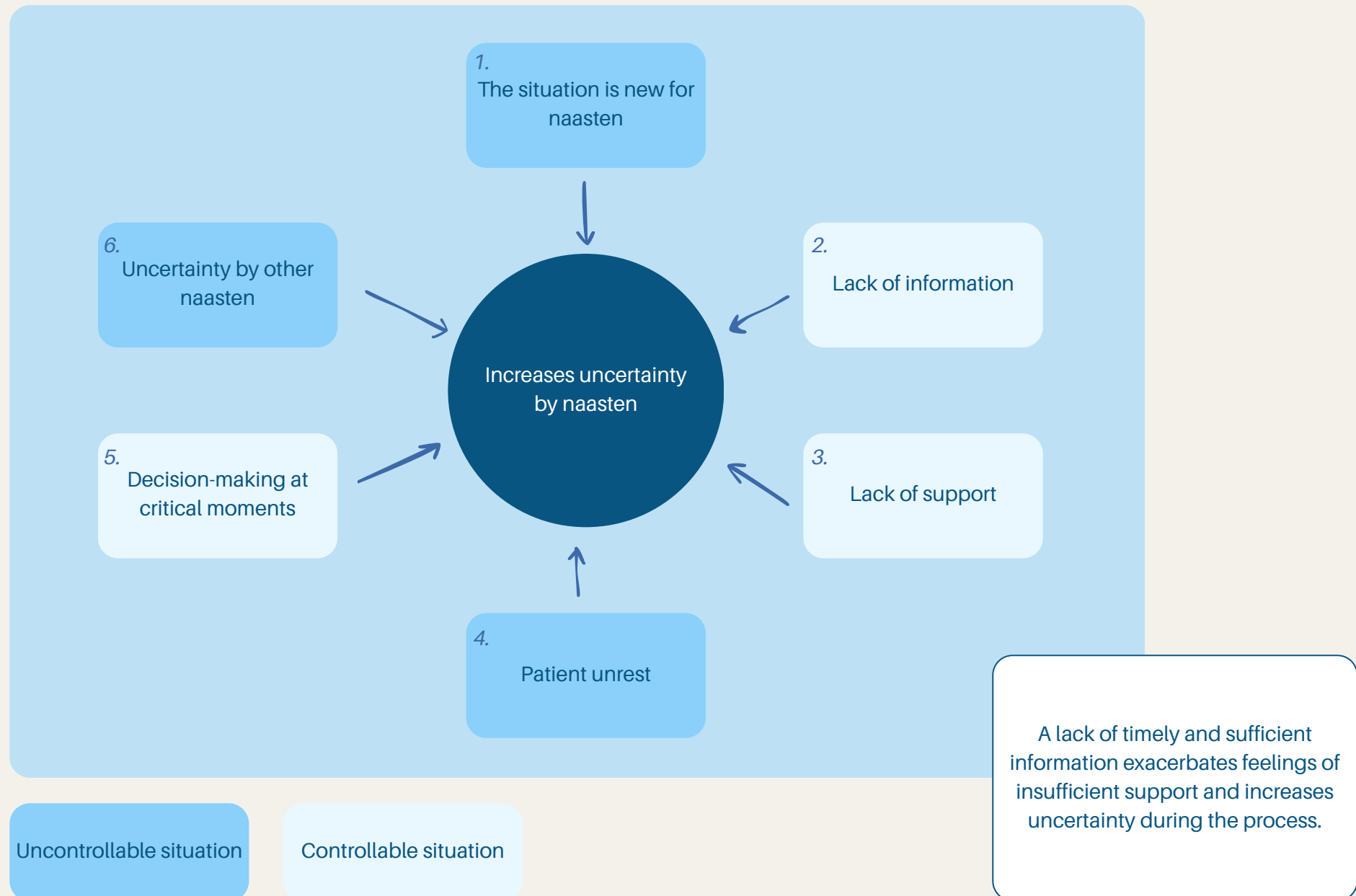


Figure 11. Factors contributing to uncertainty

5.5.2 The needs of naasten

Decision-making and responsibility at the bedside

A key insight is that responsibility for decision-making is experienced as a moment of heightened uncertainty and emotional pressure for naasten. Particularly during critical actions such as bolus administration and determining the initial dosage of palliative sedation, participants reported feeling insufficiently supported and uncertain about whether they were making the right decisions.

This uncertainty also influenced how participants related to the infusion pump, shifting the focus from interacting with the device itself to making immediate decisions about when and whether to act. As a result, the design focus shifted from 'how do users interact with the pump' towards 'how do users decide if and when to act'.

Timing and accessibility of information

Naasten indicated that communication and support become especially important when the sedation process does not follow expected trajectories. When the process is perceived as 'smooth', informational and emotional needs are lower; however, when complications or uncertainty arise, the need for guidance and reassurance increases significantly.

Participants consistently reported that information is often provided too late in the process. Naasten typically receive information only when it becomes immediately relevant or when they explicitly request it. Some questions only arise as the process progresses, because there is no prior knowledge of the issues that may be encountered. This suggests that support should be both reactive and proactive in anticipating information needs.

Furthermore, if people are unaware of the possibility that something could go wrong, such as delirium, uncertainty arises as to whether the observed behaviour was part of the expected course of events or whether additional professional support was needed. To address this, participants suggested more structured support systems, such as 'complete guidance packages,' comparable to services offered by funeral organisations. Participants noted that families are often unaware of such available support options.

In addition, suggestions were made for the use of structured tools such as checklists. These could support both healthcare professionals in ensuring that all relevant information is communicated, and naasten in gaining an overview of available options and identifying missing information or support needs.

Need for continuous guidance during the process

A recurring theme is the need for continuous guidance throughout the dying process. Participants indicated that uncertainty fluctuates at specific moments, particularly during transitions such as the initiation of sedation, dose adjustments, and the moment after death. This highlights a need for support systems that are available at the moment of decision-making, rather than only prior to or after the process.

Towards structured support: the need for a guiding role

The concept of continuous support, such as a doula-like role, emerged repeatedly. Key characteristics of such a role include being available for reassurance and able to translate complex situations into understandable guidance for naasten. Participants also highlighted the importance of proactive and reactive communication and continuous accessibility. This was particularly valuable during moments of uncertainty, helping families interpret situations, validate decisions, and understand what comes next. This reflects a need for continuous, accessible reassurance embedded in the process itself.

Role of healthcare professionals and system constraints

Participants reflected that healthcare professionals operate within constraints such as limited time, workload, and variability in practice. These constraints may contribute to inconsistencies in communication and guidance provided to families.

Well-designed pump

The infusion pump was generally perceived as barely noticeable. Additionally, its sensory feedback, including sound and visible fluid movement, was experienced as confirmation that the medication was being administered correctly. According to the naasten, the pump itself is well designed in terms of both appearance and noise and plays a role in validating actions for family members, reducing uncertainty at the moment of intervention.

Educational gap

The findings suggest a broader societal gap in knowledge about death and dying. Unlike other life events, end-of-life processes are rarely addressed in early education, despite being a universal experience. This lack of early exposure may contribute to heightened uncertainty when individuals first encounter palliative care situations, as they lack a basic framework for understanding what to expect.

Shift in direction

While the initial focus of the co-creation session was primarily on improving the pump itself, the insights from participants revealed that the critical moments occur around the device rather than during interaction with it. This, combined with the visit to the hospice, revealed that the opportunity for design lies not in changing the pump as a medical device, but in supporting the way it is experienced, understood, and contextualized by naasten in the home care setting. This shifted the design focus from 'how do users interact with the pump' to 'how do users decide if and when to act', emphasizing decision-making at critical moments.

Several needs emerged strongly from this shift (see Figure 12):

- Need for reassurance and decision support at moment of action
- Need for proactive and anticipatory communication
- Need for continuous and accessible support
- Need for clear, structured information

Thematic map

Key themes and their relations based on the co-creation session

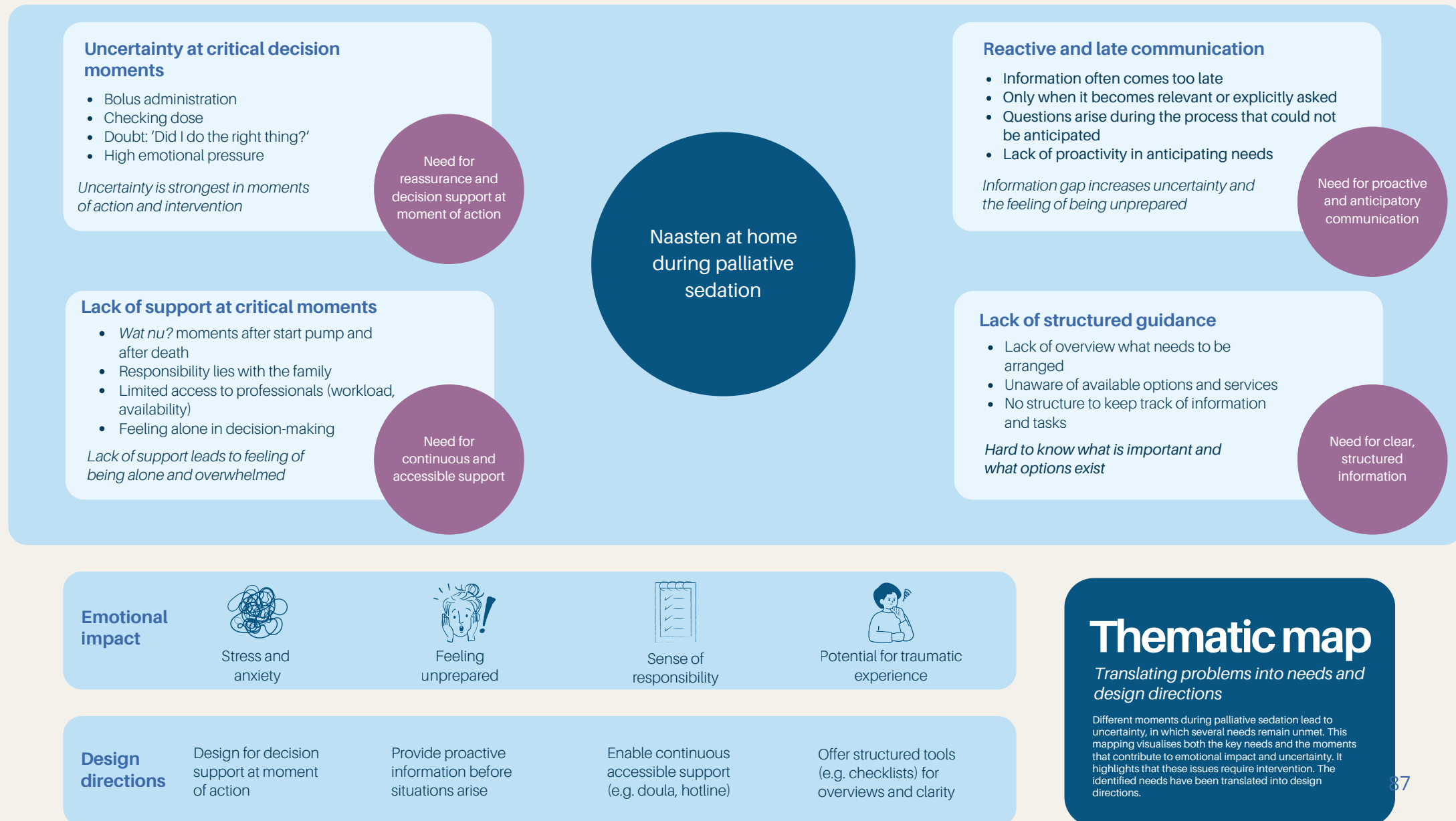


Figure 12. Thematic map translating the needs

5.6 Healthcare capacity constraints

The findings suggest that increased support from healthcare professionals could address both uncertainty and lack of guidance experienced by family members during palliative sedation. However, this potential solution must be evaluated in terms of the current and projected shortage of healthcare personnel in the Netherlands.

Both the shortage of healthcare professionals and the limited availability of volunteers represent significant constraints within the Dutch palliative care system. The healthcare workforce is already under pressure, with an existing shortage of professionals expected to increase substantially in the coming years (Rijksoverheid, n.d.). At the same time, demand for home-based care continues to rise due to demographic ageing, further increasing pressure on both formal and informal care structures (Rijksoverheid, n.d.; Zorginstituut Nederland, 2023).

VPTZ Nederland (2025) shows that volunteer-based support also faces structural limitations. Although over 18,000 people receive support from trained volunteers annually, availability is not always guaranteed, particularly during peak demand. A substantial proportion of requests require emergency deployment, and many patients die before support can be initiated, highlighting persistent issues in timely access (VPTZ Nederland, 2025).

Together, these trends indicate that solutions cannot rely solely on expanding professional or volunteer capacity. Instead, improving coordination, visibility, and accessibility of existing care and support structures may be more feasible. This includes strengthening collaboration between professionals, informal caregivers, and volunteers, and clarifying how care responsibilities can be shared (Rijksoverheid, n.d.).

In addition, making existing support services more visible could help families and professionals better navigate available resources. An example is an end-of-life doula that provides emotional, practical, and spiritual support both in preparation for and during the final phase of life. This can include support with grief processing, vigil care, and advance care planning (Ster in Zorg, n.d.).

Within this context, it is important that any proposed intervention does not place additional pressure on healthcare professionals. While addressing workforce shortages is beyond the scope of this project, Zorginstituut Nederland (2023) suggests that the integration of tools, aids, and support systems can improve efficiency and may reduce workload pressures in care delivery.

Since the availability of healthcare professionals cannot simply be increased, the focus should shift towards understanding which qualities of professional support were most valuable to naasten. The co-creation session showed that this was not primarily about physical assistance, but rather about the needs represented in Figure 12.

Cycle 1 synthesis

Cycle 1 showed that naasten may experience uncertainty about the course of palliative sedation, what they observe, what is expected of them and when professional support is needed. The interviews also revealed that the infusion pump, and particularly bolus administration, could become a concrete moment in which questions about interpretation, responsibility and reassurance emerged.

During the co-creation session, these findings were explored in greater depth. This further clarified that the support needs extended beyond the pump and occurred before, during and after palliative sedation. The session also informed design directions focused on improving preparation, understanding and access to support throughout the process. Together, the identified needs and design directions formed the basis for developing possible support interventions in Cycle 2, as visualised in Figure 13.

Cycle 2: Developing and evaluating the support system

Building on the needs and design directions identified in Cycle 1, Cycle 2 explored possible forms of support for naasten before, during and after palliative sedation. A systemic design perspective was used to develop a portfolio of intervention concepts rather than one isolated solution. These concepts were developed into prototypes, evaluated through scenario-based sessions with naasten and refined using participant feedback and supporting research. The cycle concluded with the selection of four interventions, which were taken forward into Cycle 3 to position them within the final portfolio, examine the portfolio's expected individual and systemic value and explore preliminary implementation conditions.

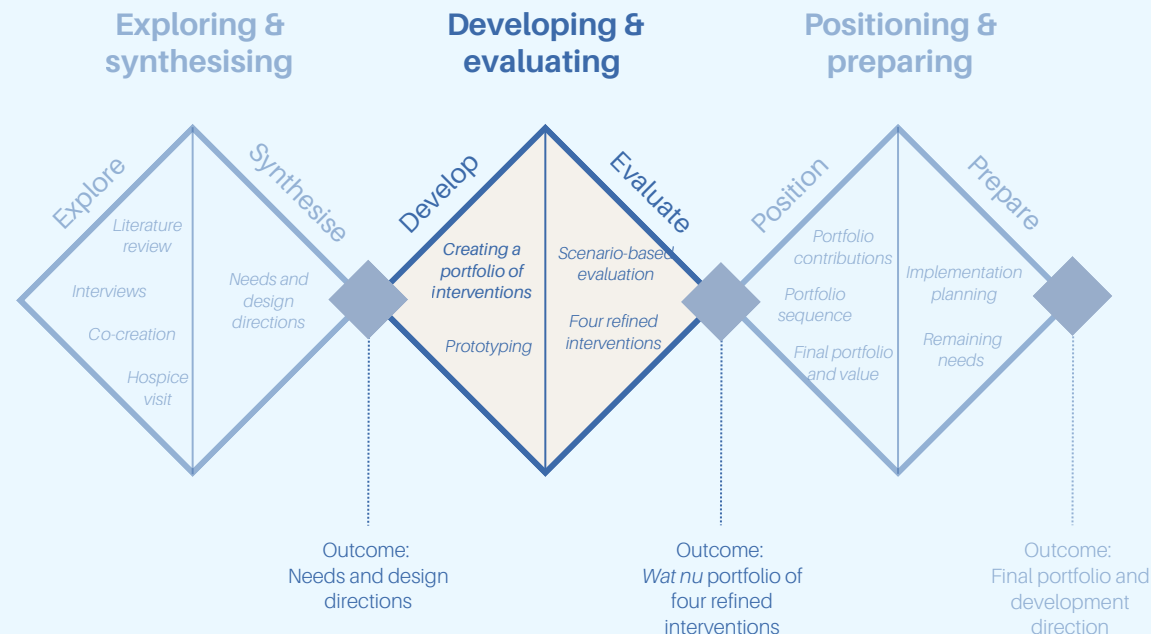


Figure 13. Transition from identified needs and design directions to intervention development

6 Developing the intervention portfolio

The co-creation findings were translated into a portfolio of interventions that responds to the different needs and moments identified throughout the palliative sedation process. This chapter introduces the portfolio and explains how the individual interventions work together.

6.1 Systemic design approach

From needs to a portfolio of interventions

The preceding findings revealed multiple needs across different moments of palliative sedation, including preparation, access to information, reassurance during uncertainty and support at critical moments. At the same time, the limited availability of healthcare professionals means that these needs cannot be addressed through additional professional support alone. A single intervention is therefore unlikely to respond to the full range of needs.

Following Van der Bijl-Brouwer and Malcolm (2020), this project adopts a systemic design perspective in which multiple interventions and their relationships within the wider context are considered, rather than immediately converging on one isolated solution. This approach fits the design challenge because the needs of naasten differ across moments, situations and individuals. A portfolio can provide complementary forms of support and does not depend on one intervention being appropriate in every situation. It also allows the interventions and their relationships to be developed iteratively as new insights emerge.

The strength of this perspective is therefore not simply that it produces multiple solutions, but that it considers how different forms of support can complement one another within the wider care process. In this project, death education, a booklet, an app, a support line and voice-support are explored as connected components that provide different routes to preparation, information and reassurance. Together, they aim to make support more accessible while preserving professional involvement for situations in which self-guided support is insufficient.

However, Van der Bijl-Brouwer et al. (2024) emphasise that complex systems cannot be fully defined or predicted. Introducing multiple interventions may therefore also create unintended effects, such as fragmented information, uncertainty about which component to use or additional complexity within the wider care context. Within this project, these risks are addressed by developing the interventions as one coherent portfolio, with consistent information, clearly differentiated roles and explicit connections between the components. The systemic perspective is therefore used not simply to add more solutions, but to organise different forms of support into a connected structure.

6.2 Initial intervention concepts

Building on the recurring 'Wat nu?' moments identified throughout the research and co-creation, five initial intervention concepts were developed to respond to the uncertainty experienced at these points: death education, the *Wat nu?* booklet, the *Wat nu?* app, a 24/7 support line and the voice-based support. From this point onwards, these concepts are referred to as the *Wat nu?* interventions.

The concepts are presented according to how they may support naasten across different levels and moments of uncertainty. Death education addresses longer-term awareness and preparation. The booklet provides a concise and tangible first source of information, while the app builds on this foundation by offering more extensive and interactive guidance. The support line and voice-support concept provide additional forms of support for moments when information alone may not be sufficient. Together, the concepts form a layered portfolio that moves from early preparation towards more immediate and accessible support.

The following section introduces these concepts individually as complementary design directions, not as the final portfolio. Their value, role and relationship within the wider support system are subsequently explored through evaluation and further development.

6.2.1 Death education

Concept 1

During the co-creation session, participants reflected on how little prior knowledge they had about death, dying and palliative sedation before encountering these situations themselves. They suggested that earlier education could make these topics less unfamiliar and provide people with the language and confidence to discuss death before a situation becomes personally acute. Death education therefore emerged as an upstream concept within the intervention portfolio.

According to De la Herrán Gascón et al. (2021), adolescence is a relevant period for introducing death education in an age-appropriate educational setting. The adolescents in their study generally supported the inclusion of death education in the curriculum and recognised its value in preparing young people for future experiences of loss.

Based on these insights, the concept of death education is used in this project to refer to age-appropriate education about death, dying, palliative care and palliative sedation in secondary schools. Rather than teaching detailed medical procedures, it aims to build basic familiarity, encourage open conversation and help young people understand what care and support at the end of life may involve.

6.2.2 *Wat nu?* Booklet

Concept 2

Participants expressed a need for earlier, clearer and more complete information, especially because unexpected moments during the process could feel overwhelming. Furthermore, the previously identified *Wat nu?* moments highlighted the need for support when uncertainty arises during home-based palliative sedation. This led to the *Wat nu?* booklet, that is designed to support these moments by providing both proactive information and reactive guidance for questions that emerge during the process. Because each patient's situation is unique, not all questions can be anticipated in advance. Therefore, the booklet emphasizes clarity, practical guidance, and emotional support rather than an exhaustive technical description. The booklet is shown in Figure 14.

The booklet is compact and addresses key moments in the process, including:

- The infusion pump has been installed
- Administering an extra bolus
- The patient has dry lips
- The patient experiences delirium
- The patient has passed away

For each moment, the booklet provides guidance on:

- What happens
- What the family member might feel
- What actions they can take
- What they might observe in the patient

Additionally, the booklet contains information on available local support resources, such as regional healthcare services, telephone hotlines, and doulas. Personal stories from other naasten are included to provide emotional support and guidance when making decisions, such as

whether to administer a bolus. These stories were incorporated because, during the co-creation sessions, naasten expressed that hearing the experiences of others helped them feel understood. At last, on the back cover of the booklet, a QR code provides direct access to the *Wat nu?* app.

A key principle of the booklet is honesty. Existing materials, such as the Palliaweb folder (2024), often portray palliative sedation in a simplified or overly positive manner, whereas the naasten from the co-creation session explained they benefit from a realistic and comprehensive understanding of the process. The Amsterdam UMC leaflet for relatives provides more detailed information about physical and psychological changes, such as reduced appetite, dry lips, changes in breathing, gurgling, and declining circulation (Amsterdam UMC, 2022). It primarily focuses on factual information. The *Wat nu?* booklet distinguishes itself by emphasizing emotional support, clarity, and practical guidance, including explicit attention to moments of delirium, pump management, and death.

Key needs addressed:

- Need for clear, structured information: by presenting key moments and recommended actions in an organized format
- Need for reassurance and decision support at moments of action: for example, when administering a bolus
- Need for proactive communication: by providing preparatory information and making key scenarios understandable before they occur



Figure 14. The 'Wat nu?' booklet

Note. The Cover and the stock photographs were sourced from the Canva content library. The individuals shown are models and do not represent research participants or the persons quoted.

6.2.3 *Wat nu?* app

Concept 3

The *Wat nu?* app was developed as a digital extension of the booklet, as shown in Figure 15. While the booklet provides a clear and tangible starting point, the app allows more information to be presented in an accessible and structured way. It builds on the same need for clear guidance but adds interactive functions that cannot be offered in a printed format. The concept also functions as a central access point for additional forms of support. It includes settings for the voice-based support and a direct button to the 24/7 support line. These interventions are introduced in more detail in the following sections.

The different options in the app:

Wat nu? FAQ: The app contains more detailed information than the booklet. This concept is designed to provide a modern, interactive medium that allows for the presentation of richer content while keeping the booklet concise and easy to navigate. The app addresses the *Wat nu?* questions with text, images, and videos, reflecting feedback from naaste 3, who suggested that visual information aids understanding.

Community function: During the co-creation sessions, naasten emphasized the value of sharing personal experiences. To address this, the app includes a community feature where naasten can post their own stories and read the experiences of others. While the booklet presents a single narrative, this interactive feature fosters engagement, mutual understanding, and emotional validation.

AI Chatbot: A chatbot integrated into the app leverages generative artificial intelligence to provide real-time guidance, answer questions, and offer emotional support to naasten. Following Volpato et al. (2025), generative AI-based chatbots have advanced in conversational fluency and are increasingly applied to relational and emotional support tasks,

such as emotional regulation. Within this context, the chatbot allows naasten to pose questions at any moment and receive immediate responses in a supportive and trust-based manner. This design addresses key needs identified during the co-creation sessions, including the need for reassurance and decision support at moments of action and continuous and accessible support.

Contact information: The app provides a directory of regional support contacts, including both practical and emotional assistance, because naasten indicated during the co-creation sessions that they lacked a clear overview of available resources and how to access them.

24/7 support line access: A dedicated button allows naasten to call the 24/7 support line directly when reassurance or additional support is needed.

The voice-based support settings: Voice-assistant settings can be managed directly within the *Wat nu?* app.

Key needs addressed:

- Need for clear, structured information: by presenting key moments and recommended actions in an organized digital format.
- Need for reassurance and decision support at moments of action: by allowing family members to access guidance and instructions quickly when critical decisions arise.
- Need for proactive and anticipatory communication: by providing preparatory information and scenario-based guidance in advance of potential events.
- Need for continuous and accessible support: by ensuring information and guidance are available at any time during the care process.

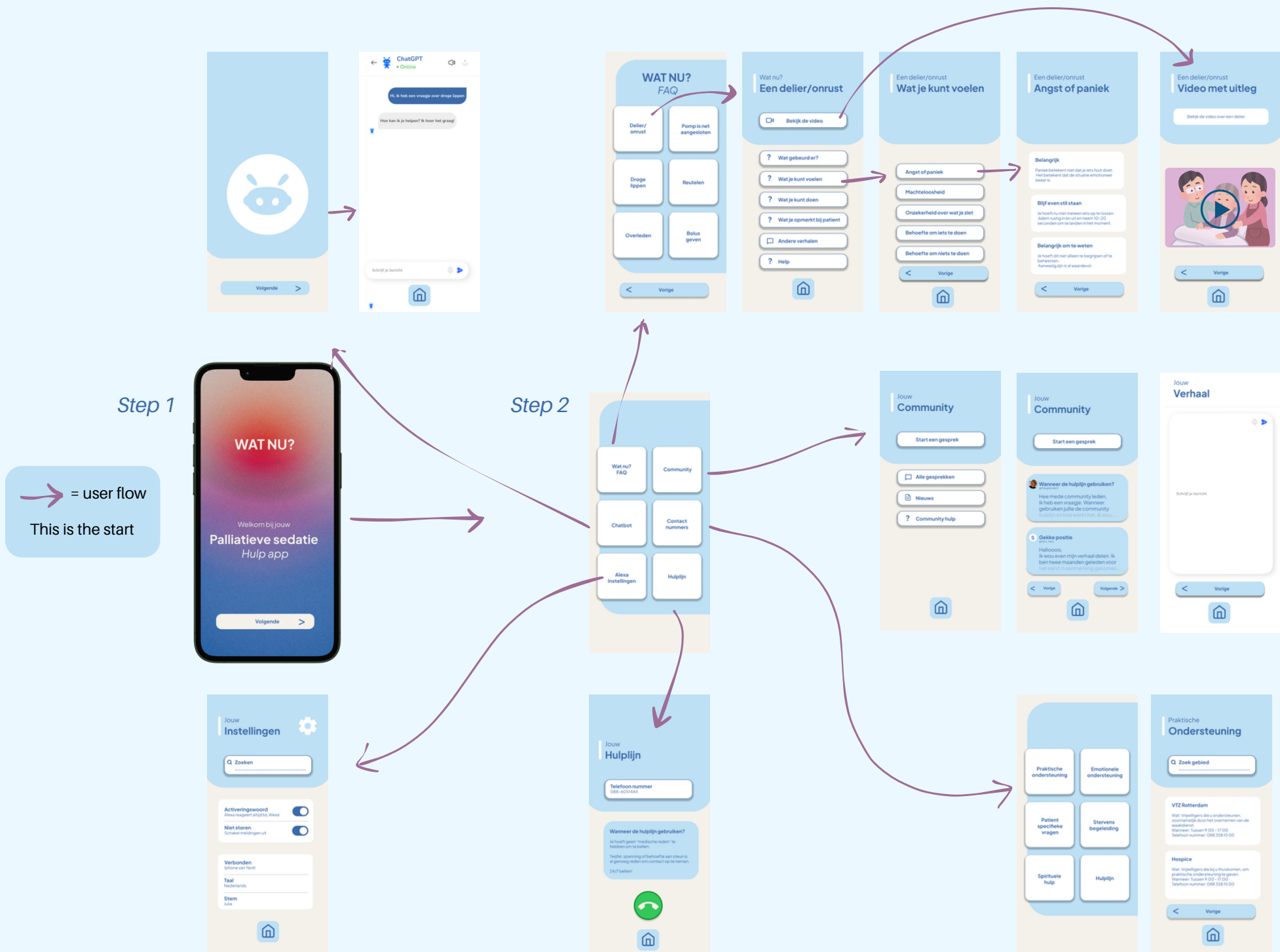


Figure 15. The Wat nu? app

6.2.4 24/7 support line

Concept 4

Participants themselves proposed several solutions for continuously accessible support, including a hotline. Naasten expressed a desire for immediate expert guidance, so that questions arising in real time could be addressed and reassurance could be provided. This led to the initial concept of a 24/7 support line.

The 24/7 support line serves as a real-time support service for naasten during palliative sedation at home. The concept builds on the existing national consultation infrastructure for healthcare professionals in the Netherlands, which has been in place for over 15 years. Following Palliaweb (2021), regional consultation teams are accessible via local numbers, and a single national telephone number (088-6051444) now connects callers to the appropriate regional team based on their postcode, providing a clear and accessible entry point for specialized palliative care advice. These teams are multidisciplinary and consist of general practitioners with additional palliative care training, elderly care physicians, nurses with postgraduate palliative care education, nurse practitioners, and medical specialists such as oncologists with supplemental palliative care expertise. Upon entering their postcode via an automated system, callers are connected to a regional consultant within seconds (Palliaweb, 2021).

According to SFK (2025), approximately 47,000 deaths in 2024 in the Netherlands involved home-based palliative sedation, averaging around 129 deaths per day, which highlights the scale of potential need for family support.

The proposed naasten oriented support line is designed to extend this concept to naasten, addressing their emotional, informational, and decision-making needs. While the professional consultation service focuses on clinical decision-making, the naasten support line aims to provide guidance, reassurance, and a point of contact for questions or uncertainty in real time. This service would provide naasten with an accessible safety net during stressful or uncertain moments at home, while complementing rather than replacing professional care.

Key needs addressed:

- Need for reassurance and decision support at moments of action: by providing immediate access to expert guidance whenever uncertainty or critical decisions arise.
- Need for continuous and accessible support: by offering 24/7 availability to ensure family members always have a point of contact for questions or emotional support.
- Need for proactive and anticipatory communication: by allowing family members to receive guidance on what situations may arise and how to respond, reducing unexpected stress.

6.2.5 Voice-based support

Concept 5

The voice-based support was developed in response to the repeated discussion of doula-like support during the co-creation session. Participants described a doula as someone who can offer calm, structured and practical guidance during an overwhelming process. The idea of a telephone doula also emerged, in which a designated person could proactively check in with naasten and provide support when needed. In combination with a more innovative approach, a voice-assisted support system is proposed, functioning similarly to Amazon Alexa. This cloud-based voice platform enables the creation of natural voice interactions that allow users to engage with technology in an accessible manner (Amazon Developer, n.d.).

This system would be specifically trained on information related to palliative sedation, enabling it to provide accurate, context-sensitive guidance. Naasten could ask questions at any moment during the care process and receive immediate responses, facilitating reassurance, emotional support, and decision-making in real time.

Mahajan and Powell (2025) argue that healthcare communication in modern clinical settings is increasingly challenged by administrative tasks and limited time with patients. Generative AI-based conversational agents could help address these challenges by providing real-time information, answering questions, documenting interactions, and assisting with decision-making in context-specific scenarios.

Key needs addressed:

- Need for reassurance and decision support at moments of action: by giving real-time, context-aware verbal guidance and validation for decisions such as monitoring the patient or responding to restlessness.
- Need for continuous and accessible support: by being always available in the home environment to respond immediately when uncertainty occurs.
- Need for proactive and anticipatory communication: by delivering anticipatory guidance and explanations about what might happen during each phase of the process.

6.2.6 Positioning the interventions

Different interventions for different times

Figure 16 maps the generated interventions across the timeline of palliative sedation. The figure shows that the interventions support different moments in the process: death education prepares people earlier in life, the booklet and app provide guidance before and during sedation, voice-based support offers hands-free spoken guidance in the room, and the 24/7 support line provides direct human support during moments of acute uncertainty.

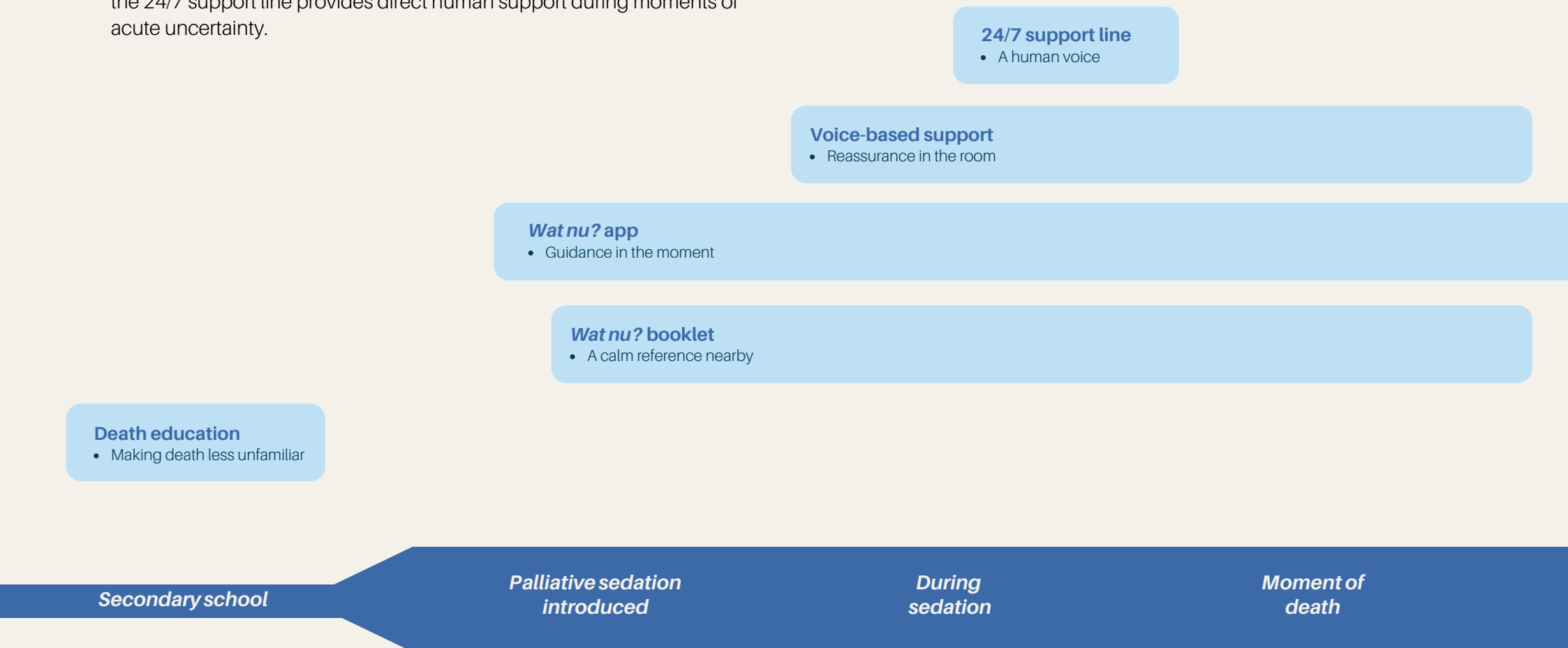


Figure 16. Timeline of the interventions

6.2.7 Intervention alignment with uncertainty

Together these interventions are designed to work as a portfolio and target the key moments that generate uncertainty for naasten during home-based palliative sedation. Figure 17 shows how the different ideas respond to different moments of uncertainty.

Education increases familiarity with the processes involved in palliative sedation, reducing the novelty of the situation and preparing naasten to anticipate and understand the unfolding events. This mitigates initial uncertainty when encountering the process for the first time.

The *Wat nu?* Booklet and *Wat nu?* App provide structured, scenario-based guidance on critical events such as bolus administration, pump use and patient delirium, addressing both information gaps and emotional support needs.

The voice-based support offers real-time guidance, giving reassurance and practical instructions at moments of action. Additionally, the 24/7 support line ensures family members have immediate access to professional support whenever uncertainty arises.

Collectively, these interventions form an integrated support system that addresses the different moments of uncertainty, from lack of information and emotional support to critical decision-making and social influence. By targeting each trigger point identified in the uncertainty diagram, they aim to reduce stress, enhance confidence, and improve the overall experience of naasten during palliative sedation at home. Together, the concepts formed an initial intervention portfolio intended to address different sources and moments of uncertainty. However, their perceived value, timing and relationship within the portfolio still required evaluation with naasten.

Factors contributing to uncertainty

Experience of naasten during palliative sedation at home

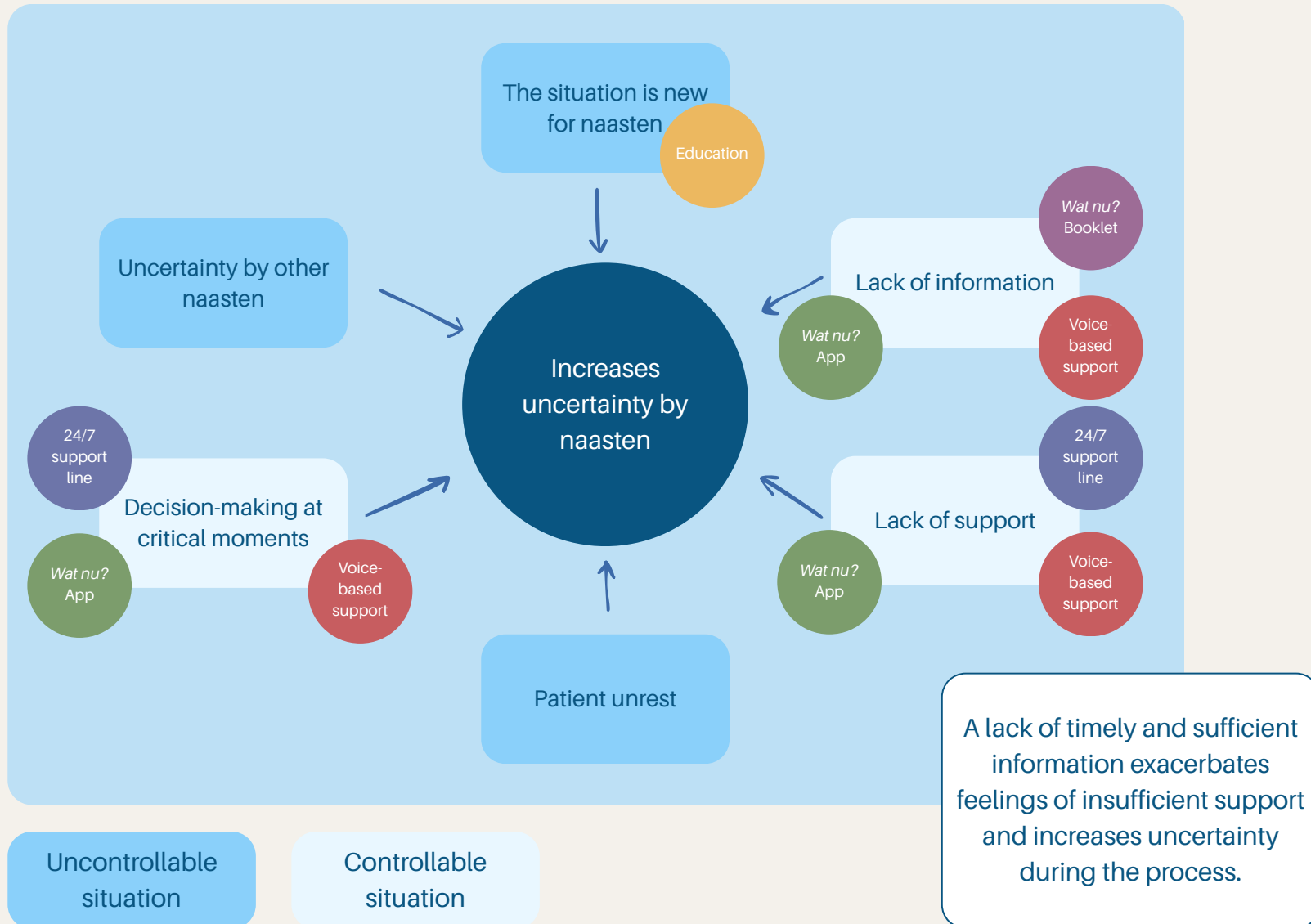


Figure 17. Uncertainty cycle with interventions

7 Evaluating the intervention concepts

To evaluate the proposed intervention portfolio, a qualitative prototype evaluation was conducted, including a scenario-based component with naasten. The aim was to explore how naasten perceived the individual intervention concepts and the combined support system, at which moments the intervention concepts might provide support and how they could help naasten navigate uncertainty during palliative sedation at home. The evaluation was guided by the following research question:

How do naasten perceive the proposed intervention concepts, both individually and as a combined support system, and at which moments might these concepts support them during palliative sedation at home?

The insights from the evaluation were used to inform decisions about which intervention concepts appeared valuable for further development, which required adaptation and which appeared less suitable for continuation.

7.1 Evaluation method

Van der Bijl-Brouwer and Malcolm (2020) describe how action in complex systems can be approached through a series of iterative, safe-to-fail experiments that enable learning about which interventions generate meaningful change. When an intervention proves to be effective, its impact can be strengthened or expanded; when it does not resonate or function as intended, it should be revised or discontinued. In this context, prototypes function as safe-to-fail interventions that help to simultaneously develop a deeper understanding of the situation and evaluate how the different interventions create traction within the system.

Hanington and Martin (2012) describe prototyping as the tangible translation of research insights and ideas into forms that can be explored and tested with stakeholders. Prototypes can vary in fidelity depending on their stage of development and the purpose of the evaluation. Low-fidelity prototypes support early, generative feedback by keeping concepts open to interpretation and revision, whereas high-fidelity prototypes allow participants to respond more concretely to aspects such as appearance, interaction, and usability. Fidelity can therefore be understood as a continuum rather than as a fixed choice between two categories.

In this study, the level of fidelity was matched to the maturity and evaluation purpose of each concept. Education and the support line were represented through low-fidelity concept sheets. These concepts were still at an early and strategic level, and their detailed development would require additional expertise from educational and healthcare stakeholders. The low-fidelity representations therefore allowed participants to reflect primarily on the relevance, purpose and potential role of these concepts without suggesting that their exact content or implementation had already been determined.

Higher-fidelity prototypes were used where the intended format or interaction needed to be experienced more concretely. The *Wat nu?* booklet was printed and visually designed to resemble a real booklet, allowing participants to browse through it physically. The *Wat nu?* app was developed as an interactive Figma prototype through which participants could navigate its main functions. Voice-based support was represented by a physical device with pre-recorded responses to simulate a conversational interaction. These prototypes provided sufficient realism for participants to respond to how the concepts might feel and function in practice.

The study applied a qualitative research approach to explore user experiences with the proposed intervention concepts. Following Holdas and Wierzbicka (2024), qualitative methods such as interviews and scenario-based prototype testing are widely used to gain in-depth insight into users' perceptions, needs, and interactions with design concepts. Scenarios were included to place the intervention concepts within specific moments of palliative sedation. Rosson and Carroll (2002) describe scenarios as narrative representations of use situations that enable design concepts to be explored in context without requiring a fully functional system. In this evaluation, they functioned as reflective prompts that helped naasten relate the interventions to their lived experiences.

Participants and recruitment

Three naasten and one nurse participated in the evaluation. Naaste 1, Naaste 3 and Naaste 6, who had participated in earlier research phases, were approached again and took part based on their availability. Their lived experience with palliative sedation enabled them to reflect on the proposed intervention concepts and address the central research question. Nurse 5, a nurse in her late twenties, was recruited through the researcher's personal network. She provided an additional professional perspective on how the intervention concepts might fit within current care practices and which practical barriers might arise.

Planning and set-up

The evaluations were conducted individually in a quiet and comfortable setting. A recording device was used to capture the conversations, and informed consent was obtained before each session. An interview guide, the intervention prototypes and a set of research-informed scenarios were prepared in advance and can be found in Appendix 7.

During the sessions with naasten, all intervention concepts were displayed together on the table to provide an overview of the portfolio, as shown in Figure 18. The concepts were then explored one by one and discussed in terms of first impressions, perceived relevance, potential value and concerns. The scenario-based component was subsequently used to explore how the perceived usefulness of the concepts might differ across specific moments of palliative sedation. Finally, the portfolio was discussed as a whole to identify possible complementarity and gaps within the combined support system.



Figure 18. Test set-up

Scenarios

interviews and co-creation session as particularly uncertain, emotionally demanding or difficult to interpret for naasten. They were used to explore whether, and in what way, the intervention concepts could provide support during these situations.

The scenarios functioned as discussion prompts, helping participants recall or imagine these moments and discuss their support needs in context. They were not intended to represent a fixed or complete sequence of palliative sedation.

The following situations were discussed:

1. Pump is installed
2. Patient agitation and uncertainty
3. The patient experiences delirium
4. An additional bolus is considered
5. Rattled breathing and dry lips
6. Family tension
7. Moment of death

For each scenario, the participating naasten were asked which intervention concept, if any, might have supported them in that situation and why. They could select more than one concept, reject all proposed concepts or suggest an alternative form of support. Follow-up questions explored when and how the selected intervention should be offered, what information or guidance would be needed in that situation, and what could make the intervention helpful or unsuitable. The discussions were also used to identify which situations should be explicitly addressed in the interventions. These insights subsequently informed the content of the booklet and app.

Adapted evaluation with the nurse

The scenario-based part was not conducted with Nurse 5. The scenarios primarily concerned moments of uncertainty that often occur when healthcare professionals are not present. As these situations centred on the lived needs of naasten, it was considered more appropriate for naasten themselves to reflect on what support might be valuable at those moments, rather than asking the nurse to infer their needs.

The session with Nurse 5 instead focused on how the intervention concepts might fit within current care practices and which practical barriers might arise. She was asked to reflect on how healthcare professionals could introduce or support the concepts and which concerns could influence their use in practice. Her responses provided an initial professional perspective alongside the evaluations with naasten.

Generating data and analysing

After transcription, the structure of the analysis was determined by the predefined scenarios and intervention designs used in the interviews. According to Braun and Clarke (2006), in a top-down approach, it is important to look beyond the predefined themes and search for patterns of meaning that transcend them. Within this framework, patterns, experiences, and perceptions of both naasten and healthcare providers were compared across participants. Themes were developed iteratively from the data, allowing both expected and unexpected insights to emerge. This approach enabled a structured comparison of situations while simultaneously leaving room for participant-driven interpretations.

7.2 Evaluation results

Following the evaluation sessions, the participants' responses were organised and analysed to identify recurring perceptions, differences between participants and practical considerations for further development. The findings are presented in three parts. First, the individual intervention concepts are discussed, combining the perspectives of the three naasten with the additional professional reflections of Nurse 5. Second, the scenario-based findings show how the perceived relevance of the concepts differed across specific moments of palliative sedation; this section is based only on the evaluations with the naasten. Finally, the intervention portfolio is considered as a combined support system, focusing on how the concepts may complement one another, where gaps remain and which aspects require further development.

7.2.1 Individual intervention concepts

Death education

Perspectives on death education about death and palliative sedation were mixed. Naaste 3 and Naaste 6 considered secondary education a potentially valuable setting for introducing these topics. They felt that early education could help normalise death as part of life and provide basic knowledge about the dying process and concepts such as palliative sedation. Naaste 6 summarised this view by stating:

Naaste 6: Het is gewoon een wezenlijk onderdeel van het leven, dus Waarom niet?

(English: Naaste 6: It is simply an essential part of life, so why not?)

He also suggested that education could clarify the distinction between palliative sedation and euthanasia and create awareness among students who had already experienced a loss. Naaste 3 similarly reflected that earlier knowledge of the dying process might have helped him ask healthcare professionals more informed and specific questions later in life. In contrast, Naaste 1 reported that during secondary school she was not yet aware of or engaged with the topic of death. She indicated that such information would likely not have been retained or had a lasting impact at that time in life:

Naaste 1: Dat zou voor mij te vroeg zijn geweest, want op die leeftijd was ik daar gewoon echt nooit mee bezig stond ik daar gewoon echt niet bij stil.

(English: Naaste 1: That would have been too early for me, because at that age I was really never occupied with that, I really did not think about it at all.)

Nurse 5 strongly supported the idea of early education about death and palliative sedation. She viewed education as a way to reduce the taboo surrounding death, increase awareness and encourage earlier conversations about end-of-life wishes. Although she acknowledged that not all information would be retained, she believed that initial exposure could become relevant again when people were confronted with death later in life:

Nurse 5: prachtig om mensen daar zo jong mogelijk al bewust van te maken en over in gesprek te gaan en les over te geven, dat het niet iets raars is, maar dat het iets is wat eigenlijk heel normaal is.

(English: Nurse 5: Beautiful to make people aware of that as young as possible, and to talk about it and give lessons about it, that it is not something strange, but that it is something that is actually very normal.)

Wat nu? booklet

The *Wat nu?* booklet was consistently perceived as a trusted and accessible first point of reference. All three naasten valued having a tangible overview that could be revisited when questions or uncertainty arose. They emphasised that the booklet should remain simple and clear, containing the main steps of the process, while the app could provide more extensive information for further exploration.

The naasten also considered the way in which the booklet is introduced important. They preferred to receive it before the infusion pump was installed and to have it briefly explained by a healthcare professional. This would allow them to become familiar with its purpose and content in advance and make it easier to retrieve relevant information during more turbulent moments.

Naaste 6 compared the booklet to a quick guide and explained that its limited and structured content could make information easier to find than when searching online:

Naaste 6: Als je online, dan zie je toch vaak dat dat beetje: waar stond het nou, weet je wel? Ik heb het ergens gelezen en dat zou je hier ook hebben, maar dan is de kans dat je het weer vindt. Dat is het voordeel van het boekje. En, dat zou ook het voordeel van een app kunnen zijn ten opzichte van het World Wide Web. Daar staat gewoon de hoeveelheid informatie en daar blijft het bij. Weet je, dus je raakt minder je, ook als je dan wat onrustig bent. Dan raak je minder gauw de weg kwijt.

(English: Naaste 6: If you are online, then you often see that a bit: where was it again, you know? I read it somewhere, and you would also have that here, but then the chance that you find it again. That is the advantage of the booklet. And that could also be the advantage of an app compared to the

World Wide Web. There is simply the amount of information, and it stays at that. You know, so you lose your, also if you are a bit restless then, you lose your way less quickly.)

Nurse 5 similarly considered the booklet a valuable and accessible preparatory resource. She expected that many naasten would appreciate having a tangible overview of what to expect and the opportunity to revisit information after conversations with healthcare professionals. At the same time, she stressed that professionals should consider whether naasten are ready to receive detailed information, as not everyone may wish to prepare in the same way. Nevertheless, she viewed offering the booklet and making the topic discussable as part of the professional role.

Wat nu? app

The *Wat nu?* app was generally perceived as the most comprehensive and continuously accessible intervention concept. The naasten valued the possibility of consulting information at their own pace and returning to it whenever questions arose. Naaste 1, for example, described how she could imagine browsing the app during a quiet moment:

Naaste 1: Ik zou ook als ik 's avonds in mijn bed lig, zou ik even door een app heen scrollen.

(English: Naaste 1: I would also, if I am lying in my bed in the evening, I would scroll through an app for a bit.)

Naaste 3 considered the app complete and indicated that he would have used it extensively during his mother's palliative sedation. He particularly valued visual content, such as videos, because this could make complex information easier to interpret. The community function was also positively

received by Naaste 1 and Naaste 3. They appreciated being able to read how others had experienced similar situations, both in preparation for difficult moments and when reflecting afterwards. Naaste 3 also indicated that he would be willing to share his own experience.

Nurse 5 similarly viewed the app as a contemporary and accessible way to provide information and support. She considered it a way to reduce some of the burden on naasten by enabling them to retrieve information and ask questions when needed. She highlighted its value for both immediate and later consultation. She noted that usability may vary across age groups but suggested that family members such as children or grandchildren could support those with less digital literacy. Overall, she considered the app well aligned with contemporary digital behaviour:

Nurse 5: Ik denk dat het heel erg van deze tijd is en dat Mensen gewoon alle tools hebben van, oh ja, weet je wel, ik word volledig ontzorgd en kan ik kan alles terugvinden Als ik een vraag heb, dan kan ik die aan de chatbot stellen. Ja, Dat is gewoon. Ja mooi en ja super mooi gemaakt.

(English: Nurse 5: I think it is very much of this time, and that people simply have all the tools, like, oh yes, you know, I am fully taken care of and I can find everything again. If I have a question, then I can ask the chatbot. Yes, that is simply. Yes, beautiful, and yes, super beautifully made.)

24/7 support line

The support line was perceived as a valuable safety net within the support system, although not necessarily as the first point of contact. The naasten differed in when they would use it. Naaste 3 considered it particularly relevant during critical or emotionally intense moments, such as delirium or uncertainty about administering an additional bolus. Naaste 1 would

instead prefer to contact the home-care team directly. Naaste 6 indicated that he would initially try to manage situations independently to avoid unnecessarily burdening healthcare services, but would value having the support line available as a safety net:

Naaste 6: Dat noodnummer wil je ten alle tijden hebben, want stel dat je die niet meer vertrouwt, dan wil je dat noodnummer.

(English: Naaste 6: You want to have that emergency number at all times, because suppose you no longer trust it, then you want that emergency number.)

Nurse 5 similarly considered the support line a valuable addition to existing care. She emphasised that healthcare professionals often have broad expertise but may not always be able to answer highly specific questions about palliative sedation. A dedicated support line could therefore complement existing services by providing specialised knowledge and reassurance during moments of uncertainty.

Voice-support

The voice-support concept received mixed responses. Naaste 6 emphasised that a calm and trustworthy voice could provide reassurance. However, it did not matter whether reactive support was provided through the app or a voice-assistant:

Naaste 6: Een rustige stem die door zo'n beetje iedereen als prettig ervaren wordt jouw antwoorden geeft, dat brengt altijd rust.

(English: Naaste 6: A calm voice that is experienced as pleasant by just about everyone gives you the answers. That always brings calm.)

Naaste 1 and Naaste 3 were less likely to use the concept because voice-assistant technology felt unfamiliar to them. They were uncertain whether they would turn to it during palliative sedation.

Nurse 5 was also less familiar with voice assistants and therefore found it difficult to fully assess its potential. However, she suggested that it could be valuable for people who struggle with smartphone use. She described it as a tool that could lower barriers to accessing information, especially in

situations where searching is too complex or emotionally demanding. She also anticipated that initial curiosity or hesitation might shift over time as people become more familiar with such technologies.

Table 2 provides an overview of whether the participating naasten indicated that they would use each proposed intervention, alongside the nurse's assessment of its suitability for naasten.

	Naaste 1	Naaste 3	Naaste 6	Nurse 5
Education	Unlikely: she felt she would not have engaged with the topic during secondary school.	Likely: earlier knowledge could have helped him ask more informed questions.	Likely: he considered death an essential part of life that should be discussed.	Likely: she believed early education could reduce taboo and encourage conversations.
Wat nu? booklet	Likely: she would use it as a first step to understand what to expect.	Likely: he valued it as an initial source, particularly when introduced by a healthcare professional.	Likely: he viewed it as a simple and accessible reference guide.	Likely: she considered it a valuable preparatory tool when introduced by professionals.
Wat nu? app	Likely: she would use it independently and at her own pace.	Likely: he would use it extensively as a main source of information.	Likely: he valued having information and answers together in one place.	Likely: she considered it a contemporary tool for independently accessing information
24/7 support line	Unlikely: she preferred contacting the existing home-care team directly.	Likely: he valued immediate professional reassurance during uncertain moments.	Conditional: he would use it as a back-up after first trying to manage independently.	Likely: she considered it useful for specialised questions and escalation.
Voice-based support	Unlikely: the technology felt unfamiliar to her.	Unlikely: he did not expect to use it regularly.	Conditional: he would consider it if the voice felt calm and trustworthy and the system worked reliably.	Conditional: she saw potential value for people who struggle with smartphones, but found the concept difficult to assess.

Table 2. Expected use and suitability of proposed interventions

7.2.2 Support across scenarios

After discussing the concepts individually, the three naasten reflected on their potential value across specific moments of palliative sedation. This section explores how the perceived relevance of the concepts differed between scenarios. Nurse 5 did not participate in this component of the evaluation.

Pump is installed

At the start of the sedation process, tool usage was limited. The naasten primarily relied on the booklet or app for orientation.

Patient agitation and uncertainty

Naaste 6 indicated that he would engage with the voice-based support tool, if it offers a reassuring and calm voice. Naaste 1 and Naaste 3 expressed a preference for accessing similar information through the booklet or the app.

The patient experiences delirium

A delirium was identified as a highly stressful moment across participants. Naasten expressed a need for clear explanations of what a delirium is, how long it may last, and reassurance that what the dying person perceives is not necessarily reality, in order to avoid conflict or attempts to correct their experience. Naaste 3 and naaste 6 indicated that they would prefer to be informed in advance about what a delirium is, for example through the app, but would want real-time support during the situation. Naaste 3 indicated that he would have used the support line for this support. For naaste 6 the app or voice-based support could provide continuous verbal guidance through the situation, helping naasten perceive time in a calmer and more structured way, as moments of distress often feel significantly longer than they actually are. Naaste 6 also emphasised the importance of maintaining calmness in the environment, as this may contribute to reducing distress for the patient as well.

Naaste 1 reported that she had primarily learned about delirium through stories from others, which she found helpful. She therefore valued the inclusion of experiential stories within the app as a form of support and preparation.

An additional bolus is considered

This moment was associated with high emotional burden and uncertainty. Both naaste 1 and naaste 3 indicated they would not want to take responsibility for this action and would prefer professional or community support.

Naaste 1 indicated that she had not administered a bolus and would not do so, even with additional support. However, she had many questions about this moment, particularly regarding why the dose was increased, why a higher dose was not given immediately, and why the patient needed to regain consciousness before adjustment. She also questioned whether the patient's brief return to consciousness indicated unmet needs or was related to dosage or body weight.

In his own experience, naaste 3 also preferred not to administer a bolus but ultimately did so. He indicated that in such situations he would either turn to the community feature or contact the support line, as he would need reassurance and support:

Naaste 3: Daar zou ik ja Misschien een community wel, daar zou ik dan wel gebruik van maken. Hoe Mensen dat hebben ervaren en hoe hun daar mee om zijn gegaan.

(English: Naaste 3: I would, yes, maybe a community, I would then make use of that. How people have experienced it and how they dealt with it.)

Rattled breathing and dry lips

The three naasten expressed a general need for clearer information and real-time guidance regarding symptoms such as rattled breathing and dry lips, as it was often unclear whether these required action for the patient or were primarily distressing for naasten.

Naaste 3 emphasised that rattled breathing was experienced as unexpected and emotionally confronting, particularly because no prior information was provided during the care process. He indicated that access to explanations or stories from others, as well as the ability to ask the voice-based support for guidance, would have helped reduce uncertainty. Naaste 3 added that if he had known he could do something about the patient's dry lips, he would have acted accordingly, but he lacked this awareness during the process. He therefore expressed a need for accessible information explaining such symptoms and possible responses.

Naaste 6 suggested that support via the app or voice-based support could be appropriate, as real-time guidance would be more useful than information provided in advance. He described digital assistance as potentially reassuring when it guides users step-by-step through uncertainty.

Family tension

Naaste 1 and Naaste 6 described how differences in emotional readiness within families could create additional stress during the care process. Naaste 1 expressed a need for guidance that would help family members recognise and consider each other's perspectives. Naaste 6 similarly suggested that some form of external support could help families acknowledge where they were in the process together:

Naaste 6: Als je dan allemaal wel fysiek aanwezig ben, dan is het denk ik heel behulpzaam. Dat hoeft dat niet per se een een werkelijk bestaand persoon te zijn, maar als iets jou helpt naar dat je meer qua fase op elkaar aansluit, dat je met zijn allen ook beseft; we zitten op dit punt.

(English: Naaste 6: If you are all physically present, then I think it is very helpful. That does not necessarily have to be an actual existing person, but if something helps you so that you are more aligned with each other in terms of the phase you are in, that you all also realise: we are at this point.)

Naaste 3 similarly described how tensions within the family increased his own stress, which he felt also affected his father, who was present at the bedside. He suggested that clearer information about what to expect could have reduced this stress and supported both of them during the process.

Moment of death

At the moment of death, participants emphasised different needs regarding clarity and guidance. Naaste 6 indicated that he would appreciate a clear action option in the app, such as a prompt stating 'the patient has died, what should I do?', to support next steps in that moment. Naaste 1 expressed a need for reassurance that immediate action was not required, as naasten experienced different emotional and practical responses, with her brother wanting to act immediately while she preferred a moment of pause and orientation. Naaste 3 expressed that he was grateful to be able to speak with a friend who had also experienced the loss of a parent. His main need was to talk to someone who understood the situation, as well as to temporarily distance himself from the immediate care context.

7.2.3 The intervention portfolio

A combined support system

Finally, the intervention concepts were considered as a combined support system. Drawing on the individual and scenario-based findings, this section explores how the concepts might complement one another, where overlap or gaps remained and which forms of support were considered most important.

Overall, naasten expressed that the proposed intervention portfolio could provide structure and reassurance in an otherwise uncertain care process. At the same time, they emphasised that the concepts should not feel like several disconnected systems. Although different forms of support could be valuable at different moments, they should be presented as parts of one coherent and easily understandable support system.

Naaste 6 was particularly concerned that having to choose between multiple separate platforms could create confusion and reduce trust:

Naaste 6: Ja, ik zou het niet keuze uit 3 systemen willen hebben inderdaad, Dat is wel een goeie. Dat je een app en een boekje en een en een en een Alexa, dat zou dan wel weer onrustig vinden. Dat geeft geen vertrouwen.

(English: Naaste 6: Yes, I indeed would not want to have a choice between three systems, that is a good one. That you have an app and a booklet and an Alexa, that I would then find restless again. That does not give trust.)

He therefore suggested connecting the different concepts more closely. For example, information previously shared through the app or voice-support concept could, with appropriate consent, be available to the support line professional. This could reduce the need for naasten to repeatedly explain the situation and allow support to be provided more efficiently.

Among the concepts intended for use during palliative sedation, the booklet and app were valued most consistently, while the perceived usefulness of the support line and voice-support concept depended more strongly on familiarity, trust and the specific context of use.

Nurse 5 viewed the overall portfolio positively and considered it a potentially valuable addition to existing care. She suggested that it could relieve some pressure on healthcare professionals by enabling naasten to find answers independently and take greater control in uncertain situations. At the same time, she emphasised that the human aspects of care would remain essential and that the portfolio should complement rather than replace professional support:

Nurse 5: Misschien dat dat een hele juist heel mooi iets is om de om de zorg iets te ontlasten, zodat mensen meer zelf die antwoorden op vragen kunnen krijgen meer die zelfregie kunnen nemen. En dat de menselijke aspecten die nodig zijn, dat zal gewoon blijven, denk ik. Dat is een mooie samenwerking daarin van technische en het menselijke.

(English: Nurse 5: Maybe that that is actually something very beautiful to slightly relieve the care system, so that people can find more answers themselves and can take more of that self-direction themselves. And that the human aspects that are needed will simply remain, I think. That is a nice collaboration between the technical and the human.)

She noted that some users might initially experience hesitation or a learning curve when using digital forms of support. Over time, however, she expected people to recognise their value in providing preparation and reassurance. She also suggested that better-prepared naasten could support care delivery by creating greater alignment in expectations and understanding.

7.3 Evaluation discussion

The scenario-based evaluation provided insight into both the portfolio as a whole and the perceived relevance of the individual interventions. It also revealed a remaining challenge surrounding bolus administration, as information and reassurance did not necessarily make every naaste feel able or willing to carry out this action. To interpret the findings and translate them into design implications, the discussion is structured into three sections: the support system as a whole; the roles and relevance of the interventions; and the remaining challenge and system value.

7.3.1 The support system as a whole

Importance of coherence and system simplicity

This study explored how a portfolio of interventions can support naasten during the uncertain and emotionally intensive process of palliative sedation at home. The findings show that support needs are highly contextual and vary across moments, tools, and individuals. Rather than one single solution, the test results suggest that value emerges through a combination of interventions that each address different aspects of uncertainty, such as information, reassurance and emotional support.

Concerns about system complexity were raised by a naasten that indicated that working with multiple separate systems could feel confusing and reduce trust, comparing it to receiving different types of signals from different sources. This lack of coherence could create uncertainty about which system to rely on. This highlights the importance of a single, integrated system that provides clarity rather than fragmentation.

The naasten and nurse focused on the complementary nature of different tools depending on timing and need. The booklet was consistently described as an initial orientation tool, while the app was seen as more suitable for continuous and in-depth support.

Nurse 5 supported this systemic framing by emphasising that digital tools may help relieve pressure on healthcare professionals by enabling naasten to access information and support more independently. At the same time, she stressed that these tools should complement rather than replace human care. This concern aligns with Horton and Hardie (2021), who argue that although technology can create opportunities for healthcare, it may also challenge empathy and person-centred care when it reduces or mediates human interaction. Maintaining access to responsive human support is therefore important, particularly in emotionally sensitive care situations.

This suggests a tension between diversity of tools and perceived system coherence. The findings indicate that the success of a portfolio approach depends not only on the functionality of individual tools but also on how clearly they are perceived as part of one coherent system. From a systemic perspective, the interventions function as interconnected elements within a broader care system. This aligns with the systemic design approach by Van der Bijl-Brouwer and Malcolm (2020) in which value is not located in isolated solutions but in the relationships between interventions and actors within the system.

7.3.2 Roles and relevance of the individual interventions

Following the need for coherence identified on the previous page, the interventions should form complementary layers that become relevant at different moments. This does not imply that every naaste must use every component. Instead, the portfolio provides different routes depending on timing, preference and need.

Education as a preparatory context

Education is positioned before palliative sedation becomes personally relevant. It may create basic familiarity with death, dying and palliative sedation, providing a frame of reference for later conversations. It therefore functions as a broader preparatory layer rather than as direct support during the care process.

Booklet as a guided entry point

When palliative sedation becomes relevant, the *Wat nu?* booklet provides the first concrete point of entry. Introduced by a healthcare professional, it offers a concise overview of what naasten may encounter and where further support can be found. Its role is to support orientation and preparation without presenting an overwhelming amount of information.

App as an ongoing digital environment

The app builds on the booklet when more detailed or interactive guidance is needed. It functions as the central digital environment within the portfolio, bringing together information, visual content and access to additional support. Rather than requiring naasten to search across unrelated sources, it provides one recognisable place to return to throughout the process.

24/7 support line as access route to human support

When self-guided information is insufficient or a situation remains difficult to interpret, the support line provides access to specialised human support. It is not intended as another parallel platform or as the default first point of contact. Instead, it functions as an escalation mechanism that complements existing care and preserves access to human reassurance during moments of heightened uncertainty.

Voice-based support as non-essential modality

The evaluation indicated that voice-based support did not fulfil a sufficiently distinct role alongside the app. Its main contribution lay in the mode of interaction rather than in offering a separate form of support. Since the same information and guidance could also be accessed through the app, retaining voice-based support as an independent intervention would add another system component without providing clear additional value. It was therefore not included as a separate intervention in the final portfolio. However, voice-based interaction could still be integrated into the app as an optional feature, particularly for hands-free access or for users who find smartphone navigation difficult.

7.3.3 Remaining challenge and system value

Responsibility for bolus administration

Across the evaluation, situations involving visible unrest, delirium and possible bolus administration were described as emotionally and cognitively demanding. Bolus administration made this tension particularly visible, as naasten had to interpret the patient's condition while also considering whether to carry out a medication-related action themselves.

Participants differed in how manageable they considered this responsibility. One naaste indicated that she would not administer a bolus herself and would prefer someone else to take responsibility for the action. Another also preferred not to administer a bolus, but indicated that prior information and reassurance during the moment could help him if doing so became necessary.

For some naasten, administering a bolus therefore remained beyond what they considered an acceptable level of personal responsibility, even when informational and emotional support was available. Although the interventions may increase understanding and confidence, they may not remove the moral weight associated with physically carrying out the action. This variation raises an important question about the boundary of the current support system: for whom can information, reassurance and access to professional support make this responsibility manageable, and for whom does administering a bolus remain too burdensome?

Because the evaluation was scenario-based and involved naasten with previous experience of palliative sedation, it cannot yet determine how naasten encountering the situation for the first time would respond when using the support system in practice. Further real-life evaluation is therefore needed to understand how far the current support can reduce the experienced burden and when responsibility may need to be redistributed.

System-level synthesis

Taken together, the evaluation resulted in a simplification rather than an expansion of the intervention portfolio. The final design direction consists of four connected components: education, the *Wat nu?* booklet, the *Wat nu?* app and the 24/7 support line. Voice-based support is not retained as an independent intervention, as its added value compared with the app remained insufficiently distinct.

The resulting portfolio offers a flexible progression from early awareness and guided preparation towards ongoing access to information and, when needed, specialised human support. Figure 19 shows how these components relate to recurring sources and moments of uncertainty. It should not be understood as a fixed pathway that every naaste must follow, but as a support structure through which different forms of assistance can become available as needs change.

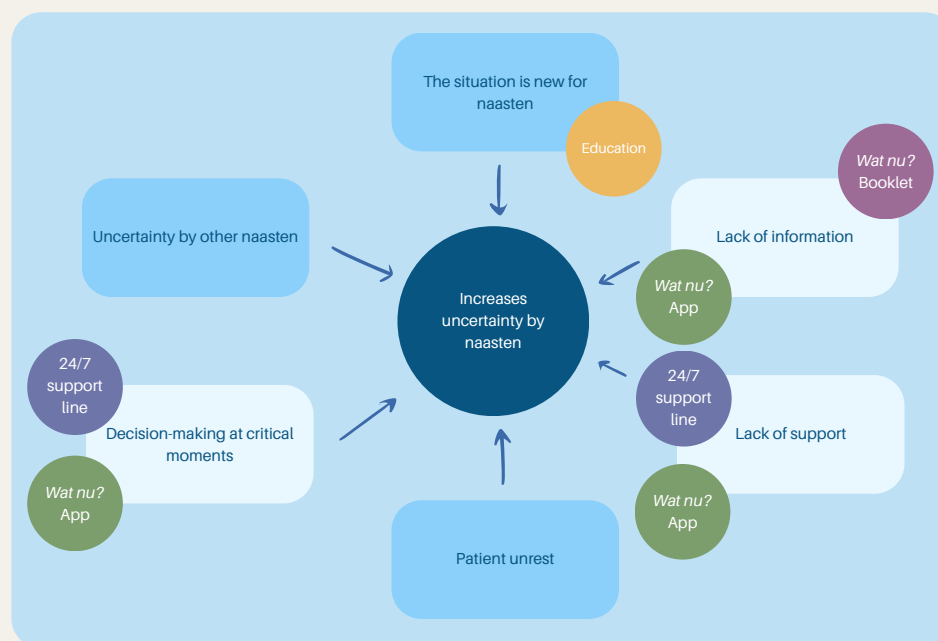


Figure 19. Uncertainty cycle with final interventions

8. Refining the intervention portfolio

The discussion highlighted that further development should focus not only on the individual interventions, but also on how they connect within the wider support system. Particular attention is needed to how the booklet and app are introduced, how access to the support line is communicated, and how coherence can be maintained across different forms of support. At the same time, the portfolio cannot remove all uncertainty or responsibility associated with palliative sedation.

These insights informed the next iteration of the intervention portfolio. As an additional source of design inspiration, a targeted exploration of literature on preparation and support surrounding childbirth was conducted.

The following section examines which principles from this analogy may be relevant to palliative sedation at home. These insights, together with the findings from the preceding discussion, are then translated into refinements of the existing intervention concepts, with particular attention to early preparation, the introduction and combined use of the different tools, access to human support, and coherence across the portfolio.

8.1 Learning from the analogy of birth

Analogy of birth and dying

Throughout the project, participants repeatedly drew parallels between dying and birth. Because of this recurring analogy, it was explored more thoroughly as a possible source of inspiration for the next phase of development.

Philipsen & Haynes (2005) highlight in their research on birth plans and living wills that both birth and death can be understood as normal, meaningful human experiences rather than purely medical events. Both are biological, cultural, and individual experiences with profound significance for those involved. This perspective provides a rationale for using birth as an analogy when studying the needs of naasten during the dying process.

Family needs in both contexts often arise from a desire for control and preparation. Just as parents develop birth plans to anticipate moments when they may not be able to communicate effectively or to conserve energy for the event itself, naasten at the end of life may create directives or care plans to prepare for moments when the patient cannot actively participate. Additionally, both types of planning aim to support individualized care, aligning the experience with personal values and goals, which benefits both the individual and their family. Finally, these instruments play a crucial role in facilitating communication between family and healthcare professionals. They help clarify choices in advance, prevent misunderstandings, and reduce the likelihood of conflict at critical moments (Philipsen & Haynes, 2005).

Thus, the processes and interventions used in birth, such as preparatory planning, structured communication, and tailored support, offer a framework for designing and evaluating interventions that meet naasten their needs during the process of palliative sedation.

The value of antenatal education

One example of how people can be prepared for an uncertain and emotionally demanding process is antenatal education. Zaman et al. (2025) describe how antenatal education, also known as childbirth preparation classes, provides expectant parents with structured information on pregnancy, labour, delivery, and early infant care. The systematic review found that antenatal education increases childbirth self-efficacy and reduces fear of childbirth by strengthening knowledge, practical coping strategies, and relaxation techniques. Group sessions further foster a sense of community, enhance confidence, and reduce isolation-related anxiety.

These findings are relevant to supporting naasten during palliative sedation at home. They suggest that structured education, anticipatory guidance, and peer or professional support can reduce anxiety, increase confidence, and improve coping in an emotionally complex and uncertain situation. Several elements of the proposed intervention portfolio already reflect these supportive mechanisms, as outlined below.

The mechanisms underlying these benefits include:

- Comprehensive, structured information that demystifies the process and reduces uncertainty. This is addressed through the design of the app and booklet.
- Practical skills and coping strategies to manage pain and stress. This is incorporated into the app and booklet by explaining what the patient may experience and how naasten can respond.
- Peer and professional support that promotes confidence in decision-making and reduces isolation. This is incorporated into the app's community function and the professional support available through the support line.

Inspiration from birth care folder

The Zwanger! folder published by RIVM (2026) provides expectant parents with accessible and professionally developed information and guidance throughout pregnancy. The 54-page folder is distributed through midwifery practices, general practitioners and gynaecologists, illustrating how people can be prepared and supported throughout an uncertain and emotionally significant care process.

This folder was used as a source of design inspiration for exploring how similar forms of preparation, communication, practical guidance and support could be incorporated into the proposed interventions.

The following elements provided design inspiration for the further development of the intervention portfolio:

1. Birth plan: The birth folder emphasizes a personalized birth plan in which parents outline preferences for location, attendees, and atmosphere. Translating this to palliative sedation, naasten and patients can create a sedation plan specifying where sedation occurs, who is present, and environmental preferences such as lighting, music, or rituals.
2. Clear alert signals for naasten: The pregnancy folder includes a visual checklist of warning signs requiring immediate action. For palliative sedation, a similar tool can guide naasten on when to seek help, enhancing a sense of control and security. This also makes it possible to determine which signals are normal during a process and which are not.
3. Pain and comfort management: Birth materials explain both pharmacological and non-pharmacological pain relief options. Analogously, the palliative sedation interventions provide guidance on sedative medications and non-medical actions naasten can take to support comfort, such as oral care or gentle touch.

4. Role of family and communication: The folder emphasizes partner involvement and communication about preferences. In palliative care, naasten often acts as the patient's voice. Interventions can therefore support naasten in advocating for the patient's wishes, managing emotional stress, and maintaining well-being during and after the process.
5. Accessibility of information (QR codes and apps): The birth folder integrates QR codes linking to apps and digital content. Inspired by this, interventions for palliative sedation include QR codes linking to short instructional videos, showing what to expect, how to care for the patient, and strategies to remain calm.
6. Post-event support (Kraamzorg): The folder describes how maternity care providers support new parents immediately after birth. This concept will be adapted to design post-death support for family members, providing guidance and reassurance directly following the patient's passing, addressing both practical and emotional needs.

Pregnancy app as inspiration

Nissen et al. (2024) show that more than half of pregnant individuals use mobile applications related to pregnancy. App developers should prioritize evidence-based content and usability rather than adding numerous features, which can compromise clarity and effectiveness. Financial incentives, such as grants, may support the development of high-quality content. Additionally, caregivers play a crucial role in guiding users toward trustworthy apps and alerting them to potential risks.

This finding highlights the importance of evidence-based, user-centered app design, professional guidance, and a focus on clear, reliable information to enhance trust, accessibility, and adoption among users.

8.2 Visual refinement of the booklet and app

The visual refinement of the booklet and app focused on creating an appearance that felt calm, reassuring and appropriate for emotionally demanding moments. Although the earlier prototypes were positively received overall, their visual appearance had initially been developed intuitively and had not yet been specifically evaluated for perceived calmness or contextual appropriateness.

Colour and visualisations

Kim and Sung's (2013) discussion of earlier colour research links green with peacefulness, calmness, health and sincerity, and blue with stability, security and serenity. Rendell et al. (2025) suggest that imagery of healthy green vegetation and clear, calm water may support positive and calming experiences in interface design. These sources informed the decision to explore colour and nature imagery as parallel starting points for the visual refinement. They did not predetermine the final design, as responses to colours and images may differ between people and contexts. Figure 20 on page 118 summarises how the visual directions were explored, refined and evaluated.

1. Research-informed visual exploration

To translate these principles into concrete alternatives, a first exploratory round was conducted. Robinson et al. (2024) describe formative evaluation as a way to identify opportunities for improvement during an ongoing design process rather than to validate a final design. Accordingly, the first two rounds aimed to identify promising visual elements and guide further refinement.

Multiple visual alternatives were developed, varying in colour, contrast and imagery. The alternatives combined blue and green tones with water, vegetation, dunes and abstract light effects. The original visual design was

also included as a reference to explore whether the new alternatives were perceived differently.

The concepts were reviewed by three participants recruited from my personal network. As they were not naasten, their responses were treated as formative design feedback rather than as evidence of suitability for the target group. One participant had a background in Strategic Product Design and provided additional feedback on text-background contrast, saturation and hue.

The green directions were perceived as less appropriate for the sensitive context of the booklet. Darker imagery was described as heavier and more unsettling, while the original design was not considered sufficiently calming. However, its gradual colour transition and suggestion of a point of light were valued. Dune imagery was perceived as calm, although highly literal imagery could become distracting.

2. Formative refinement

Based on the first review, the second exploration focused on light-blue tones, gradual colour transitions, subtle nature imagery and restrained uses of light. Literal nature photographs were replaced by softer and more abstract representations of water, landscape and vegetation. Some directions also incorporated subtle green tones or a point of light. The refined alternatives were reviewed by the same three participants. Designs containing several prominent elements were perceived as busy and were compared to festival posters rather than supportive health information. Strong points of light were also considered too dominant. Softer colour transitions, restrained imagery, and clearer contrast between text and background were preferred. Based on this feedback, three visual directions were selected for evaluation with naasten.

3. Evaluation with naasten

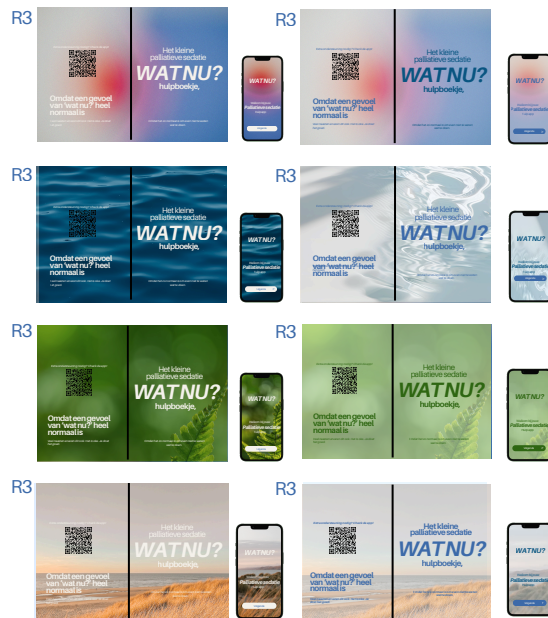
The evaluation followed a visual preference-testing approach. Chan (2024) describes preference testing as an attitudinal method in which participants compare two or three design variations and explain their preferences. Participants were asked which direction felt most calm, trustworthy and appropriate to the context, and why.

The directions were evaluated with four naasten: Participants 1, 3, 5 and 6. Participant 6 first completed the evaluation in person, while the other three subsequently participated remotely through WhatsApp due to time constraints. After completing the preference task, Participant 6 contributed to a brief co-refinement of the selected direction. This included removing all-capital lettering, which was perceived as visually dominant, and making minor textual adjustments. The background imagery and colour transitions remained unchanged. The other three participants then evaluated these refined versions using the same core preference questions.

All four participants preferred Direction B. Direction C was perceived as visually busy, and elements within the abstract imagery were associated with figures or ghosts. Direction A was considered calm but was also described as potentially sombre. Explanations for choosing Direction B referred to its water imagery, soft colour transition and combination of colours. Direction B was therefore selected as the final visual direction for the booklet and app.

1 Research informed visual exploration

- Blue and green tones explored
- Water, vegetation, dunes and abstract light imagery
- Original design included as a reference



Key outcome

- Light-blue tones and gradual transitions appeared calmer
- Dark: too heavy and unsettling
- Green: less appropriate for the context
- Highly literal imagery could become distracting

2 Formative refinement

- Lighter colours and softer transitions
- More abstract and restrained nature imagery
- Improved text-background contrast



Key outcome

- Busy compositions were simplified
- Dominant light effects were reduced
- Three directions selected for evaluation with naasten

3 Evaluation with naasten

- Four naasten compared directions A, B and C
- Evaluated on calmness, trustworthiness and appropriateness
- Preferences were explained in follow-up questions



Key outcome

- All 4 participants preferred Direction B
- Direction A could appear sombre
- Direction C was perceived as busy
- Direction B selected as the final visual direction

Figure 20. Three-stage visual refinement process for the Wat nu? booklet and app

Note. External visual references used in the visual exploration:

R1. Following the Moon. (n.d.). *New gallery 87* [Artwork]. <https://www.followingthemoon.com/#/new-gallery-87/>

R2. Simmons, J. (2013). *Watercolors* [Watercolour series]. Studio Flodeau. <https://www.flodeau.com/2013/09/jeffrey-simmons-watercolors/>

R3. Licensed visual element from the Canva content library.

R4. AI-generated by the author using ChatGPT Images

R5. Photograph by the author.

8.3 Resulting intervention refinements

Selection of the booklet and app visual direction

To refine the visual design of the booklet interior and app interface, four variations were informally compared with the three participants recruited from my personal network and with Naaste 6 in a real-life setting (see Figure 21). Because the original layout and light-blue colour could potentially appear clinical, alternative directions explored the use of a blue background and warmer blue tones. Nevertheless, direction A was preferred for both interventions and was perceived as calm and trustworthy. Naaste 6 described its appearance as medical rather than clinical and considered this to contribute to the sense of trust. The personal stories in the booklet were appreciated, although the photographs were considered too prominent. For the app, participants preferred consistently aligned content cards over the staggered layout to maintain a calm and orderly interface. These findings were incorporated into the final designs presented in the next section.

Building on the findings from the preceding discussion and the design inspiration drawn from childbirth preparation, the intervention portfolio was further refined. The following sections present the revised interventions and show how these combined insights informed their content, timing and role within the wider support system.

The scenario-based evaluation confirmed which moments required particularly clear and accessible guidance, including delirium, physical changes, bolus administration and the moment of death. These findings informed the refinement of the booklet and app, in which these situations were made more explicit and guidance was structured around what naasten might observe, experience and do at each moment.

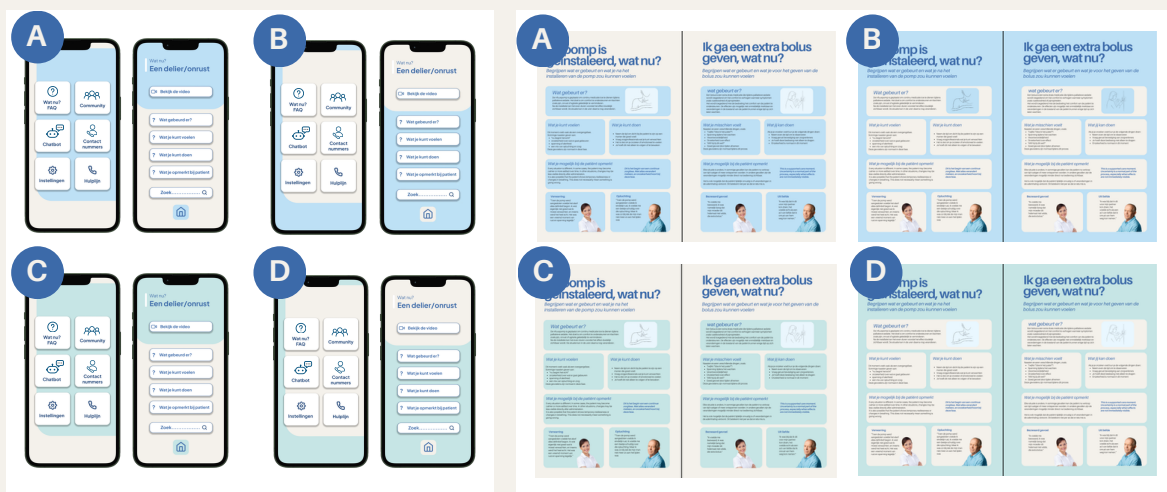


Figure 21. Four visual directions compared for the Wat nu? booklet and app

Note. Stock photographs were sourced from the Canva content library. The individuals shown are models and do not represent research participants or the persons quoted.

8.3.1 Death education

Education as intervention

During the test review, participants suggested that education about death should begin before people are directly confronted with end-of-life care. Such education could address death and dying more broadly, while also introducing different end-of-life trajectories, including palliative sedation. However, developing a complete educational programme would require pedagogical expertise, curriculum development and collaboration with schools and healthcare professionals. As this falls outside the scope of this project, the intervention was not developed into a complete lesson package. Instead, its potential role within the wider portfolio is briefly explored.

The Raad voor Volksgezondheid & Samenleving (RVS, 2021) argues that learning to live with death is a responsibility of society as a whole and that greater space is needed to discuss experiences of dying and grief. Bureau & MAES (2020) similarly describe that education could help young people understand ageing and dying as part of life and develop language for discussing these topics. Allard et al. (2024) describe awareness-raising and education as potential ways to challenge the taboo surrounding death and dying. They explain that death literacy develops through experiences and learning that strengthen individuals' and communities' ability to act in situations involving death and dying. By recognising young people as social actors and citizens of tomorrow, educational initiatives can better equip them to understand death and end-of-life care and to support others facing these experiences. They identify schools as an important setting because they can reach young people broadly. Paul (2022) further emphasises that death education should proactively prepare children and school communities. Rather than focusing only on information, it should combine education with action and embed learning, support and relevant practices within the wider school community.

Within this project, death education is therefore retained as a long-term, upstream intervention that could provide age-appropriate knowledge about death, grief and different end-of-life trajectories, but requires further development by educational and healthcare stakeholders.

Existing initiatives

Several Dutch organisations already provide educational materials about death, dying and end-of-life decisions aimed at schools.

The NVVE (n.d.) offers a lesson package and guest lesson about euthanasia, using films, facts and assignments to inform students. The topic is approached from medical-ethical, societal, cultural, religious and personal perspectives, with attention to values and norms surrounding life and death. Museum Tot Zover (2018) developed the digital lesson material Doodgewoon in de klas for pupils in groups 7 and 8. This programme introduces death, farewell and loss in an accessible way, addressing questions such as what happens when someone dies, what condolence means, how people remember the dead in different cultures and how children can deal with grief and remembrance.

These examples show that education about death and end-of-life topics already exists in the Netherlands. However, the initiatives reviewed here address specific aspects of death and dying rather than combining grief, emotional support, death literacy and factual knowledge about different end-of-life trajectories, including palliative sedation.

8.3.2 Booklet as preparatory layer

The *Wat nu?* booklet was designed to serve as a trusted and accessible starting point for family members during home-based palliative sedation. The tests reflected the importance of providing a chronologically organized quick guide to events that may occur during the process, offering concise explanations and visual aids to reduce overwhelm during moments of uncertainty.

The booklet is most useful when provided before the sedation process begins, ideally when palliative sedation is first discussed as a potential option. This early introduction allows naasten to scan and familiarize themselves with the content in advance. However, participants emphasised that the booklet should be accompanied by explanations from healthcare staff to ensure clarity and emotional support.

According to OECD data, 16% of adults in the Netherlands have low literacy proficiency (Level 1 or below), meaning they can only understand short texts or simple lists and identify key information when clearly presented (OECD, 2023). This highlights the importance of including clear language and supporting images, which also aligns with feedback from the co-creation sessions indicating that participants found visual aids helpful. Research by CBS (2023a) shows that older adults in the Netherlands, particularly those aged 75 and above, have the lowest levels of digital literacy. Therefore, the booklet must be designed to be highly understandable and accessible for this population, as they may find it difficult to navigate the digital app.

Adjustment to bridge introduction and use

A tension arises between providing the booklet early in the process and ensuring that it remains available when palliative sedation begins. Early distribution may increase the risk of the booklet being misplaced before it is needed. As an adjustment to the concept, it is therefore proposed that the booklet be provided in a visually distinctive folder that signals its importance and makes it easier to recognise. The folder follows the same blue visual language as the other *Wat nu?* interventions, creating visual coherence across the support system. A more saturated shade of blue was selected to improve visibility while maintaining a calm and trustworthy appearance. Figure 22 visualises the proposed folder concept.

The front of the folder includes a clear instruction to keep it in a fixed and easily accessible place. It also provides space for other relevant documents, helping naasten keep essential information together and increasing the likelihood that the booklet remains available when needed.

Beyond this timing-related adjustment, further refinements to the overall content and design of the booklet are presented on the following page.



Figure 22. *Wat nu?* folder

Adjustments

Design adjustments based on tests and research:

- Scenario-based content: Situations emphasised during the scenario-based evaluation, such as delirium, physical changes, bolus administration and the moment of death, are addressed explicitly.
- Visual refinement: The layout and use of colour were refined to create a calm and trustworthy appearance, while photographs were made less prominent to maintain visual balance.
- Logical chronological order: Events are presented in the order they are likely to occur.
- Concise explanations: Each section provides a short description of what may happen, what family members might feel, and what actions they can take.
- Visual support: Use of images to enhance comprehension and reduce cognitive load.
- Timing of delivery: Provided early in the process for proactive preparation.
- Guided review: Encourages discussion with healthcare staff at home to reinforce understanding.
- Retention risk mitigation: To address concerns about losing the booklet, it is accompanied by the visually distinctive folder.
- Accessible language: The content should be understandable for people with lower literacy levels.

Features for the booklet, based on birth analogy

- Sedation plan: Since the booklet is something people flip through beforehand, a small section will be devoted to a sedation plan (small version of a birth plan)
- Clear alert signals: Checklist of warning signs and routine changes, enabling naasten to differentiate between normal process events and situations requiring professional attention.
- Pain and comfort management: Guidance on non-medical comfort measures naasten can implement, such as oral care and gentle touch.
- Role of naasten and communication: Guidance on discussing the patient's wishes, sharing observations with healthcare professionals and recognising naasten's own needs and well-being.
- Accessibility of information (QR code linking to the app): Providing a QR code linking to the app for more detailed or interactive content.
- Post-event support (postpartum care analogy): Offers guidance and reassurance directly after the patient's passing, supporting both emotional and practical needs.

These design decisions ensure that the booklet functions as both a stabilising and preparatory layer, supporting naasten before and during palliative sedation by providing structured information, reassurance, and guidance. The refined booklet is presented in Figures 23 and 24.



Figure 23. The refined 'Wat nu?' cover



Figure 24. The refined ‘Wat nu?’ booklet pages

Note. Stock photographs were sourced from the Canva content library. The individuals shown are models and do not represent research participants or the persons quoted.

8.3.3 App as central support layer

The *Wat nu?* app functions as a central hub within the support system for naasten during home-based palliative sedation, combining informational, reflective, and peer-based support. It provides a complete and continuously usable platform, offering both real-time guidance and the ability for retrospective reflection on the care process.

Digital Government (2025) indicated that in 2023 83% of Dutch citizens aged 16–75 had at least basic digital skills, suggesting that most users can engage with the app. However, the app must maintain clarity, accessibility, and ease of navigation, particularly for users with lower (digital) literacy.

Following Pharos (2025), in the Netherlands, approximately 2.5 million people have a first language other than Dutch. Many of them may encounter difficulties in communicating effectively with healthcare providers without additional language support. Overcoming these language barriers is crucial to ensure that care and support are delivered appropriately and equitably. The app can offer content in multiple languages to bridge communication barriers and provide equitable access to care.

Palliaweb (2025) shows a relevant existing example of a digital app for healthcare professionals in palliative care, PalliArts. PalliArts provides practical national and regional information, including links to palliative care guidelines, guideline summaries, medication information, checklists, patient information folders and contact details of palliative care consultation teams (Palliaweb, 2025). This shows that digital support is already used within the professional side of palliative care. However, the *Wat nu?* app differs in its target group and purpose: rather than supporting healthcare professionals in clinical decision-making, it is

designed to support naasten with accessible information, reassurance and guidance.

Adjustment to bridge introduction and use

The app can be accessed through a QR code on the back of the booklet, allowing naasten to explore it when they first receive the printed information. However, a tension remains between this early introduction and the moment at which the app may become most relevant. Naasten may only perceive its value once palliative sedation is approaching or has begun, when questions and uncertainties become more immediate. As an adjustment to the concept, healthcare professionals should therefore reintroduce the app shortly before palliative sedation starts. This reminder may help naasten become familiar with its structure and functions before they need to use it during more stressful moments. As some naasten may still access it for the first time during the sedation process, the app should remain immediately understandable and easy to navigate.

Further refinements to the overall content and design of the app are presented on the following page.

Adjustments

Design adjustments based on tests and research:

- Scenario-based content: Situations emphasised during the scenario-based evaluation, such as delirium, physical changes, bolus administration and the moment of death, are included as recognisable entry points for more extensive guidance.
- Visual refinement: The colour use and interface layout were refined to create a calm and trustworthy appearance.
- *Wat nu?* function: Users indicated that this feature could be improved with additional visual content. Videos were positively received and should accompany text wherever possible.
- Community feature: Naasten valued the ability to share and read stories. To prevent hierarchies, no “likes” are included, but a commenting system is proposed. Context-specific search functionality allows users to find relevant stories for particular situations.
- Chatbot: With the voice-based support no longer in use, the chatbot now provides voice interaction, enabling conversational guidance similar to AI systems such as ChatGPT.
- Contact information and support line: Regional contact numbers and the 24/7 support line remain essential and are fully integrated.
- Booklet integration: The app references the booklet, ensuring visibility and complementing guidance from healthcare professionals.
- Multilingual support: The app can offer content in multiple languages to bridge communication barriers and provide equitable access to care.
- Digital accessibility: The app should remain simple and user-friendly.

Features for the app, based on birth analogy

- Sedation plan: Allows naasten to specify where sedation will occur, who will be present, and environmental preferences such as lighting, music, or rituals.
- Clear alert signals: A checklist of warning signs requiring immediate action, alongside signs considered normal during the dying process, helping naasten distinguish between routine changes and events needing intervention.
- Pain and comfort management: Guidance on non-medical actions that naasten can take to support comfort, such as oral care, gentle touch, or positioning.
- Role of naasten and communication: Supports naasten in advocating for the patient’s wishes, managing emotional stress, and maintaining well-being during and after the process.
- Accessibility of information (QR Codes and links): Integrates additional resources and information through links to the booklet (PDF) or other guidance materials.
- Post-event support (postpartum care analogy): Offers practical and emotional support immediately after the patient’s passing, addressing both guidance and reassurance.
- Practical skills and coping strategies: Includes tips to manage stress and emotional strain during the process.
- Peer and professional support: Peer support was already incorporated via community features; professional support is now added.
- Design principles: Emphasizes evidence-based content and usability. The app avoids excessive features to maintain clarity, simplicity, and organization.

The refined app is presented in Figure 25.



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8.3.5 24/7 support line as escalation and safety mechanism

Given that participants indicated that having a support line served as a valuable safety net, and that the nurse highlighted the benefit of access to specialized consultation teams, a 24/7 support line is proposed as a real-time support service for naasten during home-based palliative sedation. The support line would allow naasten to ask questions and receive guidance on both practical and emotional aspects of care.

The existing consultation teams, currently reachable via local numbers and the national line 088-6051444 for specialized palliative care advice, could potentially extend their services to naasten (Palliaweb, 2021). Considering that around 129 home-based palliative sedations occur per day in the Netherlands, (SFK, 2025), there is a clear demand that may support both the feasibility and viability of this intervention.

8.3.6 Positioning the interventions

Different interventions for different times

Figure 26 positions the refined interventions across the timeline of palliative sedation. The two colours distinguish between when each intervention is introduced and when it is actually used. This illustrates how the portfolio supports naasten through both earlier preparation and moments of uncertainty.

Death education contributes to earlier familiarity with death and dying, while the booklet and app are introduced around the start of palliative sedation and remain accessible throughout. The support line provides an additional layer of human reassurance when questions or uncertainty arise. Together, this timeline forms the basis for examining the individual and combined value of the refined interventions in the following chapter.

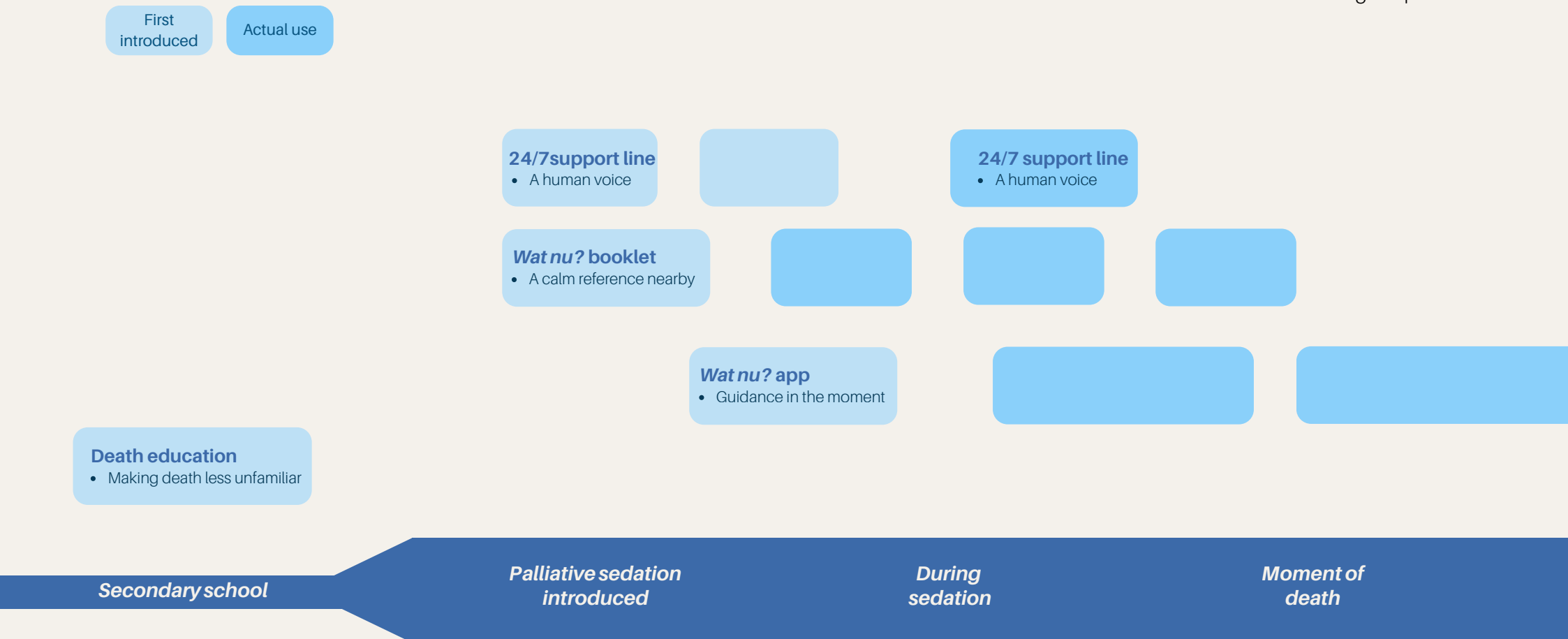


Figure 26. Positioning the interventions second iteration

Cycle 2 synthesis

Cycle 2 translated the needs and design directions identified in Cycle 1 into a portfolio of intervention concepts. These concepts were developed into prototypes and evaluated through scenario-based sessions with naasten. The evaluation indicated that different interventions could contribute to preparation, access to information and reassurance at different moments, although participants varied in which interventions they considered relevant or would use.

Based on the evaluation and subsequent refinement, education, the *Wat nu?* booklet, app and 24/7 support line were selected as four components of the proposed support system. These four interventions were taken forward into Cycle 3 for final portfolio positioning and preliminary implementation planning, as presented in Figure 27.

Cycle 3: Positioning and preparing the final portfolio

Cycle 3 presented the four refined interventions as the final *Wat nu?* portfolio and positioned them within the broader experience of palliative sedation at home. The revised experience timeline and systemic value overview visualised when the interventions could provide support and how the portfolio was expected to create value at individual and system level. Preliminary implementation planning then explored the stakeholders, activities and organisational conditions required for further development. The cycle clarified the final intervention portfolio and provided a preliminary direction for further development, validation and implementation planning.

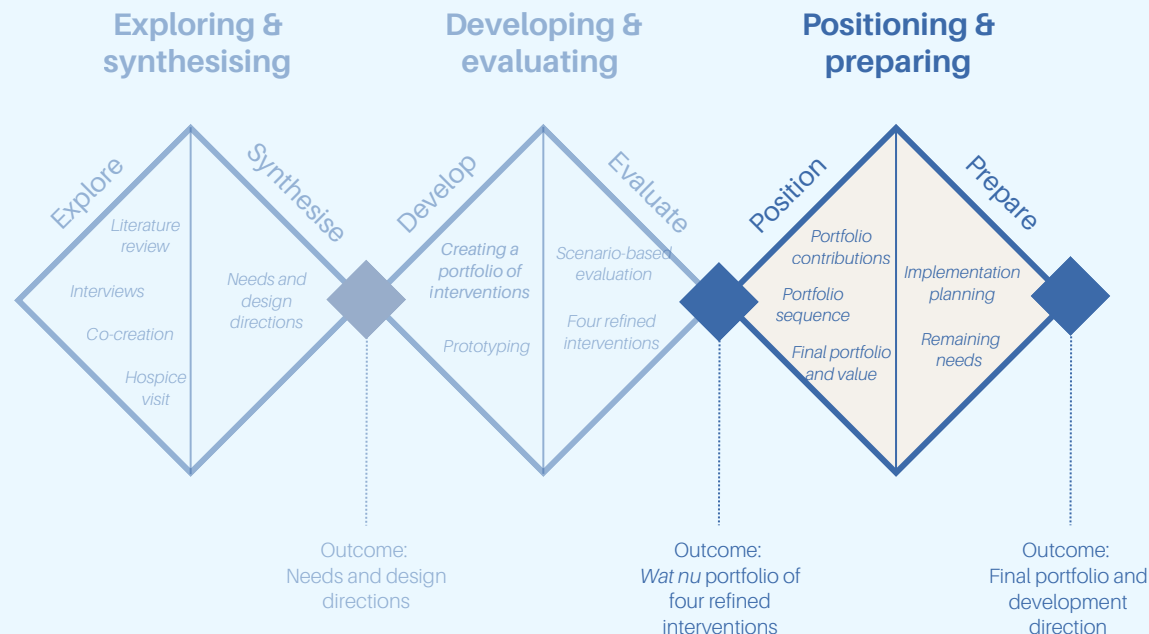


Figure 27. Transition from four refined interventions to final portfolio positioning

9 Final *Wat nu?* portfolio

This chapter brings the four refined interventions together as the final integrated *Wat nu?* portfolio. It first presents the portfolio as a whole and explains the sequence of its interventions throughout palliative sedation at home. It then examines the intended contributions of the portfolio and its anticipated value at both individual and system level.

9.1 Final portfolio overview

The final *Wat nu?* portfolio consists of four interventions that support naasten throughout the process, from early preparation to the period immediately after the patient's death: death education, the *Wat nu?* booklet, the *Wat nu?* app and a 24/7 support line. Drawing on the portfolio approach outlined by UNDP (2022), the interventions are positioned as a complementary set that addresses interconnected needs at multiple points in the process. Within the *Wat nu?* portfolio, this complementarity means that limitations of one intervention are addressed by another layer of support. Their specific composition and roles were developed from the research and evaluation findings discussed in Section 7.3.2.

Together, the interventions form a layered sequence that moves from early preparation to accessible printed and digital guidance and, when necessary, direct human support. Death education operates upstream, before palliative sedation becomes personally relevant, by building basic familiarity with death, dying and palliative sedation. When palliative sedation becomes relevant, the *Wat nu?* booklet provides a calm and tangible first point of orientation. The *Wat nu?* app offers more detailed and situation-based guidance as questions arise, while the 24/7 support line provides specialised human reassurance when self-guided information is insufficient.

This sequence should not be understood as a fixed pathway that every naasten must follow. Instead, the interventions can be accessed and revisited according to timing, preference and need. Their complementary design allows naasten to move between different forms of support when one layer is insufficient, from general orientation to more detailed guidance and direct human reassurance. Figure 28 presents the composition and sequence of the final portfolio.

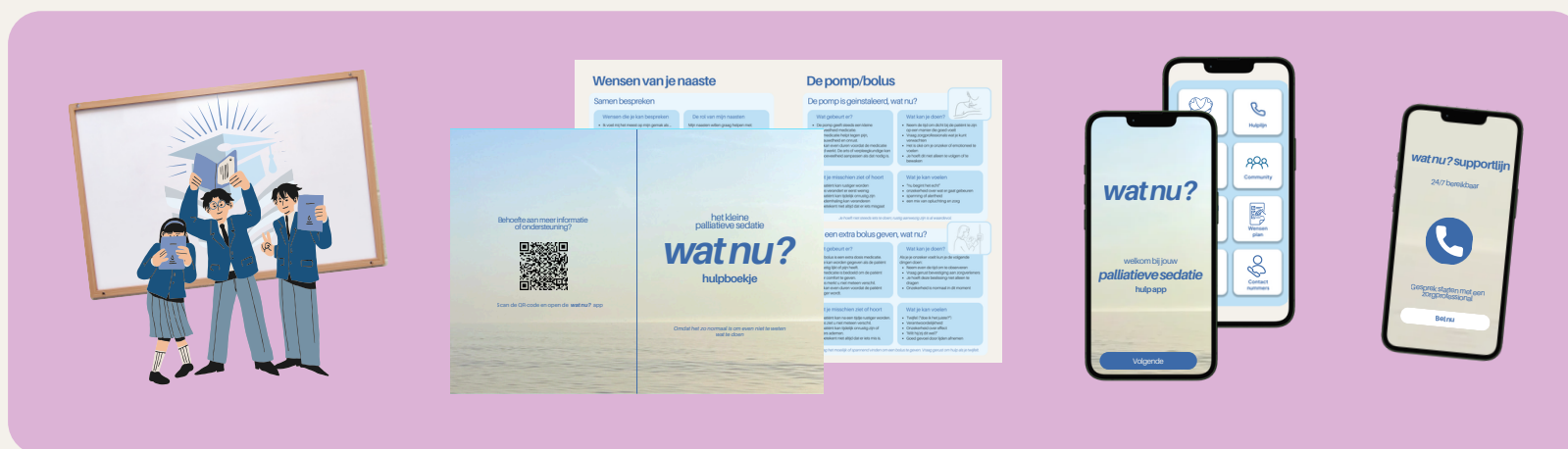


Figure 28. The final intervention portfolio

9.2 Portfolio contributions

The guidebook of UNDP (2022) was used to define the overall change and the suite of outcomes the portfolio aims to contribute to. In this project, this direction is based on the findings from the initial research, interviews, co-creation session, the tests, and further desk research.

What desirable change are we after?

The desired change is to reduce and better support the uncertainty experienced by naasten during home-based palliative sedation. Uncertainty cannot be removed completely, as the situation remains emotionally intense, unfamiliar, and uncontrollable. However, the support system aims to help naasten feel more prepared, reassured and calm by providing timely information, continuous guidance and access to human support when needed.

What would a positive difference look like?

A positive difference would mean that naasten enter the process with a clearer understanding of what may happen, feel supported during the different stages of palliative sedation, and feel less alone in moments of doubt or emotional pressure. Ideally, the system helps them look back on the care process with more peace, less distress and less fear that they did something wrong.

Where do we need to seed effort to effect change?

Effort needs to be seeded at multiple points in the wider support system. First, awareness and basic understanding need to be introduced before people become directly involved in palliative sedation through education. Additionally, the interventions need to reach naasten at the start of the care process, when healthcare professionals such as the GP or nurse explain what palliative sedation involves.

How might we activate these areas of focus?

Activating these areas of focus would require coordinated action across both education and healthcare. The potential implementation routes, actors and organisational conditions are explored in Section 10.1.

9.3 Portfolio value

Figure 29 summarises the expected individual and systemic value of the *Wat nu?* support system. It follows the systemic design reasoning of Van der Bijl-Brouwer et al. (2024), in which a design proposal is connected to the human and systemic mechanisms through which it is expected to contribute to value at both the individual and system level.

At the individual level, the portfolio aims to support preparation, access to information and reassurance for naasten before, during and after palliative sedation at home. At the systemic level, the portfolio creates a layered support structure across earlier education, printed and digital guidance, and access to professional support when further interpretation or clinical judgement is needed. This is expected to contribute to a more connected support environment in which naasten can access different forms of support as their needs change.

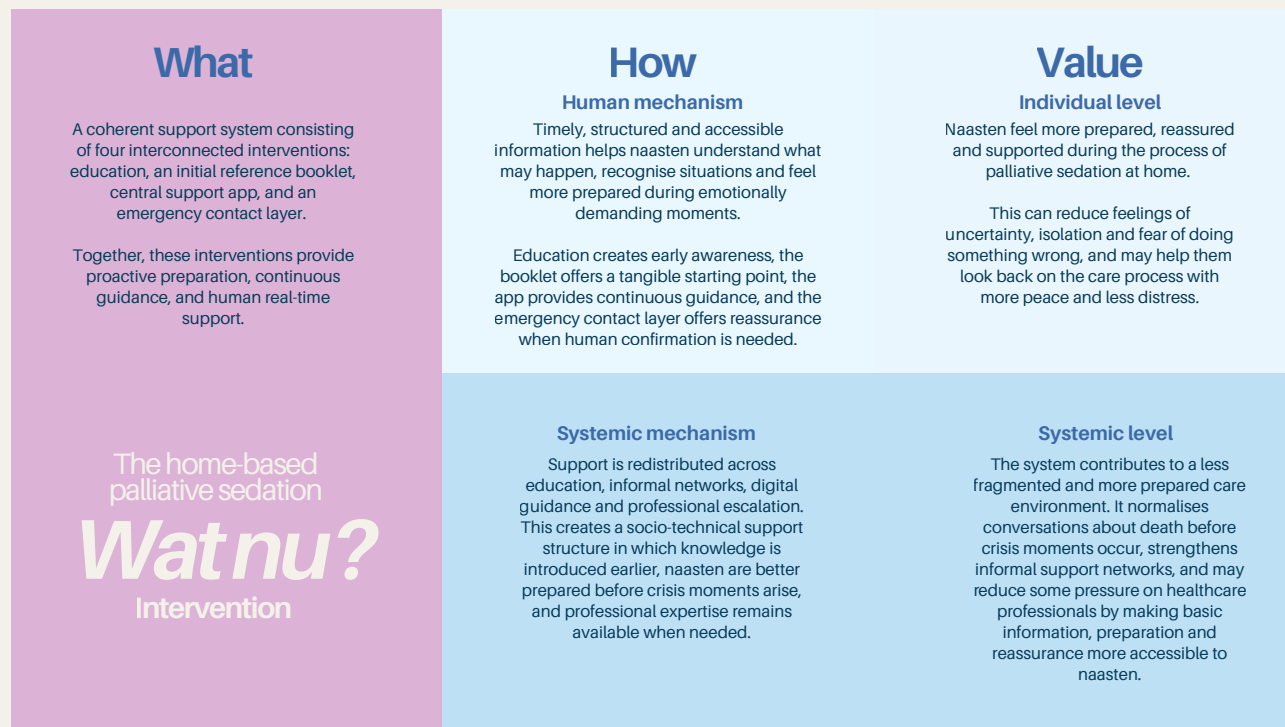


Figure 29. Uncertainty cycle with final interventions

10 Preparing the portfolio for practice

This chapter considers the further development of the *Wat nu?* portfolio towards practice. It outlines the preliminary implementation planning and the actors and conditions involved, before discussing the remaining limitation surrounding responsibility for bolus administration. Together, these sections clarify both what is needed to move the portfolio forward and where further development is still required.

10.1 Preliminary implementation planning

To explore what would be required to move the proposed support portfolio towards practice, the five tasks of Implementation Mapping described by Fernandez et al. (2019) informed the structure of this preliminary implementation exploration. Implementation Mapping is an iterative, theory- and evidence-informed approach that supports the identification of relevant actors, required implementation behaviours, determinants, strategies and implementation materials.

Within the scope and timeframe of this graduation project, the framework was used for a preliminary implementation exploration rather than a complete implementation study. The exploration was informed by findings generated throughout the project and supplemented by relevant Dutch guidelines and targeted desk research.

To further strengthen this preliminary implementation map, future research should directly involve the proposed adopters, implementers and responsible organisations across the relevant implementation contexts. Practical pilot testing could then be used to examine and refine the proposed roles, strategies, materials and conditions for adoption, delivery and long-term maintenance.

Task 1 — Proposed implementation actors

The first task identified the proposed adopters, potential implementers and end users for each intervention. Proposed adopters are the people or organisations that may decide whether an intervention is used or offered, while potential implementers are the actors who may introduce, deliver or maintain it in practice. The proposed roles and implementation routes differ across the four interventions.

For death education, future curriculum development represents one possible route. Within the Dutch context, SLO develops and actualises core objectives on behalf of the Ministry of Education, Culture and Science, while the Ministry initiates their formal incorporation into legislation (SLO, 2026). SLO and curriculum developers are therefore included as provisional adopters who could explore how death education might be translated into age-appropriate learning goals, learning lines or educational materials. Curriculum developers and teachers are positioned as potential implementers, while students are the end users, as they may later encounter palliative sedation as patients, naasten or healthcare professionals.

For the *Wat nu?* booklet and app, one possible route would be alignment with existing professional guidelines or patient-information structures. The Nederlands Huisartsen Genootschap (NHG), the Dutch professional association for general practitioners, develops evidence-based guidelines and related resources for general practice (Nederlands Huisartsen Genootschap, n.d.). As GP practices play an important role in palliative sedation at home, the NHG is included as one provisional actor that could explore whether the interventions might be aligned with or incorporated into guidance and information for general practice. GP practices, home-care organisations and palliative care networks are also included as potential adopters or implementation partners. Healthcare professionals

may introduce the interventions at an appropriate moment, while naasten are the end users.

The 24/7 support line would require a different implementation route and could potentially build on existing specialist palliative-care consultation structures (Palliaweb, 2021). Relevant healthcare organisations or palliative care networks may act as adopters, while specialised staff would deliver the support and healthcare professionals could introduce the service to naasten.

Table 3 summarises the proposed adopters, potential implementers and end users for each intervention. These actors and routes remain provisional and require validation with the organisations concerned. Their research basis and provisional status are further explained in Appendix 8.

Intervention	Proposed adopters	Potential implementers	End users
Death education	School board, Curriculum committee, The Ministry of Education, Culture and Science (OCW), SLO	Curriculum developers and teachers	Students (as potential future patients, naasten or healthcare professionals)
Wat nu? Booklet	GP practices, home care organisations, palliative care networks, potentially NHG (or other guideline/patient-information bodies)	GPs, nurses, home-care professionals and palliative care teams (introduction)	Naasten
Wat nu? App	GP practices, home care organisations, palliative care networks, potentially NHG or another organisation responsible for patient information	GPs, nurses and home-care professionals (introduction); app/content managers (maintain/update app)	Naasten
Support line	Organisation responsible for the national palliative care consultation service	Specialised palliative care consultants (delivery); GPs, home-care professionals and palliative care teams (introduction)	Naasten

Table 3. Task 1: Implementation actors

Stakeholder map

Figure 30 presents potential entry points through which the proposed support system could be introduced within the existing care network. Nurses and GPs are positioned as potential initiators because they are often in close contact with both the patient and naasten during home-based palliative sedation. They monitor the patient's condition, administer medication and provide guidance to naasten throughout the process. These existing roles suggest that they may be well positioned to introduce the booklet or app at an appropriate moment and explain how these tools could support naasten during periods of uncertainty.

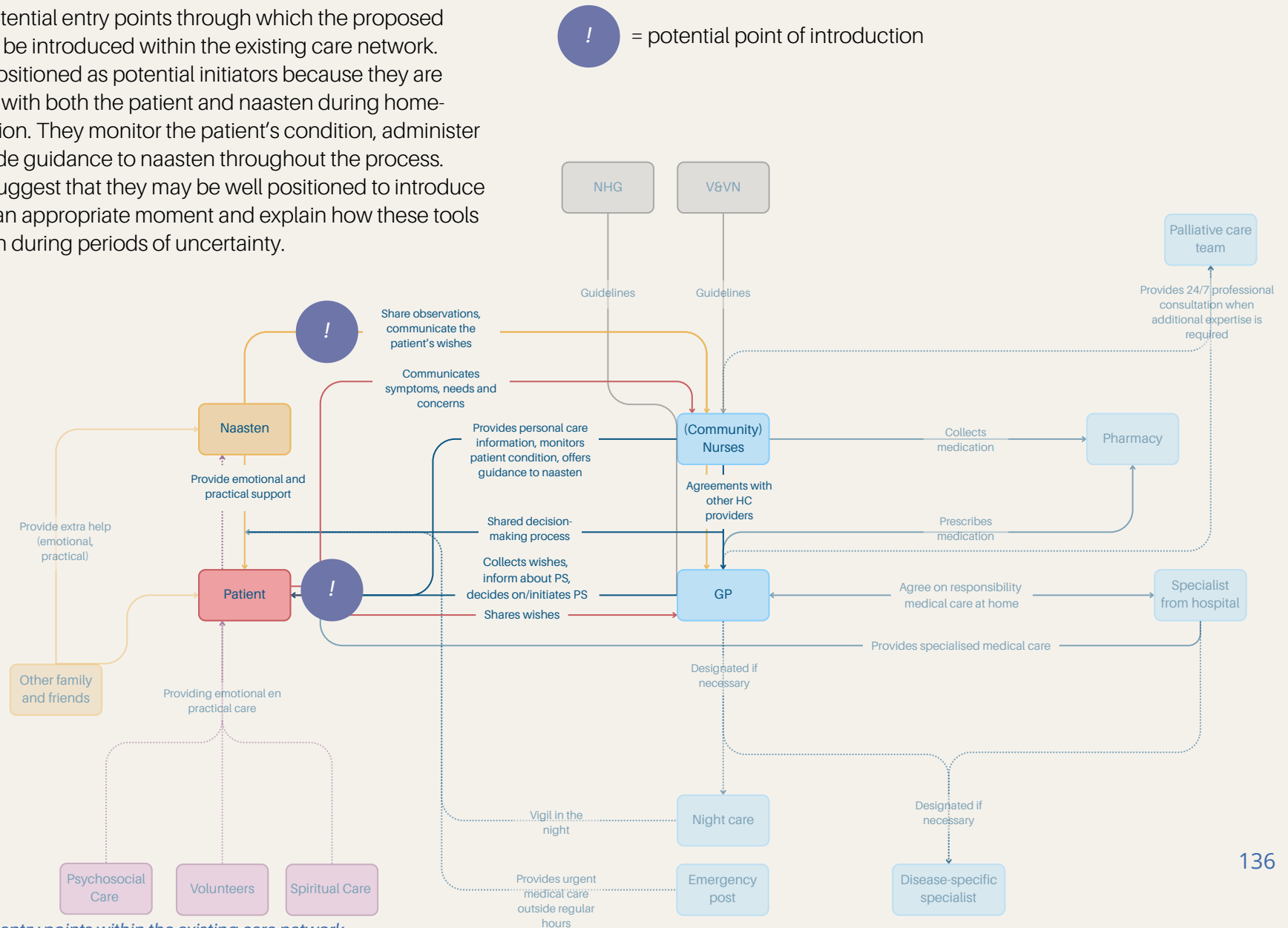


Figure 30. Potential implementation entry points within the existing care network

Task 2 — Preliminary adoption and implementation outcomes

The second task translated the proposed implementation roles into preliminary adoption outcomes, implementation outcomes, performance objectives and determinants. Adoption outcomes describe the decisions that organisations or other adopters may need to make before an intervention can be introduced. Implementation outcomes describe what implementers may need to do to introduce, deliver or maintain the intervention in practice.

The performance objectives specify the actions that may be required from adopters and implementers. The determinants describe factors that could influence whether these actions can be performed, such as perceived relevance, time pressure, trust, professional skills, digital literacy, ownership and available resources (see Table 4).

Intervention	Adoption outcome	Implementation outcome	Key performance objectives	Provisional determinants
Death education	Educational organisations or schools decide to include death, remembrance and palliative sedation in educational material	Curriculum developers and teachers integrate and deliver the lesson in an age-appropriate and sensitive way	Approve the lesson package, translate the topic into learning goals, facilitate safe classroom discussion	Perceived relevance, curriculum space, sensitivity of the topic, teacher skills, parental concerns, cultural and religious diversity
Wat nu? Booklet	Care organisations or GP practices decide to use the booklet as part of the information process around palliative sedation at home	Healthcare professionals hand out and explain the booklet before or at the start of sedation	Give the booklet at the right moment, explain its purpose and structure, encourage naasten to use it as a reference during the process	Time pressure, fit with the current workflow, perceived usefulness, trust in the content, clarity about when and how to provide it
Wat nu? App	Care organisations or professional bodies decide to refer naasten to the app as a central support layer	Healthcare professionals introduce the app, content managers keep the information reliable and up to date	Explain the app's purpose, help naasten access it, maintain medically reliable content, ensure usability during moments of uncertainty	Digital literacy, trust, privacy, ethical considerations (AI), medical accuracy, content ownership, maintenance capacity, integration into care communication
24/7 support line	The organisation responsible for the national palliative care consultation service decides to include the support line as an escalation layer	Professionals introduce the support line to naasten, and trained staff provide support when contacted	Give the number to naasten, explain when calling is appropriate, reduce feelings of guilt about calling, provide calm and specialised support	Funding, staffing, responsibility, availability, legal/medical accountability, professional trust, naasten's threshold for calling

Table 4. Task 2: Adoption and implementation outcomes

Task 3 — Proposed implementation strategies

The third task explored strategies that could support the proposed adopters and implementers in carrying out the required actions and could help address the provisional determinants identified in Task 2. The proposed strategies include briefing or training professionals, creating clear handover moments, developing call criteria for the support line, connecting the booklet and app through a QR code, and piloting the interventions in a limited implementation context before broader deployment (see Table 5).

Task 4 — Potential implementation materials

The fourth task translated the proposed implementation strategies into practical materials that may be needed to support their delivery. For the educational intervention, these materials could include a lesson plan, teacher guide, student worksheet and guidance for handling emotional responses. For the booklet and app, potential implementation materials include professional handover checklists, short introduction scripts and a content governance plan. For the support line, call criteria, triage and escalation protocols, staffing plans and responsibility agreements may be required (see Table 5).

Intervention	Proposed implementation strategies (task 3)	Potentially required implementation materials (task 4)
Death education	Develop a teacher guide, create lesson material, provide guidance for sensitive classroom discussions, pilot the lesson with teachers and students before broader use	Lesson plan, teacher guide, student worksheet, reflection prompts, guidance for handling emotional responses
Wat nu? Booklet	Integrate the booklet into the existing preparation process for palliative sedation, create a short checklist outlining what GPs and nurses should explain, define a clear handover moment, and pilot the booklet in one municipality before broader deployment	Professional handover checklist, short explanation script, QR code linking to the app, link to a printable PDF
Wat nu? App	Introduce the app through a QR code in the booklet, create a short onboarding flow for naasten, provide professionals with an explanation of the app, assign responsibility for content updates and medical review, and pilot the app in one municipality before broader deployment	Professional handover checklist, short introduction script, content governance plan
24/7 support line	Train professionals to introduce the support line as a normal and acceptable support option, develop appropriate protocols, clearly display the phone number in the app and booklet, and pilot the support line in one municipality before broader deployment	Call criteria, professional introduction script, triage protocol, escalation protocol, staffing plan, responsibility agreements

Table 5. Tasks 3 and 4: Implementation strategies and materials

Task 5 — Preliminary framework for future evaluation

Because the portfolio was not implemented or tested in a pilot, implementation outcomes could not yet be measured. The fifth task of Implementation Mapping was therefore adapted into a preliminary framework for future evaluation. The desirability, feasibility and viability framework of IDEO U (n.d.) was used as an additional design-oriented lens to structure questions for the further development and practical testing of the portfolio.

Desirability focuses on whether the interventions are perceived as relevant, appropriate and valuable by naasten and other stakeholders. Feasibility addresses whether the interventions can be introduced within existing workflows, educational contexts and care processes. Viability considers whether the interventions can be maintained over time, including ownership, funding, content governance and organisational responsibility.

The questions and possible indicators presented in Table 6 should therefore be understood as proposed directions for future evaluation rather than as demonstrated implementation outcomes. Each intervention is considered separately because education, the booklet, the app and the support line depend on different actors and implementation conditions. The portfolio is also considered as a whole to examine whether the interventions could function as a coherent support system rather than as separate tools (see Table 6 on next page).

Desirability

The evaluation with naasten and one nurse provide an initial indication of the perceived desirability of the portfolio. Naasten appreciated the combination of preparatory education, accessible reference materials and interactive guidance, while the nurse recognised its potential to improve

support for families. The complementary roles of the interventions may contribute to this perceived value, as they offer different forms of support before and during moments of uncertainty. However, these findings remain preliminary and should be further evaluated with a broader range of stakeholders.

Feasibility

Several characteristics of the portfolio suggest practical potential. The printed booklet and interactive app prototype demonstrate that both concepts can be translated into tangible and testable formats, providing an initial indication of design feasibility. The booklet requires relatively limited further technical development, although content validation, production and distribution still need to be organised. The app would require software development, medical content review, privacy assessment and maintenance capacity. The support line concept could provide a human support layer when written or digital guidance is insufficient, but its implementation feasibility depends on staffing, triage, professional accountability and integration with existing services. Overall implementation feasibility has therefore not yet been established.

Viability

The layered structure may support phased development and allow different forms of support to be maintained separately. At the same time, it creates a need for clear coordination, ownership and responsibility across the interventions and organisations involved. The nurse indicated that elements of the portfolio might be incorporated into existing care practices. Nevertheless, long-term viability depends on conditions that were outside the scope of this project. Further research is required to determine organisational ownership, funding, content governance, staffing, maintenance responsibilities and alignment with existing care pathways.

	Desirability	Feasibility	Viability
Death education	Key question: Do teachers, students and educational stakeholders perceive the topic as relevant and appropriate? Possible indicators: Stakeholder feedback; perceived relevance; perceived emotional safety.	Key question: Can the topic be delivered in an age-appropriate and sensitive way within the educational context? Possible indicators: Curriculum fit; lesson duration; required teacher preparation; support needs.	Key question: Can the educational material be maintained over time with clear organisational responsibility? Possible indicators: Organisational ownership; curriculum integration; update process; continued support.
Wat nu? booklet	Key question: Do naasten and healthcare professionals perceive the booklet as a helpful and accessible starting point? Possible indicators: User and professional feedback; perceived clarity; perceived usefulness; emotional appropriateness.	Key question: Can healthcare professionals introduce and explain the booklet at an appropriate moment within existing workflows? Possible indicators: Timing of handover; workflow fit; clarity of the professional introduction.	Key question: Can the booklet remain available, accurate and aligned with professional information over time? Possible indicators: Organisational ownership; production and distribution; content review; update process.
Wat nu? app	Key question: Do naasten perceive the app as valuable and trustworthy for guidance and reassurance? Possible indicators: User feedback; perceived usefulness; perceived reassurance; trust in the information.	Key question: Can naasten use the app during stressful moments, and can healthcare professionals introduce it clearly? Possible indicators: Usability; accessibility; need for assistance; clarity of the professional introduction.	Key question: Can the app be maintained as a reliable and medically appropriate support layer? Possible indicators: Responsible organisation; content-review process; technical maintenance; long-term responsibility.
24/7 support line	Key question: Do naasten perceive the support line as a reassuring and acceptable safety net? Possible indicators: Willingness to call; perceived permission to call; perceived reassurance after contact.	Key question: Can the service be introduced clearly and accessed when support is needed? Possible indicators: Clarity of purpose and access route; accessibility; responsiveness; organisational capacity.	Key question: Can the service be maintained over time with clear organisational responsibility? Possible indicators: Organisational ownership; required capacity; long-term responsibility; integration with existing services.
Portfolio as a whole	Key question: Do naasten experience the interventions as a coherent support system rather than as separate tools? Possible indicators: Perceived coherence and continuity; perceived complementarity; feedback on how the interventions work together.	Key question: Can the interventions be introduced at appropriate moments without overburdening healthcare professionals? Possible indicators: Workflow fit; clarity of handover moments; professional feedback.	Key question: Can the portfolio be maintained with clear coordination and responsibility across the interventions? Possible indicators: Overall ownership; coordination; long-term responsibility; maintenance.

Table 6. Task 5: Preliminary framework for future evaluation

10.2 A remaining research challenge

Responsibility around bolus administration

As discussed in Sections 3.3.3 and 5.3.3, bolus administration emerged early in the project as a particularly visible moment of uncertainty and responsibility. However, the research showed that this moment formed part of a broader experience involving limited preparation, uncertainty, difficult decisions and limited access to reassurance when it was needed. The project therefore did not focus solely on the bolus button, but translated these interconnected needs into the layered *Wat nu?* support system.

The project's contribution lies in combining preparation, accessible information and professional reassurance across different moments in the process. As discussed in Section 7.2.3, this support may make the responsibility associated with bolus administration more manageable for some naasten. For others, however, physically administering medication may remain beyond the level of responsibility they are willing or able to assume. Further research is therefore needed to understand when the current support is sufficient and when responsibility needs to be redistributed rather than only supported.

This remaining question also fits the logic of a portfolio approach. The UNDP (2022) emphasises that portfolio design and implementation are iterative processes that evolve as new dynamics and insights emerge. Evaluation and experimentation can reveal unresolved tensions and show where a portfolio may need to be adapted or expanded. In this project, the evaluation showed differences in how participants viewed responsibility around bolus administration. This identifies an area for further real-life research and may point to the need for an additional layer of support or a redistribution of responsibility.

This question is particularly relevant in light of the healthcare capacity constraints discussed in Section 5.6. Although greater professional presence could reduce the responsibility experienced by naasten, current and projected workforce shortages mean that responsibility cannot simply be redistributed by adding more professional care. Alternative directions should therefore preserve appropriate professional oversight without depending on the continuous physical presence of a healthcare professional.

If further research confirms that some naasten remain uncomfortable with administering a bolus themselves, a human and community-based direction could be explored. This could build on participants' appreciation of a doula-like form of support: a trusted person from the wider community who is present during the dying process, offers guidance and helps share responsibility when professional care is not continuously available. In the future, such a role could potentially also involve supporting or taking over bolus administration, where this is legally and clinically permitted. This could reduce the feeling that naasten have to carry the responsibility alone.

A second direction concerns technical forms of mediated administration. A healthcare professional could assess the situation remotely and activate an additional bolus without requiring the naaste to press the button. In the longer term, monitoring technologies might help identify possible signs of discomfort and prompt professional assessment or, where appropriate, a controlled medication adjustment. These ideas are still at an early stage and would need to be explored further to determine whether they are safe, ethically acceptable, legally and technically feasible, and who would be responsible for their use.

Cycle 3 synthesis

Cycle 3 positioned the four interventions as complementary parts of the *Wat nu?* support system. Education introduces the subject at an earlier stage, the booklet supports preparation, the app provides accessible information throughout the process and the support line offers direct human support when questions remain. The revised experience timeline and systemic value overview clarified how these layers may support naasten at different moments and contribute to value at both the individual and system level.

The preliminary implementation exploration highlighted several conditions requiring further attention, including medical validation, organisational responsibility, maintenance, funding and evaluation in real care settings. The final outcome is therefore an integrated and research-informed design direction that provides a foundation for further development.

From design outcome to reflection

The three design cycles shown in Figure 31 resulted in an intervention portfolio for supporting naasten before, during and after palliative sedation at home. The following chapters reflect on how the project addressed the research and design objectives, which methodological and contextual limitations shape the findings, and what implications and priorities follow for further development, healthcare practice and research.

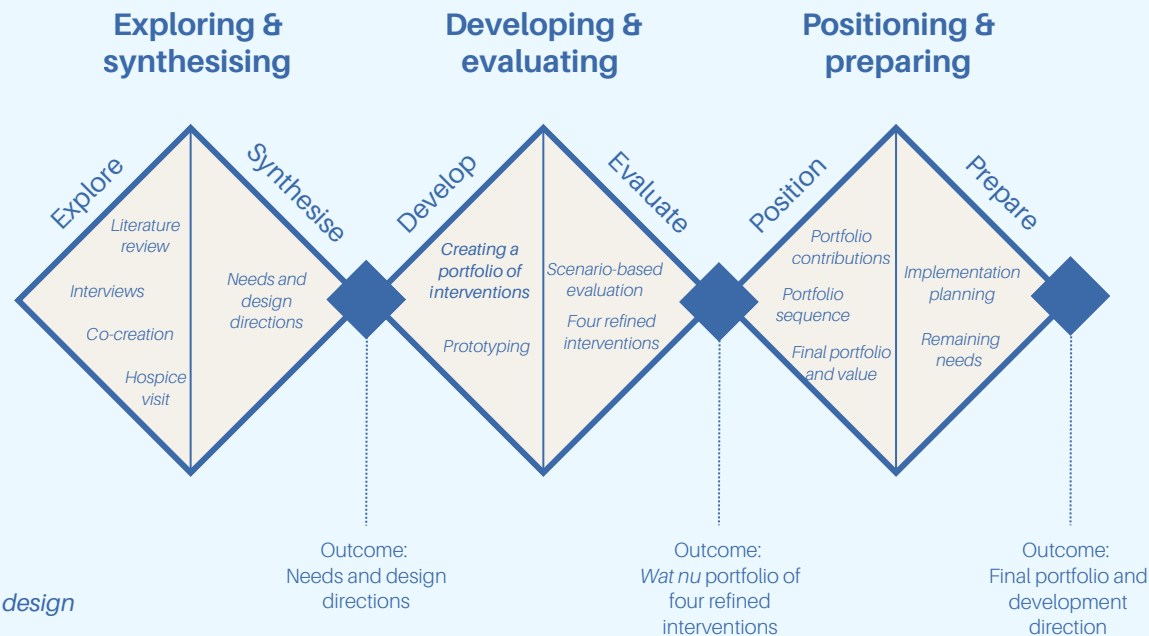


Figure 31. Completion of the three-cycle design process and final project outcome

11 Discussion

11.1 Transferability to the care context

What does this mean for the bigger picture?

Although this project focuses specifically on supporting naasten during palliative sedation at home, the findings suggest that the need for guidance may extend beyond this context. During informal conversations about the project, several people mentioned that they would also have valued more guidance during the dying process of a naaste when palliative sedation was not involved. Transferability literature of Schloemer & Schröder-Bäck (2018) shows that health interventions developed in one context can be considered for use in another when the original and target contexts are considered.

This suggests that the support system developed in this project could potentially be expanded towards a broader understanding of dying and end-of-life care. The need for clear information, preparation, reassurance and accessible support is not limited to palliative sedation alone. Similar forms of uncertainty may also occur in other dying processes, where naasten may not know what to expect, what is normal, or when to ask for help.

Therefore, while the current design direction remains focused on home-based palliative sedation, it would be valuable to further explore how the system could be adapted to other end-of-life situations. Future research could investigate whether elements such as education, a booklet, an app or an escalation layer could also support naasten during other forms of dying, both within and outside the home context.

11.2 Rituals as future extension

Room for rituals

Although rituals do not play a central role in the current interventions, they are important to acknowledge as a possible future layer of support. The interviews and literature suggest that rituals may help people give meaning to death, grief and remembrance (RVS, 2021), but further research is needed to understand what kind of ritual support naasten would need. This could inform the further development of the educational material, as well as possible content within the app or booklet.

An example that could be explored further is Allerzielen (All Souls' Day), which was mentioned by Naaste 5 during the interview as an annual day of remembrance. The RVS (2021) describes Allerzielen Alom as an example of a public ritual in which cemeteries are transformed with light, fire and artistic interventions, allowing visitors to remember their dead in a meaningful way. This raises the question of whether naasten could benefit from greater awareness of existing ritual possibilities, as well as support in creating rituals that fit their own values, relationship and situation.

Within the proposed support system, rituals could therefore be considered as a future extension. Rituals could be incorporated into the teaching materials, with special attention given to a day such as All Souls' Day. In the app or booklet, they could be included as optional inspiration for naasten who are looking for ways to create meaning, mark important moments or remember the person after death. However, because ritual needs are personal, cultural and context-dependent, this direction should be explored further with naasten before being developed into a concrete design feature.

11.3 Reflection, limitations and strengths

This section reflects on the research and design approach, the main contributions of the project and the limitations that shape how the final outcome should be interpreted.

Reflection on the approach

The project followed an iterative combination of literature research, interviews, a hospice visit, co-creation and scenario-based evaluation. Its value lay not only in using multiple methods, but in allowing each activity to build on and reconsider previous findings. Activities involving naasten helped the project remain close to their lived experiences and needs, while the involvement of healthcare professionals connected these experiences to knowledge of the wider care context. This allowed the design direction to remain responsive to emerging insights, as illustrated by the shift from the initial exploration of rituals towards the more immediate needs surrounding understanding, uncertainty and responsibility.

Although I had previously learned about systemic design, I was accustomed to design processes that gradually converge towards one tangible solution. The interventions were initially explored more separately, while the importance of positioning them as a connected system became clear later. This taught me to consider a systemic perspective from an earlier stage when working on complex challenges involving interconnected actors, needs and moments.

I also learned to use design methods less rigidly. Before the co-creation session, I initially intended to follow the planned sequence closely. Following supervisory feedback, I responded more openly to the discussion and adapted the session as it developed. An important personal lesson was therefore to use methods as guiding frameworks,

while relying on informed intuition and design judgement when the situation requires adjustment.

Strengths of the project

The project contributes a design perspective on the experience of palliative sedation at home. Combining literature with the perspectives of naasten and healthcare professionals helped reveal the emotional, practical and moral dimensions of the process. This grounded the design direction in lived experiences rather than assumptions about what support might be needed.

A particularly relevant insight was that the infusion pump itself was not necessarily experienced as disruptive. Instead, uncertainty arose around its use, interpretation and the responsibilities connected to it. Bolus administration made visible how a medically controlled action may nevertheless feel emotionally and morally charged to a naaste. This clarified that the main design opportunity did not lie in redesigning the medical device itself, but in supporting the experience surrounding its use.

A further strength is that the interconnected needs were translated into a layered portfolio rather than one isolated intervention. This is appropriate for a process in which support needs differ between people and change over time. The portfolio combines preparation, accessible information and human reassurance, while recognising that self-guided support cannot replace professional care. The evaluation further indicated that the interventions could fulfil different roles and that their combined value depended on being experienced as complementary parts of one coherent system.

Limitations

The findings are based on a small, purposively selected and context-specific participant group. Naasten were mainly recruited through personal networks, and the participant group had limited cultural, religious and spiritual diversity. These factors restrict the transferability of the findings.

Several participants contributed to multiple project activities. This supported continuity and allowed them to respond to how earlier findings had been translated into design concepts. However, their familiarity with the project may also have influenced their later responses, meaning that these did not always represent independent first impressions.

Although participants contributed experiences, ideas and evaluations, the synthesis of findings, selection of interventions and composition of the final portfolio were ultimately shaped by my interpretations as the designer. Scenario-based evaluation enabled sensitive situations to be discussed safely and systematically, but could not reproduce the emotional intensity, time pressure and uncertainty of palliative sedation in real home-care situations.

The complete portfolio has therefore not been validated as a functioning support system in practice. Its anticipated contributions should be interpreted as research-informed design propositions rather than demonstrated effects. Furthermore, as discussed in Section 10.2, the portfolio may support naasten in understanding and navigating bolus administration, but it does not remove the associated responsibility for everyone. The current outcome should therefore be understood as a grounded direction for further development rather than as a proven transformation of the care system.

11.4 Further recommendations

The intervention portfolio developed in this project offers a design direction for supporting naasten before, during and after palliative sedation at home. However, the interventions remain concepts and prototypes and require further validation, development and evaluation before implementation. The recommendations below address the further development of the portfolio, implications for healthcare practice and priorities for future research. Because the project involved a limited and context-specific group of participants, these recommendations should be examined with a broader range of naasten and healthcare professionals.

11.4.1 Further development of the intervention portfolio

Development of the educational intervention

The educational intervention should be developed further in collaboration with educational experts, palliative care professionals, teachers, pupils and parents. Future development should focus on making the intervention understandable and emotionally appropriate for schoolchildren through accessible language, an appropriate level of medical detail, relatable examples and clear visual explanations. Because the intervention has not yet been evaluated across diverse cultural and spiritual backgrounds, pupils, parents and teachers from different backgrounds should be involved to assess whether the language, examples and ways of discussing death are appropriate and inclusive. Early versions should be co-designed and tested to assess their clarity, emotional suitability and practical fit within an educational setting. Further work should also determine where the intervention could fit within existing education, who would facilitate it and what guidance or training teachers would require.

Development of the Wat nu? booklet and app

The content of the *Wat nu?* booklet and app should be reviewed by a multidisciplinary group of palliative care professionals. This review should assess medical accuracy, consistency with current care practice and alignment with the information provided by general practitioners and community nurses. Naasten should remain involved in this process to evaluate whether the information is understandable, emotionally appropriate and reassuring. Testing should identify missing information and sections that may be difficult to understand during emotionally demanding moments. The personal stories should be further developed based on the lived experiences of real naasten and tested for relevance and emotional appropriateness. The aim should be to provide sufficient preparation without creating information overload.

Accessibility should be incorporated from the beginning of further development. Relevant directions include plain language, short text sections, visual explanations, audio support and multilingual versions. These adaptations should be tested with people with varying levels of general literacy, health literacy and digital literacy. Further technical development of the app should also consider ease of navigation under stress, readability, privacy, security and long-term maintenance.

Development of the 24/7 support line

The support line should be explored as an additional real-time support layer within existing palliative care structures. It should provide explanation and reassurance when naasten are uncertain about what they observe or what they should do next. Further work should clarify which questions the support line can address, how calls would be assessed and who would provide the support. Availability, staffing, expected call volume, and integration with existing services should be investigated before implementation. The service should make clear that naasten may seek support when they are

uncertain and do not first need to decide whether their question is important enough. At the same time, clear instructions should distinguish the support line from contact routes for urgent clinical situations.

Coherence and real-life piloting

The interventions should continue to be developed as one connected support system. Further development should examine the transitions between the interventions, including how each layer is introduced and how naasten move from one form of support to another. A real-life pilot could be conducted with a regional palliative care network, GP practice or home-care organisation. This pilot should examine when the booklet and app are provided, who introduces them and how healthcare professionals refer to them throughout the process. It should also explore whether the interventions remain accessible when they are needed, whether they can be used during stressful moments and whether they fit within existing care practices without creating excessive additional workload.

Organisational feasibility and responsibility

The organisational and financial implications of each intervention should be explored before implementation. For the educational intervention, relevant considerations include the development of teaching materials, guidance or training for educators and periodic content review. For the booklet, these include content development, printing, storage, distribution and replacement. For the app, technical development, hosting, maintenance, accessibility, privacy, security and content updates require further assessment. For the support line, the operational costs and organisational requirements associated with staffing, training, availability and integration with existing palliative care services should be investigated.

Further development should explore how responsibility for the intervention portfolio could be organised. This includes considering which organisation or partnership could coordinate further development and distribution, review and approve the content, and remain responsible for keeping the information accurate and up to date. The potential involvement of healthcare organisations, government bodies and other potential funders could be explored as part of a future feasibility study. Such a study could also examine how long-term coordination, maintenance and funding could be organised beyond the initial development phase.

Support surrounding bolus administration

Future design development should explore possible community-based, professional or technical ways of sharing or redistributing responsibility around bolus administration. These directions may be relevant for naasten who, despite receiving information and reassurance, do not feel able or willing to administer the bolus.

11.4.2 Recommendations for healthcare professionals

Provide timely and repeated information

Palliative sedation should be discussed when it becomes a realistic possibility and, where possible, before the situation becomes acute. Important information should be repeated throughout the process. During emotionally intense moments, naasten may have difficulty absorbing and remembering verbal explanations. Written or digital information and clear contact arrangements can support later questions. Healthcare professionals should check what naasten have understood and provide opportunities to revisit earlier explanations.

Prepare naasten for different possible courses

Expectation management should receive more attention. Naasten need to know that palliative sedation does not always mean that the patient immediately falls into a deep and peaceful sleep. Possible events such as restlessness, delirium, altered breathing, rattling breathing, brief periods of waking or a longer-than-expected duration should be explained in advance. This may help reduce fear when these situations occur.

Communicate uncertainty honestly

Healthcare professionals should also avoid overly certain statements about what the patient does or does not experience. Since the patient's awareness during sedation cannot always be known with certainty, it may be more helpful to acknowledge uncertainty while encouraging naasten to do what feels meaningful, such as speaking to the patient, holding their hand or staying close.

Clarify roles around the pump and bolus

The possible involvement of naasten in using the bolus button should be discussed. Professionals should ask whether they feel comfortable taking on this role rather than assuming that they are willing to do so. Naasten should receive clear explanations about when a bolus may be considered, what it is intended to do, how quickly an effect may become visible and whom they can contact when they remain uncertain. Where possible, alternative arrangements should be discussed when a naaste does not wish to carry out the action.

Prepare for the period after death

Healthcare professionals should pay attention to what happens after death. The co-creation session showed that naasten may experience a *Wat nu?* moment once the patient has died. Clear information about next steps, who to call, what will happen to the medication and pump, and what support is available afterwards can help reduce uncertainty in this transition.

Terminology used in the interventions

The current interventions use the term patient to refer to the person receiving palliative sedation. Although this term is clear and commonly used within healthcare, it may feel clinical or create emotional distance for some naasten. Further development should therefore explore, together with naasten, whether a warmer and more personal term could be used without reducing clarity. Possible alternatives should be evaluated in the context of the interventions to determine which wording feels respectful, understandable and appropriate to naasten.

11.4.3 Recommendations for expanding this research

Evaluation in real home-care contexts

After further development and an initial real-life pilot, the relevant components of the *Wat nu?* support system should be evaluated in home-care contexts with naasten encountering palliative sedation for the first time. Such an evaluation could examine how the interventions are used over time, whether they support preparedness and understanding, and whether the timing and amount of information are appropriate. The evaluation should also consider possible unintended effects, such as information overload or increased concern about situations that may not occur.

Broader and more diverse participation

Future studies should include a larger and more diverse group of naasten. This should include variation in cultural, religious, linguistic and socioeconomic background, relationship to the patient, family situation, general literacy, health literacy and digital literacy. Healthcare professionals from different regions and organisations should also be included, as practices surrounding palliative sedation, professional availability and bolus administration may vary. This would help determine which needs are shared and which forms of support require adaptation.

Responsibility surrounding bolus administration

Real-life research is needed into how naasten understand and experience responsibility in relation to bolus administration. This could explore how they decide whether to administer an additional dose, which doubts arise, what forms of preparation and reassurance help and how healthcare professionals introduce this responsibility. Research should also investigate the experiences of naasten who do not wish to administer a bolus and the feasibility of alternative arrangements. The aim should not be to encourage all naasten to take on this role, but to understand how different preferences and personal boundaries can be supported safely.

11.4.4 Recommendations for future research

Broader research directions

Several topics emerged during this project but were not explored in depth. These could be valuable directions for future research.

- Public understanding of palliative sedation: Further research could examine what the Dutch public knows, assumes or fears about palliative sedation, to inform clearer public education and communication.
- Anticipatory grief: Future research could examine how anticipatory grief and meaningful conversations before death influence grief after death. This could provide more insight into how earlier moments of farewell shape the bereavement process.
- Presence at death: Further research could explore why naasten often feel a strong need to remain present until the moment of death, even when this leads to exhaustion, sleep deprivation or emotional overload.
- The analogy between birth and death: Elements such as preparation, support roles, doulas and care plans may offer inspiration, but the relevance and limits of this comparison require further investigation.
- Rituals and meaning-making: Future studies could explore how ritual-like actions support calm, connection and farewell while allowing for personal, cultural and religious differences.
- Advance care planning: Research could examine how earlier conversations about wishes, fears and possible scenarios reduce uncertainty while retaining flexibility in an unpredictable process.

Overall, further development and research should continue to approach palliative sedation at home as both a medical and human process. Supporting naasten requires medically accurate information, but also emotional reassurance, accessible professional support and sensitivity to personal boundaries, care and farewell.

12 Conclusion

This graduation project explored how naasten experience palliative sedation at home and how design can support them during this uncertain and emotionally demanding process. The study shows that palliative sedation at home is not experienced only as a medical intervention. For naasten, it is also a process of care, responsibility, interpretation and farewell.

The research began with rituals as an initial lens to understand meaningful moments around palliative sedation. This lens helped reveal the importance of presence, calm, connection and saying goodbye. However, the interviews showed that more fundamental needs first required attention. Before there is space for rituals or ritual-like support, naasten need to understand what is happening, know what to expect and feel supported in their role.

A central finding is that uncertainty strongly shapes the experience of naasten. This uncertainty can relate to the course of sedation, the patient's comfort, bodily signs such as restlessness or changed breathing, the duration of the process, and the question of when professional support is needed. When the process unfolds calmly, uncertainty may remain manageable. However, when the patient wakes up, becomes restless or appears uncomfortable, naasten can feel overwhelmed and unsure whether they are doing the right thing.

The infusion pump became an important focus within this uncertainty. Although the pump itself was not necessarily experienced as disturbing, the actions surrounding it could be emotionally loaded. This was especially visible in relation to the bolus button. For some naasten, administering an additional dose could feel like an act of care. For others, it created fear, guilt and a sense of responsibility, as if they were actively

contributing to the patient's death. This shows that a medically controlled action can still be experienced as morally charged.

The design opportunity therefore did not lie in redesigning the medical device itself, but in supporting the moments around it. Naasten need clear explanation, reassurance and accessible guidance before and during the process, especially at moments when uncertainty becomes acute. This led to the development of a layered support system rather than one single intervention.

The final design direction consists of four connected interventions: death education, the *Wat nu?* booklet, the *Wat nu?* app and a 24/7 support line. Each layer responds to uncertainty at a different moment. Education can create earlier familiarity with dying and end-of-life care. The booklet provides accessible and tangible information before and during palliative sedation. The app offers more detailed, interactive and personal guidance. The support line creates a human safety layer for moments of doubt, emotional pressure or decision-making.

Together, these interventions aim to help naasten feel more prepared, less alone and more supported. The system does not try to remove uncertainty entirely, because palliative sedation will always remain partly unpredictable and emotionally vulnerable. Instead, it aims to make uncertainty more manageable by giving naasten information, reassurance and access to support when they need it.

The project also shows that support for naasten should not be limited to medical explanation. It should acknowledge the emotional, relational and moral dimensions of home-based palliative sedation. Naasten are not passive bystanders; they are often closely involved in care, interpretation

and farewell. Designing for this context therefore requires sensitivity to both the medical process and the human experience around it.

Ultimately, this project contributes a design perspective on palliative sedation at home by showing where uncertainty emerges and how a layered support system could help naasten navigate the process. Rather than asking naasten to simply cope with the unknown, the proposed system helps them ask, understand and act when they wonder: Wat nu?

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Appendices

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Appendix 1

Interview guide naasten

Context	1. Kan je kort jezelf voorstellen en iets vertellen over jouw relatie tot de persoon om wie het gaat?
Create Journey map	1. Zou je voor mij een kunnen schetsen hoe voor u het proces van palliatieve sedatie eruit heeft gezien? <i>(Je mag zelf kiezen waar je begint en waar je stopt. Je kunt hiervoor alle materialen gebruiken die hier liggen. Het hoeft niet mooi te zijn. Het is puur om inzicht te krijgen in hoe jij het proces hebt ervaren.)</i> 1. Wat was jouw rol en ervaring tijdens dit proces? 2. Welke momenten waren belangrijk? 3. Hoe was het voor het <i>eerste punt</i> op je tijdlijn? 4. Hoe was het na <i>het laatste punt</i> op je tijdlijn?
Needs (unmet needs)	1. Welke momenten waren zwaar, vermoeiend of vervelend? 2. Hoe heb je die momenten aangepakt? 3. Welke problemen werden niet opgelost? 4. Op welke momenten voelde je gesteund of rustig?
Speciale momenten	1. Waren er momenten die in deze periode meer betekenis kregen? 2. Wat maakte dit moment betekenisvol? 3. Wat deed deze handeling met jou? 4. Wat zei deze handeling over jouw relatie met deze persoon?
<i>Nu heb ik een goed beeld gekregen van de tijdlijn. Bedankt. In mijn project wil ik kijken hoe ik deze behoeftes kan vervullen/tegemoetkomen aan de hand van rituelen. Om naasten hiermee te begeleiden. Hier gaan mijn laatste vragen over:</i>	
Rituals	1. Zijn er momenten die voelden als een ritueel? Zou je daar behoefte aan hebben? 2. Zijn er rituelen die je nu nog toepast? Zou je daar behoefte aan hebben?
Nazorg	1. Zou je graag nog iets anders kwijt willen?

Interview guide healthcare professionals

Context	1. Kunt u kort vertellen wie u bent en wat u doet op het gebied van palliatieve sedatie?
Create Journey map	1. Zou u voor mij een tijdlijn kunnen maken hoe voor het proces van palliatieve sedatie eruitziet? <i>(U mag zelf kiezen waar u begint en waar u stopt. U kunt hiervoor alle materialen gebruiken die hier liggen. Het hoeft niet mooi te zijn. Het is puur om inzicht te krijgen in hoe u het proces heeft ervaren.)</i> 1. Wat is uw rol en ervaring tijdens dit proces? 2. Welke momenten zijn hierin volgens u belangrijk voor naasten? 3. Wat gebeurt er voor het eerste punt op uw tijdlijn? 4. Wat gebeurt er na het laatste punt op uw tijdlijn?
Needs (unmet needs)	1. Welke momenten zijn zwaar, vermoeiend of vervelend voor naasten? 2. Hoe worden die momenten aangepakt? 3. Welke problemen werden niet opgelost? 4. Op welke momenten voelen naasten zich gesteund of rustig?
Speciale momenten	1. Zijn er momenten die in deze periode meer betekenis krijgen voor de naasten? 2. Wat maakt deze momenten betekenisvol? 3. Wat zeggen deze handeling over de relatie tussen deze persoon?
<i>Nu heb ik een goed beeld gekregen van de tijdlijn. Bedankt. In mijn project wil ik kijken hoe ik deze behoeftes kan vervullen/tegemoetkomen aan de hand van rituelen. Om naasten hiermee te begeleiden. Hier gaan mijn laatste vragen over:</i>	
Rituals	1. Zijn er momenten die voelden als een ritueel? 2. Hebben naasten behoefte aan rituelen?
Nazorg	1. Zou u graag nog iets anders kwijt willen?

Appendix 2

Overview of participant involvement

Involvement of naasten across project activities

	Interview	Co-creation	Evaluation	Visual refinement
Naaste 1				
Naaste 2				
Naaste 3				
Naaste 4				
Naaste 5				
Naaste 6				
Naaste 7				

	Interview	Co-creation	Evaluation	Visual refinement
Additional participants (n = 3)				

Involvement of healthcare professionals across project activities

	Interview	Co-creation	Evaluation	Visual refinement
Nurse 1				
Nurse 2				
Nurse 3				
Nurse 4				
Nurse 5				
GP 1				
GP 2				

Participated	Not participated
---------------------	-------------------------

Appendix 3

Six phases of thematic analysis

The six steps of Braun and Clarke (2006):

Phase 1: Familiarising yourself with the data

The first phase focused on becoming familiar with the data. Braun and Clarke (2006) describe this stage as essential, as immersion in the data forms the basis for the rest of the analysis. I developed familiarity with the data through conducting and transcribing the interviews. In addition, the transcripts were reread and initial notes were written on recurring, striking and more general observations within the interviews.

Phase 2: Generating initial codes

The next step involved inductively generating initial codes. In this phase, codes were used to identify meaningful features of the data and to organise the material into relevant groups. Coding was carried out as inclusively as possible, meaning that as many potentially relevant patterns as possible were considered. Relevant surrounding context was retained where necessary, and extracts could be left uncoded, coded once or coded multiple times depending on their relevance. Contradictions and inconsistencies in the data were not excluded but treated as important parts of the dataset.

Phase 3: Searching for themes

After the initial coding process, the codes were examined in relation to one another to develop broader themes. The different codes were sorted into potential themes, while continued attention was paid to the full dataset and to extracts that could contribute meaningfully to those themes. To support this process, a Miro board was used to create a visual overview of all codes. This phase also involved reflecting on the relationships between codes, between themes and between different levels of themes.

Phase 4: Reviewing themes

In the fourth phase, the candidate themes were reviewed and refined. Some themes were removed when there was insufficient data to support them, while others were combined or split into smaller themes where necessary. First, the coded extracts within each theme were reviewed to assess whether they formed a coherent pattern. Next, the themes were checked against the dataset as a whole to determine whether they accurately represented the data. This required rereading the interviews and reconsidering whether the themes and codes remained appropriate. At this stage, new codes or themes could still emerge.

Phase 5: Defining and naming themes

This phase focused on identifying the essence of each theme and determining which aspect of the data it captured. Themes were further refined to clarify what belonged within each theme and what did not. Where useful, subthemes were identified. These functioned as themes within a broader theme and helped structure larger or more complex themes more clearly.

Phase 6: Producing the report

The final phase involved writing up the analysis in a way that communicated the complexity of the data and demonstrated the quality of the analysis. Evidence from the interviews was included to support the themes and to show how the findings were grounded in the data. The aim was not only to present recurring patterns, but also to tell a coherent analytical story in relation to the research question.

Appendix 4

Co-creation execution

Design statement:

De ervaring van naasten tijdens palliatieve sedatie verbeteren door hen een rustiger en zekerder gevoel te geven bij het gebruik van de pomp.

Deelnemers:

The Resource Group (RG):

- Naaste 3: At home, pump, mother
- Naaste 5: At home, pump and injection, mother and father in law
- Naaste 6: Hospice, injection, dad

Huisregels:

1. Je mag altijd vragen stellen
2. Spreek vanuit je eigen ervaring
3. Er bestaan geen foute ideeën
4. Bouw voort op elkaars ideeën
5. Respecteer de gevoeligheid van het onderwerp
6. Deelnemers kunnen op elk moment pauzeren of de ruimte verlaten
7. Er is een bal: wanneer het allemaal even te veel wordt mag je deze bal pakken en laat iedereen je even met rust

Benodigheden voorbereiding:

1. Punaises/spijkers
2. Praatplaat
3. Grote vellen

Benodigheden sessie:

1. Sticky notes; 4 kleuren (5e kleur voor mij? Evt.)
2. Grote vellen
3. Genoeg pennen/stiften

Voorbereiden

Welkom en introductie

1. Uitleg wat we gaan doen: We gaan een co-creatie sessie doen. Een co-creatie sessie is een samenwerking waarin we met elkaar ideeën en inzichten ontwikkelen door middel van verschillende activiteiten. Het doel hiervan is om meer inzicht te krijgen in de ervaring en behoeften van naasten tijdens palliatieve sedatie thuis en te zien hoe we dit kunnen ondersteunen.
2. Nog even kort, waarom doe ik dit: Ik ben nu bezig met mijn afstudeerproject voor de TU Delft, Strategic Product Design. Ik onderzoek de behoeften van naasten tijdens palliatieve sedatie thuis, om dit uiteindelijk de vertalen naar een ontwerp die deze ervaring verbeterd voor naasten.
3. Doel sessie: Tijdens de sessie gaan we nadenken over uitdagingen en moeilijke momenten tijdens palliatieve sedatie en rondom de pomp. We zoeken manieren om deze momenten ondersteunend of rustig te maken voor naasten. We gebruiken verschillende opdrachten en activiteiten, zoals gedachten opschrijven op sticky notes. We bespreken veel samen. Alles wat jullie delen is waardevol, er bestaan geen foute antwoorden en we gaan het allemaal samen doen! Mijn doel is om meer begrip te krijgen in wat naasten nodig hebben tijdens de palliatieve sedatie en hoe dit ondersteund kan worden.
4. Bal: Het is een ingrijpend onderwerp, dus het kan zijn dat het op een gegeven moment even te veel wordt. Hiervoor heb ik deze bal. Wanneer je deze bal vast pakt, weten we dat je even met rust gelaten wilt worden. We stellen je geen verdere vragen en je neemt gewoon even lekker afstand van de situatie. Ook kan je elk moment even weglopen, je kan even naar buiten.
5. Je mag altijd vragen stellen en ik heb er zin in!
6. Consent formulieren!

Icebreaker: Jezelf voorstellen

1. Naam noemen
2. Iets met de bal doen
3. Gooien naar de volgende

Brief:

1. Waar ik mee bezig ben: ik ben dus bezig met mijn afstudeerproject en onderzoek de behoeftes van naasten tijdens palliatieve sedatie thuis. De meeste van jullie heb ik al geïnterviewd. Hierdoor heb ik meer inzichten gekregen in wat jullie behoeftes zijn en dit wil ik graag verder verdiepen.
2. Uit mijn interviews kwam onder andere dat de medicatiepomp een belangrijk onderdeel is. Deze biedt pijnverlichting, maar ook een gevoel van verantwoordelijkheid, spanning of onzekerheid oproepen.
3. Zo ben ik erachter gekomen dat het volgende nodig is:
 - Meer rust: Rust tijdens palliatieve sedatie is essentieel voor naasten, omdat het angst vermindert, emotionele verwerking ondersteunt, focus op betekenisvolle momenten mogelijk maakt, cognitieve helderheid bevordert en zowel het comfort van de patiënt als effectieve zorgverlening faciliteert.
 - Zekerheid: Naasten ervaren veel vragen en onzekerheid; het verkrijgen van zoveel mogelijk duidelijkheid binnen een situatie die onzeker blijft, kan steun bieden.
 - Begrijpelijk: Naasten moeten begrijpen wat de pomp doet, welke handelingen van hen verwacht worden en welke gevolgen hun beslissingen hebben.
 - Comfortabel: Het gaat om comfort met de aanwezigheid van de pomp in huis, de geluiden, de keuze om al dan niet de bolus te geven, en de aanwezigheid van de patiënt aan de pomp; dit kan door iedereen anders worden ervaren.

4. Dit zijn aannames die ik met jullie wil testen, dus ik ben benieuwd hoe jullie palliatieve sedatie ervaren
5. Om tot meer inzichten en ideeën te komen heb ik deze co-creatie sessie georganiseerd. Met jullie wil ik verkennen hoe de momenten rondom de pomp aangenamer kunnen worden gemaakt voor naasten. Het gaat dus niet om het medisch aanpassen van de pomp, maar de ondersteuning eromheen.
6. Design statement: Hoe kunnen we de ervaring van naasten tijdens palliatieve sedatie verbeteren door hen een rustiger en zekerder gevoel te geven bij het gebruik van de pomp?

Ground rules were established for the co-creation session to ensure a safe and structured process. Rules 6 and 7 were explicitly introduced at the beginning of the session, while the other rules emerged more implicitly throughout the interaction. The full set of rules also served as a guiding framework for me to monitor the session and ensure a respectful and comfortable environment for participants.

1. You're always welcome to ask questions
2. Speak from your own experience
3. There are no wrong ideas
4. Build on each other's ideas
5. Respect the sensitivity of the subject
6. Participants can take a break or leave the room at any time
7. There is a ball on the table: if it all gets a bit overwhelming, you can grab this ball, and everyone will leave you in peace for a moment. No questions are asked, unless you want so.

First diamond: Understanding

Diverge: Praatplaat

1. Praatplaat laten zien
2. Bekijk de momenten rondom de palliatieve sedatie op deze praatplaat. Schrijf of teken wat er in je opkwam toen je deze situatie meemaakte: hoe voelde het voor jou, welke momenten waren moeilijk of gaven rust, en hoe ervoer je de aanwezigheid van de pomp? Denk aan je eigen ervaringen en gevoelens; er bestaan geen foute antwoorden.
3. Ik stel vragen zoals:
 - Waar ontstaat onzekerheid?
 - Hoe voelde het om de pomp daar te zien?
 - Hoe voelde de aanwezigheid van de pomp?
 - Waar ontstaat rust?
 - Waar voelde je verantwoordelijkheid?
 - Wanneer was de pomp oncomfortabel voor je?
 - Welke momenten had je extra ondersteuning nodig?
4. Iedereen schrijft associaties op sticky notes en noemt ze hardop
5. Wanneer de flow stopt, vraag de RG om nog een of meer opties op te schrijven
6. Deze woorden kunnen gebruikt worden tijdens de gehele sessie

Reverge: spontaneous clusteren

1. We hebben nu met z'n allen verschillende ervaringen opgeschreven
2. Hierin gaan we nu thema's zoeken; de sticky notes die op elkaar lijken mogen bij elkaar geplakt worden
3. Overleg samen, maar je mag ook zelf verschuiven
4. Hiedoor krijgen we een overzicht van alle ervaringen
5. Deelnemers actief meekrijgen door dingen te zeggen als:
'Pak een post it, lees het, en plaats het bij vergelijkbare opties'
1. Voor clusters die niet bij elkaar passen is een optie: 'other'
2. Vraag de RG om een catchy naam te geven aan de clusters, schrijf ze op het grote vel
3. Vraag een vrijwilliger om de clusters te benoemen, om het gedeelde begrip binnen the RG te versterken – belangrijk om op te nemen

Short break + Energizer

Break

1. 5 min. Break voor RG
2. Ik schrijf duidelijk de titels op

Energizer

1. RG staat in een cirkel
2. Ik stel een vraag zoals:
 - Bedenk veel toepassingen voor een sok
3. Ik geef een voorbeeld en gooi de bal
4. Degene die de bal krijgt moet antwoord geven en de bal doorgooien
5. Dit gaat paar minuten door, max 5 min.

Second diamond: Idea Generation

Purge: Brainwriting

1. RG schrijft eerste ideeën op
2. Zeg hardop je ideeën - aanvoelen
3. Ideeën bespreken

Diverge: Brainwriting with sticky notes

1. Divergent mindset: quantity breeds quality (eerst zoveel mogelijk), hitchhike (bouw direct voort op de ideeën van anderen) and freewheel (laat je gedachten de vrije loop zonder ze te filteren)
2. Geef iedereen sticky notes en markers, laat iedereen ideeën opschrijven in stilte
3. Vragen stellen to increase fluency:
 - Wat is het meest onverwachte dat dit moment makkelijker of rustiger zou kunnen maken?"
 - Geef je wildste of gekste idee over hoe de pomp of het moment kan ondersteunen.
 - Hoe zou dit er over 50 jaar uitzien?
 - Hoe zou een kind dit oplossen?
 - Wat had naast de pomp kunnen liggen?
 - Wat had het gevoel van verantwoordelijkheid kunnen verminderen?
 - Wat zou rust hebben gegeven?

Reflecting and closing

1. Hoe voelen jullie je?
2. Welke inzichten uit de sessie van vandaag zou je graag willen delen?
3. Hoe vonden jullie het om deze sessie te doen? (niet persé feedback op de sessie, maar wat is hun gevoel)
4. Wat vonden jullie van deze sessie?
5. Bedank woordje: Ik wil jullie enorm bedanken voor deze inzichten en sowieso de deelname. Ik ga jullie inzichten verwerken en hier verder mee aan de slag voor ontwerpen. Jullie ideeën vormen waardevolle basis voor nieuwe concepten waarmee ik aan de slag ga!

Komende maand ga ik hiermee aan de slag en ik laat jullie graag weten wat voor concepten hieruit zijn ontstaan. Ook ben ik dan hartstikke benieuwd wat jullie ervan vinden. Begin augustus ben ik klaar met mijn afstudeerproject en dan zullen er dus concrete ideeën zijn, als alles goed is. Heel erg bedankt voor jullie waardevolle input!

1. Chocolate repen uitdelen

Time	What	Aim	Material	Notes
5 min.	Welcome and introduction	Doel co-creatie	Papier met regels, planning, doel Bal	Co-creatie sessie, afstudeerproject, doel, bal Consent formulieren
5 min.	Icebreaker: introducing yourself	Elkaar leren kennen en comfortabel worden met elkaar	Bal	Voorstellen, iets met de bal doen en doorgeven
5 min.	Brief: problem statement + graduation project	Uitleg wat ik heb gedaan en wat ik wil doen	Papier met problem statement	
20 min.	Diverging: Praatplaat	Ervaringen, inzichten en emoties concreet te maken	Praatplaat, sticky notes, pennen	
10 min.	Reverging: spontaneous clustering	Overzicht krijgen van de ervaringen die we opgesteld hebben	Groot vel om de post its op te clusteren, stift voor titel	Vrijwilliger benoemt clusters, om gedeelde begrip te versterken
5 min.	Break	Rusten en voorbereiden voor volgende diamond	Titels boven op vellen schrijven	Nieuwe vellen met titels, zonder sticky notes

Note. This table presents the original session plan. Deviations made during the session are described in Section 5.2

Time	What	Aim	Material	Notes
5 min.	Energizer	Losjes worden en comfortabel met elkaar worden	Bal	Bedenk zoveel mogelijk toepassingen voor een sok
5 min.	Purge: Brainwriting out loud	Eerste ideeën eruit	Sticky notes en markers	Laat iedereen hard op zijn/haar idee noemen
10 min.	Diverging: Brainwriting with sticky notes in silence	Generate ideas	Sticky notes and markers	
10 min.	Reverging: spontaneous clustering	Overzicht krijgen van de ideeën die we opgesteld hebben	Groot vel om de post its op de clusteren, pen voor titel	Zelf meekijken met de thema's die emergeren
10 min.	Reverging: Discussing ideas			Vragen stellen
5 min.	Closing and Reflecting	Reflect on experience		

Note. This table presents the original session plan. Deviations made during the session are described in Section 5.2

Appendix 5

Reflection co-creation session

First diamond

Diverging

During the brainwriting phase of the co-creation session, participants worked primarily in silence. Probably because everyone silently reflected on his or her own experience. They still felt the freedom to ask questions and reflect without feeling pressured. Silence alternated with questions in an organic way.

One limitation of using the storyboard was that it focused attention on discrete moments, whereas some experiences and insights occur between these moments or are not tied to specific points in the process.

Naaste 5: Ik vind het lastig om het per stuk, want als ik naar mijn ervaring terugkijk, dan vind ik het meest onrustige. De Mensen die het niet begrijpen, dus die vragen blijven stellen op het moment dat.

(English: Naaste 5: I find it difficult to do it piece by piece, because when I look back at my experience, then I find the most restless thing. The people who do not understand it, so who keep asking questions at the moment that.)

Highlighting this to participants helped them understand that it was acceptable to share thoughts outside of the depicted moments. For future sessions, it would be useful to provide an additional sheet for participants to note 'other' or continuous experiences. Clarifying that sticky notes did not need to be placed perfectly encouraged them to write down such thoughts.

Even when the writing and placement of sticky notes slowed down the process, meaningful conversations emerged. I wrote down these emerging thoughts on sticky notes, after which I had them verify that what I had written was what they meant. This opened new conversations. Personal experiences were not presented in advance, which allowed the narratives to emerge organically during the session. This worked out well, as everyone was only sharing information, they felt comfortable with. The composition of participants was favourable; they were curious about each other and engaged respectfully. However, some challenges arose for me as facilitator. For instance, Naaste 3 was relatively young, encountered an end-of-life experience only once, and had many questions. Naaste 5, with prior experience in healthcare, was more confident and definitive in her responses and tended to present things as facts, even though they were sometimes her own interpretations. This was only a minor instance, so no interventions were necessary. Afterwards I checked this moment with Naaste 3, who confirmed the experience had been acceptable. They even exchanged contact details. For the next session, it may be helpful to better point out that people should rely solely on their own experience. However, this is difficult when someone sincerely believes that something is a fact.

Reverging

The clustering process proceeded smoothly. Initially, participants appeared somewhat hesitant. I responded to this by pointing out a pattern I had spotted myself, which encouraged the others to look for patterns too. Additionally, I emphasized that sticky notes could be placed freely and did not need to be perfectly positioned, this helped the group engage confidently. Participants independently began rearranging and grouping

the sticky notes. Temporary cluster titles were assigned using sticky notes, which facilitated the organization and made it easier to prompt participants for final titles.

After the clusters were established, participants were invited to suggest a title and summarize the clusters. A discussion emerged regarding the meaning of each cluster, missing elements and the clarification of ambiguous sticky notes. This collaborative process was valuable, as it shaped a shared understanding of the clusters. During the subsequent idea generation phase, some cluster titles were further refined to better inspire and guide participants in generating new ideas. Overall, the collaborative clustering approach enhanced both the clarity and interpretability of the data.

Second diamond **Idea generation**

The idea generation phase initially experienced some challenges, as participants found it difficult to spontaneously generate solutions. During the preceding discussion, participants had already expressed numerous needs, which the facilitator had documented. To stimulate the start of the idea generation, a few sticky notes with these needs were placed on the board as prompts. This helped initiate conversation and gradually established a productive flow.

As the brainstorming phase got off to a slow start, I tried to get the discussion going. The participants were asked to explain what was written on the sticky notes they had put up. This stimulated others to respond and share their own thoughts. This gradually led to a collaborative conversation about the ideas on the board and a flow of new ideas.

Although generating truly 'out-of-the-box' ideas was initially challenging, a substantial number of needs and potential solutions were documented, some of which are great inspiration for the generation of design concepts. As the session progressed, participants began discussing the ideas on their own, identifying patterns and themes without formal clustering. Comments such as 'Many ideas relate to... and all lead back to...' indicated that participants were synthesizing concepts collaboratively. So, there was already a discussion on the emerging themes. This, combined with the time constraint, led to the decision to skip the next cluster phase and focus all our attention on this phase.

Reflection of participants

Although the topic of palliative sedation can be emotionally heavy, participants did not experience the co-creation session as distressing. On the contrary, Naaste 5 indicated that she gained new insights from the session, while Naaste 3 expressed that he appreciated the opportunity to revisit and reflect on the process, stating that it helped him to process his experience.

Participants also reflected positively on the facilitation of the session. They described that the topics were guided in a respectful and well-structured manner. Naaste 3 specifically noted that he felt the facilitator showed genuine interest and enthusiasm, which contributed to a safe and open atmosphere.

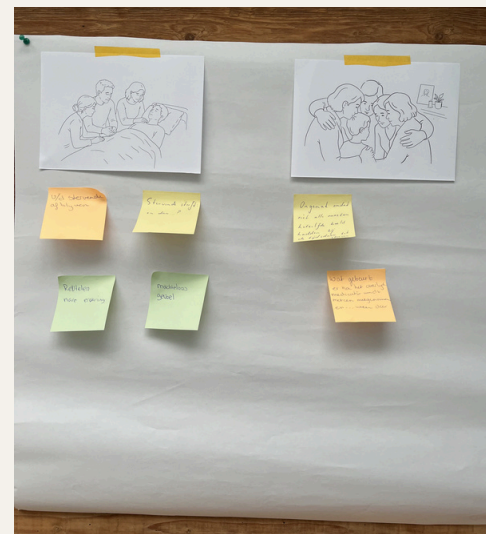
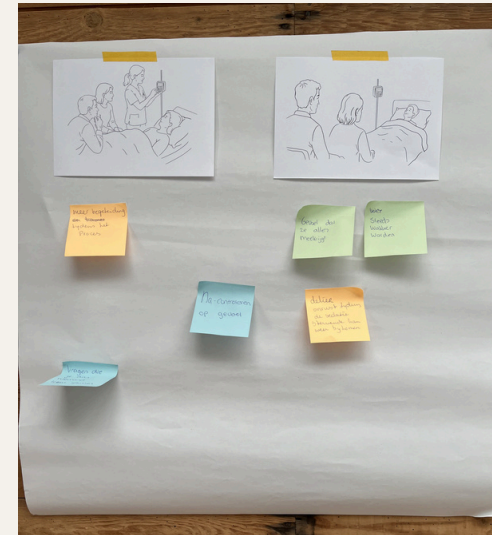
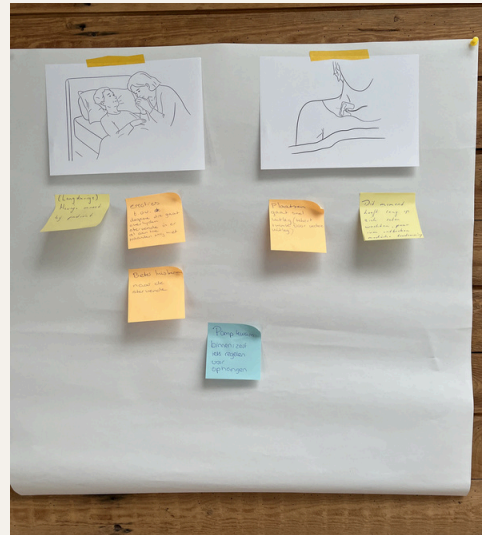
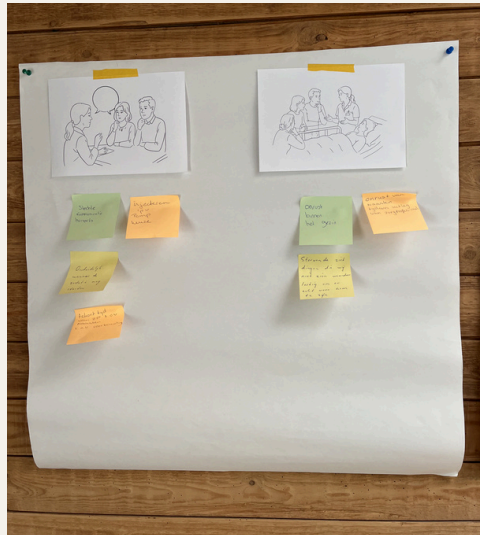
Naaste 6: Bijzonder Ik had omdat het best wel een pittig onderwerp is, zeg maar, daar had ik zelf ook wel zoiets van. Nou, Dat is best nog wel even taai ook zeg maar, maar Ik heb het helemaal niet als taai ervaren.

(English: Naaste 6: Remarkable. Because it is quite a tough subject, so to speak, I also had something like, well, that is still quite heavy too, so to speak. But I did not experience it as heavy at all.)

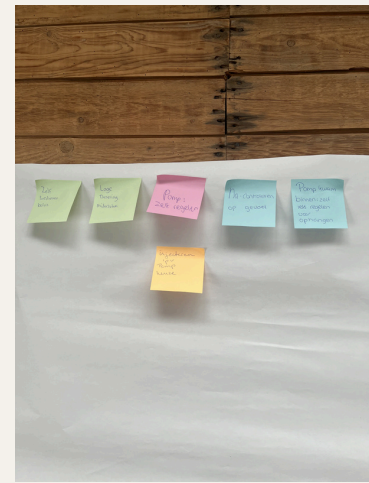
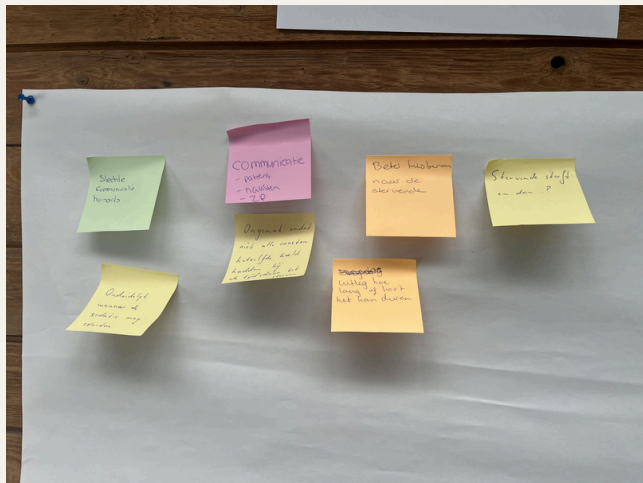
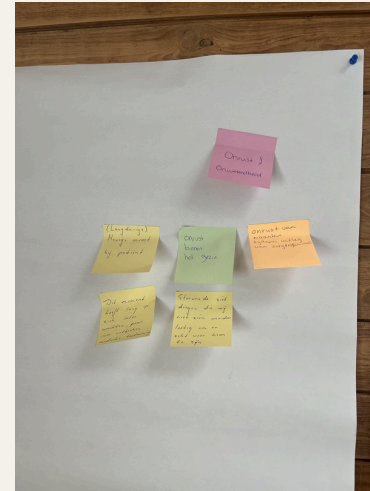
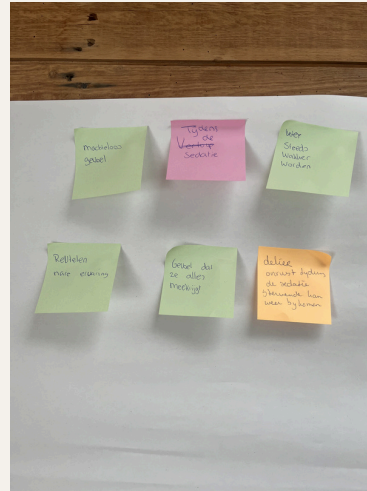
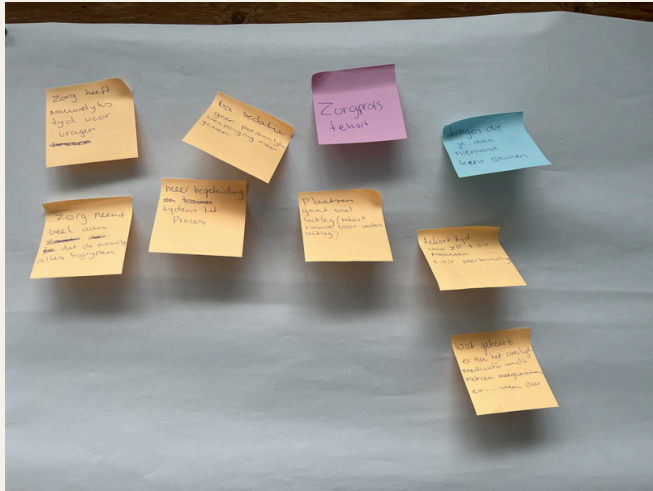
Appendix 6

Results Co-creation

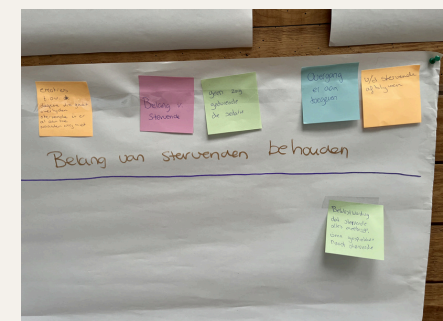
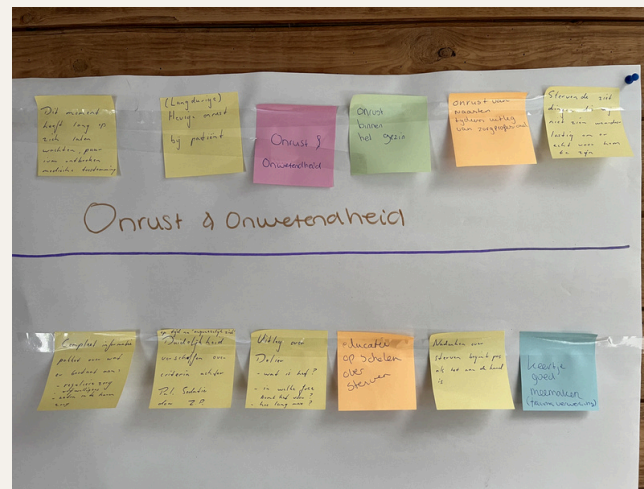
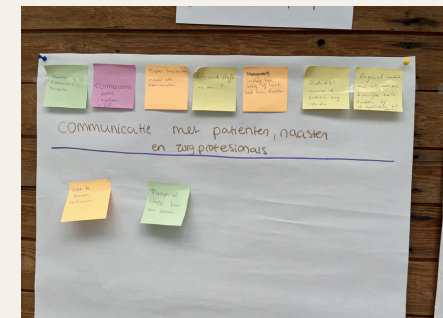
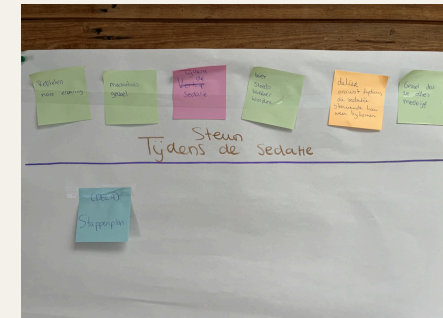
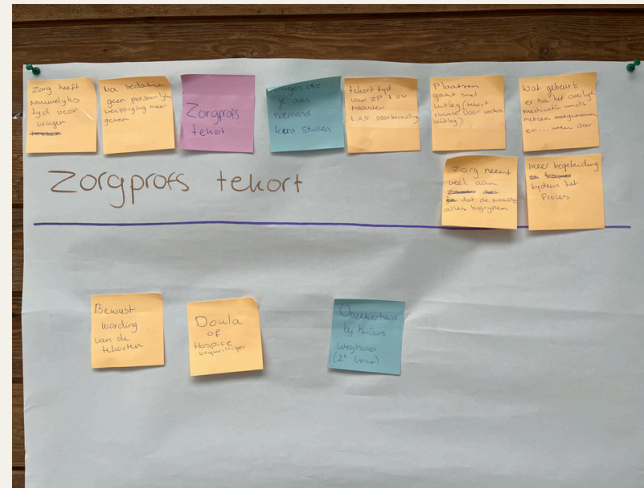
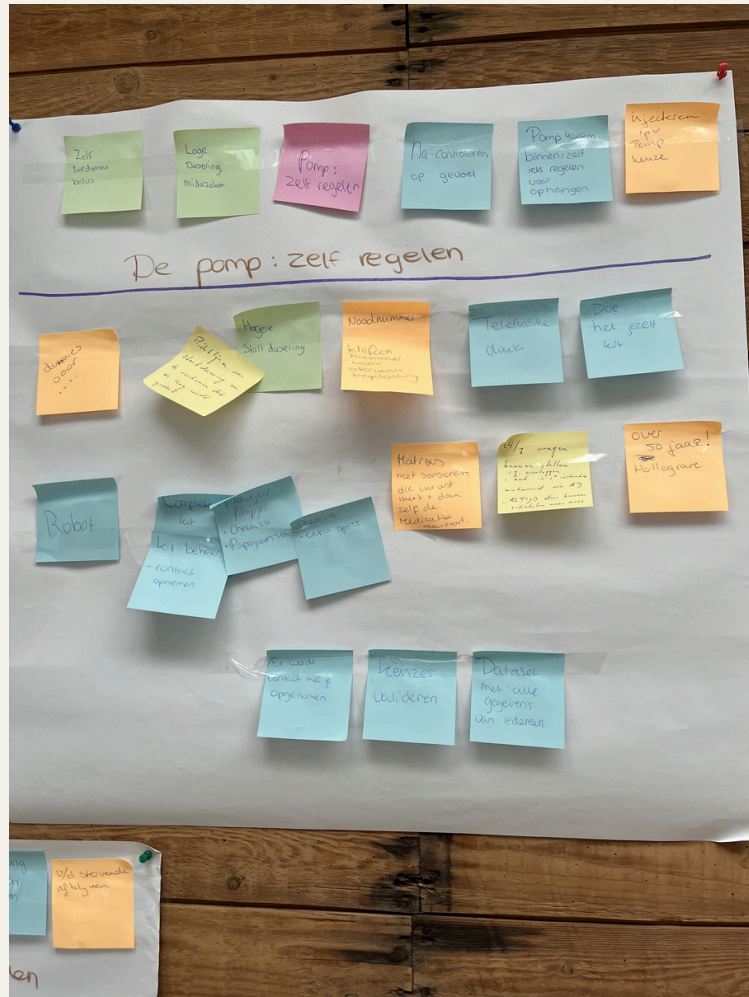
Diverging: needs



Clusters



Diverging: idea generation



Appendix 7

Testing the interventions

Initial test:

The initial test was conducted with the first participant to test the structure of the evaluation. In this version, the interview followed a chronological structure:

1. Formerly: introduction and conversation about education about palliative sedation and dying.
2. The start of palliative sedation: reflection on the *Wat nu?* app and the *Wat nu?* booklet
3. During the process: reflection on the *Wat nu?* app, the *Wat nu?* booklet, the support line and the voice-based support. Reflection on the moments:
4. Moment of dying
5. General reflection.

However, this structure proved to be confusing, particularly because several tools overlapped in functionality (e.g. the emergency contact being embedded in the app, and voice assistant settings being part of the broader system). As a result, it was difficult and confusing to separate and reflect on individual concepts. Furthermore, the participant felt the desire to share some initial thoughts on the various tools before we delved deeper into the scenarios. Based on this feedback, the structure was revised for subsequent sessions. The missing scenarios were later presented to the first participant, so that each naasten was presented with the same scenarios. The final test is on the next page.

Test naasten

Ik heb aan de hand van de interviews en de co-creatie sessie tools ontworpen, die zekerheid zouden kunnen bieden in een tijd van onzekerheid. Ik ga een paar scenario's voorstellen en paar ideeën laten zien. Ik ben benieuwd wat je van deze ideeën vindt en of ze jou zouden ondersteunen. Ik wil weten wat je voelt, wat je denkt.

Scenario 1: Voorbereiding – educatie

In het eerste scenario gaan we terug in de tijd, naar je schooltijd.

Stel je voor dat je op de middelbare school les had gekregen over sterven en palliatieve sedatie.

- Educatie voorstel laten zien
-

Vragen:

- Wat zou je hiervan vinden?
- Wat zou je geleerd willen hebben?
- Wat voor invloed zou dit hebben gehad op hoe jij de palliatieve sedatie had ervaren?

Scenario 2: proces van palliatieve sedatie

Op een gegeven moment werd jou verteld dat ze binnenkort met de palliatieve sedatie gingen starten. Nu gaan we door tijdens de sedatie. Ik ga verschillende situatie's noemen.

1. Eerst boekje laten zien!
2. Dan app
3. Daarin zie je noodnummer
4. los

Verschillende situaties

1. Je hoort voor het eerst dat palliatieve sedatie een optie is
2. De pomp is net geïnstalleerd
3. Patiënt komt bij
4. Onrust bij de patiënt
5. Delier bij de patiënt
6. Een extra bolus geven
7. Reutelen
8. Onrust onderling bij de naasten
9. Moment van onzekerheid
10. Patiënt overlijdt
11. Zijn er andere momenten waarop deze tools zouden helpen?

Vragen per situatie:

- Welke tool zou hebben geholpen tijdens jouw proces? Waarom?
- Welke tool zou je rust geven?
- Wat tool voelt onduidelijk?
- Wat mis je nog in ondersteuning?

Overall reflectie

- Welke tools zou je gehad willen hebben tijdens jouw proces? Waarom?
- Wat zouden die tools voor je gedaan hebben?
- Welke tools zou je wel willen en welke niet? Waarom?
- Waar voelde je je het meest ondersteund?
- Welke tools zou je samen (als systeem) gebruiken?

Important note: The questions were intended as a guide, not as a strictly fixed script

Test nurse

Educatie

- Wat zou je ervan vinden als mensen op school al les krijgen over sterven en palliatieve sedatie?
- Welke invloed zou dat volgens jou hebben op naasten in een later proces?
- Zie je hier risico's of juist voordelen?

Boekje

- Wat zou je ervan vinden om dit mee te geven net voor het installeren van de pomp?
- Wat zou de impact zijn?
- Hoe zou dit passen in jullie huidige communicatie met naasten?
- Wanneer zou dit gegeven worden?

App •

- Wat zou je ervan vinden om de naasten de app te laten gebruiken?
- Wat zou de impact zijn?

Voice-based support

- Wat zou je ervan vinden om dit mee te geven?
- Wat zou je ervan vinden als ze hun vragen aan the stellen ipv aan jou?
Wat zou de impact zijn?

Hulplijn (24/7 support)

- Wat vind je ervan als de hulplijn word gebeld ipv jij?
- Wat zou de impact zijn?

Desirability

- In hoeverre zou je dit wenselijk vinden voor naasten?
- Wat zou je willen gebruiken of aanraden?
- Wat absoluut niet?
- Op welke momenten zou dit echt helpen? Op welke momenten niet?

Feasibility (haalbaarheid in huidig systeem)

- Past dit binnen de huidige palliatieve zorg thuis?
- Welke onderdelen zouden niet passen in de huidige workflow?
- Hoe wel?

System impact

- Wat zijn volgens jou de sterkste punten van dit systeem?
- Wat zijn de grootste risico's?
- Zou dit systeem de zorg verbeteren of compliceren?

Important note: The questions were intended as a guide, not as a strictly fixed script

Appendix 8

Provisional implementation actors

	Proposed actors and roles	Research basis	Still to be confirmed
Death education	• Direct adopters: schools and school boards • Potential enabling actors: OCW and SLO • Potential implementers: curriculum developers and teachers • End users: students (as potential future patients, naasten or healthcare professionals)	• Literature identifies schools as a relevant setting for death education (Allard et al., 2024; Paul, 2022). • SLO develops national curriculum goals and supporting materials on behalf of OCW and in collaboration with the educational field (SLO, 2026). • Existing Dutch lesson materials show that end-of-life topics can be addressed in schools (Museum Tot Zover, 2018; NVVE, n.d.). • The evaluation with the nurse and naasten showed potential value	• Whether schools are willing to adopt the intervention • Where the topic could fit within the curriculum • The precise roles of OCW and SLO • Required pedagogical expertise and teacher support
Wat nu? booklet	• Potential adopters: GP practices, home-care organisations and palliative-care networks • Potential endorsing actor: NHG or another patient-information body • Potential implementers: GPs, nurses, home-care professionals and palliative-care teams • End users: naasten	• Dutch guidelines position GPs and nurses as providers of information and guidance during palliative sedation at home (Palliaweb, 2022a). • Desk research shows that NHG develops GP guidelines and supporting implementation and patient-information materials (Nederlands Huisartsen Genootschap, n.d.). • Naasten and Nurse 5 perceived the booklet as a useful starting point and it should be introduced and explained by a healthcare professional.	• Which organisation would adopt, own and distribute the booklet • Whether introduction fits existing professional workflows • The most appropriate handover moment • Whether NHG or another national body could review or endorse it
Wat nu? app	• Potential adopters: care organisations or professional bodies • Potential endorsing actor: NHG or another patient-information body • Potential introducers: GPs, nurses and home-care professionals • Potential maintainers: app and content managers • End users: naasten	• Naasten and Nurse 5 perceived value in accessible and continuous information and reassurance. • Naasten indicated that the app should be introduced or reintroduced by a healthcare professional. • Desk research shows that NHG develops GP guidelines and supporting implementation and patient-information materials (Nederlands Huisartsen Genootschap, n.d.). • The evaluation showed that the concept could be translated into a tangible and testable format.	• Which organisation would adopt and own the app • Whether healthcare professionals can and want to introduce it • Responsibility for medical review, content updates and technical maintenance • Privacy, data governance and the possible role of NHG
24/ support line	• Potential implementation partner: organisation responsible for the existing palliative-care consultation infrastructure • Potential providers: specialised palliative-care consultants or other trained staff • Potential introducers: GPs, home-care professionals and palliative-care teams • End users: naasten	• Co-creation identified a need for continuously accessible human support during uncertain moments. • The evaluation showed potential value as a safety net, although preferences regarding its use differed. • Desk research identified an existing national consultation structure for healthcare professionals (Palliaweb, 2021).	• Whether the existing service could or would support naasten directly • Organisational ownership and responsibility • Staffing, funding, triage and escalation procedures • Medical and legal accountability