

Hospice Diary

For Eating and Drinking

Improving the experience of food
care in Dutch hospice institutions

Master thesis by Maxim Houdijk



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Preface

This report is the result of the master thesis assignment: Eating & drinking in Dutch hospice care: coping difficulties and conflicts, performed within the Design for Interaction master programme at Delft University of Technology. It proposes a design for an improved experience during the food care routine within a Dutch hospice institution context.

For this project I would like to first express my gratitude to my chair, Marieke Sonneveld, and my mentor, Annemiek van Boeijen. I would like to thank them for their guidance, their interference when it was necessary, and most importantly their patience. Some of the key breakthroughs happened while speaking to you, as you helped me recognize what this project truly needed to end up succesful.

I would also like to express my gratitude to the volunteers and nurses of hospice De Vier Vogels, who have helped me immensely during this project. They shared their experiences and knowledge with me, they expressed their enthusiasm for the project, and shared their opinions on what I presented with honesty. Without their contribution this project could not have reached the result that it now presents.

Finally, I would like to thank my parents for the rich conversations we shared on the themes and topics of the project, and all the other support your offered me throughout.

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Abstract

Hospice care is a care approach that prioritizes the quality of life of their residents, during their final phase of life. An important part of their care is advising and supporting those near and dear to their residents. They aim to ensure that they also experience the final phase of their loved one's life as positive as possible, however, also they want to ensure that this does not harm the well-being of their residents in the process.

Considering this, one harmful situation that can occur is within food care. Those near and dear can take on a "fight back" care attitude. In hospice care the curative treatment for the recovery from illness has been discontinued. Therefore, people can sometimes see eating and drinking as the last beacon of hope to extend the life of a loved one. The "fight back" attitude can lead to harmful food care, where the denial of food is resisted, sometimes to the point of force feeding. Unfortunately, those efforts are often harmful to the ill person's well-being, instead of benefiting their health.

This thesis involves an analysis consisting, firstly, of literature research, to learn how those involved with a life-limiting illness form their care attitudes, and how the role of eating and drinking within this care is shaped. Secondly, a contextual analysis at a small-

sized Dutch hospice institution is performed to get an impression of the context and its stakeholders. Mapping out the food care by the different stakeholder groups (hospice care givers, and relatives of hospice residents), lead to the following main insights:

- **Hospice residents may have a lacking sense of autonomy over their meals, particularly when it comes to how much they eat.**
- **The food care can be inconsistent, even between hospice care givers, due to the methods of communication they use that are sensitive for subjectivity.**
- **Those near and dear may prioritize the nutritional values of food too much, playing down the emotional and social values that food may hold.**
- **Interventions of hospice care givers, in case of harmful food care, demand those near and dear to let go of food in an unnatural manner.**

Based on those insights, as well as the rest of the analysis, design goals were set up:

- 1. The design should increase the sense of autonomy hospice residents have over how much they eat and drink.**
- 2. The design should facilitate consistently well-adapted food care among both; the hospice care providers, and those near and dear to hospice residents.**
- 3. The design should provoke a (re) introduction of social values related to eating and drinking.**

This led to the 'hospice diary for eating drinking' as a design solution. It is a diary that centralizes everything that has to do with food care. It provokes a registration of the food and drink preferences of hospice residents, to ensure instantly well-adjusted food care that can be provided consistently between different care provider groups. Furthermore, through daily questions on topics related to the emotional and social values of food, those values are (re)introduced to the context, to distract from the prioritized nutritional values. Finally, fill-in pages stimulate the daily assessment for desired meals. Combined with "instructions" for the assessments, the care providers should become more aware of the necessity to make correct and complete assessments of what the resident truly desires for their meal.





Introduction

Project Brief

This design project was established in cooperation with the chair of this project: Marieke Sonneveld, assistant professor at Industrial Design Engineering at the Delft University of Technology, lab director of the Design for End of Life Lab and volunteer at hospice institution De Vier Vogels in Rotterdam. As a volunteer she experiences and witnesses the many struggles accompanying the final phase of life. One of the struggles she shared was the motivation behind this design project.

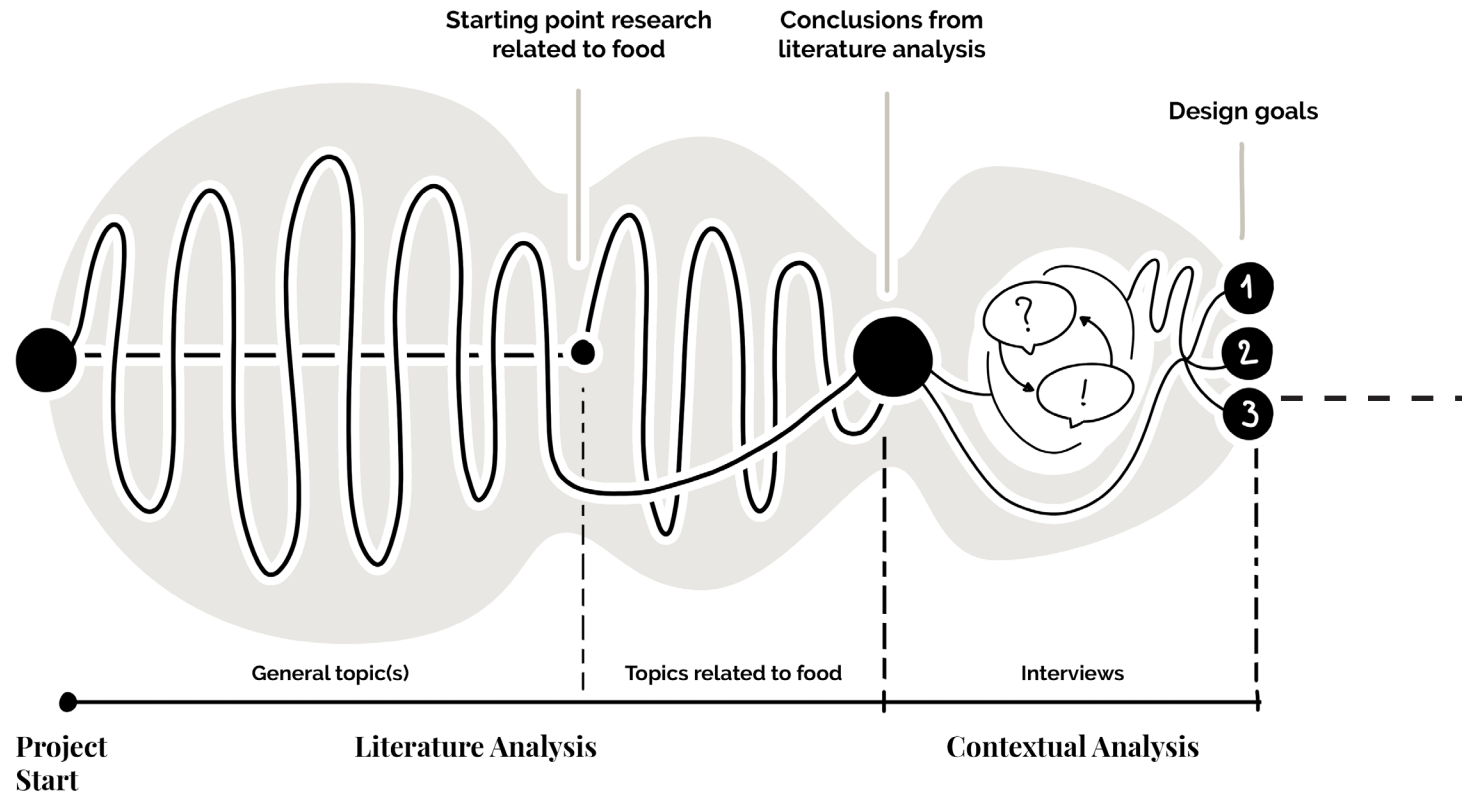
In hospice care a common development among residents is a diminishing appetite, initially for food and later for drinks as well. The amount of food they eat decreases and after some time their meals are ended with an abundance of food left on the plate. Sometimes those near and dear to the resident struggle to cope with this development. An early conclusion to a meal can be met with resistance, usually this would be mildly by urging their loved one to eat more, however, in some occasions it can reach the point of force feeding.

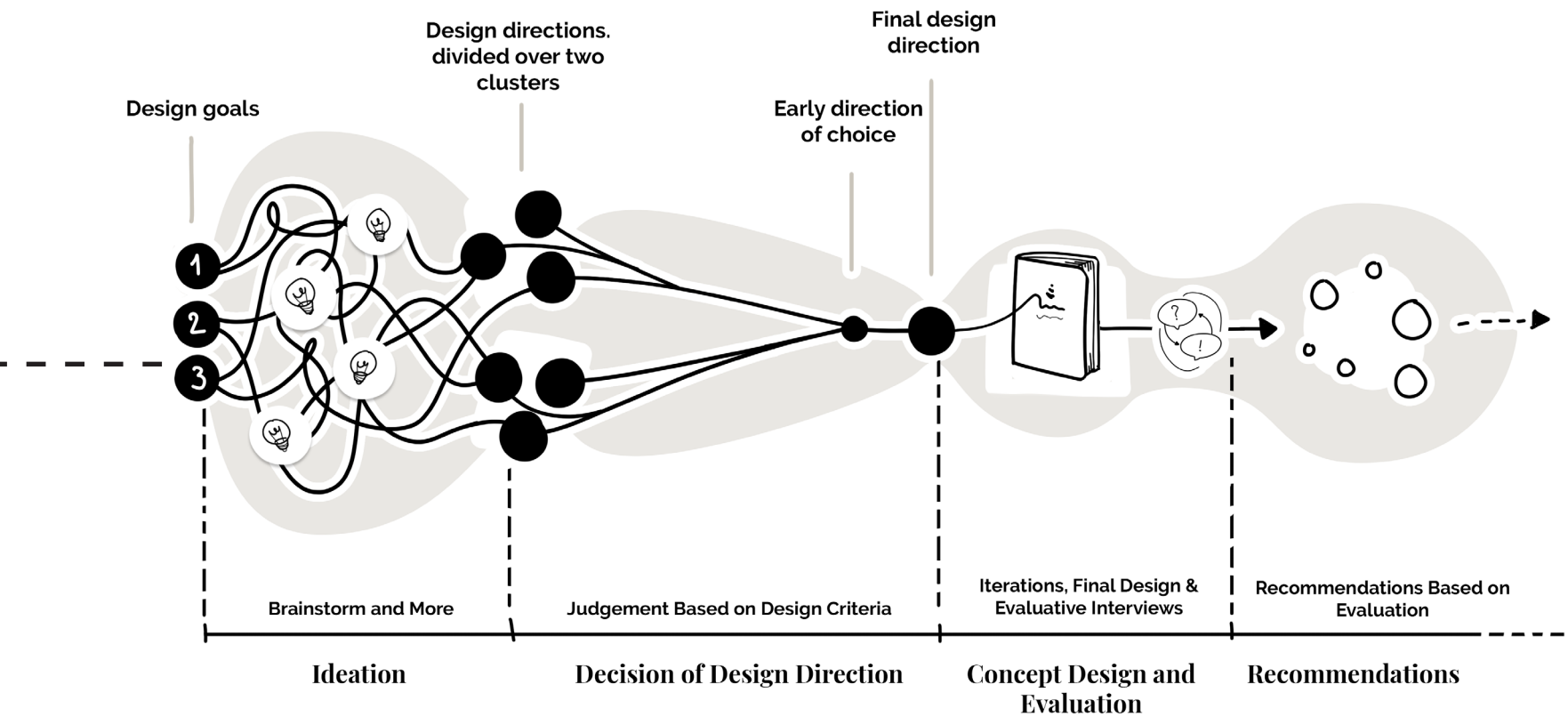
These troublesome interactions between residents and those near and dear can negatively affect the well-being of the resident in question. Mentally, they experience distress as those near and dear repeatedly urge the resident to eat more than they are comfortable with. Were they to give in to the pressure of those near and dear, the harmful physical repercussions follow, with nausea, stomach pains or diarrhea as some of the possible consequences of overeating. The struggles surrounding eating and drinking are detrimental to the relationship between someone in the final phase of life and those near and dear, in a time that craves as little hostility between each other as possible.

Therefore, the goal of this design project is to design something that helps those near and dear to cope with the diminishing appetite for food of their ill loved one. This should reduce conflict between those involved, improving both the well-being of the patient and the experience of those near and dear when providing care in the hospice environment.

Project Process Overview

This figure displays an overview of the process of this design project in an abstract way. It displays key points in the project and the route between those points. The report itself, of course, elaborates on the shown section in great details, and will touch upon all of the key points of the design project.







Literature Analysis

For someone suffering a life-limiting illness, a common development in the final phase of life is a diminishing appetite for food and drinks. Those near and dear to their dying loved one can often struggle to cope with this development, and attempt to "fight it". The goal of this literature analysis is to gain a comprehensive understanding of the factors that play a role in the conception of this attitude, the resistance against a declining food and drink intake.

The analysis comprises two main areas of research. The first part will examine how a life-limiting illness is experienced in general, and what aspects influencing this experience may contribute to the attitude that those involved take on once they reach a point where a short term passing of the ill person is deemed unavoidable. This is followed by an analysis that focuses more closely on the role that food and drinks plays before and throughout a life-limiting illness, as it can say a lot about why those near and dear may resist the declining consumption of food and drinks by their ill loved one.

Experiencing a Life-limiting Illness

Upon the diagnosis of a life-limiting disease, the patient and those closely related, in an instance, are confronted with the cruel reality of dealing with that illness. They often face harsh treatments with demanding rehabilitation, filled with uncertainty of a good conclusion. Their lives transform into a continuous battle, as they engage in a joint attempt to beat the disease, no matter how pessimistic the outlook may be. It is a process that strongly affects everyone involved, both physically and mentally

For many, the experience with a life-limiting disease, can be the first close encounter with the reality of death. A remote ordeal that they have not yet learned to cope with. The most important advice they receive from medical professionals is to remain hopeful for a recovery, it fuels positivity in a situation so bleak and is considered essential for rehabilitating from the harsh treatments they receive. However, this emphasis on hope is also a crucial factor of the potentially troublesome attitude that is maintained when death in the near future is unavoidable.

Development of a Life-limiting Illness

For every person the battle with a life-limiting illness is different, a unique path consisting of prosperity and adversity. Nonetheless, patterns can be recognized in the development of different categories of life-limiting illnesses. Murray (2017) illustrates this through well-being trajectories that involve the physical, social, psychological and spiritual well-being of people suffering from a life-limiting illness (figure 1). He identifies three trajectories by the type of decline these diseases display:

1. **rapid functional decline** most often relating to cancer.
2. **intermittent decline** relating to diseases such as lung and heart failure.
3. **gradual decline** relating mostly to frailty and dementia.

With gradual decline, there is a final mental downfall towards death after a long period of low physical well-being. The death is more predictable and seems like a slowly approaching, inevitable conclusion to a drawn-out decline. However, the former two trajectories show how patients, and those near and dear

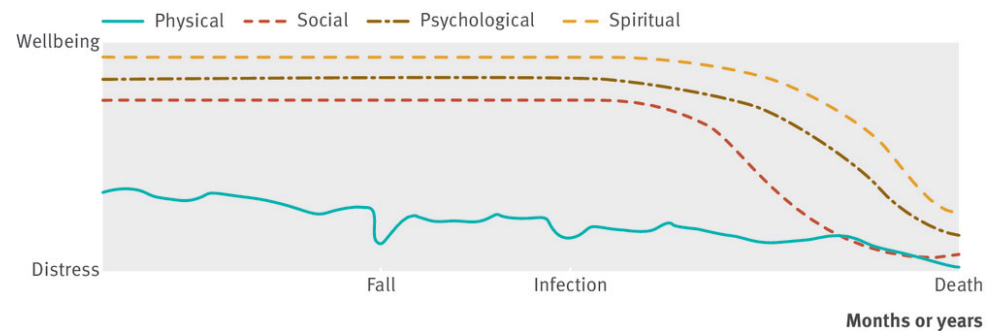
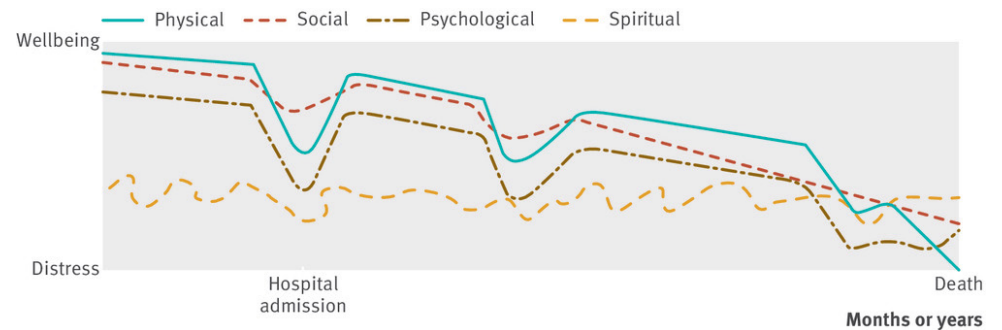
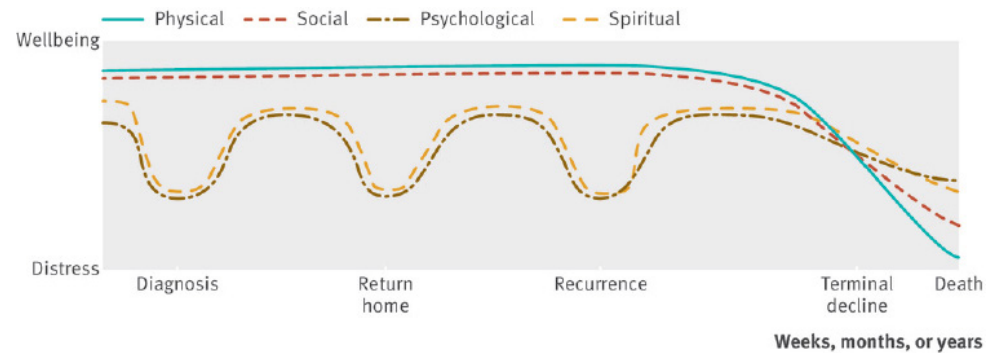


Fig. 1:
Well-being trajectories diseases in order: 1) rapid functional decline, 2) intermittent decline and 3) gradual decline (Murray, 2017).

concurrently, experience multiple adversities that they learn to overcome, before eventually reaching the final downfall towards death. It is not hard to imagine that patients and those near and dear may see that downfall as yet another adversity they have to fight hard for to overcome. An assumption that seems correct looking at the point at which the decision often is made to stop the curative treatment of the patient.

In the trajectory of a life-limiting illness that eventually reaches the point of becoming incurable, four phases can be identified in which the medical care needs change for patients (Dalgaard, Thorsell & Delmar, 2010).

1. **Curative phase.** The disease is still considered curable by medical professionals with treatment reflecting that judgement.
2. **Early palliative phase.** The patient is considered incurably ill, with the goal of the treatment mostly being disease control.
3. **Late palliative phase.** Disease control is no longer possible or relevant. Treatments focus on alleviating suffering, improving the quality of life and some forms of life-prolongation.
4. **The terminal phase.** The patient is dying and any form of life-prolongation is irrelevant. Treatment focuses on alleviating suffering and improving the quality of the last days or weeks of life.

Ideally, for the overall well-being of the person suffering the illness, the transitions between these phases are recognized accurately with the treatment changing accordingly. Especially transitioning from the curative phase towards the following palliative phases can improve the patient's well-being. Curative treatments are often harmful for a person's health and involve a demanding recovery process (e.g. chemotherapy for cancer treatment).

However, the unfortunate reality is that, despite these phases being present, for a majority of patients the curative treatment is not discontinued until they reach the terminal phase. At this point the patient may only have a few days or weeks left to live (Dalgaard, Thorsell & Delmar, 2010). This corresponds with the earlier assumption that the final downfall towards death may still be seen as an adversity that can be overcome. The choice for harsh curative treatments continues to be made, undermining the patient's well-being in attempt to achieve the unrealistic goal of complete recovery.

This knowledge may highlight an important facet of the attitude that those near and dear occupy during a life-limiting illness of a loved one. The belief is maintained that prolonging life is possible, well beyond the point of a recovery being considered a realistic goal. Thus, they may believe that actions detrimental to the well-being of their loved one are worth it, if it is for the ambition of keeping their loved one alive.

The Effect of Death Avoidance on End-of-life Care

People have a tendency to avoid death in their thoughts and actions. This is induced by their fear of the concept of death, and its existence in relation to themselves (Mason, 2015). This tendency to avoid death as a concept altogether throughout life, may be a factor that is harmful to people's capability to deal with death, when it eventually does present itself. Kasternbaum (2016) argues how particularly in western society death avoidance is very common. By many death is seen as a distant matter, not relevant to themselves, only to others. This attitude in a sense feels like denial, seeing that death is an inevitability for any person. However, rather it can be seen as a way of postponing, often extended to the point where it is "too late".

Death avoidance and death attitudes

Kastenbaum (2016) explains how people's *attitudes* towards death, their *beliefs* about death, and their *feelings* related to death are all influenced by their *experiences* with death. This can refer to direct experiences with death, for example when a close relative passes away, but also indirect experiences with death, think about reading about death or seeing it on tv or in movies. When our society as a whole seeks to avoid the deeper complexities of death, the indirect experiences do not prepare people for a direct experience. Suffering a life-limiting illness is the first direct experience with facing (potential) death for many people.

Upon the diagnosis of a life-limiting illness, people are abruptly confronted with a potential short term death. As explained, a concept they avoided even imagining to become a reality. With a lack of referential experiences for this circumstance, they are at loss for how to cope with the foresight of potentially dying. The so-called 'death attitudes' can be positively affected by death experiences, particularly a reduced death anxiety as a result

(Bluck, Mackay & Dirk, 2008). It brings you knowledge of what to expect of what is coming, and may put you in a position that makes you reflect on death and dying, and what that means.

In the context of caring for someone who is dying from a life-limiting illness, this ability to take on the correct death attitude can be defined as 'death literacy': "a defined set of knowledge and skills that make it possible to possible to gain access to understand and act upon end-of-life and death care options". It is considered "an outcome of people's experiences of and learnings about, death and dying" (Noonan, Horsfall, Leonard & Rosenberg, 2016). It underlines how the avoidance of the topic of death can induce situations where someone providing support and care during the end-of-life phase does not understand and carry out the proper care for the patient. It explains why the actions of relatives who take care of a dying loved one may be in conflict with the psychosocial and physical needs of their loved one. They simply lack the knowledge and experience to understand how the loved one feels and are therefore not capable of fully empathizing with how they feel.

Different backgrounds, different attitudes

While our society avoids the concept of death, there are still clear differences in people's attitudes when facing death. These can be ascribed to their different sociocultural and religious backgrounds. Research clarified how people with a non-western background tend to take on a different attitude towards end-of-life care, than what would be the "standard" in a western society (De Graeff, et al., 2012).

The three factors Kastenbaum (2016) names, attitudes, beliefs, and feelings, for the majority are established through someone's exposure to the concept of death. This could be through upbringing, schooling, media consumption or first-hand experiences, which are all vastly different for every individual. Obviously patterns can be recognized based on people's sociocultural and religious background. Nonetheless, people can deal with a life-limiting illness in very different ways, even at an individual level.

The influence of people's sociocultural and religious background on how they cope with a life-limiting illness is not always expressed very directly. People form habits, nurture specific values, have different worldviews, and much more. In a multicultural society, such as The Netherlands, this brings a wide variety of behaviour, especially because it can differ even on individual level. Generalizing people's attitudes, beliefs, feelings and experiences is close to impossible and to truly understand someone's view on death likely demands a very personal evaluation.

The Role of Hope Throughout Illness

A sense of hope, any sense of hope, is essential throughout a life-limiting illness. Elliot and Olver (2009) speak about hope while suffering from a life-limiting illness. Most people see hope in the context of illness, as hope for cure. This hope for cure is indeed important, especially during a time when the disease is still deemed curable. It will motivate those involved to fight back, even when the circumstances appear bleak. It is what makes some of the harsh disease treatments possible, as self-motivated efforts are a large part of recovering from treatments. However, the assumption that 'all hope is lost' when someone's illness is deemed incurable is wrong.

Death avoidance and death attitudes

During the curative phase of a life-limiting illness hope for cure is nurtured by patients, those near and dear and also medical staff involved in a patient's treatment. Research clarifies that medical staff is urged to maintain, protect, increase and even instill hope in a patient, and those near and dear. At times they may even withhold information from patients and those near and dear, if it is expected to be detrimental to their sense of hope. This can be understandable, considering their mission is a patient's complete recovery. Without hope, many curative treatments are less likely to be successful, as hope supports patients and those near and dear in their self-initiated efforts to fight the disease during the recovery from the medical treatments they undergo (Elliot & Olver, 2009).

Earlier in this report, at the chapter *Development of a Life-limiting Illness*, it was mentioned how people often do not steer away from curative treatment until the terminal phase is reached, when the patient has only a few more weeks or days left to live (Dalgaard, Thorsell & Delmar, 2010). The hope for cure is maintained until the point that there is simply no more denying that a short term death is inevitable.

However, even after the realisation that the illness is truly incurable, hope continues to play an important role for patients and those near and dear. While hope for cure sometimes remains, the sense of hope tends to slowly transition towards hoping for (more) life, the hope to live another day. Any sense of hope is considered essential to help endure adversities in life, therefore it may just especially be important when 'approaching death'. A route that knows many adversities on its way (Elliot & Olver, 2009).

Hope for (more) life in itself does not describe a whole lot, as life in itself doesn't mean much if you don't speak of what life brings you. People continuously alter their sense of hope towards something they consider achievable, with the capabilities they have. Some mention how it is about hoping for things: for example attaining goals, maintaining independence or having meaningful interactions. Those are the things that life offers them, the motive behind hoping for more life (Buckley & Herth, 2004).

It can be concluded that those involved with the illness, the patient and those near and dear, attempt to fulfill their hope in some way. They do so by seeking something they consider achievable, and pursuing it.

Care Attitudes in the End-of-life Phase

As discussed in previous chapters, people take on a specific attitude towards the approaching death caused by a life-limiting illness. These death attitudes are formed by a number of things: their earlier experiences with death, or lack thereof, the personal sociocultural and religious background of those involved, the course of the illness itself, how the illness was dealt with, and the role that hope played throughout the illness, and finally, the role that hope still plays once the unavoidable death starts to close in. The attitudes determine largely how a dying person desires to spend the final phase of life, and how those near and dear choose their approach to support and care for a dying loved one. Unfortunately, the harmonious interactions between those involved, resulting from their corresponding death attitudes, are most definitely not self-evident.

Three recognized care attitudes

Research showed that those near and dear to a dying person attempt to "do what is best" for their loved one. This research was based on how the attitude towards nutritional care in particular, however, it does illustrate a state-of-mind in a more general sense. Three categories were identified in how those near and dear approached the care for their loved one: 1) *fighting back*; 2) *letting nature take its course*; and 3) *waffling* between those two (McClement, et al., 2013).

Those near and dear that "fight back" feel that the right thing to do is to continue fighting the disease, with the intention to extend the lifespan of their loved one. During the curative phase, this approach is encouraged even by medical professionals. Despite the fight being harmful to the well-being of the patient, it is seen as the right thing because the chance of complete recovery remains (Elliot & Olver, 2009). Once someone is deemed incurable, medical staff adjusts their approach to enhance the quality of life instead of pursuing recovery. People who "fight back" instead may disapprove of this approach, considering it an overly passive approach "against the disease". There is a knowledge gap about the

end-of-life phase that contributes to them believing that they should make active efforts against the disease. They appear to mostly assign value to the time their loved one remains alive and undermine the quality of life during that time.

Those who decide to "let nature take its course" take on a much more passive approach to providing support and care for their loved one. Similar to the change medical staff makes once someone is deemed incurable, they transition towards activities that are beneficial to the quality of life of their loved one. There seems to be a better understanding about the end-of-life phase and the needs and desires of a person approaching death. Their hopes seem more focused on sharing as many pleasant, meaningful experiences with their loved one as they can in the time that remains.

The final group are those who "waffle" between the former two. They are often inconsistent in their actions, shifting between passive and active approaches to providing care and support. They understand that a passive approach is in accordance with the needs and desires of their

Chapter Takeaways

loved one, but have a hard time being at peace with a completely passive stance against the disease. Unsuccessful methods to actively fight the disease are discontinued, but they remain hopeful to find alternatives that may work out. It is a consideration between what their loved one desires and needs, and finding an approach that fulfills their hopes to extend the life through an active care approach.

Conflictful interactions due to care attitudes

The "fighting back" and "waffling" attitudes can both potentially bring about problematic interactions between those involved in the end-of-life care. When a dying loved one is in disagreement with this attitude towards the care they receive, the interactions will be conflictful. Those near and dear continue to pursue actively fighting the disease, which is both physically and mentally demanding for their loved one. Meanwhile their loved one desires rest and passive support, allowing them to, at the very least, spend the time they have left enjoying meaningful moments alone or in company of others. The "fight back" attitude of those that provide care disrupts those aspirations, thus forcing the person into a conflict with those near and dear to acquire what they aspire.

The previous chapters give some insight why those near and dear to a dying person may continue to "fight back", despite their loved one protesting it because of how detrimental it is to their quality of the life they have left. Part of the cause appears to be their lack of understanding about the end-of-life phase, and the needs and desires of someone going through this phase. To cope with the emotional strain and anxiety of the approaching death of a loved one, those near and dear attempt to actively fight the disease to fuel their sense of hope for a longer life of their loved one. It is a continuation of the approach that medical staff encouraged them to employ during the curative phase. After the illness is deemed incurable, they remain convinced that actively fighting the disease is beneficial to the well-being of their loved one, and therefore, see a passive stance against the disease as "giving up". Being passive harms their ability to cope with the approaching death, which is why they prefer to avoid "letting nature take its course".

The Role of Food During a Life-Limiting Illness

The Meaning of Food in Life

You might treat yourself with your favourite bar of chocolate, talk about your day when having dinner with your family, or maybe receive a warm bowl of soup to help you recover from a flu. Those activities, in which food plays the central role, possess a range of values. Nutritions that aid you physically, the pleasant taste that uplifts you emotionally, or the social bond that is established when sharing a meal or offering food as an expression of love and care. Knowing what food means for different people is important for this project. It says a lot about what values are lost when someone's appetite for food starts to diminish, for both that person and those near and dear.

Nutritional values of food

People eat to still the hunger their body communicates to them, to nourish their physical needs. The nutritional values are relevant in many ways. First and foremost, eating is a basic need for life, to stay alive you need to eat (Ellis, 2017). However, the type of nutrition that food offers also plays a role in how people value different types of food. Some take on a specific diet, rich with specific types or nutrition, to remain healthy or stay fit. Others are less strict when it comes to the nutritional values, which in a way also illustrates the value of nutrition. Not taking nutrition into consideration allows people to enjoy any food they would like, without boundaries.

Beyond seeing food as a means to sustain a healthy body, some may also see it as a means to treat your body in times of illness, to stimulate the healing process from the illness. This attitude is underlined when you see ready-made food supplements with the purpose to supply the consumer with a compact collection of vitamins, minerals, and other nutritions to boost your health. Examples are vitamin tablets, or health-centered "shots" like Yakult (Chamberlain, 2004).

Emotional values of food

Obviously, the value in food lays not only in what it offers your body, but also emotionally. Emotional responses to food are very recognisable in everyday life. Children show their disgust when their least favourite vegetables are put on their plates, but get all too excited when a parent mentions they will be eating pancakes for dinner. Throughout life people find joy in food that they enjoy to eat. A tasty meal can be something to look forward to, to get excited about, but, the foresight of eating an unappetizing meal can just as much be something to dread. While of course, the emotional responses towards food are much more complicated, this contrast is particularly important to know within the context of this project.

One should wonder, how would you be affected if food becomes progressively less tasteful, or if eating progressively becomes a larger struggle? How do you react to that development? They are relevant questions, as becomes clear in the next section *coping with eating deficiencies*. Questions that some people are forced to ask themselves in their final phase of life.

Social values of food

Food is not something that only holds value in what it is, something you consume as a person, with taste and nutrition. Food plays a vital role in your social life, in many ways (Wallin, et al., 2015). Many families have dinner together every single day. During dinner they talk about what has happened throughout the day. The necessity to eat, to have dinner, brings you together and puts you into a context that provokes social interactions. For some this is the only moment spent together with the entire family.

Beyond those daily moments, food just as much plays a role in more special occasions. Many celebrations are paired with having dinner together, think of birthdays, christmas dinners, easter breakfast, or in some cultures eid-al-fitr. While the celebration is not just about the food, it does play a major role in the celebration. They involve routines, traditions, and rituals that have been formed through many generations of celebrating together (Wallin, et al., 2015).

Because food plays such a major role in these social gatherings, like explained for the emotional values of food, the questions is raised: how will those social

gatherings be affected when food is no longer something to be excited about, or when it is something that is entirely off-putting? Not just the excitement for the food itself is affected, but it may very well affect how someone experiences the social contexts in which food plays a major role.



Fig. 2: Food can play a central role in many types of social gatherings. Some rich with traditions and rituals, such as a christmas dinner shared with the family (Kasteelhoevewange, n.d., & The Star, 2012.)

Coping with Eating Deficiencies

Throughout a life-limiting illness, struggling with eating is a common occurrence. The curative treatments that patients receive turn eating into a physically and mentally demanding endeavour that they have to repeatedly undergo to be able to recover. The hope for cure is a strong incentive to push through together. Together is an important addition here; the pursuit of cure is a shared goal that makes those involved take on a similar attitude. Those near and dear work hard to provide meals for their loved one, who in turn tries hard to finish as much as possible.

Once deemed incurable, the treatments stop and so might the struggle of eating, initially. However, as someone starts to approach death, eating deficiencies start to occur. For various reasons the appetite for food starts to diminish. Those near and dear will still put in the effort to care and support for their loved one by providing them with meals. Unfortunately, this time the incentive that the hope for cure brought is absent and, as a result, the attitude towards eating of those involved can start to show discrepancies.

Eating deficiencies in the end-of-life phase

Research shows that a common development for people suffering a progressive life-limiting illness are eating deficiencies, often presenting themselves in the form of a diminishing appetite and weight loss. It is often related to a wasting syndrome called cachexia, that often occurs with people suffering from cancer or other diseases that cause breakdown of muscles and make the assimilation of food difficult. In other words you could say, it happens because the disease makes that the body needs less food and therefore can not take in much food. Additionally other symptoms such as changing taste, nausea, constipation and mouth problems can occur that hamper the appetite for food (Wallin, et al., 2015).

It becomes difficult for a someone to find the motivation to eat. When nauseous, the idea of eating alone is off-putting, and the knowledge that the food may not even taste right is not encouraging either. This being followed up with an exhausting digestion process, with potential vomiting when you ate too much or the body does not take the food well, makes it hard to move oneself to eat much if anything at all.

Coping difficulties with the eating deficiencies of a loved one

Earlier, care attitudes during the end-of-life phase were discussed. It became evident that those near and dear to a dying person can take on a "fight back" attitude against the disease. Many of those people see the inability of their loved one to eat as a sign of an impending death (Ellis, 2017). With their role as a carer, they see it as a duty to ensure that their loved one continues to eat, to extend the life, or in other words, protect their loved one from the impending death. This is done by encouraging or urging their loved one to continue eating, despite the difficulties experienced with taking in food (Hopkinson, 2018).

The motivation behind this attitude of those near and dear seems to lay in three factors: 1) anxiety for the impending death of there loved one, 2) the hope that they can postpone this death through food, and 3) the lack of knowledge about eating deficiencies in the end-of-life phase. Research stated how those near and dear *"feared that the patient would "starve to death" or experience a painful, hastened death"*, speaking about their loved one discontinuing the intake of nutrients (McClement, et al., 2003). This highlights how, out of a fear of a hastened death, they want to encourage their loved one to eat

Conflict due to coping difficulties

more. In that statement there is also the believe that the death is approaching because of a lowered food intake, instead of the food intake going down because the death approaches, which is what is usually is the cause of eating deficiencies in these circumstances (Wallin, et al., 2015). It exemplifies their lack of understanding of the eating deficiencies, why they remain hopeful that they can extend the lifespan of their loved one through food, and why they believe that pursuing that goal is the right thing to do.

As a result of those near and dear struggling to cope with the eating deficiencies of their loved one, conflicts between them can arise. Eating while your body refuses the intake of food is an unpleasant experience, and the assimilation of the food becomes a troublesome, exhausting process. Altogether, the amount of food that is considered pleasurable, or at the very least realistic to eat is not very high. Opposed to that, those near and dear have a much higher expectation of what they believe their loved one should (be able to) eat. This gap is what causes conflict between the groups (Hopkinson, 2018). Situations arise where the amount of food that is served is vastly greater than the amount of food that the ill person wants to eat. That person has to deny a lot of the food that was prepared for them, which is hard for the carer to deal with. It feels as a denial of the care they provided, which they put a lot of effort in. Furthermore, they hoped that their loved one would maybe be able to finish the meal they prepared. When that does not happen, they feel distress and their hope is crushed. They try to turn things around by encouraging their loved one to eat more, sometimes this reaches the point of someone being forced just to get more food into

their stomach. It compromises the sense of autonomy of their loved one, which leads to them protesting the care they receive. It is a conflictful circumstance between the ill person and those near and dear.

How ill person deals with the conflicts

The eating deficiencies can result into numerous situations (Wallin, et al., 2015).

- Patients eat as a mean of resisting death. Despite their body struggling with the consumption, they eat with the intention to maintain their physical well-being. Often supported by the care giver who urges the patient to continue eating and not give up.
- Patients may eat with the intention to please the care giver, to raise their hope or give off a sign of appreciation for their efforts. As opposed to that, if the patient simply cannot eat, a care giver may feel guilty, or offended by the denial of their 'unsatisfactory efforts'.
- A major part of the social side behind eating and food may be avoided altogether, to avoid the distress that comes from them. However this may also negatively affect the social well-being of those involved.

It can be concluded that the eating deficiencies can be strainful for everyone involved, even despite efforts made to improve the circumstance some way. A study that supports this concluded that patients with eating deficiencies in general gain less enjoyment from food altogether (McGreevy, et al., 2014). Another study suggests patients rather put effort into finding enjoyment elsewhere, avoiding the distress that food gives them (Hopkinson & Corner, 2006).

Food as the Last Resort

Once someone is deemed incurable, they start to receive palliative care (see section *Development of a life-limiting illness*). At this point, the curative treatment will be discontinued. Eventually, in the late palliative phase the treatments people receive are merely for the alleviation of pain and not so much on extending someone's life. The main focus is to improve the quality of life for the time that remains. At this point, those near and dear only have food left as a means to provide care for their loved one. It is their last resort for extending the life of their loved one.

This puts a lot of focus on the eating behaviour of the ill person, as a denial of food takes away what for those near and dear may be their last beacon of hope. This causes great distress, and makes coping with the eating deficiencies particularly hard.

In some non-western cultures, this attitude is particularly strong. In their eyes, not eating is simply not an option. Especially with certain religious influences, they argue that not eating is against the will of their god. They should continue to fight for the life they received, despite the body clearly

refusing to take it in. They may even decide to not communicate the prognosis of the disease being deemed incurable, to ensure that the believe of the ill person remains that eating may eventually lead to a complete recovery (De Graeff, et al., 2012).

The final hope that food instills in people is what makes it particularly distressing to let go of that aspect of care. So much so that at times it reaches the point of forcefeeding, just for someone to achieve a sense of hope that maybe that food being eaten may extend the life of their loved one just that little bit.



Contextual Analysis

In the final phase of life people can receive the care they desire in various contexts. These options for receiving 'palliative care' introduce different characters of care, a different environment, and different roles and for the stakeholders involved in the care. Therefore, prior to carrying out a contextual analysis, a choice of context is made.

Following this choice, the analysis of the context is carried out through interviewing stakeholders active in the context. The aim of this analysis is to get a thorough understanding of the cultural context, and what roles each stakeholder group fulfills. This is followed by an analysis specifically of the food care in the hospice context, to understand how the food care is carried out and figure out what the attitudes, feelings and incentives are of the stakeholders when it comes to providing food care.

Finally based on these analyses areas of concern are identified within the food care routines in the hospice context. Based on these areas of concern design opportunities are established as a starting point for the design phase that follows.

Contexts for Palliative Care

In the Netherlands, a person suffering from a life-limiting illness can get involved with various types of health care, potentially multiple types throughout the development of the illness. First and foremost there is the clear distinction between facilities for curative care and those for palliative care. Where curative care focuses mostly on fighting a disease, even if this will temporarily lower someone's quality of life, palliative care facilities employ methods solely to increase a person's quality of life while suffering from their disease. However, the characters of the palliative care options differ a lot as well. How the care is provided, the context in which it takes place and the role of the stakeholders are all vastly different between the options.

Palliative care

The character of palliative care is vastly different from curative treatments. As an overarching care approach, the goal of palliative care is to improve the quality of life for a person suffering from a life-limiting illness and those near and dear. Care givers identify pains and problems that may be detrimental to the physical, psychosocial or spiritual well-being of a person, and find a suitable treatment to ease the harm (Graeff, et al., 2017). Dutch organisation Netwerk Palliatieve Zorg points out a number of options that are available for receiving palliative care (n.d.). The following options are considered most relevant for this analysis.

Care at home

Often the preferred option for people is to receive care in the familiar environment of their own home. Those near and dear take on a large role in the care, their presence at home is also an important requirement for home care to succeed. They are supported by care givers and sometimes volunteers who visit daily to provide some of the necessary care. They can also provide supportive materials for those near and dear to use. This is also the most common option that is only avoided if those near and dear are not available for or capable of providing the necessary supervision and care for their loved one.

'Bijna-thuis-huis'

A small-scale institution that provides a homely environment nearby to your own living place. Like home care you receive daily visits from care givers and sometimes volunteers to provide the necessary care. They can potentially cooperate with those near and dear to provide care.

Context choice

Care at a hospice institution

At a hospice institution a specialized team of care givers and volunteers are available 24 hours per day, 7 days a week to provide care and supervise the residents. While not required, those near and dear often take on some care, most notably food care. In the Netherlands, people are only able to receive care at a hospice institution if estimated their life expectancy is less than 3 months.

Palliative unit at a hospital

Unlike the other options, a palliative unit is meant for short term stay, where specialized care givers try to set up a fitting care plan for someone and get them in the right condition that allows them to move to another location of their choice, which could be any of the options named before.

For this design project, making a choice for a single palliative care context is deemed beneficial to the process. Since each context is very different on multiple levels, taking into consideration all of them makes for a near impossible task. The result will likely be more valuable and purposeful if designed for one single context.

For that reason, the choice is made to focus on palliative care at a hospice institution. This context is considered to have a large potential for influencing the troublesome interactions related to eating and drinking. Those near and dear still play a role in food care, however in this case there are volunteers who also provide food care parallel to them. They witness the eating behaviour of hospice residents and can thus oversee the changes. This awareness opens up a possibility for those volunteering care givers to play a supportive role in a potential design intervention. However, in the first place it simply makes it easier to identify a problematic attitude among those near and dear when it comes to food care.

Furthermore, in a practical sense for the project the hospice institution is also a good choice. It presents a context with a collection of experts who experienced a large variety of cases, thus providing a rich source of information that can be used for a context analysis. And of course, with a chair who is a volunteer at a hospice institution as well, there is a direct connection with the context available as well.

Research in a Dutch Hospice Institution

For the contextual analysis the choice was made to do research at hospice institution *De Vier Vogels*, located in Rotterdam. The hospice has four rooms available that provide a warm and homely stay for anyone and everyone (figure 3). The volunteers and medical nurses offer sincere, affectionate attention for the residents and those near and dear to them. They learn to know their residents and their needs, desires, worries, and problems, and they do their best to find a way to provide the care that suits that identity.



Fig. 3: The interiors of a room, and the general living space of hospice *De Vier Vogels* (Hospice *De Vier Vogels*, n.d.).

Goal of the Analysis

The goal of this context analysis is to get a thorough understanding of a variety of topics relevant to the context of the hospice care institution, both in general and specifically related to food.

- The character and dynamics of the palliative care approach in the hospice context for all stakeholders involved in the care.
- The attitudes of hospice residents and those near and dear towards the circumstances.
- Activities enjoyed and values by hospice residents, alone or together with those near an dear.
- The stance of stakeholders on the diminishing appetite during their time at the hospice institution.
- The aspects of food that are valued and therefore pursued by stakeholders.
- What is the material culture within the context, both in a general sense and specifically related to food.

The analysis of these topics should shed light on the needs and desires of the stakeholders of the hospice context. Furthermore it can substantiate points of interest, or opportunities relevant to a design perspective towards the coping problems related to the diminishing appetite of hospice residents. These may form minor or major contributions for finding design directions with a large potential.

Research method

To achieve the goal of the analysis the choice for qualitative, in-depth interviews was made. Both medical nurses (3) and volunteers (3) were interviewed about an array of topics, each interview lasting between 45 minutes to an hour.

Medical nurses

The medical nurses at a hospice institution are responsible for supporting the residents through the process towards their death with the aim to offer them to best quality of life throughout this process. Working in shifts they are available any time of the day to provide medical care and support for the residents. Their care consists of managing pain and other symptoms, physically and mentally nurturing the residents, supporting and assisting the residents and those near and dear, and at times provide medical equipment and supplies for those near and dear to use for the care of their loved one. These care activities happen in close cooperation with the volunteers; the work of volunteers is dependent on what the nurses do and the other way around.

Volunteers of the hospice

The volunteers at a hospice institution, like the medical nurses, provide care and support. However, they do so in different fields. They support the medical nurses in the nurturing of residents and carry out the householding tasks; volunteers cook meals for residents, serve drinks such as tea and coffee, do grocery shopping, and wash and clean the rooms as well as the clothing and sheets of residents. Besides that they can fulfill a socially engaging role with the resident. Being a sympathetic ear, sharing activities with residents, or simply being there, can all improve the well-being of the residents. A similar role can be fulfilled with those near and dear to a resident, if they are in need of social support.

The following topics were discussed, categorized in three sections.

Impressions on the hospice residents and those near and dear

- The attitude of hospice residents and those near and dear towards the circumstance they are in.
- The physical and mental condition of hospice residents upon entering the hospice institution.

Impressions on the care and support that hospice residents receive from those near an dear

- The (care) activities shared and enjoyed between hospice residents and those near and dear who visit.
- The tangible 'things' that hospice residents attach value to.

Impressions on the situations that occur between hospice residents and those near and dear related to eating and drinking

- The situations that arise as a result of the diminishing appetite of hospice residents.
- The aspects of food that hospice residents attach value to.
- Food-related, tangible things that are used (and valued) in the hospice institution.

The topics were presented in combination with a printed visual that give a rough introduction to the topic by showing examples of potentially recognizable things related to the topic (see figure 4). The interview had an open nature, with an emphasis on the interviewees sharing their personal experiences and impressions regarding the topics. This decision was made to have a more qualitative and explorative interview, making the interviewees ponder the events they remember and the feelings that were involved (also see appendix B).

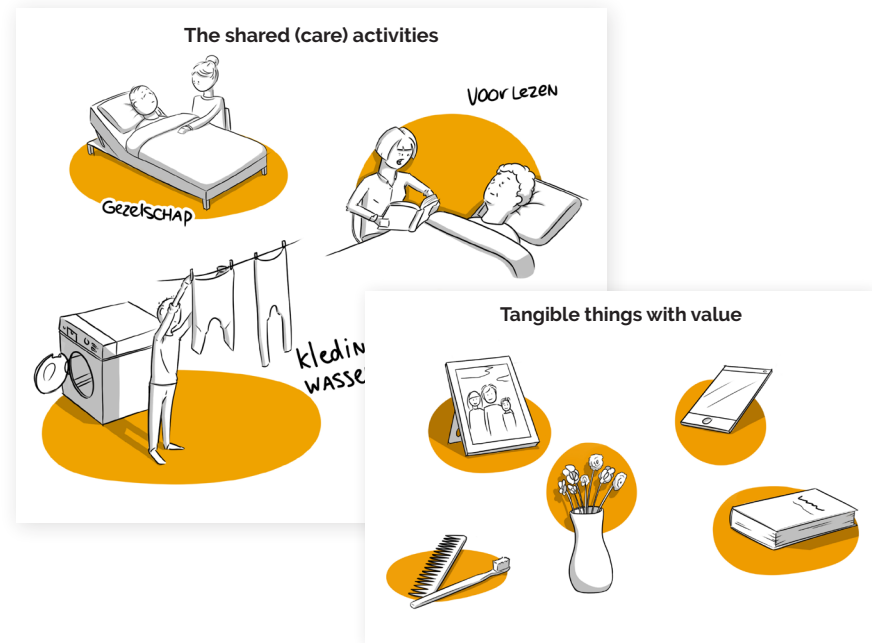


Fig. 4: Examples of visuals that were shown to the interviewees during the interviews (appendix B).

Main Findings of the Interviews

The main findings of the interview analysis are grounded on qualitative statements that carried a sense of significance within a number of interviews. This ensured that the experiences shared by the interviewees taken into regard for the rest of the project were, at least to some extent, relevant in a general sense. This approach led to the following findings.

Individuality of residents and those near and dear

"Every individual is simply different. The diversity has simply really stood out to me. It is also about the dynamic between the residents and care providers, it forms a symbiosis that is simply never comparable."

Each person that comes to the hospice to receive care is entirely different. The residents have diverse personalities, attitudes, conditions, needs, and desires. This complex arrangement of factors creates the necessity for care providers to carefully make an assessment of each resident, to allow them to provide care that suits the resident well. To add to the complexity, those near and dear to residents are just as diverse and may very well need a separate assessment from the resident, to achieve support that fits. The care providers "start from scratch" each time someone new arrives at the hospice.



Fig. 5: Information is often exchanged by writing it down in a binder. The binder has an open nature (not standardized), making it more sensitive for the subjectivity of the writer, and the reader (Stichting de Mantelleeuw, n.d.).

Inconsistencies due to the exchange of information

"The communication between care providers is complicated. There are many types of information, exchanged over different shifts, this already brings risks. How is this carried over, and how is it interpreted?"

In the hospice there are a number of shifts each day. Because of the instable nature of the needs and desires of residents, the exchange of information is essential to provide the correct care. Unfortunately, the current methods for exchanging information are prone to the subjectivity of the care providers, on the addressing end and the receiving end of the information. This can lead to inconsistencies in the care that residents receive.

Exchange of knowledge with those near and dear

There are many occasions of those near and dear to hospice residents not being able to provide the appropriate support and care for their loved one. Either they lack the sufficient knowledge to understand what their loved one needs and desires, or they can not cope with the situation, resulting in an improper care attitude. Sometimes this leads to those near and dear treating their loved one in a way that is detrimental to the well-being of that person, such as making them overeat or having large numbers of visitors come by when the resident desires rest.

It is the duty of care providers to inform those near and dear, when these situations occur. The existing written guidance is often lackluster, and approaches the knowledge exchange in a rather formal and blunt way, both in substance and in visual form (see figure 6). Because of that, the informing process is usually done through conversations. While this makes it easier to adjust the way of communicating to the personality of those near and dear, there is also a sense of subjectivity to the exchange of situation (on both ends of the conversation). This makes exchanging information less consistent and accurate.

The image shows a page from a patient information folder. At the top left is the logo for 'Reinier de Graaf' and at the top right is the text 'Palliatieve zorg'. Below this is a blue header bar with the text 'Patiënteninformatie'. The main title of the page is 'Vocht en voeding in de laatste levensfase'. The text is organized into several sections with bold headings: 'U ontvangt deze informatie...', 'Gevoelens', 'Als het lichaam sterft', 'Minder pijn', and 'Afname zwellingen'. The page number 'Pagina 1/3' is located at the bottom right.

Reinier de Graaf  Palliatieve zorg

Patiënteninformatie

Vocht en voeding in de laatste levensfase

U ontvangt deze informatie, omdat uw dierbare in zijn of haar laatste levensfase minder is gaan eten en drinken. Dit kan voor u een situatie zijn waarmee u misschien moeilijk kunt omgaan. In deze informatie kunt u meer lezen over uw eigen gevoelens, maar ook over de reactie van het lichaam op minder voeding en vocht. Spreekt u ons aan wanneer u vragen heeft. Wij staan u graag bij in deze moeilijke periode.

Gevoelens
Het is normaal dat u zich emotioneel voelt door de situatie waarin uw dierbare zich bevindt. Eten en drinken is tenslotte een noodzaak en voedsel wordt vaak gelijkgesteld aan zorg en liefde. Gezonde eetlust zien we als een bewijs voor een gezond lichaam. Soms ontstaat een gevoel van schuld of machteloosheid, omdat het niet mogelijk lijkt om voor deze basisbehoefte te zorgen. Als uw pogingen tot het laten eten van uw naaste falen, kan dit tot spanningen leiden. U kunt de hoop verliezen als uw naaste achteruit gaat, zonder dat u daaraan iets kunt doen.

Als het lichaam sterft
Als het lichaam aan het sterven is, gaan alle organen steeds minder goed werken en houden zij langzamerhand op met functioneren. Zo zullen onder meer het hart, de hersenen, de lever en de nieren hun taken steeds minder goed kunnen verrichten. De spijsvertering raakt ook uitgeschakeld, vaak zelfs zodanig dat er geen voedsel meer verteerd kan worden. Uw naaste heeft dan geen trek meer in eten en drinken en kan last hebben van misselijkheid en braken. Zo laat het lichaam merken dat voeding niet meer nodig is. Dit hoort bij het stervensproces. Het verminderen van voedselinname in deze fase is de natuurlijke weg naar een vredige dood, hoe vreemd dat ook kan klinken.

Minder pijn
Wanneer een stervende minder vocht inneemt, droogt het lichaamsweefsel uit en krimpt het. Bij een tumor ontstaat er minder druk, waardoor de pijn afneemt. De tumor kan in omvang afnemen. Het kan de behoefte aan pijnmedicatie verminderen.

Afname zwellingen
Door de verminderde vochtinname neemt zwelling van voeten, benen en overig lichaamsweefsel af. Ook kan het eventueel aanwezige vocht in de buik (ascites) of rond de longen (pleuravocht) sterk afnemen. De mate van welbevinden neemt toe, omdat er minder druk op de interne organen is. De ademhaling verloopt ook gemakkelijker.

Pagina 1/3

Fig 6:
An example of a page from a folder meant for people in their final phase of life, or those near and dear, to help with the troubles surrounding eating and drinking in the end-of-life phase (Reinier de Graaf, 2015)

Autonomy and a sense of control

The residents themselves know best what they want or do not want. Unfortunately, at times, it can be difficult for them to express those desires. They lose their autonomy and sense of control over their life. This is most often in relation to those near and dear to the resident. They may urge their loved one to eat more than they desire, visit in large numbers when the resident wants to rest, or they insist the resident to discuss or arrange certain matter that the resident would rather avoid talking about altogether. Those near and dear may do so to help themselves to cope with the situation, disregarding what their loved one really wants.

Meanwhile, the resident may have a hard time expressing their desires because of a lack of energy, or because they feel guilty towards those near and dear. The resident might understand that what they do is with good intentions, which makes them feel that denying their efforts may be cruel.



Fig. 7: A ready-made meal doesn't communicate the sense of care that a meal made from scratch, with attention and effort, does (KRO-NCRV, 2018 & Hospice Dôme, n.d.).

Attention and effort for food preparation

"I think that when you prepare something with effort and attention, no matter how simple, it always leaves an impression. Someone can really sense that, if something is simply from a factory or truly self-made."

One thing that is seen as valuable for the care providers is how the meal is prepared and served to the resident. First of all the taste should suit what the resident desires. However, besides that how the meal looks is very valuable, it can make them feel that the care providers truly care, that is what it transmits.

The task of presenting a pleasant looking meal can get progressively harder, once the resident starts to eat less food. It becomes harder to not present a flimsy looking meal.

The necessity of letting go

It is common for residents or those near and dear to not be able to "let go of life". They are not at peace with the approaching death and therefore they take on an attitude of "fighting back" against the disease, which often comes with trying out remedies or aids that they believe will extend the life. Another common occurrence is those near and dear to hospice residents urging, or even forcing, their loved one to continue eating, even if they don't want any more. It causes stress for residents and wears them out; "fighting back" is a, both physically and mentally, exhausting endeavour.

This underlines how important it is for both residents and those near and dear to go through the process of letting go. To be able to approach a sense of peace about the situation. This is beneficial to the quality of life of the residents and takes away a lot of distress for everyone involved.

The process of letting go

"It is important that people can express themselves, and that you can respond to that. When you show understanding for someone's situation, you will notice that acceptance can come quickly."

Letting go of life, it receives a lot of attention at the hospice and the care providers try their best to support residents and those near and dear in the process. Time is spent to arrange things before passing away, to say things that people do not want to leave unsaid, saying farewell to the important people in life, and find closure for yourself with the approaching death. In all these activities care providers can play a role, to guide them in the process of letting go. They can listen to the troubles and worries of people, and respond with advice and support to help them.

Value of social connections for hospice residents

The residents of the hospice see the social interactions they have as very important. They enjoy the company of those near and dear and the meaningful moments they can share. They also like to keep their social bond alive through symbolic tangible objects, such as photos, cards, presents, and so on. Residents gladly present those things in their room, for them they can work as conversation starters to share their story with visitors or with the care providers of the hospice.

However, balance is very important for the residents when it comes to being social. The amount of energy they have to spend is low and large numbers of visitors can quickly exhaust them. Therefore, in cooperation with the care providers, efforts are often made to schedule the visitors so they can enjoy moments with those who they love without being overwhelmed by the circumstances.



Fig. 8: From a documentary 'Bijna Thuis Huis - Leven in een Hospice', resident Piet still spent a lot of his time painting bird houses while at the hospice (Gageldonk, 2011).

Resident's connection to their "normal life"

"One lady was very creative with painting and after a while the room was filled with paintings. At a certain point she couldn't paint anymore, at that point we took over a part of that."

Residents enjoy maintaining a connection to their "normal life". They enjoy sharing stories that are reminiscent of their past, and to be surrounded with things that remind them of that past as well, such as photos or objects. Beside that they gain joy from doing activities that were, and still are meaningful in their life. It humanizes them and makes them feel "normal again".

Design considerations based on findings.

The main findings of the interview analysis lead to the following considerations that can be taken into regard when searching for a design direction in a later stage of the project.

- How could the design be sensitive for the differences between stakeholders up to an individual level?
- How could the design enhance the knowledgeability of those near and dear about providing the proper care?
- How could the design aid in a more consistent exchange of information between care providers?
- How could the design stimulate meaningful social activities between the stakeholders?
- How could the design provide residents with an increased autonomy and sense of control over the care they desire?
- How could the design aid residents and those near and dear in the process of "letting go of life"?
- How could the design reinforce the resident's connection to their "normal life"?
- How could the design stimulate carers to provide residents with a well-suited, pleasantly presented meal?

Food Care Journey Maps

The previous findings lead to more general considerations that could be taken into account for a later design phase. However, it does not illustrate specifically how the food care is carried out at the hospice institution and the interactions that take place throughout a food care routine. Therefore, based on the interviews, journey maps were set up to map out the activities and interactions that take place, related to the food care in the hospice context. These journey maps take into consideration three relevant paths of activities.

- 1. Food care routine by hospice care providers.**
- 2. Food care routine by someone near and dear to the resident.**
- 3. Interventions by hospice care providers after incorrect food care by someone near and dear to the resident.**

The choice was made to map out the food care from both care providers and someone near and dear to the resident. Initially to function as a reference to compare the food care by someone near and dear

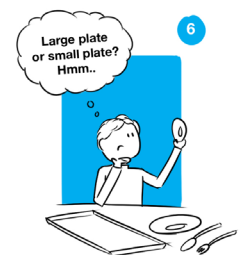
to the food care of the hospice care providers. To identify where it "goes wrong" for someone near and dear, in comparison to the journey map of the hospice care provider. However, the interview findings already pointed out that the care of hospice care providers may also contain areas open for improvement. Therefore their food care routine should also be critically analyzed.

Based on these journey maps, taking into consideration the literature analysis and the main findings of the interview, discussed earlier, areas of concern will be identified. These areas are considered to be activities that contribute to potentially troublesome interactions, or unpleasant experiences within the food care routine. They may form opportunities for design interventions.

Food care routine by hospice care providers.

Residents lack control over food portioning

Situations



Description

The hospice care giver makes an assessment of the available stock.

After the meal is decided, the hospice care givers will look into any comments left previously by other care givers about the resident's eating habits and needs

The resident is asked whether they want to eat and drink something.

The resident is asked what he/she would like to eat, followed up with suggestions based on the available stock (meals from relatives, ingredients).

The hospice care giver will do the preparation of the meal.

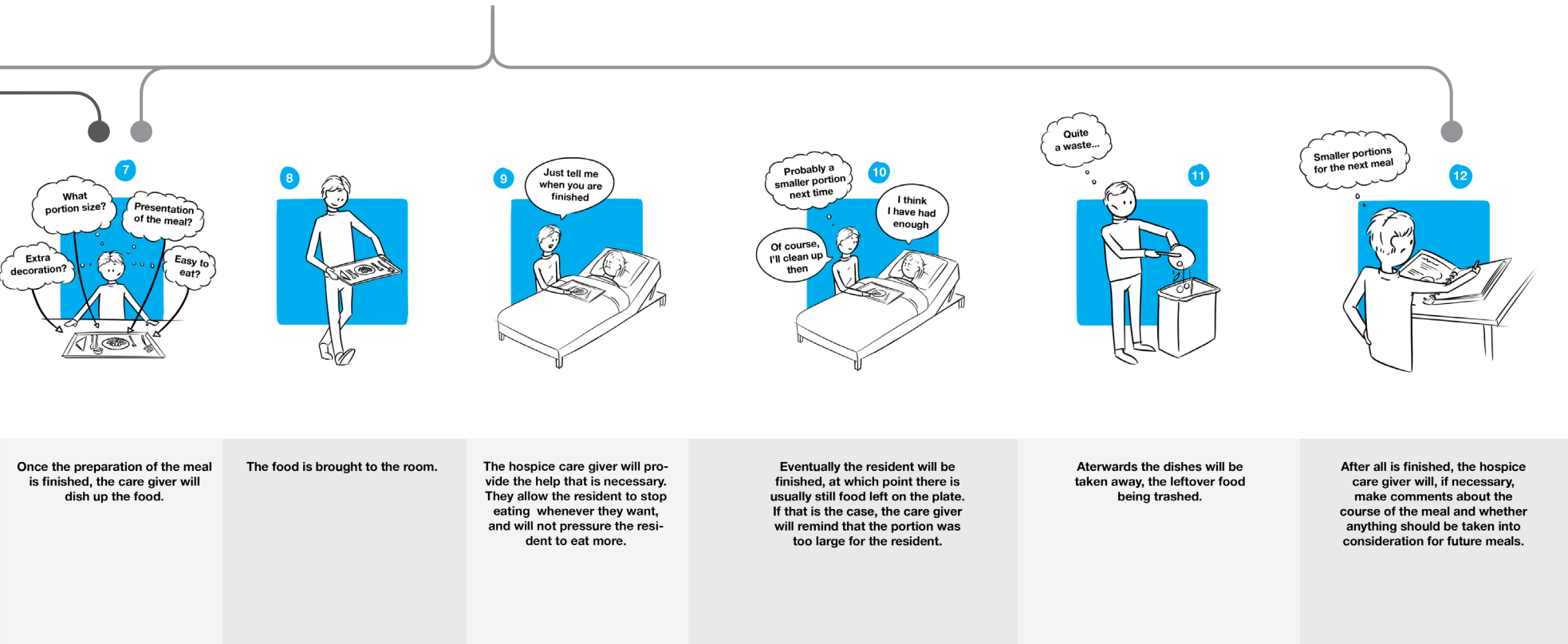
While preparing the meal the choice of tableware is made, considered best suitable by the care giver.

Mood

positive
negative



Inconsistencies in care due to subjectivity in communication



Areas of Concern

Residents lack control over food portioning

It is not uncommon for hospice care providers to not consider the desires of residents when it comes to the amount of food that is served. Instead, the care provider serves up an amount of food that they see fit; intentionally overestimating the amount may occur to avoid the risk of residents receiving too little. As a result, day after day the resident faces the "challenge" of a meal that is larger than they can realistically finish. After struggling to eat some of it, they consistently end up having to turn down a good amount of the food that was prepared for them. This can potentially lead to feelings of guilt, as they know care and effort went into the preparation of the meal.

Inconsistencies in care due to subjectivity in communication

The personal notions of hospice care providers can be a cause of inconsistencies or mistakes in the preparation of meals. Their personal notions influence what they communicate, and how they communicate it, but also how they perceive the information that was previously communicated by others. There is a factor of subjectivity on both ends. For example, when one care provider makes a note saying they served a "large portion of food". That care provider has a personal notion of what they see as a large amount, then the care provider reading the note, again has an own idea what a large amount is. This can skew the information and lead to two vastly differently sized meals for one and the same resident.

Food care routine by someone near and dear to the resident.

Important values of food are played down

Situations



Description

A resident's relative will ask what the resident wishes to eat, and may suggest meals, that may function as a way to form enthusiasm in the resident.

The relative will do grocery shopping, buying the ingredients for the meal that was decided on. The relative may choose for fresher ingredients, in the hope that the meal is healthier and more tasty.

At home, the relative prepares the food for the loved one. They may put in an extra effort, in the hope that it will help entice the loved one to eat (more). It is also likely for them to prepare more than necessary.

After preparation the food will be put into containers, in which it can be taken to the hospice and also be preserved over there.

The relative brings the food to their loved one at the hospice, potentially enthusiastic towards the loved one about bringing tasty, familiar food from home.

When it is dinner time, the meal will be warmed up. This is done either by the relative or by hospice care givers.

Mood

positive
negative



Overestimation of meal sizes sets up inevitable disappointment

7



The food is brought to the room.

8



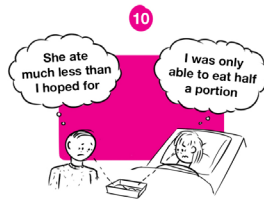
The relative may emphasize that it is "what you enjoy eating", in the hope to spark an enthusiasm for the meal in the loved one.

9



The relative will provide the help that is necessary for eating. The care giver continues offering food as long as the resident pleases it. Once the resident starts to deny food, the relative may urge the resident to eat more.

10



Likely the plate of food is not finished, clearly signifying that the loved one was not able to finish what the relative hoped/intended the loved one to eat.

11



The relative will likely try to figure out what can be changed about the food preparation to have the loved one eat more. Maybe a different meal they prefer to eat?

Areas of Concern

Important values of food are played down

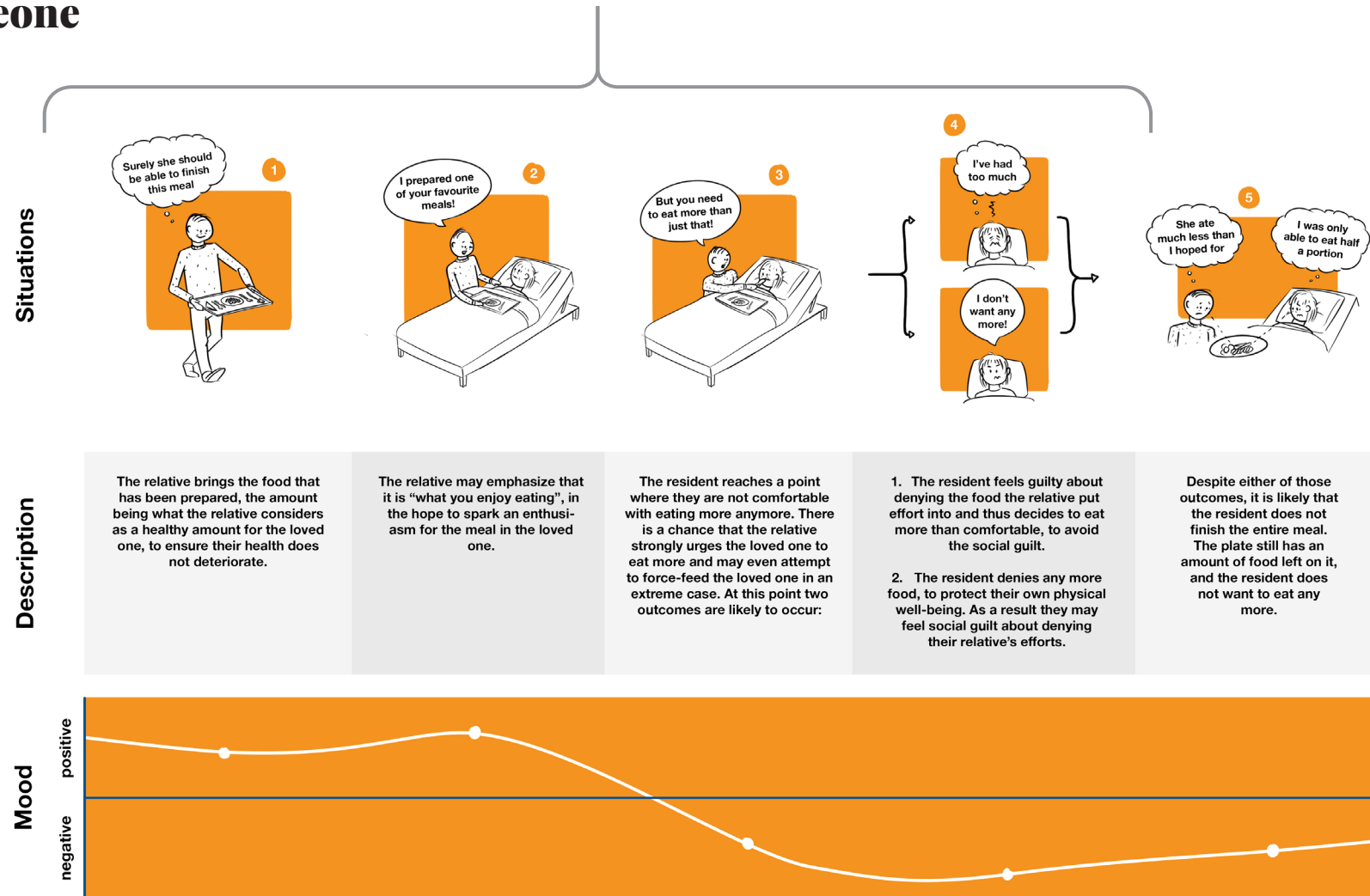
Those near and dear to residents see food as a source of hope, their last resort to extend the life of their loved one. When they prepare food they usually try to excite their loved one by suggesting, and preparing, some of their favourite meals, with the hope that maybe their loved one will eat more. The focus is still on the intake of nutrients that are necessary to live longer. Other values of food are played down a lot, or even disregarded entirely. A lot of the social values of food are lost, the food is often presented in the plastic container they brought it in with, the sense of autonomy during meals is lost when they are urged to eat more when they do not want to, or they are helped when they did not ask for help. Their sense of dignity is damaged, and they feel less well cared for when meals are seemingly only about them consuming as much food as they possibly can.

Overestimation of meal sizes sets up an inevitable disappointment

The judgement of those near and dear to hospice residents about what would be a "healthy amount of food", is often much larger than what the resident can eat. As a consequence the inevitable disappointment, of their loved one not finishing the meal they prepared, is incorporated into their food care routine. The hope they attempt to fuel through the food they provide is damaged when their loved one can not finish a meal. The cause of this inevitable disappointment finds itself in the lack of say that the resident has when it comes to the amount of food they receive, and instead having those near and dear determine what they believe their loved one should, or what they hope their loved one would be able to finish.

Interventions after incorrect care by someone near and dear.

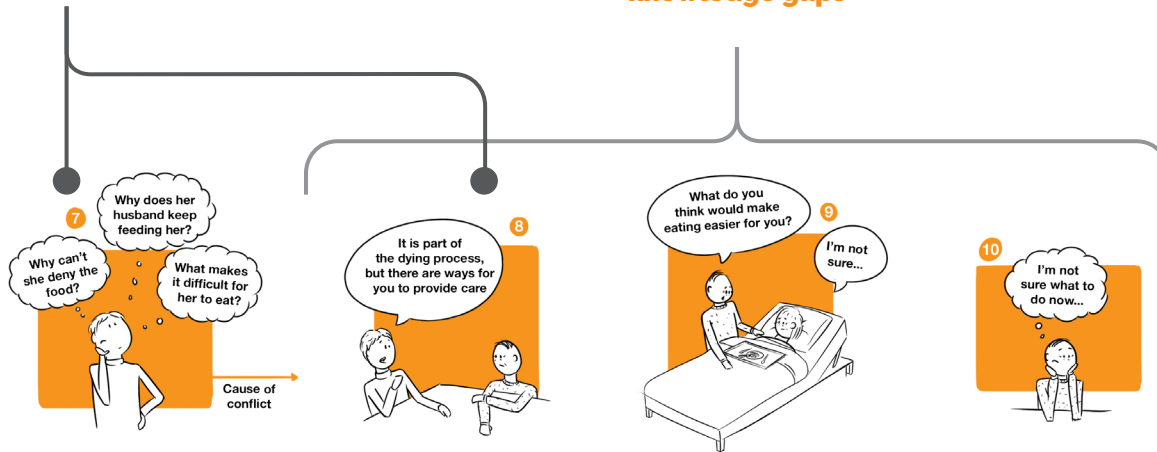
Negative consequences of oversized portions



Letting go of food in an unnatural fashion



Information exchange leads to intentional or unintentional knowledge gaps



- The hospice care giver can become aware of conflictual situations in multiple ways.
1. The resident privately communicates the conflictual situations.
 2. The hospice care sees the conflict occur first-hand.
 3. The resident displays symptoms that may relate to over-eating.

After the hospice care givers have become aware of the problematic situations, they can react by looking for the cause.

Depending on the cause, the hospice care giver can inform the relative to form understanding and give tips on how they can change their care methods.

The relative will attempt to adjust the diet together with the loved one, to make it fit the physical restraints from the illness.

If the resident is not able to voice a preferred meal, the relative has to come up with their own ideas. This can be difficult, as the relative is just as much uncertain about what works and what does not.

Areas of Concern

Negative consequences of oversized portions

Residents receive oversized portions, not just from those near and dear but also from hospice care providers. Because of that a situation consistently presents itself where the resident has to deny a part of the food they receive, combined with the realization that they, once again, were not capable of finishing a "normal sized meal". Feelings of guilt arise about the denial of food and feelings of despair about "not eating enough". This in itself is already a negative consequence of oversized portions, however, these feelings can sometimes evoke residents to overeat. This is harmful to the physical well-being of the resident and could have been avoided if the portion they received would have corresponded with their preference in the first place.

Letting go of food in an unnatural fashion

In most cases when an intervention from hospice care providers is necessary, this is because those near and dear were not capable yet of letting go of food; an active "fight back" attitude against the disease is still maintained. The negative consequences of oversized meals make it that intervening is necessary to prevent potential harm to the resident's well-being. Unfortunately, this forces those near and dear to instantly let go of food and turn around their attitude. This makes for a very unnatural process of letting go, as opposed to the process they go through with other important things (e.g. when residents have to let go of interests or hobbies, they are able to gradually let go and reduce their engagement with the interest or hobby.)

Information exchange leads to intentional or unintentional knowledge gaps

The exchange of knowledge from hospice care givers usually happens through conversations. There are several drawbacks to this type of exchange. Things can be left undiscussed unintentionally; hospice care providers may simply forget or due to a lack of available time less important things are left out of the conversation. Later this can lead to people still being left with unanswered questions that puts them into an uncertain position.

Because the information is not registered anywhere, therefore people can not refer back to the information. Additionally, this creates the risk that the recipient of the information may intentionally not communicate it, to the relative of other people; people with non-western backgrounds do hold back sensitive information at times, if they believe this is beneficial to the well-being of those people.

Discussion of Findings

The journey maps, and the findings based on these journey maps were to some extent based on personal interpretations from the literature analysis and contextual analysis. Therefore two people experienced in palliative care were questioned to confirm the correctness of the journey maps, and to receive input on the identified areas of concern.

Firstly, a conversation was had with a medical nurse active at a hospice institution. This was one of the medical nurses that was also interviewed earlier for the contextual analysis.

Secondly, there was a conversation with a general practitioner, Leonie de Bont, who is also active as a chair of the general management, and the executive committee for Netwerk Palliative Zorg Rotterdam & omstreken (NPZR&o).

Conversation Takeaways

In both conversations the journey maps were recognizable and deemed to be an accurate representation of how the food care routines, and the interventions in food care tend to go. As for the areas of concern, these were the main takeaways from the conversations:

Conversation with medical nurse of the hospice institution

- Both the care providers and those near and dear may not realize the necessity of assessing how much a resident wants to eat. They need to be made aware, or receive guidance when it comes to this part of the food care.
- When it comes to those near and dear, situations can vary from people overfeeding, fully convinced that it is the right thing to do, to people being entirely accepting if their loved one does not finish the meals they receive. An important sidenote here is that in both circumstances, the portions of the served meals are still usually too large. What it does conclude is that some circumstances just seem too difficult to "enforce" a change in the attitude towards food care.
- There is a lot of value in creating a situation in which the resident and those near and dear together tailor the food serving to the desires of the resident. A situation should be created where those near and dear will always ask the resident how much they want to eat.
- The assessment of the desires of residents is something that should happen on a daily basis, since their desires can vary greatly from day to day.
- A sense of flexibility should be maintained in the autonomous decision making of the residents.
- A lot can be benefited by introducing a system in which the desires of the residents are addressed properly from the very moment they enter the hospice. It can help to set up a food routine that is well-adjusted from the very start.

Conversation with Leonie de Bont

- Those near and dear to residents have the desire to feel that they can also offer something of value in the care. Food is possibly the most important way for them to provide that care. This makes the denial of their food difficult to cope with, as they lose the ability to care for their loved one's health. And it also makes the step to stop giving (well-sized) meals more difficult.
- It is very important to create awareness for those near and dear that their loved one will start to eat less as they approach their death. And that they should be sensitive towards this change in the food care they provide. Their focus should not remain on how much their loved one eats.
- Informing of those near and dear should be something that happens from the very beginning, they should be "warned" beforehand so they know what they could expect.
- Those involved in the food care should make assessments of the desires of residents on a daily basis, because their desires are not very stable. They can change greatly from day to day.



Conceptualisation

Design Goals

Based on the findings of the literature and contextual analysis, design goals for the conceptualisation phase have been set up. These design goals especially focus on the areas of concern that were identified in the food care routines of both the care providers, and those near and dear to residents, and the method of care providers for intervening in incorrect food care by those near and dear. The design goals that resulted from this are as follows.

Design Goal 1 The design should increase the sense of autonomy hospice residents have over how much they eat and drink.

Design Goal 2 The design should facilitate consistently well-adapted food care among both; the hospice care providers, and those near and dear to hospice residents.

Design Goal 3 The design should provoke a (re)introduction of social values related to eating and drinking.

Boundaries of the problem

Before entering the design phase it was important to define the boundaries of the problem that needed to be solved. The analysis has clarified the areas of concern, and where the opportunities are to play into these areas of concern. However, it has also become obvious that a design intervention can cover only so much ground. Therefore the intended reach of a design solution was defined, as illustrated in the figure on the next page.

There is “no problem”

Although the resident is being overserved, the inability to finish the meal is not met with protest. Therefore, usually this situation is seen as unproblematic. This situation can involve either care givers or relatives as the person providing food.

Despite being considered “unproblematic”, this situation still leads to the unpleasanties of residents being confronted with meals larger than their appetite, the struggle of trying to finish it and having to turn down a good amount of food, the leftovers. Meal times remain burdensome for both residents and relatives.

Hope for more food

Many residents and their relatives deal with this situation at one point during the resident's illness. The inability to finish the meals that the relative provides is met with attempts of the relative to get the resident to continue eating.

For those relatives, food is a beacon of hope for survival, however this hope is paired with unrealistic standards for the amount of food they want their loved one to eat. Because of that, the unpleasanties of the “unproblematic” situation are followed with the distress that comes from the relative urging the resident to eat more, as a desperate attempt to fuel their hope.

Demand more consumption

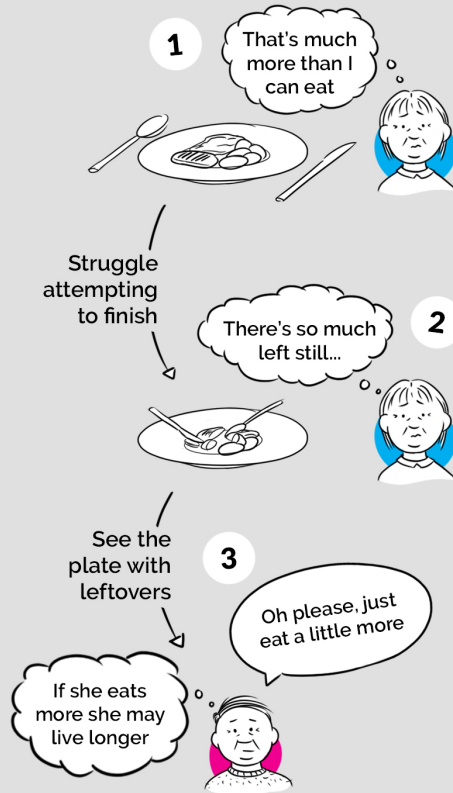
In this situation the relatives take very drastic measurements in an attempt to keep their loved one alive, to the point of force feeding or resorting to alternative curative remedies.

The cause of these situations are often rooted in religious beliefs, or personal beliefs about the illness (e.g. doubt about the correctness of the diagnosis). Those involved are often convinced that their decisions in the food care are the right decisions

There is "no problem"



Hope placed in food



Demand more consumption



appropriate option for this design project

not appropriate for this design project

Appropriate Options for the Design Project

Options appropriate for the design project

The former two groups are considered appropriate options for an intervention. The difficult situations are mostly due to the food care not being adapted to the needs of the residents, especially in the amount of food that is being served.

For relatives a part of the cause of this is them placing hope in the food that can only be satisfied by the resident eating more than they would prefer to: a "healthy amount of food" is already too much. Hospice care givers do see the opportunity to change this attitude, and successfully do so through informing and educating relatives. However, these interventions can be enhanced by providing means of support that add to the informing of care givers.

The other cause is the lacking awareness and ability to properly adapt the food care to the patient's desires and needs. Here lays an opportunity to introduce a design that offers guidance for the food care provider (both care givers and relatives) to improve in those areas.

Option not appropriate for the design project

The last group is not considered as an appropriate option for an intervention in this design project. The causes of the difficult situations are deeply rooted into the view those involved have on the circumstance. They are deeply convinced that their methods of care are right.

Hospice care givers mentioned how this group may often oppose their advices about food care and continue their efforts to fight the oncoming death, despite clearly being detrimental to the well-being of their loved one. This situation is a lot more complicated than the first wo. The attitudes of the stakeholders, especially of relatives, is unlikely to change and therefore the situation is not considered an appropriate option to tackle within this design project.

Defining the Design Touchpoints

For the design phase, the choice was made to focus on three touchpoints that form the most important moments of interaction between the resident and the care provider (hospice care giver or relative) when performing the food care routine. These touchpoints are defined as follows:

1. Assessment of the resident's desires.

The intention behind this interaction is to find out what the desires of the resident are for the meal they will receive. The design intervention should drive care givers and relatives to take into consideration the resident's desired amount of food, thus increasing the sense of autonomy over the amount of food they eat.

2. Presenting the meal to the resident.

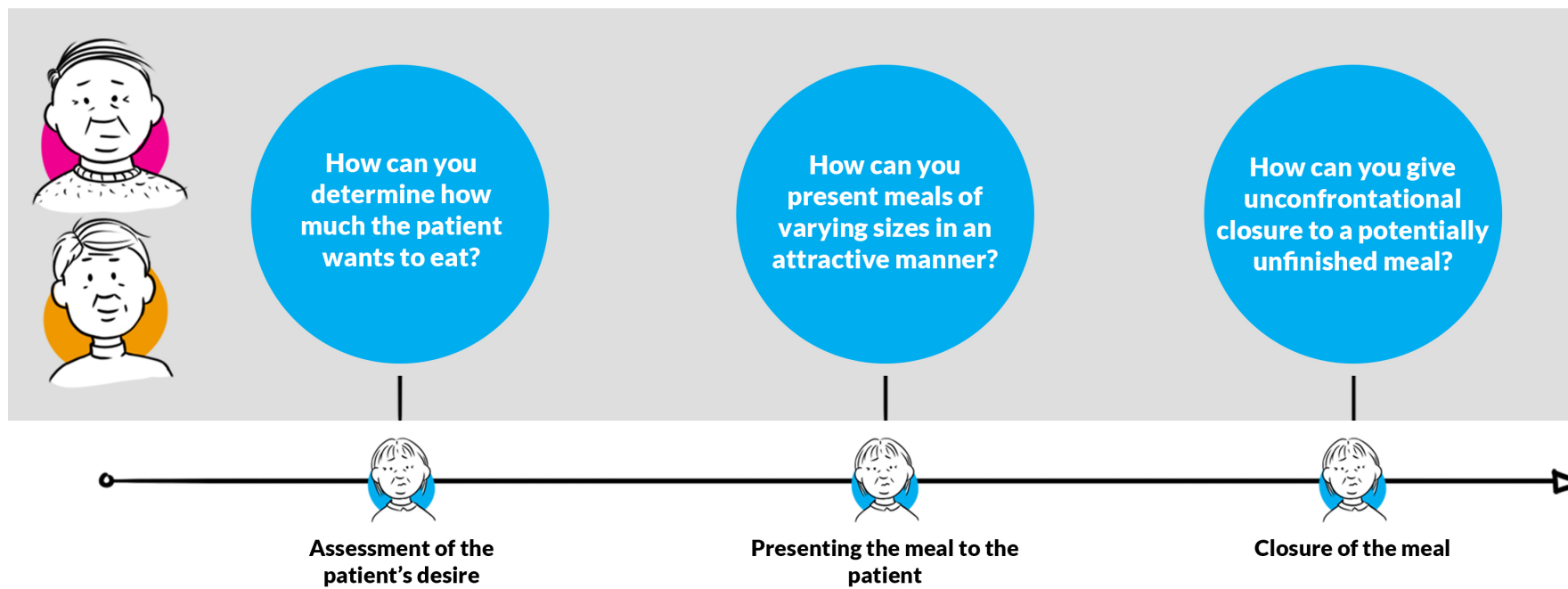
This is the moment where the resident gets the first impression of the actual meal, and how it is presented to them. The design intervention should ensure that residents receive a meal that is presented in an attractive matter, even when the portion is of a very small size.

3. Closure of the meal.

At this point the resident gives closure to the meal, after which it is cleaned away by a care giver or relative. The design intervention should relieve residents from potential unfavourable social confrontations, even with an unfinished meal.

Involving all touchpoints into a overarching design intervention should lead to a harmonious food care routine. This routine should put a higher priority on the resident's sense of autonomy over the amount of food they eat. Furthermore it should offer care givers and relatives with the guidance and means to provide food care that is well-adapted to the desires that residents have expressed as part of their autonomous decision making, and to do so in a consistent manner.

Food care routine Three interaction touchpoints and connected design questions



Interaction Qualities

The design intervention should evoke interactions that are considerate towards the needs of the stakeholders, with the needs of residents in particular being prioritized.

Nonetheless, whether the other stakeholders see the design as viable will also be dependant on those interaction qualities. If the design fully serves the resident while being unfavorable for other stakeholders, the design is still not satisfactory. Taking that into consideration the design should include the following two interaction qualities

Sensitive

Hospice residents are often unstable, their needs and their state of mind shifting continuously. The intended interactions should bring opportunity for the varying needs to be considered for, in a way that is compassionate towards the fluctuating feelings of the residents.

Effortless

Hospice residents usually have less energy to spend in a day, their illness exhausts them quickly. The interaction should thus be effortless. If it is too demanding it will be noticeably bothersome for the resident, in which case care givers and relatives will also refrain from engaging in the interaction.

An emotive collage describes, in a visual way, how those two interaction qualities come together (see figure 9).



Fig. 9: Emotive collage of the sensitive and effortless interaction qualities

Ideation

To explore the design space, the decision was made for a creative group session in the form of a brainstorm. The objective of this session is to get a broad range of ideas that would fall within the food care routine introduced earlier. The session would be carried out with four participants, all master students of Industrial Design Engineering.

The design questions that form the starting points of the brainstorm are based on the three interaction touchpoints of the food care routine.

1. How can you determine how much the resident wants to eat?
2. How can you present meals of varying sizes in an attractive manner?"
3. How can you give unfrontational closure to a potentially unfinished meal?

To guide the creative group session into a suitable direction, the desired interaction qualities: sensitive and effortless, are introduced and explained prior to the brainstorms. A time of 15 minutes would be reserved for the brainstorm for each design question (also see appendix C-1).

Clusters and Relations

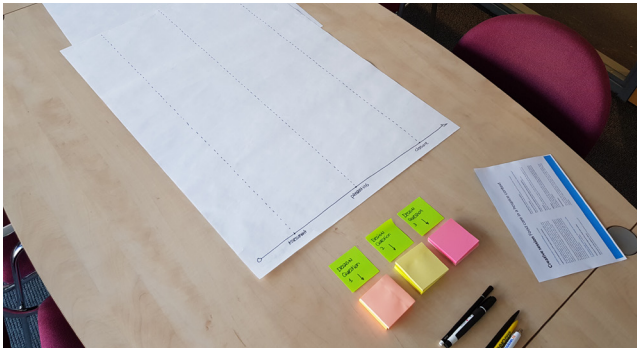
After brainstorming, two steps are used to find more defined directions within the broad collection of individual rough ideas.

- **Clusters**

Within each separate step of the food care routine, clusters of similar ideas were made. The goal of this step is to find overarching areas with larger potential, while simultaneously getting a grasp of all the individual ideas that resulted from the brainstorms.

- **Sequences**

A very important facet of a good food care routine, would be a harmonious sequence of steps. Therefore sequences of ideas with the potential to work in harmony are searched.



Conclusions

Within the results of the brainstorm, the participants recognized three overarching themes: ***changing methods***, ***changing materials*** and ***changing the setting***. The majority of the ideas positioned itself in the food routine's three touchpoints, however a few ideas would function outside of the routine, the main idea being a feedback assessment after the closure of the meal and using that feedback in the following food care routine.

The clusters provided a large variety of directions, some of which showed more potential than others. Some of the clusters even extending beyond just one touchpoint, in those cases the ideas could serve a purpose within both touchpoints. This formed the first idea of how sequential relations could be formed across touchpoints, which was further discussed in the next step of the session.

The sequential relations mostly limited itself to relations between methods and materials, that complimented each other. Those relations were limited to the first two touchpoints: assessment and presentation. An unsurprising finding as the meal that is presented is largely dependant on the expressed desires of the resident. The final touchpoint, closure, only had one major relation to the former two. This being that, if the assessment and presentation of the meal accurately encapsulates the resident's desires, the value of an unconfrontational closure would be of lower value than if they did not.

Design Directions

As a result of the ideation session and further analysis of the results of that session (see appendix C-2 & C-3), design concepts were formed. Those design concepts can be placed within two main categories, each involving the stakeholders in a different way. Those categories are:

- **Food serving routines**

These concepts combine food serving methods with fitting materials to support the methods. These concepts are actively present within the food care routine.

- **Food care documentation**

These concepts play into the communicative side of the food care routine. Combining assessments and feedback on the food care, and the documentation of those two, to improve the consistency of the food care and how well it adapts to the desires of residents.

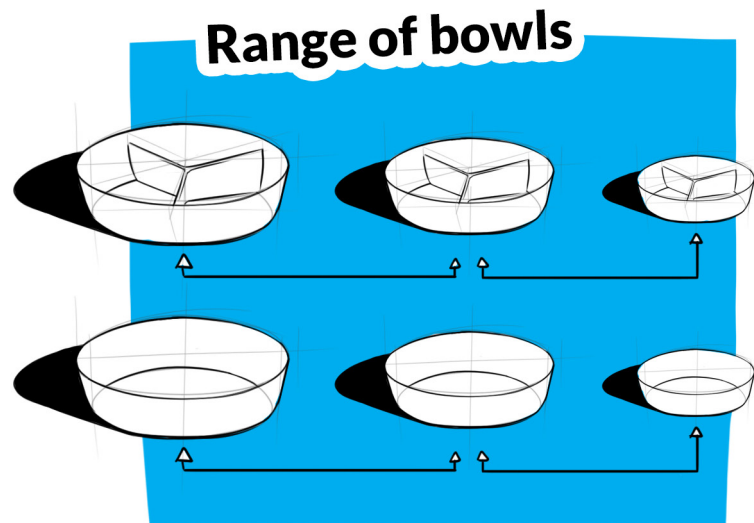
Food Serving Routines

Range of bowls

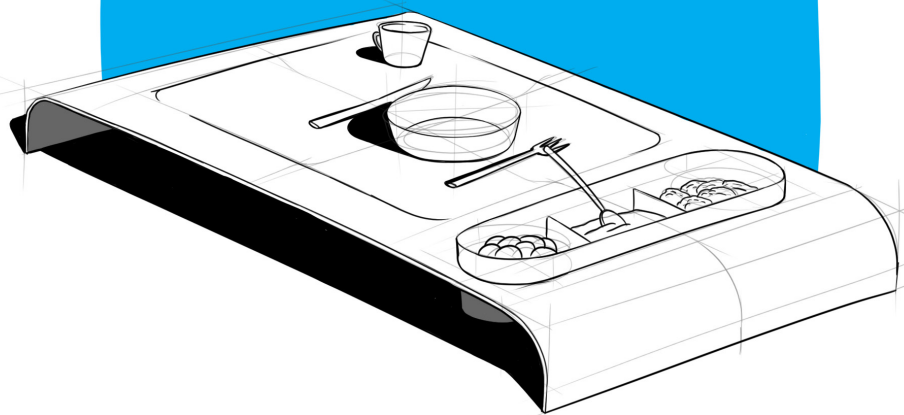
This concept plays directly into the changing appetite of residents as their illness progresses during their final months. This range of bowls in itself is simple but can be very effective in achieving multiple goals.

By providing a range of dishware, the awareness grows among care providers that the portion size is also of importance, it even sets fixed boundaries for the amount of food that can be served as you start downscaling the bowl sizes for the resident.

This concept also tackles the problems that occur with the presentation of smaller meals. Not only do bowls from itself make smaller portions look more substantial, by having a scale range the harmony between portion sizes and the dishware can be kept as the resident's appetite start to shrink. It makes serving an attractive meal easier for the food care provider.



Buffet in the room



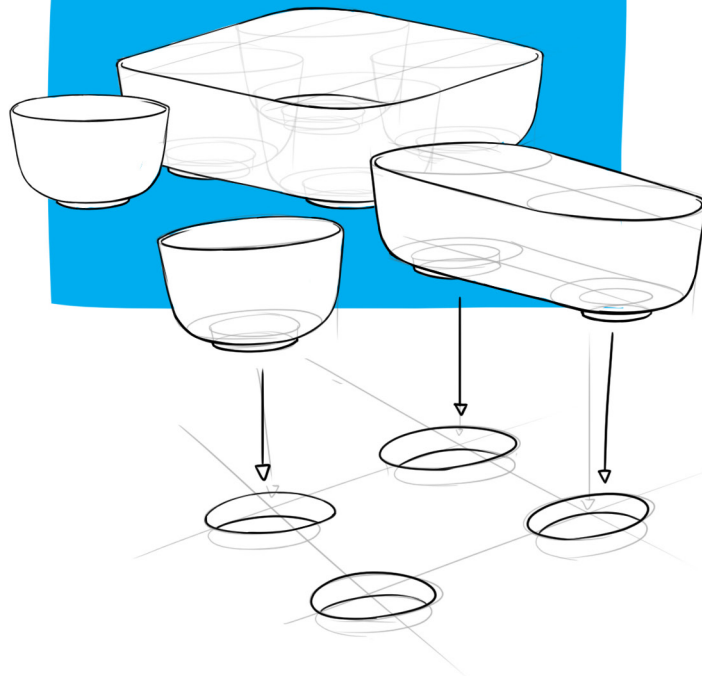
Food Serving Routines

Buffet in the room

This concept very strongly prioritizes the sense of autonomy for the resident, putting them in direct control of how much they eat and how they eat their meal.

After the preparation of the food, it is all served in a separate serving container from which the resident, with or without help, can intuitively serve up the meal they desire to have. It offers a very direct sense of control over the meal and the freedom for residents to eat their meals exactly how they like it.

Modular dishware



Food Serving Routines

Modular dishware

This concept takes a different approach at providing size varieties in the dishware. It adds additional emphasis on the presentation of the meal, offering a lot of freedom for the food care provider to play around with various ways of serving up a meal.

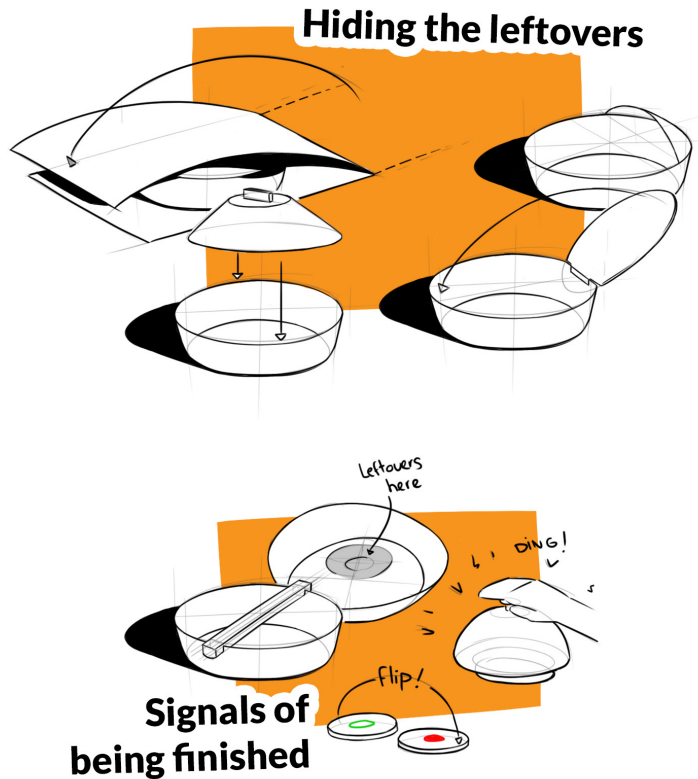
Not only does it create awareness among the food care provider about the importance of food portioning, but also about the presentation of the meal. Assessments can be made about how much residents want to eat and how they prefer to have it presented to them.

By providing scale variety within the modular system, not only can harmony be maintained between the portion sizes and the shrinking appetite of residents. The variety of options and combinations with the dishware can make the portion downscaling into a more interesting process for all involved.

Unconfrontational Closure

As an addition to the food serving routine concepts, ideas for an unconfrontational closure were drawn out. The goal of these designs is to reduce the undesirable social confrontations that may occur when a resident does not manage to finish a meal (guilt when returning a plate with leftovers or relatives urging the resident to eat more). Within the ideas for a less confrontational closure, two categories come forward.

- **Tangible signals for being finished**
Often residents find it difficult to speak out against the actions of relatives, to express that they truly do not want any more food. These ideas attempt to replace this way of communicating with a more simple interaction with a tangible object, that sends off a signal to the food care provider that the resident has simply had enough food.
- **Hiding the leftovers**
Many times the undesirable social confrontations occur due to the sight of an unfinished plate of food. It is openly visible when the plate is sent back, and relatives may urge a resident to eat more when they see a lot of leftover food. By allowing residents to hide the leftovers, the sight of an unfinished plate is gone. Additionally, covering up the dishware can work as a signal of being finished.



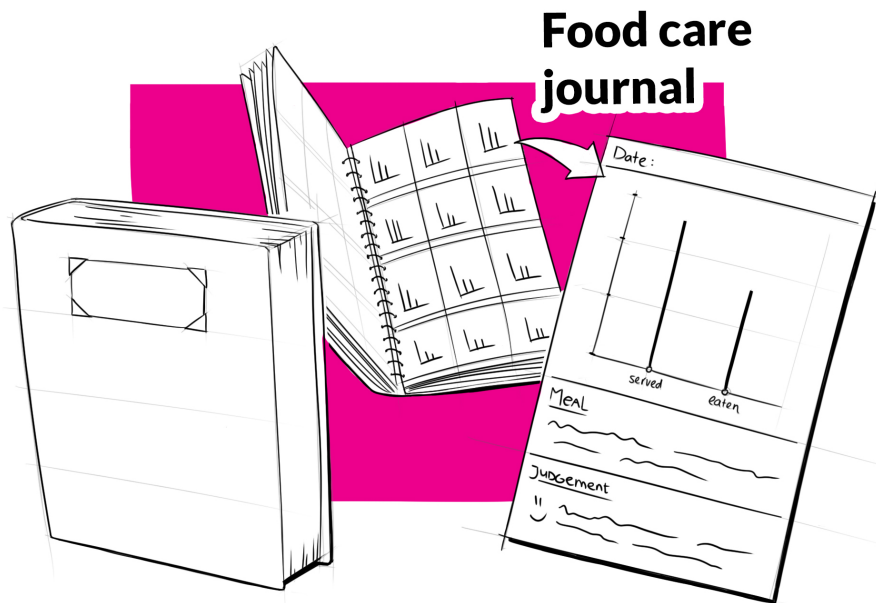
Food Care Documentation

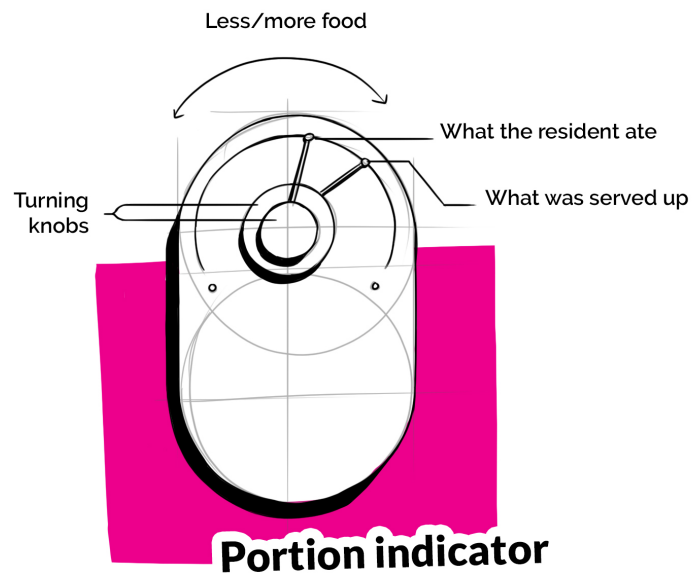
Food care journal

This concept aims to provide consistent food care that is well adapted to the needs of residents. Doing so through the documentation of the provided food care in an objective and concentrated manner. A chronological framework that the care provider fills in will show the needs of residents in terms of food care, and its development over time.

By including the portion sizing into this framework, care providers become aware of the necessity to assess for the amount of food. And by drawing comparisons to the previously offered portions, care providers can become more consistent in their food serving behaviour.

Registering additional information, such as feedback from residents on the meal, can help care providers to form an identity of the preferred food of residents. This will allow them to better adapt their food care routine towards the desires of residents.





Food Care Documentation

Portion indicator

This concept aims to simplify the registration of food portioning for care providers. It puts more emphasis on making care providers aware of the importance of assessing for the amount of food, and less on the detailed, objective registration of food care over time.

Through this more minimalistic form of documentation, the care provider will be more free in making an assessment in their own way. The indicator's role in the assessment is only to make care providers have a point of reference to base the preparation of their meal on. This will allow the food care to become more consistent between different care providers.

Food Care Documentation

Food care diary

This concept takes a more compassionate and sensitive approach at documenting the resident's impressions of the food care they receive. It makes the documentation less of a mandatory complicated task, and rather an additional valuable moment within the food care routine. This makes it not only more accessible for relatives as a food care provider, but it can actually add value to the meaning of food for both relatives and residents during their time at the hospice.

The diary takes a positive tone, asking about what the resident enjoyed and looks forward to, as an addition to more regular notes such as the descriptions of the meals a resident had during a day. It creates an incentive to share thoughts and talk about people's experiences with food, both from the past and in the current circumstances.

All the stakeholders have access to the diary, to write, draw and add other material into it. This provides a rich source of information, creating a clear image of the resident's "food identity" and how their attitude towards food changes overtime. That information can then be used to provide a consistently well-adapted food care routine for the resident.



Decision of Design Direction

Concept Criteria

To measure the potential of each concept, a list of criteria was decided upon. The criteria was based on the problem and context analysis, combined with the needs of the three stakeholder groups: hospice residents, relatives and care givers. The order of criteria is based on the level of relevance they have for a suitable concept.

1. Awareness about the sizes of meals

The concept makes care providers more aware of the importance to adjust the sizes of meals to what the resident desires to have.

2. Peace of mind resident

The concept provides peace of mind for the resident during the food care routine.

3. Let go naturally

The concept promotes letting go of food in a way that feels natural.

4. Sensitive approach

The concept invokes sensitive interactions between the stakeholders.

5. Adapt to changing diet

The concept allows the food care to adapt to the changing diet of residents.

6. Accessibility relatives

The concept is well accessible for relatives to get engaged with.

7. Resident autonomy

The concept gives residents a heightened sense of autonomy over the food care they receive.

8. Consistency

The concept makes the food care between relatives and care givers consistent.

9. Variety serving forms

The concept makes various serving forms possible, well adapted to a resident's desire.

10. Attractive presentation

The concept helps enhancing the attractiveness of the presented meal.

11. Food identity

The concept triggers the exploration and utilization of the "food identity" of residents in the food care.

12. Simplicity

The concept is straightforward and easy to employ.

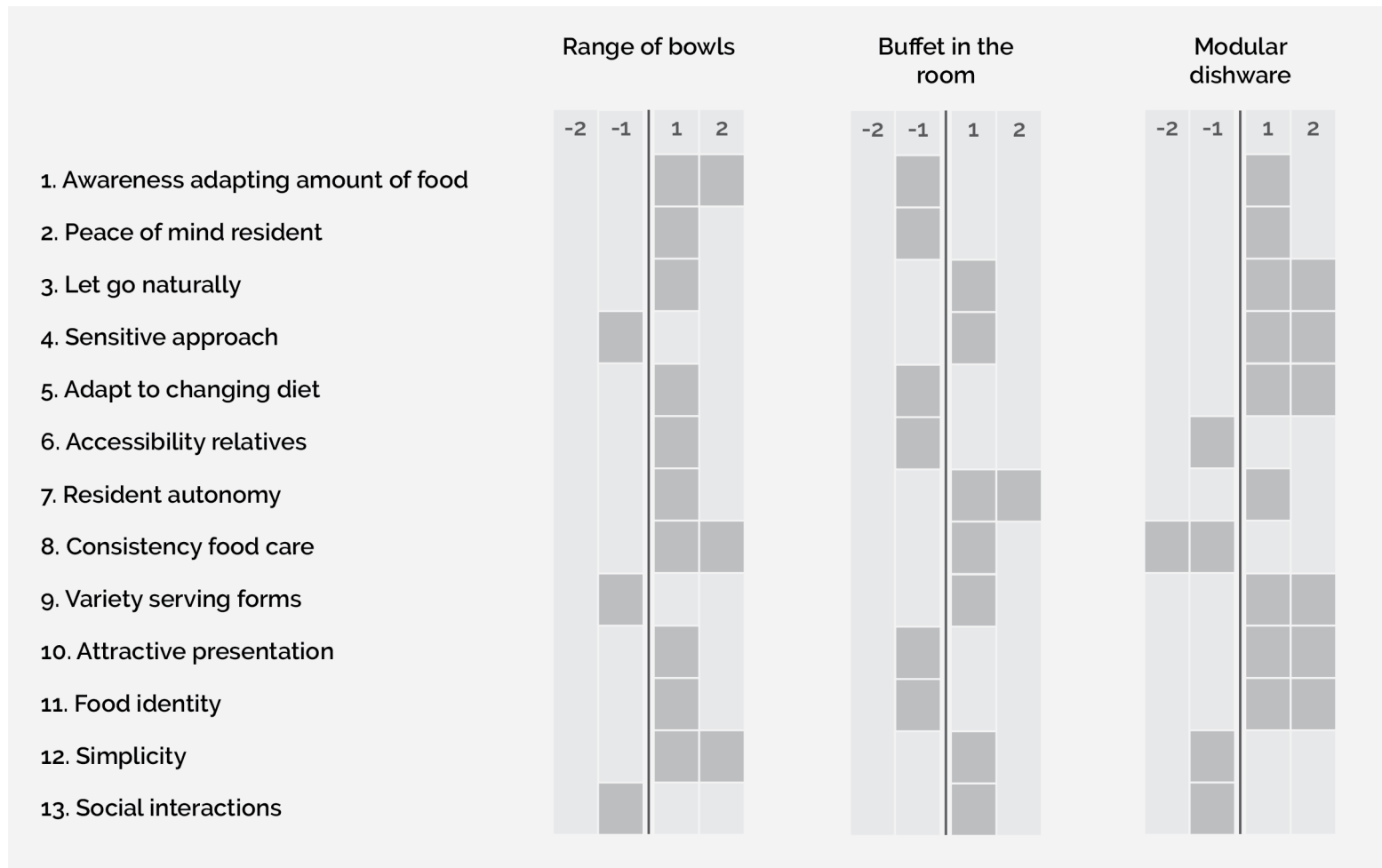
13. Social interactions

The concept mediates social interaction between residents and relatives during food care.

Decision Based on Criteria

Based on these points of criteria, the design directions are judged (ratings of -2, -1, 1, and 2). Both the *food care routines* and *food care documentation* design directions are judged separately, but with the same design criteria. Within each category a design direction is chosen for having the best potential. After that a consideration should be made whether a single direction will be pursued, or if they could function as an extension of each other to fulfill a larger potential.

Criteria Judgement Food Serving Routines



Modular Dishware

Based on the concept criteria, the *modular dishware* concept shows the most potential. While the intention behind the various sizes may not instantly be clearly correlated to the diminishing appetite of residents, it is this subtlety that makes the concept stronger. The concept still clearly gives the opportunity to adjust the dishware, and thus the served meal, to the resident's needs. However, how this is carried out feels a lot less artificial than it would with the *range of bowls*. The downsizing process is more nuanced, making letting go of food feel more natural.

Furthermore, the modular dishware offers a lot of freedom and variety when it comes to serving up a meal. This invites care providers to explore different ways of presenting a meal, to figure out the desired serving forms of different resident, knowing that they have the ability to fluidly adjust the meal properly to those desires. The served meals become more attractive, more interesting, and well adapted to the resident's 'food identity'.

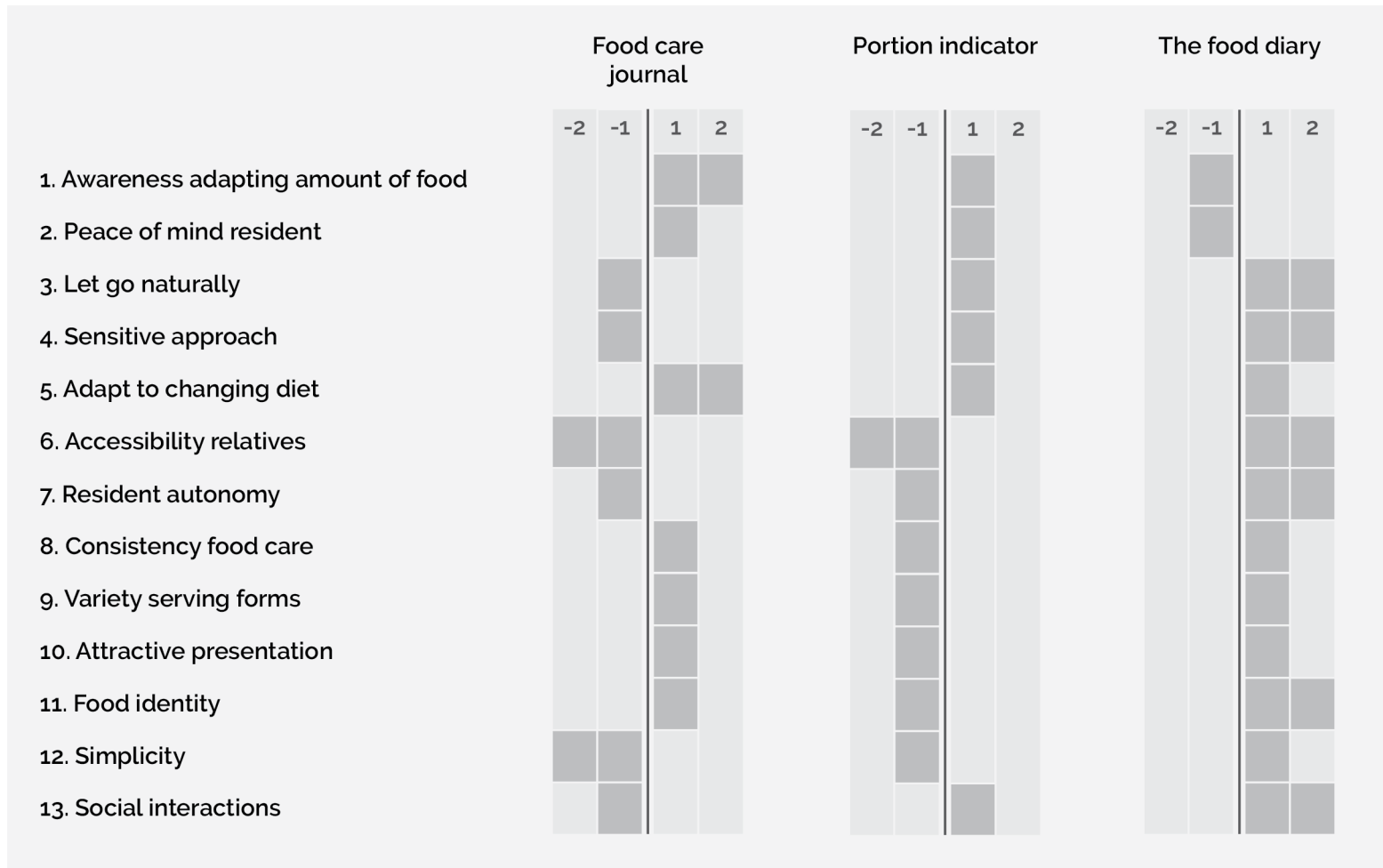
There are two weaker points to this concept. The concept is less straightforward which may make it harder to get used to, and more difficult to provide consistent food care. On top of that, it may make it less accessible for relatives to engage with the concept. The issue of consistency can be tackled with *food care documentation* but making sure the relatives get engaged may require another addition to the concept.

Hiding the Leftovers

In addition to the modular dishware, the unfrontational closure of meals will be supported by a design that allows residents to hide the leftovers they have. Between this direction and that of a *signal of being finished*, this direction showed the best potential.

Hiding the leftovers is a much more simple and straightforward interaction that leaves little to the interpretation of those involved. It is a very obvious action that, in fact, can also work as a signal of being finished. Furthermore, the threshold is much higher for relatives to overrule the resident's decision to close off access the dishware, than it would be if they only signify that they are finished. This gives relatives less opportunity to urge a resident to continue eating, if they are even able to see if there are any leftovers left in the first place.

Criteria Judgement Food Care Documentation



The Food Diary

Of all the *food care documentation* concepts, this concept showed the best potential to succeed within the hospice context. It is by far the most sensitive approach at creating an image of a resident's desires and needs for the provided food care. Keeping a positive tone on top of that will make it much more inviting to get involved with for both residents and relatives. Residents can speak their mind and express how they feel about food during their final months. Both relatives and hospice care givers can use those thoughts and adapt their food care to what the resident truly enjoys and desires, or does not desire.

The form of documenting is also much more lenient. The process does not feel restrained to rules and boundaries which makes it less intimidating to engage with. This makes it much more easily accessible for relatives.

The diary does not just help the food care providers to adapt the food care to the desires and needs of the resident, and maintain a sense of consistency in the food care. By being sensitive, and allowing residents to express their feelings, it can become a very rich and valuable source for both relatives and care givers to form an understanding of what food means during these final months. It may help everyone in letting go of food through mutual understanding and provoking those involved to talk about the topic of food.

Concept Decision

Initial "ideal" design choice

Initially upon judging the potential of the design directions, a combination of the modular dishware design and a food diary design appeared to offer the best potential for a final design concept.

The modular dishware could facilitate enhanced presentations of the meals that are served, and offer guidance through the form factor of the dishware. As an addition, the food diary can stimulate care providers, or those near and dear to make assessments of all of the desires and needs of the residents. By documenting them on a daily basis they remain aware of the need to make those assessments, and to take into account previous days as well as a point of reference. This will facilitate consistently well-adapted care from day to day.

Realistic reconsideration

However, after further discussion of the design directions an important consideration was made. The expected expenses involved with either design direction should not be left unmentioned. Hospice institutions largely depend on donations. Besides those incomes their monetary capabilities are limited, and therefore it is important to remain realistic with what is achievable in that domain. Furthermore, hospices are of a small size and the amount of institutions is limited. One might say, you could expand the idea into different palliative care institutions. However, the hospice care is unique in that it offers a highly adaptive care methodology compared to other palliative care options. Especially when it comes to food care.

With this consideration in mind, and a re-evaluation of the design directions, the final concept choice fell on the food diary. While the modular dishware does provide an interesting addition to improve the presentation of served meal, and a level of guidance in the serving process. This does not add enough value to justify the costs of such a design, as such custom-made, newly produced dishware is an expensive investment. Implementing the usual, existing dishware of a hospice institution in the food diary in a tactical way may also achieve a similar goal to a large extent in a much more cost-efficient way.



Concept



The Diary for Eating and Drinking

The diary for eating and drinking is a medium that positively enhances the experiences during a food care routine in the hospice. It is designed to increase the sensitivity towards the hospice residents, regarding eating and drinking. To achieve this goal, the diary introduces three elements, that become part of the food care routine in the hospice context.

- **Documentation of the preferences of hospice residents** that leads to a collection of the desired and undesired foods and drinks of a hospice resident.
- **Daily questions about eating and drinking for residents** that stimulate thinking and talking about the (potentially forgotten) emotional and social values of food.
- **Daily assessments of the desired meals** that raise the awareness in food care providers to properly take into consideration the desires of the resident.

To present the concept in an accurate way, a prototype of the design was made. The prototype is seen in the images presented throughout the concept section. Later in the evaluation of the concept, the same prototype was used as an example for the participants in the evaluation.

This chapter will go deeper into each separate part of the diary; presenting photos of the diary prototype, elaborate explanations of the parts and the intention behind them, visuals of the content of each part, and finally, visual use scenarios that explain how the stakeholders interact with the diary.



Documenting the Preferences of Hospice Residents

Upon the hospice take-in, the diary is introduced to the resident and those near and dear that join the take-in. As a part of the take-in, the preferences of the resident, regarding food and drinks, are documented. This can be a joint endeavour between the resident, those near and dear, and the hospice care givers.

Due to this documentation hospice care givers are aware of the resident's identity when it comes to food. They can organize the food care around the preferences and effortlessly suggest and provide meals that are to the resident's liking. In a consistent manner the care givers can provide well-adapted meals to the residents.

As a resident's illness develops, the eating behaviour may change. Due to changes in taste, or problems with food ingestion, residents may no longer enjoy the food that they used to love before. The collection of preferences can be changed accordingly, moving previously desired meals towards the undesired collection. Furthermore, hospice care givers may use their knowledge to search for new food that the resident may be able to enjoy despite their eating

difficulties. If the hospice care givers are successful at finding such a meal, they can add it to the collection of desired meals.

The dynamic collection of preferences can be valuable for those near and dear, to use as an educational source of information. Once the familiar meals are no longer enjoyed by the resident, those near and dear may be lost and uncertain of what else to prepare for a loved one. By consulting the collection they can find newly suggested meals from the hospice care givers, that they know their loved one enjoyed previously, and is therefore a suitable option to prepare.

Voorkeuren

- Ontbijt
- Lunch
- Afvandeten
- Overig

Ontbijt
Hoe laat wil je ontbijten?



Wat ik graag zou willen
Drinken

Wat mijn ontbijt drink ik graag een:

- | | |
|-----------------------------------|----------------------------------|
| <input type="radio"/> Beker | <input type="radio"/> Kopje |
| <input type="radio"/> Mok | <input type="radio"/> Glas |
| <input type="radio"/> Tuilbeker | <input type="radio"/> Met rietje |
| <input type="radio"/> Water | <input type="radio"/> Melk |
| <input type="radio"/> Koffie | <input type="radio"/> Thee |
| <input type="radio"/> iets anders | |

Met iets erin?



melk? suiker? zoetjes?

Verdere opmerkingen



Wat ik graag zou willen
Eten



Vermijden

Absoluut Niet
Allergisch of verboden

- Absoluut Niet
- Niet Lekker



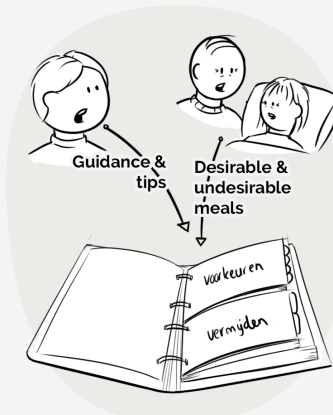
Overview of Diary Pages: Documenting Preferences

Documenting the preferences of hospice residents



1

At the hospice take-in, the diary is introduced to the resident and those near and dear. This is done for the residents for whom food is expected to be relevant still.



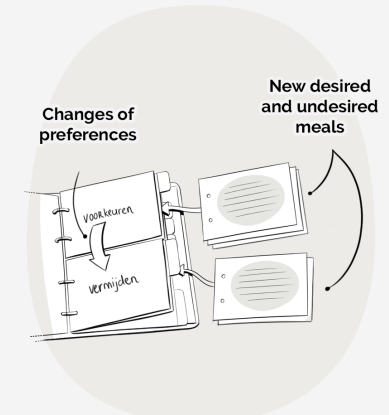
2

As part of the take-in for the hospice, the preferences for food and drinks of the resident are documented. This is done as a joint endeavour between the resident, those near and dear, and the hospice care givers.



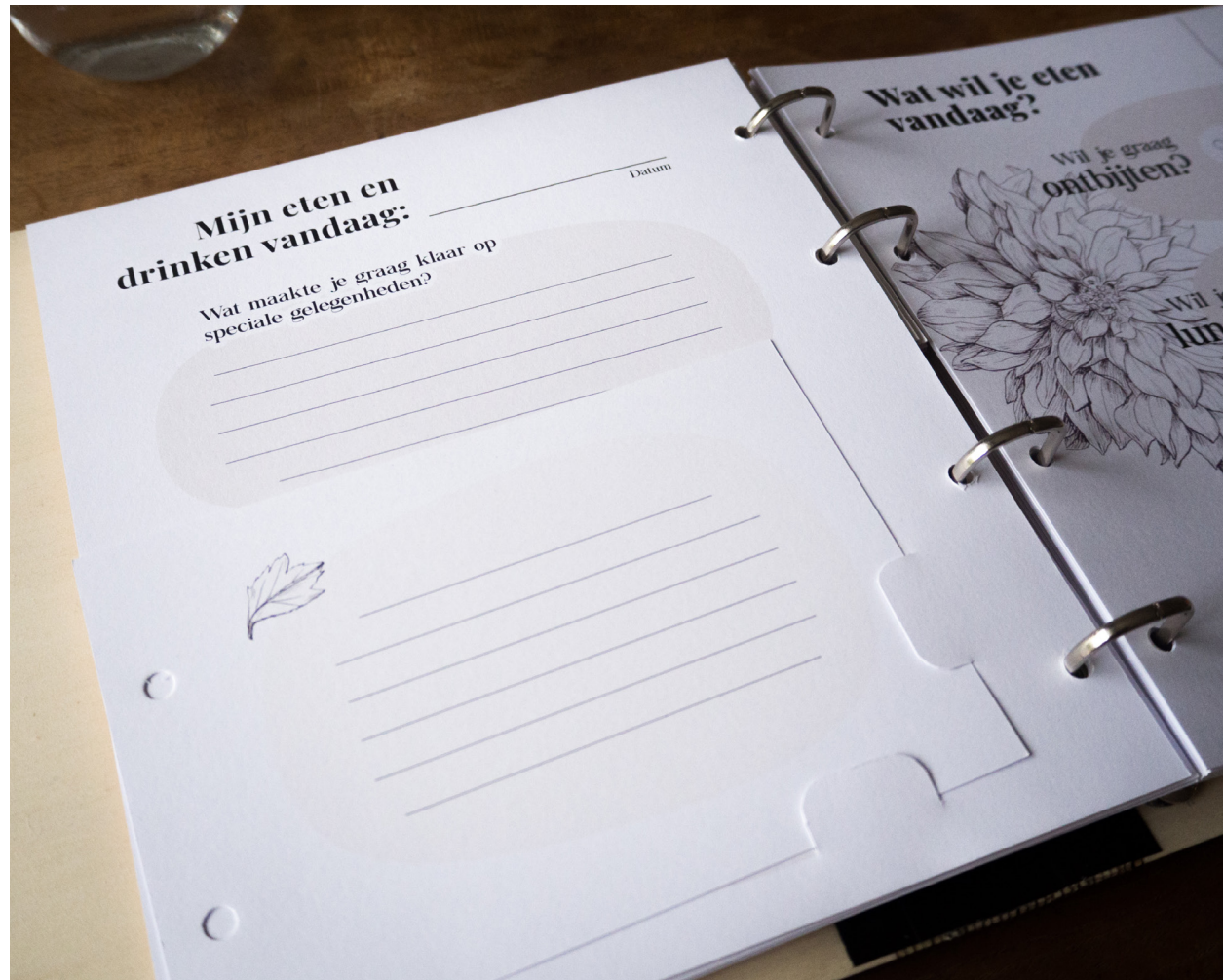
3

With the food care the hospice care givers and those near and dear can use this collection of preferences as an example for the meals they intend to prepare for the resident.



4

During the time at the hospice the collection of preferences can be changed and expanded. All of those involved can play a role in this. Care givers can suggest new meals that the resident enjoyed, despite the difficulties the resident has with "normal food".



Daily Questions About Eating and Drinking

Every day a new question is presented in the diary, for the resident to read, think through, and answer. The questions relate to eating and drinking, but they highlight the emotional and social values of eating and drinking, rather than the nutritional values (eat to stay alive) that are so often prioritized in the hospice context. They are questions that refer to memories from the past, or to things that can be looked forward to. Examples of such questions can be: *What did you love to eat when you were a child?*, and *with whom would you like to share a meal?* They are simple questions that can stimulate conversations. Conversations that can be very surface level if preferred, but that can also spark more meaningful exchanges of thoughts, if the desire is there to have such a conversation.

The questions allow hospice care givers to get to know the resident better, on a deeper level. For those near and dear, the questions can reintroduce the social and emotional values behind eating and drinking. The values that may have been forgotten as the priority shifted entirely towards the nutritional value that food offers, as a means to extend the life of their ill loved one. The questions can provoke the resident and those near and dear to reflect on eating and drinking, and what it meant in their life, which may help with the process of letting go of eating and drinking. But it may also just be a pleasant distraction from the burdensome feelings that food and drinks can carry during the final phase of life, often caused by them putting too much priority on the nutritional values of food.

Examples of Diary Pages: Daily Questions and Writing Space

**Mijn eten en
drinken vandaag:** _____ Datum

Wat maakte je graag klaar op
speciale gelegenheden?

Berichtjes, notities,
foto's, kaartjes, en
meer

**Mijn eten en
drinken vandaag:** _____ Datum

Met wie wil je graag eens
samen eten?

Berichtjes, notities,
foto's, kaartjes, en
meer

Daily writing about eating and drinking



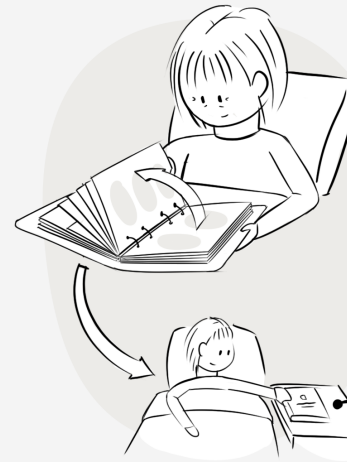
1

The resident opens the diary and flips to a new day. Here a new question, related to eating and drinking, is presented. Such a question asks about the past; a nice memory related to food, or to the future; what may a resident look forward to?



2

By thinking about those questions, a positive aspect of food and drinks is re-introduced to the hospice context. Writing about it also allows others to get involved with the topics that the residents write as answers.

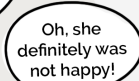


3

After writing the answer, the resident can look back at previous days. Maybe there are pleasant messages or pictures left previously that the resident wants to look at again. After that the diary is closed and put away next to the bed.

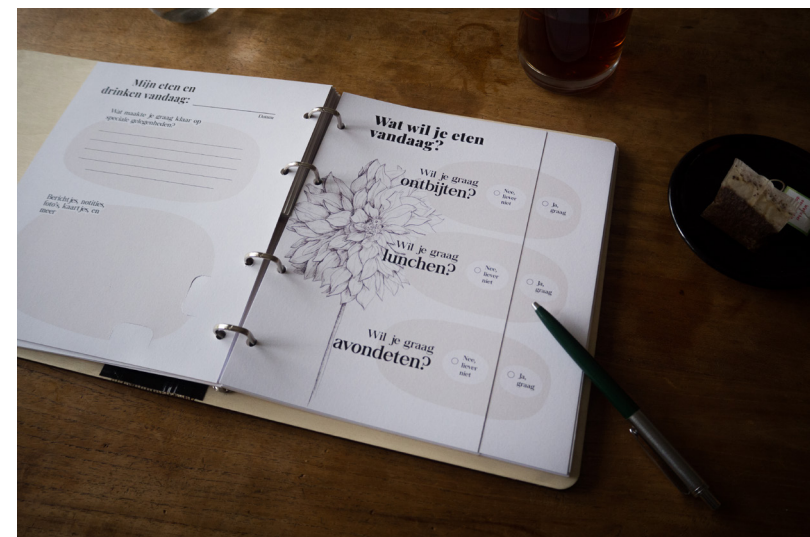
When someone near and dear comes to visit

When a care giver is in the resident's room



4

Later those questions can lead to conversations about eating and drinking, and the more cheerful side to those topics. Especially for those near and dear it can reintroduce the social and emotional values of food and drinks.



Daily Assessments of the Resident's Desired Meals

Every day the diary presents the resident a overlay page with the question: *would you like to eat?*, which the resident can mark with yes, or no. If the answer is no, the meal can be disregarded and unnecessary assessments about a meal can be avoided, the resident can be left to rest. However, if the answer is yes, flipping the overlay pages present a fill-in page that is intended for noting down the meals (breakfast, lunch and dinner) that are provided to the resident. Additionally, an "instruction" is provided that displays the factors of a meal that should be taken into consideration when making an assessment for a desired meal. Those instructions are especially intended for the hospice care giver, or those near and dear, that will be preparing the desired meal for the resident.

Additionally, by noting down the meals each day, the person providing the food care can consult previous days to get a grasp of the eating behaviour of the resident. It can make that person more aware of what the resident may or may not desire for their meal.

The design intends to form awareness among the food care providers to remain sensitive towards the desires of the resident among all the aspects of the meal. And by providing a fill-in page accompanied with the instructions, in the diary that is owned by the resident, the incentive is formed for both hospice care givers, and those near and dear, to actually make the assessment into a joint "ritual" between the care provider and the resident. Because you keep track, and because it is open for everyone, you want to continue to stay on track and not neglect the documentation of the (desired) meals.

The ability to consult the meals of previous days, gives the care provider a point of reference which they can base their meal on. Especially for those near and dear, the awareness can be raised that, really, their loved one can not finish a full plate of food anymore, the portions need to be smaller, and the food has to be cut smaller. Additionally, becoming aware of the eating behaviour allows those involved in the food care to discuss it and educate each other on it. Particularly between care givers and those near and dear to the resident this can be a large benefit.

Overview of Diary Pages: Daily Assessments of Desired Meals

Wat wil je eten vandaag?



Wil je graag ontbijten?

Nee, liever niet Ja, graag

Wil je graag lunchen?

Nee, liever niet Ja, graag

Wil je graag avondeten?

Nee, liever niet Ja, graag

Hoe wil je de maaltijd?

Wat zou je graag willen eten?

Voorkeur?

Hoeveel zou je willen eten?

Klein beetje Veel eten

Hoe wil je het eten bereid hebben?

Gewone bereiding Klein gesneden

Hoe heb je het graag opgediend?

Gescheiden Gemengd

Welk serviesgoed heeft jouw voorkeur?

Groot bord, kleine bordjes, schaaltes?

Mijn maaltijd wensen

Ontbijt

Eten _____ Ja, graag

Drinken _____

Lunch

Eten _____ Ja, graag

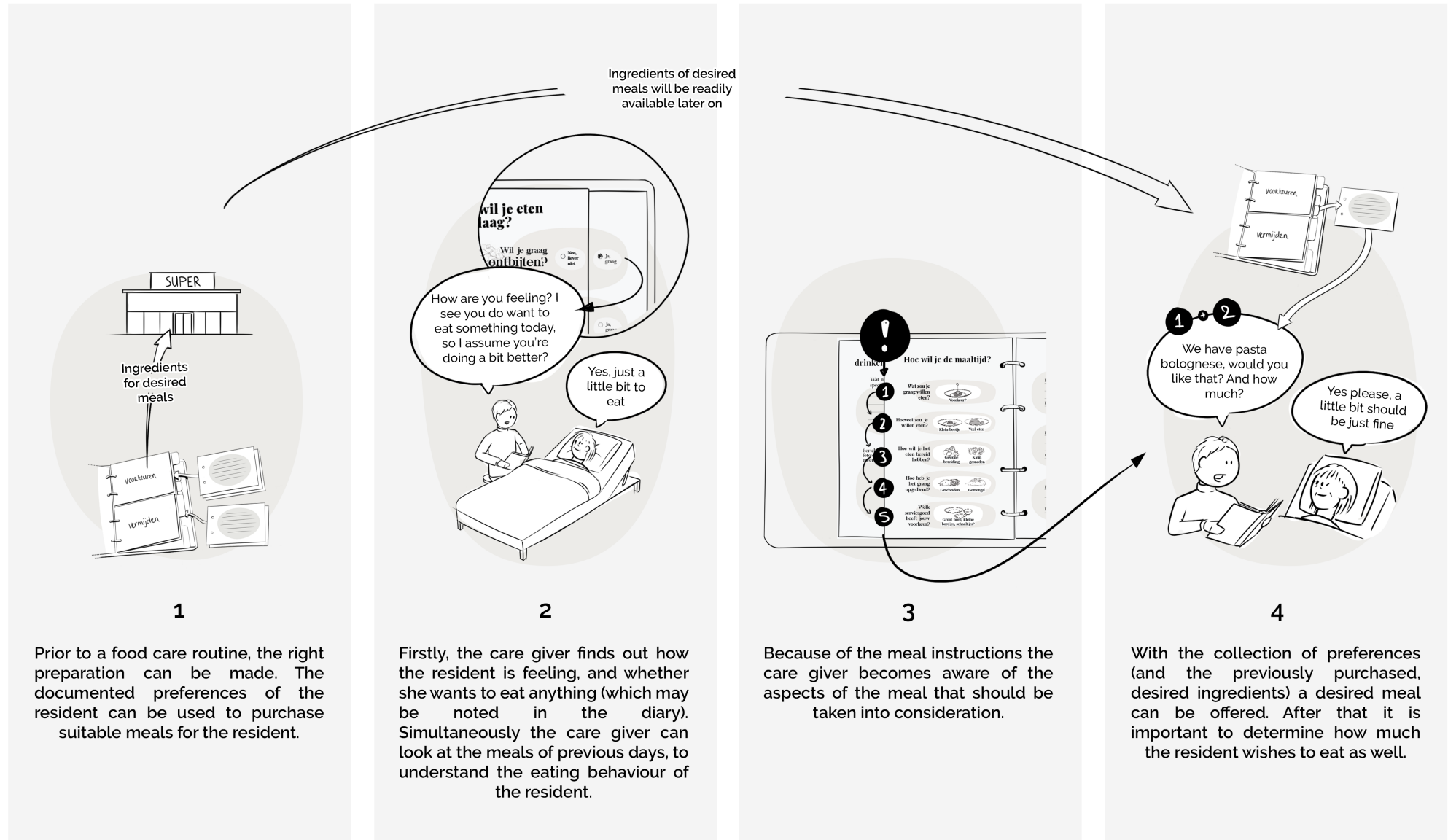
Drinken _____

Avondeten

Eten _____ Ja, graag

Drinken _____

Daily Assessments of the Desired Meals



Ingredients of desired meals will be readily available later on

1

Prior to a food care routine, the right preparation can be made. The documented preferences of the resident can be used to purchase suitable meals for the resident.

2

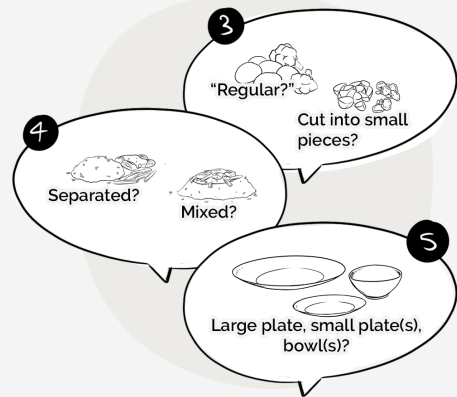
Firstly, the care giver finds out how the resident is feeling, and whether she wants to eat anything (which may be noted in the diary). Simultaneously the care giver can look at the meals of previous days, to understand the eating behaviour of the resident.

3

Because of the meal instructions the care giver becomes aware of the aspects of the meal that should be taken into consideration.

4

With the collection of preferences (and the previously purchased, desired ingredients) a desired meal can be offered. After that it is important to determine how much the resident wishes to eat as well.



5

After that, the other factors of the meal are determined, necessary to offer the resident a meal that fits her desires.



6

While determining the meal of choice, the care giver can go into what was written before in the diary. For example what the resident answered for the daily question. After a conversation, the care giver can go to prepare the food.



7

The meal is prepared according with the desires of the resident. After that, the meal is served up in a fitting way.



8

The resident receives the meal from the care giver, after which the resident can peacefully eat the meal.



9

After the meal is finished, the resident can discuss the course of the meal with the care giver, and if necessary notes can be made about it in the diary, as reference for the next day.



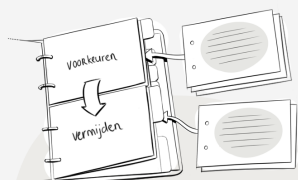
10

Afterwards the serving plate can be taken away. Because the meal suits the desires of the resident, the chance will be larger that the resident was able to finish the meal. The "denial" of leftover food is no longer relevant, and therefore the resulting feelings of guilt aren't either.

The Main Benefits for Those Near and Dear

While already briefly mentioned in the previous parts that described the concept, this will recap the main benefits that the concept provides within the food care by those near and dear to a resident. What the diary aims to do is to inform those near and dear and steer them into the direction of food care that is in harmony with the approach that the care givers in the hospice apply. Furthermore, it attempts to provoke residents and those near and dear to become more socially sensitive and expressive towards each other when it comes to eating and drinking. The communication should help to have them achieve a similar attitude towards eating and drinking.

Benefits of the Diary for Those Near and Dear



She doesn't like some of her favourite dishes anymore, what can I prepare now..



The care givers gave her pumpkin soup which she enjoyed. I'll try to prepare that then

Changing Preferences

Those near and dear may be lost when their loved one's food preferences start to change, and they lose the appetite for some of their favourite dishes. They can receive new suggestions from care givers, when they add new meals that the resident enjoyed to the collection of preferences.



I see you wrote about cooking for christmas, you really loved doing that, didn't you.

I'll leave a nice message for her to read later today.



Social Incentives

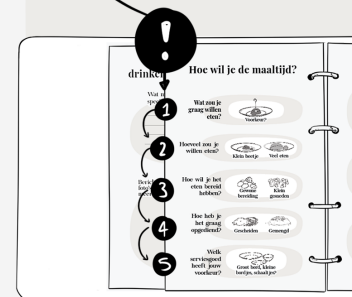
The daily questions in the diary may spark conversations between the resident and those near and dear about topics with a more social incentive, related to food. The diary may also stimulate those near and dear to leave messages or pictures in the book, for the resident to later see and enjoy.



I noticed you eat mostly soft food, how about I prepare you some rice with a soft sauce?

And how should I prepare it for you?

Yes, that sounds nice



Meal Awareness

The meal "instructions" will create awareness for those near and dear about the important aspects of a meal that should be taken into consideration. Reading about meals their loved one previously received from the hospice may add to that awareness as well.

Hmm, I see she has mostly eaten soft meals recently



I see that Linda brought cake yesterday. That's so nice of her!



Food Care Information

The diary contains a lot of information related to the food care. Those near and dear become aware of the eating behaviour of their loved one, and they can also see if anything special happened on previous days. For example, a visitor brought food or the hospice treated the resident with a special meal.

Aesthetic and Form

An important part of the design of the concept, that will help to make it fit within the hospice context, is the design form. The aesthetic of the design was based on four descriptive labels, that were seen as harmonious with the mentality of the care with the hospice institution. The aesthetic should be **sincere**, **gentle**, **friendly**, and **serene**, for it to fit within the context.

With those terms in mind, a collage was made that would help as a source of inspiration for designing the form language of the diary (see figure 10). It combines soft, warm colours with more subdued, neutral tones, for a gentle and friendly quality. The materials and textures are sincere, with their original characteristics left mostly unaltered. Symbols or text are simple and to the point, to give off a calm and serene feel. This serenity extends itself in the colour combinations, that fall within a limited spectrum to form a harmonious imagery. Finally, a single splash of yellow was added to give a cheerful and friendly character to the simplistic body of elements.

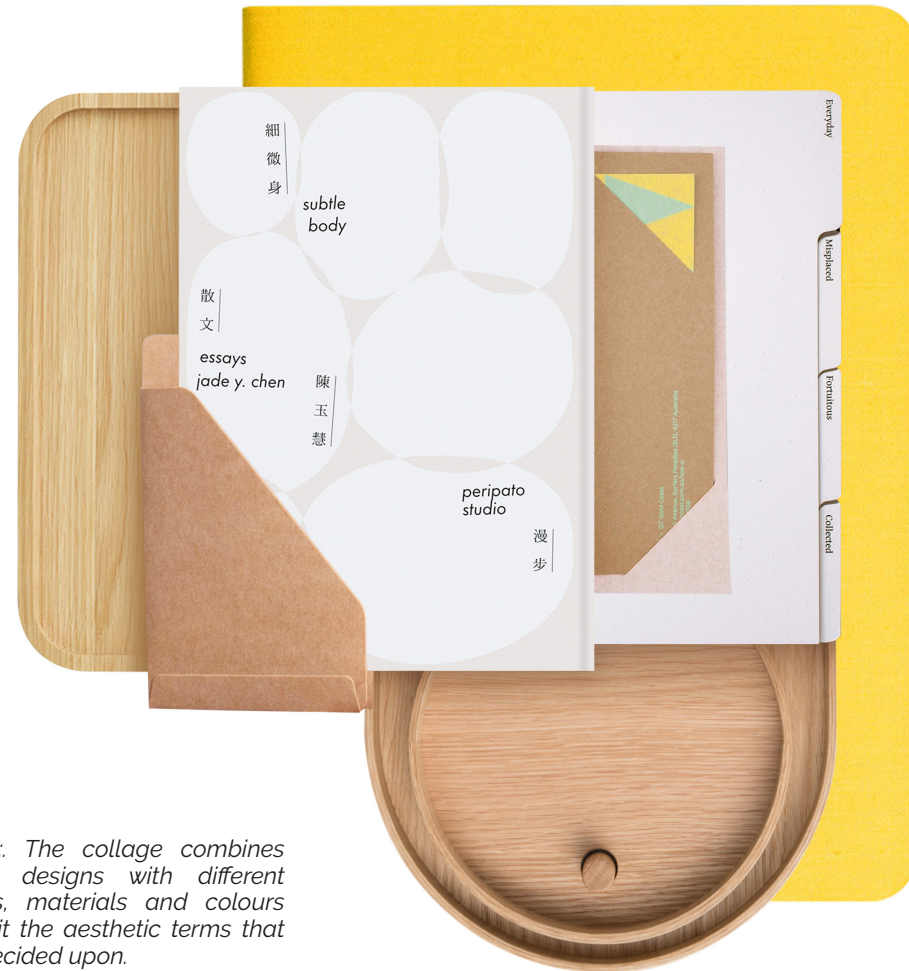


Fig. 10.: The collage combines various designs with different textures, materials and colours that suit the aesthetic terms that were decided upon.

The aesthetic of the diary shows the clear inspiration from the collage. The body of the inside uses muted colour combinations with only slight tonal variations. The substance is displayed as it is, without forcing a specific mood onto the user through the visual style. It does contain imagery of nature, especially flowers, in the form of sketch-like art. This was inspired by the hospice care givers who, during the interviews, often mentioned the use of flowers as a decorative element for the presentation of a meal.

The sections of the diary are divided with yellow covers, with floral imagery as a decorative element (see pages 96 and 104). It gives the diary its friendly character.

Finally, the diary is held within a wooden binder. It gives the outside of the diary a gentle, friendly and inviting appearance. Also, it makes the diary into an item that stands out as it is placed in a resident's room. It sparks interest and invites peoples to look into it. Additionally, it makes the diary into something that holds value, and is therefore worthy of paying attention to and getting engaged with.





Evaluation of Concept

Goal of the Evaluation

For the evaluation of the concept there are two main purposes.

- **To understand how the use of the concept would be experienced by those involved in the food care in the hospice environment.**
- **Find out whether the intentions behind the concept, in its current form, is seen as beneficial to the food care in the hospice environment.**

The thought behind these two goals is that, obviously, the use of the concept should offer a pleasant experience that the stakeholders consider suitable for the context. Furthermore, it is important that the "problems" that the concept attempts to resolve are recognized as something that needs to be tackled, and that the concept is seen as a valuable design solution to do exactly that. The goals can be used to judge the potential of the concept within the hospice context. That way, the evaluation should clarify which aspects of the concept hold substance, and where there is room for improvement.

Research questions

Based on those evaluation goals, the following research questions were formulated. They take into consideration the experience with the concept, and the intentions behind the different parts of the concept, which are largely based on the set design goals.

1. What kind of experience do the participants feel that the concept brings about?
2. Does the concept enhance the sense of autonomy for residents over their eating and drinking behaviour?
3. Does the concept offer food care providers a medium to provide residents with food care well-adapted to the desires of residents?
4. Does the concept improve the consistency of food care among the care providing stakeholders?
5. Does the concept successfully (re)introduce social and emotional values related to eating and drinking?
6. Is the concept well-accessible for all of the stakeholders involved in the food care in the hospice context?

Evaluation

Approach

To evaluate the concept it was important to consider what was possible within the context. The unfortunate reality is that the stakeholder groups of hospice residents and those near and dear were not a realistic possibility to have as participants in the evaluation, Therefore the decision was made to rely on the expertise of hospice care givers as participants in the evaluation, similar to earlier interviews in the context analysis.

The evaluation consisted of a qualitative evaluative interview that went through the following steps (also see appendix E):

1. A brief explanation of the project is given to the participant.
2. By showing visualized scenarios, and presenting an accurate prototype of the design (as seen in the 'concept' section), the use of the various parts of the concept are explained to the participants.
3. After explaining the use, the intentions behind the parts of the concept are clarified.
4. This is followed by an interview part that discusses the parts of the concept separately. The interview had a semi-open nature, to ensure answers to a specific set of questions but also allowing it to flow deeper into specific topics if the conversation asks for it. The specific questions would first discuss what the participants felt about the intention behind each part of the concept, and then how they judge the experience of the concept within the hospice context.

This approach gives the participants an idea of the use of the concept and allows them to judge whether they think the intention behind it would be valuable or beneficial to the food care in the hospice context covering both of the evaluation goals.

Participants

The participants in this case were two trained care givers at hospice institution *De Vier Vogels*, where the context analysis interviews also took place. One of the participants has been a volunteer for a year and a half at the hospice. The other participant has been a volunteer for a longer time, and is currently also following a study in the field towards becoming a medical nurse.

Findings of the Evaluation

The participants of the evaluation definitely recognized how the intention behind the concept held substance and was considered as beneficial to the food care in their hospice institution. However, the current design also had room for improvement, both in the interactive experience it was expected to bring about, and in the use of the concept by those involved. The findings will be presented in a categorized manner, by the parts of the concept as they were presented during the evaluative interviews: *1) documenting the preferences of hospice residents, 2) daily writing about eating and drinking, and 3) daily assessments of the desired meals.*

Documenting the preferences of hospice residents

The intention was to aim for consistently well-adapted meals, according to the desires of the residents, from the moment they arrive at the hospice institution. The participants considered this intention as coherent with what they pursue in the food care they want to provide. Therefore, the documentation of the preferences and desires at a central place (the diary), was seen as a beneficial asset to the food care in the hospice environment.

However, the scenario of use that was presented to the participants was also judged as an overwhelming experience for new residents and those near and dear. The initial idea was to make a complete assessment of the food and drink preferences, right at the moment of the hospice take-in.

"It is good to have a single place where the existing preferences for food and drinks are documented, and that those involved in the food care know that those preferences can be found back at that specific place." - P. 1

"What I encounter often is that the resident and those near and dear have a lot to deal with, and then I arrive to obtain even more information from them. So that is why I think of this, I already arrive with a binder for information, and this adds yet another binder. This wouldn't be something that should all happen on day one, it is simply too exhausting." - P. 2

"What I could imagine is that you make a sort of layout, that the information you ask for is something you divide over a number of days." - P. 1

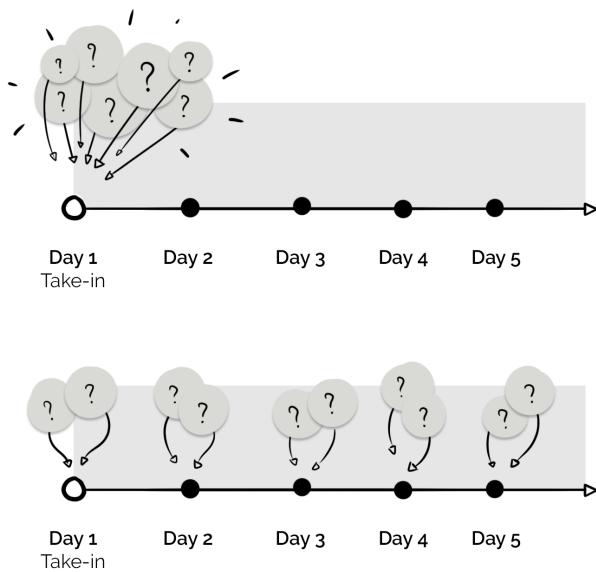


Fig. 11: Asking for the resident's preferences over the course of days is a less overwhelming experience.

The participants expected that a more gradual approach would be a better route to take, where the preferences are documented step by step over a period of time. This process can be accompanied with an instruction for hospice care givers, guiding them through the steps. What was also important when having residents engage with this documentation process were a few factors: the state of well-being of the resident, the willingness to get involved in the assessment, and the remaining interest they have for eating and drinking. These were considered important factors to determine the expected interest of residents to engage in the documentation process. Potentially, the design should even facilitate partial engagement, for example having the option to only take drinks into consideration for someone who can not eat anymore.

"I can also imagine that there is a place where the basic things are just instantly clear, so you don't have to look up the basic things one by one. You know, that it is just clear at one glance." - P. 1

What the participants mentioned is that there is a divide between things that change actively, and basic things that are consistently the same when it comes to the preferences for eating and drinking. Currently the design does not present a clear distinction between those two, making everything part of a more intricate collection of preferences. Instead, the consistent basics should be separated into a single, to-the-point overview. The more extensive, variable preferences should be presented as a collection that can be explored, offering a variety of options to choose from. This distinction is especially important to ensure that looking for the basic preferences does not feel like a unnecessarily tedious task.

Daily writing about eating and drinking

The daily questions related to eating and drinking were positively enjoyed by the participants. They could see how it might induce conversations and bring about thoughts for those reading the questions. It is definitely a useful medium to (re)introduce social bonds over topics that are related to food and drinks, in a different way than how food and drinks usually play a role in the lives of residents in the end-of-life phase. And while it is definitely to be expected that residents engage with the questions on various levels, the questions do accommodate that. In itself they are not overly personal, and they don't have to be, but if the resident has the desire for it, they can engage with the questions on a deeper, more personal level.

I do really think that it can help with bonding, and that the way you ask questions plays an important role in that. (...) I think they are simply pleasant general questions. They aren't overly personal, but they can be a trigger for a more personal conversation if the resident would like it." - P. 1

With some residents you will get a lot to talk about. It is of course very dependant on the person. What I did like, when I read this question: what did you enjoy eating when you were an adolescent? It instantly made me think of 'kaassouflés'. It instantly sparked a memory. - P. 2

Daily assessments of the desired meals

The participants recognized how the interaction during assessments with the diary would be more sensitive towards the needs of the resident. Since food can be a very important part of care, this extra attention is very much justified. In doing so however, the care giver should recognize whether the resident has the desire for this approach. Some residents may not see this assessment approach as "effortless" and could therefore argue it. The individuality of resident continues to play a role which the care giver would need to react to in their approach of using the diary. It is the question whether the design could be adjusted to suit a variety of approaches better.

"You make the assessment into an activity, and the diary instantly makes clear, there is going to be an exchange of information. I really like that about it. It simply carries less meaning if you just ask it in between things. So I find that positive about the design, because eating is simply important." - P.1

*"For one person it may work very well, for the other it is all redundant information: don't bother me with it, just give me some bread with cheese, done. You see.. there is so much variety in people."
- P. 2*

Currently the design introduced five factors of a meal that the resident can express their desires for: what meal, the amount of food, the way it is prepared, how it is served, and what dishware is used. While it is seen as important to be remembered of, as a visual reminder, the assumption should not be formed that these questions have to be asked every day. In fact, the participants said that some of those factors are usually consistent and should therefore simply be generally known after a few meals. However, currently the design does form the assumption for the participants that the five factors should be assessed for every day. Because of that a change may be needed, that does bring the visual reminder of those factors every day, but does not communicate the necessity to ask about them every assessment.

"You see, this question, that's also a question that is very much basic. It's a question that shouldn't have to be asked every day. But it is definitely good to see it, to see every day how it was exactly." - P. 1

"It's a 'bijna-thuis-huis', and not a hospital where things are asked each and every day." - P. 2

If someone wants porridge then I will always put it in a bowl, and never on a plate or a deep plate. Myself, I don't find that.. you of course have your own habits as well." - P. 2

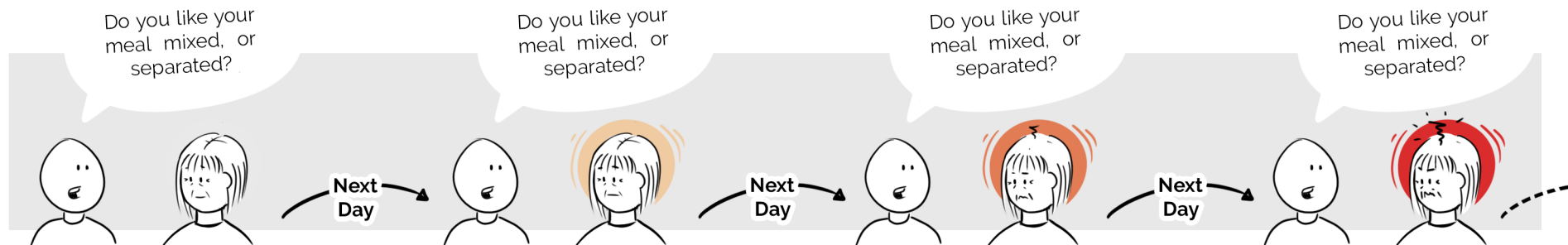


Fig. 12: Making assessments on the same thing becomes frustrating very quickly for residents

What became clear is that currently those near and dear to residents are not very informed about the eating and drinking activities of their loved one. Those near and dear also rarely ask to be informed, however that may be because they are unaware that they can ask. This concept could definitely introduce this type of informing in a sensitive and natural way. Through further testing in the actual context, it could then become clear whether this is something that is appreciated widely by those near and dear, and whether it also changes the way they serve food for their loved one. Currently, that is something that can not be said through this evaluation, only assumptions can be made.

Some relatives like to stay informed. We do have a sort of information report, but food is often not mentioned in it. But especially for relatives who are very much on top of it, for them I can imagine it being important to know what their father, or mother, or whoever, what they have been eating. - P. 1

"I do think some relatives would enjoy being able to read what has been eaten. Sometimes they do ask to be informed about it, but that's minimal. Also, I wouldn't know if that is because they assume they can not ask about it?" - P. 2

Conclusion

From the evaluation it can be concluded that the concept has the potential to fulfill the set design goals, with some necessary adjustments.

The design successfully (re)introduces social and emotional values related to eating and drinking, in two ways, through the daily questions. Firstly, it can evoke conversations between the stakeholders about the questions, allowing them to (re)connect over those topics. Secondly, many of the questions ask residents to think about situations where the social or emotional values of eating and drinking played, or could play, a significant role.

Furthermore, the concept introduces a method of food care that is much more sensitive towards the autonomously expressed desires of residents for their meals. In its current form, the interactions that the concept brings about are not always "effortless". To some extent that is to be an expected response once you make the food care routine into a process that desires more attention than the current routine. However, as the main findings clarified, there are areas in which improvement in this area is possible.

First and foremost, the documentation of the preferences of residents is currently expected to be overwhelming. Therefore, it is necessary to make this into a process that happens step by step over the course of some days. The concept should support this process as well in the design.

Secondly, both in the documentation of preferences, and in the daily assessments, the design can improve. Looking for consistent, basic meal preferences is tedious when they are "hidden" with all the other preferences. The basic preferences should be available in a clear, direct overview. As for the daily assessments, the meal "instructions" can prompt interactions that feel redundant, or become redundant over time (e.g. asking if someone wants the meal mixed, after having it mixed every meal before). The design should offer the option to record such consistent preferences, to do away with the redundant repetition of those questions.

Finally, the evaluation gave away some signs of the concept being a helpful tool for more consistent food care. Having a concentrated collection of preferences allows everyone to easily become

knowledgeable of what the resident desires in terms of food care. The insights for whether the daily assessments would improve the consistency of food care, among both care givers, and those near and dear, were limited. There were mentions that certain preferences should "simply be known after a while". Documenting those things at least allows care givers not yet familiar with a resident, to become aware of those preferences. Also, it was mentioned that all the "instructions" for determining the desired meal were considered a bit redundant, because as a care giver you would have your own way of doing things. This once again presents the potential inconsistencies in food care due to a care givers' personal notions on how to provide food care. The necessity of the "instructions", to ensure that the served meals consistently correspond with the desires of the resident, once again become clear. As for deeper insights on this topic on consistency, a more lengthy period of testing would be necessary with the concept. The testing should be performed with the actual stakeholders, in context, to really see how it affects the food care attitudes and behaviours. This is likely to lead to other iterations to refine the concept design.

Recommendations

Based on the evaluation there are a number of recommended steps that should be taken in continuation of this design project. Some of these recommendations are supported with materials; adjustments to the current design of the diary, based on the findings of the evaluation. The rest are; additional concept elements that support the effectiveness of the diary, recommended procedures for using the diary in different circumstances, and endeavours that should be made to refine the design of the diary.

Improving the documentation of preferences

To improve the documentation of preferences of residents there are two main recommended adjustments to the concept design:

- The design should make a distinction between consistent basic preferences, presenting them in a clear-cut overview (see figure 13), and the preferences that may vary from day to day, presenting them in a collection that holds a more explorative nature, like the current design does.
- The concept should facilitate a step-by-step process for the assessment of the resident's preferences, that can be completed in the pace that the resident desires.

The former is to make the use of the diary, particularly for the care provider, more effortless. It makes looking for the most basic preferences less tedious to do. The second is to make the assessment of the preferences less overwhelming for residents and those near and dear.

Less redundant questions in the daily assessments

An option could be given to note certain preferences for meals down. This can prevent redundant questions about desired meal choices that are consistent each and every day. Since it was mentioned in the evaluation that it is still important to be reminded of such preferences every day, they should still be "presented" to the care provider every day.

A potential design change is to make the "instructions" for the meal desires part of the bookmark that is in the diary (see figure 14). It is kept on the current day and therefore the "instructions" are seen by the care provider every day. The awareness to ask about the desires of the resident remains, and the consistent preferences are instantly clear as well, even for those who are less familiar with the preferences of the resident.



Fig. 14: The "instructions" for a meal can be presented on the bookmark, including the option to mark a choice if it is consistent for every day.

Conforming to residents who do not eat

What was often mentioned in the evaluative interviews was how quite often people arrive at the hospice who are not capable of eating anymore. For various reasons they have stopped eating (almost) entirely. To make the diary more widely applicable in the hospice, an additional component can be added to conform to the residents who do not eat anymore.

An example would be to replace the "daily meal assessments" into something smaller, mostly related to drinks, because usually the residents who do not eat do still attempt to drink. It is a much more sensitive approach for someone who does not eat anymore, instead of bothering them with a diary that puts most of the emphasis on food. In fact, that can be very disheartening. By putting the focus on drinks, having food play a very minor role in the diary, that group of residents can also engage with the diary. Potentially it can just as much help the care providers with enhancing the care around drinks, to maybe create a sense of excitement around it beyond just drinking water and tea out of necessity to stay hydrated.

Instructions for the diary

Using the diary in the right way may not be entirely straightforward, especially considering that how the diary is introduced and used can be different for different residents. Therefore, besides the actual diary, instructions are likely a necessary addition. These instructions can explain the following things:

- The step by step course of introducing the diary to new residents, and how to use them throughout their stay at the hospice institution.
- When to propose using the diary to residents and those near and dear. How to make an appraisal of the resident to find out whether the diary can be beneficial to their stay at the hospice.

Both of these aspects are very important for hospice care givers to understand. They are essential for ensuring whether the diary will be experienced positively by the resident and therefore will positively influence the well-being of the resident, instead of negatively.

Determining when (not) to use the diary

As mentioned in the previous recommendation about instructions as an added component to the diary, an important part of making the diary successful is making an appraisal of the resident. Not every resident may have an interest to engage with the diary. During the evaluative interviews it was mentioned how the resident's personality, physical and mental well-being, and (remaining) interest in food and drinks, can all be important factors for making the experience with the diary a positive or negative one.

As part of the use of the diary, hospice care givers are recommended to make an appraisal of such factors to determine whether the resident has a large interest, some interest, or no interest at all in using the diary. That way it can be determined how the diary is used, if used at all. Using the diary against the resident's will should always be avoided as it can negatively influence their time at the hospice.

Refining the design after testing in the hospice context

The current design is of course based on a combination of a literature analysis, context analysis, and the evaluation of the design is limited to evaluative interviews with experts in the context. Unfortunately, this does not give much information about the actual experiences of residents and those near and dear, when using the diary in the hospice context. Neither did it give insight on the benefits of the long-term use of the diary, which is assumed to be one of the qualities of the diary. The day by day use of it over time makes it into a collection of knowledge, and shared thoughts and experiences, of which the value grows as that collection grows.

A follow-up step of this design project would be to develop versions of the current final design, that are usable within the context. Using that, the diary should be tested within the actual context of the hospice institution. It will give insights on the qualities and shortcomings of the current design of the diary, both in the direct interactive experiences, and in the long-term benefits. With those insights, iterations of the diary can be made to refine the concept design towards its best version.

Project Reflection

Before the start of this project I already expected a number of challenges that would provide me with opportunities to learn something new. Those challenges varied, and of course more challenges came about as the project evolved.

Research and design for the end-of-life

What initially comes to mind are the context of the project, and the content of the project; they are complicated to comprehend and burdensome in its content. Thinking about the end-of-life phase, the care someone receives during this phase, the experience of going through this phase, and the death that follows. They are things I would usually avoid thinking about. Therefore, it was completely unknown territory for me, which led to me delving into the complex depths of the topics, without always having a clear direction to go into. It could leave me with more questions than answers. In hindsight, a more hypothetical approach would have been much more efficient. To start by mapping out what I knew, or thought I knew, and from there raise my own questions that I wanted the answers to, to lead myself into the right direction. That may have helped me to find focus earlier on in the project.

Later in the project, particularly when actually designing, the context and the topics involved with the project proved to raise new challenges. The stakeholders, particularly hospice residents and those near and dear, demanded a sensitive approach. At times, this felt very limiting to the design process, as the design had to be very nuanced and subtle, to not become an item forced into the hospice care setting, causing more disturbance than it offers aid. Eventually, I learned to be at peace with a more low-key design, understanding that sometimes this serves its purpose better than some "groundbreaking" design may do.

Furthermore, the context proved difficult for me to research in the field. Of course there were stakeholder groups that were not very openly available to involve in the project, in that case I am talking about hospice residents and those near and dear to them.

In hindsight I do believe attempts could have been made to find alternatives to get involved. Especially people who experienced someone's illness and passing in the past. They could have been a valuable addition to my analysis of the context and topic.

What I did not expect for this project, is how well I was able to put myself into a designer role, trying to set myself aside from the burden that the themes and topics within the project carried. I think that was a very valuable asset for me during this project. If I were to empathize too much, it might have disturbed myself mentally, which may have hurt the project as a result. Thankfully, I was able to separate myself in such a way that I was able to empathize with the stakeholders in an analytical way, but no more than that.

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Appendices

Appendix A: Project Brief

IDE Master Graduation

Project team, Procedural checks and personal Project brief

This document contains the agreements made between student and supervisory team about the student's IDE Master Graduation Project. This document can also include the involvement of an external organisation, however, it does not cover any legal employment relationship that the student and the client (might) agree upon. Next to that, this document facilitates the required procedural checks. In this document:

- The student defines the team, what he/she is going to do/deliver and how that will come about.
- SSC E&SA (Shared Service Center, Education & Student Affairs) reports on the student's registration and study progress.
- IDEs Board of Examiners confirms if the student is allowed to start the Graduation Project.

! USE ADOBE ACROBAT READER TO OPEN, EDIT AND SAVE THIS DOCUMENT

Download again and reopen in case you tried other software, such as Preview (Mac) or a webbrowser.

STUDENT DATA & MASTER PROGRAMME

Save this form according the format "IDE Master Graduation Project Brief_familyname_firstname_studentnumber_dd-mm-yyyy".

Complete all blue parts of the form and include the approved Project Brief in your Graduation Report as Appendix 1 !



family name Houdijk
 initials M. given name Maxim
 student number 4303741
 street & no. Prinses Mariannelaan 152
 zipcode & city 2275 BL Voorburg
 country The Netherlands
 phone 06 39644583
 email maxim_houdijk@hotmail.com

Your master programme (only select the options that apply to you):

IDE master(s): IPD Dfl SPD
 2nd non-IDE master: _____ (give date of approval)
 individual programme: _____
 honours programme: Honours Programme Master
 specialisation / annotation: Medisign
 Tech. in Sustainable Design
 Entrepreneurship

SUPERVISORY TEAM **

Fill in the required data for the supervisory team members. Please check the instructions on the right !

** chair M.H. Sonneveld dept. / section: Industrial Design / AED
 ** mentor A.G.C. van Boeijen dept. / section: Industrial Design / DA
 2nd mentor _____
 organisation: _____
 city: _____ country: _____

Chair should request the IDE Board of Examiners for approval of a non-IDE mentor, including a motivation letter and c.v.

! Second mentor only applies in case the assignment is hosted by an external organisation.

comments (optional)

! Ensure a heterogeneous team. In case you wish to include two team members from the same section, please explain why.

Eating & drinking in Dutch hospice care: coping difficulties and conflicts

project title

Please state the title of your graduation project (above) and the start date and end date (below). Keep the title compact and simple. Do not use abbreviations. The remainder of this document allows you to define and clarify your graduation project.

start date 08 - 04 - 2019

09 - 09 - 2019

end date

INTRODUCTION **

Please describe, the context of your project, and address the main stakeholders (interests) within this context in a concise yet complete manner. Who are involved, what do they value and how do they currently operate within the given context? What are the main opportunities and limitations you are currently aware of (cultural- and social norms, resources (time, money,...), technology, ...).

In The Netherlands there is a system of care for people in their final phase of life. This care is referred to as terminal palliative care or end-of-life care, and relates to people whose remaining life expectancy is around 3 months. Most often this concerns elder people. The purpose of end-of-life care is to make that final phase of someone's life as comfortable as the circumstances allow it to be. The care system provides options for care at home or outside of home, one of those being hospice care in an institution. In hospice care, care is provided by trained professionals and volunteers for 24 hours a day, 7 days a week. Beside the professional care, those near and dear to a patient are also given the opportunity to contribute in providing the necessary care (Network Palliatieve Zorg, n.d.). Providing the patient with food and drinks is a major facet of this care.

When people go through their final phase of life, they deal with many hurdles and developments through time. A common development is a diminishing appetite for food and drinks. The patients themselves and the trained care givers often don't worry a lot about this development; they experience it as a natural part of the circumstance. Those near and dear to the patient, however, usually find this development more difficult to cope with (Raijmakers, 2013). Eating and drinking is fundamental to life in a literal sense, as a lack of it may lead to someone's passing. However, it also holds a substantial affective meaning. It may bring people joy, give a feeling of togetherness, and signify the love between people among many other things. Those near and dear thus worry not only about the physical health of their loved one, but also the loss of those important symbolic values between the patients and those near and dear.

The nurtured symbolic values around eating and drinking are heavily reliant on both at small scale the personal background of a person and at a larger scale the cultural and religious background. These symbolic values in turn present themselves through the activities and interactions people have related to eating and drinking, and their attitudes and beliefs towards it. Clearly, in a situation where a patient's appetite for food starts to diminish, these symbolic values will become very relevant and will largely determine how those near and dear will treat the situation when providing care for their loved one (Graeff, et al., 2012).

Topics such as this one are actively being researched and designed for in the Delft Design for End of Life Lab. For this reason, this graduation project will be in cooperation with the lab, through active meetings with staff and (graduation) students involved with the lab.

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Main stakeholders and relevant problematic interactions in Dutch hospice care institution

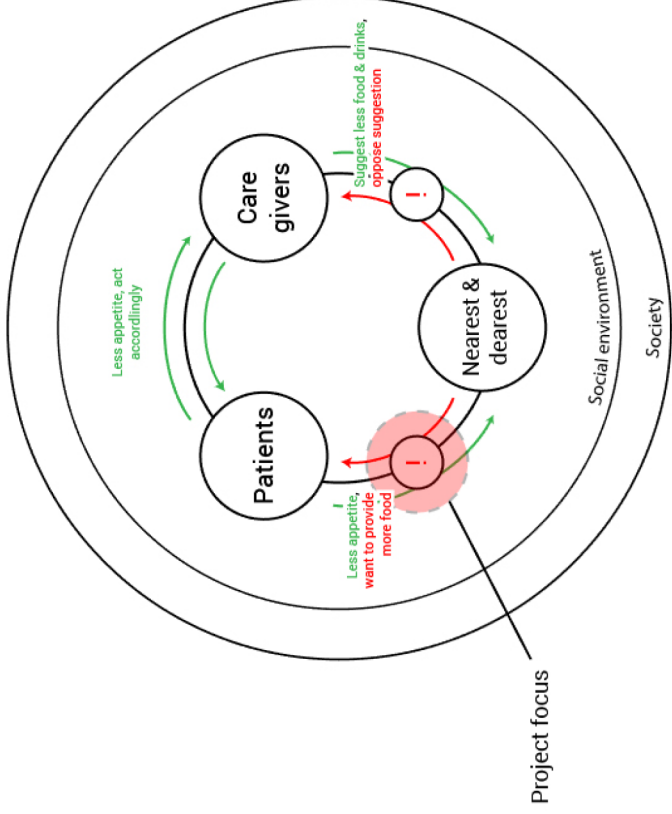


image / figure 1: Stakeholders in hospice environment (Sonneveld, 2019) with highlighted conflicts and project focus

image / figure 2:

PROBLEM DEFINITION **

Limit and define the scope and solution space of your project to one that is manageable within one Master Graduation Project of 30 EC (= 20 full time weeks or 100 working days) and clearly indicate what issue(s) should be addressed in this project

In Dutch hospice care institutions it has become evident that those near and dear to a patient have difficulties coping with the diminishing appetite for food and drinks of the patient in question. As mentioned in the introduction, there is a discrepancy between the attitudes of the patient and of those near and dear within this 'problem' of diminishing appetite for food and drinks. This can result into conflicts between them, leading to undesired interactions with a negative emotional aftermath for both. Patients may not want to eat or drink, for example, due to pain, lack of appetite, lack of energy or an incapability to digest. Simultaneously, those near and dear want to offer the care related to eating and drinking, attempting to extend the life of their loved ones, and make them feel good. Despite patients voicing their wish, and trained care givers advising to comply, those near and dear may still act adversely, which may also create conflict between care givers and those near and dear. The conflicts that arise can be experienced by those near and dear as a rejection of the valuable care, both in a literal and symbolic sense, they want to provide for their loved one. This may even affect the mourning process afterwards even harder for those near and dear.

The different personal, cultural and religious backgrounds of the patients and those near and dear makes the circumstance especially difficult to handle for trained care givers. It influences how they handle eating and drinking as a part of care for the patient, why they struggle to cope with this part of care diminishing, and how they act as a result of this struggle. The behavior obviously differs at larger scale (culturally or religiously), but even at individual level (personal background) the circumstance may demand a different approach to resolve the coping difficulties or conflicts that exist.

Unfortunately current solutions are limited to spreading information about the diminishing appetite for food and drinks. The goal of current solutions is to create understanding among those near and dear, comfort them and give tips about what they can do. Unfortunately these do not always prove effective at resolving the problem.

ASSIGNMENT **

State in 2 or 3 sentences what you are going to research, design, create and / or generate, that will solve (part of) the issue(s) pointed out in "problem definition". Then illustrate this assignment by indicating what kind of solution you expect and / or aim to deliver, for instance: a product, a product-service combination, a strategy illustrated through product or product-service combination ideas, ... In case of a Specialisation and/or Annotation, make sure the assignment reflects this/these.

Design a tool of support for those near and dear to an elder patient spending the last phase of life in a hospice institution in The Netherlands, that helps those near and dear cope with the diminishing appetite for food of the patient in question. This should reduce conflict between those involved, improving both the well-being of the patient and the experience of those near and dear when providing care in the hospice environment.

The foundation of this project will be the research of the context: a hospice care institution in The Netherlands. The focus will be on elder people and those near and dear that provide care in the hospice environment, this is considered the largest stakeholder group.

Analyzing the context and stakeholders should give an impression about the behavior related to eating and drinking in hospice care. In a general sense: how food and drinks are provided, the types of food and drinks, the related artifacts that are used, and what other related activities take place, but also directly related to the defined problem: why the coping difficulties of those near and dear occur, why they oppose their loved one and the trained care givers, how the resulting conflicts progress and how those in turn affect the stakeholders, even after the passing of the patient.

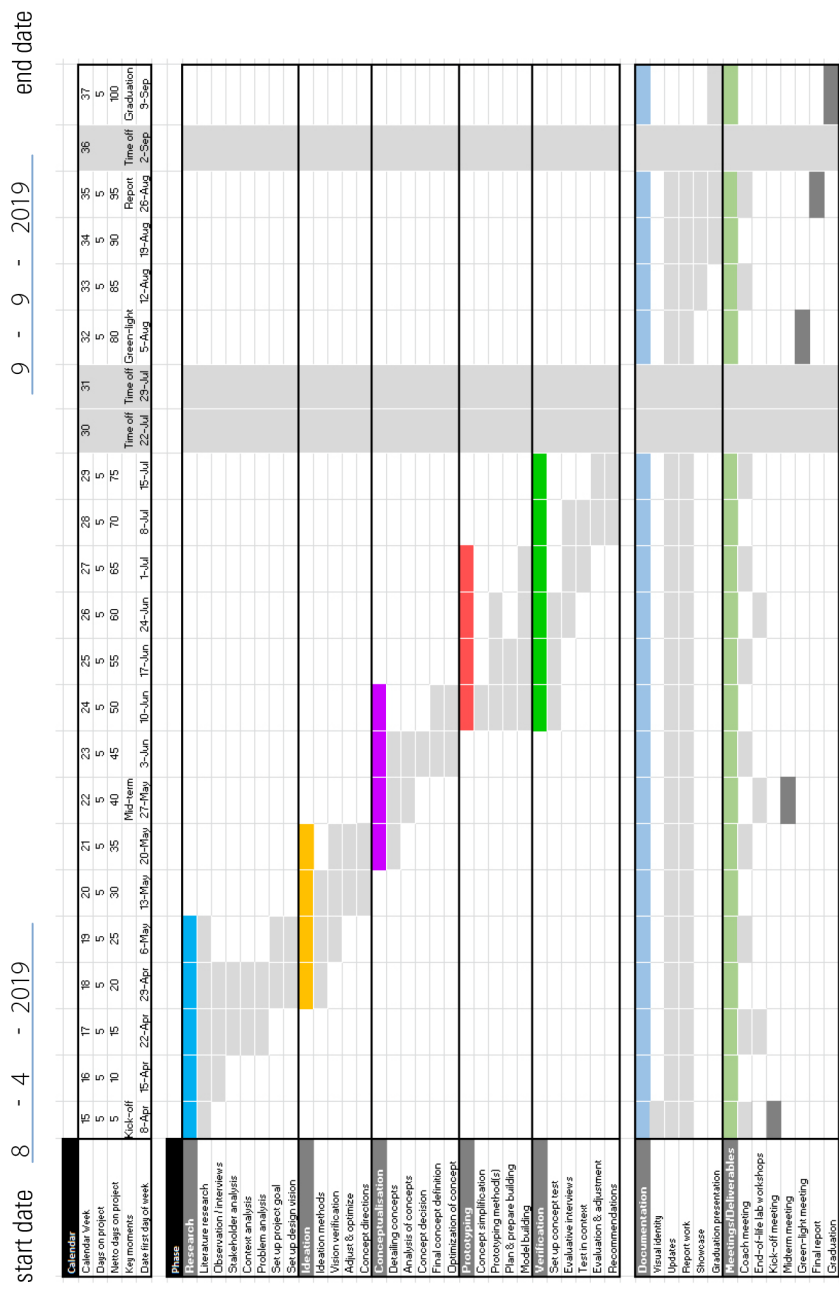
Considering that, even on individual level, the personal background of the stakeholders has influence on the problem, it will likely be necessary to set boundaries for a specific stakeholder group. Otherwise, space for adjustment upon use has to be available to make a solution that fits the personality of the different stakeholders.

The final goal is to design something that either allows those near and dear to continue addressing the lost symbolic values (to some extent) through a new interaction, or to make it easier to cope with the loss of them. The aim to realise this goal is by designing a product/tool of support that is provided by a hospice, to be used by those near and dear.

Personal Project Brief - IDE Master Graduation

PLANNING AND APPROACH **

Include a Gantt Chart (replace the example below - more examples can be found in Manual 2) that shows the different phases of your project, deliverables you have in mind, meetings, and how you plan to spend your time. Please note that all activities should fit within the given net time of 30 EC = 20 full time weeks or 100 working days, and your planning should include a kick-off meeting, mid-term meeting, green light meeting and graduation ceremony. Illustrate your Gantt Chart by, for instance, explaining your approach, and please indicate periods of part-time activities and/or periods of not spending time on your graduation project, if any, for instance because of holidays or parallel activities.



The foundation of research will be composed out of a combination of literature research, observation in the context and interviews with stakeholders (as far as the circumstances allow it) and experts on the topic. This should form a rich collection of information resources for analyzing the context, stakeholders and the problem as a whole. The result of the analysis will inspire the design vision for the rest of the project.

With the design vision in mind I will go through an ideation and conceptualisation phase to come to a valuable result for solving the defined problem. Which is followed up with a simultaneous verification and prototyping phase, as the execution of both rely on each other.

As for the verification phase specifically, creative solutions may be necessary since a 'typical verification process' with direct involvement of the stakeholders may not be realistic. Instead, the design solution should verify its value through testing with simulation or from the opinions that are shared by experts on the topic upon presenting the design solution. It's a phase that will require creative thinking and acceptance that typical verification methods may not be feasible.

At the bottom section of the planning the documentation is clarified: continuous report work, the project showcase and the graduation presentation. And it also displays the planning for meetings and official deliverables: this involves coach meetings every other week, workshops with the end-of-life lab to discuss the related ongoing graduation projects, and the dates for official key meetings of the project.

MOTIVATION AND PERSONAL AMBITIONS

Explain why you set up this project, what competences you want to prove and learn. For example: acquired competences from your MSc programme, the elective semester, extra-curricular activities (etc.) and point out the competences you have yet developed. Optionally, describe which personal learning ambitions you explicitly want to address in this project, on top of the learning objectives of the Graduation Project, such as: in depth knowledge a on specific subject, broadening your competences or experimenting with a specific tool and/or methodology, Stick to no more than five ambitions.

The two main reasons that motivate me for this graduation assignment:

- It gives the opportunity to design a product that improves the interaction between people within a context where such a solution can truly flourish. The Exploring Interactions course taught me a lot about working with a similar premise, but results often felt forced within the context. With this assignment, improving the interactions between a patient and those near and dear will not only be beneficial to the mental and physical well-being of the patient. It will also improve the experience of those near and dear as they share their last bit of time together with their loved one.
- A context that is challenging and complicated, but also very rich. I find it interesting to learn about hospice care and how people act (both care givers and those near and dear to a patient) to provide comfort for a patient in his final phase of life. Furthermore, I am curious to learn about the mental challenges that those involved go through in this process. Hopefully, through this assignment, I can even contribute to improving the experience of hospice care for the people involved, as far as the circumstances allow it.

For this graduation assignment I have a few learning ambitions:

- Doing user & context research in a complex context, like the hospice environment.
- Learn to understand how personal and cultural background influence people's beliefs and attitudes about a complex topic, and how to implement the knowledge in a design process.
- Learn how to study a topic that carries an emotional load, both for stakeholders but also potentially for yourself. Learn to separate yourself from the subject when necessary.
- Learn how to perform valuable verification methods within a complex context where the 'usual verification methods' with direct stakeholder involvement may not be feasible. Learning how to do this may even be beneficial for others, who may find themselves in similar situations. For example other students doing project for the Delft Design for End of Life Lab.

FINAL COMMENTS

In case your project brief needs final comments, please add any information you think is relevant.

Appendix B: Interview Set-Up Contextual Analysis

HOSPICE INTERVIEW

Voorafgaand

Ten eerste ontzettend bedankt voor het deelnemen aan het interviewen

Dit interview is voor mijn afstudeerproject. Hiermee hou ik me bezig met de afnemende eetlust bij iemand in de laatste levensfase en hoe hiermee wordt omgegaan.

Ik wil met het interview een aantal onderwerpen bespreken en daarbij laat ik afbeeldingen zien die ermee te maken kunnen hebben. Wat ik vooral wil met het interview is verhalen bespreken die bij jou naar boven komen bij die onderwerpen, die bijvoorbeeld heel relevant zijn of die jij heel aangrijpend vond. De afbeeldingen kunnen daarbij als inspiratie dienen maar je bent vrij om aan te passen of dingen toe te voegen. Wat ik wil benadrukken is dat je niet moet denken dat alle plaatjes per se behandeld moeten worden.

Omdat het voor mij moeilijk zal zijn om alle verhalen zomaar te onthouden wil ik ook vragen of ik het geluid van het interview mag opnemen? Daarbij wil ik ook gelijk zeggen dat het interview anoniem is, dat gaat om zowel jou maar ook om de mensen waarover je praat.

En voordat we beginnen heb ik een formulier voor toestemming om dit interview te gebruiken voor mijn project, of je deze zou willen ondertekenen voordat we beginnen.

Design for Interaction Graduation Project

Eten en drinken in Nederlandse palliatieve zorg

Maxim Houdijk 4303741

Impressie van de hospice bewoners en hun naasten

Ten eerst wil ik graag een beeld vormen van de hospice bewoners en hun naasten.

1. Houding en gesteldheid hospice bewoners

- **Wat kom je tegen wat betreft de houding en gesteldheid van bewoners in het hospice?**

*Houding naasten
Invloeden op houding*

*Lichamelijke en geestelijke gesteldheid
Invloed op omgang naasten*

Impressie van de zorg voor hospice bewoners door naasten

Nu wil ik graag ingaan op de zorg en de activiteiten waar de bewoners en naasten bij betrokken zijn

1. Zorg, activiteiten en visite in het hospice

- **Wat voor zorg en activiteiten tussen bewoners en hun naasten heb je zien voorkomen?**

*Opvallend / aangrijpend voorbeeld
Belang van activiteiten
Respons bewoners
Emoties & gevoel*

2. Materiële cultuur in het hospice

- **Wat voor materiële dingen ben je tegengekomen waar bewoners of naasten veel waarde aan hechten?**

*Waarden van materiaal
Emoties & gevoel
Culturele invloeden*

Impressie van de situatie tussen bewoners en naasten gerelateerd aan eten en drinken

Nu wil ik graag ingaan op de situaties die kunnen ontstaan tussen bewoners en naasten vanwege een afnemende eetlust.

1. Voeding bij afnemende eetlust

- **Kan je iets vertellen over situaties die ontstaan vanwege de afnemende eetlust van de bewoner?**

Invloed op gedrag (cultuur, achtergrond, houding, etc.)

Communicatie naar naasten

Zeggenschap naasten en bewoners

Gevoel en emoties

- **Situatie die juist heel positief was verlopen OF situatie die juist moeilijk verliep? (afhankelijk van antwoord eerste vraag)**
- **Wat zie je dat er wordt gedaan om zo'n moeilijke situatie op te lossen, of hoe had je ermee om willen gaan?**

2. Waarde van voeding voor bewoners en naasten

Nu wil ik iets meer ingaan op de waarde die bewoners en naasten uit voeding halen, daarin heb ik een splitsing gemaakt tussen functionele en emotionele waarde.

- **Wat ben jij hierin tegenkomen bij naasten die zorgen voor eten en drinken?**

Behoeften van naasten

Behoeften van bewoners

Motivaties

Gevoel en emoties

3. Spullen bij eten en drinken in het hospice

Naast de dingen die bewoners en naasten doen, zullen ze ook een bepaald gevoel hebben bij het materiaal dat voorkomt.

- **Wat voor materiaal zie je in het hospice dat te maken heeft met eten en drinken?**

*Hospice materiaal
Waarde van materiaal
Mening over materiaal*

- **Wat voor specifiek materiaal ben je tegengekomen dat bewoners en naasten gebruikten bij eten en drinken?**

*Betekenis
Waarde
Gevoel
Culturele invloeden*

4. Oplossingen voor verminderen moeilijke situaties

Nu is het doel van mijn project om de moeilijke situaties te verminderen, dit kan op verschillende manieren.

- **Wat denk jij dat het gewenste effect van een oplossing zou zijn?**
- **En hoe denk je dat dit effect bereikt kan worden? Bijvoorbeeld:**

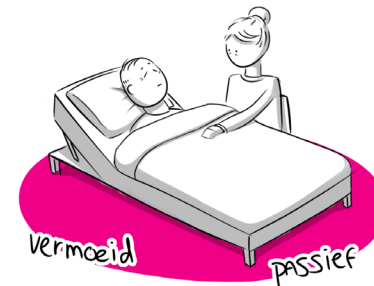
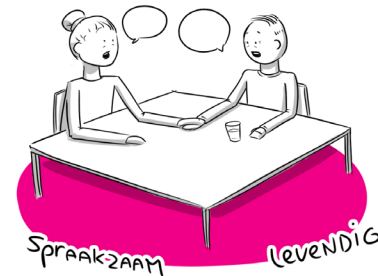
*Bewoners meer controle geven
Nadruk bij naasten leggen op andere soorten zorg of activiteiten
Informereren van naasten*

Houding en gesteldheid van bewoners

Houding



Gesteldheid



Zorg en activiteiten bij bewoners en naasten

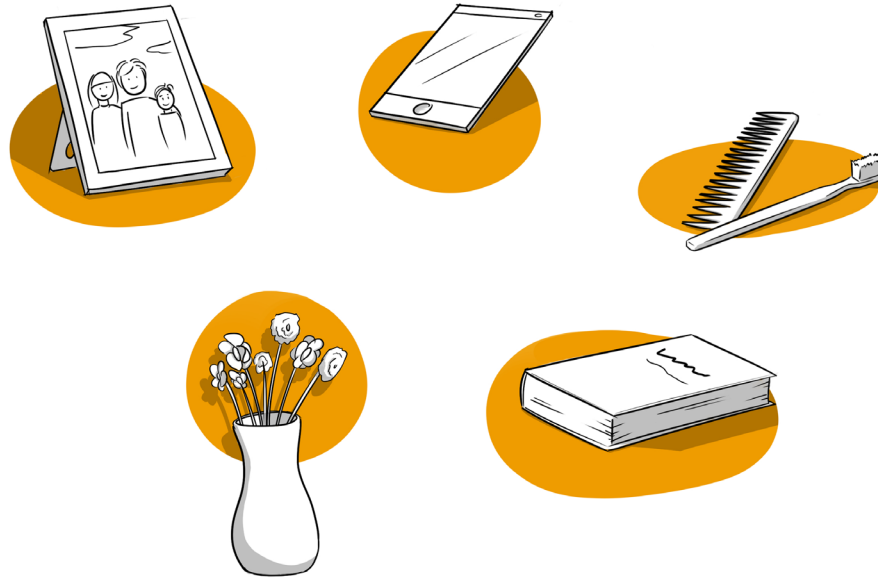
Zorg en activiteiten



Visite



Persoonlijke spullen in het hospice



Voeding bij afnemende eetlust



De waarde van eten en drinken

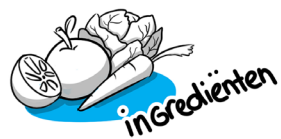
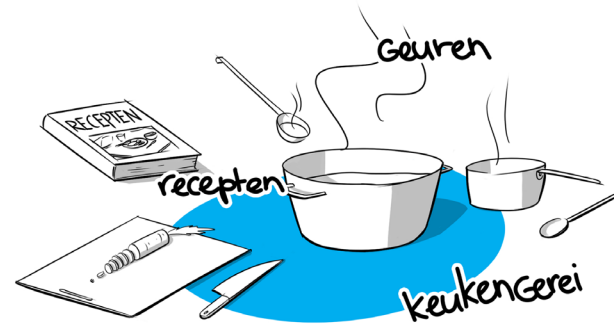
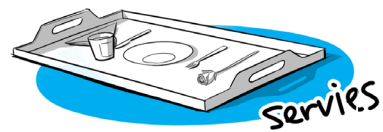
Functioneel



Emotioneel



Spullen bij eten en drinken in het hospice



Appendix C: Ideation

Appendix C-1: Ideation Session

Creative session Food care in a hospice context

1. A general explanation of the topic/project and context.
2. Explaining the scenarios of the food routine for both hospice care givers and relatives
3. Introduce the identified problematic areas:
 - **There is little sense of autonomy for patients about food portioning.** Due to this they usually receive more food than they desire followed by situations where they may feel obliged to eat more than they are capable of.
 - **There is too much influence from the personal notions of care givers and relatives on the food care.** As a result of this the food care routine can be inconsistent when performed by different people, something that the current interpersonal communication also does not prevent.
 - **Struggling relatives have to let go of the values that food provide in a very abrupt manner.** It makes the process of letting go of food unnatural and contradicting with other processes

Where is the room for change?

Assesment of the patient's desire.

- **Care givers:** There is some concern about the amount of served food, but plenty of volunteers choose to simply serve what they judge as a "regular" meal. In most cases that is more than the patient is capable of eating.
- **Relatives:** Relatives rely on food as a beacon of hope. They choose to serve what they see as a healthy amount. They usually do not shrink the servings as they remain hopeful for their loved one to eat a healthy amount, even when it is very unlikely to happen.

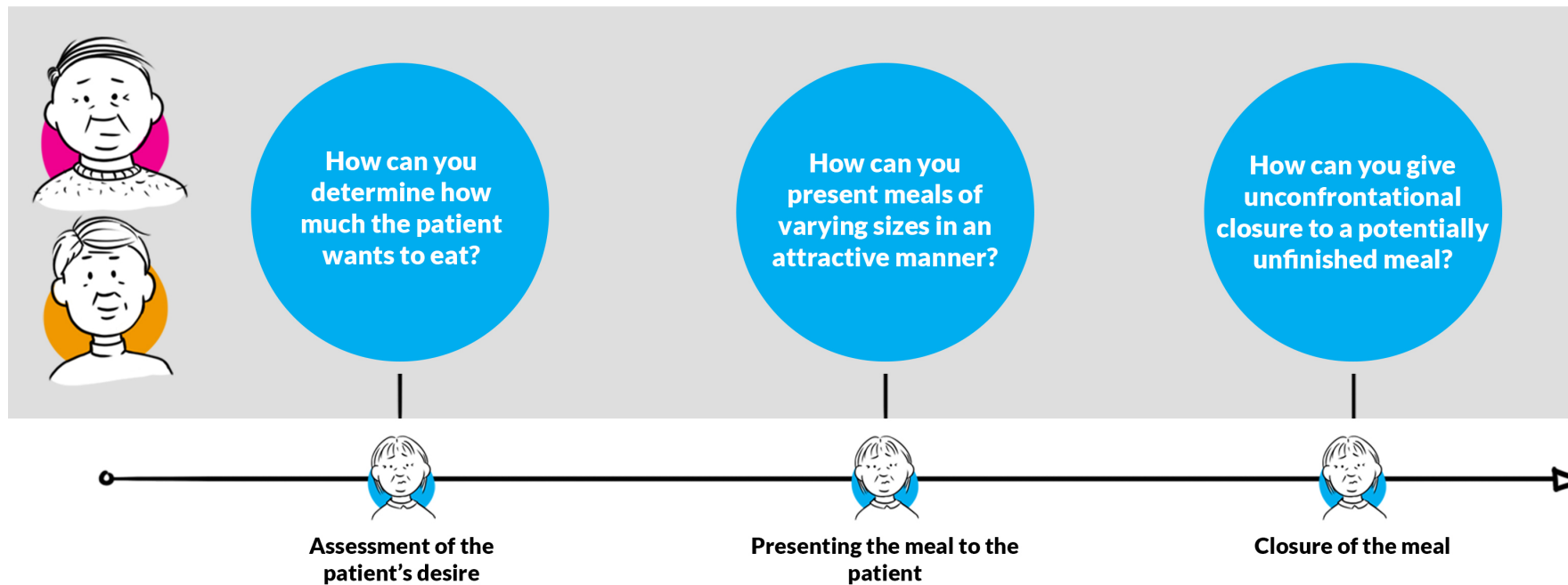
Presenting the meal to the patient.

- **Care givers:** While some volunteers are quite well capable at presenting a meal well, others not so much. Those who are not might struggle presenting a meal that doesn't look flimsy or when the food portions become smaller, or the food becomes less appetizing (e.g. liquid foods or mashed foods)
- **Relatives:** Relatives tend to focus mostly on the nutritional value of food. Because of that, the food they prepared is also often served in the plastic container they put the food in after preparing it at home.

Closure of the meal.

- **Care givers:** The care givers are very accepting towards patients not finishing their oversized portions. For patients however, feelings of guilt or despair may still arise when confronted with large amounts of leftover that the care giver has to take away.
- **Relatives:** While some relatives are accepting towards patients not finishing their meals, others may resist more. In those cases the meal will finish after attempts of urging the patient to eat more. The feelings of guilt and despair may be even larger, in this case experienced by both the patient and the relative.

Food care routine Three interaction touchpoints and connected design questions



Design questions

Assesment of the patient's desire.

Within this touchpoint between the patient and a care giver or relative, the following design question is set up:

How can you determine the portion size for the patient's meal?

Presenting the meal to the patient.

Within this touchpoint between the patient and a care giver or relative, the following design question is set up:

How can you present

Closure of the meal.

Within this touchpoint between the patient and a care giver or relative, the following design question is set up:

How can you pleasantly give closure to the

Ideation Session Result

measure brain-
wave response
to certain
plate sizes

weighing
too complicated
to do

put it
into
the rest

learn a
bit more
every day
(keep quality)

additional things
they can put in value
they want

see comparisons
as much
as much
cost

"Basic" with people
making food is plates.

regions
plate

making
plates
easier

ask them
to tell you
how much of
each piece of
food they want

make face
how many do you
want filled

introducing a
range of plate
sizes

scale on the
container

many
plate sizes
to handle?

How much do I
like it?
by

yellow
more
than
knowledge

put everything
on bread
(considering plates)

Focus on the experience
than merely the looking

using different
color
silver
solid
other
finer colors

decoration
the plate
(take attention
away from the plate)

interestingly shaped
plates

Blue & white
makes something
look fresh

used shaped
cooking

Modular

modular
plates

bowl & spoon
in one

Serving them
in a bowl

all small
w/

using up a lot as
from progress

different depth
plates
small plate

different depth
plates
small plate

look similar, but different
layers

not including
family
with feeding

never having
seen the meal
in the first place

leave
them
alone
eating

take
plate
away
the
area?

lets save it
for tomorrow

push
food
around
and
eat
disappoint

half covered
bowl
push lettuce under
the rim

push
lettuce
under
the
rim

using lid

push
lettuce
under
the
rim

put a "tip" of
food pushed on
the bowl to show how
full it is
hide away
admittedly

hide away
admittedly

hide away
admittedly

"Let go" conviction
Let the food go fully
Let me go empty

Choose full-filled
emptily
(gesture)

Start talking
instead of eating

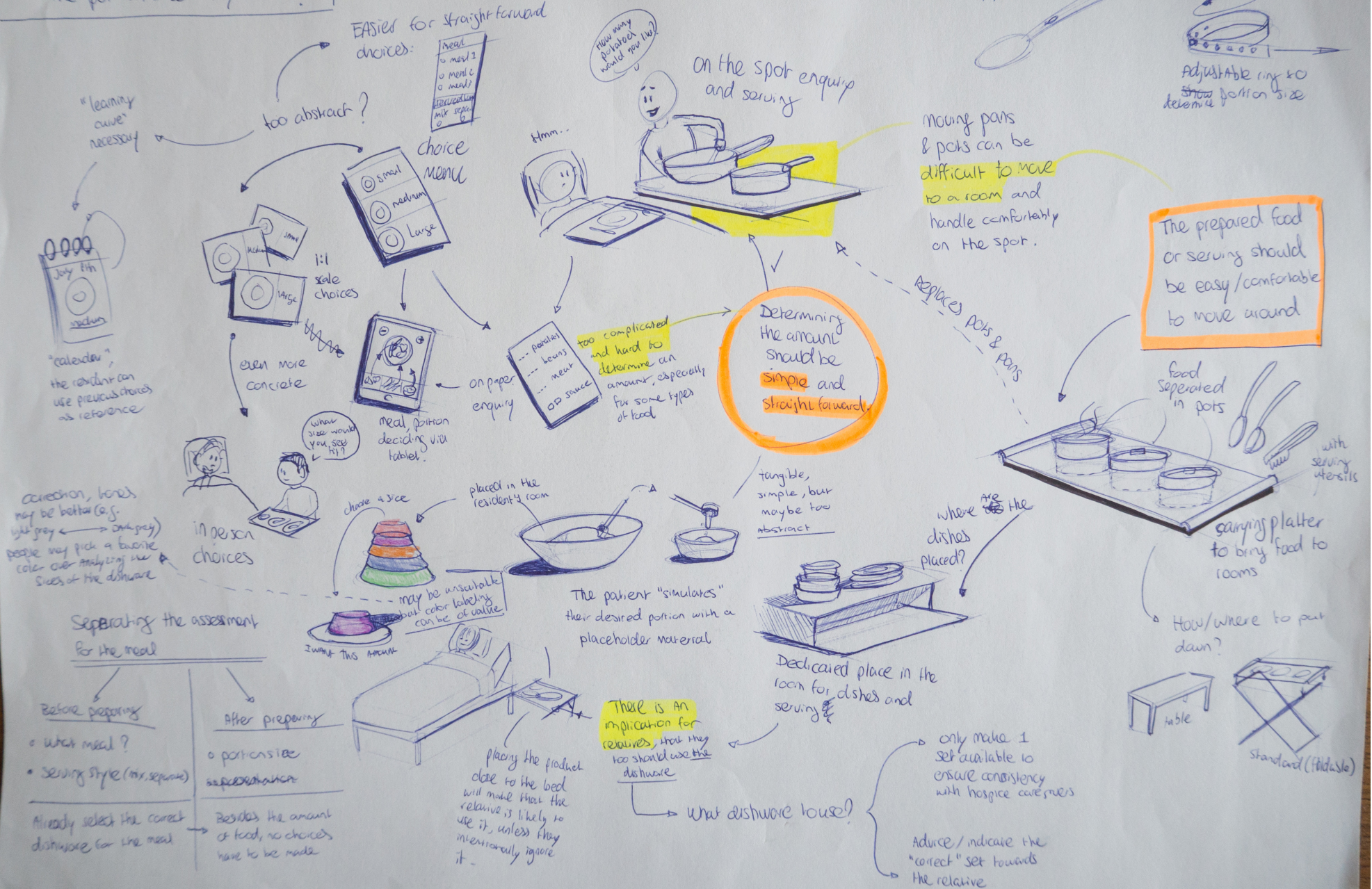
assessment

presenting

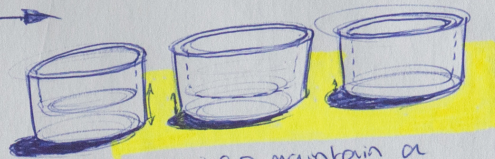
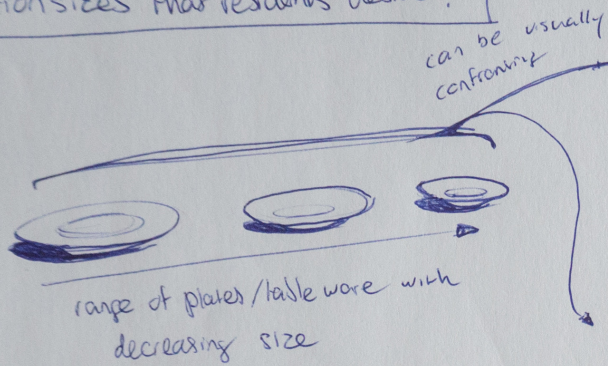
closure

Appendix C-2: Further Ideation

1 How can the residents establish the portion size they desire?

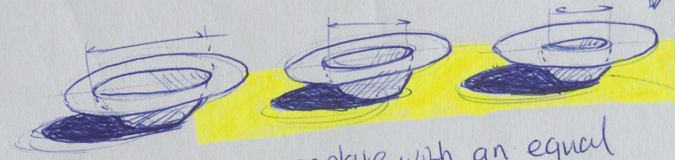


2 How can the tableware remain suit with the continuously shrinking portion sizes that residents desire?

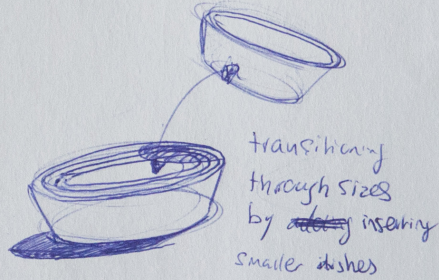
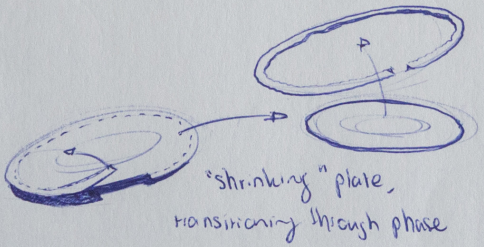
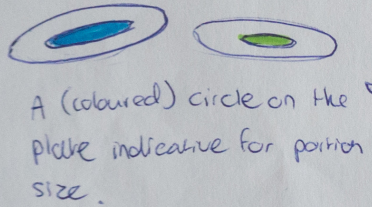


consistent diameter & outer height can take away some of the visual confrontation

can suit a multitude of meal types (regular, soft, soup)



bad balance



3 How can a small-sized meal be presented well, considering the physical diet wishes of the resident?

The presentation should suit the various preferences and wishes of the residents (and relatives)

presenting the meal can only require a realistic amount of effort and skill within the given context.

demands effort and education, thus hard to realize

Luxurious presentation AS a "gourmet meal"

may not suit all residents, some may have an aversion towards such meals

"bank-like plate"

decorative tableware

decorative ingredients

How to present well?

Blended meals

Liquid soups

small pieces

different dish for each

CAN look more substantial than the same amount on a single plate

serving style

Mixed

separate dishes for each part
many different items needed

separation in the dish

Separated

A (large) plate can serve both purposes

inset for separate meal
mixed

higher?

balance out height

one dish serves all

dietary needs

the edge of plates quickly makes visual serving look even smaller

But, it is necessary to prevent spilling

why not just plates?

down-sizing the plate's diameter will easily make it look insignificant

only way to reduce size to fit portion size

AND

regular dish ware

separate pieces for separated meals

regular dish ware

pattered

In the hospice, by volunteers and/or relatives of residents

Different colored plate to undermine the absence of food. (less contrast)

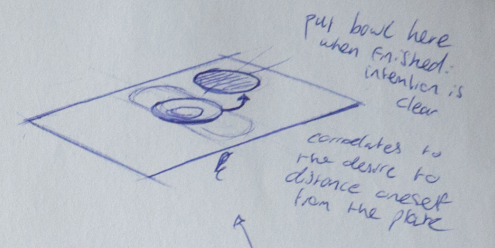
prevent spilling with a more upright edge

looks much more substantial

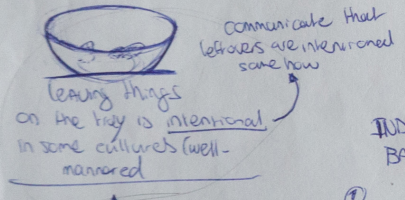
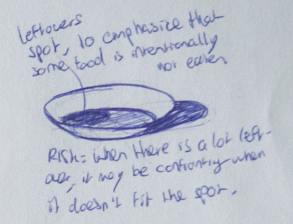
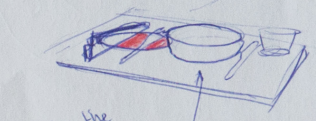
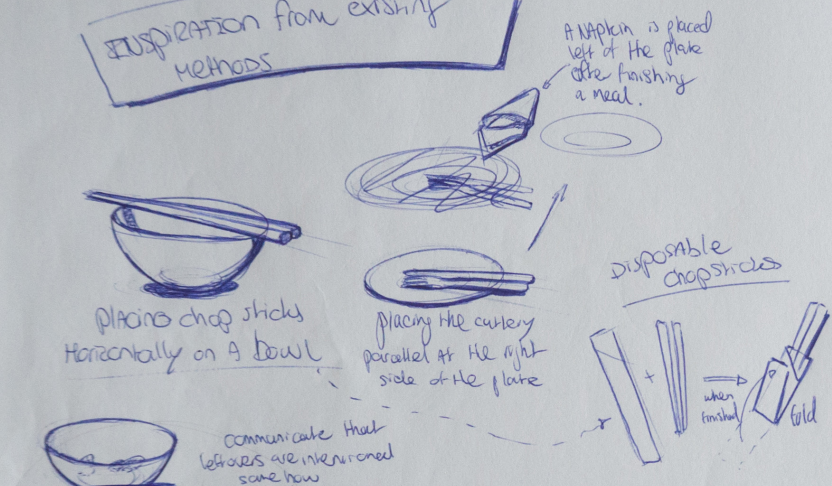
How can you educate about the dying process in a structured manner towards people with strongly religious characters and views on life?

How can a resident effectively signify that they are finished with eating?

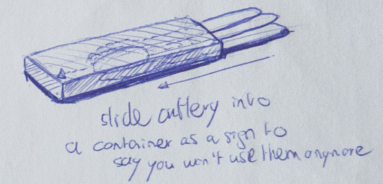
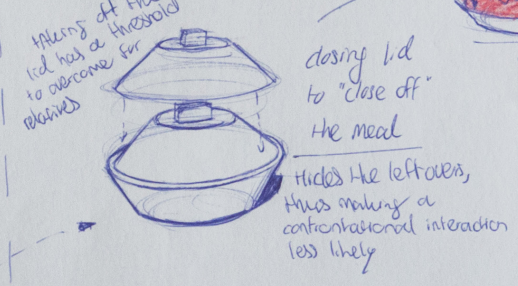
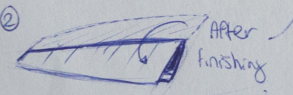
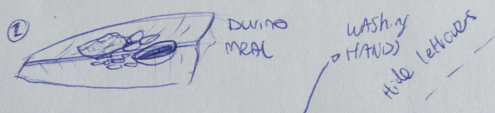
Effective = A relatively simple action, yet hard to overturn by a relative (a large threshold). It should allow the resident to experience a less confrontational interaction when having leftovers



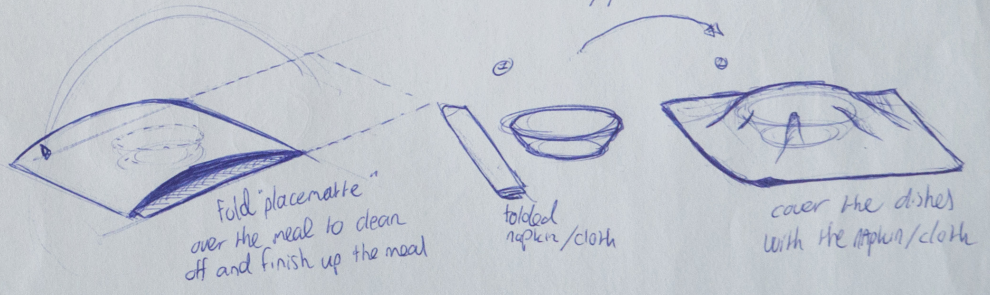
INSPIRATION from existing METHODS



INDIAN DINNER with BANANA LEAF



Other cultures, denying food and/or not finishing your meal is frowned upon, you have to finish your plate

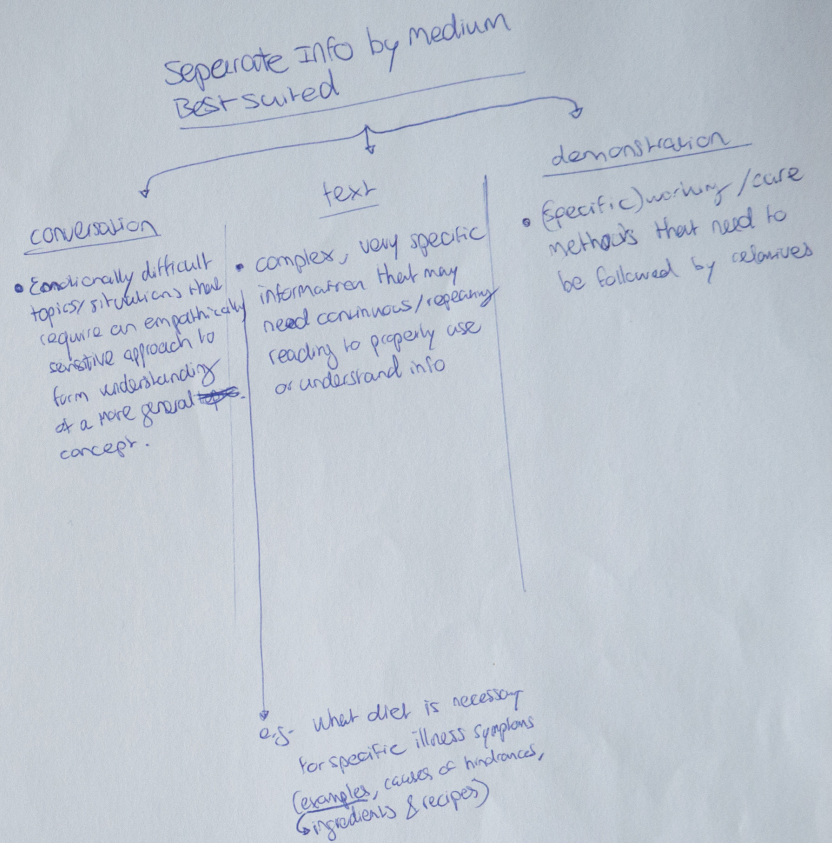
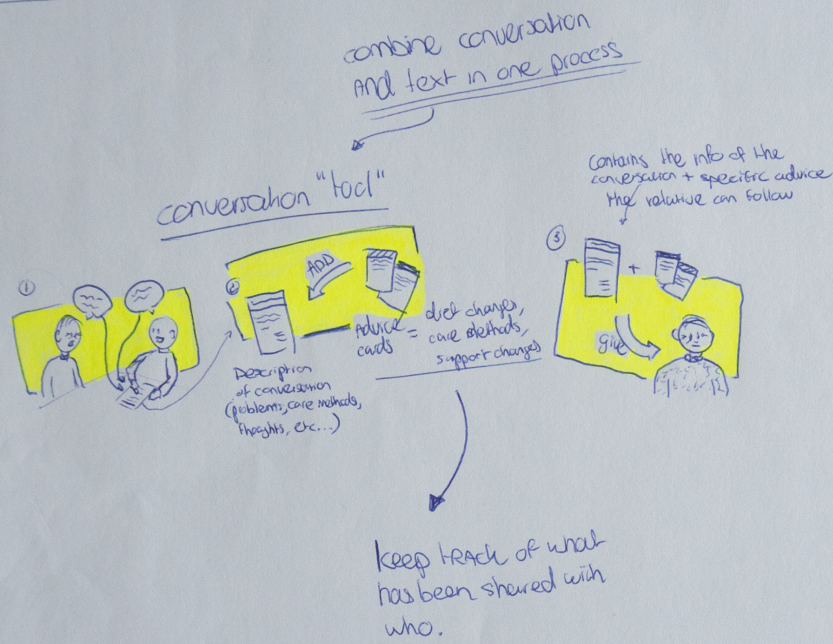


Wat zeg je na een maaltijd?

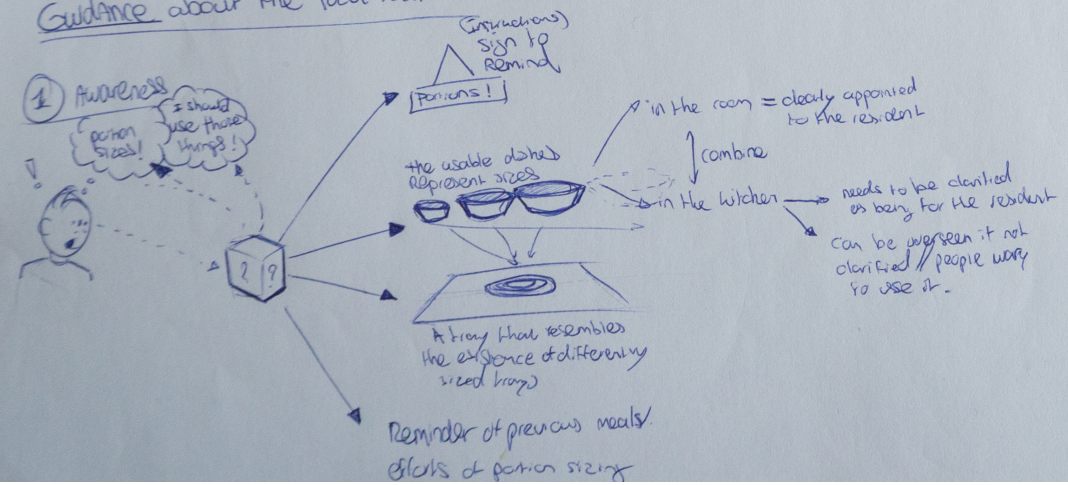
- of wat doe je?
- prayer
- closing words
- wait until your elder is done

or say the meal is finished

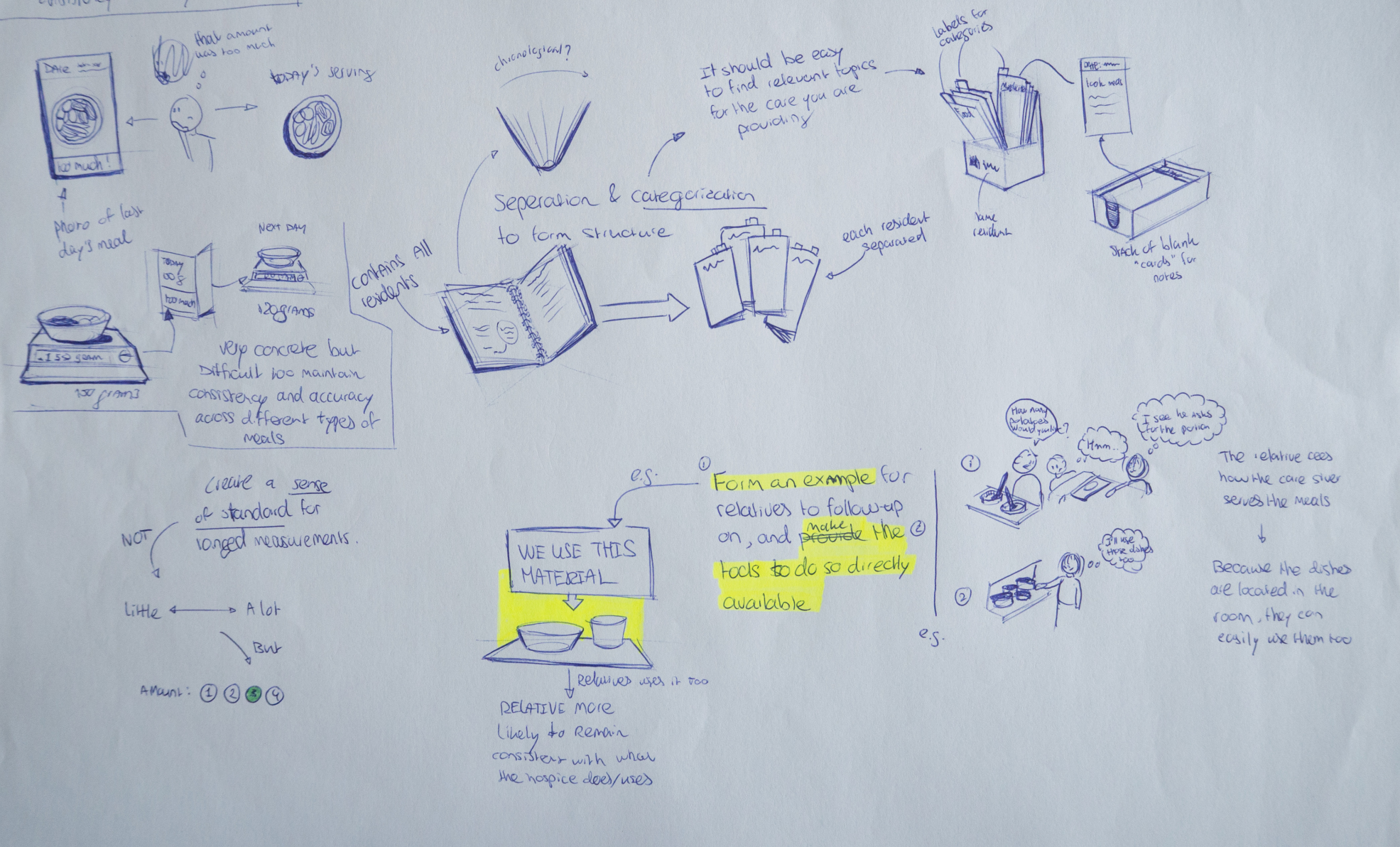
5 How can you advise stakeholders about care in a structured manner, considering the varying backgrounds and abilities of those involved



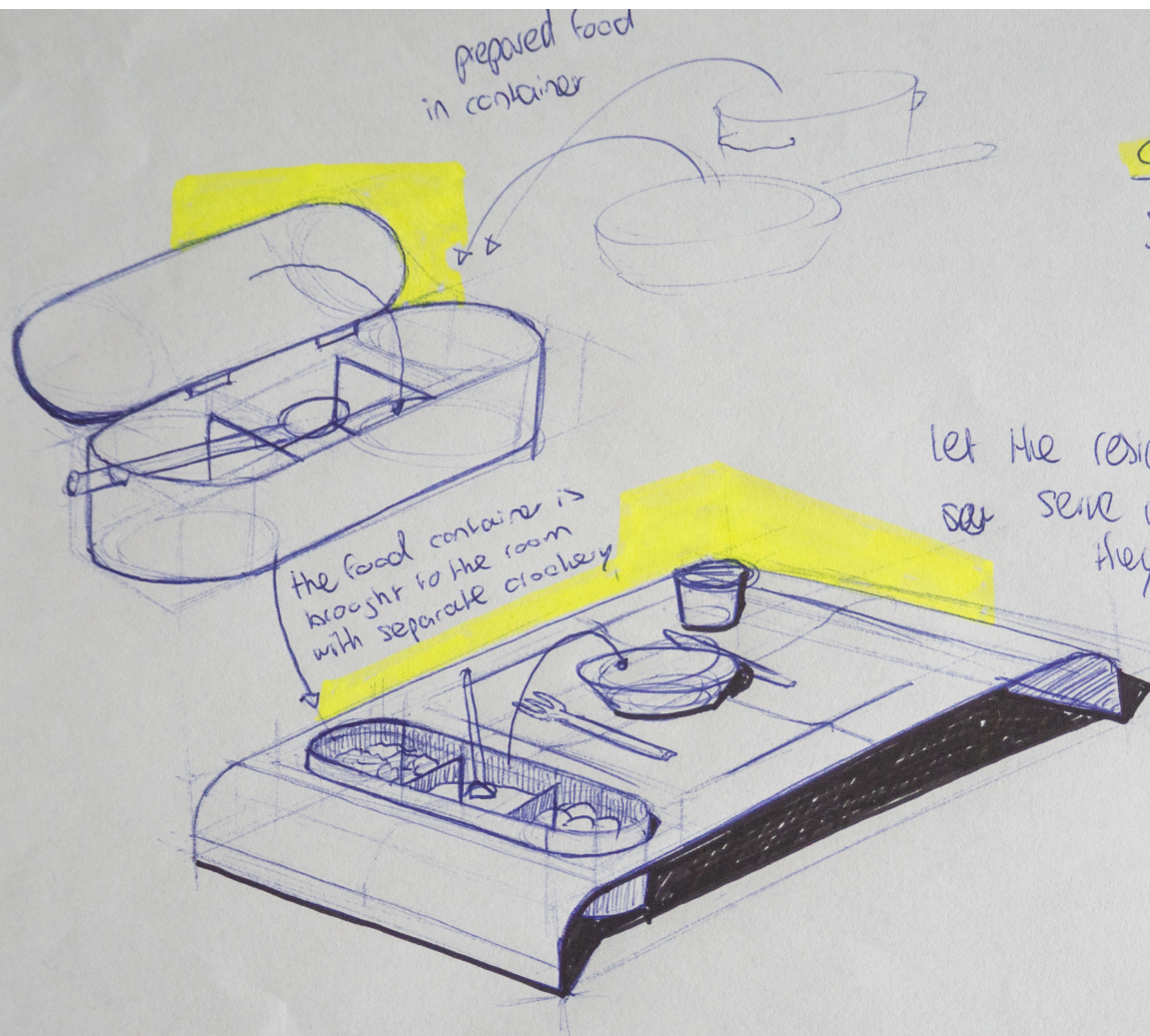
Guidance about the food routine



6 How can you communicate in a structured manner between those involved, to ensure coherence, consistency and clarity of knowledge



Appendix C-3: Initial Concept Sketches



prepared food
in container

concept 1

servings ~~at~~ in
the room

the food container is
brought to the room
with separate crockery

let the resident
say serve up the amount
they want

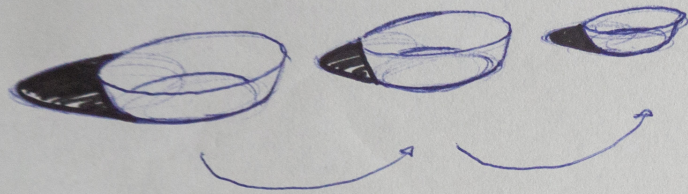
or

help them serve up
but let them indicate
the amount on the
spot.

the proportions need to
be refined into a fitting
size.

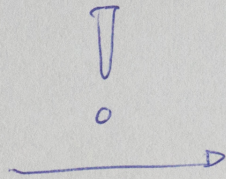
concept 2

A RANGE of Bowls to serve the food in.

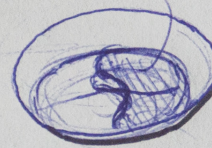


By introducing various sizes of bowls, care givers and relatives become aware that portioning is important. It also puts limits on the food volume and makes attractively serving small portions easier.

The amount of food can still be too large so the design should support good closure



1 section dedicated for leftovers

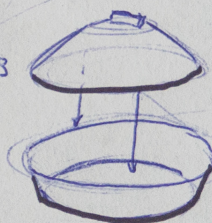


combine?

2 partial cover of the bowl too "hide" leftovers

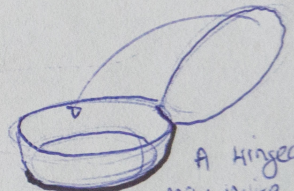


3 cover to take off & put on again



4

A hinged cover, may inspire more to close off



5 give off a sign through a tangible object



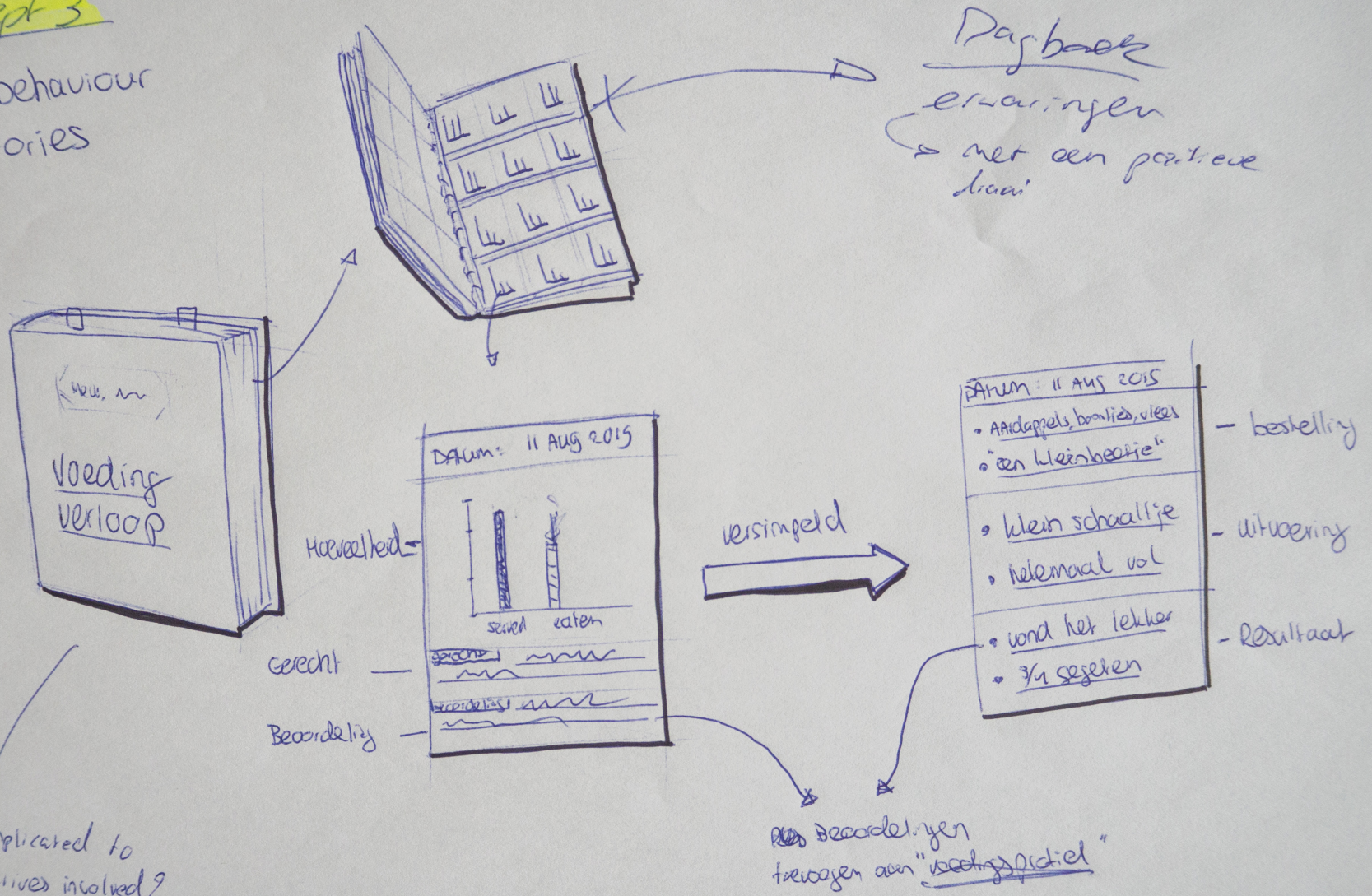
6



A clear signal that you are finished by sounding a bell

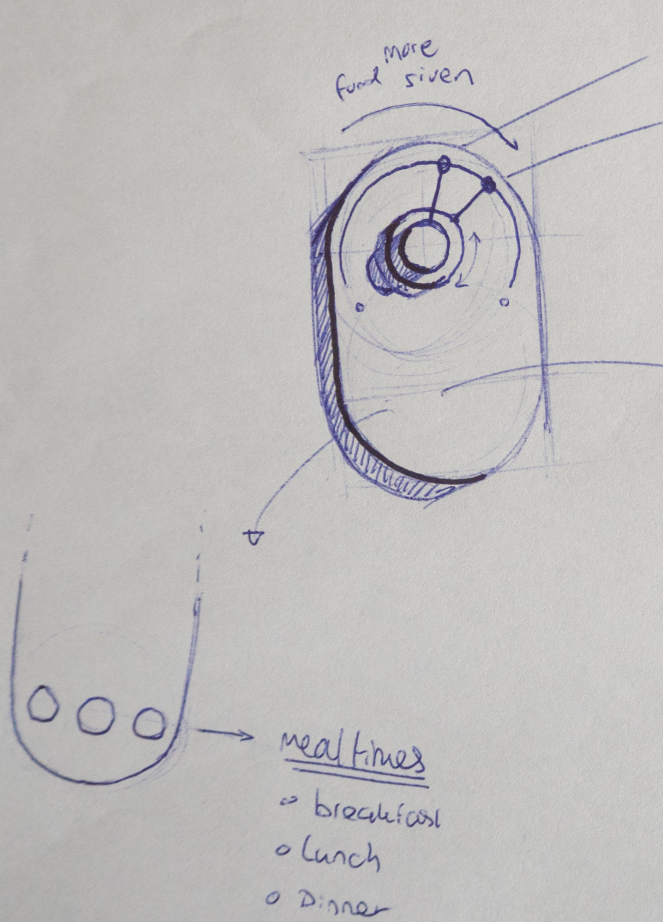
Concept 3

Food behaviour trajectories



Concept 4

The food behaviour clock.

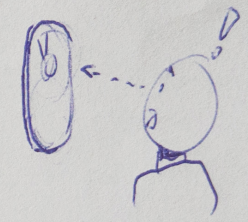


the amount that was eaten
the amount that was served

An addition could be made to ensure more consistency

Adding a standard (such as concept 2) can ensure more consistency by lowering the range of influence from personal implications

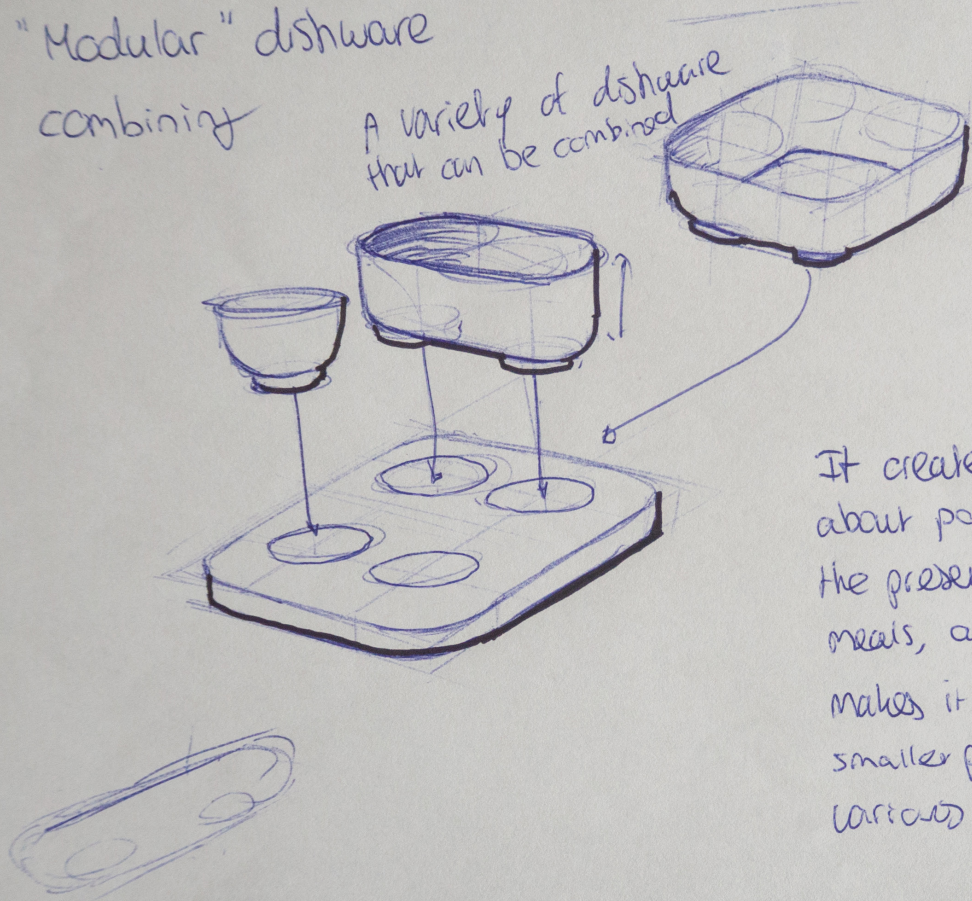
create awareness about the importance of portioning



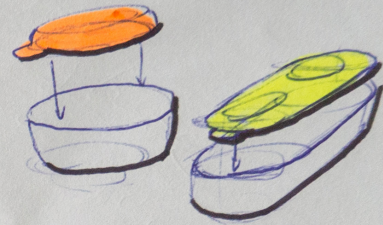
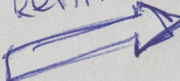
Concept 5

"Modular" dishware
combining

A variety of dishware
that can be combined



Involve the
relatives



Offering the relatives
the option to take home
dishware, with a fitting
cover, may automatically
move them to bring food in
a more consistent matter
to the care givers

It creates awareness
about portioning and
the presentation of the
meals, additionally it
makes it easier to present
smaller portions and
various serving forms

Appendix D: Concept Iterations










The first iteration that is shown shows the first version of the concept, in terms of content of the diary. This iteration attempted to be very complete, to involve all the details that come about during a food care routine. The shortcomings of this iteration were the style in which it presents itself; it is very formal and comes off more as a book for administration, rather than a sensitive diary made for a hospice resident.

The second iteration is closer to the final concept, but still lacks a lot of content that is still necessary to be addressed during a food care routine. It is more of stylistic exploration, to settle on the mood that the final concept should radiate.

The third iteration contains the majority of the content of the final concept design. The main shortcoming is still in the style of the design. Particularly, the colour schemes used in the design are too busy, and too gloomy. Instead, for the final design a simplistic colour scheme was chosen, based on a design collage that was made as inspiration. The collage was helpful to settle on a mood that fit well, before actually designing the final version.

Iteration 1

Voedingszorg Datum _____

Ontbijt	Gevoel en eetlust	Maaltijd	<input type="checkbox"/> 
	_____		<input type="checkbox"/> 
	_____		<input type="checkbox"/> 
Lunch	Gevoel en eetlust	Maaltijd	<input type="checkbox"/> 
	_____		<input type="checkbox"/> 
	_____		<input type="checkbox"/> 
Avonddmaal	Gevoel en eetlust	Maaltijd	<input type="checkbox"/> 
	_____		<input type="checkbox"/> 
	_____		<input type="checkbox"/> 
Andere maaltijden	Gevoel en eetlust	Maaltijd(en)	_____
	_____		_____
	_____		_____
	_____		_____
	_____		_____

Wat wil je delen over vandaag en morgen?

Voorkeuren

Wat vooral wel klaarmaken?

Vermijden

Wat vooral niet klaarmaken?

Iteration 2

Jouw voorkeuren

Bij mijn ontbijt drink ik graag een:

① beker kopje rietje mok glas turkbeles

lunch
middag
avondeten

② water koffie thee melk iets anders:
warm
maar saur
met

tyd?

③ Met iets erin? _____

melk? _____
suiker? _____
zoetjes? _____

Als ontbijt eet ik graag:

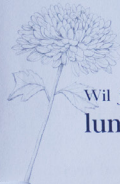
Dagboek voor eten en drinken

Wat wil je eten vandaag?

Wil je graag ontbijten?

Nee, liever niet

Ja, graag



Wil je graag lunchen?

Nee, liever niet

Ja, graag

Wil je graag avondeten?

Nee, liever niet

Ja, graag

- Wat zou je graag willen eten?
- Hoeveel zou je willen eten?
- Hoe heb je het graag opgeserveerd?
- Welk serviesgoed heeft daarbij de voorkeur?

Jouw gewenste maaltijden

Ontbijt

Ja, graag

Lunch

Ja, graag

Avondeten

Ja, graag

Iteration 3



Ontbijt

Hoe laat wil je ontbijten?

[Faint oval graphic]

Absoluut niet

Allergisch of verboden



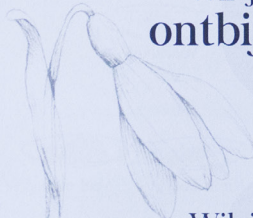
Mijn eten en drinken vandaag:

Datum _____

Met wie wil je graag nog eens
samen eten?

Berichtjes, notities,
foto's, kaartjes, en
meer

Wat wil je eten vandaag?



Wil je graag
ontbijten?

Nee,
liever
niet

Ja,
graag

Wil je graag
lunchen?

Nee,
liever
niet

Ja,
graag

Wil je graag
avondeten?

Nee,
liever
niet

Ja,
graag

Appendix E: Evaluative Interview

Ontwerp Evaluatie

Voorafgaand

Ten eerste bedankt dat je mijn ontwerp wil bekijken en jouw gedachten erover wilt delen.

Zoals je weet heb ik mij voor mijn project bezig gehouden met eten en drinken in het hospice, en hoe de zorggevers en naasten hierin betrokken zijn. Op basis van mijn onderzoek ben ik gaan ontwerpen, en vandaag wil ik graag het resultaat hiervan laten zien.

Ik wil het ontwerp laten zien met een prototype, met scenario's die het gebruik van het ontwerp uitleggen. Daarnaast zal ik ook uitleg geven wat de intentie achter het ontwerp is. Dan hoop ik dat ik daarmee het ontwerp duidelijk genoeg maak om samen in te kunnen gaan op de inhoud van het ontwerp. Bij het bespreken van het ontwerp wil ik uiteraard dat je gewoon eerlijk je mening en gedachten met mij deelt, dat is natuurlijk het meest nuttig voor mij om mijn ontwerp te kunnen verbeteren.

Zoals de laatste keer wil ik graag vragen of ik het gesprek mag opnemen om later terug te luisteren, en bovendien heb ik weer een formulier om te ondertekenen voor het officiële.

Design for Interaction Graduation Project
Eten en drinken in Nederlandse hospice zorg

Maxim Houdijk 4303741

Bespreken van het ontwerp met de scenario's

- Beginnen met voorkeuren deel, introductie van het boek zoals dat ook in het hospice zou gebeuren. Daarna de rest van het gebruik uitleggen.
- Introduceren van dagelijkse deel, met twee onderdelen: dagelijkse vragen, en dagelijks noteren van gewenste maaltijden.
- Dagelijkse vragen uitleggen met visuals.
- Dagelijks noteren aan de hand van gebruik scenario, eerst zorggevers en daarna in het kort van naasten (belangrijke punten eruit pakken).

Intenties van het ontwerp uitleggen

- **Voorkeuren vastleggen** om te zorgen dat de voedingszorg vanaf het begin goed aansluit op de behoeften van de bewoner, en ook consistent blijft aansluiten bij alle zorggevers. Daarnaast biedt het op een later moment een bron van info voor naasten, wanneer zorggevers nieuwe maaltijden gaan uitproberen als het eten moeilijker wordt. Als hiervan iets bevalt kan dit via dit middel gedeeld worden met naasten.
- **Dagelijkse vragen** zijn bedoeld om bepaalde waarden van eten en drinken terug te brengen. Met name een sociaal aspect wordt teruggebracht doordat anderen kunnen reageren op de antwoorden op vragen.
- **Dagelijks noteren van gewenste maaltijden** heeft twee intenties. ten eerste moet het zorgen dat de autonomie van de bewoner over eten en drinken wordt vergroot en het bewustzijn bij de zorgbieder creëren hiermee rekening te houden. Ten tweede, het moet de voedingszorg consistenter maken. Tussen zowel de zorggevers van het hospice, als de naasten die eten en drinken verzorgen. Het doel hiervan is dat de maaltijden die de bewoner krijgt beter bij de behoeften passen en daardoor minder vaak situaties ontstaan waarbij er teveel eten is, of het eten niet goed te eten is, waardoor bewoners eten moeten afwijzen met de lastige gevolgen hiervan.

Vragen evaluatie

Voorkeuren vastleggen

Om te zorgen dat er, zowel door zorggevers als naasten, consistent eten en drinken aangeboden wordt, passend bij de behoeften van de bewoner.

1. Hoe kijk jij naar het vastleggen van de voorkeuren voor eten en drinken om zo eten en drinken te kunnen aanbieden dat aansluit bij de behoeften die de bewoner heeft aangegeven?

Problematiek herkend?
Oplossing nuttig?
Betrekking van iedereen (ook naasten)

2. Wat vind je van de manier waarop dit ontwerp dat doet?

Verwachte gebruikservaring?
Is de informatie die wordt vastgelegd volledig genoeg?
Hoe is de manier van vastleggen?
Efficiëntie van toepassen tijdens de voedingszorg?
Passend in werkwijze van het hospice?

Dagelijkse vragen bewoner

Om “vergeten” waarden van eten terug te brengen en er een gespreksonderwerp van te maken tussen betrokkenen. Het nodigt bewoners uit om na te denken over leuke herinneringen of dingen waar ze naar kunnen uitkijken.

1. Hoe kijk je naar zulke dagelijkse vragen voor een bewoner, onder andere om gesprekken te stimuleren?

Ervaring van de bewoners bij het gebruik?
Type vragen voor bewoners?
Terugkijken en vooruitkijken?
Stimulatie van gesprekken tussen betrokkenen?
Antwoorden helpen om bewoner beter te leren kennen?

Dagelijks noteren van wensen bewoner

Om zorggevers en vooral ook naasten bewuster laten bezig te zijn met het vaststellen van de behoeften van de bewoner over alle aspecten van de maaltijd. Het dagboek helpt vervolgens om bij te houden wat het eetgedrag van de bewoner is, wat naasten bewuster maakt van de gewenste eet- en drink behoeften van de geliefde en zich daar ook op aan gaat passen, waardoor de voedingszorg bij alle betrokkenen consistent wordt.

1. Hoe denk jij over dit vaststellen van die behoeften van de bewoner voor hun maaltijden?

Verhoogd gevoel van controle?
Het dagelijkse vragen naar alle aspecten?
Deelname naasten hierbij?
Verhoogd bewustzijn van aspecten van maaltijd?

2. Wat vind je van het bijhouden van de gewenste maaltijden, om het mogelijk te maken het eetgedrag te herkennen, te kunnen bespreken en de voedingszorg erop te kunnen aanpassen?

Gebruik door zowel zorggevers als naasten?
Welke informatie is nuttig om vast te leggen?
Waardevol voor zorggevers?
Bewustzijn/educatie/kennis opdoen door naasten?

3. Hoe vind je dit ontwerp als middel hiervoor?

Gebruikservaring van het dagboek?
Interactie met bewoner?
Instructies voor maaltijden?
Informatie die wordt opgeschreven?
Wisselwerking met voorkeuren deel?
Passend in werkwijze van het hospice?

Ten Slotte

Afsluitende vragen over het ontwerp.

1. Zijn er verder nog specifieke dingen waarin jij vindt dat het ontwerp tekort komt? Waar je denkt dat het anders moet, of waarbij je denkt dat er iets mist?

2. Wat vind je van de vorm van het ontwerp, hoe het eruit ziet?

Duidelijk?
Passend bij de context?
Uitnodigend?

