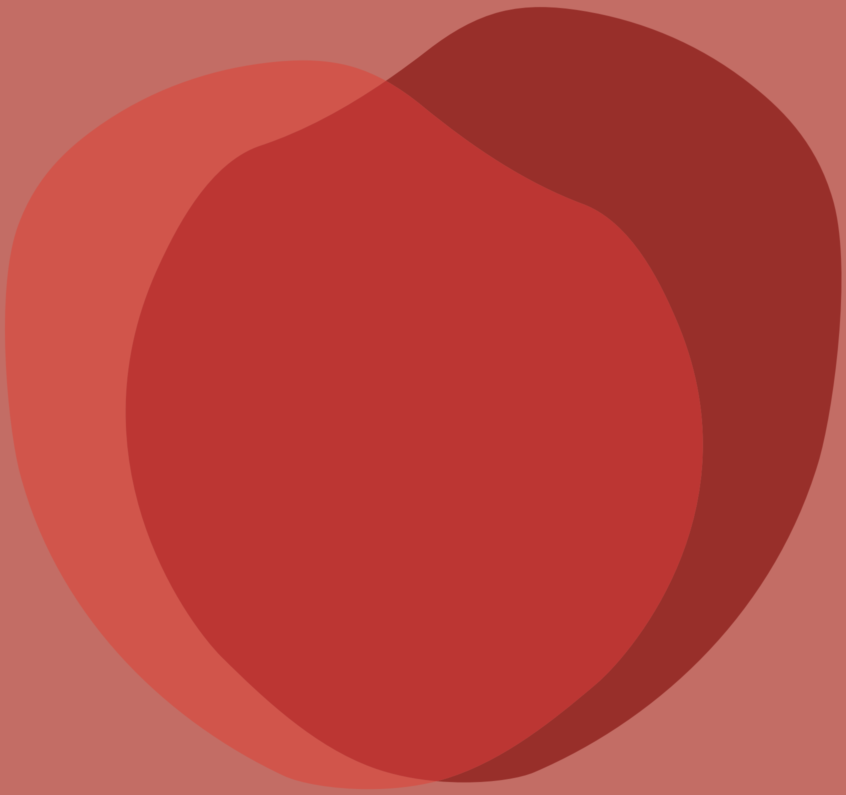


Deciding with heart

Appendix

Martina Pozzoni

Index

B. Explanation of “Pumping Marvellous Foundation” flyer

The Pumping Marvellous Foundation is a British patient led heart failure charity.
Its aim is to promote self-care and self-education through peer to peer coaching and support.
The foundation introduces the visualization of heart failure as metro lines, which served as an inspiration to the visualization of the life-prolonging treatments.
Figure A1 is the front of the flyer and shows the visualization and legend of the treatment path, while Figure A2 shows the back of the flyer, which explains what to expect about the illness management depending by the “zone”.
This flyer lacks information about life-prolonging choices and end-of-life.

Navigating Heart Failure in the NHS

We believe you'd agree that being diagnosed with heart failure is difficult enough to get your head around but having to navigate your way through what care and support you should expect is a completely new problem. We believe our map will give you a good overview of what you may encounter and answer those questions you might find tough.

The Lines

Blue Line

Guidelines and pathways dictate the way patients interact with their heart failure services. The blue line represents this journey; you start at diagnosis and the stations indicate who you interact with whilst managing your heart failure.

Community Line

Where do you spend most of your time? At home of course. Heart failure lives nearly all of its time in the community. This line represents what you should expect from heart failure services outside of the hospital. You may never come off the community line and that's not a bad thing!

Unplanned Hospital Line

Sometimes you may have to visit hospital if your symptoms become difficult to manage. Hopefully you won't spend much time on this line.

Planned Hospital Line

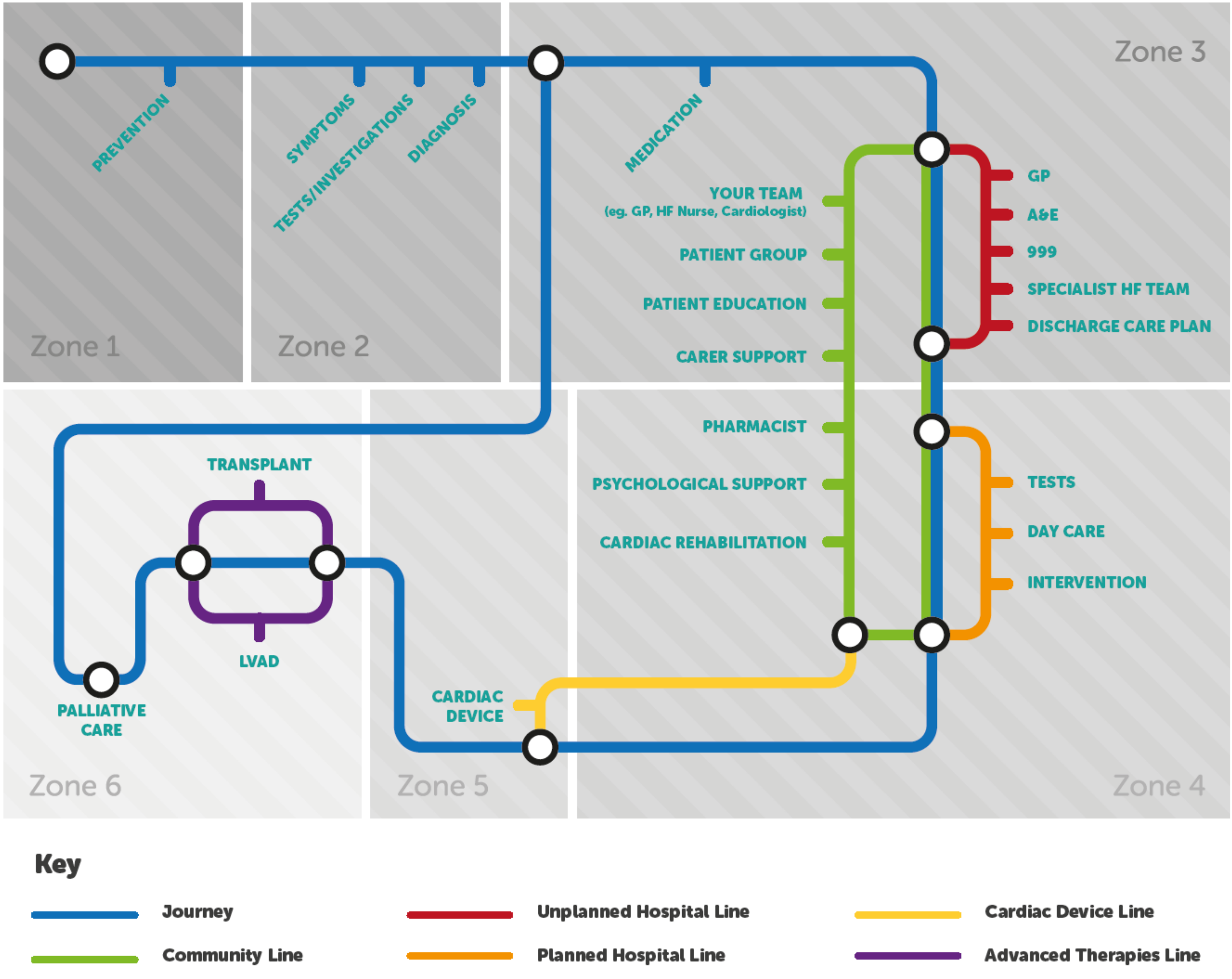
This is a bit of a hop on and off line. It's important for your heart failure team to fully understand your condition so they can ensure you are being treated to the best standards. Planned hospital visits are organised through your heart failure team, they are not unexpected.

Cardiac Device Line

Your heart failure treatment starts off with drug therapy, however your Cardiologist may refer you to have a cardiac device. There are various types of devices that do different things. Once you have had the device you'll probably go back onto the community line. For in depth information about cardiac devices ask your heart failure team for our 'Marvellous Guide to Having a Cardiac Device Fitted.'

Advanced Therapies Line

A heart failure journey can be very complex, and you may find that you are referred to a specialist centre for consideration for a mechanical pump and/or heart transplant.



Pumping Marvellous
The heart failure charity

Welcome to your marvellous map of heart failure in the NHS. This is not a patient's journey, but a reflection of the stops that you can access on your own journey. The stops represent treatment and services that are available to you in our NHS. It could be that you visit many of the stops, get on and get off, and revisit stops that you have been to on other occasions. There may be stops that you do not feel are for you. You may like to try them and see what they have to offer.

We have considered the many guidelines, audits, pathways, and documents that have been produced by the NHS in the UK in relation to heart failure, with the aim of providing you with a patient friendly, easy to understand document of what Clinicians feel is 'best practice'.

Clinicians seek to provide the very best care that they can for their patients, however they are not always able to due to circumstances beyond their control. If after reading this guide you feel you are not being given the care and treatment that you feel you are entitled to, then discuss this with your heart failure team or doctor.

For further information on any of the zones, please visit **www.pumpingmarvellous.org**.

ZONE 1
PREVENTION

We do know that the earlier that your condition is diagnosed, the better you will do. The underlying cause of a patient's heart failure will often determine if this is something that has occurred very quickly, for example if a virus has caused heart failure or if there has been a gradual onset. If you have high blood pressure or have previously had a heart attack, then your GP should be monitoring you every 12 months to ensure that you are not developing heart failure. We do know that these two conditions, in time, can lead to 75% of heart failure diagnoses.

ZONE 2
DIAGNOSIS

This will depend on when you first see someone due to the symptoms of heart failure that you have begun to experience such as breathlessness, tiredness, swollen ankles or feet. Depending on how severe your symptoms are, you may feel you need to go to your hospital or your General Practice. If you present to your GP your doctor will wish to understand your symptoms.

- Your GP will ask you detailed questions about your previous history including any heart problems in your family
- They will take your blood pressure, pulse, and a tracing of your heart (ECG)
- They will also arrange a number of blood tests including how effectively your kidneys and liver are working, if you are anaemic, or have a thyroid problem
- They may arrange a chest X-ray

Importantly they should perform a blood test called B-type Natriuretic Peptides or BNP. When the heart is under stress it releases a hormone, called a natriuretic peptide. If this is above normal it means there is a possibility that you have heart failure. If this is very high your GP will refer you to hospital for an ultrasound scan of your heart (echo) to be completed within two weeks, otherwise you should have an appointment in six weeks. If you have had a previous heart attack, again the aim should be for you to be seen in two weeks. An echo will confirm a diagnosis of heart failure and the reason why you have it.

Heart Failure Care in the Hospital

If you have been admitted into hospital with suspected heart failure, there is evidence to suggest certain care and treatment will provide you with the best outcome. The National Heart Failure Audit in England and Wales has shown that you will do significantly better if you are given good clinical management, are under the care of a Specialist Cardiologist and are followed up by a heart failure team after you have been discharged. The aim should be that you get the right treatment, at the right time, in the right place. If you are admitted with severe symptoms, including severe breathlessness, extreme swelling, this is called acute heart failure.

Tests and Investigations

If it is suspected that you are in acute heart failure then you should have the specialist blood test, natriuretic peptides (as above). If this comes back raised then you should have an ultrasound scan of your heart (echo) within 48 hours. If you are in acute failure you should see the specialist team within 24 hours.

Treatment

You are likely to be offered diuretic therapy in order to rid the body of excess fluid that may have gathered in your lungs and other parts of the body. This is likely to be given via an injection or drip and you will be closely monitored to see how your body is coping. If you are critically unwell the team should assess you for specialist intervention therapy which may include life support machines to assist your breathing and machine support to help your kidneys to function. You will be started on treatment that is known to treat heart failure in the most effective way, including tablets such as Beta Blocker therapy, ACE inhibitors and specialist diuretics (water tablets).

Discharge Arrangements

You should not be discharged from hospital until you are stable and you are on optimised treatment. Your wishes and those of your carers should be taken into account, support services in the community should have been arranged and your GP and any supportive services in the community should be aware of your treatment plan. You should be given education, support and monitoring advice to ensure you know what to do if you experience any difficulties and who you should contact. You should also be seen by a specialist heart failure team, who are either hospital based or who sit in the community, within two weeks of leaving hospital, as early reviews reduce the chance of you being re-admitted and ensures that your long-term outcomes are better and that you are able to have a better quality of life.

ZONE 3
MANAGING HEART FAILURE - MEDICATION

Research has identified key medication which can help your heart to function more efficiently and improve your quality of life and life expectancy. If your heart is failing to pump efficiently it is called HFrEF or LVSD. Listed below is a group of drugs you should be assessed for and prescribed if they are appropriate for you. You can look up how they work and the side effects on our marvellous website in the Patient Academy or our 'Marvellous Pocket Guide to Living Well with Heart Failure.'

ACE inhibitor or ARB (ease the workload by relaxing the blood vessels around the heart)
Beta Blocker (make the heart beat slower but stronger)
Diuretic therapy (remove fluid)
MRA (a type of diuretic)
You may also be considered for the following drugs;
Ivabradine (if you are unable to tolerate a Beta Blocker, or as an addition if your heart rate is too fast)
Sacubitril Vaslsartan (a new type of drug that block enzymes which may strain your heart and enhances the systems that protect your heart)

Usually, these drugs are started at low dosages and are gradually increased until you are on the target dose or a maximum dose that you are comfortable with. During this process you should be seen every two weeks to ensure your pulse and blood pressure are within normal range and that your potassium levels aren't affecting your kidneys. If a heart failure specialist believes that your heart failure is due to your heart being unable to relax and fill sufficiently it is called HFpEF, you will be prescribed a diuretic and possibly other medication to control high blood pressure or diabetes. Your team should include as a minimum a Cardiologist, Heart Failure Nurse and your GP.

ZONE 4
MANAGING HEART FAILURE - REHABILITATION

Cardiac rehabilitation should be offered to patients with a menu of a choice of activities including education and psychological support, offered in the patients preferred setting, either at home, or in a community or hospital setting, and at a time which makes accessibility easy for everyone. The guidance also recommends that you have access to psychological support if you have any anxiety or depression issues. This support should be offered via a team of health professionals that are devoted to heart failure. You will find as you are getting used to managing your heart failure that the pharmacist will have a big role to play to help you understand your medications and their interactions with common off the shelf medications. The guidance recommends patient to patient support, so do visit **www.pumpingmarvellous.org** where you will find a vast range of interactive support tools to support and advise you and your family.

ZONE 5
CARDIAC DEVICE

Depending on your symptoms and along with a number of tests and investigations which will show how efficiently your heart is working, you may be appropriate for a complex pacemaker. The criteria to ensure that you are a suitable candidate for a device is complicated, therefore we recommend that you have a look at our 'Marvellous Guide to Having a Cardiac Device Fitted' which is available in our Patient Academy section on our website.

ZONE 6
ADVANCED THERAPIES

In severe heart failure, your Clinician will discuss with you the various options that may be available to you and a detailed assessment may be offered to you at a specialist cardiac centre (known as a tertiary centre). At various times palliative care services may be suggested to you. At Zone 6, all treatment options are supported by palliative care services.

Left Ventricular Assist Device (LVAD)

An LVAD is a mechanical pump that assists the heart to pump. This is a highly-complex procedure that requires open heart surgery, as the device sits inside the chest connected to a control system and a battery that sits outside the body. The device may be permanent or as a bridge to transplant.

Heart Transplantation

Specialist referral should be considered for those patients with severe symptoms that are not improving despite good drug and device treatment.

Palliative Care

The guidance also acknowledges that for some patients their condition may deteriorate markedly and are not suitable for heart transplant. Early discussion with patients and their carers around prognosis and how their heart failure is failing to improve should be undertaken and palliative services offered. We believe that Palliative care isn't just end of life care, it has positive impact on your quality of life. Hence our branch line connecting you back into the community line where you have as much right as anyone to access services if you need them.

PLEASE NOTE: This document should not replace and/or substitute the interactions with and advice you are given from your Healthcare Professional. If you have any concerns about your condition then do discuss them with your Healthcare Professional at the earliest opportunity.

Our thanks go to the Marvellous Clinicians of the NHS who supported us in the production of this document and our Marvellous patients and carers of Pumping Marvellous. We would also like to thank Boston Scientific for providing this unrestricted educational grant.

C. Topic list for the interviews with healthcare providers

Questions used as a guide in the interviews with healthcare providers:

In English:

- What kind of life-extending treatments involve heart failure patients at the end of their life? (antibiotica, sondevoeding, vocht opname…)
- Could you think of a situation where you were involved as a nurse/as a doctor with a patient who had to make a treatment choice about life-extension?
    - [I could use the timeline?]
    - How do you usually proceed? (Who talks with whom?)
- Who is involved in the discussion with the patient? And in the decision?
- Who is responsible for the decision?
- What is your role in the decision of a treatment?
- Where is the discussion held?
    - What is important for you in the discussion with the patient?
    - Would you do it differently?

In Dutch:

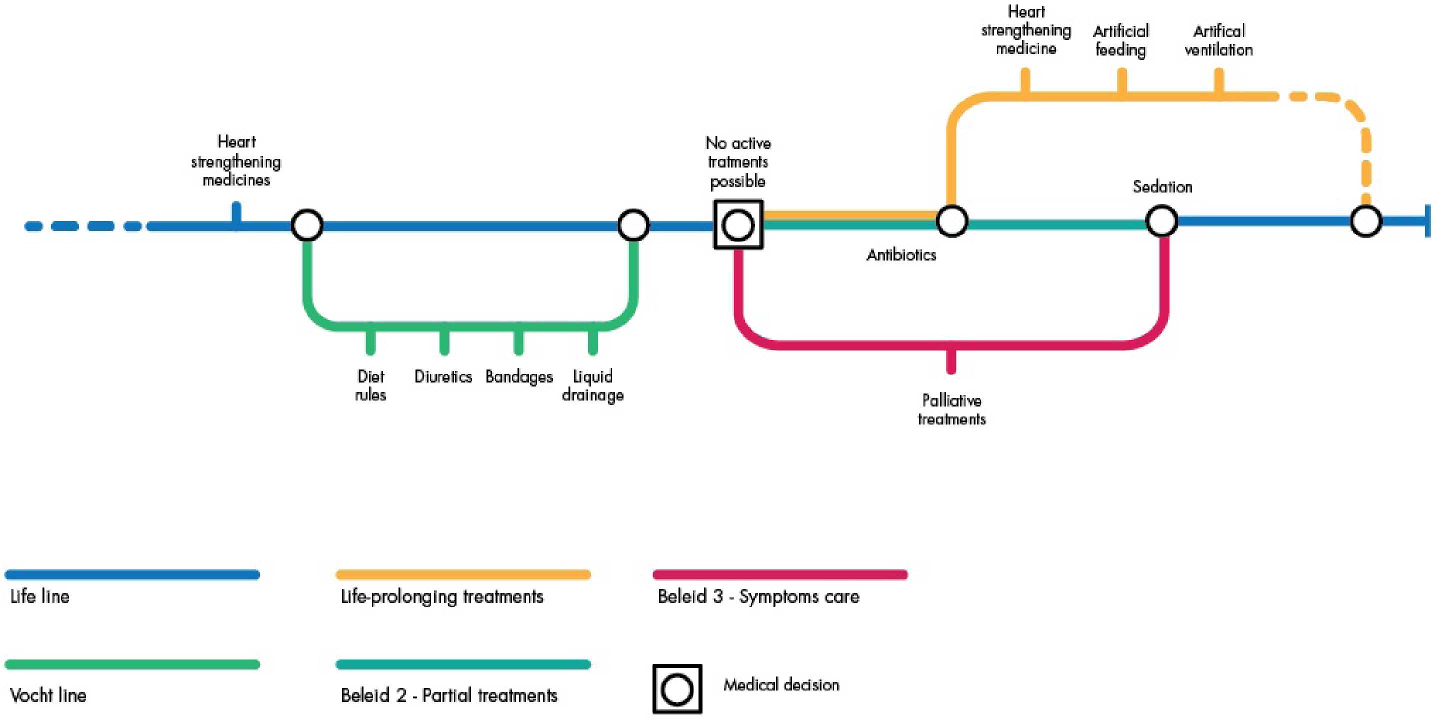
- Welke levensverlengende behandelingen hebben hartfalenpatiënten aan het eind van hun leven? (antibiotica, sondevoeding, vocht opname…)
- Kun je een situatie bedenken waarin je als verpleegkundige / als arts betrokken was bij een patiënt die een behandelkeuze moest maken over levensverlenging?
    - [Kan ik de tijdlijn gebruiken?]
    - Hoe gaat u gewoonlijk verder? (Wie praat er met wie?)
- Wie is betrokken bij de discussie met de patiënt? En in de beslissing?
- Wie is verantwoordelijk voor de beslissing?
- Wat is uw rol in de beslissing van een behandeling?
- Waar vindt de discussie plaats?
    - Wat is belangrijk voor u in de discussie met de patiënt?
    - Zou je het anders doen?

D. Progess of the life-prolonging options visualisation

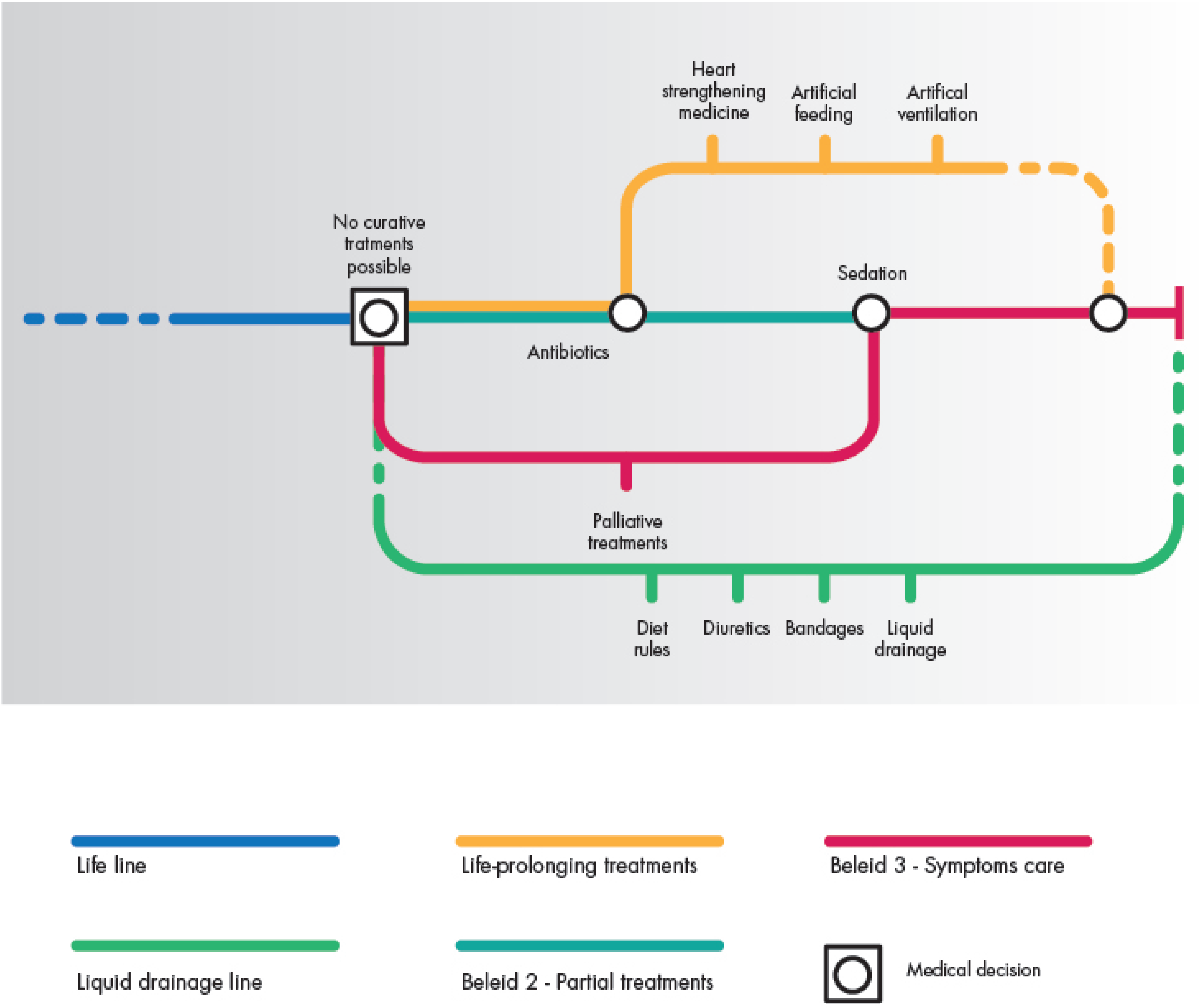
The visualization of the life-prolonging treatments had three iterations.

The first version showed the “Vocht line” or “Liquid drainage line” before the medical decision of stopping treatments. This was incorrect, since the treatments for the drainage of liquids continue during the whole illness trajectory.

First Version

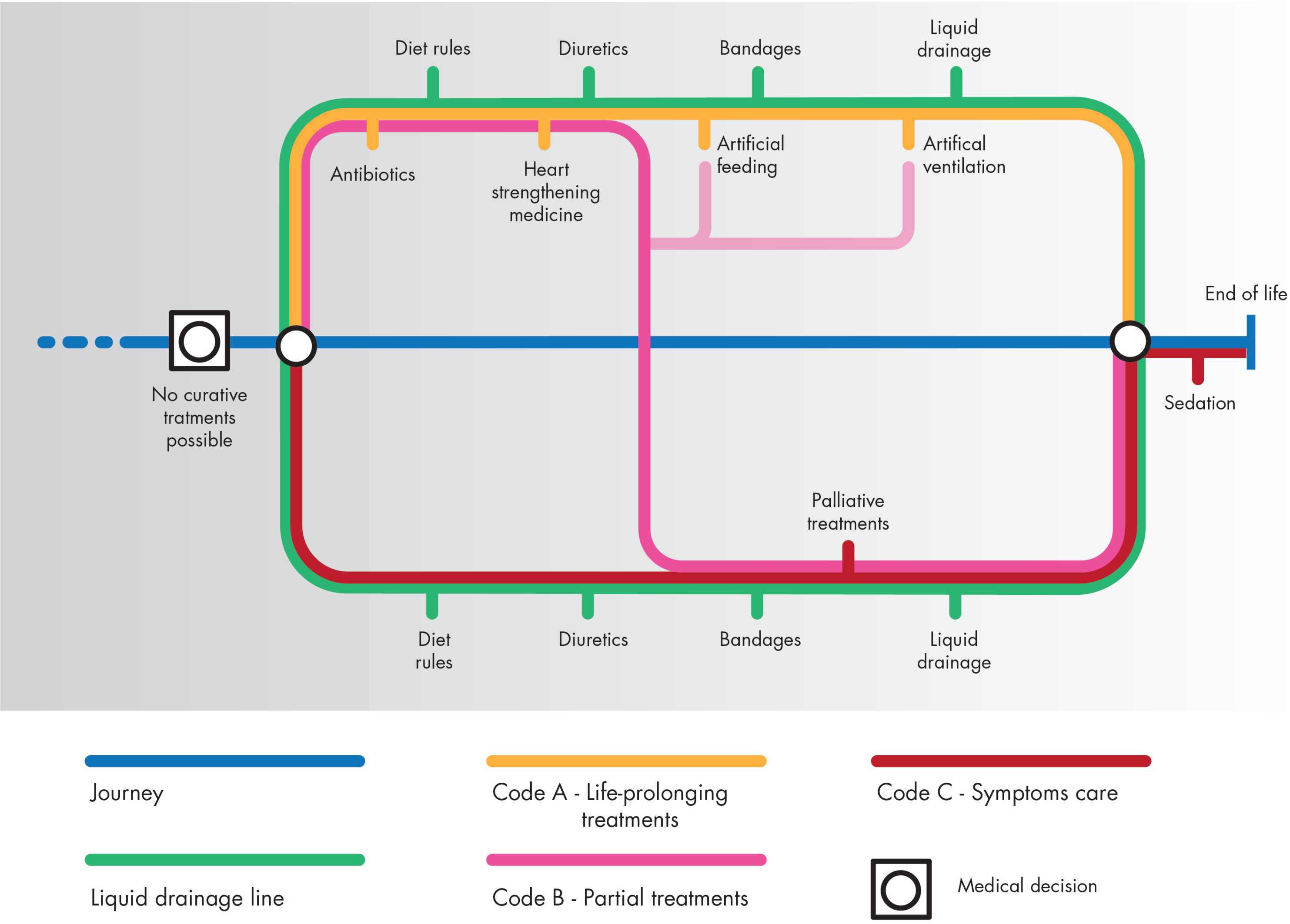


Second Version



The second version included the liquid drainage line as a treatment after the medical decision of interrupting medical treatments. This visualization was not clear since the life line seemed interrupted and there was no mention of the end of life. The dotted line were also confusing.

Last Version



The last version includes a staright Journey line, which terminates with the wording "End of life". The term journey was more approprate for coherence with the Pumping Marvellous Foundation flyer and for clarity of its meaning.

The name have been changed from the Dutch term Beleid 1,2,3 to Code A,B,C.

Both the "Code A - Life-prolonging treatments" line and the "Code C- Symptoms care" line include the liquid drainage treatments.

The line "Code B - Partial treatments" shares the path with Code A and C, and represents the chance for the patient to change their mind halfway.

The end of the line includes sedation as a possibility for all trajectories.

E. Topic list for the interviews with heart failure nurses

Intro:
Hello, thank you for giving me the chance to interview you. I am Martina Pozzoni and I am a graduating student from TU Delft. My graduation project is part of ZonMw Palliantie project: “Appropriate care in the patient last phase of life by involving nurses in shared decision making” started in 2018 in collaboration with VUmc, Red Cross Hospital, and Spaarne Hospital, of which dr. Irene Jongerden is the project leader.
My project focuses in particular on supporting shared decision making process about life-sustaining treatment decisions with heart failure patients, in the end-of-life stage.

Toestemming + Recording

Questions:
- What does it mean to be a heart failure nurse?
- Why did you choose to become a heart failure nurse?

I observed that sometimes you are involved in the MDO in Cardiology with doctors, specialists and nurses in deciding the aftercare plan with the patients and in the discussion of treatment decision with the patients.

- Could you think of a situation where you were involved as a nurse with a patient who has to make a choice about life-prolonging treatments?
  - Are you often involved?
  - How do you usually proceed?

- Show process and lines of treatments: do I miss something?

- What is important for you in the discussion with the patient?
- What do you find difficult?
- What would you make different?

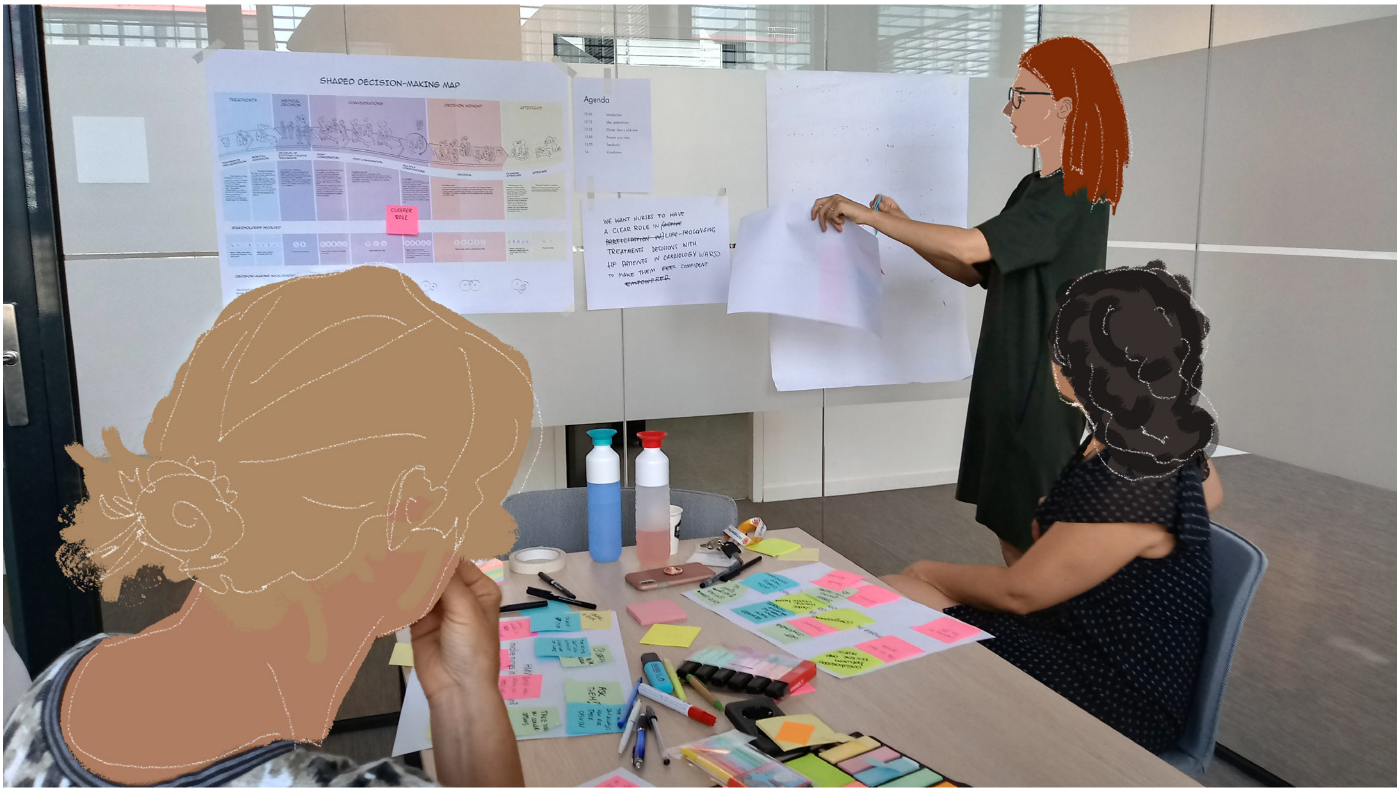
- Would you consider decision aids in the conversation with a patient?
  - Why? What do you think is important in a decision aid?

F. Creative sessions

For the ideation phase, three creative sessions have been organized: one in the VUmc and two in collaboration with the course "Creative Facilitation" with TU Delft students.

Creative session with VUmc employees

I personally organized and participated to the with other three VUmc employees.

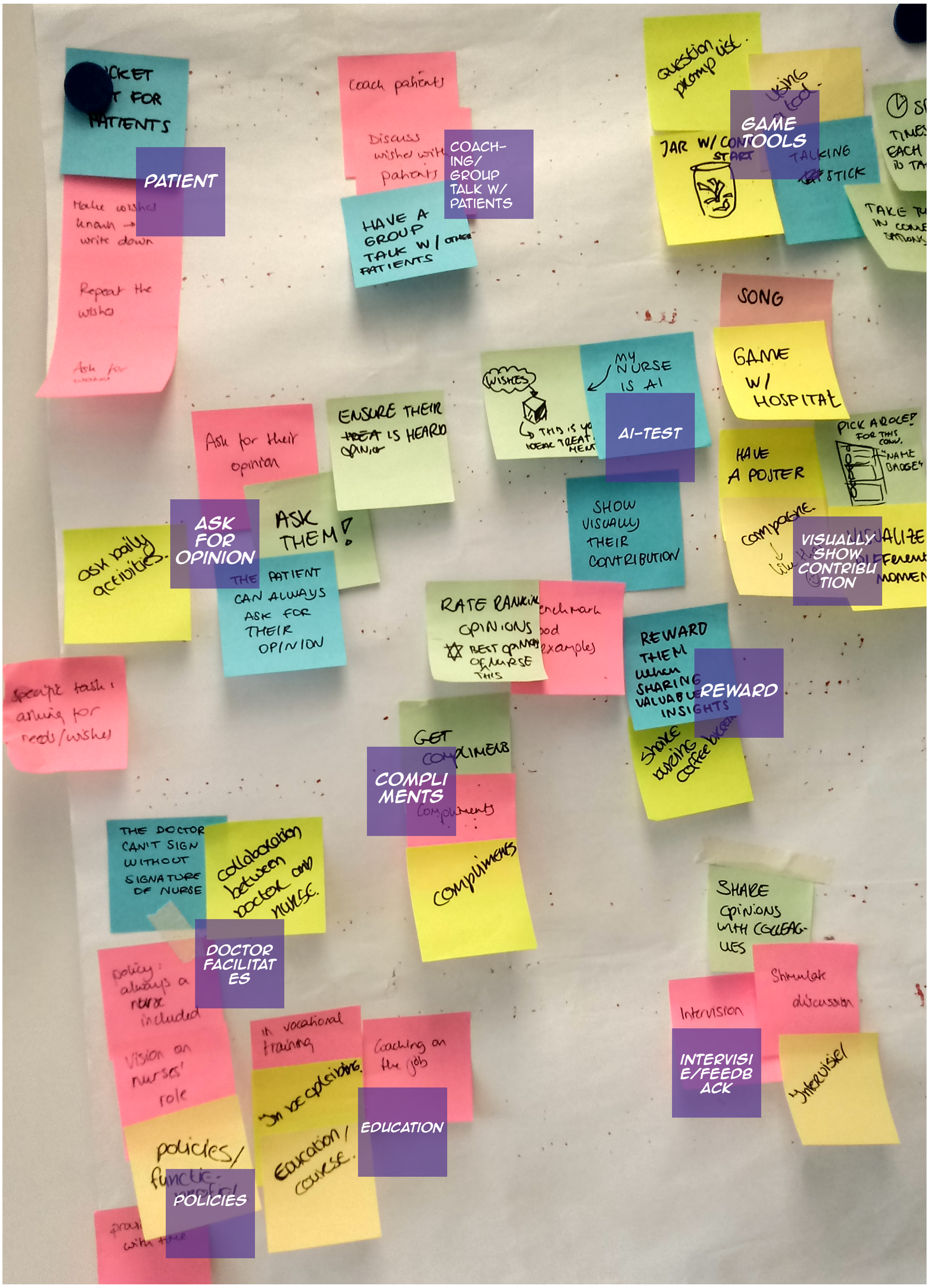


The session started by understanding the problem using the 5Ws. After this step, we formulated the design goal, which is the following: "We want nurses to have an active role in life-prolonging treatments decision with heart failure patients in the Cardiology ward, to make them feel confident."
Then we did used the ideation method of "How might we" to generate ideas. The approach involves the development of sheets of paper with "How might we" questions that are shared among the participants. The participants have 1 minute to generate solutions to a question and write them on post-its. When the time is up, the paper sheet is shared to the next participant. During the session we did two rounds of ideas for sheet. The questions where:

How might we…

a. Involve nurses in the conversation?
b. Make nurses more confident of their opinion?
c. Support patient's treatment wishes?

This led us to have multiple ideas that are shown in Figure D2. The different ideas were clustered and served as inspiration for the development.



PATIENT
COACHING/ GROUP TALK W/ PATIENTS
GAME TOOLS
AI-TEST
ASK FOR OPINION
VISUALLY SHOW CONTRIBUTION
REWARD
COMPLIMENTS
DOCTOR FACILITATES
EDUCATION
INTERVISIE/FEEDBACK
POLICIES
Make wishes known → write down
Repeat the wishes
Coach patients
Discuss wishes with patients
HAVE A GROUP TALK W/ OTHER PATIENTS
question list prompt
JAR W/ CONV. START
using tool
TALKING STICK
TAKE TURNS IN CONVERSATIONS
SONG
GAME W/ HOSPITAL
Ask for their opinion
ENSURE THEIR IDEA IS HEARD
WISHES
MY NURSE IS AI
THIS IS YOUR IDEAL TREATMENT
HAVE A POSTER
PICK A ROLE FOR THIS CONV.
NAME BADGES
ASK THEM!
ask daily activities
THE PATIENT CAN ALWAYS ASK FOR THEIR OPINION
SHOW VISUALLY THEIR CONTRIBUTION
compagne
VISUALIZE DIFFERENT MOMENTS
RATE RANKING OPINIONS
BEST OPINION OF NURSE THIS
Benchmark good examples
REWARD THEM WHEN SHARING VALUABLE INSIGHTS
Share during coffee break
Specific task: asking for needs/wishes
GET COMPLIMENTS
compliments
THE DOCTOR CAN'T SIGN WITHOUT SIGNATURE OF NURSE
collaboration between doctor and nurse
compliments
SHARE OPINIONS WITH COLLEAGUES
Intervision
Simulate discussion
Intervisie
policy: always a nurse included
vision on nurses' role
in vocational training
Coaching on the job
on the job
Education/ course
policies/ function profile

Creative sessions with TU Delft students

Two other sessions were organized by the students of the course “Creative facilitation” from TU Delft. In these sessions, I was involved as a project owner and I participated in session A as a participant.

Session A

During this session I was involved as a project owner and as a participant. The session last 2 hours and it was organized by Emanuele Gandini.

The session included:

- Energizing exercise
- Problem exploration
- Problem statement and design goal
- Interaction vision
- Brain writing
- Clustering ideas
- Developing concept ideas

Session B

Session B was organized by Maira Ribelles. I personally did not participate at the session, but the ideas and procedure were shared with me.

The 2-hours session included:

- Enacting the situation
- Context understanding
- Ideation through crazy thinking

Concept ideas from the sessions:

Artwork
The nurses colour their confidence level on an artwork on the wall.

Bucket list decision based
The patient writes or draws what they still want to do, then they can see what treatment it may be more suitable.

Boardgame nurse-patient
The patient plays this boarding game in which they imagine and take the roles of the people involved in the decision. Outcome: overview of the consequences of the decision.

Celebrating day
The patient shares their decision with friends and family with a party.

Bury a decision
The patient writes the decision on a piece of paper and buries it in a pot with a plant. The plant will grow with the decision, even after the patient's death.

Tea party
The nurses schedule a moment in the day for "tea parties" with patients, in which they get to know them and share time together.

Positive nature
Bringing positivity to the patient through nature by having excursions or experiencing it through VR. This to distract the patient from their depressing real-life experience.

Comfort hug-blanket
The patient and the nurse lie next to each other with a blanket with sensors. It aligns their breath while taking the decision, fostering intimacy between the two.

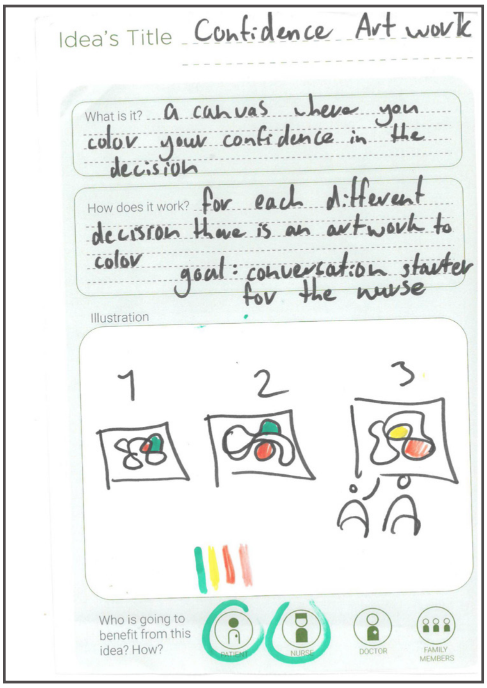
Ending "like an animal"
Using a tool to help the communication of end-of-life. Inspiring patients with animal metaphors, by showing how an animal death in a natural way. An example showing a fish disappearing in the sea.

Emotion cards
Life-game in which cards represent emotions nurse and patient play to plan therapy accordingly.

Multisensorial room
A toolbox, including VR, that controls sound, smell, light and temperature to create harmonic situations to improve the patient's experience.

It's all about you
1. The patient writes a script with their memories, and their story turns into a movie.
2. Teddy bear records the patient's stories, buffering emotion between nurse/patient.

Then nurses can understand the emotional value.



Idea's Title Confidence Art work

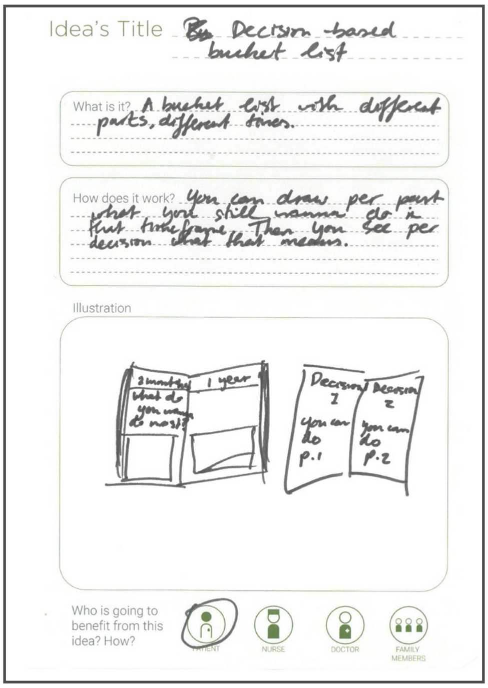
What is it? a canvas where you color your confidence in the decision

How does it work? for each different decision there is an artwork to color

goal: conversation starter for the nurse

Illustration

Who is going to benefit from this idea? How? [✓ PATIENT] [✓ NURSE] DOCTOR FAMILY MEMBERS



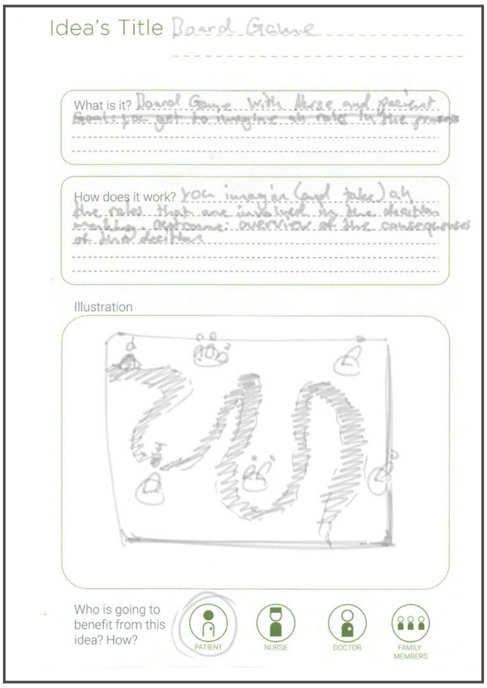
Idea's Title ~~Bu~~ Decision-based bucket list

What is it? A bucket list with different parts, different times.

How does it work? You can draw per part what you still wanna do in that timeframe. Then you see per decision what that means.

Illustration

Who is going to benefit from this idea? How? [✓ PATIENT] NURSE DOCTOR FAMILY MEMBERS



Idea's Title Board Game

What is it? Board Game with Nurse and patient ~~Goal: you get to imagine all roles in the process~~

How does it work? you imagine (and take) all the roles that are involved in the decision making. outcome: overview of the consequences of [illegible] decision

Illustration

Who is going to benefit from this idea? How? [✓ PATIENT] NURSE DOCTOR FAMILY MEMBERS

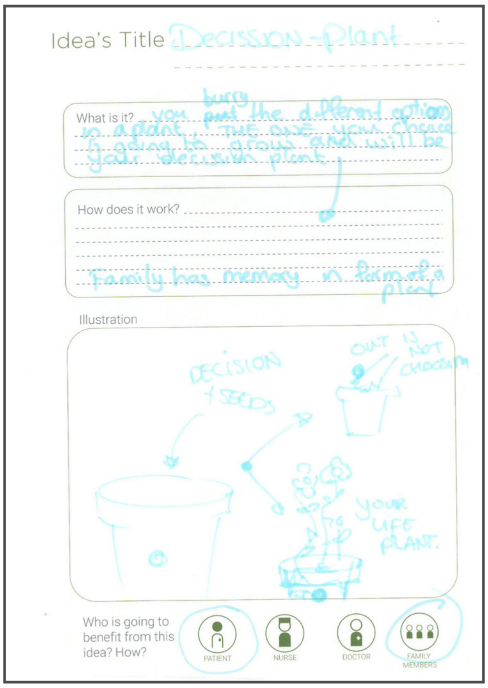
Idea's Title REVEAL DAY!

What is it? CELEBRATING DAY YOU SHARE WITH FAMILY AND FRIENDS

How does it work?
3 WHAT IS CHOSEN
2 WHY IS IT CHOSEN
1 WISHES

Illustration

Who is going to benefit from this idea? How? PATIENT NURSE DOCTOR FAMILY MEMBERS



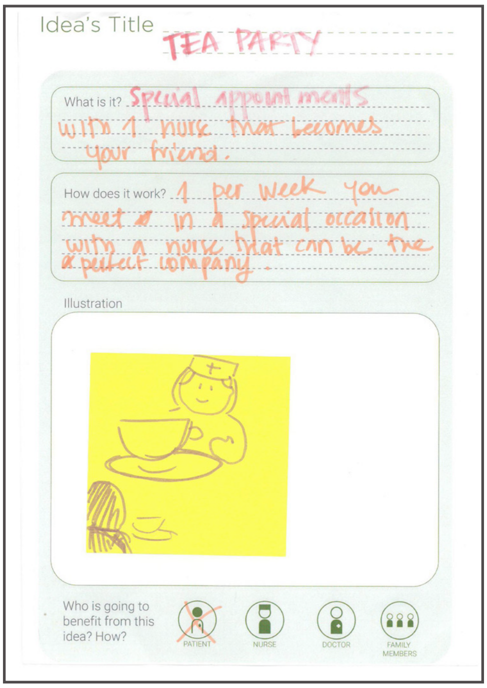
Idea's Title Decission-Plant

What is it? you ~~put~~ burry the different options in a plant. THE ONE YOU CHOICE is going to grow and will be your decision plant.

How does it work? Family has memory in form of a plant

Illustration

Who is going to benefit from this idea? How? [✓ PATIENT] NURSE DOCTOR [✓ FAMILY MEMBERS]



Idea's Title TEA PARTY

What is it? Special appointments with 1 nurse that becomes your friend.

How does it work? 1 per week you meet ~~a~~ in a special occasion with a nurse that can be the ~~a~~ perfect company.

Illustration

Who is going to benefit from this idea? How? ~~PATIENT~~ NURSE DOCTOR FAMILY MEMBERS

Key-takeaways

Although some of the final ideas were not applicable for the context, I found great inspiration from these sessions. In fact, having different people looking at the problem and reframing it in a different way was really helpful for my creative process. Some ideas paid particular attention to certain aspects of the situation, such as the emotional value, which was a concern that I tried to implement in my final design.

G. Topic list for the evaluation of Booklet “Deciding with heart”

Topic list for evaluation of the concept with nurses:

Think of a situation where you were involved as a nurse with a patient who has to make a choice about life-prolonging treatments. After the patient had the conversation with the doctor about the end of his treatments, he is accompanied back to his room by the nurse. In this moment the nurse explains the content of the conversation in simpler terms.

No written information is shared.

My design is a booklet that can be used to explain the patient his prognosis and his options. The first part of the booklet is a bout understanding what and who is important for the patient and his fears, to support him in making the right decision.

- Could you use it in practice? Why/Why not?
- Would this help you in talking with the patient?
- What do you think about it?
- Is there something that you like? Something that you don’t like?
- Is it clear?
- What would you make different?
- Is there something missing?
- Would you advise this to a colleague?

Topic list for evaluation of the concept with patients’ representatives:

- How would you like to receive it? From whom?
- Would this help you in asking questions to your healthcare provider?
- What do you think about it?
- Is there something that you like? Something that you don’t like?
- Is it clear?
- What would you make different?
- Is there something missing?

H. Patient decision aids

Brochure: “Hartfalen: wat is dat?”

The brochure “Hartfalen: wat is dat?” is a detailed booklet developed by the Hartstichting, which provides information about heart failure. It describes the characteristics of the illness, the symptoms, the medicines and treatments that are available for a patient with heart failure.

Strengths and limitations: This booklet is targeted to newly diagnosticated patients. End-of-life care is not mentioned. The booklet consists of 47 pages of information regarding living with heart failure. The font size is not accessible to older patients.

Hartstichting

Hartfalen: wat is dat?

Onderzoek en behandeling

De toekomst

Het succes van de behandeling bij hartfalen is voor een belangrijk deel afhankelijk van de werking van de medicijnen. Voor een ander groot deel hangt het resultaat van de behandeling ook af van de wijze waarop je er zelf mee omgaat: door het nauwkeurig volgen van de adviezen over rust en inspanning, zout, vocht en voeding.

Een grote groep deskundigen met gespecialiseerde kennis en ervaring kan je steunen en helpen: artsen, diëtisten, verpleegkundigen. Vaak krijg je begeleiding op een hartfalenpoli. Maar denk ook aan je naasten, partner, familie en vrienden. Bij Harteraad kun je terecht voor lotgenotencontact. Meer informatie over Harteraad vind je op pagina 45.

Jijzelf, je naasten en medepatiënten weten het beste hoe je hartfalen in je leven een plaats kunt geven en hoe je de kwaliteit van je leven kunt verbeteren. Immers: hartfalen is meestal chronisch. Dat wil zeggen dat je er wel voor behandeld kunt worden, maar dat je er niet van kunt genezen.

Samen beslissen

‘Samen beslissen’ betekent dat je samen met je arts beslist over welke zorg voor jou het beste is. Bij hartfalen is dat extra belangrijk, omdat dat meestal niet meer over gaat. De arts geeft informatie over de mogelijkheden. En wat de medische voor- en nadelen hiervan zijn. Je bespreekt wat dit betekent in jouw situatie en wat voor jou belangrijk is (zie **watertoedoet.info**). Samen nemen jullie vervolgens een beslissing over de behandeling. Kijk eens op **3goedevragen.nl** om meer te weten te komen over ‘Samen beslissen’.

39

Figure H1 and H2
Hartstichting brochure “Hartfalen: wat is dat?” cover and page 39

Knmg checklists

The Royal Dutch Medical Association (in Dutch “Koninklijke Nederlandsche Maatschappij tot bevordering der Geneeskunst”, abbreviated as KNMG) defined two checklists for the conversation about the end-of-life.
The first checklist, shown in Figure 20a, is targeted to patients. It has a series of questions for the patients to reflect on the issues about the end-of-life. The questions are pretty detailed and they include issues such as where the patient wants to die and who should take decisions about their life if the patient cannot do that.

The questions are divided in the following categories:

- How are you now?
- What does your doctor think about your situation and prospects?
- What are you worried about?
- Which treatments are possible and which are not?
- Where do you want to die?
- Tips to ensure that the conversation runs smoothly

The second checklist, shown in Figure 20b, is targeted to doctors. It contains the same type of questions that a physician should ask their patients.

Strengths and limitations: The document consists of one page, with text divided in two columns. The font is rather small for elderly patients. The checklist contains many questions, which can be rather confronting for the patient.

Checklist

Praat op tijd met uw patiënt over het levenseinde

Tips en bespreekpunten om het gesprek met uw patiënt goed te laten verlopen

Praten over sterven is niet altijd makkelijk. Zowel patiënten als dokters vinden het vaak een moeilijk onderwerp. Maar een tijdig gesprek over verwachtingen en wensen is cruciaal om passende zorg in de laatste levensfase te realiseren. Dit vergt van uw kant betrokkenheid en een proactief beleid. Maar hoe begint u, en wat bespreekt u tijdens dit vaak moeilijke maar belangrijke gesprek?

Mogelijke en onmogelijke behandelingen

- Welke medische mogelijkheden zijn er voor het behandelen en verlichten van klachten/complicaties?
- Welke mogelijkheden zijn er voor het verlengen van het leven?
- Wat kan daarmee worden bereikt, hoe snel en ten koste van wat?
- Zijn er behandelingen die medisch zinloos zijn of kunnen worden? Zo ja, waarom? Benoem wat er gebeurt als u niet meer behandelt en wat daarvan het effect op duur en kwaliteit van het leven kan zijn.
- Wat zijn de voordelen en nadelen van eventuele palliatieve behandelingen?
- Hoe belastend kunnen deze palliatieve behandelingen zijn? Wat zijn de gevolgen als de patiënt een (palliatieve) behandeling weigert?
- Overweegt de patiënt zelf te stoppen met eten en drinken?
- Heeft de patiënt (schriftelijk) vastgelegd in welke situatie(s) hij of zij wel of niet behandeld of gereanimeerd wil worden? Zo ja: is deze wilsverklaring duidelijk geformuleerd? Is er een vertegenwoordiger benoemd? Zijn alle betrokken behandelaars, zorgverleners en naasten hierover geïnformeerd?

Waar wil de patiënt sterven?

- Kan de patiënt onder alle omstandigheden thuis blijven?
- Welke maatregelen zijn daarvoor nodig?
- Hoe wordt dat geregeld en door wie?
- Wil de patiënt opgenomen worden in het ziekenhuis, verpleeghuis of hospice?
- Zijn de afspraken met de patiënt en zijn of haar wensen opgetekend in het dossier? Draag deze informatie schriftelijk over bij een opname in het ziekenhuis, verpleeghuis of hospice.
- Is er een (schriftelijk) euthanasieverzoek of zijn er andere wilsverklaringen?

Tips om het gesprek goed te laten verlopen

- Wijs de patiënt erop dat hij of zij bijvoorbeeld de partner, een kind of goede vriend kan meenemen naar het gesprek.
- Voorkom vaktermen. De begrippen in de achtergrondinformatie kunnen u en de patiënt ondersteunen.
- Geef niet teveel informatie in één keer. U kunt beter het gesprek faseren. Vooral als de patiënt gespannen is, is het voor hem of haar moeilijk om informatie te verwerken.
- Ga na of de patiënt u heeft begrepen, bijvoorbeeld door hem of haar het besprokene te laten samenvatten. Luister goed.
- Ga tijdens het gesprek na of ú de patiënt heeft begrepen.

g praten over het levenseinde'. Er is een artsen- en
ook en een pdf die eenvoudig kan worden geprint

Checklist

Praat op tijd met de dokter over uw levenseinde

Tips en bespreekpunten om het gesprek met uw dokter goed te laten verlopen

Praten over sterven is niet altijd makkelijk. Zowel patiënten als dokters vinden het vaak een moeilijk onderwerp. Toch is het heel belangrijk om op tijd met uw dokter te praten over uw wensen en verwachtingen rond uw levenseinde. Zo kunt u ervoor zorgen dat u in het laatste deel van uw leven de zorg krijgt die bij u past.

Wat kunt u bespreken?

U kunt het gesprek beginnen met te vertellen waarom het juist nu belangrijk voor u is om over uw levenseinde te praten. Ook kunt u vertellen hoe u zich voelt, of u pijn of andere klachten heeft, en waarover u zorgen en vragen heeft. Daarnaast zal uw arts u waarschijnlijk enkele vragen stellen. Hieronder vindt u een aantal vragen die u kunnen helpen om uw situatie en wensen duidelijk te maken. Ook staan er vragen bij die u zelf aan uw dokter kunt stellen. Denk hier van tevoren alvast over na. Dat helpt om het gesprek te voeren.

Hoe gaat het nu met u?

- Hoe voelt u zich?
- Waarom is het gesprek juist nu belangrijk voor u?
- Heeft u pijn of andere klachten?
- Wat kunt u door uw ziekte niet meer doen en wat nog wel?
- Waar beleeft u (nog) plezier aan?

Hoe denkt uw arts over uw situatie en vooruitzichten?

- Hoe verwacht de arts dat uw ziekte zal verlopen?
- Welke klachten kunt u verwachten?
- Wat kunt u zelf doen om uw klachten te verminderen?
- Wat kan de arts doen om uw klachten te verminderen?
- Hoe denkt de arts dat u zich zult voelen in de komende tijd?
- Welke psychische spanningen kunt u krijgen? Wat kan de arts doen om deze te verminderen?
- Wat kan de arts zeggen over hoe lang u nog te leven heeft?

Waar maakt u zich zorgen over?

- Voor welk lijden bent u bang?
- Waarom bent u daar bang voor?
- Heeft u dit lijden meegemaakt in uw eigen omgeving?
- Wat wilt u beslist niet meemaken? Waarom is dat zo?
- Wat vindt u (nog) belangrijk om te doen zodat u gerust afscheid kunt nemen?

Welke behandelingen zijn mogelijk, en welke niet?

- Stel dat de dokter u niet meer kan behandelen om te genezen: wat gebeurt er dan met u? Wat merkt u ervan?
- Welke behandelingen zijn er nog om ervoor te zorgen dat u langer blijft leven?
- Welke behandelingen zijn er om ervoor te zorgen dat u minder pijn of andere klachten heeft?
- Wat kan uw arts bereiken met deze behandelingen? En hoe snel kan dat gaan?
- Wat zijn de voor- en nadelen van deze behandelingen? Hoe verwacht de arts dat deze behandelingen voor u zullen verlopen?
- Zijn er in uw situatie behandelingen die medisch gezien op een gegeven moment geen zin meer hebben? Welke behandelingen zijn dat? En hoe komt dat?
- Wat gebeurt er als u niet meer zelf kunt eten en drinken? Krijgt u dan een infuus en sondevoeding? Wat zijn de voor- en nadelen daarvan?
- Wat gebeurt er als u zelf zou stoppen met eten en drinken?

Waar wilt u sterven?

- Op welke plek wilt u het liefst sterven? Thuis, in de instelling waar u nu verblijft, in het ziekenhuis of bijvoorbeeld in een hospice?
- Is het in uw situatie mogelijk om thuis te sterven? Wat moet er geregeld worden? En wie regelt dat?
- Is er volgens uw arts een kans dat u wordt opgenomen in een ziekenhuis, verpleeghuis of hospice?
- Als u naar een hospice wilt, wat moet u daar dan voor regelen?

Tips om het gesprek goed te laten verlopen

- Gebruikt de dokter woorden die u niet begrijpt? Vraag dan om uitleg.
- Controleer tijdens het gesprek af en toe of u de dokter goed heeft begrepen. Dit kunt u bijvoorbeeld doen door in eigen woorden na te vertellen wat de dokter heeft gezegd. Of vraag de dokter zelf om het gesprek samen te vatten.
- Controleer of de dokter u begrepen heeft door daar af en toe naar te vragen.
- Maak aantekeningen tijdens het gesprek of vraag vooraf of u het gesprek mag opnemen.
- Vraag uw arts of hij aantekeningen wil maken voor in uw medisch dossier. Ook voor later is dit heel belangrijk. Want misschien moeten andere behandelaars ook deze informatie krijgen. Bijvoorbeeld de artsen op de huisartsenpost en in het ziekenhuis, of de specialist ouderengeneeskunde.

Meer informatie en tips vindt u in het e-book 'Praat op tijd over uw levenseinde'. Gratis te bekijken en ook te downloaden in eenvoudig te printen pdf op knmg.nl/praten-over-levenseinde.

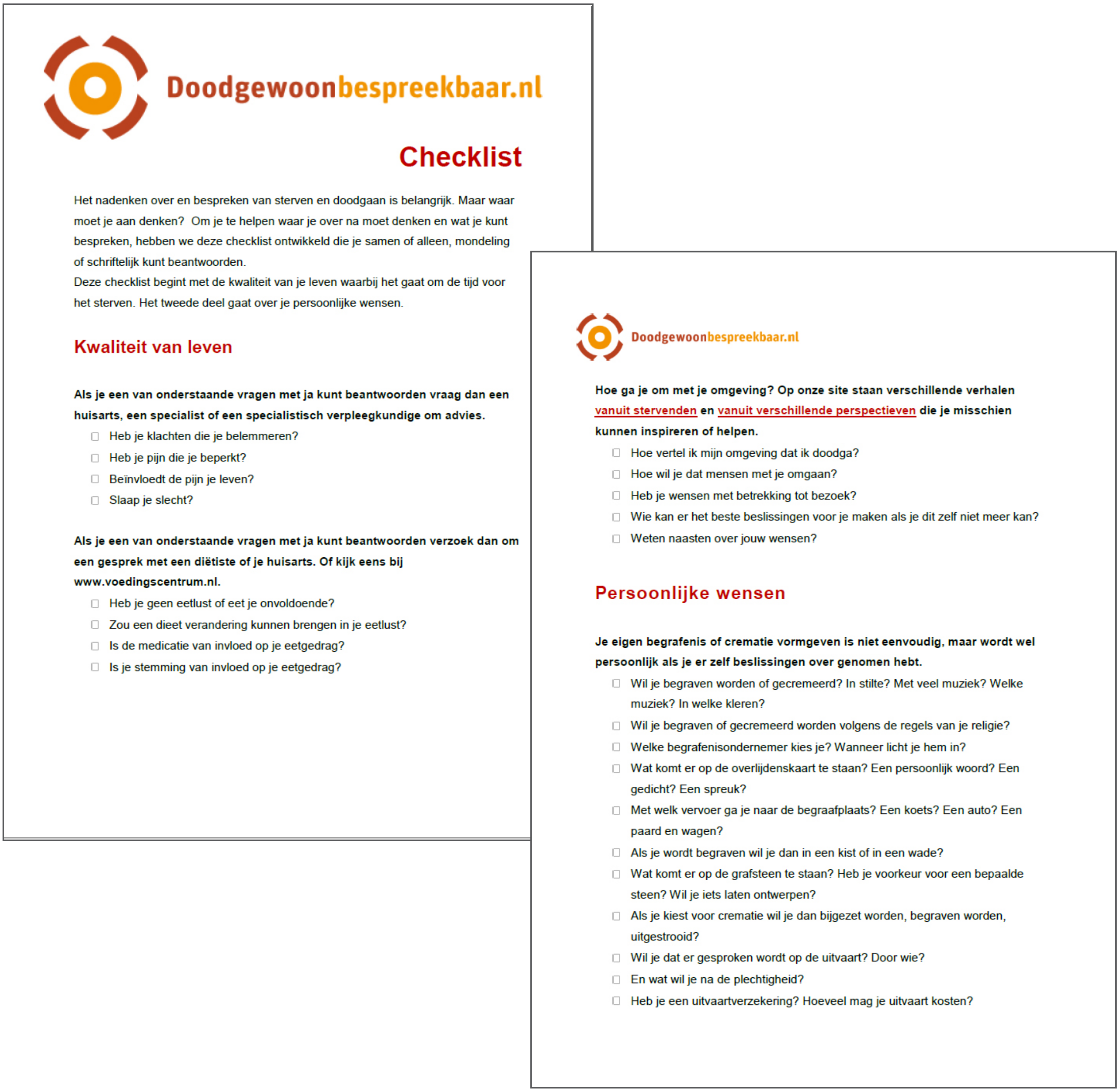
knmg
nhg
Patiëntenfederatie Nederland

Figure H3
Knmg checklist for patient and doctor

Doodgewoonbespreekbaar checklist

Another tool that healthcare providers can use with patients is the Doodgewoonbespreekbaar.nl checklist. The checklist is focused on the last stage of life. The first part asks yes or no questions about the condition of the patient and their quality of life. In the second part, the checklist has questions about the personal wishes about dying.

Strengths and limitations: The questions are spread out on three pages. The yes and no questions are easier to answer and can assess the current situation of the patient. The font is bigger and more accessible to patients.



Doodgewoonbespreekbaar.nl

Checklist

Het nadenken over en bespreken van sterven en doodgaan is belangrijk. Maar waar moet je aan denken? Om je te helpen waar je over na moet denken en wat je kunt bespreken, hebben we deze checklist ontwikkeld die je samen of alleen, mondeling of schriftelijk kunt beantwoorden.
Deze checklist begint met de kwaliteit van je leven waarbij het gaat om de tijd voor het sterven. Het tweede deel gaat over je persoonlijke wensen.

Kwaliteit van leven

Als je een van onderstaande vragen met ja kunt beantwoorden vraag dan een huisarts, een specialist of een specialistisch verpleegkundige om advies.

- ☐ Heb je klachten die je belemmeren?
- ☐ Heb je pijn die je beperkt?
- ☐ Beïnvloedt de pijn je leven?
- ☐ Slaap je slecht?

Als je een van onderstaande vragen met ja kunt beantwoorden verzoek dan om een gesprek met een diëtiste of je huisarts. Of kijk eens bij www.voedingscentrum.nl.

- ☐ Heb je geen eetlust of eet je onvoldoende?
- ☐ Zou een dieet verandering kunnen brengen in je eetlust?
- ☐ Is de medicatie van invloed op je eetgedrag?
- ☐ Is je stemming van invloed op je eetgedrag?

Doodgewoonbespreekbaar.nl

Hoe ga je om met je omgeving? Op onze site staan verschillende verhalen vanuit stervenden en vanuit verschillende perspectieven die je misschien kunnen inspireren of helpen.

- ☐ Hoe vertel ik mijn omgeving dat ik doodga?
- ☐ Hoe wil je dat mensen met je omgaan?
- ☐ Heb je wensen met betrekking tot bezoek?
- ☐ Wie kan er het beste beslissingen voor je maken als je dit zelf niet meer kan?
- ☐ Weten naasten over jouw wensen?

Persoonlijke wensen

Je eigen begrafenis of crematie vormgeven is niet eenvoudig, maar wordt wel persoonlijk als je er zelf beslissingen over genomen hebt.

- ☐ Wil je begraven worden of gecremeerd? In stilte? Met veel muziek? Welke muziek? In welke kleren?
- ☐ Wil je begraven of gecremeerd worden volgens de regels van je religie?
- ☐ Welke begrafenisondernemer kies je? Wanneer licht je hem in?
- ☐ Wat komt er op de overlijdenskaart te staan? Een persoonlijk woord? Een gedicht? Een spreuk?
- ☐ Met welk vervoer ga je naar de begraafplaats? Een koets? Een auto? Een paard en wagen?
- ☐ Als je wordt begraven wil je dan in een kist of in een wade?
- ☐ Wat komt er op de grafsteen te staan? Heb je voorkeur voor een bepaalde steen? Wil je iets laten ontwerpen?
- ☐ Als je kiest voor crematie wil je dan bijgezet worden, begraven worden, uitgestrooid?
- ☐ Wil je dat er gesproken wordt op de uitvaart? Door wie?
- ☐ En wat wil je na de plechtigheid?
- ☐ Heb je een uitvaartverzekering? Hoeveel mag je uitvaart kosten?

Figure H4 and H5
Doodgewoonbespreekbaar.nl checklist about quality of life and end-of-life wishes page 1 and page 3

Doodgewoonbespreekbaar wishes booklet

The booklet is a detail questionnaire to understand what is important for the patient, in life and in the end-of-life phase.
The booklet is composed of 28 pages.

Strengths and limitations: The font dimension is appropriate for patients and the questions elicit prefences and values, including space for writing answers. However, the booklet is lengthy and not visually appealing and it does not provide information over the possible treatments.

Doodgewoon bespreekbaar

Wensen voor mijn leven
in de laatste fase

Wat vind ik belangrijk in mijn laatste levensfase?

Denk aan de aanwezigheid van familie en vrienden, geen pijn, waardigheid, zelf beslissen over levenseinde, goede verzorging door..., afscheid nemen van..., volledig bij bewustzijn blijven, rituelen en gebruiken vanuit mijn levensovertuiging, medische zorg, thuis blijven, genieten van...

In de laatste fase is voor mij belangrijk:

Dit is belangrijk voor mij, omdat

Wat kan ik doen om dit te realiseren?

Wie of wat zou mij hierbij kunnen ondersteunen?

Figure H6
Doodgewoongesprekbaar wishes booklet