TALLINN UNIVERSITY OF TECHNOLOGY
SCHOOL OF ENGINEERING
Department of Mechanical and Industrial Engineering

SOCIETALLY INVISIBLE LOSS: DESIGNING FOR INCLUSIVENESS AND INDIVIDUAL EXPERIENCE IN STILLBIRTH

ÜHISKONDLIKULT NÄHTAMATU SURM: KAASAARVAV JA INDIVIDUAALSE KOGEMUSEGA ARVESTAV DISAIN SURNULT SÜNNI SÜNDMUSES

MASTER THESIS

Student: Helen Susan Selirand
Student code: 182586MADM
Supervisor: Ruth-Helene Melioranski, Engineer

Tallinn, 2020

AUTHOR’S DECLARATION

Hereby I declare, that I have written this thesis independently. No academic degree has been applied for based on this material. All works, major viewpoints and data of the other authors used in this thesis have been referenced.

“.......” .... 2020.

Author: ....
/signature /

Thesis is in accordance with terms and requirements

“.......” .... 2020.

Supervisor: ……………………….
/signature/

Accepted for defence

“.......”....................2020.

Chairman of theses defence commission: ……………………………………………….
/name and signature/

Non-exclusive Licence for Publication and Reproduction of Graduation Thesis[1]

I, Helen Susan Selirand (08.02.1990) hereby

1. grant Tallinn University of Technology (TalTech) a non-exclusive license for my thesis
   Societally Invisible Loss: Designing for Inclusiveness and Individual Experience in Stillbirth,

supervised by Ruth-Helene Melioranski,

1.1 reproduced for the purposes of preservation and electronic publication, incl. to be entered in the digital collection of TalTech library until expiry of the term of copyright;

1.2 published via the web of TalTech, incl. to be entered in the digital collection of TalTech library until expiry of the term of copyright.

1.3 I am aware that the author also retains the rights specified in clause 1 of this license.

2. I confirm that granting the non-exclusive license does not infringe third persons' intellectual property rights, the rights arising from the Personal Data Protection Act or rights arising from other legislation.

---

[1] *Non-exclusive Licence for Publication and Reproduction of Graduation Thesis is not valid during the validity period of restriction on access, except the university`s right to reproduce the thesis only for preservation purposes.*

Department of Mechanical and Industrial Engineering

THESIS TASK

Student: Helen Susan Selirand, 182586MADM
Study programme: MADM10/18, Design and Technology Futures
Main speciality: Design
Supervisor: Engineer, Ruth-Helene Melioranski, +372 5660 3440

Thesis topic:

English	Societally Invisible Loss: Designing for Inclusiveness and Individual Experience in Stillbirth
Estonian	Ühiskondlikult nähtamatu surm: Kaasaarvav ja individuaalse kogemusega arvestav disain surnult sünni sündmuses

Thesis main objectives:

1. Understand the current experience in stillbirth
2. Explore inclusive opportunities for support in the experience
3. Design concept for inclusive support that offers individual experience

Thesis tasks and time schedule:

No	Task description	Deadline
1.	Research and analysis	26.03.2020
2.	Concept design finalisation	05.05.2020
3.	Thesis finalisation	24.05.2020

Language: English **Deadline for submission of thesis:** “25”.05.2020

Student: Helen Susan Selirand .... “....” 2020

Supervisor: Ruth-Helene Melioranski .... “....” 2020

Head of study programme: Martin Pärn .... “....” 2020

ABSTRACT

Stillbirth is a delicate subject, due to which, its handling in society lacks necessary attention. The extent of the impact of stillbirth is not fully considered by the existing system of support on offer in Estonia. Adopting the constructive design research methods and analysing the current situation through feminist design perspectives I argue that whereas there is moderate knowledge of the influence on the bereaved families and further social circle, the support on offer, focusing on the medical procedures and counselling for the mother, fails to recognise the interdependency of the needs of all affected in the event. Emotional resilience and the availability of strong social support are key to minimising the long-term outcomes for the families. However, the lack of relationship and memories built with the lost child can make it difficult for the people to relate to the event.

The design concept I propose is a three-layer platform, that fits into the current service ecosystem, designed with the individual needs of its users in mind. Users can customise their experience, only using functions they see beneficial to them. Families and their social circles are provided structure and support in the experience through managing communication and proceedings along with structured and comprehensive information relevant to them. The user's individual grief is supported through a discreet outlet that focuses on memory building. The feeling of aloneness that families go through is lessened through the possibility of sharing and exploring a variety of experiences securely among the community of bereaved families. The community has a place to voice their experiences outwards to society, raising attention to the experience and lessening the taboo in the topic.

EESTIKEELNE KOKKUVÕTE

Surnult sünd on vaikne kaotus, olles tihti nähtav vaid perekonna lähedastele. Lapse kaotuse mõistmine on keeruline nii perekonnale kui ka kõrvalsesjatele, sest puuduvad lapsega loodud mälestused. Kuna tegemist on surmaga enne sündi, siis teemast rääkimine on keeruline ning vestlustes välditud. See on loonud olukorra, kus surnult sünnist on saanud ühiskondlikult nähtamatu kaotus. Samas on lapse kaotusel tugev mõju perekonnale, millega kaasnevatel negatiivsetel emotsioonidel võivad olla pikaajalised tagajärjed vaimsele tervisele depressiooni ja arevushäire kujul. Surnult sündi nähakse peamiselt kui kaotust ema jaoks, kuid sellel on tugev mõju mõlemale vanemale kui ka nende tugivõrgustikule. Peredele pakutav toetus piirdub hetkel meditsiinilise abi ja psühholoogilise nõustamisega, mis keskendudes peamiselt ema kogemusele.

Uurides surnult sünni kaotust läbi feministlike disainiperspektiivide ja inimkeskse analüüsi tõdesin, et puudub ühtne kindel viis, kuidas kaotust kogetakse. Sellest lähtuvalt on vaja kasutada kaasavat lähenemisviisi, mille kaudu pakkuda tuge kõigile, kes seda vajavad, läbi individuaalse kogemuse võimaldamise.

Minu disainkontseptsioon on olemasolevasse riigiteenuste süsteemi paigutuv mitmetasandiline, omavahel integreeritud platvorm. Platvorm ei raamista leinavate perede kogemust vaid võimaldab erinevate tasandite kasutamist viisil, mil pere ise saab valida, mis neid kaotusega toimetulekus kõige paremini toetab

Riigi poolt nõutud menetlevates toimingutes pakub platvorm vanematele proaktiivset tuge struktureeritud ja personaliseeritud informatsiooni kaudu, mille sisu kohandab end vastavalt hääletooni eelistusele. Leinavatel vanematel on võimalus anda oma lähedastele liigipääsu platvormi erinevatele tasanditele, hoides neid end koormamata kursis nii olukorra kui ka enda vajadustega toetuse osas. Perekonnal on võimalik saada tuge erinevates mentlevates toimingutes andes usaldusväärsele isikule volituse tegutseda nende nimel. Surnult sündinud last leinates on vanemate lootused raseduse ajast ja üksikud lapsega haiglas veedetud hetked ainsad mälestused lapsest. Leinajad vajavad tuge kaotusega suhestumises, mida võimaldab platvormi tasand Memento, andes võimalused luua isiklikku kogemust mälestustega, mis tugevdab ühendust kaotatud lapsega. Kogukonna tugi kaotuses vähendab leinavatel peredel kogemuses üksi olemise tunnet, sest neid mõistetakse ja nad on toetatud. Stories tasand platvormist tugevdab seda kogukonda luues keskkonna, kus on võimalik jagada mitmesuguseid kogemusi nii kogukonna siseselt kui ka laiemale üldsusele, et anda neile teadmisi, kuidas kõige paremini tuge pakkuda surnult sündi kogenud inimestele.

TABLE OF CONTENTS

PREFACE

This Master thesis is the final thesis for the joint study program Design and Technology Futures between the Estonian Academy of Arts and Tallinn University of Technology. The projects in the study program have always tackled uncomfortable real-life problems through design methods and this gave me the courage to approach the experience of stillbirth from a design perspective, trusting it would provide a different viewpoint to this topic and enable a different conversation about the issue.

Hereby I would like to thank my supervisor Ruth-Helene Melioranski for her guidance throughout the thesis project, her feedback was constructive, supportive and always pushing me further enabling me to learn and grow as a designer. Another thanks goes out to professor Martin Pärn, the head of the study program, for the constant improvements in the program that have made Design and Technology Futures what it is today and kept things interesting.

I send my biggest thank you for everyone I consulted with and interviewed during this thesis project. Thank you for trusting me with your insight and personal stories.

LIST OF ABBREVIATIONS

MTÜ - *Mittetulundusühing* - Non-profit Organisation
SA - *Sihtasutus* - Foundation

EHIF - Estonian Health Insurance Fund
ECTS - European Credit Transfer and Accumulation System
GP - General Practitioner
HR - Human Resources

1 INTRODUCTION

One in four pregnancies ends in miscarriage.[2] As medical developments enable one to determine pregnancy as early as five days before the start of a missed period[3], it allows for the parents for an extremely early establishment of mindset. As 80% of all miscarriages occur in the first three months of pregnancy[4], the early knowledge of pregnancy and attachment can magnify the emotional strain of a miscarriage.

Loss of pregnancy after the 20th-week mark (stillbirth) is far less common than miscarriage, happening in less than 1% of pregnancies in the more economically developed countries[5] and 1 in 45 worldwide. Stillbirth has a traumatising effect on the mothers as they are required to give birth to their dead foetus (cesarean is advised against), deal with their changed and changing bodies, handle grief for death before birth and explain to the people in their social circles about the loss of pregnancy. The medical services and system often lack awareness of the burden of the pain owners. Families have made arrangements and plans for the next months or years in their lives and work and the sudden loss of life brings on an abrupt stop to all that was to be. In the interviews conducted with an expert from Estonian Health Insurance Fund, midwives and counsellors, all interviewees admitted, that besides the mothers, miscarriages and stillbirths additionally affect the fathers and further social support network. However, currently, there is no system in place to better support the partners and families throughout this experience.

Although the knowledge on stillbirth has increased over the last years, there is still much to be uncovered in the impact it has on the parents and further family and social circles.

In their article "The psychological, social, and economic impact of stillbirth on families" Murphy and Cacciatore argue that the bereaved parents' disenfranchised grief has consequences beyond psychological ones and that for example in the US alone, the annual burden of child death is US$1.6 billion. They recognise "the lack of societal

---

[2] Bellhouse, C., Temple-Smith, M. J., & Bilardi, J. E. (2018). “It’s just one of those things people don’t seem to talk about...” women’s experiences of social support following miscarriage: A qualitative study. *BMC Women’s Health*, *18*(1), 176. https://doi.org/10.1186/s12905-018-0672-3

[3] *How soon can I do a pregnancy test?* (2018, June 27). Nhs.Uk. Retrieved 10 March 2020, from https://www.nhs.uk/common-health-questions/pregnancy/how-soon-can-i-do-a-pregnancy-test/

[4] Dugas, C., & Slane, V. H. (2020). Miscarriage. In *StatPearls*. StatPearls Publishing. http://www.ncbi.nlm.nih.gov/books/NBK532992/

[5] Erlandsson, K., Säflund, K., Wredling, R., & Rådestad, I. (2011). Support After Stillbirth and Its Effect on Parental Grief Over Time. Journal of Social Work in End-of-Life & Palliative Care, 7(2-3), 139-152.

recognition assigned to perinatal death incites maternal vulnerability to mental, emotional, and social health risks that eventuate to global financial burden."[6]

The topic is recognised as taboo in society by all experts I conducted interviews with alongside the parents who shared their experiences. A study conducted in the UK in 2015 on the topic of Stillbirth and Stigma by Brierley-Jones, Crawley, Lomax, and Ayers found revealed that "stigma" was experienced by most women participating in the study. "Stigma was reported as arising from interactions with professionals, family, friends, work colleagues, and even casual acquaintances" and "results suggest that stillbirth can spoil the identities of "patient," "mother," and "full citizen."[7]

In research into the topics of antenatal and perinatal death and bereavement, it is vital to take into account the widely recognised variations in classification internationally that influence the literature. Miscarriage, stillbirth and neonatal death all share similarities, but alongside this, within each category of loss, there are differences.[8] In this thesis research, my focus is on the experience of stillbirth, but often the information cannot be differentiated from the other classifications. In discussions with midwives and experts from *MTÜ Vaikuse Lapsed*, it was often noted, that for the parents, it makes little difference how their loss is classified, as for them, the loss is unique and painful regardless of the term used to describe it.

Considering the impact stillbirth has on the bereaved mothers and families and contrasting stigma recognised surrounding the topic, the importance of exploring stillbirth should be clear. Service design methods allow for a human-centred process and offer an alternative view of the topic. In this thesis, I offer a design concept based on a feminist design perspective through focusing on allowing for individual experiences and decisions rather than specific rulesets.

Feminist discourse has not just brought about a change in approach to women's health in the design discipline, but a change in approach to the issues related to women in western society in general. Women make up half of the population. The feminist strive to bring about a change in approach to women in society has slowly but surely opened

---

[6] Murphy, S., & Cacciatore, J. (2017). The psychological, social, and economic impact of stillbirth on families. *Seminars in Fetal and Neonatal Medicine*, *22*(3), 129–134. https://doi.org/10.1016/j.siny.2017.02.002

[7] Brierley-Jones, L., Crawley, R., Lomax, S., & Ayers, S. (2015). Stillbirth and Stigma: The Spoiling and Repair of Multiple Social Identities. *OMEGA - Journal of Death and Dying*, *70*(2), 143–168. https://doi.org/10.2190/OM.70.2.a

[8] Wright, P. M. (2011). Barriers to a Comprehensive Understanding of Pregnancy Loss. *Journal of Loss and Trauma*, *16*(1), 1–12. https://doi.org/10.1080/15325024.2010.519298

up discussions about women's issues. Caroline Criado Perez argues in her book Invisible Women that adopting a feminist perspective along with collecting more sex-disaggregated data would enable decisions that not only benefit women but also lead towards a more inclusive society. The gender data gap affects the amount of adequate information available on the topic of miscarriage and stillbirth.[9]

Katherine Martinelli, in her article in the Washington Post, discusses that society would vastly benefit from lifting the taboo from the topic of miscarriage and gain from an open discussion. In the current state, there is a lack of script for dealing with the bereavement of fetal losses (according to the Centers for Disease Control and Prevention estimates there are more than 1 million fetal losses each year in the US).[10] A qualitative study in 2007 with 47 women found that mothers, after a stillbirth, did not receive sufficient professional support.[11]

The psychological distress following a perinatal death is often unrecognised by medical professionals. Follow-up care is not universally given, despite being desired by more than 90% of the patients. While the medical studies question the effectiveness of follow-up care based on non-conclusive statistics in the instances of the loss of a pregnancy, the desirability of it in the eyes of the patients should speak volumes about what services of support these patients feel they require. Here it is important to note that the benefits of supportive counselling are promising for women with high levels of psychological distress.[12]

Support from family and friends is seen to be important two years after the stillbirth. The need for psychological counselling strongly depends on the support offered by the surrounding social networks.[13] Currently, as the topic of loss of pregnancy is perceived in society as taboo, this damages the ability to communicate about it and reaching out to ask for the needed support of close ones in the instance of a stillbirth.

---

[9] Perez, C. C. (2019). Invisible Women: Exposing Data Bias in a World Designed for Men. Random House.

[10] *Miscarriage is common. So why is it such an isolating experience? - The Washington Post*. (n.d.). Retrieved 16 January 2020, from https://www.washingtonpost.com/news/parenting/wp/2016/10/13/talking-about-miscarriage-might-be-upsetting-but-we-need-to-do-it/

[11] Cacciatore, J., & Bushfield, S. (2007). Stillbirth: The mother’s experience and implications for improving care. *Journal of Social Work in End-of-Life & Palliative Care*, *3*(3), 59–79. https://doi.org/10.1300/J457v03n03_06

[12] ibid.

[13] Kong, G. W. S., Chung, T. K. H., & Lok, I. H. (2014). The impact of supportive counselling on women’s psychological wellbeing after miscarriage—A randomised controlled trial. *BJOG: An International Journal of Obstetrics and Gynaecology*, *121*(10), 1253–1262. https://doi.org/10.1111/1471-0528.12908

Miscarriage and stillbirth do not only affect the mothers but also their partners and further families, although, generally less severely.[14] Here the femininity of the topic clouds the statistics as little research has been conducted over the psychological impact on men and further family.

As a female designer, once I became aware of the extent of androcentrism in design and moreover, in society at large, it has become impossible to overlook these issues. Female health issues and the lack of sufficient data, information and discourse on the topic have motivated me to work to alleviate the situation at hand. As I embrace the understanding that the topic of stillbirth is especially sensitive, I find it valuable to approach it using the methodology of service design.

The personal motivation behind choosing the topic of stillbirth is related to my firm belief that society needs to take more responsibility in offering support to women experiencing severe distress. Stillbirth is one of these events where I see a significant lack of understanding and discussion about the topic. Considering how common miscarriages are and how distressing stillbirth is for the mothers and the close family, holding the topic taboo and leaving the families as a result without sufficient support is condemnable. In different societies and health care systems, the methods of support offered in stillbirth vary. However, what is on offer leaves the majority of patients feeling uncared for.

The western healthcare system can be considered conservative, relying on medical research and sufficient data in decisionmaking. Changes can, therefore, be slow. Service design methods could bring insightful results and improvements as these rely on observations, interviews and active collaboration with the stakeholders rather than looking for conclusive, measurable results. Design methodology allows comparing approaches in other fields, and through applying the obtained insight, advance the outcome of the project.

---

[14] Chavez, M. S., Handley, V., Jones, R. L., Eddy, B., & Poll, V. (2019). Men's Experiences of Miscarriage: A Passive Phenomenological Analysis of Online Data. *Journal of Loss and Trauma*, *24*(7), 664–677. https://doi.org/10.1080/23802359.2019.1611230

2 METHODOLOGY

2.1 Frame: Feminist design perspectives

Current feminism discourse does not categorise women and thus allows for various forms of being a woman. This understanding has caused complexities in feminism that have generatively influenced feminist design to reframe design problems "from the perspective of third and fourth-wave feminism… to celebrate difference, inclusiveness and complexity around what it means to be a woman in today's society."[15]

In her paper, Reframing Design Problems Within Women's Health, Sarah Homewood offers "a feminist reading of the visible increase in design research within the category of "women's health".

In design, like in many other disciplines, addressing female health as a stand-alone topic, has until recently, been only seldom addressed. Although to this date there is a large gap in knowledge, research and design in female issues, in the past seven years, there has also been a considerable increase in the quality of research on women's health carried out by female designers. Homewood states that the location and perspective of the researcher will influence the qualities of knowledge produced. Thus the need to further pursue the feminist goals in design within the definition of design problems it is crucial for female designers to address the androcentrism of research methodology and data produced so far.[16]

Feminist empiricism and feminist standpoint theory epistemologies have been critiqued as not changing the existing methodological norms of scientific inquiry. The researcher's own influence in methodologies and methods used can obscure the value and claim to objectivity. Including women as a marginalised group in the design process can be enabled by feminist tools offered by methodologies such as participatory design and critical and speculative design. These enable imagining alternative futures, thus rejecting the reification of existing biases within society.[17]

The fourth-wave feminism in its ideas and practices challenges the set rules of being in the society and with that has influenced also a movement towards a discourse about

---

[15] Homewood, S. (2018, June 28). Reframing Design Problems Within Women's Health. https://doi.org/10.21606/drs.2018.337

[16] ibid.

[17] ibid.

what it is to be a man. A growing amount of movements have embraced feminist doctrine and adopted feminist ethics to address issues before barred due to problematic constructs and embodiments of masculinity.[18]

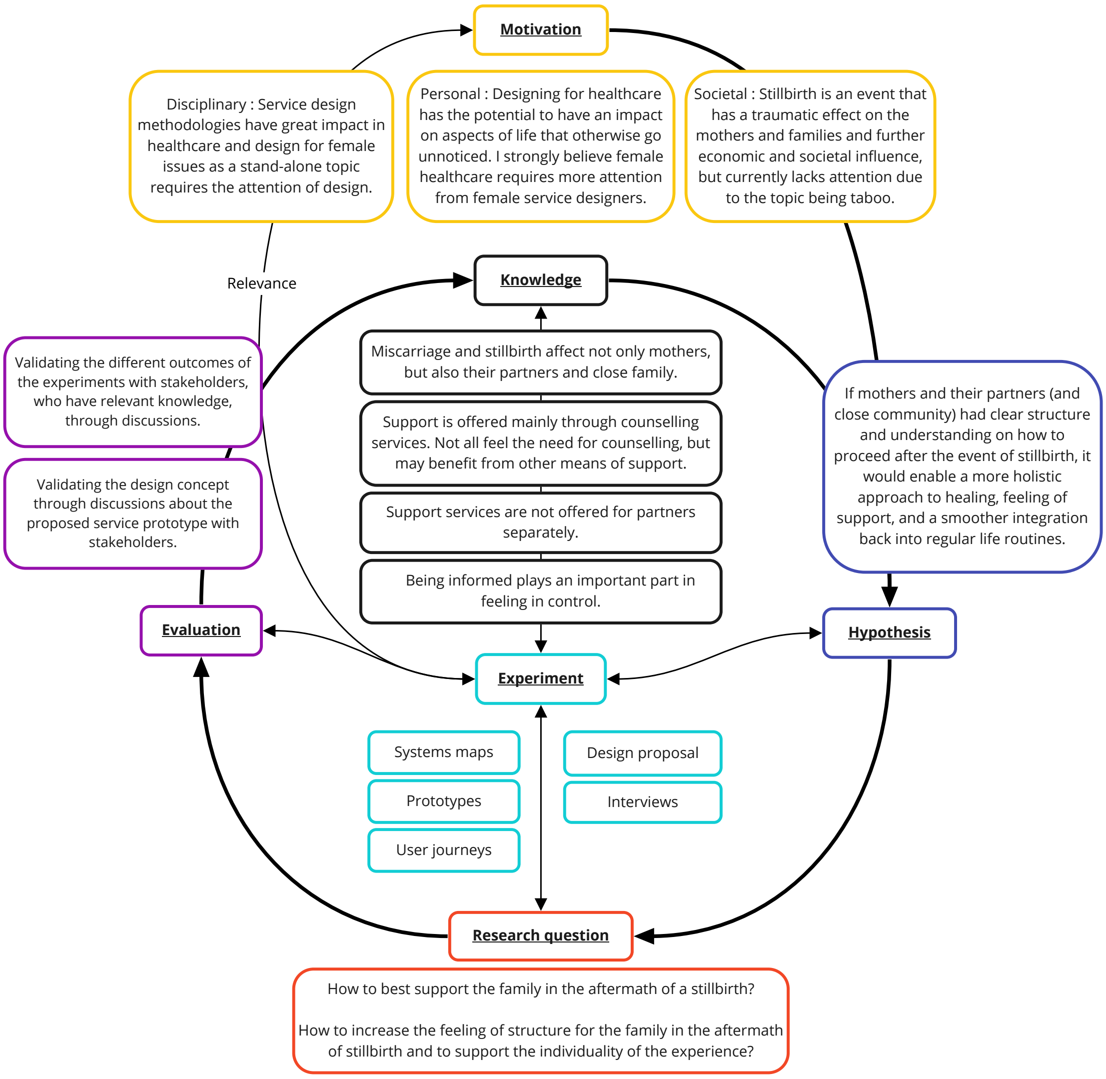
Adopting a feminist design perspective in addressing the experience of stillbirth permits a perspective of inclusivity and individuality in the concept design.

---

[18] Waling, A. (2017). Men and Fourth-Wave Feminism: Acceptance, Ambivalence, Resistance. *New Community*, *14*, 34–37.

2.2 Methods: Constructive design research

Approaching the research and design concept development, I planned the process through constructive design research wheel model suggested by Bang, Krogh, Ludvigsen and Markussen in their conference paper The Role of Hypothesis in Constructive Design Research[19]. This model allows for constant evaluation of experiments in research, and as I expanded my knowledge in the topic continuously throughout the research and design process, it fits to describe the process taken. The research wheel to describe the complete thesis process follows:



Disciplinary : Service design methodologies have great impact in healthcare and design for female issues as a stand-alone topic requires the attention of design.

Personal : Designing for healthcare has the potential to have an impact on aspects of life that otherwise go unnoticed. I strongly believe female healthcare requires more attention from female service designers.

Societal : Stillbirth is an event that has a traumatic effect on the mothers and families and further economic and societal influence, but currently lacks attention due to the topic being taboo.

Miscarriage and stillbirth affect not only mothers, but also their partners and close family.

Support is offered mainly through counselling services. Not all feel the need for counselling, but may benefit from other means of support.

Support services are not offered for partners separately.

Being informed plays an important part in feeling in control.

Validating the different outcomes of the experiments with stakeholders, who have relevant knowledge, through discussions.

Validating the design concept through discussions about the proposed service prototype with stakeholders.

If mothers and their partners (and close community) had clear structure and understanding on how to proceed after the event of stillbirth, it would enable a more holistic approach to healing, feeling of support, and a smoother integration back into regular life routines.

How to best support the family in the aftermath of a stillbirth?

How to increase the feeling of structure for the family in the aftermath of stillbirth and to support the individuality of the experience?

Figure 2.1 Constructive design research model

---

[19] (PDF) The Role of Hypothesis in Constructive Design Research. (n.d.). ResearchGate. Retrieved 8 May 2020, from https://www.researchgate.net/publication/276264315_The_Role_of_Hypothesis_in_Constructive_Design_Research

2.3 A human-centred approach to journey

Estonian governance is in transition: while there are many areas where the system operates from the perspective of areas of responsibilities, there is also an increasing number of human-centred service design-minded projects in development in collaboration between different government agencies.

In governance, adopting the human-centred approach has benefits that go beyond offering people services that align with their goals and beliefs. It enables governmental bodies to design the services strategically, also considering where the system could be made to operate more efficiently and require less active intervention to function. Additionally, it can free up resources for the government, because when the state digital systems are more capable of fulfilling people’s needs proactively, it enables further development of those systems to be more inclusive in the services and content on offer.

There has been no study into the human-centred view of the experience of perinatal death by Estonian government agencies and the current proceedings from the parents’ perspective can be described more as existing in legal loopholes[20]. While it may be unimaginable to design the system singularly from the perspective of the bereaved family, understanding the current journey is necessary to ease the process and unify the journey.

The gaps in the legislation and proceedings become evident when the experience is seen from the perspective of the family.

2.4 Research and design process

A stillbirth is a multi-level event that begins as a medical issue but has a further effect on various aspects of the bereaved parents' life. I set out to form a holistic understanding from a human-centred perspective to analyse the experience of the pain-owners and for the design concept to answer best to the needs of this experience.

To best guide the research process, the following research question was formed:
How to best support the family in the aftermath of a stillbirth?

---

[20] Bereaved mother. (2020, March 23). [Personal communication].

Furthermore, to support and expand on this framing, the previous question was expanded on:
How to increase the feeling of structure for the family in the aftermath of stillbirth and to support the individuality of the experience?

2.4.1 Gaining understanding

To form a detailed view of the experience of the parents in the event of stillbirth from the healthcare perspective, I initially aimed to collaborate with East-Tallinn Central Hospital maternity clinic, but due to the outbreak of COVID-19 in spring 2020 this collaboration in its extent became impossible. However, I acquainted myself with the guidelines of best practices in the UK and Sweden (as these guide many best practices adopted in Estonia) and the materials compiled by *MTÜ Vaikuse Lapsed* for the bereaved parents to gain the fundamental knowledge needed to conduct constructive interviews.

In my research, I analysed the experience of the bereaved families through interviews conducted with experts and bereaved parents and supported the findings whenever possible by analysing studies and articles written on the same issues to have a comprehensive foundation for the design concept.

From the feminist perspective, two books were most influencial for forming a background understanding:

Invisible Women[21] by Caroline Criado Perez, discussing the gender data gap present in all aspects of human society. It gives an insight that whenever tackling issues dealing with women sources of information must be critically reviewed to lessen the gender data gap rather than extend it.

Bodies[22] by Susie Orbach exploring the importance of bodies for humans and states clearly the issues of the society that have led us to distance ourselves from our physical bodies discussing the possibilities to reduce the bodily anxiety stating that body distress is causing mental distress. On the topic of pregnancy loss, there is an element of the body failing us. Although autopsies are mandatory for the loss of pregnancy after the 20th week, the causes are determined only in about 40% of the cases.

---

[21] Perez, C. C. (2019). Invisible Women: Exposing Data Bias in a World Designed for Men. Random House.

[22] Orbach, S. (2019). *Bodies*. Profile Books.

An essential part of the process was conducting qualitative semi-structured interviews with people related to the issue. The goal of these interviews was to gain first-hand knowledge of the different aspects affecting the event of stillbirth in Estonia. The interviewees included:

Kairi Tozen-Pütsepp, a pregnancy crisis counsellor (01.10.2019)

- *SA Väärtustades Elu* purpose, aim, and practice
- General emotions of people needing pregnancy crisis counselling
- Bereaved parents and handling loss in stillbirth
- Main themes in counselling in the case of stillbirth
- Returning to everyday after a stillbirth
- The need for support in the following pregnancy
- The state of awareness of the partners in pregnancy
- General awareness of the risks in pregnancy
- Support of partners and further family
- Counselling availability

Eidi Aidla, a lived-experience counsellor with *MTÜ Vaikuse Lapsed* (19.02.2020)

- Experience as lived-experience counsellor
- Assessment of the support offered in maternity clinics
- Main themes in counselling in stillbirth
- Main pain-points for the families
- Current journey in the event of stillbirth
- Difference in needs for support of women and men
- Return to everyday, problematic situations, causes
- Public awareness, its role in returning to everyday
- Bodily changes
- Need for options in the journey
- Memory boxes, workshops, use in maternity clinics
- Personal experience in loss

Made Bambus, Chief Specialist of the Primary Care Framework Development of Estonian Health Insurance Fund (21.02.2020)

- Perspective of the Estonian Health Insurance Fund in mental health counselling during pregnancy
- Assessment of the care available in the case of stillbirth
- Systems view of healthcare support for various situations related to pregnancy

- Future perspectives of responses to miscarriage and stillbirth
- Integrated services model in development
- Pregnancy crisis counselling
- The fragmentation of responsibility from the state’s perspective

Juta Palmeri, board member of *MTÜ Vaikuse Lapsed* (18.03.2020)

- *MTÜ Vaikuse Lapsed* aim and practice
- Collaboration with the maternity clinics
- Differences in the approach of parents
- The needs of the bereaved parents
- Varied length of grief
- Public view of the issue
- The differences in grief management of mothers and fathers
- Managing the loss
- Personal experience in loss
- Importance of memory making, Memory Box
- Community, Facebook group, Memory Box workshops
- Future aims of *MTÜ Vaikuse Lapsed*
- Development of network of support persons
- The awareness and support of medical personnel
- Experiences from communities abroad
- The place of peace at Risti cemetery

Dagmar Mankin, a midwife from the East-Tallinn Central Hospital who in her own thesis explored the aspects of stillbirth from the midwifery perspective (23.03.2020)

- Patient journey in stillbirth in the East-Tallinn Central Hospital
- Best practice guidelines
- Painpoints in the journey
- Role of the partners and support available for them
- Role of counselling and social workers, use of Memory Boxes
- Communication and tone of voice importance in diagnosis and in conversations with the family
- Birth induction
- Birth
- Spending time with the baby
- Making memories, handling memories
- Available data of the baby from the period of pregnancy
- Emotions of the parents

- Empathy of the medical personnel
- Support in further arrangements for the family through social worker
- Bodily recovery of mothers, support in this, options available
- Following pregnancy
- Example cases

A mother (25.03.2020) and a father (04.04.2020) of a premature child who passed away after two days

The separate interviews aimed to compare the different experience, attitude and memories of parents from the same family, along with gathering an understanding of the personal experience and memories. I hypothesised that the perception of the experience and loss, as well as memories, are individual and can differ between parents.

- Pregnancy
- Previous pregnancy and miscarriage
- Role of the communication with medical personnel, its influence on the journey
- Hospital experience
- Birth
- After birth experience
- Experience with seeing the baby
- Death of the child
- Experience in the morgue
- Bureaucracy and necessary documentations
- Organising the send-off
- Further family experience
- Support from others
- Role of counselling
- Influence of the public perception
- Role of empathy and understanding from the public
- Communication about the loss to others
- Bodily recovery
- Next pregnancies
- Remembrance of the loss
- Perception of the event by siblings
- The role of giving a name and identity number

A couple currently pregnant (28.03.2020)

- The awareness of the risks in pregnancy
- Gathering memories during pregnancy

- Preparations before birth
- Use of search engines, information sources, forums, applications
- Monitoring the pregnancy
- Relationship between the parents and separate perception of the pregnancy and expectations

Additionally, a bereaved mother of a stillborn (passed away half a year ago) shared her experience and emotions in an e-mail.

Part of the process was gathering information as a bereaved parent would, going through the different materials and websites publicly available and seemingly relevant. This process included observing accounts of people's experiences through online forums and the support offered through different services and analyzing the impact of these. I also relied on the personal account of a friend of bereaved parents.

The knowledge first-hand knowledge gained from interviews, along with field research and observations was supplemented through reading numerous research papers, studies and articles on the different aspects tied to stillbirth. Due to the sensitivity of the topic, I did not interview people who had a recent experience but relied on studies conducted by different researchers.

2.4.2 Experimentation and evaluation

The information gathered from the different sources was used to compile a map of the current journey from the family's perspective, where the various pain points in the different stages of the journey are highlighted. Midwife Dagmar Mankin validated the content of this journey map.

The pain points from the current journey informed the brief for the design concept. The design concept does not aim to alleviate all pain points, but rather provide support and increased individual experience. The conceptualisation process was iterative and done while the research was still ongoing. The concept was expressed through a bilateral map that covered both the systemic view and the user experience.

To illustrate the differences in people affected by stillbirth, personas based on the research outcomes were compiled to show the different possibilities of interfacing with the proposed system. Based on the personas, individual user journey maps were created.

As the system is hard to grasp as a map and small nuances in the user experience play a significant role in the overall success of the concept, high-fidelity prototypes were created that covered some aspects of the concept. These prototypes were used to validate with stakeholders.

3 ANALYSIS OF THE SYSTEMS SUPPORTING STILLBIRTH IN ESTONIA

The healthcare system is the entrypoint of the experience of stillbirth, and the experience in the hospital has a strong effect on the overall journey of the parents. Thus, it is important to understand how the healthcare and social system itself handles stillbirth and what kind of support is on offer. The following analysis explores how the level of access to healthcare, medical terminology used, support options offered, ways of communicating and available information affect the experience.

3.1 Access to healthcare and related services

Public hospitals operate on the principle human right of equal access to healthcare, which requires standardisation of procedures in order to be universally available. In order to maintain a high quality of healthcare, related to the low population density of Estonia in rural areas, roughly 70% of births registered in Estonia take place in the three largest maternity hospitals.[23] Concerning this, the expertise of the healthcare providers in these centres is considerably higher, and the perinatal mortality rate in Estonia has fallen to 2,7‰.[24] Maternity clinics in Estonia vary in their equipment, expertise, personnel and practice dependent on the size of the hospital and the location, but still aim to follow the best practice guidelines regardless. In the largest maternity clinics located in Tallinn and Tartu, there are various rooms of different purposes available in large and well-equipped wards. This allows the clinic to manoeuvre in its general practice to facilitate the stillbirth event guidelines when needed. There is a clinical psychologist available for the patients to consult with and pregnancy crisis counsellors are available to respond near-immediately. The situation is vastly different in the hospitals in more rural areas, where the number of births dictates the size of the clinic, the available staff and services, therefore following the best practices and stillbirth event guidelines is not possible in the same manner as in the largest hospitals.

---

[23] Tervisestatistika ja Terviseuuringute Andmebaas, (2019, July 19). *Sünnid haigla ja naise elukoha järgi.* Retrieved January 2020, from https://pxweb.tai.ee/PXWeb2015/pxweb/et/01Rahvastik/01Rahvastik__02Synnid/SR03.px/?rxid=66951fe5-6003-4a52-9252-ec8ba4f46e69&fbclid=IwAR2DoVl7UYnbUJUBL70kxi9lOIZFRVHwRYNWCIKbwQ3r7D7ZhMNEu5MOG1Q

[24] Keskhaigla, (n.d.). *Kas plaanime lõhkuda seda, mis töötab järjest paremini? | Veebruar | 2019 | Kõik uudised | Uudised | Ida-Tallinna Keskhaigla*. Retrieved 15 January 2020, from https://www.itk.ee/uudised/koik-uudised/2019/2/kas-plaanime-lohkuda-seda-mis-tootab-jarjest-paremini

In 2018, Valga hospital maternity clinic closed, and in 2020, Põlva hospital maternity clinic followed suit. Although the patients from these areas are now referred to South-Estonia Regional hospital, and the quality of the services is higher in the central hospitals, the services families might require after birth, are less accessible to them due to their distance from large centres once they leave the hospital. As most services families may require are available near the major hospitals, it can, therefore, be reasoned, that accessibility of services varies throughout Estonia.

The potentially problematic pregnancies are referred to the East-Tallinn Central Hospital Perinatal Centre in order to receive the best possible care. After the women who have experienced stillbirth are discharged from the hospital, they return home where medical and support services may not be as easily accessible as in Tallinn.

3.2 Medical terminology defining the proceedings

Medical terminology differentiates between different perinatal mortality. When the pregnancy ceases at an early stage, in miscarriage (before 22nd week of gestation), the medical procedures required are less invasive than when the foetus is lost in the third trimester, stillbirth (after the 22nd week of gestation, with a foetal weight of at least 500g). In the third trimester, the foetus is more developed and the procedures in stillbirth more extensive. Respectively, the healthcare system recognises that as the pregnancy has been carried further, the parents have had more time to form a connection with the foetus. Therefore, strong emotions are expected considerably more than with miscarriages. A neonatal death, when a newborn passes during the first 28 days of life, is recognised separately, the family is expected to hold strong emotions in this event.

In 2018 1790 miscarriages (spontaneous abortion)[25], 46 stillbirths[26], and 23 infant deaths (under one year old) were registered.[27]
The medical system addresses all three of these in the development of separate best practice guidelines to follow. The legislation has similarly addressed the events by differentiating between the medical classifications.

---

[25] *Abordid, aasta—Eesti Statistika*. (n.d.). Retrieved 9 May 2020, from https://www.stat.ee/34273?highlight=abort

[26] Anderson, E. (n.d.). Vastsündinute haigestumise statistika kvaliteediraport. 21.

[27] *Imikusuremus, aasta—Eesti Statistika*. (n.d.). Retrieved 9 May 2020, from https://www.stat.ee/34269

The state has adapted the medical classifications in proceedings and differentiates between these three perinatal mortality experiences.
In miscarriage, the event is only noted in the mother's medical history, and birth and death certificates are not issued, an autopsy is necessary with foetal weight over 500g. The baby is not registered in the population register. The woman is not eligible for maternal leave but is entitled to a medical leave issued by her gynaecologist, the partner's medical leave needs to be issued by their GP. If the parents have given the child a name, this is not registered in any documentation. There is no regulative legislation for burial or hand-over from the hospital of a baby under 500g. The parents should clearly state their wishes at the hospital, because otherwise, the miscarried baby may be disposed of as medical waste.

In stillbirth, the event is similarly only noted in the mother's medical history, and birth certificate and death certificate are not issued.[28] — the hospital issues perinatal death notice and perinatal death reason.[29] [30] An autopsy is obligatory if the foetal weight is over 500g. If the reason for death is determined or the parents do not agree with an autopsy, the requirement is dismissed.[31] The baby is not registered in the population register, but a modified identity code is issued (last identifying numbers between 995-999). The 140-day maternal leave is cancelled only upon the mother's request, in case the mother was not yet on maternal leave, the leave is started and lasts 140 days. Further maternity leave is not started. The partner's medical leave needs to be issued by the GP. The perinatal death notice is needed for burial procedures. The parents can choose between burial or cremation.[32]

In neonatal death, a digital birth certificate is issued. An autopsy is similarly required if the weight is over 500g, but if the reason for death is determined or the parents do not agree with an autopsy, the requirement is dismissed.[33] If If the child is born in the hospital, the birth can be registered online. Otherwise, it should be registered at the local government. The death is registered digitally by the hospital, and the doctor issues the death certificate. The 140-day maternal leave is cancelled only upon the mother's request, in case the mother was not yet on maternal leave, the leave is started and lasts 140 days. Further maternity leave is not started. The partner's

---

[28] MTÜ Vaikuse Lapsed. (n.d.). Juhend toimingute osas pärast lapse kaotust. 8.

[29] Tehik. (2019). Surma digitaalne dokumenteerimine. 3.

[30] Tehik. (2019). Surma registreerimise teenus. 18.

[31] Mankin, D. (2020, March 23). [Digital personal interview].

[32] MTÜ Vaikuse Lapsed. (n.d.). Juhend toimingute osas pärast lapse kaotust. 8.

[33] Mankin, D. (2020, March 23). [Digital personal interview].

medical leave needs to be issued by their GP. The parents may be eligible for local government childbirth allowance.[34] The baby receives a full identity code, and the name is registered on the death certificate, if the parents wish, it is also registered on the birth certificate. The death notice is needed for burial procedures. The parents can choose between burial or cremation.[35]

3.3 Counselling as the main service of support, related issues

The state-managed support for the bereaved families is focused, besides medical care, on counseling, overseen and directed by the funding plans of the Estonian Health Insurance Fund (EHIF). The list of services covered by public health insurance limits the services provided in all medical cases to the determined necessary. This is also partially the reason why stillbirth is perceived in greater part as a woman's experience, as medically speaking, there is nothing wrong with the father. EHIF monitors the use of the funding vigorously through issued referrals. Due to the rigid procedural structure, the EHIF funded support available to the bereaved parents is limited to medical care and counseling.

EHIF directs the funding according to the health care strategies developed by the Ministry of Social Affairs. EHIF's current service partner in mental health counselling during pregnancy is *SA Väärtustades Elu.* The foundation offers emergency counselling, and the counsellors are available, in case of emergency (which is determined by the medical personnel) to offer rapid response emergency counselling on the spot at the clinic. The pregnancy crisis counsellors' qualifications and background vary, making the service inconsistent (all counsellors have gone through necessary pregnancy crisis counselling qualification training — previously 40ECTS, from 2018 90ECTS[36]).

Pregnancy crisis counselling requires a referral either from the midwife, general physician or the gynaecologist in order for the costs to be covered by EHIF. Outside Tallinn, the counselling is available in the larger county centres, making it less accessible for the people living in rural areas. *SA Väärtustades Elu* also offers free phone-counselling from 9-21 every day and answers questions sent by e-mail within a

---

[34] *Childbirth allowance > Tallinn*. (n.d.). Retrieved 10 May 2020, from https://www.tallinn.ee/Teenus-Childbirth-allowance

[35] MTÜ Vaikuse Lapsed. (n.d.). Juhend toimingute osas pärast lapse kaotust. 8.

[36] SA Väärtustades Elu. (n.d.). Raseduskriisi nõustamise täiendkoolitus 2018-2020.

week. Although the service is primarily offered to women up to 2 years after the birth, *SA Väärtustades Elu* counsellor Kairi-Tozen Pütsepp[37] explained that anyone who feels the need for the counselling is welcome in that time period (usually the mother makes the initial contact). As the rest of the system does not have the means to care of the remainder of the family and social support network, this approach aims to alleviate this.

The East-Tallinn Central Hospital maternity clinic has a productive collaboration with *SA Väärtustades Elu* and sees value in the provided counselling as the counsellors support the families in ways midwives do not feel qualified in and lack time for. The service system for mental health counselling during pregnancy and related issues is currently under evaluation to be restructured to make it more accessible for people and easier to oversee for EHIF. Made Bambus, Chief Specialist of the Primary Care Framework Development of EHIF explained the problems in the current service system and pregnancy crisis counselling from the overseeing standpoint. The purpose and content of the service are poorly defined, and the qualifications of the counsellors vary. A Crisis is by definition a passing state, from which counselling would be offered once or twice, but current pregnancy crisis counselling resembles in most instances psychotherapy, for which the pregnancy crisis counselling is not qualified.[38] Based on the expert analysis requested by EHIF[39], the service system in development would see the majority of mental health counselling during pregnancy be offered by the primary care level. Subsequent to a stillbirth, the counselling offered to bereaved parents should guarantee the qualification of the counsellor's capability of handling such topics.

The Professional Association of Clinical Psychologists in Estonia has urged the need for government funding for the training of the clinical psychologists in order to enable better access to counselling and stresses the current lack of adequate help in rural areas and growing issues with the availability of services in the cities.[40]

---

[37] Tozen-Pütsepp, K. (2019, January 10). [Personal interview].

[38] Bambus, M. (2020, February 21). [Personal interview].

[39] Pruul, P. (2016). Eksperthinnangu „Raseduskriisi nõustamise kvaliteet" Kokkuvõte. Estonian Health Insurance Fund.

[40] Vaimse tervise spetsialistid: Maal on meilt juba raske abi saada, varsti läheb hulluks ka mujal. (2019, October 9). Delfi. Retrieved January 16 2020, from https://www.delfi.ee/a/87702833

The effectiveness of psychological counselling depends on many variables. The ease of access to the service, the readiness of the participant to accept support and express emotions, the compatibility with the counsellor and the trust formed, but above all the experience of the counsellor. Additionally, whether the participant is able to find time to seek out counselling and commits to the progress and how much the friends and family support this decision affect the successfulness of the psychological aid.

3.3 Additional support

The healthcare system, along with the state proceedings uses clear divisions to differentiate between different perinatal losses, however, the bereaved families do not view their loss defined through the given categories. Whilst most commonly it can be determined that a loss at a later stage of gestation provokes stronger and longer-lasting influence on the parents than an early-stage miscarriage, such simplification of the situation should be avoided. Comparing the experiences described by the experts from *MTÜ Vaikuse Lapsed*, it must be concluded that a range of influencing factors influence the significance of the impact the loss has on the family.

3.3.1 MTÜ Vaikuse Lapsed

Besides health care and state structure, the non-profit organisation *MTÜ Vaikuse Lapsed* aims to offer support to the bereaved parents in their loss through a few initiatives. The foundation retains a place of peace at Risti since 2011 available to all parents as a burial place for the lost children and as a remembrance location. The foundation organises events for the medical personnel where the bereaved parents' community offers insight into how best talk to the bereaved family. In 2016 *MTÜ Vaikuse Lapsed* issued two information booklets to better inform and support the bereaved families in their loss. Since 2015, the foundation leads the initiative of Memory Boxes that are gifted to the bereaved parents to aid with memory-making and handling grief. Currently, the foundation's website and information booklets are in Estonian and not available for non-Estonian speakers.

The Memory Box initiative, besides recognising the parents at the difficult moment when society does not, also offers support to the medical personnel. Juta Palmeri[41] described the Memory Box as aiding the hospital personnel in the difficult conversations with the family after the loss, giving them something to focus on describing rather than going to the family empty-handed and struggling to find

---

[41] Palmeri, J. (2020, March 18). [Digital personal interview].

something to talk about. Additionally, the Memory Boxes are compiled during workshops and bring together mothers and family members that feel they want to offer support. Although these are not structured as group counselling sessions, people take comfort in seeing others who know what they have been through.

3.3.2 Opportunities for alternative approaches

Cacciatore [42] found that attending support groups can lessen the levels of post-traumatic stress in women. Another study saw influencing factors such as the mother's social situation, attachment style and the quality of the current partnership.[43] While attending support groups and counselling have been seen as beneficial in lessening negative outcomes, not everyone feels comfortable opening up about their emotions in such settings. When the current support on offer in Estonia focuses on counselling, community network and group gatherings, it limits the support to only those willing to share. There is an opportunity for alternative approaches that would touch the same purpose as group gatherings and forums have besides allowing sharing one's own story — to lessen the aloneness of the experience. Being exposed to a variety of people's experiences besides one's own helps to make sense of the situation and develop one's methods of coping.

In the interviews conducted with experts and bereaved parents, it was revealed that the personalities and attitude influence the experience and decisions greatly. While some of the interviewees had found great comfort from bereaved parents group online, others would rather avoid these and prefer their circle of friends. Similarly, not everyone is comfortable expressing themselves in counselling. The current system, with its focus on counselling and support groups, should not be seen as universally functioning support. There is a need for alternatives.

In pregnancy-related topics and later in parenthood, there is a wide variety of solutions that make use of enabling a diversity of information and experiences besides group gatherings. When family school lessons follow a similar format to group gatherings, alternatives for families disliking this particular type of knowledge-sharing

---

[42] Cacciatore, J. (2007). Effects of Support Groups on Post Traumatic Stress Responses in Women Experiencing Stillbirth. *OMEGA - Journal of Death and Dying*, *55*(1), 71–90. https://doi.org/10.2190/M447-1X11-6566-8042

[43] Scheidt, C. E., Hasenburg, A., Kunze, M., Waller, E., Pfeifer, R., Zimmermann, P., Hartmann, A., & Waller, N. (2012). Are individual differences of attachment predicting bereavement outcome after perinatal loss? A prospective cohort study. *Journal of Psychosomatic Research*, *73*(5), 375–382. https://doi.org/10.1016/j.jpsychores.2012.08.017

are articles, books, apps, webinars, and others. As the perinatal death follows a pregnancy, there is an opportunity to draw inspiration from the various models parents already have become accustomed with.

In 2017, an article analysed the bereaved parents' online communities[44] to explore the effect of these and found that although the forums and social media groups are safe havens for the bereaved parents' for expressing their grief and sharing the experience with people who have gone through similar experiences, the groups may also self-impose restrictive norms for how grief practices and experiences should be shaped and expressed. Although online communities can be beneficial bringing together the bereaved families with similar experiences and lessening the feeling of being alone with the sorrow, it is important to make sure the community is inclusive and the value of an individual experience is supported.

3.4 Unexpectedness of the loss influencing communications

The loss of a child is always unexpected. Even if the family is informed of the risks in pregnancy, in the interviews with experts and parents, it became apparent that thinking of the possible negative outcomes is avoided as it adds unnecessary worry and stress. Expecting parents may be aware of the possible risks, but tend to think that this will not happen to them.

Eidi Aidla[45], a lived-experience counsellor, noted that although the unpreparedness for the loss intensifies the shock at the moment, it would not be in any way positive for all expecting families to live in a constant state of worry. Parents are meant to prepare themselves and their lives for the changes a baby brings, living with worry affects this negatively.

Therefore, the diagnosis falls onto the parents as a shock, and the handling of the journey's first steps strongly influences the impact of the event on parents. "Parental recovery from the experience of stillbirth can be influenced as much by staff attitude

---

[44] Christensen, D. R., Hård af Segerstad, Y., Kasperowski, D., & Sandvik, K. (2017). Bereaved Parents' Online Grief Communities: De-Tabooing Practices or Relation-Building Grief-Ghettos? *Journal of Broadcasting & Electronic Media*, *61*(1), 58–72. https://doi.org/10.1080/08838151.2016.1273929

[45] Aidla, E. (2020, February 19). [Personal interview].

and caring behaviours as by high-quality clinical procedures."[46] It is recognised that everyone involved has only one opportunity to get the experience right.[47] Midwife Dagmar Mankin described that parents take the news as a shock and sometimes refuse to believe the diagnosis, seeking a second opinion in another clinic where they then stay for the following procedures. The first natural emotion parents often go through is denial, and it puts the parents in direct inner conflict with the doctor that gave them the confirmation, making it difficult to process the information. Mankin added that she has accepted that the parents feel the hospital and the personnel is to blame and does not argue against these emotions if these are expressed by the parents.[48]

A bereaved mother, who lost her baby in 2019, expressed how the doctors' communication style caused her great distress and she remembers receiving sharp comments from the observing midwife and later a nurse about her crying.[49] Another bereaved mother,[50] being pregnant after going through a stillbirth and a miscarriage, remembers a nurse calling her irresponsible for trying again. Although the best practice guidelines in this clinic put much focus on empathy and softening the family's experience, and midwife from East-Tallinn Central Hospital stated that in her opinion parents do not express their emotions enough and could feel freer in this also in the hospital setting as the medical personnel understands the situation well[51], these examples illustrate how communication can still go wrong in the state of heightened emotions. There can be many reasons for these descriptions. Regardless, here these do not matter. Rather it is important to conclude that stillbirth is an event that puts a sudden strain on the capabilities to handle communications.

While communication with the medical personnel is afflicted, the clinic is still the primary source of information and support for the parents in stillbirth. There are no additional official, clearly structured, comprehensive, and up-to-date sources to aid this communication. Currently, the medical personnel guidelines for informing the parents see that to avoid needing one parent to inform another of the difficult

---

[46] Downe, S., Schmidt, E., Kingdon, C., & Heazell, A. E. P. (2013). Bereaved parents' experience of stillbirth in UK hospitals: A qualitative interview study. *BMJ Open*, *3*(2). https://doi.org/10.1136/bmjopen-2012-002237

[47] ibid.

[48] Mankin, D. (2020, March 23). [Digital personal interview].

[49] Bereaved mother. (2020, March 23). [Personal communication].

[50] Bereaved mother. (2020, March 25). [Digital personal interview].

[51] Mankin, D. (2020, March 23). [Digital personal interview].

situation. It would be best if they are given information about their case at the same time. Although this suggestion cannot always be honoured, analysing the purpose of such guideline gives an insight that the hospital aims to avoid placing additional pressure on the parents in informing one-another and the risk of unintentional disinformation.

In order to support the family in communication, and lessen the dependency on the healthcare provider, on-demand access to information supporting their experience should be enabled. This would equally lessen the tension between the family and medical personnel as the informedness of the family would depend less on the use of correct tone of voice or choosing the right moment to give information to the family. The information should be made proactively available to the bereaved parents from the moment of diagnosis and be personalised according to their medical journey.

3.5 Need for better structured information

To counterbalance the current situation, a few non-profit organisations have published their brief guides for bereaved parents. *MTÜ Vaikuse Lapsed,* in collaboration with the Estonian Association of Midwives, created a guidebook[52] that should be available for the parents at the clinic and on *MTÜ Vaikuse Lapsed* website. However, it is not easily found using search engines. The most easily found through an online search is the article "*Ootuse Kaotus"*[53] on the website of *Laste ja Noorte Kriisiprogramm MTÜ.* Compared to information available online to parents about pregnancy and childbirth, the information available about perinatal death is unreasonably small.

Information about perinatal loss is generally only directed to the bereaved families, making the target audience of the online websites relatively small. Additionally, as non-profit organisations and charities run the majority of the websites, these may lack funding and knowledge of search engine optimisation, lowering the visibility of these websites. These two reasons, in combination, are why the small number of good local and international websites do not show up at the top of the search results.

As non-profit organisations compile the guidebooks and articles, these are at risk of becoming outdated when updates occur in government services and legislation. This has happened to the only seemingly comprehensive guide available to parents about

---

[52] Palmeri, J., MTÜ Vaikuse Lapsed (2013). Infomaterjal lapse kaotanud perele. 36.

[53] *Ootuse kaotus—Laste ja Noorte Kriisiprogramm*. (n.d.). Retrieved 13 May 2020, from https://www.lastekriis.ee/lugemist/artiklid/88-ootuse-kaotus.html

proceedings in the event of a miscarriage, stillbirth or neonatal death "*Juhend toimingute osas pärast lapse kaotust"* compiled by *MTÜ Vaikuse Lapsed.*[54] It is missing the updates about the death notice and death certificates and does not cover the stillbirth personal identity codes issued. It also directs the parents to the local government to register the birth and death in the event of neonatal death. Registering the birth can now be done online, and the death notice is registered by the doctor who then can issue the death certificate to the parents or their representative (the funeral home).

Although state-issued guidelines are more reliable in the descriptions of proceedings, these may equally suffer from obsolete info that ends up in the source due to fragmentation of areas of responsibility between different ministries and departments. A guideline for the death registering service[55] that was issued 13.06.2019 (updated 29.06.2019) for healthcare providers mistakenly states that registering birth online is only available to married parents. The service was made available to all parents in 2016. As the specialists are most informed about their area of expertise, it is unfeasible to prevent all mistakes.

---

[54] [54] MTÜ Vaikuse Lapsed. (n.d.). Juhend toimingute osas pärast lapse kaotust. 8.

[55] Sims, A. (2019, June 13). Surma registreerimise teenus. 18.

4 COMPREHENSIVE UNDERSTANDING OF THE EXPERIENCE

Stillbirth research has focused mostly on either the medical practice or the emotional experience of the mothers, and occasionally of the fathers. From this, it may appear it would be possible to classify stillbirth as a medical issue with mental health consequences, but in conversations with parents and experts, acquainting myself with the experiences parents have shared on online forums, and following analyses that focus on understanding the common underlying emotions such as grief, shame, guilt, blame and stigma, it has become clear, that the journey in stillbirth has an impact on all parts of life. It touches the lives of many more than just the mother and father.

In order to conduct a more thorough analysis of the situation and inform the design process, a comprehensive, detailed visualisation of the journey of the parents was required. I created this visualisation (See appendix A) in the form of a detailed map, which was informed by the desktop research and interviews with experts and parents and upon completion was validated with Dagmar Mankin, a midwife at East-Tallinn Central Hospital.

The journey map covers the different stages and themes of the experience from the first concerns, to what parents go through after leaving the hospital and points out the pain-points from the family’s perspective. When compiling the map, it became evident that while the experience in the hospital can be viewed as a linear one, although it does not always have a set progression, the experiences separate from the medical proceedings cannot be visualised linearly.

This is why the visualisation is split in two. The first half is structured in a relatively linear way, with the map covering the stage of the journey, the medical practices, parents’ experience in that stage along with the pain points that are tied to those practices and experiences. After the parents leave the hospital, the visualisation changes, there is no longer a clearly defined structure, and the time frame can vary. This part focuses on the different themes of the experience, along with the linked pain points.

While the journey has many pain-points for the parents, there are overarching paint-points, which influence the journey in all stages:

- People have difficulties relating to the loss and grief of the parents as they had no actual connection with the child that was lost.

- The way parents are talked to and treated is of utmost importance, but people have different capabilities in this regard. This can lead to extremely negative experiences that emphasise the feeling of failure, guilt and shame.
- The feeling of the body failing the mother, failing its purpose. This creates shame and a sense of failure that can underline the rest of the experience. The changes in the body after birth can be difficult to handle.
- Many bereaved parents can be unintentionally influenced to make decisions before they are ready. This should be avoided in all aspects.
- Emotions such as guilt and shame expressed towards themselves, the child, partner (mother/father), further family, medical personnel, friends, colleagues, and others can shadow and complicate the experience.

The visualisation gave an overview of the full journey of stillbirth in Estonia, something which previously did not exist. It highlighted the complexity of the situation, showed how the pain-points are interlinked and what the overarching pain-points are. Communication is essential, especially in the first stages of the journey, because it can heavily influence later processing of the experience and grief. The analysis revealed how the journey is not experienced linearly, as after leaving the hospital, there is no structure for how to proceed. Parents have a whole range of proceedings they need to deal with and have little in the way of support.

4.1 The human-centred viewpoint to the experience

Perinatal loss is unique, as life ends before it begins. It is sudden and difficult to relate with as, before the diagnosis, the parents were expecting their family to grow. Making sense of the loss can push parents into difficult thought-patterns that further complicate the whole journey of the stillbirth experience. Emotions such as guilt, blame, regret, fear, grief, shame, stigma and even wanting to die have been all recognised in both mothers and fathers by researchers and recent studies suggest that predisposition to shame and guilt intensifies the grief following a perinatal death.[56]

The experience in the hospital influences the emotions greatly as it is the initial environment in the experience. After the diagnosis and discussion of possible options, most mothers prefer to immediately stay at the clinic to start with the induction process. Usually, in these cases, the partners head home to gather necessary items

---

[56] Murphy, S., & Cacciatore, J. (2017). The psychological, social, and economic impact of stillbirth on families. *Seminars in Fetal and Neonatal Medicine*, *22*(3), 129–134. https://doi.org/10.1016/j.siny.2017.02.002

for the mother.[57] At this stage, the focus of the experience is on the mother as she needs to undergo the difficult birth. The father, usually, focuses on the mother's experience and supporting her to the best of his ability leaving his own emotions to the background. However, the midwife emphasised that not all partners know how to be supportive in these moments and some fathers only come to pick up the mother from the hospital after she has been discharged leaving the couple dealing with their emotions separately.[58]

The clinic aims to place the mother in a separate room, or at least, separate from pregnant women. Before birth, the father is allowed to stay with the mother during visiting hours. The time between the induction and the beginning of the birth varies but can take a few days if the mother has not given birth previously. The midwives are available for the family as much as possible. They aim to bring in a pregnancy crisis counsellor or the clinic's clinical psychologist to support the mother and the family. The tone of communication that best fits the family differs between people and is therefore difficult to get right for the medical personnel. Personality traits play a role, even if the best possible support is offered, the perception of that support depends on the recipient's perspective.[59] One bereaved mother[60] wished the hospital personnel would have communicated with more empathy. In contrast, the interviewed bereaved father[61] expressed that he would rather have a rational tone of communication without additional emotion from the personnel.

Everything in this experience: the diagnosis, the urgency of the care, the separation of the partners, the unnatural clinic environment and placement in a different ward, the additional attention — however necessary, draw further attention to the experience and heighten the mixture of emotions related to it. As the experiences of the mother and father differ in the time between the diagnosis and birth, the partners may draw different conclusions from the event and have difficulties communicating their feelings to each other later. The pregnancy-crisis counsellor[62] noted in the interview of the importance of communication between the parents to avoid the development of

---

[57] Mankin, D. (2020, March 23). [Digital personal interview].

[58] ibid.

[59] Cacciatore, J., Schnebly, S., & Froen, J. F. (2009). The effects of social support on maternal anxiety and depression after stillbirth. *Health & Social Care in the Community*, *17*(2), 167–176. https://doi.org/10.1111/j.1365-2524.2008.00814.x

[60] Bereaved mother. (2020, March 23). [Personal communication].

[61] Bereaved father. (2020, April 4). [Digital personal interview].

[62] Tozen-Pütsepp, K. (2019, January 10). [Personal interview].

separate narratives of the event that would distance the parents from each other and heighten the negative feelings of shame, guilt and blame.

The partner is assumed to take a supporting role during the time the mother is in the hospital. He is also processing the event, and his emotions, but may consciously intend to divert his focus to better cope with the experience and be more supportive of the mother.[63] While the mother is in the hospital, the father returns home. Compared to the hospital, home may seem like a more familiar environment, yet the sudden loss may make it seem alien. Additionally, if the family has prepared for the arrival of the baby, the father may suddenly face the reminder of this alone. The midwife stated, that although at the clinic, the father is not a patient, when they see that the father is overwhelmed with emotion, the doctor may hand depressants to him, which is then noted in the mother's medical history. It is viewed as the only support the clinic can provide at this time.[64]

The impact stillbirth has on a person varies due to many influencing factors. The manner of hospital communications plays a role[65], but also the strength of the communication between partners and their emotional bond[66], including the strength of the social support network. Emotional resilience of a person and previous experience in loss seem to allow maintaining a more rational mindset[67] lessening the self-blame, whereas personal proneness to negative self-conscious emotions tends to heighten feelings of self-blame, guilt and shame.[68] Some evidence has shown that in bereaved

---

[63] Bereaved father. (2020, April 4). [Digital personal interview].

[64] Mankin, D. (2020, March 23). [Digital personal interview].

[65] Downe, S., Schmidt, E., Kingdon, C., & Heazell, A. E. P. (2013). Bereaved parents' experience of stillbirth in UK hospitals: A qualitative interview study. *BMJ Open*, *3*(2). https://doi.org/10.1136/bmjopen-2012-002237

[66] Hutti, M. H., Armstrong, D. S., Myers, J. A., & Hall, L. A. (2015). Grief Intensity, Psychological Well-Being, and the Intimate Partner Relationship in the Subsequent Pregnancy after a Perinatal Loss. *Journal of Obstetric, Gynecologic, & Neonatal Nursing*, *44*(1), 42–50. https://doi.org/10.1111/1552-6909.12539

[67] Cacciatore, J., Schnebly, S., & Froen, J. F. (2009). The effects of social support on maternal anxiety and depression after stillbirth. *Health & Social Care in the Community*, *17*(2), 167–176. https://doi.org/10.1111/j.1365-2524.2008.00814.x

[68] Barr, P. (2012). Negative self-conscious emotion and grief: An actor–partner analysis in couples bereaved by stillbirth or neonatal death. *Psychology and Psychotherapy: Theory, Research and Practice*, *85*(3), 310–326. https://doi.org/10.1111/j.2044-8341.2011.02034.x

parents, guilt and shame can predict more intense grief reaction, whereas self-blame can predict posttraumatic symptomology, anxiety and depression.[69]

Immediately after the diagnosis, the parents start to develop their understanding of the experience and explore their emotions related to the loss. These influence all later events, including managing grief, relationships, communications, returning to everyday life and work, as well as the next pregnancy. It is therefore essential to create additional accessible means, besides methods requiring interpersonal communications, to support the development of the understanding of the loss and to strengthen the more rational thought-patterns to avoid the mental tuning towards the most negative outcomes of the stillbirth experience.

4.2 Unique grief

Perinatal loss brings forward grief that differs from regular mourning. Parents find themselves dealing with a loss when earlier, their mind was set on the arrival of the baby. The only memories made with the child are the ones during the pregnancy, and this often raises the question of what feelings are appropriate in the experience. The most emotionally complicated losses are births of twins where one of the children is stillborn. It brings about joy and grief simultaneously, leaving the family in a storm of emotions. In an interview with Juta Palmeri[70], she expressed that parents often struggle with the legitimacy of their loss, lacking proof of the child's existence. They perceive an expectation for them to move on, while the time needed to grieve dramatically varies from person to person, sometimes requiring years to make peace with the death. Talking about the loss and making sense of the event by putting it in words and learning about others' similar experiences seems to allow a more natural grieving process.[71] As the loss is perceived as the family's own and often not even known to their wider social circle, the bereaved family may be left without such opportunities.

In research and studies about stillbirth, the benefits and risks of parents spending time with and holding the child after birth have been discussed. There are arguments both for and against this practice. In a systematic review of studies about this topic,

---

[69] Duncan, C., & Cacciatore, J. (2015). A Systematic Review of the Peer-Reviewed Literature on Self-Blame, Guilt, and Shame: *OMEGA - Journal of Death and Dying*. https://doi.org/10.1177/0030222815572604

[70] Palmeri, J. (2020, March 18). [Digital personal interview].

[71] Cacciatore, J. (2010). The Unique Experiences of Women and Their Families After the Death of a Baby. *Social Work in Health Care*, *49*(2), 134–148. https://doi.org/10.1080/00981380903158078

21 of 23 studies concluded positive outcomes for the parents.[72] This practice is associated with lower risks of depressive and anxious symptoms, although this may be temporarily reversed during a subsequent pregnancy. Mothers who had not seen their child after birth have later expressed regretting this decision. In the decision whether to see or not see the child, parents often trust the suggestions of the medical personnel as an authority in these matters.[73] In a study conducted to determine if the way medical personnel offers opportunities to see and hold a stillborn baby affects the feelings of the mother about the experience, it was concluded that if the staff supported assumptive bonding by simply offering the baby to the mother.[74] It created an atmosphere where the experience was normalised as "asking any mother if she wants to see her baby is an 'unnatural question'."[75]

One of the difficulties in grieving for a perinatal loss is the absence of memories. *MTÜ Vaikuse Lapsed* has developed Memory Boxes that are given to the parents in hospitals. These boxes contain a few items that should guide the parents in making memories and building a connection with the child. The baby's handprints and footprints can be taken, and it holds a small card offering condolences from other bereaved parents who have made the box. The midwife Dagmar Mankin explained that the clinic's social worker or a midwife introduces the box to the family after the birth and also, with the parent's permission, takes pictures of the baby. It is common that once discharged, the parents want to leave the hospital experience behind and also leave the Memory Box and the photos at the hospital, but later return to ask for these. The clinic keeps hold of these items and files for a minimum of six months, if possible, longer.

Most of the "evidence" of the child is in their parents' collective possession. The ultrasound images, photos taken during the pregnancy, items purchased, hospital memories, and others are all items that could be used for building stronger memories

---

[72] Kingdon, C., Givens, J. L., O'Donnell, E., & Turner, M. (2015). Seeing and Holding Baby: Systematic Review of Clinical Management and Parental Outcomes After Stillbirth. *Birth*, *42*(3), 206–218. https://doi.org/10.1111/birt.12176

[73] Cacciatore, J., Rådestad, I., & Frøen, J. F. (2008). Effects of Contact with Stillborn Babies on Maternal Anxiety and Depression. *Birth*, *35*(4), 313–320. https://doi.org/10.1111/j.1523-536X.2008.00258.x

[74] Erlandsson, K., Warland, J., Cacciatore, J., & Rådestad, I. (2013). Seeing and holding a stillborn baby: Mothers' feelings in relation to how their babies were presented to them after birth—Findings from an online questionnaire. *Midwifery*, *29*(3), 246–250. https://doi.org/10.1016/j.midw.2012.01.007

[75] Murphy, S., & Cacciatore, J. (2017). The psychological, social, and economic impact of stillbirth on families. *Seminars in Fetal and Neonatal Medicine*, *22*(3), 129–134. https://doi.org/10.1016/j.siny.2017.02.002

of the child, but as these are in shared possession, it creates a barrier for individual grief. The father may perceive his position in relating to the loss as secondary to the mother’s as she was the one carrying the child in pregnancy and needing to give birth to them. The hospital experience may also influence his role if the father feels he is not welcomed there as he is not the patient. From the mother’s perspective, common emotions in this experience like shame and guilt may make her feel reluctant to openly interact with these memories, sensing the expectation set for her to move on. If the family members do not share the same perception of the event and loss and are dealing with a mixture of emotions such as guilt, shame, blame, regret, but also perceive specific roles for themselves in the event, they may decide not to interact with the little memory-items they have. With that, they may suppress their grief, making the experience more complicated. This situation could be eased if every person would have their own access to these items building an individual connection to these. It would allow the individual experience to be untied from the expectations of handling memories uniformly and allow people to explore their own emotions in grief with less pressure.

In the interviews, I explored the grief experience and the importance of memories. Not all parents I spoke to have been able to build memories. When discussing the importance of memories with a bereaved father[76], he expressed that although they had thought of a name for the child during the pregnancy, indicating an emotional connection with the foetus, he feels that with the loss, they had no memories to hold onto, only lost hopes. While he got to meet the baby (he describes him as a “martian” because he was born at 22 weeks of gestation and looked almost transparent to him), his wife was unable to meet the child and later regretted this. Separately, the mother[77] expressed difficulties making sense of the loss without having seen the child, her emotions were more tied to bodily recovery and sensing her body failing her in motherhood. She seemed to have later found emotional alleviation processing the loss as inevitable. Although the father remembers that the child bore a name from an early stage of the pregnancy, the mother, when asked about a name, did not recall the same memory, expressing that the child did not have a name. The send-off ritual, of which organising was lead by the father, was appreciated by both. The family holds onto the yearly commemoration ritual. However, the mother expressed some reluctant feelings towards it as it brings the loss to the foreground not allowing to forget it.

---

[76] Bereaved father. (2020, April 4). [Digital personal interview].

[77] Bereaved mother. (2020, March 25). [Digital personal interview].

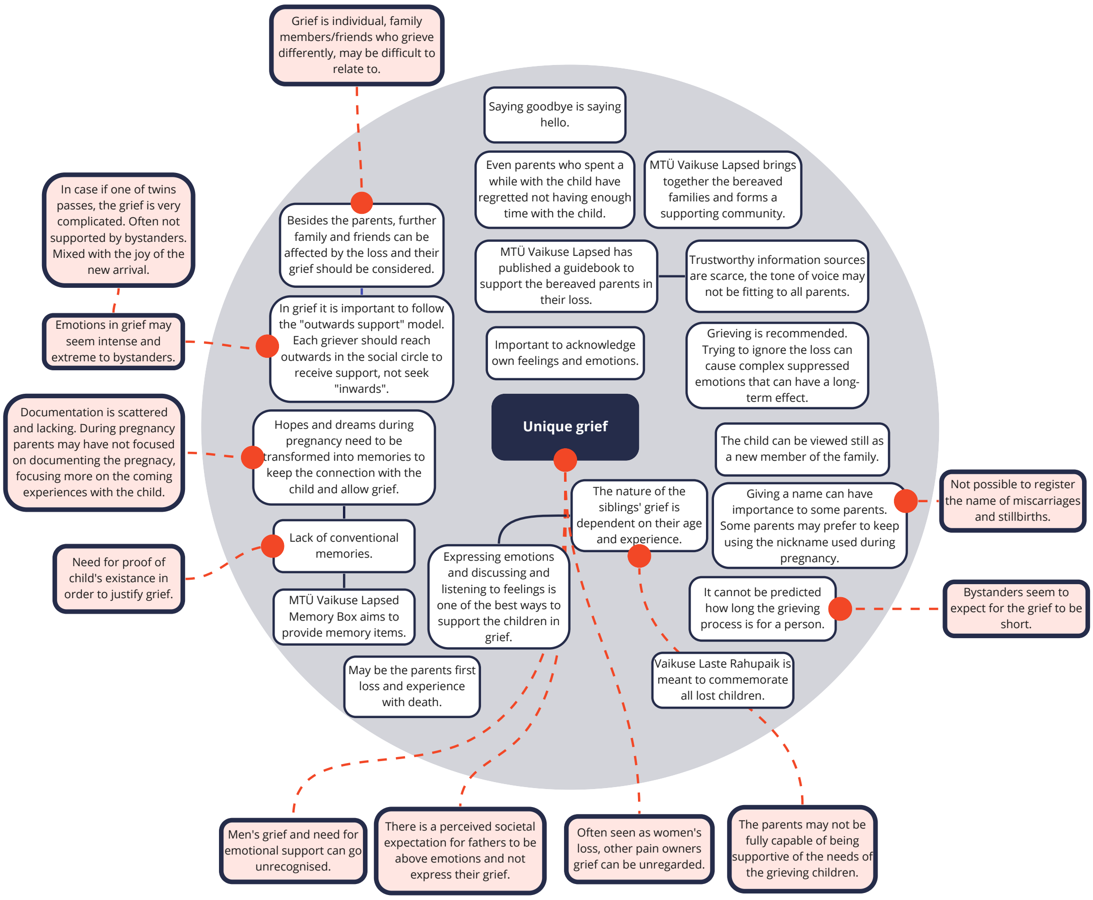


Figure 4.1 Main themes in unique grief

Besides the family, other members of the social circle may be in mourning — grandparents who had built hopes and expectations during the pregnancy, siblings, whose perception of the event depends on their age, but whose experience and emotions need to be considered. It also includes people from the social circle, who may strongly feel the loss, but whose such emotions are societally perceived “over-reactive” and “inappropriate”. Currently, they do not have access to keepsakes from the child, but the loss may be even more difficult for them to make sense of as, during the pregnancy, they were not always present. They may, similarly to the parents, struggle with the legitimacy of their feelings and experience. Without intervention, this can lead to people sharing the loss distancing from each other due to not knowing how to make of their own grief.

> *“Congruent with the family stress and coping theory, mothers of stillborn babies who perceived family support in the period after stillbirth experienced levels of anxiety and depression that were notably lower than those of their counterparts. Nurses, physicians and support groups also were important sources of support after a stillbirth; however, these sources of support alone were not statistically significant in reducing anxiety and depression in grieving*

> *mothers. Community interventions should focus on the grieving mother and her family system."*[78]

When the loss is as societally invisible as perinatal death, and it is difficult to find people to talk to who would listen and understand the experience, the collapsing of the social network supporting the bereaved family, should be avoided at all costs.

4.3 Returning to the everyday

After the mother has been discharged from the hospital, the family returns home. Juta Palmeri[79] expressed, that for the family it can be emotionally distressing to return from the hospital "empty-handed", having once set the expectation of arriving from the hospital with their baby in their arms. At home, the family faces the everyday. As hospital is always perceived as a deviation from everyday, the family may be more accepting of the abnormality of the experience. Upon returning home, the permanence of the loss is fully felt.

The experience of the parents after the loss is currently non-linear and fragmented, the path of it dependent mostly on the capability of the parents to deal with certain steps, the intimacy of their relationship and the support given by their social network.

While the mother's 140-day maternity leave continues (if it was not started previously, it is started for 140 days from birth), the father is not given a leave by default, but needs to consult with their general practitioner or take out a vacation. This gives another suggestion to the family to perceive it as a mother's loss. Although this difference is surely made due to the need for the mother to recover from the birth, encouraging both of the parents to take time to talk about and process the experience and offer each other support in the necessary proceedings and communication would lessen the incline towards negative self-conscious emotions in both of the parents. The link between stillbirth and relationship dissolution has only recently become a research interest, but a research article[80] suggests that the odds for a divorce increase with having experienced a stillbirth (29% vs 17%). The researchers recognise many

---

[78] Cacciatore, J., Schnebly, S., & Froen, J. F. (2009). The effects of social support on maternal anxiety and depression after stillbirth. *Health & Social Care in the Community*, *17*(2), 167–176. https://doi.org/10.1111/j.1365-2524.2008.00814.x

[79] Palmeri, J. (2020, March 18). [Digital personal interview].

[80] Shreffler, K. M., Hill, P. W., & Cacciatore, J. (2012). Exploring the Increased Odds of Divorce Following Miscarriage or Stillbirth. *Journal of Divorce & Remarriage*, *53*(2), 91–107. https://doi.org/10.1080/10502556.2012.651963

reasons that may contribute to the partners' differences in the aftermath of stillbirth that can be summarised as: the experience is different for all people, but are also influenced by social and gender norms, parental attachment, coping methods, strength of the social support network and other factors. In order to lessen the strain on the relationship, time for grieving and mental recovery should be enabled proactively to both parents.

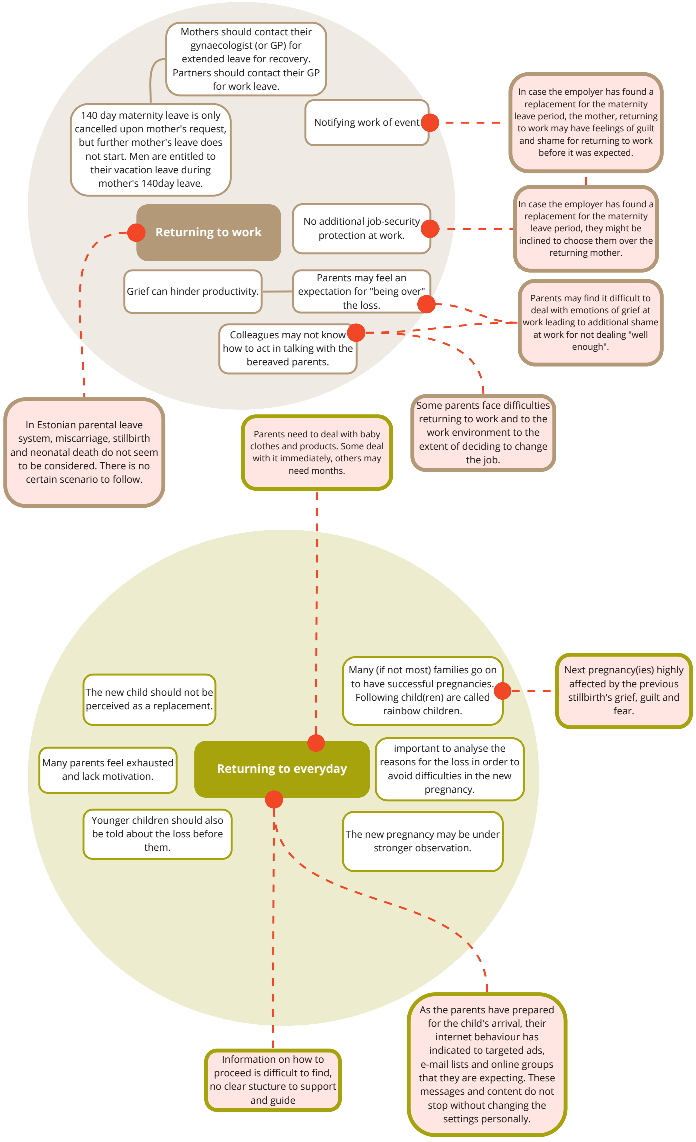


Figure 4.2 Main themes in returning to everyday

4.3.1 Proceedings

As the parents settle into their new reality after the loss they are required to deal with several proceedings. Although the bureaucracy is being constantly lessened and the intention of the state is to start many of the related procedures proactively, the state developments consider perinatal death only as an edge-case, for which the user-scenario is built as an afterthought. While a bereaved mother[81] of a stillborn child expressed sorrow over not being able to register the name in the official documents as it was important to her in giving her child legitimacy, a bereaved father[82] of a son born prematurely and passed at two days old, found it cruel that they had to give a name to their child and expressed the experience as being forced. Certain flexibility in the state system should be possible with developments in technology and statistics, especially in the case of perinatal losses that matter little in the large scale of state data collection.

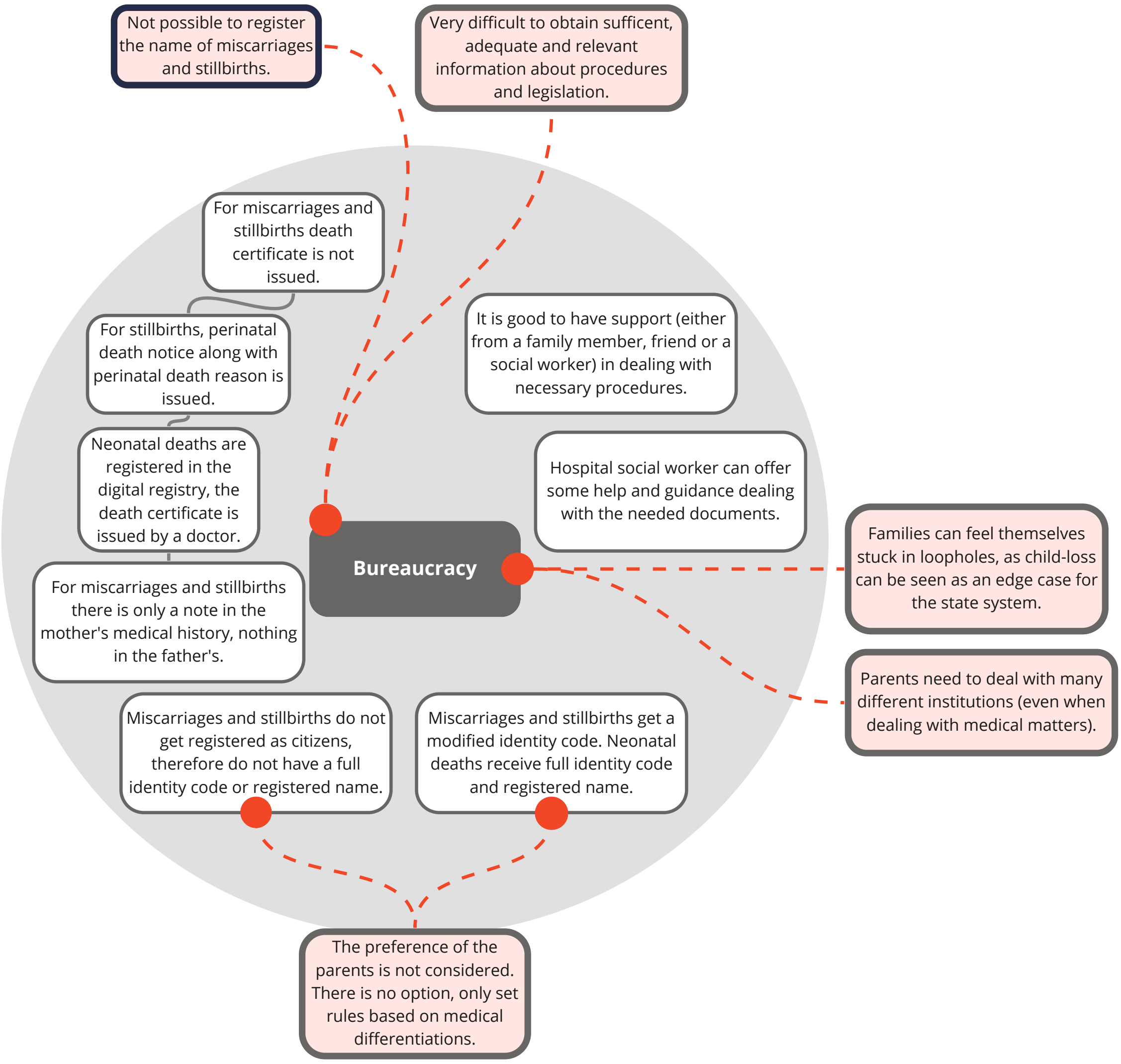


Figure 4.3 Main themes in bureaucracy

At the hospital, the social worker, besides providing support in grief to the parents, is supposed to also give guidance in handling the proceedings and next steps, but the

---

[81] Bereaved mother. (2020, March 23). [Personal communication].

[82] Bereaved father. (2020, April 4). [Digital personal interview].

merit of it depends highly on how good a relationship the social worker can build with the family and how knowledgeable they are in these matters.

While there are several governmental guides available online to describe the process in various proceedings, there are none available to support bereaved parents. Organising the send-off for a small baby is unnatural and people are less prepared mentally for it than for organising the funeral for an adult family member. Despite that, guides for funerals and proceedings offer little for the bereaved parents in the event of stillbirth. These describe an "average" death and are therefore difficult to relate with. Funeral homes have developed their websites to offer clear price breakdowns and descriptions of services, but yet again, these are designed around the event of adult death. The comprehensiveness of the websites guides the family to search through the website looking for relevant info, tiring the family emotionally, only to leave them to realise it would be best to contact the funeral home directly. People dealing with death daily may be desensitised to the loss of people and take their work routinely and can be quick to make assumptions and thus seem unsympathetic. A bereaved father[83] recalled the experience of visiting the morgue to collect his son and being asked to provide clothes for the deceased, leaving the father uncomfortably needing to clarify the size of his lost son.

4.3.2 The aftermath of the pregnancy excitement

If the parents have prepared for the arrival of the baby during the pregnancy, it can be difficult to handle the items acquired from different friends, relatives and stores. This can bring up a lot of difficult emotions and needs to be done at a time when both parents decide they are ready to take this step. Further family and friends can be supportive in this experience, but here, the difficulties in communicating outwards the needs for the parents may cause strain.

Besides the preparations the parents may have done in their home, the parents' online activity footprint is another unexpected situation they most probably need to face. Pregnancy-related forums, social media accounts, e-mail subscriptions as well as targeted advertisements are all oblivious to the changed status of the pregnancy and can therefore become a painful reminder. This situation is informed by a profile that has been developed over time through analysis of user-behaviour and as a result cannot be changed instantly. It requires the algorithms that create the profile to re-analyse the users changed behaviour over time to start suggesting different content,

---

[83] Bereaved father. (2020, April 4). [Digital personal interview].

although even this might not be enough. Within the data management strategies and regulations, there is currently little that can be done to answer this problem.

4.3.3 Difficulties in communication

If the parents have previously announced their pregnancy to their social group, the feelings of shame, guilt and failure may play a role in interactions past the loss. Parents may feel they were prematurely excited for the pregnancy and the more they have shared, the more they might feel they owe an explanation. As the loss is difficult to hide, it may push parents to deal with the communication without feeling fully ready for it. Mothers have expressed the urge to explain the reasons for the stillbirth to clarify that they had been taking care during the pregnancy, in fear that people, and society at large, would assume it was the mother's fault.[84] Other times, when parents have not shared the pregnancy with their social group and outside world, it is hard to then start opening up about the loss and the pregnancy. If the parents do not find a way to open up about their experience, the loss remains unseen by others and leaves the social support network unable to solace the family. The parents may feel the urge to distance themselves from the social groups or to hide their grief and internalise their emotions, increasing the risk of long-lasting negative psychological impact. Besides the difficulties of opening up to the social groups, the relationships with wider social networks may be problematic, as stillbirth is often unacknowledged and invalidated in society. Parents' experiences and changes in their behaviour may go unrecognised and leave feeling they no longer fit in with the group of friends or families.[85]

Families of the bereaved parents, close friends, but also wider social networks should not be seen as unwilling to understand the loss or support the bereaved family, rather strongly influenced by the social taboo surrounding death and especially stillbirth. This has not been widely researched, but people who have bereaved parent in their social network, have expressed initial difficulty understanding the situation, the changes (if any) it brings to the communication, what is expected of them and how much or how little to be present and available to the parents. Here again, internet search-results deliver no adequate information to support the process.

---

[84] Murphy, S., & Cacciatore, J. (2017). The psychological, social, and economic impact of stillbirth on families. *Seminars in Fetal & Neonatal Medicine*, *22*(3), 129–134. https://doi.org/10.1016/j.siny.2017.02.002

[85] Cacciatore, J. (2010). The Unique Experiences of Women and Their Families After the Death of a Baby. *Social Work in Health Care*, *49*(2), 134–148. https://doi.org/10.1080/00981380903158078

Friends and family could be of aid to the parents in many proceedings and tasks, like communicating on the behalf of the family with further social network or associations and businesses. In the existing state system, as the event is only recorded in the mother's medical history, anything related to the aftermath of stillbirth requiring verification can only be achieved through the mother's identity and therefore places her in a position, where regardless of her ability to cope with dealing with the proceedings, she is required to be involved.

As a supportive social network is seen as a strong influencer in the aftermath of a stillbirth,[86] in order to better support the bereaved families in their experience, the members of the network should be better informed and encouraged.

4.3.4 Returning to work

Lack of information and the influence of societal view of stillbirth has a strong impact on the families experience in all aspects of their life. Returning to work should not be rushed after a stillbirth, but even when the parent feels ready, there may be unexpected situations at work that catch the parent off guard. Eidi Aidla, lived-experience counsellor, explained in an interview[87], that at work, the bereaved parents may feel misunderstood by colleagues and employers as they may require time to pick up previous levels of productivity. The bereaved mothers may even feel attacked when colleagues bring their children to work without realising that this may be triggering to the bereaved woman. Of course, it is important to find a middle-ground in these situations, but as this requires open communication with the employer and is hindered by societal stigma, it can be difficult or even impossible to initiate these for the bereaved parent. Stronger support for the employers in these matters from experts in workplace happiness or psychologists and the community of bereaved families would ease the burden on both sides. Openly accepting the needs of the bereaved parent at the workplace is not just an act of good will of the employer, but supporting these needs enables quicker recovery of the bereaved parent's productivity, thus providing financial benefit as well. If the workplace is seen as a positive and accepting environment, the feeling of safety promotes the loyalty of all skilled workers.

---

[86] Cacciatore, J. (2010). The Unique Experiences of Women and Their Families After the Death of a Baby. *Social Work in Health Care*, *49*(2), 134–148. https://doi.org/10.1080/00981380903158078

[87] Aidla, E. (2020, February 19). [Personal interview].

In Estonia, parents of children under three years of age, are provided with additional job security by the law and cannot be made redundant. This protects women returning to work after the maternity leave started following the initial 140day leave. Although the same protection covers the duration of the 140 day maternity leave, the bereaved parents, when returning to work, are no longer protected. When the mother's initial maternity leave is started, the employer finds a temporary replacement, often assuming the mother will stay on the leave for the whole duration of the second maternity leave. Her return, after stillbirth, can be very unexpected for the employer, with the additional considerations needed, it may seem easier to make her redundant. A bereaved mother[88] explained she found herself in a legal loophole as returning to work she lost her job and in the next pregnancy would be treated differently from other mothers in the calculations of the maternity leave amount.

The midwife pointed out that in her experience most of the bereaved mothers return to the clinic as they go through a subsequent successful pregnancy. In the subsequent pregnancy, the loss often resurfaces and the experience differs greatly between people. The medical system attempts to take this into account and provide additional analysis and check-ups to ease possible worries. The parents should also be supported by empathic information that supports dealing with this experience to lessen the taboo surrounding their experience.

4.4 Bodily recovery from stillbirth

Stillbirth is primarily seen in society as a woman's loss, and there is some truth to it, for its intrauterine nature. It is not just the loss of life, but a loss of life before birth that makes it so distressing. The mother has carried and bonded with the unborn child for months while waiting to meet them. The confirmation from the doctor for the intrauterine death is horrific to receive, but although the mother may be in shock and wanting the experience to end immediately, it is recommended to deliver the child vaginally. It can be days between the induction and the birth if the mother has not given birth before, and for the mother, it may be extremely difficult to cope with and make sense of, although the time also allows the mother and family to prepare mentally for the birth and letting go.

The birth itself is described as a difficult and traumatic event for the mother,[89] but although the child has passed away, the mother's body still goes through the same

---

[88] Bereaved mother. (2020, March 23). [Personal communication].

[89] Mankin, D. (2020, March 23). [Digital personal interview].

changes afterwards as in the case of a live birth. A bereaved mother called it nature's cruel trick[90]. The vaginal bleeding can last up to six weeks, the breasts start producing breastmilk and the hormone levels change. It takes up to six months for the body to fully recover from the pregnancy and birth.

In Estonia, breast milk suppressants are generally not prescribed, the mothers are advised to use a cold compress to ease the discomfort, or to apply pressure to the breasts with ties.[91] In online forums mothers share tips like wearing sports-bras and using refrigerated cabbage leaves. A bereaved father[92] described the ordeal his wife had to go through with great sympathy, wishing there would have been a way to lessen the bodily agony.

Although it is possible to instead donate breastmilk to the breastmilk bank, communicating this option is generally avoided as the mothers are seen to be already suffering enough and instead of suppressing the milk production, this would incite it instead. On bereaved parents forums, many mothers share thoughts on donating breast milk and see it as a valid alternative to suppressing and an opportunity to find something positive from the negative, supporting another baby to life. Talking to Juta Palmeri,[93] she expressed that this option should be communicated to the parents, seeing that although not many would choose this, it could offer an outlet for the bodily experience.

Currently, the medical system, after the stillbirth, asks the mother to return for a check-up six to eight weeks after the birth to check up on her recovery. Although the best practice sees the mother seeing the gynaecologist who was also involved with her pregnancy, this is not always possible and therefore the mother is advised to remind the doctor in advance to have enough time for the appointment and to meet at a time it would be possible to avoid pregnant women in the waiting area. Although the medical history should be available to the doctor for them to acquaint themselves before the appointment, Juta Palmeri expressed mothers may still encounter accidental slip-ups from the doctor like questions how their breast-feeding is going.[94] The health-care system handles the recovery like any other recovery after birth and besides aiming to follow the best practice guidelines, offers little additional support to the bereaved mothers dealing with their bodies.

---

[90] Bereaved mother. (2020, March 25). [Digital personal interview].

[91] Mankin, D. (2020, March 23). [Digital personal interview].

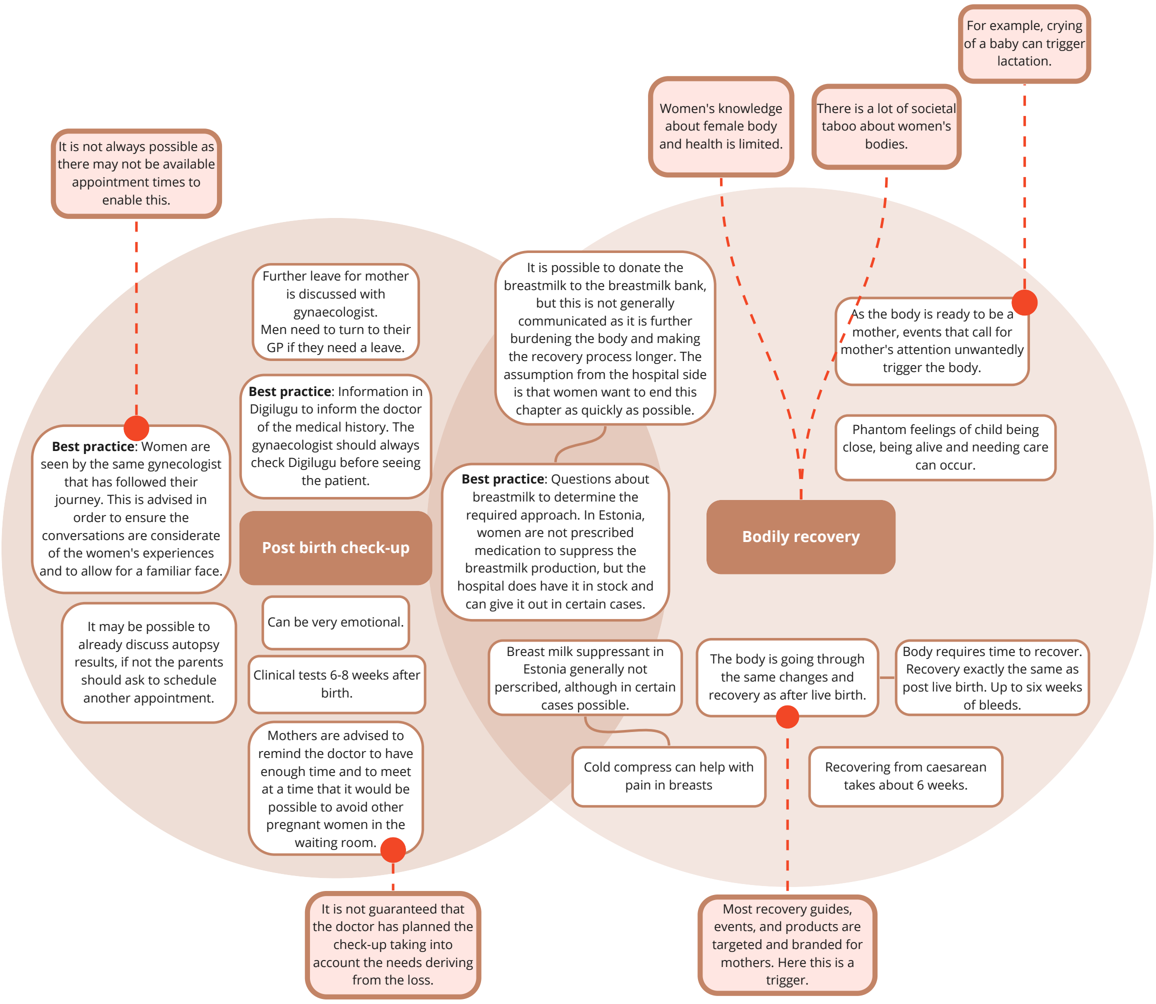
[92] Bereaved father. (2020, April 4). [Digital personal interview].

[93] Palmeri, J. (2020, March 18). [Digital personal interview].

[94] ibid.

The bodily changes can be seen unwelcome or as a mockery of the mother’s loss and induce negative emotions and anger towards the body. In stillbirth it is easy to perceive the body failing the mother as motherhood is seen as something every female body should be successful at.

The desire to have immaculate control over the body has led to bodily anxiety. Without understanding that, as a biological being affected by chemical and hormonal balances, it is incredibly challenging to be in charge of the biological complexity the body consists of, the relationship with one’s body cannot be peaceful.[95] A bereaved mother expressed that from the emotional shock of the loss and the hormonal changes, it was difficult to maintain control of her body and she had difficulties she otherwise has never had for five years following the stillbirth.[96]



It is not always possible as there may not be available appointment times to enable this.

Best practice: Women are seen by the same gynecologist that has followed their journey. This is advised in order to ensure the conversations are considerate of the women's experiences and to allow for a familiar face.

It may be possible to already discuss autopsy results, if not the parents should ask to schedule another appointment.

Further leave for mother is discussed with gynaecologist. Men need to turn to their GP if they need a leave.

Best practice: Information in Digilugu to inform the doctor of the medical history. The gynaecologist should always check Digilugu before seeing the patient.

Can be very emotional.

Clinical tests 6-8 weeks after birth.

Mothers are advised to remind the doctor to have enough time and to meet at a time that it would be possible to avoid other pregnant women in the waiting room.

It is not guaranteed that the doctor has planned the check-up taking into account the needs deriving from the loss.

It is possible to donate the breastmilk to the breastmilk bank, but this is not generally communicated as it is further burdening the body and making the recovery process longer. The assumption from the hospital side is that women want to end this chapter as quickly as possible.

Best practice: Questions about breastmilk to determine the required approach. In Estonia, women are not prescribed medication to suppress the breastmilk production, but the hospital does have it in stock and can give it out in certain cases.

Breast milk suppressant in Estonia generally not perscribed, although in certain cases possible.

Cold compress can help with pain in breasts

Women's knowledge about female body and health is limited.

There is a lot of societal taboo about women's bodies.

For example, crying of a baby can trigger lactation.

As the body is ready to be a mother, events that call for mother's attention unwantedly trigger the body.

Phantom feelings of child being close, being alive and needing care can occur.

The body is going through the same changes and recovery as after live birth.

Body requires time to recover. Recovery exactly the same as post live birth. Up to six weeks of bleeds.

Recovering from caesarean takes about 6 weeks.

Most recovery guides, events, and products are targeted and branded for mothers. Here this is a trigger.

Figure 4.4 Main themes in bodily recovery

---

[95] Orbach, S. (2019). *Bodies*. Profile Books.

[96] Bereaved mother. (2020, March 25). [Digital personal interview].

Although the bodily changes are identical to those after live birth, bereaved mothers have difficulties supporting their recovery at the identical level. The products meant to be used after birth are all marketed as for mothers. The exercise routines and gym classes beneficial are all marketed as for mothers. The supportive clothing aiding bodily recovery is marketed for mothers. The online articles describing best care is marketed for mothers. For bereaved mothers this reminds them of what they have lost. It is easy to imagine them reluctant to using any of these. Understandably, companies benefit from marketing products and services for mothers. It is a large target group and it is easy to associate the product with positive emotions. In order for the bereaved mothers to benefit from these products, services and content, all that is needed is to change the marketing and tone of voice to neutral. The small change would make a great difference in allowing for the bereaved mothers to build a more peaceful relationship with their bodies.

4.5 Societally invisible loss

2.6 million babies are stillborn worldwide every year.[97]

In 2018 1790 miscarriages (spontaneous abortion)[98], 46 stillbirths[99], and 23 infant deaths (under one year old) were registered in Estonia.[100] It is impossible to see behind each of these numbers, but with some simplification, it could be assumed 1859 women were impacted, another 1859 fathers or partners makes the number of impacted 3718. All of whom have further families and friends, acquaintances and colleagues. With a modest presumption of each perinatal death affecting seven people with varied impact, the sum is 13 013 people, 1% of Estonia's population, in one year. Perinatal loss, therefore, should not be described as a rare event, affecting a small number of population unworthy of the wider attention.

> *"It's not always easy to convince someone a need exists, if they don't have that need themselves."*[101]

---

[97] Pollock, D., Pearson, E., Cooper, M., Ziaian, T., Foord, C., & Warland, J. (2020). Voices of the unheard: A qualitative survey exploring bereaved parents experiences of stillbirth stigma. *Women and Birth*, *33*(2), 165–174. https://doi.org/10.1016/j.wombi.2019.03.002

[98] *Abordid, aasta—Eesti Statistika*. (n.d.). Retrieved 9 May 2020, from https://www.stat.ee/34273?highlight=abort

[99] Anderson, E. (n.d.). Vastsündinute haigestumise statistika kvaliteediraport. 21.

[100] *Imikusuremus, aasta—Eesti Statistika*. (n.d.). Retrieved 9 May 2020, from https://www.stat.ee/34269

[101] Perez, C. C. (2019). Invisible Women: Exposing Data Bias in a World Designed for Men. Random House.

In the start of this thesis project, discussing the topic choice with gynaecologists, a few of them suggested for me to choose a different topic altogether, or at least, instead of stillbirth, to focus on miscarriages, as these occur more often, and the impact of these on families is less severe. Of course, using the same arbitrary multiplier, I “only” end up with 322 people affected every year. But like explored previously, for these people, the impact is severe and enduring.

Stillbirth falls onto unfortunate crossroads, for one, it is death, for second, it is primarily seen as a women’s issue. The combination of these creates discomfort, which impedes the handling of the issue. Research about women’s health issues is chronically underfunded although affecting half of the population, resulting in lesser quality than what current technology could already achieve. Discussions about death make people face their mortality, something that is avoided at all costs in our culture.

Stillbirth, a death before loss, is a difficult one to make sense of already to the parents. Even the medical personnel at maternity clinics, who presumably have seen a few of such losses during their careers, face difficulties communicating with the parents. The social circle of the family might have been aware of the family expecting a baby, but lack connection with the child and memories that would allow them to connect more deeply with the loss. If people surrounding the family were unaware of the pregnancy, the parents may decide to pretend that nothing has happened for the sake of avoiding causing discomfort. It is a quiet loss, felt in a close circle of family and friends, invisible when looking from the outside in.

Avoiding the awkward conversations adds up. It adds up to a society where people are unaware 1/4 of pregnancies ends in a miscarriage, where gynaecologists say not enough mothers go through stillbirth to tackle it in a simple master thesis. It adds up to a social structure that does not consider these issues to the full extent in planning its services. It not only hurts the bereaved parents, but everyone in the society.

5 NEED FOR INCLUSIVITY AND INDIVIDUAL EXPERIENCE (DESIGN BRIEF)

In the project research it became apparent that as stillbirth and perinatal deaths are considered medical events, the current support relies on the healthcare system. However, exploring the experience of the bereaved families, the impact of stillbirth extends beyond medical needs. Therefore there is an opportunity to design a platform that takes into account the already available support, and considers the individual needs of all affected in order to enable structure for inclusive support and individual experience.

5.1 Informed by main themes

The concept design does not aim to fully remove the negative aspects of the event, this is impossible considering the nature of stillbirth, but rather to alleviate the unnecessary pain caused by the lack of a human-centred, inclusive view of the experience. The concept design is informed by main themes deriving from research:

- **Invisible**
  Stillbirth is surrounded by stigma, people are unaware of the issue even when expecting a child. Even on system level, the experience has not been considered as a whole.
- **Unexpected**
  Even when the parents are aware of the risk, the loss is still unexpected. Parents prepare for the arrival of new life, losing it before birth is a shock.
- **Information is scattered**
  Information is not readily available because of social taboo. How informed the family is, is highly dependent on the medical caregivers.
- **Sensitive communication**
  The medical personnel have “one chance to get it right” in communication, but as every grief is different and midwives are not trained in psychology, a lot can go wrong.
- **Experience defined by classification**
  Miscarriage, stillbirth and neonatal death are handled according to the classification. The extent of grief is more dependent on the person than the classification of the loss.
- **Complicated loss**
  It is difficult to place the loss. Others have very little connection to the child lost and parents may feel the expectation to “get over it” quickly.

- **Individual experience**
  No loss is the same and varies from person to person. Even the mother and father may experience and relate to the situation in very different ways.

- **Lack of memories**
  Losing a child before their birth means grieving for the connection with the baby and the hopes and plans that were made during the pregnancy.

- **The body failing**
  A lost pregnancy/child can make the parent’s (most often mother’s) relationship with their body and bodily recovery more difficult.

- **Underlying guilt and shame**
  Parents admit having these feelings towards their child, partner, parents, social circle, medical personnel, society at large.

- **Communication with others**
  Not feeling alone in the loss is important, but the loss can be difficult to relate with and understand for others. Bereaved parents communities are of support, but can have an influence on the grief.

- **Considered a women’s loss**
  Fathers can be left feeling like they lack the right to grieve. It is emphasised by the system that does not see them part of the experience (no record, no right for leave).

- **More than just the parents’ loss**
  Although the current focus is on the family, further social circle is also influenced by the loss, but lack structure and support to make sense of the experience.

- **Social support network is important, but unsupported**
  Further family and social circle could assist the family and support each other, but currently lacking information and the means to do so.

The quality of the current available support is dependent on the family’s location and the relationship with the medical personnel, the support is not equally accessible. The design concept should alleviate this through offering structured personalised information independent from the medical personnel and social workers, individual support in grief in addition to counselling to all affected and enable conversations and sharing the experiences between the bereaved families and further communities.

5.2 Defining main needs

An important take-away from the research is that there is no one way of experiencing the loss of stillbirth and that the impact is not defined by the role of a person. The bereaved parents loss is unexpected and difficult to immediately cope with, the support of the social circle plays an important role in reducing the negative long-lasting impacts, but in order to achieve this, they need to be supported and offered means to support the family.

These defined main needs are only a guideline for the concept design. As the position of a person in the social circle does not define the impact of the loss, the availability of support should not be strictly defined by this.

Mother

- Lifted burden of proceedings when needed
- Control and a clear understanding of the situation, next steps and the support available to them
- A way of managing the communication with their social circle
- A discreet outlet for her grief that would be available to her always and for however long she requires it without influencing anyone else's experience
- Advice for supporting the other children in the loss
- To feel they are not only ones with this experience and recognise that life can go on without forgetting
- Perceptive support in bodily recovery and guidance in strengthening the positive relationship with her body

Father/ partner

- Lifted burden of proceedings when needed
- Control and a clear understanding of the situation, next steps and the support available to them
- A way of managing communication with their social circle
- A discreet outlet for his own emotions and grief without further influencing anyone else's experience
- Advice for supporting the other children in the loss
- To learn from others who have gone through similar experience
- Support from the community for his role as a partner

Further family (for example grandparents/adolescent or adult siblings)

- Support to make sense of their own loss
- Information to better understand the situation
- Access to relevant information and mandate to be able to support the family in proceedings if applicable
- Support from the community to understand how different people cope with similar losses
- An individual outlet for their grief as it is unique if needed

Close friends

- Information on how to best assist the family with proceedings and communication with their social circle
- Access to relevant information and mandate to be able to support the family in proceedings if applicable
- An individual outlet for their grief if needed
- Understanding how to best be of support to the family
- Support from the community in their role

Acquaintances, wider circle

- Understanding of the situation and how to communicate with the bereaved family
- Support in making sense of the situation

Employer/colleague

- Information to know how to support the bereaved employee/ colleague and to consider their needs when they are ready to return to work

Medical personnel

- Confidence in knowing how to best support the mother and the family in the hospital experience
- Relying on the actual experience and stories of the people with the experience along with experts in the field

5.3 Considering the service ecosystem

The state of Estonia offers near-universal social security and healthcare to its residents. Stillbirth requires medical attention that is covered by the Estonian Health Insurance Fund, the further support for the family to overcome the negative impacts should be offered by the state to ensure equal access to it for all who require it. In order to offer a design concept that integrates with what is already available and functioning, it is important to consider the already existing infrastructure and services.

State information infrastructure

The delicate nature of the information related to stillbirth requires an approach that ensures that personal data is handled with respect and privacy. The individual experience should be made available to those affected without them having to search for it. The privacy requirement also means that this personal data should not be stored by a separate non-compliant website or system.

In Estonia, state level digital infrastructure exists that allows creating a seamless and safe individual experience. Different platforms that are connected through this infrastructure are available, for example, Digilugu gives access to health related data, the e-government systems enable access to personalised information and to give consent to different services and people, all of which are accessed using the national ID-card, securely confirming the identity. The Estonian digital strategy involves developing pro-active state services, which initiate proceedings when certain predetermined events occur. The aim is to relieve the unnecessary burden of bureaucracy.

Memory Box initiative

Stillbirth is a loss that is complicated by the lack of memories. For the family, it may seem there are only broken hopes and dreams for the child they were expecting, further family and friends may not have bonded with the idea of the child yet, but may still be impacted by the loss. Building memories from the positive feelings that were had during the pregnancy can strongly assist with making sense of the emotions and grief.

The Memory Box initiative by MTÜ Vaikuse Lapsed guides parents in making memories and building a connection with their child. It gives physical form to the memories through the objects in it that the family can connect with and create keepsakes from the short time spent with the baby. As it is a physical collection and the bereaved parents share it, creating an individual relationship with the objects, memories and emotions related to grief is not possible, nor is the Memory Box accessible to further family members and friends. Because of its size, it is impossible to interact with the items discreetly.

Community support

Bereaved parents can feel misunderstood by their social circle and people surrounding them. The stigma surrounding stillbirth may make it seem like they are alone with their grief and unable to find consolation. Bereaved parents communities (online and offline) lessen the feeling of isolation and aloneness with the loss through sharing variety of experiences, but may unintentionally instead impose restrictive norms on how loss should be experienced. The role of the person, personality traits or intrapersonal barriers may stop people from joining these. Additionally, wider social circle could benefit from the knowledge and encouragement the community could offer to those supporting the bereaved family.

Currently inaccessible support

Many of the needs of the in stillbirth are similar to those in live birth. The mother goes through the same bodily changes following birth and requires the same alleviation in bodily recovery. The family may want to take best possible quality pictures of the moments spent with the child. The items and services that could be ideal supporting the family are often heavily targeted to new mothers or new families, which keeps the parents from using these, not to be reminded by a wound cream of what they have lost. The content of the products and services required has already been created, but it is marketed and delivered in an unsuitable manner.

Third sector

Besides the Estonian state, non-profit organisations bring together people who are driven by the cause. *MTÜ Vaikuse Lapsed* brings together people who have lost a child. Additionally there are other non-profit organisations that advocate for related causes. Enhancing such symbiosis in creating supportive methods allows answering actual needs accessible to all who require it.

Accessibility

The current available support is focused around counselling, the accessibility of which is dependent on the location. In larger centres, counselling is more easily available and it is possible to choose the counsellor according to best fit. The accessibility is tied to budgetary constraints.

5.4 Platform tasks

Informed by the main themes, based on the needs and considering the service ecosystem, I defined goals of the platform and deriving tasks to consider in the design. These fell into three categories: e-governance, memory-making support and voice of the community. Additionally I defined overarching tasks to consider throughout the platform.

Proactive state	
Goals	**Tasks**
• To minimise unnecessary bureaucracy at a sensitive moment as the state has access to data that enables smooth and informed decision-making. • To support the families in these moments by making the management of bureaucracy transparent and easy to follow. • Empowering the family's social network through giving legitimate access to information and means, thus enabling them to better support the family.	**1 Relevant info on proceedings** All needed information pro-actively available to the family in an understandable structured manner from the moment of the diagnosis. **2 Customising tone-of-voice in communication** The manner of communication depends on a personal preference. Achieving the right tone of voice has a large impact on the person's ability to process information. **3 Sharing responsibilities** Both parents equal in the event and the following proceedings. Mother's personal medical information remains personal. Possible to have support from trusted person in proceedings through enabling a mandate. **4 Lessened unnecessary bureaucracy** Proactively initiating proceedings with predefined events. More options whenever possible (forms enabling leaving information out or adding it). **5 Enabling sharing information with the social circle** Allowing the family to communicate the loss and their needs to their social circle with lessened effort.

Voice of the community	
Goals	**Tasks**
• To give the feeling of community and add to the diversity of experiences regardless of the role of the person. • To lift the feeling of being alone with the issue and provide support for dealing with the situation at hand from others’ experiences and experts advice. • To lift the taboo for the general public and provide information to those who feel they need it (co-workers, acquaintances, others). • To enable the community members “give back” in form of knowledge, experience, events etc.	**1 Structure for sharing** To enable sharing of variety of experiences safely, structure is required. The content is created by community and related experts, but the structure for this needs to support various media. **2 Filtering content pinned** To avoid triggering content, a user can hide themes that they are not ready to see. Similarly they can set their interests for the content to be filtered accordingly. The settings are pinned to allow and encourage making changes. **3 Curation by the community** To make sure there is a variety of content and that all experiences are supported, curation by the community and related non-profit organisations should be enabled. **4 Layered access** Log-in layer allowing for secure sharing of stories within the community, public access to more general knowledge and stories. **5 Outwards communication** Allowing public access to layers of information that empower the by-standers to offer better support lessens the burden and taboo from the topic.

Memory-making support	
Goals	**Tasks**
• To enable individual memory making in order to support the individual experience of grief and have a place for the emotions and feelings regardless of the memory-maker's position. • To strengthen the realness of the experience by providing a "safe-place" for the evidence of the child lost. • To ensure safe and discreet access to the memories whenever it is needed.	**1 Individual handling of memory items** Enabling each member to process, sort and create memories individually. **2 Discreet access anywhere, anytime** Makes use of the devices already in use to ensure discreet use. Privacy of the sensitive data is protected through safe back-ups and log-in through ID. Accessible through multiple devices. **3 Allow personalisation of the experience** Enabling a personal experience of grief through individual processing of the loss through handling and creating mementos.

Overarching tasks

Flexibility to enable individual experiences and journey
There is no one way of using the platform, users should be able to access the content they need without being required to use other irrelevant aspects.

Support and guidance when and if needed
Access to support & guidance easily available and accessible in all layers of the platform to all users, giving clear overview of the options and allowing direct contact or booking of an appointment.

Settings respected across the platform
The tone-of-voice of the system, trigger settings, and other profile information carries across the platform.

Platform connects to support from outside the community
Additional support from volunteers, companies, and products are connected with those in need of these through the platform

6 DESIGN CONCEPT

Informed by the design brief and research, the design concept focuses on the individual experience of the bereaved families and their social support network aiming to make the support more structured and inclusive and lessen the burden of strict bureaucracy on the proceedings. It offers the bereaved families the opportunity to manage the loss and their experience in a manner that is most suited for them choosing their own points of interaction with the platform that support them in the ways they most require.

6.1 Systems map

In order to design a platform with multiple layers, considering the current service ecosystem and understanding the interdependency of its parts, a systems map of the concept is required. The bilateral map shows how the full concept functions, from both the system and non-linear user journey perspectives, and best shows the interconnectedness of all layers. Please refer to the map in Appendix 2.

The functions of the platform are enabled by the operational systems side of it. It handles everything happening in background and generates the output for the user in the form of an interface or interaction. The systems side of the map on the left, describes the process of how the system gathers and stores necessary data, how it uses it and what sort of output it generates for the user of the system. The arrows here describe the movement of data and generation of output in the system.

To take into account the various users’ needs and ways of interacting with the platform, I incorporated the user journey view to the map on the right, as a mirror of the systems view. This part of the map describes how the user can practically interface with the system and what they do. This was done to represent the human-centred perspective in a clear way and show the non-linearity of the interactions with the platform. The arrows here describe the possible paths the user can take through the system.

The middle portion of the map shows the common system elements and the foundation of the platform. As all the layers of the platform and the experience are interconnected, this allows this to be illustrated on the map as well.

6.2 Proactive state layer

The systems view and interconnections with other layers of the platform visualised in the systems map in Appendix 2.

The proactive state level of the platform is designed as part of the existing e-governance system accessible for the users through their ID from either eesti.ee or Digilugu. It is meant to minimise the unnecessary bureaucracy, support families in managing it and provide them with information relevant to their situation.

Once the stillbirth is determined by the doctor and noted in the system, the parents have access to additional information about the medical situation and proceedings through the e-governance system that they can access by logging in with their ID through Digilugu. This enables them to access information and process the situation at their own speed and even when the parents cannot be together at the hospital, both of them are up to date with the information and they are no longer solely dependent on the hospital personnel for information about the medical procedures, the stillbirth, proceedings and support.

As the ability to process information at the heightened state of emotions depends among other variables on the tone of voice, the users can set their preferences that are respected across the platform through customisation of the official information and platform communication.

The content is structured according to the stage of the journey and personalised to be fitting with the parents' experience, taking into account, besides the medical case, also the parents' data and profile to give only relevant information in the journey and proceedings. Parents do not have to filter through large quantities of information generally about stillbirth or proceedings, but receive the information that is relevant to them. This saves them emotional strength and time to focus on what is important.

The bereaved parents can choose to inform their social support network and communicate their needs in support and communication without needing to directly interact or face questions when they do not feel ready yet. This is not a time-limited feature and parents can revisit the settings and information and make changes. It is possible to give different level access to the platform, for example close friends the family would like to keep informed so they can offer them support may be given access to all information relating the loss and following proceedings, while grandparents may not receive access to proceedings, but are informed and can access the Memento layer and community.

At all layers of the platform, including the state level, the user is informed of the importance of support in the experience and is given the information on available counselling and other support. They can book an appointments directly or in case of online services are directed to these.
At determined intervals the user is given the opportunity to fill in a follow-up self-assessment questionnaire to gauge their mental well-being. In case of worrying results, their doctor is notified (if the user has given permission for this). The user is reminded of the availability of support and can directly access it. Like with other medical information, the user can toggle the permissions of doctors to this information.

The bereaved parents may not be ready to face the sudden proceedings relating the death of their child. Many families already use trusted friends or family members to lessen the load of the burden. It is important to allow this through enabling a mandate to lessen the hurdle even further. The bereaved parents can set a mandate to a trusted person to act on their behalf in the journey related matters like proceedings, organising the send-off or contacting companies to return items bought during the pregnancy meant for the child.

The state is able to support the parents in managing the proceedings as through comparing the diagnosis and medical information against eligibility for support (financial, social, psychological, work leaves) the system displays this information to the bereaved parents and set mandate. The applications are proactively filled in for the user to approve.

The platform enables the parents to access and download all available data and recordings collected during the pregnancy and birth (ultrasound images, heart-beat recordings, pictures taken of the baby after birth, etc) in one set. The list of data can be filtered before the download.

Businesses, non-profit organisations and volunteers who offer services to support the bereaved family can check the eligibility for support through the ID of the parent or mandate. For example, for the moments spent together with the child after birth, parents can book a volunteer professional photographer to take high quality photos of this time. The communication and booking is done via the state platform that confirms the eligibility of the family without needing further proof or explanation.

6.3 Memento

The systems view and interconnections with other layers of the platform visualised in the systems map in Appendix 2.

In stillbirth, the bereaved family may have difficulties placing the loss as there is a lack of memories and time spent with the child. However, during the pregnancy, the family has had many positive moments to remember and documentations of this. Often there is an abundance of photos on the phone and on social media accounts. Besides these, from the hospital check-ups, the family may have ultrasound images, audio files of the heart-rate monitoring or the additional 3D imagery. At stillbirth the clinic personnel also takes hand- and footprints of the baby. All of these can be used to build the foundation of memory-making and connection with the child.

Some bereaved family-members feel like they lack evidence of the child to allow themselves to grieve. As grief is non-linear, it is important to have access to the memories and proof of the child when needed. Memento is accessible on the devices the users already carry and on the web, making it digitally accessible everywhere.

Memento is non-conspicuous as it accessed through the devices people use often, it does not raise attention of the by-standers.

With the digital access to the available memories, many people can access the data and create their own individual experience in grief. This removes the question of who is allowed to grieve for the lost child and enables family members further from the loss (like grand-parents) to organise their thoughts and emotions.

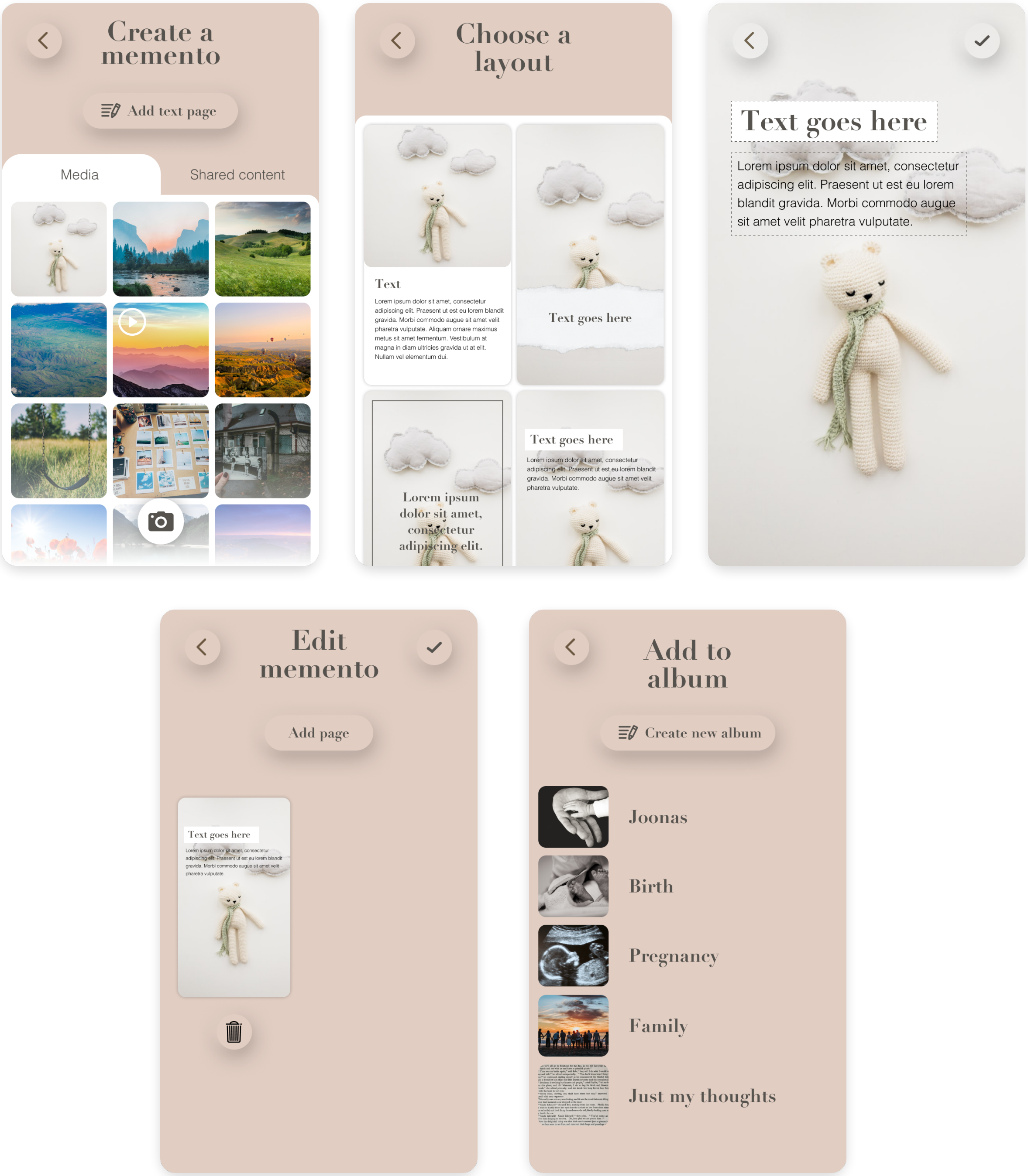
For my Little Prince

“The most beautiful things in the world cannot be seen or touched, they are felt with the heart.

– Antoine de Saint-Exupéry”

The times I got to see you growing

Figure 6.1 Memento memory view



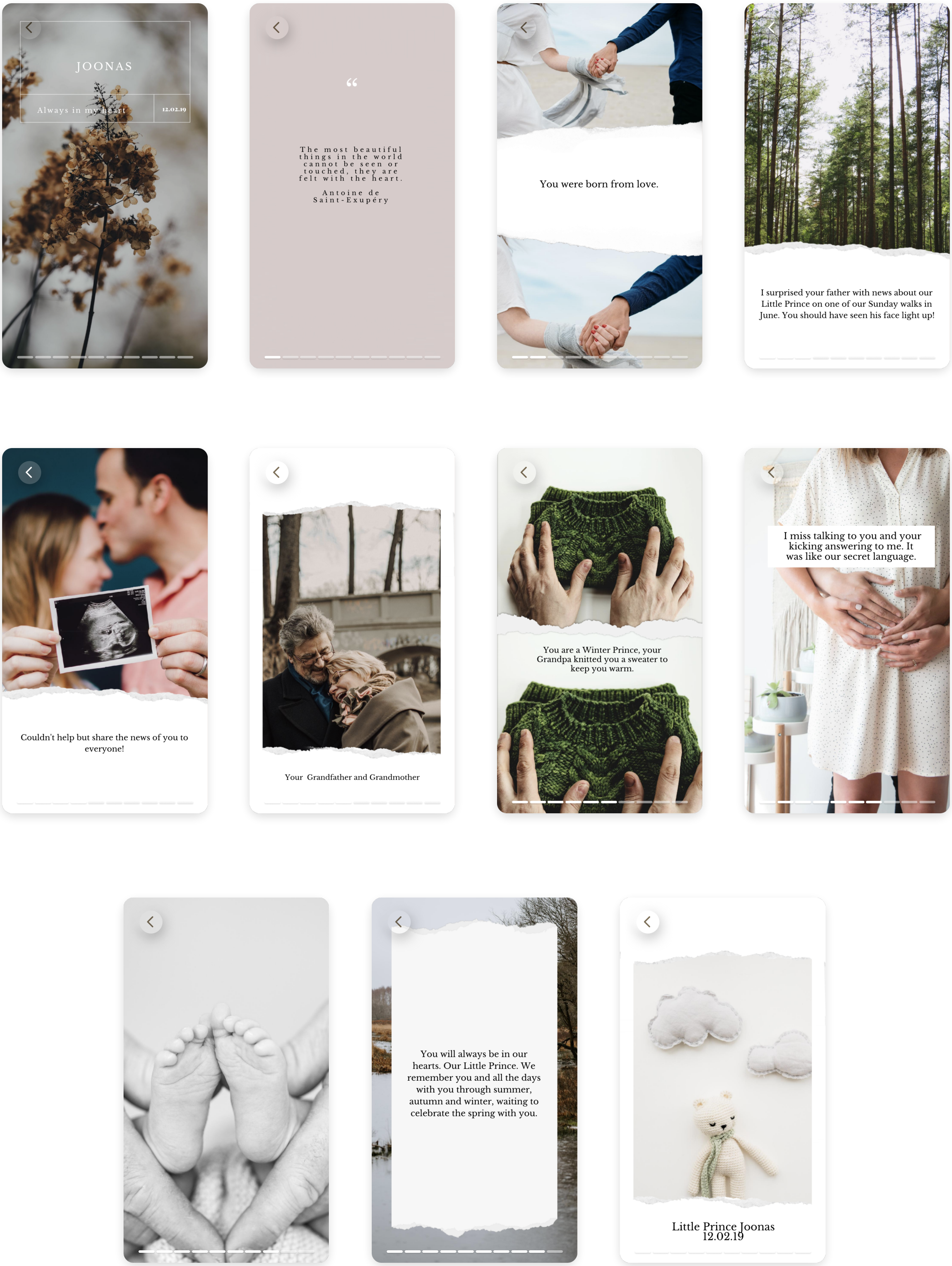
Text goes here

Lorem ipsum dolor sit amet, consectetur adipiscing elit. Praesent ut est eu lorem blandit gravida. Morbi commodo augue sit amet velit pharetra vulputate.

Figure 6.2 Creating a memento

The user can add data to Memento and organise the memories in albums or combining these into stories. The application allows writing, taking photos, recording audio or video. As it functions across platforms, the user can choose which device to use, for example, they might feel that writing longer texts may be more comfortable on a computer, adding audio recordings on a phone.

The user can choose to share the content they upload with other family members, but this is not done by default. Memento considers the memories uploaded and made private and personal.



JOONAS

Always in my heart

12.02.19

“

The most beautiful things in the world cannot be seen or touched, they are felt with the heart.

Antoine de Saint-Exupéry

You were born from love.

I surprised your father with news about our Little Prince on one of our Sunday walks in June. You should have seen his face light up!

Couldn't help but share the news of you to everyone!

Your Grandfather and Grandmother

You are a Winter Prince, your Grandpa knitted you a sweater to keep you warm.

I miss talking to you and your kicking answering to me. It was like our secret language.

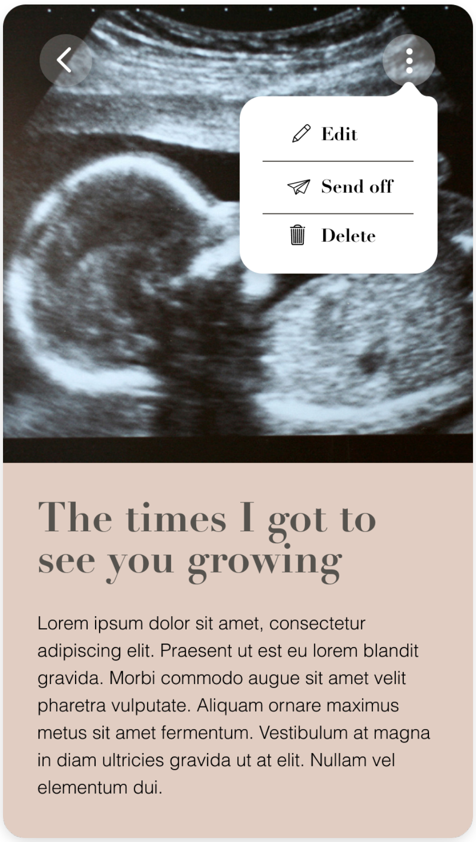
You will always be in our hearts. Our Little Prince. We remember you and all the days with you through summer, autumn and winter, waiting to celebrate the spring with you.

Little Prince Joonas
12.02.19

Figure 6.3 Example of possible use for building stories in Memento

The user can determine the meaning of these memories, stories and notes made, one possible way is addressing these to the lost child (when sending these away, the application does not save the memory made).

The style of the application is simplistic to allow the focus to be on the content. It never sends out push-notifications to ask for the user's attention. Even if there have been uploads by other family members and new data is available to download to the app, the user is notified of this only when using the application.



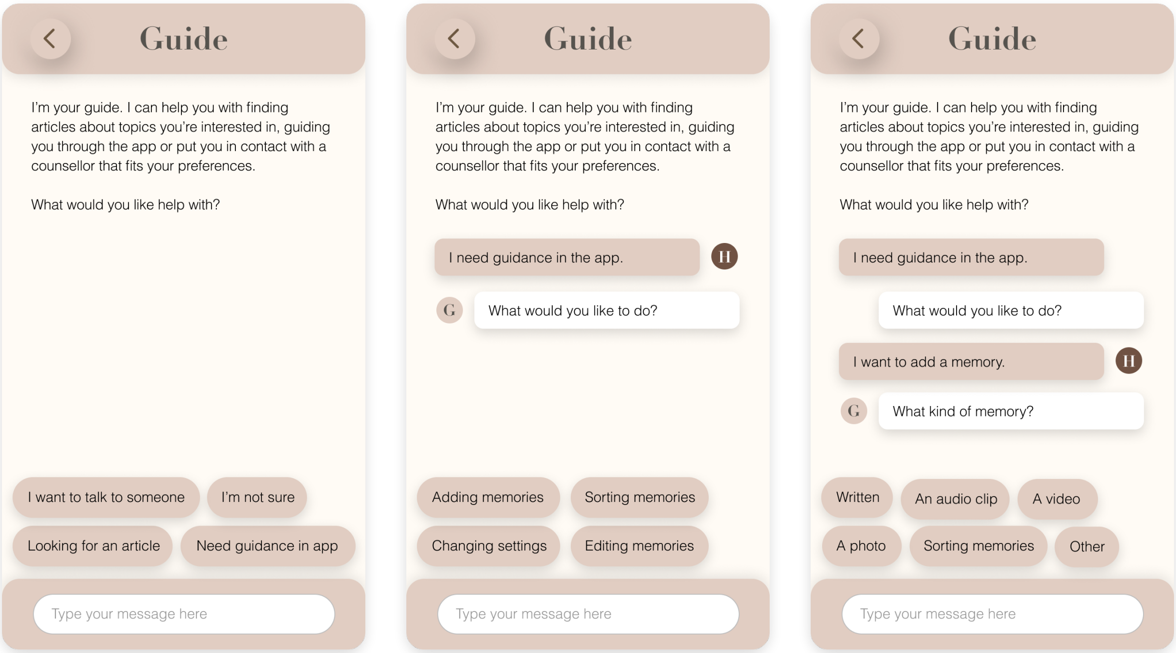
The times I got to see you growing

Lorem ipsum dolor sit amet, consectetur adipiscing elit. Praesent ut est eu lorem blandit gravida. Morbi commodo augue sit amet velit pharetra vulputate. Aliquam ornare maximus metus sit amet fermentum. Vestibulum at magna in diam ultricies gravida ut at elit. Nullam vel elementum dui.

Figure 6.4 Sending off a memento

Memento can make use of various media to build the memories. A feature that can be made use of is to place the hand on the actual-size handprint on the screen and through the haptic vibration motor of the phone feel the heartbeat of the child. In case this data is not available or for other reasons, the user can customise this screen. For example using a mindfulness breathing visualisation instead to guide their focus in the moment.

Figure 6.5 Memento connection feature



I'm your guide. I can help you with finding articles about topics you're interested in, guiding you through the app or put you in contact with a counsellor that fits your preferences.

What would you like help with?

I'm your guide. I can help you with finding articles about topics you're interested in, guiding you through the app or put you in contact with a counsellor that fits your preferences.

What would you like help with?

I need guidance in the app.

What would you like to do?

I'm your guide. I can help you with finding articles about topics you're interested in, guiding you through the app or put you in contact with a counsellor that fits your preferences.

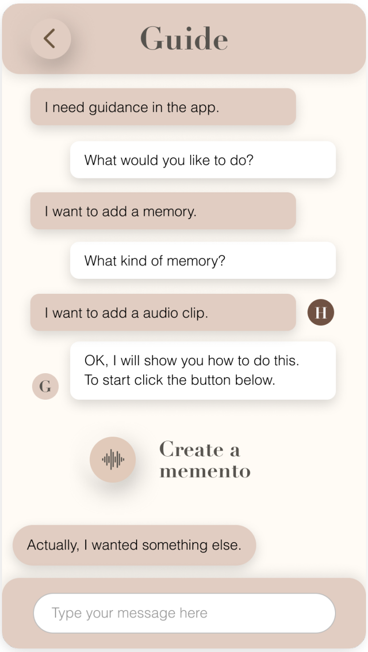
What would you like help with?

I need guidance in the app.

What would you like to do?

I want to add a memory.

What kind of memory?



I need guidance in the app.

What would you like to do?

I want to add a memory.

What kind of memory?

I want to add a audio clip.

OK, I will show you how to do this.
To start click the button below.

Figure 6.6 Memento guide

Whenever the user needs guidance, whether within Memento or support in their grief, the guide can assist them. If the question is about a certain feature of the application, the guide guides the user through the process, if the person is looking for support with their emotions, the guide can help them find the needed information or assist them in finding the counselling suitable for their personal preference. The chatbot is utilised here not to create a barrier for asking help with their question immediately from a person.

The homescreen of the application is a calm discreet imagery that the user can select for their liking. The main aim for this is to make sure that no specific content is displayed immediately so that it would not cause unintentional upset, also, the non distinct homescreen ensures whenever the application is opened unintentionally, it does not show its content immediately. For additional security the user can lock the application and open it with either using their ID or fingerprint scan.

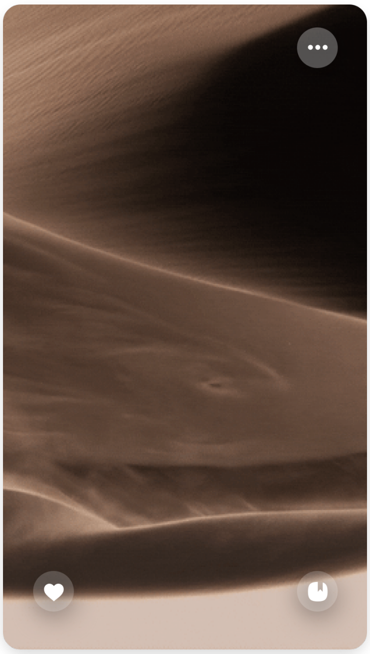
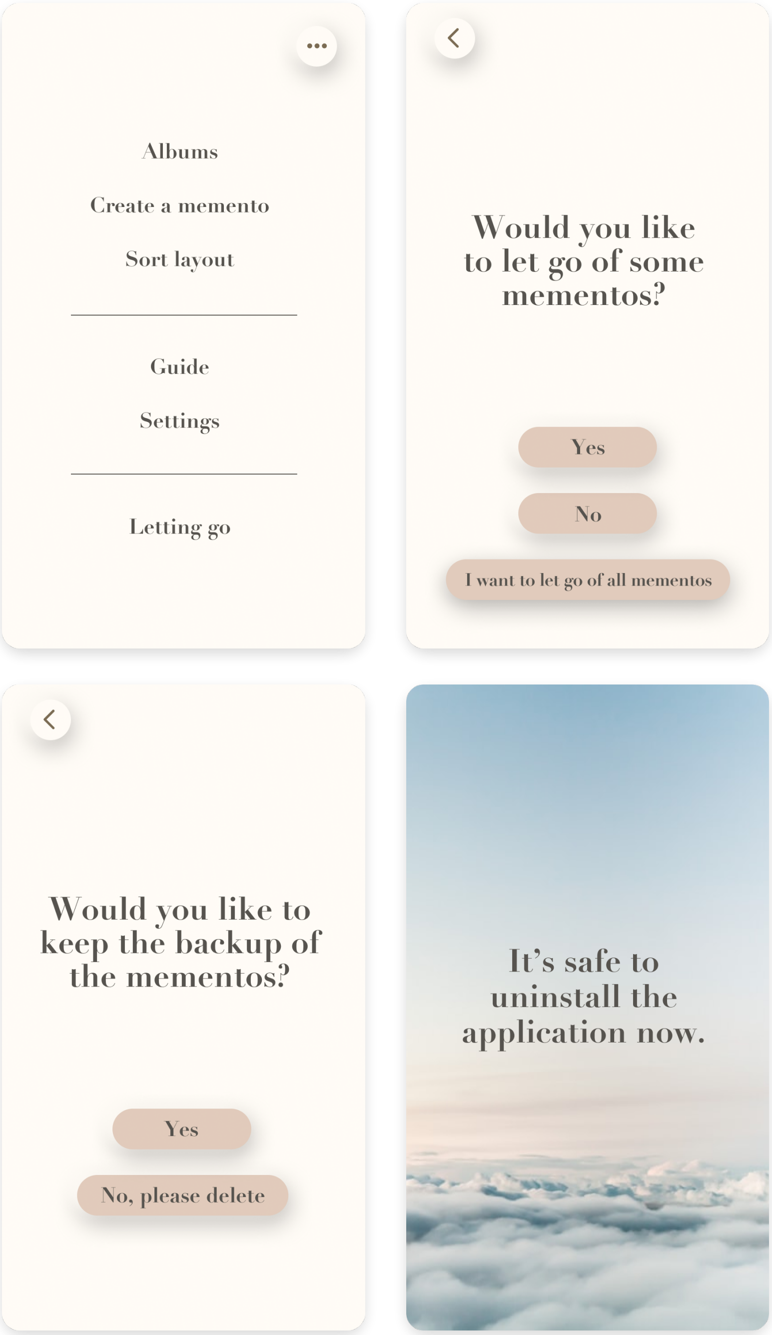


Figure 6.7 Memento homescreen



Would you like to let go of some mementos?

Would you like to keep the backup of the mementos?

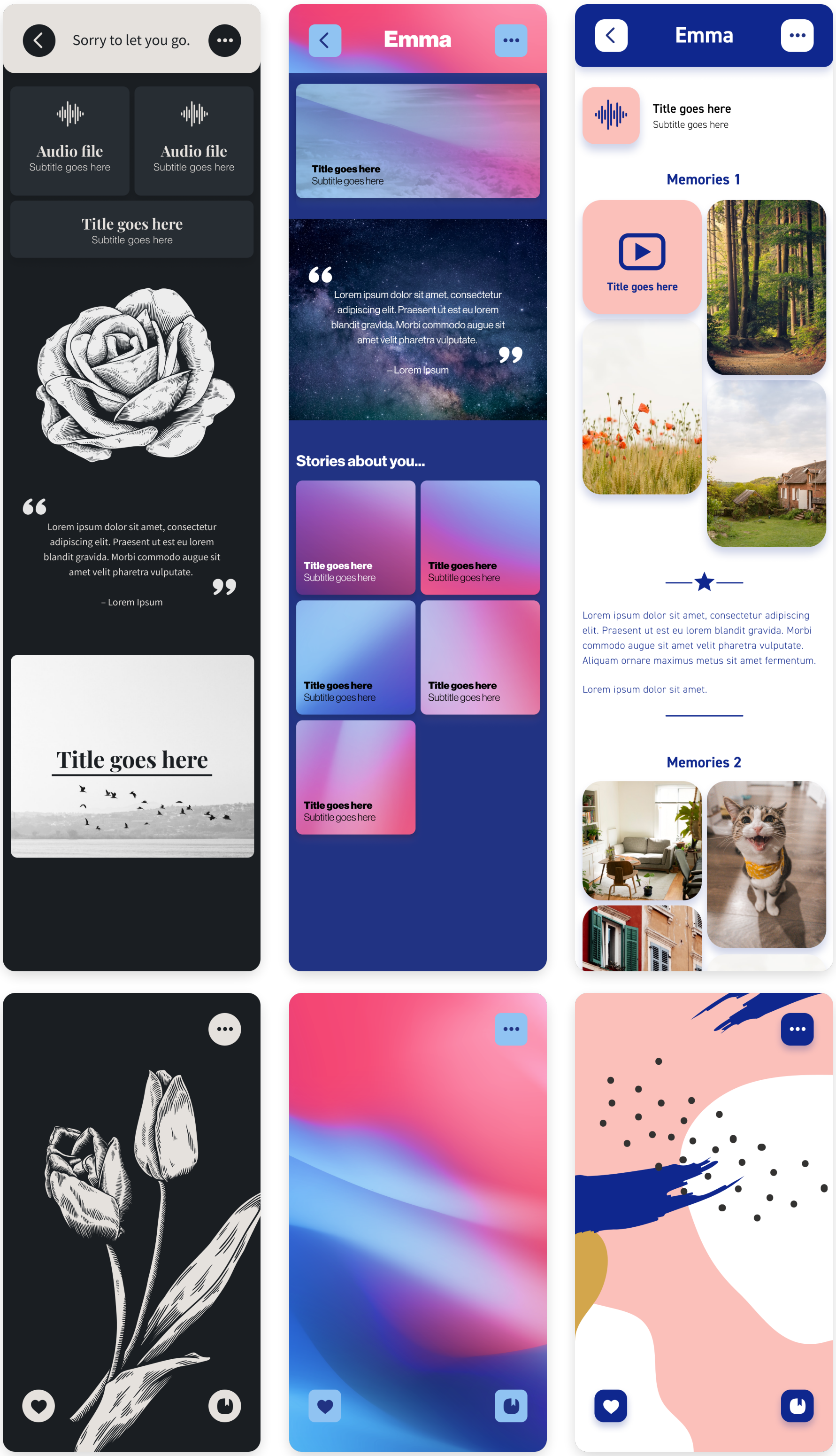
It's safe to uninstall the application now.

Figure 6.8 Letting go of mementos

When the person feels they want to let go of a certain memory or are ready to move on from keeping hold of the memory collection, Memento enables "letting go", which allows the user to say goodbye to certain mementos or the whole application without feeling guilty about deleting content.

Memento is backed up to the personal cloud storage available of the e-government. This ensures that the sensitive content is secure and cannot be accessed by third parties. Created memories can be downloaded from Memento and stored separately.

In order to relate with the memories made, Memento must fit the person. The application is customisable through choosing between different themes, and as the layout depends on the content created and the way the memories are organised, the user’s experience is unique to them.



Lorem ipsum dolor sit amet, consectetur adipiscing elit. Praesent ut est eu lorem blandit gravida. Morbi commodo augue sit amet velit pharetra vulputate.

Lorem ipsum dolor sit amet, consectetur adipiscing elit. Praesent ut est eu lorem blandit gravida. Morbi commodo augue sit amet velit pharetra vulputate.

Lorem ipsum dolor sit amet, consectetur adipiscing elit. Praesent ut est eu lorem blandit gravida. Morbi commodo augue sit amet velit pharetra vulputate. Aliquam ornare maximus metus sit amet fermentum.

Lorem ipsum dolor sit amet.

Figure 6.9 Examples of possible themes

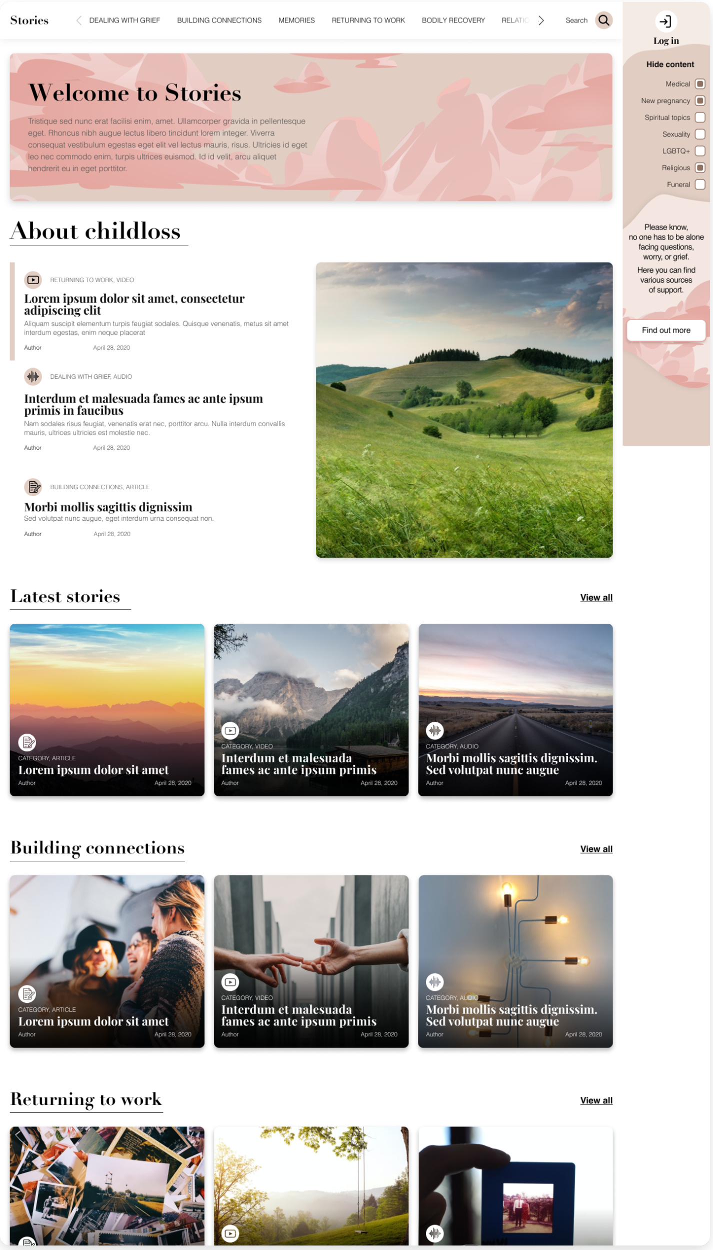
6.4 Stories

The systems view and interconnections with other layers of the platform visualised in the systems map in Appendix 2.

The loss is sudden, unexpected and difficult to relate with for the bereaved parents and for their social support network, therefore it is important that they all have access to stories shared by other people who have gone through the same experience. With that it is crucial that the community and the stories shared are diverse, so that the user does not feel pressured to experience their loss in a certain way. The rich variety of stories shared and the freedom to discover these helps to counterbalance the influence and pressure that may be put on the bereaved family by the people surrounding them.

Besides the people who have gone through similar experience, it is beneficial to have advice on the topic given by the experts in their field. Psychologists, midwives, yoga instructors, human resource experts, etc. sharing their knowledge to support the family and the social support network in the time when they require support.

The Stories website collects these experiences making them available for the bereaved family and social support network. The website displays content in a structured manner and allows both, searching for particular content as well as browsing.



Welcome to Stories

Tristique sed nunc erat facilisi enim, amet. Ullamcorper gravida in pellentesque eget. Rhoncus nibh augue lectus libero tincidunt lorem integer. Viverra consequat vestibulum egestas eget elit vel lectus mauris, risus. Ultricies id eget leo nec commodo enim, turpis ultrices euismod. Id id velit, arcu aliquet hendrerit eu in eget porttitor.

Please know, no one has to be alone facing questions, worry, or grief.

Here you can find various sources of support.

About childloss

RETURNING TO WORK, VIDEO
Lorem ipsum dolor sit amet, consectetur adipiscing elit
Aliquam suscipit elementum turpis feugiat sodales. Quisque venenatis, metus sit amet interdum egestas, enim neque placerat
Author April 28, 2020

DEALING WITH GRIEF, AUDIO
Interdum et malesuada fames ac ante ipsum primis in faucibus
Nam sodales risus feugiat, venenatis erat nec, porttitor arcu. Nulla interdum convallis mauris, ultrices ultricies est molestie nec.
Author April 28, 2020

BUILDING CONNECTIONS, ARTICLE
Morbi mollis sagittis dignissim
Sed volutpat nunc augue, eget interdum urna consequat non.
Author April 28, 2020

Latest stories

CATEGORY, ARTICLE
Lorem ipsum dolor sit amet
Author April 28, 2020

CATEGORY, VIDEO
Interdum et malesuada fames ac ante ipsum primis
Author April 28, 2020

CATEGORY, AUDIO
Morbi mollis sagittis dignissim. Sed volutpat nunc augue
Author April 28, 2020

Building connections

CATEGORY, ARTICLE
Lorem ipsum dolor sit amet
Author April 28, 2020

CATEGORY, VIDEO
Interdum et malesuada fames ac ante ipsum primis
Author April 28, 2020

CATEGORY, AUDIO
Morbi mollis sagittis dignissim. Sed volutpat nunc augue
Author April 28, 2020

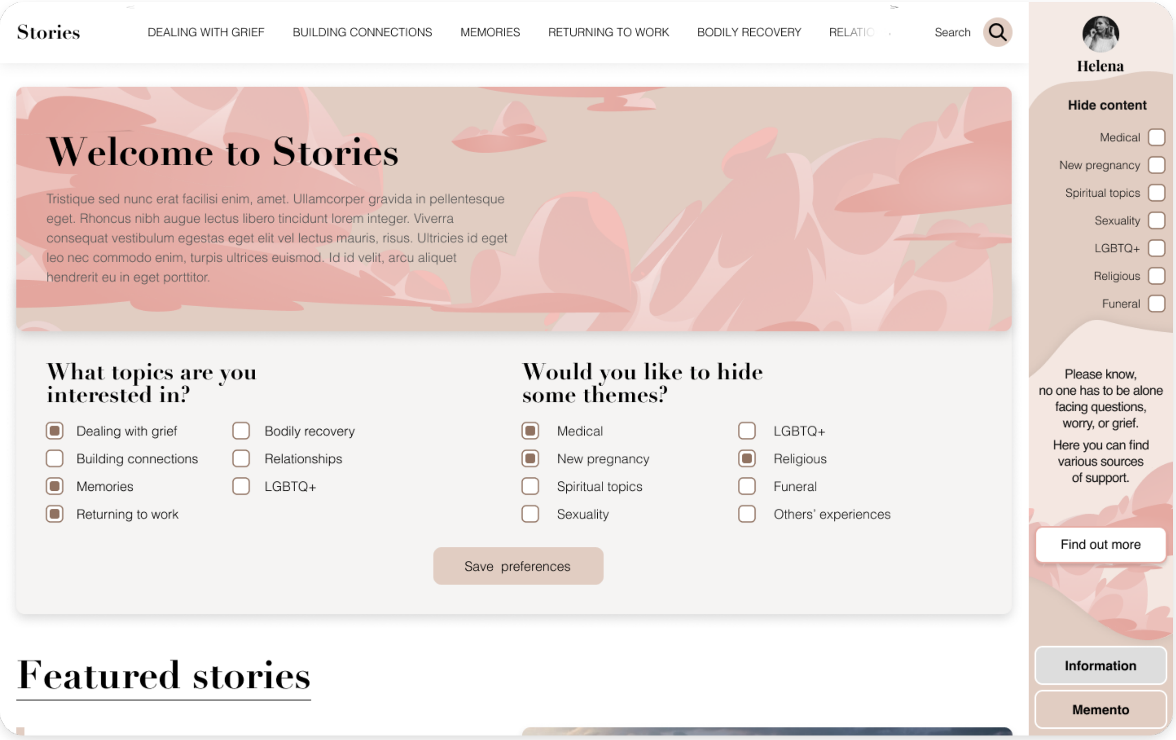
Returning to work

Figure 6.10 Stories main page view

The website functions on two levels, the community level and public view. The community level can be accessed logging on with the ID (carrying on the settings already determined in the state level). This ensures that community members can share more personal content among people who have had similar experiences. This community level forms the core of Stories. The inner layer of community is not only accessible for the bereaved parents, but all members of their social support network they decided to give access to the community support website. It is important to involve and inform the people who are directly supporting the families, as when they are more informed and aware, the support they can provide is more in tune with the families needs. Stories allows different community members share their own experiences, and so it is not perceived as only the mother’s right to feel the impact.

The public view may feature less personal stories, but still holds an important benefit for the community and the public allowing anyone who needs information or would like to know more have access to content created by people who know and care. This enables the community to voice their experience and needs to the larger circle, making the loss more visible and understandable, lessening the taboo surrounding the topic. Even when the bereaved parent does not have the energy or will to express to others what they are going through and how people could offer support, Stories ensures these people are not left in the dark and are offered support in their doubt and uncertainty.

Just like support groups or forums, Stories allows the members to share their stories and experiences and offer hope that it is possible to cope with the loss. The content is structured by topics and it is possible to filter and search through keywords. Stories, in its essence, is similar to a web magazine (like Medium).



Welcome to Stories

Tristique sed nunc erat facilisi enim, amet. Ullamcorper gravida in pellentesque eget. Rhoncus nibh augue lectus libero tincidunt lorem integer. Viverra consequat vestibulum egestas eget elit vel lectus mauris, risus. Ultricies id eget leo nec commodo enim, turpis ultrices euismod. Id id velit, arcu aliquet hendrerit eu in eget porttitor.

What topics are you interested in?

- ☒ Dealing with grief
- ☐ Building connections
- ☒ Memories
- ☒ Returning to work
- ☐ Bodily recovery
- ☐ Relationships
- ☐ LGBTQ+

Would you like to hide some themes?

- ☒ Medical
- ☒ New pregnancy
- ☐ Spiritual topics
- ☐ Sexuality
- ☐ LGBTQ+
- ☒ Religious
- ☐ Funeral
- ☐ Others' experiences

Featured stories

Hide content

- Medical ☐
- New pregnancy ☐
- Spiritual topics ☐
- Sexuality ☐
- LGBTQ+ ☐
- Religious ☐
- Funeral ☐

Please know,
no one has to be alone
facing questions,
worry, or grief.

Here you can find
various sources
of support.

Figure 6.11 Stories logged in, setting interests and triggers

When first visiting Stories, the user is asked about the content they are interested in, allowing the website to structure the Stories according to the user's interests. To a new visitor and in public view introductory stories are displayed too. When a person defines their role (for example an acquaintance, employer or a medical personnel) the content is filtered through this relevancy.

Important is to note that Stories features a pinned filter on all pages, that allows the user to hide certain topics. Bereaved users may find certain content triggering at different stages and can choose to hide it. Having these options available always when using Stories encourages people to use it, but also reminds them of their choices allowing making changes whenever they feel ready for it. In public view, the triggers are saved through cookies.

Stories supports various media, besides text, photos, video and audio, making it interesting to browse and giving people an opportunity to share their stories in ways they are most comfortable doing so.

It is the perfect place for the community and experts to share support for families and mothers in returning to everyday. As the experience can be seen gruesomely related to successful pregnancies and parenthood, yet the exact opposite, the support of people and the community who understands is valuable. Stories can share content on bodily recovery, whether it is tips on best ways to manage the changes in the body, building positive body relationship or instruction videos on bodily recovery exercises.

In returning to work, the situation is similar, as the bereaved parents have expressed they sometimes do not receive much understanding at work, the content in Stories can be helpful both for the families, but also for the employer and colleagues.

In order to allow richness and variety in Stories, the website is curated by the community and the non-profit organisations related to it. *MTÜ Vaikuse Lapsed* has experience that enables encouraging people to share their stories and gives a position from which to involve people in Stories. *MTÜ Peaasi* could also be involved in providing insight in psychology-related content. The structure of Stories allows the community itself and the curators to see what content could be beneficial and shows what people care most about and where to direct the attention and support. In the outward communication to the public, the community is empowered to voice their own experience and influence the manner the society sees the issue.

6.5 Fragments of support connected through the platform

The platform is supported by small acts of kindness that in combination support the experience greatly. These include, but are not limited to:

Bodily recovery kit

Although after the stillbirth, the mother's bodily changes are identical to the changes after a live birth, it is difficult make use of the products and services marketed to new mothers as these harshly remind of what went wrong. The mother is handed a kit when leaving the clinic that is filled with white label products easing the bodily recovery. The products do not have to withhold branding just targeted marketing, making it possible for companies to use it as an opportunity to donate products for a good cause and collaborate with the non-profit organisations in putting these kits together. The benefit of such kit is that the mother already has the products she needs to aid the bodily recovery and rebuilding the positive relationship with her body, therefore she is more likely to use these and does not have to question whether she is entitled to such products entirely.

Partner's leave can be started by the gynaecologist

For a doctor to start a medical leave, the person needs to be their patient. Currently, the mother is the patient and father's medical leave should be discussed with the GP. Seemingly small difference can have a large impact on the bereaved family's wellbeing if both of the parents' leaves can be issued simultaneously at the clinic.

(Volunteer) network of professional photographers

When parents decide to spend the time with their child after birth, it is an important time for building a connection with the lost child and making memories. Currently the social worker takes pictures of the child so that the family can have mementos of these moments. Professional photographers are, besides being able to take beautiful pictures, able to make their subjects feel at ease and bringing out the beauty in the moments without overstepping the boundaries. The photographs the family gets to keep are the only ones of the family together with the child. Photographers can join this initiative volunteer-based and knowingly. Similar initiative is being run in Australia and New-Zealand and the feedback from the bereaved families has been showing how valuable both, the atmosphere the photographers know to create and the quality photographs add for the family.[102]

Kids’ stores pledging for products to be returned

Many families prepare for the arrival of the baby during pregnancy by setting up the kid’s room and purchasing items. These feed the family’s excitement in expecting. However in stillbirth, these suddenly become difficult reminders of the loss and the family may struggle to how to handle the situation. As the products remain unused, these do not lose value. The platform enables the kids’ stores to sign up to pledge to take the products back whenever the family feels ready. This information is communicated through the information layer of the platform. The eligibility is given immediately once the diagnosis is connected with the profiles and the store is able to confirm it through the ID of the parents or the mandate.

6.6 Personas and individual user journeys

The platform offers various means of support, but as every user’s experience and needs are different, the user journey is non-linear and does not require for the user to interact with all services and support on offer. Throughout the platform, the user is nudged to be aware that support and counselling is available to them should they feel the need for it and can also ask for help handling the platform. The set profile and triggers are respected throughout the platform in all layers. As people use various devices, all layers of the platform support this.

In order to illustrate the different use cases and journeys, based on the interviews conducted I created five interconnected personas and described their experience and interactions with the platform. The user journeys connected to each user are available in the appendices 3-7.

---

[102] *Home2*. (n.d.). Retrieved 24 May 2020, from https://www.heartfelt.org.au/

HELENA

mother, 31

stillborn son
Joonas at 35+2

first child

traits

Non-religious, spiritual

Strong connection with partner

Large social circle

Wants to have two kids, scared she started too late

Scared of her body failing her

Sensitive to tone of voice

proceedings

Feels she cannot cope with dealing with organising the funeral and bureaucracy.

Partner's friend helps organising the send-off and is the main support person for the family.

The idea of dealing with the kid's room, clothes and toys taunts her.

communication

She had difficulties dealing with medical terminology and felt the hospital personnel was cold towards her. She found herself distancing from the experience in the hospital.

She was very worried of her partner's reaction and his emotions, but her partner was very supportive and insisted they share their emotions and talk about the event.

Her biggest fear is telling her friends. She shared her pregnancy very openly on social media, now feels shame.

Partner was very supportive and took the lead in communicating the event with their friends.

returning to everyday

She decided to take time before returning to work, she was worried if the person hired for the duration of her maternity leave would be let go. She would have felt guilty, but fortunately, workload had increased, so there's work for both.

Her company was understanding and the HR manager initiated conversations about how to best create a supportive trigger-free work-environment for Helena's return.

With her partner's initiative they started to be more social little-by-little. Her partner set up very clear communication, so the friends were supported in this and it felt less awkward.

grief

For her, her son had a name since very early in the pregnancy.

It's been difficult to accept the loss.

Initially she felt like they were the only ones who have gone through such tragedy, she was surprised to find many people who share a loss of a child.

She found support in these stories, but didn't actively join the community.

Over time she organised memories from the pregnancy and photos from the check-up along with photos of her child into a digital album. She felt she can channel her thoughts into stories to tell her son and it helped her have a more gradual letting-go.

shared grief

She felt her partner was less shook by the event. Jan was her rock and he initiated talking about their emotions and helped with easing back in to the everyday.

Helena's parents were waiting for their first grandchild and therefore her mother fell more distant for a week, after which she got back in touch and was open to share conversations of the loss. Helena felt guilty because she was confused about the sudden distance, but it lifted as her mother explained her trouble with her own emotions.

bodily recovery

Helena felt anger for her body failing her and the relationship with her body took a toll.

Bodily recovery was difficult and to her, it was a constant reminder of her loss and failure.

She avoided places like gyms and spas as she felt like everyone would see her as a mother although she had lost her child.

Reading articles about bodily recovery from experts and other women helped her change her mindset and become more accepting of the changes her body was going through.

The care-kit she received as she left the hospital allowed her to take care of the body even when her mindset was not the kindest towards it. Later she found additional products to use and she recovered well.

psychological support

Helena and Jan were not strong believers of support meetings and counselling as they had a negative experience with Perekool, that, to them, felt too baby-ing in their use of language. During pregnancy they had both used the internet for information and relied on the information their midwife and doctor had provided, therefore felt at ease using the internet to search for relevant articles and information and found support from the web-magazine along with other sources.

Figure 6.12 Persona for mother (Helena)

Corresponding user journey in Appendix 3

JAN

father, 36

stillborn son
Joonas at 35+2

first child

traits

Non-religious, rational

Strong connection with partner

Large social circle

Looking forward to starting a family

Down to earth

Emotionally aware

proceedings

Asked his best friend Paul to help them out with the organising of the send-off, is involved in explaining what him and Helena would like, but doesn't want to get buried in planning.

Trusts his friend and is grateful for his support. Gave him a mandate to deal with the proceedings.

Feels guilt for not seeing a possibility stillbirth as a possibility and takes the lead in organising the kid stuff they prepared.

communication

As his partner had difficulties with communicating with the medical personnel, Jan took the lead.

Jan realised that in this moment, communication and supporting each other is important in the relationship, and initiated many conversations and explained Helena that he does not blame anyone.

After reading about stillbirths and miscarriages, Jan realised how often these happen and felt angry that he did not know this before. Decided to fight the taboo by explaining their situation openly to their friends. He set guidelines for communication for their friends, so they would know how to talk to them about their loss.

returning to everyday

He was grateful he was also entitled for a leave without needing to book an appointment with his GP (does not have that great of a relationship).

During his leave he focused on strengthening the relationship and being there for Helena. Making sure that they both deal with their emotions but don't leave each-other behind.

They have a strong and large social circle, he felt the need to make sure they keep the friends and that friends know how they can be of support.

grief

For him, their son had a name since very early in the pregnancy.

He finds the loss unfair. Finds it unfair that it's a taboo even when miscarriages and stillbirths are common. It frustrates him.

Even though he is quite in touch with his emotions, he finds it difficult to accept the death before birth and the lack of memories.

He feels he needs time to overcome the loss and to place the emotions.

Reading about the experience of others and the advice of professionals, Jan organised the photos and other media into memories and the organising process worked well for him.

shared grief

Although shook by the loss, Jan found his partner more emotionally distraught and prioritised being there for her and strengthening their relationship.

He initiated communicating emotions with Helena.

Jan himself confided in his best friend who was of immense help in dealing with the matters and made sure that Jan had someone to talk to.

Jan had always had a large circle of friends. Although it might have become overwhelming to deal with them, having a possibility to give out information to them in one go, made it less of a burden and allowed him to not worry whether his friends understand and respect their needs.

bodily recovery

It was difficult for him to see Helena go through the bodily changes. It felt cruel to him that her body acted in a motherly manner and he tried to the best of his ability to support her in this even though he didn't quite know how.

psychological support

Helena and Jan were not strong believers of support meetings and counselling as they had a negative experience with Perekool, that, to them, felt too baby-ing in their use of language. Jan found a lot of support from his friend Paul and could talk to him about his emotions. Jan felt at ease using the internet to search for relevant articles and information and found support from the web-magazine along with other sources.

Figure 6.13 Persona for father (Jan)

Corresponding user journey in Appendix 4

PAUL

close friend, 34

has a 4 yo son himself

has been friends with Jan since childhood

traits

Non-religious, spiritual

Strong connection with Jan and his partner Helena

Large social circle

Finds Jan's and Helena's experience unfair and wants to help them with the bureaucracy that he feels should not be part of the experience

proceedings

Paul offered himself to help the couple as soon as he heard from Jan.

Took charge in dealing with bureaucracy and planning the send-off, made sure the plans are what the parents want.

Jan assigned Paul as his mandate for stillbirth related matters.

As he understands the most difficult for the parents is the kids stuff, he does not want to rush them, but aims to support their process.

In making the decisions, Paul researched other people's experiences and read through articles. He double checked with Jan and Helena to confirm.

communication

Paul had to offer Jan a few times that he's there to listen, but he was patient with him opening up.

Paul helped manage the closest group of friends with information, knowing that Helena had trouble with shame in hindsight for sharing their positive emotions during the pregnancy.

Some friends were afraid of saying the wrong thing, but Paul helped communicate Jan's and Helena's needs to everyone.

For Paul, he had support from his wife, who was very understanding and supportive for him helping Jan and Helena.

Figure 6.14 Persona for father's friend (Paul)

Corresponding user journey in Appendix 5

EVE

grandmother, 64

stillborn son
Joonas at 35+2

first grandchild

traits

Non-religious, spiritual

Retired, married

Strong relationship with her daughter Helena

Would love to have grandchildren and was very excited to hear about Helena's pregnancy

Has difficulty processing the loss, but wants to be there for her daughter

communication

It was difficult for her to process the loss and the news and although she tried to be supportive and available for her daughter, her own emotions got in the way.

After focusing on her own feelings and understanding these better, she was better available for her daughter and had a heartfelt conversation with Helena, after which Eve knew better how to support Helena and Jan while allowing for her own experience.

returning to everyday

As Eve is retired, she did not need to take time off work and therefore felt less pressured to return to life as it was.

For a few months she was less social and returned to everyday gradually.

grief

Eve had been quite close to Helena during her pregnancy and felt a connection to Joonas, yet still had difficulty dealing with the loss and making sense of it as the expectation was for a successful pregnancy.

It's been difficult to accept the loss and Eve felt a lot of anger initially. She had never considered a stillbirth as a possibility and found it unfair that her daughter needs to go through this.

She found support in stories on the website, she took comfort in seeing that people usually go on to have successful pregnancies. She did not want to actively join the discussion. She felt that her own emotions became more understandable to her.

She had support from having access to images and documents from the pregnancy to which she added stories she compiled addressed to Joonas. She felt safe doing so knowing that she won't take the experience away from Helena and Jan.

shared grief

Supporting her daughter's family gave an outlet for her own grief. It took a week for Eve to find a place for her own emotions, but then she made sure to be available for supporting the parents.

Eve had support from her husband, who did not seem as shook by the loss.

bodily recovery

Eve tried to, as well as she could, be available for Helena to talk about whatever she wanted to express.

psychological support

Eve used the guidance offered and for a few times consulted with a pregnancy crisis counsellor. It allowed her to understand her emotions and how to best deal with the situation.

Figure 6.15 Persona for grandmother (Eve)

Corresponding user journey in Appendix 6

EVELYN

HR manager, 37

first time dealing with employee returning to work after a stillbirth

traits

Non-religious, spiritual
Manages about 100 employees
Holds good work environment important
Holds employee happiness important
Good relationship with employees

proceedings

As Helena very recently took a maternity leave, Evelyn hired a replacement.

When Helena notified the company of her situation, Evelyn tried to reassure her she has a job to return to, but that she should take the time she feels needed to recover.

Helena's replacement was notified, but as they had proven to be valuable as an employee, the company decided to hold onto both of them. With increasing workload, being able to distribute tasks more evenly became a benefit.

Evelyn had to research best practice of proceedings for a return after a stillbirth. She holds good work environment and employee happiness in high regard and wanted to make sure the company can do as much as possible to maintain this.

Evelyn got guidance from reading articles from experts in workplace happiness who discussed work-environment after stillbirth.

Following the guidelines, Evelyn spoke with Helena before her return to work about proceedings and the environment. As Evelyn initiated this conversation, Helena did not need to feel embarrased about needing special treatment.

Evelyn allowed as many working-from-home days as needed and moved Helena's desk away from the kitchen and offices where employees sometimes brought their children with them.

communication

With the agreement from Helena, before her return to work, Evelyn held a meeting in the office to clarify Helena's return and the circumstances and offer support and clarity for communication. She gave additional information sources and enabled everyone to ask questions to make sure everyone felt at ease.

Figure 6.16 Persona for mother's HR manager (Evelyn)

Corresponding user journey in Appendix 7

7 COMMENTS ON THE CONCEPT

The experience of stillbirth or perinatal death in general has a large impact not only on the bereaved parents, but also on the further family and social circle. The current invisibility of the situation magnifies the negative impacts as no one is sure how to act in these situations, from the family to the medical personnel and friends. The influence of the loss drags on and the research shows stillbirth can have long-lasting negative outcomes for the bereaved family members.

People experience loss differently and therefore the platform enables various ways of being informed and supported, therefore does not require a linear journey from the users.

The design concept offers a platform that creates structure for the information and support in order for the experience of the bereaved family to be smoother to allow the families to focus on the important aspects of their emotions and feel supported. I see the main value of the concept as a structure or framework onto which it is possible to build. The state layer describes the foundation of support, but it can be further built upon. Memento is a tool that the user can customise to make it their own and add, create and organise the content so that it speaks to them about their experience. Stories is similarly a framework, that the community can build layers of support upon and when the foundation of the needs is required can explore additional topics.

The current support for the bereaved parents focuses on counselling (for the mother). Understanding the loss from the human-centred perspective opens up new opportunities for supporting all bereaved family members, including the social support network. Through this, they are empowered to better support both themselves and each other, lessening the negative impact of stillbirth and therefore making it a valuable investment for the state.

7.1 Feedback on the concept

The sketches and prototypes of various aspects of the concept with the focus on Memento (as the clickable prototype developed was the most plausible for testing) were given to the experts from *MTÜ Vaikuse Lapsed* to receive feedback. Unfortunately an in-person feedback session was not possible due to the COVID-19 outbreak. However the feedback received was helpful in finalising the concept design.

Juta Palmeri[103] expressed that the concept understands the needs of the bereaved parents on a deep level. She pointed out the positive aspects in Memento as the ability of all members of the family to create individual relationship with the memories. Sending-off mementos could be quite therapeutic in grief for some people. Juta Palmeri emphasised that the platform should be free to use so it could support all families that require it.

Triinu Tints[104], boardmember of *MTÜ Vaikuse Lapsed* added that as it is possible to download the content from Memento, people might appreciate compiling it into a physical book.

Eidi Aidla[105], a lived-experience counsellor, saw Memento as a tool that could add benefit to the parents' lives who have experienced a loss. The digital capabilities like playback of heartbeat recording can offer a strong connection with the lost child.

It was very encouraging to receive such positive feedback to the prototype and I took the comments I received into account in finalising the concept design. I look forward to introducing the full concept to the experts and discussing it with them once it becomes possible in a workshop format.

7.2 Scalability of the concept

As the concept is developed as a framework there are many opportunities for customising the content to provide support and structure in various situations.

All experiences of perinatal loss (not only stillbirth)

The thesis research focused mainly on the experience of stillbirth, but often it became impossible to distinguish it from the broader view of perinatal loss. Although there are various nuances to different stages of perinatal loss and the concept was developed first and foremost with the loss of stillbirth in mind, the concept should be applicable within all perinatal losses due to its malleability of content and user journey.

Experiences of rare illness and loss

---

[103] Palmeri, J. (2020, May 13). [Personal communication].

[104] Tints, T. (2020, May 13). [Personal communication].

[105] Aidla, E. (2020, May 19). [Personal communication].

Similarly to perinatal death, there are many illnesses in which the people suffering from it and the supporting family may feel alone with the proceedings and experience. If the illness has an impact on the person's and/or family's life, it may be difficult to adjust the lifestyle and figure out a way to manage the needed proceedings in the sudden change. In many of these cases, the people have found support in the community as it makes them feel understood however it takes time before the people find their way to these. Same framework of the platform can be adopted to offer support in proceedings and community.

Memento during pregnancy

With small modifications, memento can be used during the pregnancy to build a stronger connection with the foetus and have an outlet for the thoughts for the baby. As the pregnancy is an important development in the relationship and family, documenting this journey would be valuable and a nice memory to have for the family and for the child. This would ensure the memories are stored in an organised manner and there is a lot to look back on.

The concept design offers a framework that can be directly implemented, modifying only aspects of design and content, to fit other use cases besides perinatal loss. This adds value to the concept, making it more financially feasible for the state to implement it.

7.3 Further opportunities for research and design

In the thesis research I touched a few topics that I was not able to fully embrace within the design concept, but which I do believe deserve the attention of research and design.

Mother's bodily recovery after stillbirth

The design concept touches the topic through aspects like bodily recovery kit and Stories topics focusing on the bodily recovery and rebuilding the positive relationship with one's body. However, I believe that the topic deserves far more attention this thesis was able to give and holds interesting possibilities to explore in design.

Hospital experience from the perspective of service design

While the maternity clinics have developed best practice guidelines to inform the personnel in their practice and the medical procedures take priority over comfort, approaching the experience in the hospital through the methods of service design could open new opportunities in the patient journey in stillbirth. Initially I aimed to explore this in the thesis, but the outbreak of Covid-19 made the collaboration with the hospital impossible in the thesis timeframe.

8 CONCLUSION

Stillbirth is a loss of which the impact is misjudged as influencing only the bereaved parents and mostly the mother. Consequentially the experience has received insufficient attention in society and by the state. I tackled the issue in research and design through feminist design perspectives and a human-centred approach, structuring the process through constructive design methods.

The feminist design perspectives gave me the viewpoint of aiming for inclusiveness and individual experience in the design concept. Stillbirth may be seen as only a woman’s loss, but with this, as a consequence, not only the other members of the family and social circle are robbed from their loss and emotions, the mothers are singled out and left without the support from the social circle.

In my research, I analysed the experience of the bereaved families through interviews conducted with experts and bereaved parents and supported the findings whenever possible by analysing studies and articles written on the same issues to have a comprehensive foundation for the design concept.

The design concept supports the bereaved family and the social support network in dealing with the aftermath of stillbirth through a three-level interconnected platform that is part of the digital state services. It offers the bereaved families the opportunity to manage the loss and their experience in a manner that is most suited for them. The platform offers support not just to the bereaved parents, but to further families and social support network to lessen the taboo and enable people to feel informed and empowered in their decisions and communication about the loss.

The state level provides information in a comprehensible manner for the parents allowing them to process it at their own pace and lessens the bureaucracy of the proceedings following a stillbirth. It simplifies communicating the information and needs of the parents to their social support network and allows for the bereaved parents to have help from a trusted person in managing the necessary proceedings. Memento focuses on the memory-building aspect and enables users to build individual memories related to the child without influencing others’ grief process. Stories enables opening up the experience to a broader community and lessens the feeling of being alone with the loss. It does so through sharing a variety of experiences and support in two levels: within the secure community and outwards with whoever needs support.

The process of this thesis has challenged me in various ways. In research, it pushed me to find scientific articles and studies on a topic that is not widely explored but also to grow as an interviewer in empathy and ability to divert the conversation when necessary in interviews about a sensitive issue. In design realisation, I grew through creating a comprehensive visual overview through the systems map visualisation. I thoroughly enjoyed the process of channelling the various emotions and experiences people shared with me in research to the design of Memento, aiming for a tool, that in many ways differs from the applications fighting for our attention, by letting the focus be on the experience of memento-making and remembering, letting the application itself fade to the background.

My hope is that the thesis offers an insight to the experience of stillbirth and points towards the opportunities in supporting not just the parents, but the whole social support network surrounding them as it is important never to feel hopelessly alone. Stillbirth is not seen in our society, when not talking about it adds up, here is to hoping that this thesis may lead to even just one conversation, that then, in turn, can start adding up.

9 SUMMARY

Stillbirth is a quiet loss, often only visible within the close family. The lack of connection and memories with the child makes the loss difficult for the family to place, but also others to understand. As it is essentially death before birth, it is a topic mostly avoided in conversations, and in consequence, it has become a societally invisible loss. However, in contrast, the impact of the stillbirth is significant, the negative emotions deriving from the loss can lead to long-term mental health issues like depression and anxiety. While stillbirth is often seen and dealt with as the mother’s loss, both of the parents, along with the social support network, are strongly influenced by the experience. The current support on offer for the families is limited to medical aid and counselling, focusing mostly on the mothers.

Engaging with the topic of stillbirth through feminist design perspectives and human-centred analysis in the research I recognised that for the bereaved families there is no one defined way of experiencing the loss and that there is a need for inclusive approach supporting individual experience in offering support in the event of stillbirth.

The design concept I offer is a multilevel interconnected platform integrated into the state service system. It offers the bereaved families the opportunity to manage the loss and their experience in a manner that is most suited for them choosing their own points of interaction with the platform that support them in the ways they most require. In state proceedings, the bereaved parents are supported by structured, personalised information about the event customised to their preferred tone of voice, and proactive support in managing proceedings. The bereaved parents can give and manage the level of access to the platform to their social circle to keep them informed and with that announce their needs in support to them without extra burden. The bereaved family can have support from a trusted person in the proceedings by giving them a mandate to act on their behalf. In grief for a stillbirth, there is a lack of memories with the child, only the parents have their dreams and hopes from the period of pregnancy and the brief moments spent with the child, the Memento layer of the concept enables support in grief for relating with the loss and strengthening the connection with the memories allowing for each individual to build their own unique experience. The community level of the platform, Stories, enables the bereaved families to feel understood and less alone but also supported through a variety of shared experiences among the community while giving the bereaved families also a voice outwards, supporting the wider audience with information how to best support the families who have gone through stillbirth.

10 REFERENCES

1. Abordid, aasta—Eesti Statistika. (n.d.). Retrieved 9 May 2020, from https://www.stat.ee/34273?highlight=abort
2. Aidla, E. (2020, February 19). [Personal interview].
3. Aidla, E. (2020, May 19). [Personal communication].
4. Anderson, E. (n.d.). Vastsündinute haigestumise statistika kvaliteediraport. 21.
5. Bambus, M. (2020, February 21). [Personal interview].
6. Barr, P. (2012). Negative self-conscious emotion and grief: An actor–partner analysis in couples bereaved by stillbirth or neonatal death. Psychology and Psychotherapy: Theory, Research and Practice, 85(3), 310–326. https://doi.org/10.1111/j.2044-8341.2011.02034.x
7. Bellhouse, C., Temple-Smith, M. J., & Bilardi, J. E. (2018). "It's just one of those things people don't seem to talk about..." women's experiences of social support following miscarriage: A qualitative study. BMC Women's Health, 18(1), 176. https://doi.org/10.1186/s12905-018-0672-3
8. Bereaved father. (2020, April 4). [Digital personal interview].
9. Bereaved mother. (2020, March 23). [Personal communication].
10. Bereaved mother. (2020, March 25). [Digital personal interview].
11. Brierley-Jones, L., Crawley, R., Lomax, S., & Ayers, S. (2015). Stillbirth and Stigma: The Spoiling and Repair of Multiple Social Identities. OMEGA - Journal of Death and Dying, 70(2), 143–168. https://doi.org/10.2190/OM.70.2.a
12. Cacciatore, J. (2007). Effects of Support Groups on Post Traumatic Stress Responses in Women Experiencing Stillbirth. OMEGA - Journal of Death and Dying, 55(1), 71–90. https://doi.org/10.2190/M447-1X11-6566-8042
13. Cacciatore, J. (2010). The Unique Experiences of Women and Their Families After the Death of a Baby. Social Work in Health Care, 49(2), 134–148. https://doi.org/10.1080/00981380903158078
14. Cacciatore, J., & Bushfield, S. (2007). Stillbirth: The mother's experience and implications for improving care. Journal of Social Work in End-of-Life & Palliative Care, 3(3), 59–79. https://doi.org/10.1300/J457v03n03_06
15. Cacciatore, J., Rådestad, I., & Frøen, J. F. (2008). Effects of Contact with Stillborn Babies on Maternal Anxiety and Depression. Birth, 35(4), 313–320. https://doi.org/10.1111/j.1523-536X.2008.00258.x
16. Cacciatore, J., Schnebly, S., & Froen, J. F. (2009). The effects of social support on maternal anxiety and depression after stillbirth. Health & Social Care in the Community, 17(2), 167–176. https://doi.org/10.1111/j.1365-2524.2008.00814.x
17. Chavez, M. S., Handley, V., Jones, R. L., Eddy, B., & Poll, V. (2019). Men's Experiences of Miscarriage: A Passive Phenomenological Analysis of Online Data.

Journal of Loss and Trauma, 24(7), 664–677. https://doi.org/10.1080/23802359.2019.1611230

18. Childbirth allowance > Tallinn. (n.d.). Retrieved 10 May 2020, from https://www.tallinn.ee/Teenus-Childbirth-allowance
19. Christensen, D. R., Hård af Segerstad, Y., Kasperowski, D., & Sandvik, K. (2017). Bereaved Parents' Online Grief Communities: De-Tabooing Practices or Relation-Building Grief-Ghettos? Journal of Broadcasting & Electronic Media, 61(1), 58–72. https://doi.org/10.1080/08838151.2016.1273929
20. Downe, S., Schmidt, E., Kingdon, C., & Heazell, A. E. P. (2013). Bereaved parents' experience of stillbirth in UK hospitals: A qualitative interview study. BMJ Open, 3(2). https://doi.org/10.1136/bmjopen-2012-002237
21. Dugas, C., & Slane, V. H. (2020). Miscarriage. In StatPearls. StatPearls Publishing. http://www.ncbi.nlm.nih.gov/books/NBK532992/
22. Duncan, C., & Cacciatore, J. (2015). A Systematic Review of the Peer-Reviewed Literature on Self-Blame, Guilt, and Shame. OMEGA - Journal of Death and Dying, 71(4), 312–342. https://doi.org/10.1177/0030222815572604
23. Erlandsson, K., Säflund, K., Wredling, R., & Rådestad, I. (2011). Support After Stillbirth and Its Effect on Parental Grief Over Time. Journal of Social Work in End-of-Life & Palliative Care, 7(2–3), 139–152. https://doi.org/10.1080/15524256.2011.593152
24. Erlandsson, K., Warland, J., Cacciatore, J., & Rådestad, I. (2013). Seeing and holding a stillborn baby: Mothers' feelings in relation to how their babies were presented to them after birth—Findings from an online questionnaire. Midwifery, 29(3), 246–250. https://doi.org/10.1016/j.midw.2012.01.007
25. Home2. (n.d.). Retrieved 24 May 2020, from https://www.heartfelt.org.au/
26. Homewood, S. (2018, June 28). Reframing Design Problems Within Women's Health. https://doi.org/10.21606/drs.2018.337
27. How soon can I do a pregnancy test? (2018, June 27). Nhs.Uk. https://www.nhs.uk/common-health-questions/pregnancy/how-soon-can-i-do-a-pregnancy-test/
28. Hutti, M. H., Armstrong, D. S., Myers, J. A., & Hall, L. A. (2015). Grief Intensity, Psychological Well-Being, and the Intimate Partner Relationship in the Subsequent Pregnancy after a Perinatal Loss. Journal of Obstetric, Gynecologic, & Neonatal Nursing, 44(1), 42–50. https://doi.org/10.1111/1552-6909.12539
29. Imikusuremus, aasta—Eesti Statistika. (n.d.). Retrieved 9 May 2020, from https://www.stat.ee/34269
30. Keskhaigla, A. I.-T., tn 18, R., Tallinn, 10138, Faks: 620 7002, & Infoitk.ee, E.-P. (n.d.). Kas plaanime lõhkuda seda, mis töötab järjest paremini? | Veebruar | 2019 | Kõik uudised | Uudised | Ida-Tallinna Keskhaigla. Retrieved 15 January 2020, from https://www.itk.ee/uudised/koik-uudised/2019/2/kas-plaanime-lohkuda-seda-mis-tootab-jarjest-paremini

31. Kingdon, C., Givens, J. L., O’Donnell, E., & Turner, M. (2015). Seeing and Holding Baby: Systematic Review of Clinical Management and Parental Outcomes After Stillbirth. Birth, 42(3), 206–218. https://doi.org/10.1111/birt.12176

32. Kong, G. W. S., Chung, T. K. H., & Lok, I. H. (2014). The impact of supportive counselling on women’s psychological wellbeing after miscarriage—A randomised controlled trial. BJOG: An International Journal of Obstetrics and Gynaecology, 121(10), 1253–1262. https://doi.org/10.1111/1471-0528.12908

33. Mankin, D. (2020, March 23). [Digital personal interview].

34. Miscarriage is common. So why is it such an isolating experience? - The Washington Post. (n.d.). Retrieved 16 January 2020, from https://www.washingtonpost.com/news/parenting/wp/2016/10/13/talking-about-miscarriage-might-be-upsetting-but-we-need-to-do-it/

35. MTÜ Vaikuse Lapsed. (n.d.). Juhend toimingute osas pärast lapse kaotust. 8.

36. Murphy, S., & Cacciatore, J. (2017). The psychological, social, and economic impact of stillbirth on families. Seminars in Fetal and Neonatal Medicine, 22(3), 129–134. https://doi.org/10.1016/j.siny.2017.02.002

37. Ootuse kaotus—Laste ja Noorte Kriisiprogramm. (n.d.). Retrieved 13 May 2020, from https://www.lastekriis.ee/lugemist/artiklid/88-ootuse-kaotus.html

38. Orbach, S. (2019). Bodies. Profile Books.

39. Palmeri, J. (2020, March 18). [Digital personal interview].

40. Palmeri, J. (2020, May 13). [Personal communication].

41. Palmeri, J., MTÜ Vaikuse Lapsed (2013). Infomaterjal lapse kaotanud perele. 36.

42. (PDF) The Role of Hypothesis in Constructive Design Research. (n.d.). ResearchGate. Retrieved 8 May 2020, from https://www.researchgate.net/publication/276264315_The_Role_of_Hypothesis_in_Constructive_Design_Research

43. Perez, C. C. (2019). Invisible Women: Exposing Data Bias in a World Designed for Men. Random House.

44. Pollock, D., Pearson, E., Cooper, M., Ziaian, T., Foord, C., & Warland, J. (2020). Voices of the unheard: A qualitative survey exploring bereaved parents experiences of stillbirth stigma. Women and Birth, 33(2), 165–174. https://doi.org/10.1016/j.wombi.2019.03.002

45. Pruul, P. (2016). Eksperthinnangu „Raseduskriisi nõustamise kvaliteet‟ Kokkuvõte. Estonian Health Insurance Fund.

46. SA Väärtustades Elu. (n.d.). Raseduskriisi nõustamise täiendkoolitus 2018-2020.

47. Scheidt, C. E., Hasenburg, A., Kunze, M., Waller, E., Pfeifer, R., Zimmermann, P., Hartmann, A., & Waller, N. (2012). Are individual differences of attachment predicting bereavement outcome after perinatal loss? A prospective cohort study. Journal of Psychosomatic Research, 73(5), 375–382. https://doi.org/10.1016/j.jpsychores.2012.08.017

48. Shreffler, K. M., Hill, P. W., & Cacciatore, J. (2012). Exploring the Increased Odds of Divorce Following Miscarriage or Stillbirth. Journal of Divorce & Remarriage, 53(2), 91–107. https://doi.org/10.1080/10502556.2012.651963

49. Sims, A. (2019, June 13). Surma registreerimise teenus. 18.

50. Tehik. (n.d.). Surma digitaalne dokumenteerimine. 3.

51. Tehik. (2019). Surma registreerimise teenus. 18.

52. Tervisestatistika ja Terviseuuringute Andmebaas, (2019, July 19). Sünnid haigla ja naise elukoha järgi. Retrieved January 2020, from https://pxweb.tai.ee/PXWeb2015/pxweb/et/01Rahvastik/01Rahvastik__02Synnid/SR03.px/?rxid=66951fe5-6003-4a52-9252-ec8ba4f46e69&fbclid=IwAR2DoVl7UYnbUJUBL70kxi9lOIZFRVHwRYNWCIKbwQ3r7D7ZhMNEu5MOG1Q

53. Tints, T. (2020, May 13). [Personal communication].

54. Tozen-Pütsepp, K. (2019, January 10). [Personal interview].

55. Vaimse tervise spetsialistid: Maal on meilt juba raske abi saada, varsti läheb hulluks ka mujal. (1570643501). Delfi. https://www.delfi.ee/a/87702833

56. Waling, A. (2017). Men and Fourth-Wave Feminism: Acceptance, Ambivalence, Resistance. New Community, 14, 34–37.

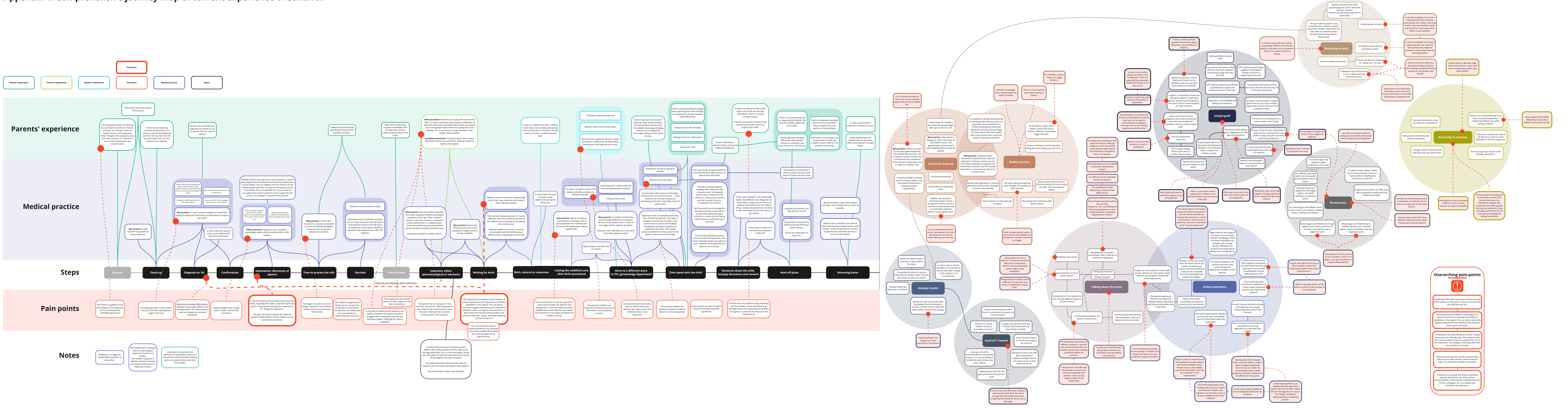
57. World Happiness Report 2019. (n.d.). Retrieved 15 January 2020, from http://worldhappiness.report/

58. Wright, P. M. (2011). Barriers to a Comprehensive Understanding of Pregnancy Loss. Journal of Loss and Trauma, 16(1), 1–12. https://doi.org/10.1080/15325024.2010.519298

11 LIST OF FIGURES

12 APPENDICES

Appendix 1: Comprehensive journey map of current experience of stillbirth



Pain point

Parents' experience

Partner's experience

Mother's experience

Pain point

Medical practice

Notes

Parents' experience

There may not be any concern from parents

The expecting mothers are directed to track fetal movements in the last trimester as a change in this can indicate issues in the pregnancy. Other changes in the pregnancy may also raise concerns. It is advised to turn to the hospital when any concerns arise.

If there has not been any concerns by the parents, the check-up may be the beginning point for the "journey" and the situation takes a turn for the parents very suddenly.

Parents may not believe the diagnosis and decide to turn to another clinic for second opinion

Collaboration with parents regarding the timing of the induction of labour.

Most women stay at the hospital immediately after the diagnosis. Partners collect necessary items from home.

Often practiced: Partners are usually sent home for the night, if it seems necessary, they are given medication to help them calm down and sleep. Before birth, the women stay in the general ward, where the visiting hours are between 15-19. Partners are usually allowed to stay longer, when possible.

Sometimes practiced: If situation allows and it seems beneficial, partners are sometimes allowed to stay the night at the hospital.

In case of a stillbirth, the birth is difficult as the baby is not actively participating in the process like in a live-birth. For this reason, the birth can take up to five days.

The body produces breast milk

Mothers suffer from somatic pains

Recovery from caesarean section or other procedure is difficult as the body keeps behaving as if the baby was born alive.

Parents may want to consider if there are other family members who would like to see the child. The midwife discourages bringing children to the hospital but encourages talking to them about the loss.

Parents may have different feelings about spending time with the baby. It is important to accept and allow these differences.

Taking pictures with the baby

Making memories, mäletuskarp

Naming the child

Parents' behaviour is related to their cultural and religious background.

Parents are advised to talk to each other and not fall into blaming themselves. There is a strong emotion of guilt.

Partners are advised to hold strong communication with mothers to support each other.

There is no state financial aid for organising the funeral. The local municipality might have one in place.

There is a dedicated memorial place cared for by the MTÜ Vaikuse Lapsed. This is an option as a funeral place.

Families deal with the body differently. Most families choose for cremation, but some choose for a full funeral.

If the body is not cremated, the morgue does not offer any transport case or coffin for the transport of the body.

In many cases mother's treatment continues at home.

Some families leave the hospital without any items, often returning later to collect those.

Medical practice

Best practice: Avoid misinforming parents or reassuring them.

Prepare parents by providing clear step by step information about induction of labour and the birthing process including potential length of labour

Discussion with parents in quiet and private area.

No delay in informing parents of their baby's death

Discuss a plan for the investigation into the cause of the stillbirth.

Best practice: To talk to parents together to avoid them having to repeat the information, to allow them to support each other.

In some cases the cause of death can be determined during the ultrasound.

Midwife calls for the pregnancy crisis counsellor or clinical psychologist (from the department) when they determine it may be helpful. This can happen from the initiative of the medical worker and does not require the family to ask for it specifically. This is to establish first contact with the counsellor and is done to allow for more support for the women. Can happen in any part of the journey.

The counselling is advised whenever the medical personnel sees potential need for it rather than to "wait it out".

Midwives have personal preferences that determine which counsellor they contact.

Often practiced: Pregnancy crisis counsellor / psychologist called in by the medical staff to offer support.

Best practice: To start with procedures as quickly as possible to avoid overwhelming negative emotions from the parents towards the situation.

Inductions are not started at night

Caesareans only if medically necessary as it is a major operation and will require more physical recovery and will cause complications at next births. (Mothers expected to get pregnant soon after the stillbirth)

Best practice: Keep the mother separated from other pregnant mothers and positive pregnancy check-ups. Other pregnant women in the clinic moved so to keep the mother before birth in a separate ward. Unless the mother has given birth before and can be taken directly to the birth room.

Not always possible in smaller centres.

Best practice: Ensure the birthing suite is set up and equipped to support parents during a stillbirth.

Midwives have no education in psychology, rely on their own experiece and intuition when talking to parents

There are two midwives present. In case of stillbirths, one of the midwives focuses on the stillbirth and is available for the family. One contact point.

Midwives explain the process, but have conversations with the families about different topics, depending on the family.

In some cases the cause of death can be determined during the ultrasound

Best practice: taking a handprint and footprint of the baby, part of putting together the "memory box" that non-proft organisation Vaikuse Lapsed offers

The child is not given a name. The identity code last numbers are between 995-999.

Dead baby given unique code (not personal identification number)

Filling out birth card

Blood analysis and other test on mother.

Best practice: To distance the families gone through stillbirth from pregnant women and successful births in order to not trigger further negative emotions.

Separate room, definitely not in the same room with pregnant women.

Preparation of child for giving to parents

Offered to hold the child

Social worker takes pictures of the baby. These pictures are stored 0,5 years – 1 year. If parents do not take the pictures immediately with them, they often return to collect these.

Babies are never immediately taken away after the birth procedures. The baby is wrapped, only the face is visible. If the parents do not want to see the baby immediately, the baby is placed on a cupboard in the room. The medical personnel leave the room to allow for the family to have time with the baby.

The social worker brings the Memory Box after the birth. Before does not have contact with them.

Parents are advised against bringing other children to the hospital to visit. The hospital environment is difficult for the children to make sense of and to see their parents' trauma is confusing for the children.

But the parents are encouraged to talk about the loss to the children as they have expected to get a brother or a sister and not talking about the loss would leave them confused.

If the family would like to spend more time with the baby than a few hours, the baby needs to be taken to cool in between time spent with the baby to cool the body.

If the cause of death is not immediately known, the stillbirths over 500g and over 22nd week of pregnancy are sent to an autopsy. The parents have the right to refuse. Usually the parents do not refuse as they would like to know the reason to get closure.

Funeral date is reliant on if and when the autopsy is conducted

The hospital's social worker is there to explain all issues with parents' leaves and next steps.

Hospital social workers can help plan the funeral

Social worker can guide the family by giving information about options.

Family can make plans on their own.

Recommended to stay in the hospital overnight, many families leave as soon as possible.

Memory box is handed to the parents when they leave the hospital by the social worker. In case the parents do not want to take the box with them, the box is stored at the hospital.

Steps

Concern

Check-up

Diagnosis w/ US

Confirmation

Explanation, discussion of options

Time to process the info

Decision

Time at home

Directly proceeding with induction

Induction, either pharmacological or mechanic

Waiting for birth

Birth, natural or caesarean

Cutting the umbilical cord, after-birth procedures

Move to a different ward, in ITK, gynaecology department

Time spent with the child

Decisions about the child, autopsy discussion and consent

Send-off plans

Returning home

Pain points

The mother is guided to track any changes in the pregnancy, but is not prepared for anything to go wrong.

Not always possible, as the mother may be at the check-up/diagnosis stage on her own

Medical terminology differentiates between miscarriage, stillbirth and neonatal death. This differentiation does not change the individual experience.

Mostly available only in large cities. Smaller centres have counsellors

In communication with the medical personnel, the family, especially the mother, may feel shame and guilt for "putting them through this experience", for "failing the pregnancy".

The guilt and shame towards the child, the partner (mother/father), further family, can also shadow the experience.

The longer the wait is, the more danger is placed on the mother's health and the more the baby deteriorates

The midwife recognises the family tries to not pull a lot of attention to themselves. Yet sees that the family could see more freedom in expressing their emotions.

In the eyes of healthcare the patient is the mother, therefore the healthcare system struggles with providing the partner with necessary support. Although the need is recognised.

The hospital has very limited options to offer support for the men and partners.

The partner has no "purpose" in this moment. The home is often prepared for the child's arrival and the partner faces this alone. Both partners are alone making sense of the situation.

The way parents are talked to and treated is of utmost importance, but midwives have different capabilities in this regard. This can lead to extremely negative experiences for some whose midwife is either not a good communicator or a good match for how the parents prefer to be communicated with. (direct, extensive explaning, soft and caring, etc.)

The communication skills of medical personnel vary and they may not be capable of handling the communication at the required level.

Ink can leave stains on the skin, gouache is used. Gouache does not allow for very detailed print. There are inkless print kits available that would allow for more detail. The footprints are as unique as fingerprints if taken correctly.

The physical condition can hinder the emotional recovery of the mother and the grieving process.

Some parents want the child to have an official name and identity code, others don't. This individual choice is not supported.

The question whether the parents would like to hold the baby may come unexpected.

Some parents who did not spend time with the baby have later regretted it

Partners have very different ways of dealing with the situation. Some would like to go through the journey supporting the mothers throughout it, some do not show up in the hospital at all.

Notes

Pregnancy is a trigger for mental health disorders to (re)surface.

The midwife sees increasing need for psychological support for women and families.
The midwife recognises a definite increase in anxiety and mental health issues in expecting mothers.

Important to understand the difference in immediate emotions of the parents and the emotions looking back to the events after some time. This changes.

In induced abortions due to medical reasons (before 20th week), parents have the right to see the baby after birth, but it is not encouraged. Seeing the child when the abortion was induced, can bring strong negative emotions and guilt.

The medical personnel discusses this with the parents before the birth and explains their options.

Very few families decide to see the baby.

Post birth check-up

It is not always possible as there may not be available appointment times to enable this.

Best practice: Women are seen by the same gynecologist that has followed their journey. This is advised in order to ensure the conversations are considerate of the women's experiences and to allow for a familiar face.

It may be possible to already discuss autopsy results, if not the parents should ask to schedule another appointment.

Further leave for mother is discussed with gynaecologist. Men can turn to their GP.

Best practice: Information in Digilugu to inform the doctor of the medical history. The gynaecologist should always check Digilugu before seeing the patient.

Can be very emotional.

Clinical tests 6-8 weeks after birth.

Mothers are advised to remind the doctor to have enough time and to meet at a time that it would be possible to avoid other pregnant women in the waiting room.

It is not guaranteed that the doctor has planned the check-up taking into account the needs deriving from the loss.

Bodily recovery

Women's knowledge about female body and health is limited.

There is a lot of societal taboo about women's bodies.

For example, crying of a baby can trigger lactation.

As the body is ready to be a mother, events that call for mother's attention unwantedly trigger the body.

Phantom feelings of child being close, being alive and needing care can occur.

It is possible to donate the breastmilk to the breastmilk bank, but this is not generally communicated as it is further burdening the body and making the recovery process longer. The assumption from the hospital side is that women want to end this chapter as quickly as possible.

Best practice: Questions about breastmilk to determine the required approach. In Estonia, women are not prescribed medication to suppress the breastmilk production, but the hospital does have it in stock and can give it out in certain cases.

Breast milk suppressant in Estonia generally not perscribed, although in certain cases possible.

Cold compress can help with pain in breasts

The body is going through the same changes and recovery as after live birth.

Body requires time to recover. Recovery exactly the same as post live birth. Up to six weeks of bleeds.

Recovering from caesarean takes about 6 weeks.

Most recovery guides, events, and products are targeted and branded for mothers. Here this is a trigger.

Autopsy results

Reason for death remains unknown in about half of the cases.

Contacting the doctor to discuss patoanatomic autopsy report. Parents can receive a copy of the report.

In some cases it may be possible for the parents to see the child after autopsy in the morgue or in a funeral home.

Autopsy results can take up to 2-3 months.

Parents can pick up the body after the autopsy from the morgue or contact a funeral home to deal with these matters already from morgue.

People working in the morgue can seem insensitive to the parents.

Send-off / Funeral

Vaikuse Laste Rahupaik at Risti Church is one option for parents for the burial place.

Parents can choose whether to have a cremation or a burial.

Usually a very private event and includes only the parents and close family or friends.

Once cremated there is no set time limit before the send-off.

Having a send-off is recommended for the grieving process. It is recommended to include the whole family, also other children.

Mandatory to bury the child after 22nd week of pregnancy (500g). Parents can choose to do so with earlier losses too.

Organising the send-off may give some sense of purpose in grief.

Parents may have difficulties relating to planning the send-off as the loss is unexpected and sudden (they were preparing themselves for the arrival of the baby).

Talking about the event

Talking about the loss is difficult. Complicated emotions affect the conversations. Families can feel like people cannot relate to their experience.

Telling friends and family can be difficult as the parents may sense an expectation of good news.

Notifying close people

Social network can be of great support.

Meetings with counsellor / psychologist. With a referral it is covered by Haigekassa.

Talking about the loss can give validation to the feelings and grief.

Feeling alone in this experience has a strong negative impact on the pain-owners.

Communication between the parents is paramount.

Parents should avoid blaming themselves/each other and distancing from each other.

People can find comfort in social media groups. Women are most active. Social networks usually gather people with similar experiences.

Sharing the experience online can increase the feeling of being understood and being among others who understand.

The experience may bring out different emotions in parents and communicating with one-another may be hard. Feelings of guilt and blame are common.

If the partners have difficulty sharing their emotions and communicating with one-another, it has a strong negative effect on the relationship.

Families can sense the topic being taboo, therefore act according to this perception unconsciously.

Online bereavement groups can encourage rumination and comparison behaviours and emphasise negative emotions.

Primarily the counselling is first meant for women. Although pregnancy crisis counselling accept sessions with anyone from the family, the general focus is on women.

Many specialists are not qualified to deal with bereavement support.

It is difficult to find a specialist that fits the person.

The availability is varied depending on distance from large centres.

Mental health specialist waiting lists are long.
Pregnancy crisis counselling and clinical psychologists are more readily available. Accessibility dependent on location.

Unique grief

Grief is individual, family members/friends who grieve differently, may be difficult to relate to.

In case if one of twins passes, the grief is very complicated. Often not supported by bystanders. Mixed with the joy of the new arrival.

Emotions in grief may seem intense and extreme to bystanders.

Documentation is scattered and lacking. During pregnancy parents may have not focused on documenting the pregnacy, focusing more on the coming experiences with the child.

Need for proof of child's existance in order to justify grief.

Saying goodbye is saying hello.

Even parents who spent a while with the child have regretted not having enough time with the child.

MTÜ Vaikuse Lapsed brings together the bereaved families and forms a supporting community.

Besides the parents, further family and friends can be affected by the loss and their grief should be considered.

MTÜ Vaikuse Lapsed has published a guidebook to support the bereaved parents in their loss.

Trustworthy information sources are scarce, the tone of voice may not be fitting to all parents.

In grief it is important to follow the "outwards support" model. Each griever should reach outwards in the social circle to receive support, not seek "inwards".

Important to acknowledge own feelings and emotions.

Grieving is recommended. Trying to ignore the loss can cause complex suppressed emotions that can have a long-term effect.

Hopes and dreams during pregnancy need to be transformed into memories to keep the connection with the child and allow grief.

The child can be viewed still as a new member of the family.

Lack of conventional memories.

The nature of the siblings' grief is dependent on their age and experience.

Giving a name can have importance to some parents. Some parents may prefer to keep using the nickname used during pregnancy.

Not possible to register the name of miscarriages and stillbirths.

MTÜ Vaikuse Lapsed Memory Box aims to provide memory items.

Expressing emotions and discussing and listening to feelings is one of the best ways to support the children in grief.

It cannot be predicted how long the grieving process is for a person.

Bystanders seem to expect for the grief to be short.

May be the parents first loss and experience with death.

Vaikuse Laste Rahupaik is meant to commemorate all lost children.

Men's grief and need for emotional support can go unrecognised.

There is a perceived societal expectation for fathers to be above emotions and not express their grief.

Often seen as women's loss, other pain owners grief can be unregarded.

The parents may not be fully capable of being supportive of the needs of the grieving children.

Online experience

The closed nature of the online group can influence the grief of the community members to become less diverse as in online communities a more common experience can start to dominate as the "correct experience".

Digital medical recordings of the foetus are not directly available via Digilugu. These are stored separately and available only through request. Medically non-essential recordings will be deleted once storage fills up.

Members of the community value the closed nature, the wealth of experiences shared, and the possibility of constant and immediate access through digital and mobile technologies.

During the pregnancy, the parents may have used various pregnancy applications installed on their phones.

Parents may have shared their pregnancy experience on social media and through these posts many of their acquaintances may be expecting good news.

Parents may feel the pressure to inform people outside their closest group before they would otherwise do it.

Communicating online includes the expectation of instant replies. Bereaved parents may need time to respond.

Delay in message replies can be taken as offence if the situation is not considered.

Many of the online communities are closed to provide privacy and security.

Parents' internet behaviour during the pregnancy have taught content algorithms about their interests.

Non-profit organisations' websites are the main and most reliable source of information about the experience.

More and more internet websites and platforms are using algorithms to customise their content.

There is a lack of comprehensive and trustworthy locally relevant information available online. People resort to less reliable sources of information and may as a result be ill- and malinformed.

Teaching algorithms requires either conscious effort or takes a while to happen organically. After the loss of a child, the personalised content about pregnancy and kids' products can be difficult for the parents.

Non-profit organisations lack funding and resources to build and maintain complex web platforms, for that they resort to already available social media networks.

Social media network platforms are not designed directly for this purpose.

Social media platforms use targeted ads that algorithms guide. After loss of child, it takes time for the algorithm to react to the change, resulting in advertisement for expecting parents.

Returning to work

Mothers should contact their gynaecologist (or GP) for extended leave for recovery.
Partners should contact their GP for work leave.

140 day maternity leave is only cancelled upon mother's request, but further mother's leave does not start. Men are entitled to their vacation leave during mother's 140day leave.

Notifying work of event

In case the empolyer has found a replacement for the maternity leave period, the mother, returning to work may have feelings of guilt and shame for returning to work before it was expected.

In Estonian parental leave system, miscarriage, stillbirth and neonatal death do not seem to be considered. There is no certain scenario to follow.

No additional job-security protection at work.

In case the employer has found a replacement for the maternity leave period, they might be inclined to choose them over the returning mother.

Grief can hinder productivity.

Parents may feel an expectation for "being over" the loss.

Parents may find it difficult to deal with emotions of grief at work leading to additional shame at work for not dealing "well enough".

Colleagues may not know how to act in talking with the bereaved parents.

Some parents face difficulties returning to work and to the work environment to the extent of deciding to change the job.

Bureaucracy

Very difficult to obtain sufficent, adequate and relevant information about procedures and legislation.

For miscarriages and stillbirths death certificate is not issued.

For stillbirths, perinatal death notice along with perinatal death reason is issued.

Neonatal deaths are registered in the digital registry, the death certificate is issued by a doctor.

For miscarriages and stillbirths there is only a note in the mother's medical history, nothing in the father's.

It is good to have support (either from a family member, friend or a social worker) in dealing with necessary procedures.

Hospital social worker can offer some help and guidance dealing with the needed documents.

Families can feel themselves stuck in loopholes, as child-loss can be seen as an edge case for the state system.

Parents need to deal with many different institutions (even when dealing with medical matters).

Miscarriages and stillbirths do not get registered as citizens, therefore do not have a full identity code or registered name.

Miscarriages and stillbirths get a modified identity code. Neonatal deaths receive full identity code and registered name.

The preference of the parents is not considered. There is no option, only set rules based on medical differentiations.

Returning to everyday

Parents need to deal with baby clothes and products. Some deal with it immediately, others may need months.

The new child should not be perceived as a replacement.

Many (if not most) families go on to have successful pregnancies. Following child(ren) are called rainbow children.

Next pregnancy(ies) highly affected by the previous stillbirth's grief, guilt and fear.

Many parents feel exhausted and lack motivation.

important to analyse the reasons for the loss in order to avoid difficulties in the new pregnancy.

Younger children should also be told about the loss before them.

The new pregnancy may be under stronger observation.

Information on how to proceed is difficult to find, no clear stucture to support and guide

As the parents have prepared for the child's arrival, their internet behaviour has indicated to targeted ads, e-mail lists and online groups that they are expecting. These messages and content do not stop without changing the settings personally.

Overarching pain-points

People have difficulties relating to the loss and grief of the parents as they had no actual connection with the child that was lost.

The way parents are talked to and treated is of utmost importance, but people have different capabilities in this regard. This can lead to extremely negative experiences that emphasise the feeling of failure, guilt and shame.

The feeling of the body failing the mother – failing the purpose of a female body. This creates shame and a sense of failure that can underline the rest of the experience. The changes in the body after birth can be difficult to handle.

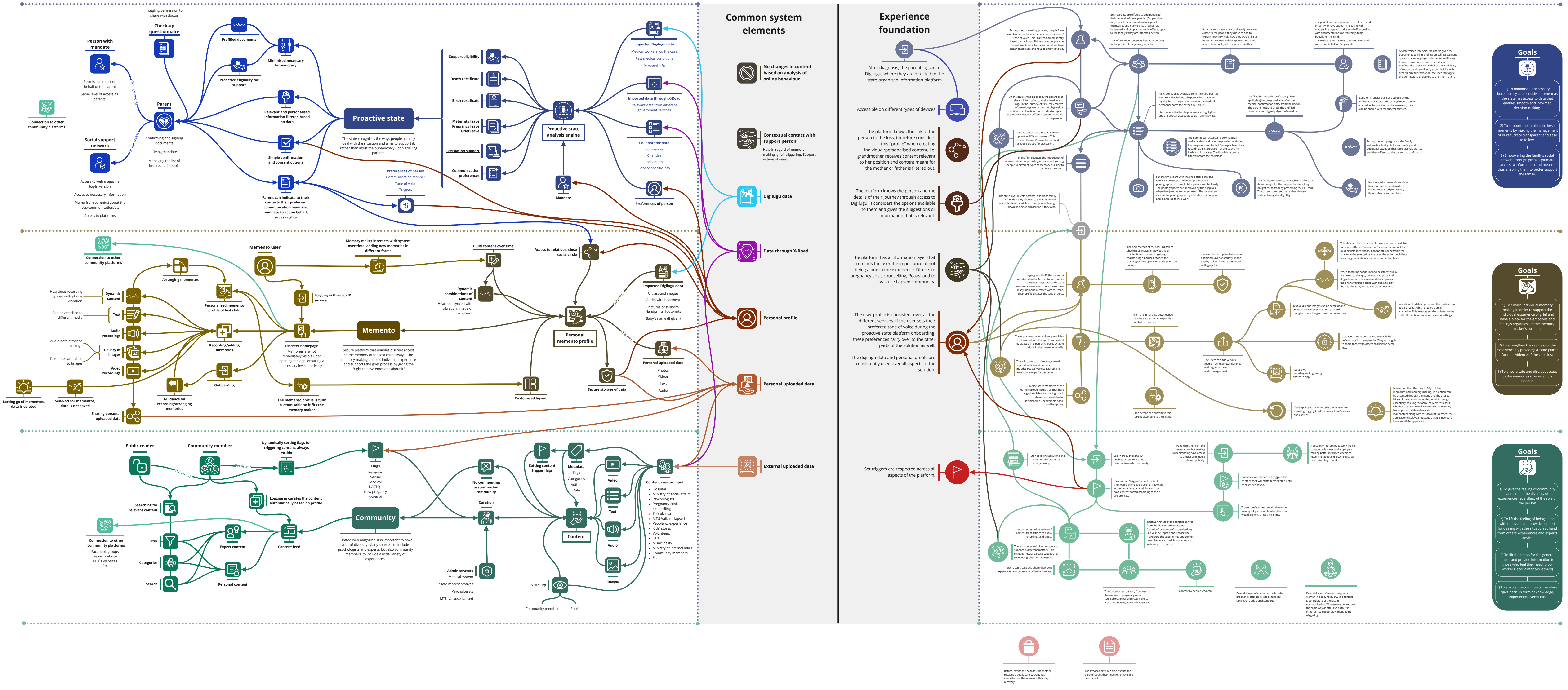
Many bereaved parents can be unintentionally influenced to make decisions before they are ready. This should be avoided in all aspects.

Emotions such as guilt and shame expressed towards themselves, the child, partner (mother/father), further family, medical personnel, friends, colleagues, etc. can shadow and complicate the experience.

Appendix 2: Bilateral systems map of the design concept

Systems view

User journey view



Toggling permission to share with doctor

Check-up questionnaire

Person with mandate

Permission to act on behalf of the parent

Same level of access as parents

Connection to other community platforms

Giving mandate

Parent

Confirming and signing documents

Giving mandate

Managing the list of loss-related people

Giving access

Social support network

Access to web magazine log-in version

Access to necessary information

Memo from parent(s) about the loss/communication/etc

Access to platforms

Prefilled documents

Proactive eligibility for support

Minimised necessary bureaucracy

Relevant and personalised information filtered based on data

Simple confirmation and consent options

Parent can indicate to their contacts their preferred communication manners, mandate to act on behalf, access rights

Preferences of person
Communication manner
Tone of voice
Triggers

Proactive state

The state recognises the ways people actually deal with the situation and aims to support it, rather than insist the bureaucracy upon grieving parents.

Support eligibility

Death certificate

Birth certificate

Maternity leave
Pregrancy leave
Grief leave

Legislation support

Communication preferences

Proactive state analysis engine

Mandate

Imported Digilugu data
Medical workers log the case
Past medical conditions
Personal info

Imported data through X-Road
Relevant data from different government services

Collaborator data
Companies
Charities
Individuals
Service specific info

Preferences of person

Connection to other community platforms

Arranging mementos

Memento user

Memory maker interacts with system over time, adding new memories in different forms

Build content over time

Access to relatives, close social circle

Heartbeat recording synced with phone vibration — **Dynamic content**

Can be attached to different media — **Text**

Audio recordings

Audio note attached to image
Text notes attatched to images
— **Gallery of images**

Video recordings

Personalised memento profile of lost child

Logging in through ID service

Recording/adding memories

Discreet homepage
Memories are not immediately visible upon opening the app, ensuring a necessary level of privacy

Memento

Secure platform that enables discreet access to the memory of the lost child always. The memory-making enables individual experience and supports the grief process by giving the "right to have emotions about it"

Dynamic combinations of content
Hearbeat synced with vibration, image of handprint

Personal memento profile

Collecting

Imported Digilugu data
Ultrasound images
Audio with heartbeat
Pictures of stillborn
Handprints, footprints
Baby's name (if given)

Collecting

Personal uploaded data
Photos
Videos
Text
Audio

Onboarding

Letting go of mementos, data is deleted

Send-off for mementos, data is not saved

Guidance on recording/arranging memories

The memento profile is fully customisable so it fits the memory maker

Customised layout

Secure storage of data

Sharing personal uploaded data

Public reader

Community member

Temporary

Persistent

Dynamically setting flags for triggering content, always visible

Flags
Religious
Sexual
Medical
LGBTQ+
New pregancy
Spiritual

Searching for relevant content

Logging in curates the content automatically based on profile

Connection to other community platforms
Facebook groups
Peaasi website
MTÜs websites
Etc

Filter

Categories

Search

Expert content

Personal content

Content feed

Community

Curated web magazine. It is important to have a lot of diversity. Many sources, to include psychologists and experts, but also community members, to include a wide variety of experiences.

No commenting system within community

Curation

Administrators
Medical system
State representatives
Psychologists
MTÜ Vaikuse Lapsed

Setting content trigger flags

Metadata
Tags
Categories
Author
Date

Content

Visibility
Community member
Public

Video

Text

Audio

Images

Content creator input
- Hospital
- Ministry of social affairs
- Psychologists
- Pregnancy crisis counselling
- Töötukassa
- MTÜ Vaikuse lapsed
- People w/ experience
- Kids' stores
- Volunteers
- GPs
- Municipality
- Ministry of internal affirs
- Community members
- Etc.

Common system elements

No changes in content based on analysis of online behaviour

Contextual contact with support person
Help in regard of memory making, grief, triggering. Support in time of need.

Digilugu data

Data through X-Road

Personal profile

Personal uploaded data

External uploaded data

Experience foundation

After diagnosis, the parent logs in to Digilugu, where they are directed to the state-organised information platform

Accessible on different types of devices

The platform knows the link of the person to the loss, therefore considers this "profile" when creating individual/personalised content, i.e. grandmother receives content relevant to her position and content meant for the mother or father is filtered out.

The platform knows the person and the details of their journey through access to Digilugu. It considers the options available to them and gives the suggestions or information that is relevant.

The platform has a information layer that reminds the user the importance of not being alone in the experience. Directs to pregnancy crisis counselling, Peaasi and to Vaikuse Lapsed community.

The user profile is consistent over all the different services. If the user sets their preferred tone of voice during the proactive state platform onboarding, these preferences carry over to the other parts of the solution as well.

The digilugu data and personal profile are consistently used over all aspects of the solution.

Set triggers are respected across all aspects of the platform.

During the onboarding process, the platform asks to choose the manner of communication / tone of voice. This is altered automatically based on the input. This ensures people who would like direct information wouldn't have sugar-coated use of language and vice versa.

Both parents are offered to add people to their network of close people. (People who might need the information to support themselves and make sense of what has happened and people that could offer support to the family if they are informed better).

The information content is filtered according to the profile of the journey member.

Both parents (separately or shared) can leave a note to the people they chose to add to explain how they feel / how they would like to be communicated with or approached. A set of questions will guide the parents in this.

The parent can set a mandate to a close friend or family to have support in dealing with matters like organising the send-off or dealing with documentations or returning items bought for the child.
The mandate gets access to related data and can act on behalf of the parent.

At determined intervals, the user is given the opportunity to fill in a follow-up self-assessment questionnaire to gauge their mental well-being. In case of worrying results, their doctor is notified. The user is reminded of the availability of support and can directly access it. Like with other medical information, the user can toggle the permissions of doctors to this information.

On the basis of the diagnosis, the parent sees relevant information to their situation and stage in the journey. At first, they receive information given to them at diagnosis + additional explanations and articles to explain the journey ahead + different options available to the parents.

All information is available from the start, but the journey is divided into chapters which become highlighted in the person's view as the medical personnel notes the entries in Digilugu.

Steps related to the chapter are also highlighted and are directly accessible to do from this view.

Pre-filled birth/death certificates (when applicable) becomes available after the medical confirmation entry from the doctor. The parent needs to check the prefilled document and digitally sign confirmation.

Send-off / funeral plans are guided by the information chapter. The arrangements can be started in the platform as the necessary data can be shared with the funeral services.

There is contextual directing towards support in different matters. This includes Peaasi, Vaikuse Lapsed and Facebook groups for discussion.

In the first chapters the importance of memento/memory-building is discussed, guiding people to different types of memory-building to choose their own.

The parents can access and download all available data and recordings collected during the pregnancy and birth (US images, heart-beat recordings, pictures taken of the baby after birth, etc) in one set. The list of data can be filtered before the download.

During the next pregnancy, the family is automatically eligible for counselling and additional attention that is pro-actively started and then offered to the parents to confirm.

For the time spent with the child after birth, the family can request a volunteer professional photographer to come to take pictures of the family. The photographers are approved by the hospitals when they join the volunteer team. The parent can choose the photographer by their description, photo and examples of their work.

The family (or mandate) is eligible to take back items bought for the baby to the store they bought these from by presenting their ID-card. The parents can keep items they choose without losing the eligibility.

Necessary documentations about financial support and available leaves are started pro-actively. Parent checks and confirms.

The state layer directs parents (also close family / friends if they choose) to a memento tool which is also accessible on their phone through downloading an application if they wish.

The homescreen of the tool is discreet, showing an indistinct view to avoid unintentional use and triggering, maintaining a barrier between the opening of the application and seeing the content.

The user has an option to have an additional layer of security on the app by locking it with a password or fingerprint.

This view can be customised in case the user would like to have a different "connection" view or to account for missing data (heartbeat / handprint). For example the image can be selected by the user, the action could be a breathing meditation visual with haptic feedback.

When footprint/handprint and heartbeat audio are linked to the app, the user can place their finger/hand on the screen and the app uses the phone vibration along with audio to play the heartbeat rhythm to enable connection.

Logging in with ID, the person is introduced to the Memento tool and its purpose – to gather and create mementos even when there hasn't been many memories created with the child. Their profile dictates the tone of voice.

Text, audio and images can be combined to create more complex memos to record thoughts about images, music, moments, etc.

In addition to deleting content, the content can be also "sent", which triggers a small animation. This imitates sending a letter to the child. This option can be removed in settings.

From the initial data downloaded into the app, a memento profile is created of the child.

The app shows content already available to download into the app from medical databases. The person chooses what to include in their memory-profile.

There is contextual directing towards support in different matters. This includes Peaasi, Vaikuse Lapsed and Facebook groups for discussion.

The users can add various media from their own galleries and organise these. audio, images, text.

Uploaded data is private and available by default only for the uploader. They can toggle to share these with others sharing the same loss.

App allows recording/writing/taking photos in-app.

In case other members of the journey upload media that they have tagged available for sharing, this is shared and available for downloading. For example hand- and footprints.

The person can customise this profile according to their liking.

If the application is uninstalled, whenever re-installing, logging in will restore all preferences and content.

Memento offers the user to let go of the memories and memory-making. This option can be accessed through the menu and the user can let go of the content separately or all in one go, essentially deleting the account. Memento asks whether the user would like to save the memory back-ups or to delete these also.
If all content along with the account is erased, the application displays a message that it is now safe to uninstall the application.

Stories talking about making memories and stories of memorymaking.

Log-in through digital ID enables access to articles directed towards community.

People further from the experience, but seeking understanding have access to articles and media shared publicly.

A section on returning to work-life can support colleagues and employers making better-informed decisions, lessening taboo and lessening stress over returning to work.

User can set "triggers" about content they would like to avoid seeing. They can at the same time tag their interests to have content sorted according to their preferences.

Public-view user can set triggers for content that will remain respected until cookies are saved.

Trigger preferences remain always on view, quickly accessible when the user would like to change their mind.

User can access wide variety of content from articles to audio recordings and video.

Trustworthiness of the content derives from the clearly communicated "curation" by non-profit organisations like Vaikuse Lapsed and Peaasi who make sure the experiences and content is as diverse as possible and covers a wide range of topics.

There is contextual directing towards support in different matters. This includes Peaasi, Vaikuse Lapsed and Facebook groups for discussion.

Users can create and share their own experiences and content in different formats.

The content creators vary from users themselves to pregnancy crisis counsellors, experience counsellors, artists, musicians, opinion-leaders etc.

Content by people who care.

Essential layer of content considers the pregnancy after child-loss as families can require additional support.

Essential layer of content supports women in bodily recovery. The content is considerate of the loss in communication. Women need to recover the same way as after live birth, it is important to support it without being triggering.

Before leaving the hospital, the mother receives a bodily care package with items that aid the woman with bodily recovery.

The gynaecologist can discuss with the partner about their need for a leave and can issue it.

Goals

1) To minimise unnecessary bureaucracy at a sensitive moment as the state has access to data that enables smooth and informed decision-making.

2) To support the families in these moments by making the management of bureaucracy transparent and easy to follow.

3) Empowering the family's social network through giving legitimate access to information and means, thus enabling them to better support the family.

Goals

1) To enable individual memory making in order to support the individual experience of grief and have a place for the emotions and feelings regardless of the memory-maker's position

2) To strengthen the realness of the experience by providing a "safe-place" for the evidence of the child lost

3) To ensure safe and discreet access to the memories whenever it is needed

Goals

1) To give the feeling of community and add to the diversity of experiences regardless of the role of the person

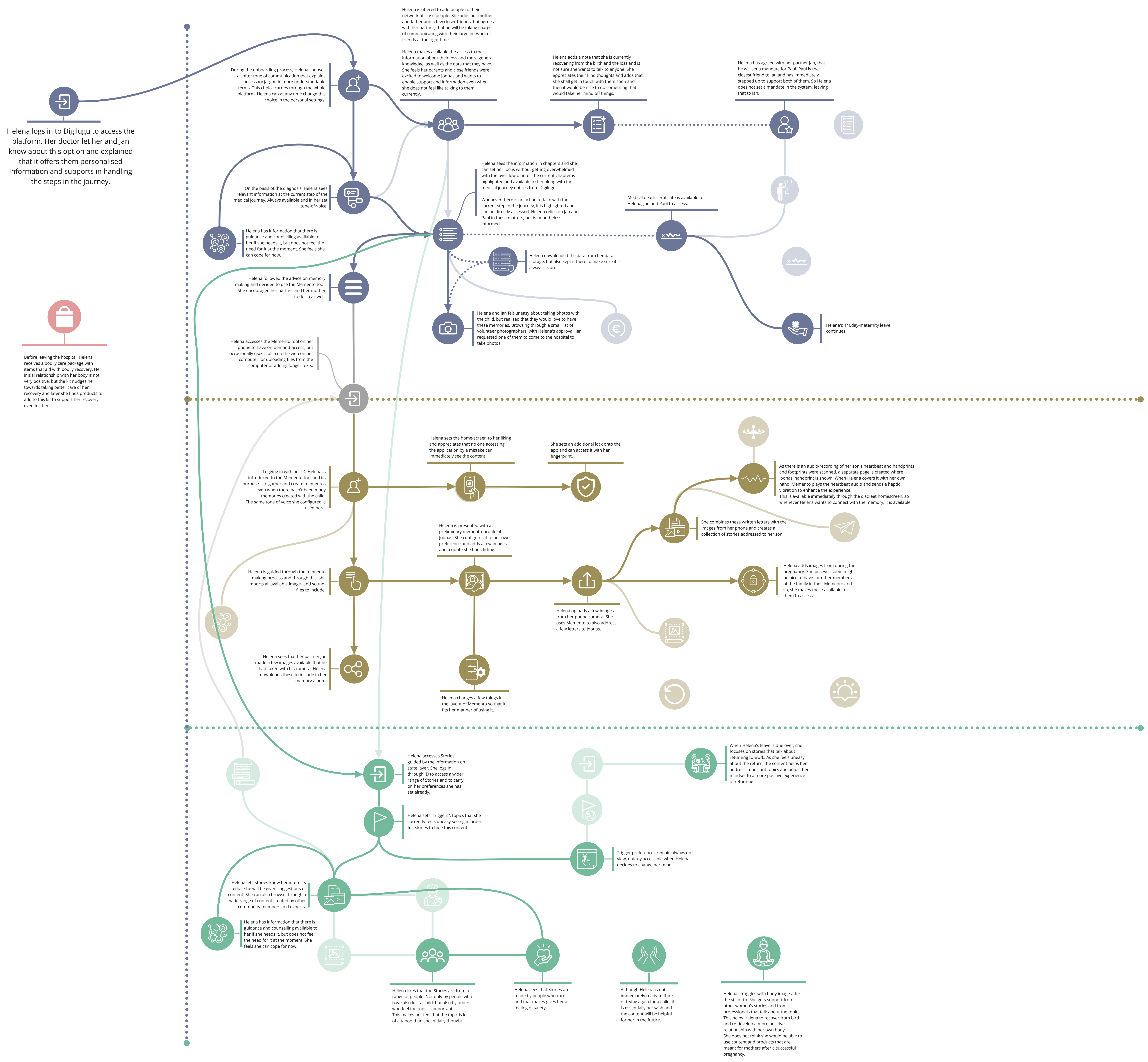
2) To lift the feeling of being alone with the issue and provide support for dealing with the situation at hand from others' experiences and experts advice

3) To lift the taboo for the general public and provide information to those who feel they need it (co-workers, acquaintances, others)

4) To enable the community members "give back" in form of knowledge, experience, events etc.

Appendix 3: Mother's (Helena) journey

Design concept experience



Helena logs in to Digilugu to access the platform. Her doctor let her and Jan know about this option and explained that it offers them personalised information and supports in handling the steps in the journey.

During the onboarding process, Helena chooses a softer tone of communication that explains necessary jargon in more understandable terms. This choice carries through the whole platform. Helena can at any time change this choice in the personal settings.

Helena is offered to add people to their network of close people. She adds her mother and father and a few closer friends, but agrees with her partner, that he will be taking charge of communicating with their large network of friends at the right time.

Helena makes available the access to the information about their loss and more general knowledge, as well as the data that they have. She feels her parents and close friends were excited to welcome Joonas and wants to enable support and information even when she does not feel like talking to them currently.

Helena adds a note that she is currently recovering from the birth and the loss and is not sure she wants to talk to anyone. She appreciates their kind thoughts and adds that she shall get in touch with them soon and then it would be nice to do something that would take her mind off things.

Helena has agreed with her partner Jan, that he will set a mandate for Paul. Paul is the closest friend to Jan and has immediately stepped up to support both of them. So Helena does not set a mandate in the system, leaving that to Jan.

On the basis of the diagnosis, Helena sees relevant information at the current step of the medical journey. Always available and in her set tone-of-voice.

Helena sees the information in chapters and she can set her focus without getting overwhelmed with the overflow of info. The current chapter is highlighted and available to her along with the medical journey entries from Digilugu.

Whenever there is an action to take with the current step in the journey, it is highlighted and can be directly accessed. Helena relies on Jan and Paul in these matters, but is nonetheless informed.

Medical death certificate is available for Helena, Jan and Paul to access.

Helena has information that there is guidance and counselling available to her if she needs it, but does not feel the need for it at the moment. She feels she can cope for now.

Helena downloaded the data from her data storage, but also kept it there to make sure it is always secure.

Helena followed the advice on memory making and decided to use the Memento tool. She encouraged her partner and her mother to do so as well.

Helena and Jan felt uneasy about taking photos with the child, but realised that they would love to have these memories. Browsing through a small list of volunteer photographers, with Helena's approval, Jan requested one of them to come to the hospital to take photos.

Helena's 140day-maternity leave continues.

Before leaving the hospital, Helena receives a bodily care package with items that aid with bodily recovery. Her initial relationship with her body is not very positive, but the kit nudges her towards taking better care of her recovery and later she finds products to add to this kit to support her recovery even further.

Helena accesses the Memento tool on her phone to have on-demand-access, but occasionally uses it also on the web on her computer for uploading files from the computer or adding longer texts.

Helena sets the home-screen to her liking and appreciates that no one accessing the application by a mistake can immediately see the content.

She sets an additional lock onto the app and can access it with her fingerprint.

Logging in with her ID, Helena is introduced to the Memento tool and its purpose – to gather and create mementos even when there hasn't been many memories created with the child. The same tone of voice she configured is used here.

As there is an audio-recording of her son's heartbeat and handprints and footprints were scanned, a separate page is created where Joonas' handprint is shown. When Helena covers it with her own hand, Memento plays the heartbeat audio and sends a haptic vibration to enhance the experience.
This is available immediately through the discreet homescreen, so whenever Helena wants to connect with the memory, it is available.

She combines these written letters with the images from her phone and creates a collection of stories addressed to her son.

Helena is presented with a preliminary memento-profile of Joonas. She configures it to her own preference and adds a few images and a quote she finds fitting.

Helena is guided through the memento making process and through this, she imports all available image- and sound-files to include.

Helena uploads a few images from her phone camera. She uses Memento to also address a few letters to Joonas.

Helena adds images from during the pregnancy. She believes some might be nice to have for other members of the family in their Memento and so, she makes these available for them to access.

Helena sees that her partner Jan made a few images available that he had taken with his camera. Helena downloads these to include in her memory album.

Helena changes a few things in the layout of Memento so that it fits her manner of using it.

Helena accesses Stories guided by the information on state layer. She logs in through ID to access a wider range of Stories and to carry on her preferences she has set already.

When Helena's leave is due over, she focuses on stories that talk about returning to work. As she feels uneasy about the return, the content helps her address important topics and adjust her mindset to a more positive experience of returning.

Helena sets "triggers", topics that she currently feels uneasy seeing in order for Stories to hide this content.

Trigger preferences remain always on view, quickly accessible when Helena decides to change her mind.

Helena lets Stories know her interests so that she will be given suggestions of content. She can also browse through a wide range of content created by other community members and experts.

Helena has information that there is guidance and counselling available to her if she needs it, but does not feel the need for it at the moment. She feels she can cope for now.

Helena likes that the Stories are from a range of people. Not only by people who have also lost a child, but also by others who feel the topic is important.
This makes her feel that the topic is less of a taboo than she initially thought.

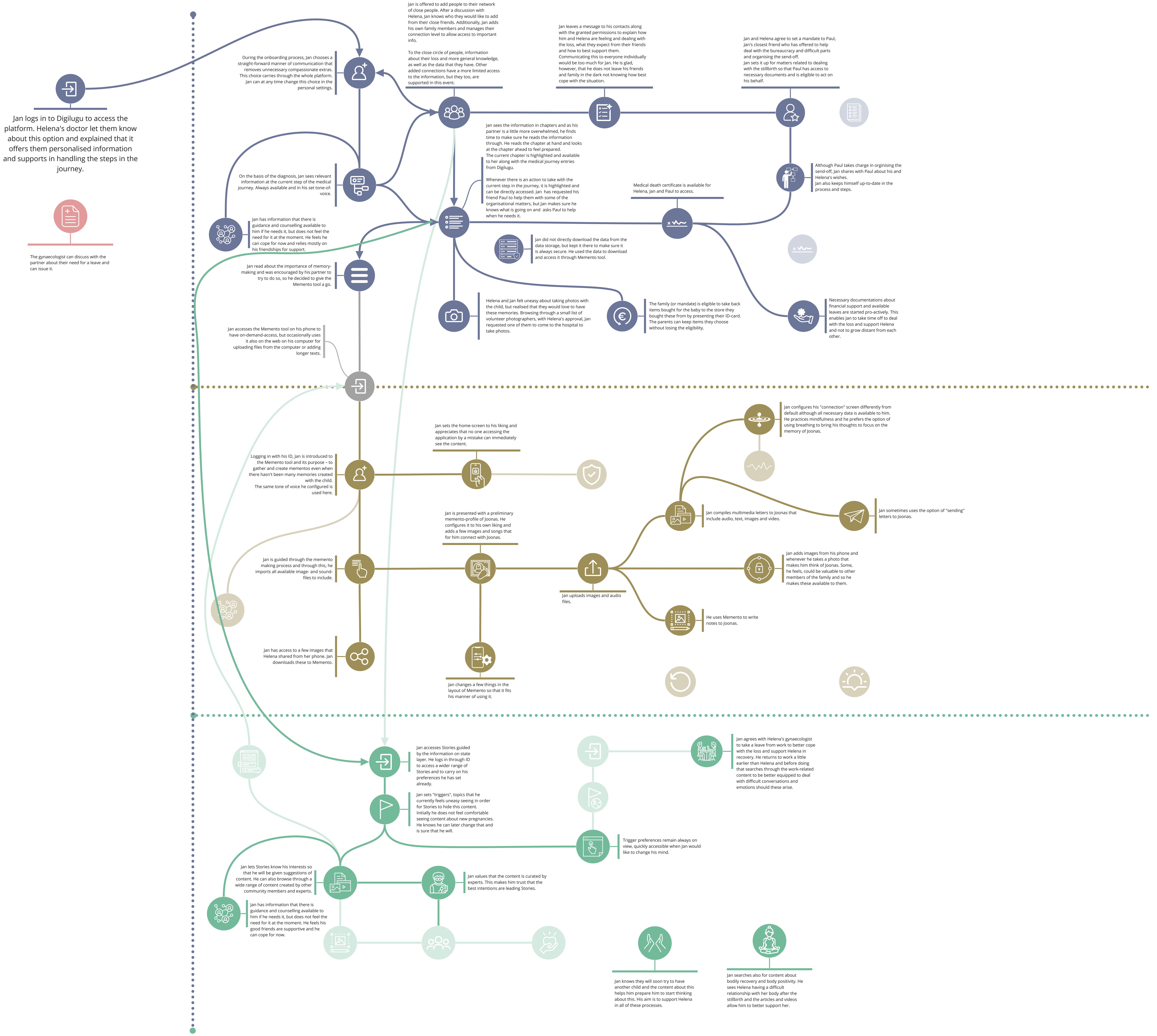
Helena sees that Stories are made by people who care and that makes gives her a feeling of safety.

Although Helena is not immediately ready to think of trying again for a child, it is essentially her wish and the content will be helpful for her in the future.

Helena struggles with body image after the stillbirth. She gets support from other women's stories and from professionals that talk about the topic.
This helps Helena to recover from birth and re-develop a more positive relationship with her own body.
She does not think she would be able to use content and products that are meant for mothers after a successful pregnancy.

Appendix 4: Father's (Jan) journey

Design concept experience



Jan logs in to Digilugu to access the platform. Helena's doctor let them know about this option and explained that it offers them personalised information and supports in handling the steps in the journey.

The gynaecologist can discuss with the partner about their need for a leave and can issue it.

During the onboarding process, Jan chooses a straight-forward manner of communication that removes unnecessary compassionate extras. This choice carries through the whole platform. Jan can at any time change this choice in the personal settings.

Jan is offered to add people to their network of close people. After a discussion with Helena, Jan knows who they would like to add from their close friends. Additionally, Jan adds his own family members and manages their connection level to allow access to important info.

To the close circle of people, information about their loss and more general knowledge, as well as the data that they have. Other added connections have a more limited access to the information, but they too, are supported in this event.

Jan leaves a message to his contacts along with the granted permissions to explain how him and Helena are feeling and dealing with the loss, what they expect from their friends and how to best support them. Communicating this to everyone individually would be too much for Jan. He is glad, however, that he does not leave his friends and family in the dark not knowing how best cope with the situation.

Jan and Helena agree to set a mandate to Paul, Jan's closest friend who has offered to help deal with the bureaucracy and difficult parts and organising the send-off.
Jan sets it up for matters related to dealing with the stillbirth so that Paul has access to necessary documents and is eligible to act on his behalf.

Although Paul takes charge in orginising the send-off, Jan shares with Paul about his and Helena's wishes.
Jan also keeps himself up-to-date in the process and steps.

On the basis of the diagnosis, Jan sees relevant information at the current step of the medical journey. Always available and in his set tone-of-voice.

Jan sees the information in chapters and as his partner is a little more overwhelmed, he finds time to make sure he reads the information through. He reads the chapter at hand and looks at the chapter ahead to feel prepared.
The current chapter is highlighted and available to her along with the medical journey entries from Digilugu.

Whenever there is an action to take with the current step in the journey, it is highlighted and can be directly accessed. Jan has requested his friend Paul to help them with some of the organisational matters, but Jan makes sure he knows what is going on and asks Paul to help when he needs it.

Medical death certificate is available for Helena, Jan and Paul to access.

Jan has information that there is guidance and counselling available to him if he needs it, but does not feel the need for it at the moment. He feels he can cope for now and relies mostly on his friendships for support.

Jan did not directly download the data from the data storage, but kept it there to make sure it is always secure. He used the data to download and access it through Memento tool.

Jan read about the importance of memory-making and was encouraged by his partner to try to do so, so he decided to give the Memento tool a go.

Helena and Jan felt uneasy about taking photos with the child, but realised that they would love to have these memories. Browsing through a small list of volunteer photographers, with Helena's approval, Jan requested one of them to come to the hospital to take photos.

The family (or mandate) is eligible to take back items bought for the baby to the store they bought these from by presenting their ID-card. The parents can keep items they choose without losing the eligibility.

Necessary documentations about financial support and available leaves are started pro-actively. This enables Jan to take time off to deal with the loss and support Helena and not to grow distant from each other.

Jan accesses the Memento tool on his phone to have on-demand-access, but occasionally uses it also on the web on his computer for uploading files from the computer or adding longer texts.

Jan sets the home-screen to his liking and appreciates that no one accessing the application by a mistake can immediately see the content.

Logging in with his ID, Jan is introduced to the Memento tool and its purpose – to gather and create mementos even when there hasn't been many memories created with the child.
The same tone of voice he configured is used here.

Jan configures his "connection" screen differently from default although all necessary data is available to him. He practices mindfulness and he prefers the option of using breathing to bring his thoughts to focus on the memory of Joonas.

Jan compiles multimedia letters to Joonas that include audio, text, images and video.

Jan sometimes uses the option of "sending" letters to Joonas.

Jan is presented with a preliminary memento-profile of Joonas. He configures it to his own liking and adds a few images and songs that for him connect with Joonas.

Jan is guided through the memento making process and through this, he imports all available image- and sound-files to include.

Jan uploads images and audio files.

Jan adds images from his phone and whenever he takes a photo that makes him think of Joonas. Some, he feels, could be valuable to other members of the family and so he makes these available to them.

He uses Memento to write notes to Joonas.

Jan has access to a few images that Helena shared from her phone. Jan downloads these to Memento.

Jan changes a few things in the layout of Memento so that it fits his manner of using it.

Jan accesses Stories guided by the information on state layer. He logs in through ID to access a wider range of Stories and to carry on his preferences he has set already.

Jan agrees with Helena's gynaecologist to take a leave from work to better cope with the loss and support Helena in recovery. He returns to work a little earlier than Helena and before doing that searches through the work-related content to be better equipped to deal with difficult conversations and emotions should these arise.

Jan sets "triggers", topics that he currently feels uneasy seeing in order for Stories to hide this content. Initially he does not feel comfortable seeing content about new pregnancies. He knows he can later change that and is sure that he will.

Trigger preferences remain always on view, quickly accessible when Jan would like to change his mind.

Jan lets Stories know his interests so that he will be given suggestions of content. He can also browse through a wide range of content created by other community members and experts.

Jan values that the content is curated by experts. This makes him trust that the best intentions are leading Stories.

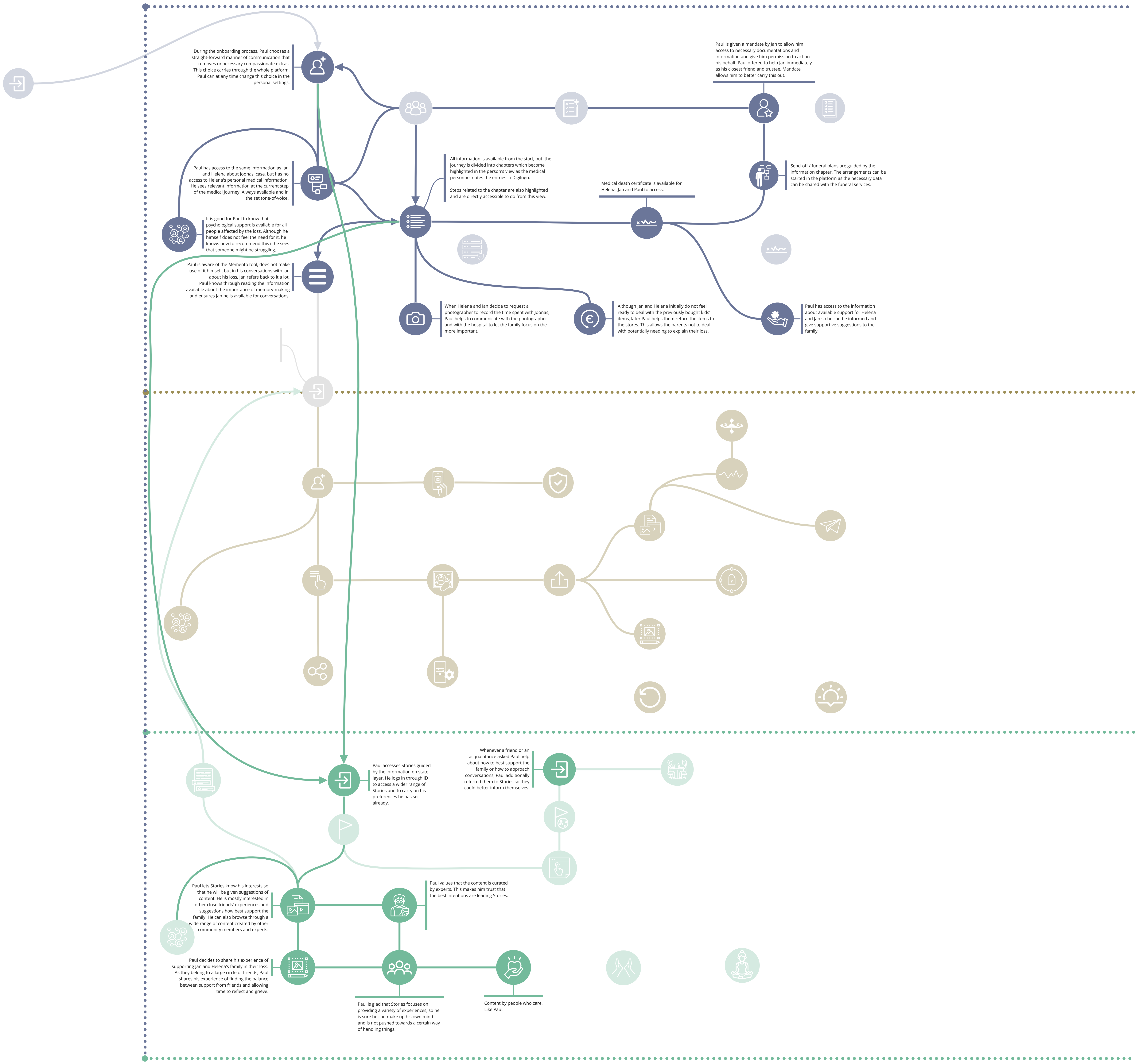
Jan has information that there is guidance and counselling available to him if he needs it, but does not feel the need for it at the moment. He feels his good friends are supportive and he can cope for now.

Jan knows they will soon try to have another child and the content about this helps him prepare him to start thinking about this. His aim is to support Helena in all of these processes.

Jan searches also for content about bodily recovery and body positivity. He sees Helena having a difficult relationship with her body after the stillbirth and the articles and videos allow him to better support her.

Appendix 5: Father's friend's (Paul) journey

Design concept experience



During the onboarding process, Paul chooses a straight-forward manner of communication that removes unnecessary compassionate extras. This choice carries through the whole platform. Paul can at any time change this choice in the personal settings.

Paul is given a mandate by Jan to allow him access to necessary documentations and information and give him permission to act on his behalf. Paul offered to help Jan immediately as his closest friend and trustee. Mandate allows him to better carry this out.

Paul has access to the same information as Jan and Helena about Joonas' case, but has no access to Helena's personal medical information. He sees relevant information at the current step of the medical journey. Always available and in the set tone-of-voice.

All information is available from the start, but the journey is divided into chapters which become highlighted in the person's view as the medical personnel notes the entries in Digilugu.

Steps related to the chapter are also highlighted and are directly accessible to do from this view.

Send-off / funeral plans are guided by the information chapter. The arrangements can be started in the platform as the necessary data can be shared with the funeral services.

Medical death certificate is available for Helena, Jan and Paul to access.

It is good for Paul to know that psychological support is available for all people affected by the loss. Although he himself does not feel the need for it, he knows now to recommend this if he sees that someone might be struggling.

Paul is aware of the Memento tool, does not make use of it himself, but in his conversations with Jan about his loss, Jan refers back to it a lot. Paul knows through reading the information available about the importance of memory-making and ensures Jan he is available for conversations.

When Helena and Jan decide to request a photographer to record the time spent with Joonas, Paul helps to communicate with the photographer and with the hospital to let the family focus on the more important.

Although Jan and Helena initially do not feel ready to deal with the previously bought kids' items, later Paul helps them return the items to the stores. This allows the parents not to deal with potentially needing to explain their loss.

Paul has access to the information about available support for Helena and Jan so he can be informed and give supportive suggestions to the family.

Whenever a friend or an acquaintance asked Paul help about how to best support the family or how to approach conversations, Paul additionally referred them to Stories so they could better inform themselves.

Paul accesses Stories guided by the information on state layer. He logs in through ID to access a wider range of Stories and to carry on his preferences he has set already.

Paul lets Stories know his interests so that he will be given suggestions of content. He is mostly interested in other close friends' experiences and suggestions how best support the family. He can also browse through a wide range of content created by other community members and experts.

Paul values that the content is curated by experts. This makes him trust that the best intentions are leading Stories.

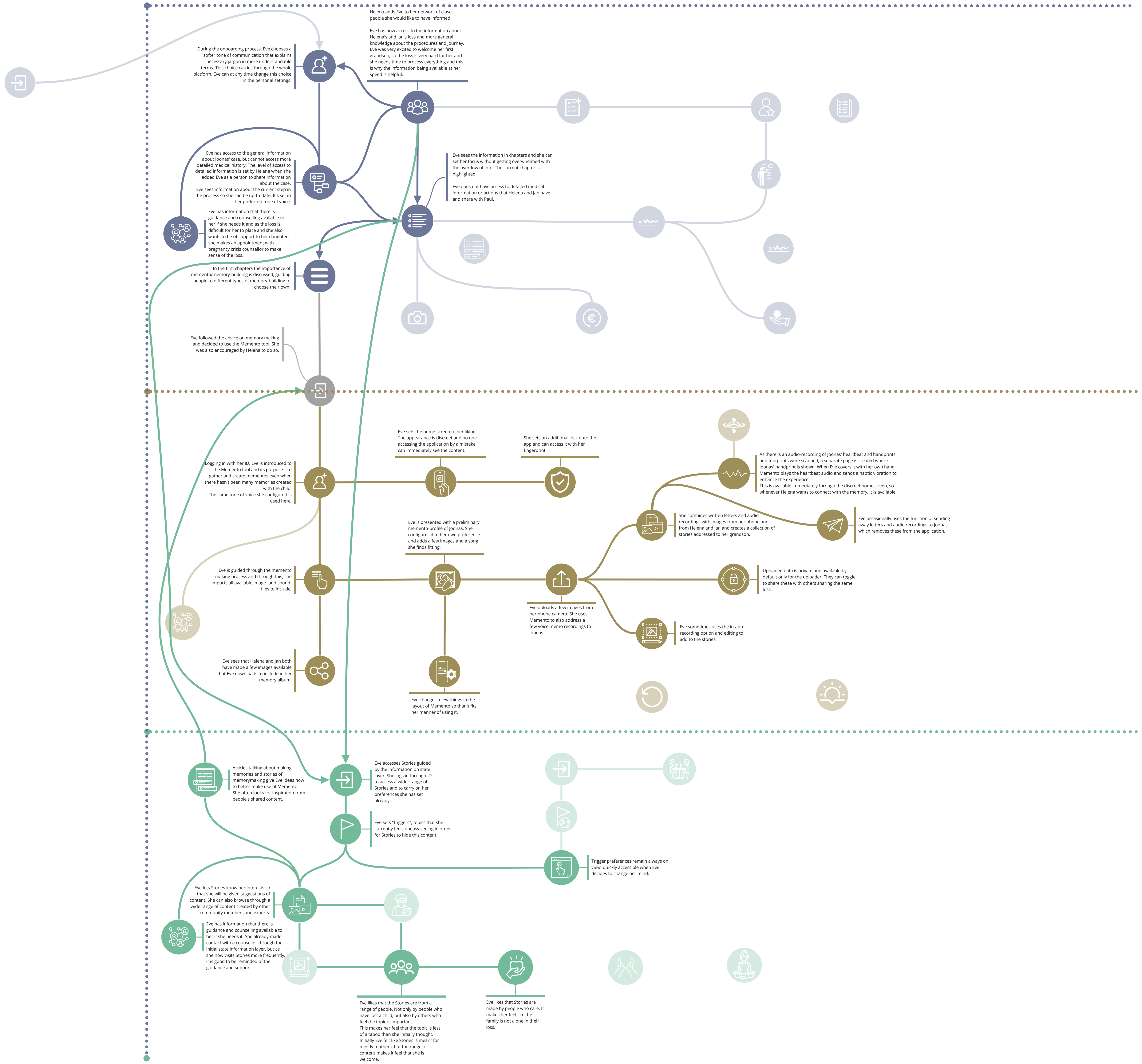
Paul decides to share his experience of supporting Jan and Helena's family in their loss. As they belong to a large circle of friends, Paul shares his experience of finding the balance between support from friends and allowing time to reflect and grieve.

Paul is glad that Stories focuses on providing a variety of experiences, so he is sure he can make up his own mind and is not pushed towards a certain way of handling things.

Content by people who care. Like Paul.

Appendix 6: Grandmother's (Eve) journey

Design concept experience



During the onboarding process, Eve chooses a softer tone of communication that explains necessary jargon in more understandable terms. This choice carries through the whole platform. Eve can at any time change this choice in the personal settings.

Helena adds Eve to her network of close people she would like to have informed.

Eve has now access to the information about Helena's and Jan's loss and more general knowledge about the procedures and journey. Eve was very excited to welcome her first grandson, so the loss is very hard for her and she needs time to process everything and this is why the information being available at her speed is helpful.

Eve has access to the general information about Joonas' case, but cannot access more detailed medical history. The level of access to detailed information is set by Helena when she added Eve as a person to share information about the case.
Eve sees information about the current step in the process so she can be up-to-date. It's set in her preferred tone of voice.

Eve sees the information in chapters and she can set her focus without getting overwhelmed with the overflow of info. The current chapter is highlighted.

Eve does not have access to detailed medical information or actions that Helena and Jan have and share with Paul.

Eve has information that there is guidance and counselling available to her if she needs it and as the loss is difficult for her to place and she also wants to be of support to her daughter, she makes an appointment with pregnancy crisis counsellor to make sense of the loss.

In the first chapters the importance of memento/memory-building is discussed, guiding people to different types of memory-building to choose their own.

Eve followed the advice on memory making and decided to use the Memento tool. She was also encouraged by Helena to do so.

Logging in with her ID, Eve is introduced to the Memento tool and its purpose – to gather and create mementos even when there hasn't been many memories created with the child.
The same tone of voice she configured is used here.

Eve sets the home-screen to her liking. The appearance is discreet and no one accessing the application by a mistake can immediately see the content.

She sets an additional lock onto the app and can access it with her fingerprint.

As there is an audio-recording of Joonas' heartbeat and handprints and footprints were scanned, a separate page is created where Joonas' handprint is shown. When Eve covers it with her own hand, Memento plays the heartbeat audio and sends a haptic vibration to enhance the experience.
This is available immediately through the discreet homescreen, so whenever Helena wants to connect with the memory, it is available.

She combines written letters and audio recordings with images from her phone and from Helena and Jan and creates a collection of stories addressed to her grandson.

Eve occasionally uses the function of sending away letters and audio recordings to Joonas, which removes these from the application.

Eve is presented with a preliminary memento-profile of Joonas. She configures it to her own preference and adds a few images and a song she finds fitting.

Eve is guided through the memento making process and through this, she imports all available image- and sound-files to include.

Uploaded data is private and available by default only for the uploader. They can toggle to share these with others sharing the same loss.

Eve uploads a few images from her phone camera. She uses Memento to also address a few voice memo recordings to Joonas.

Eve sometimes uses the in-app recording option and editing to add to the stories.

Eve sees that Helena and Jan both have made a few images available that Eve downloads to include in her memory album.

Eve changes a few things in the layout of Memento so that it fits her manner of using it.

Articles talking about making memories and stories of memorymaking give Eve ideas how to better make use of Memento. She often looks for inspiration from people's shared content.

Eve accesses Stories guided by the information on state layer. She logs in through ID to access a wider range of Stories and to carry on her preferences she has set already.

Eve sets "triggers", topics that she currently feels uneasy seeing in order for Stories to hide this content.

Trigger preferences remain always on view, quickly accessible when Eve decides to change her mind.

Eve lets Stories know her interests so that she will be given suggestions of content. She can also browse through a wide range of content created by other community members and experts.

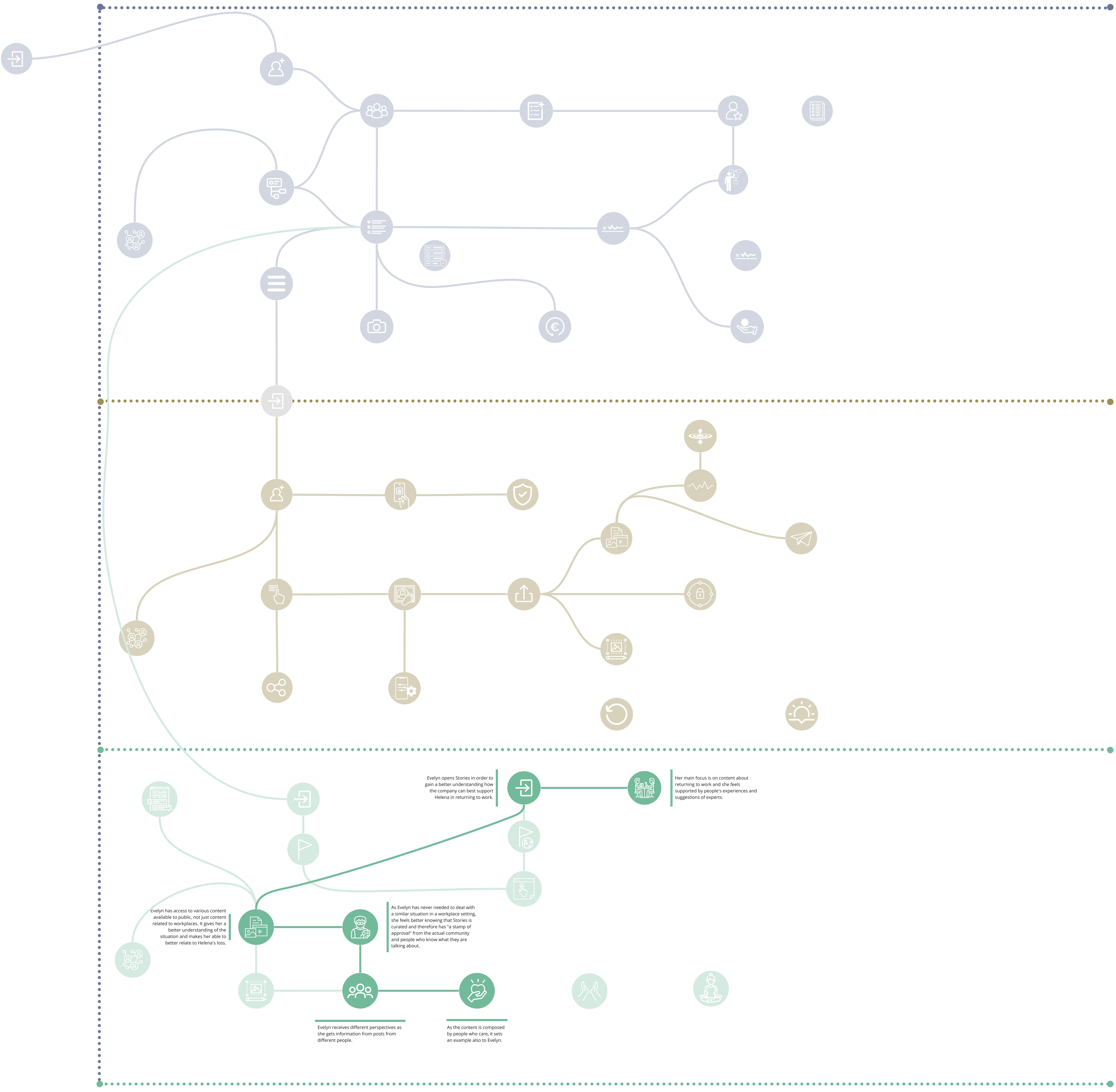
Eve has information that there is guidance and counselling available to her if she needs it. She already made contact with a counsellor through the initial state information layer, but as she now visits Stories more frequently, it is good to be reminded of the guidance and support.

Eve likes that the Stories are from a range of people. Not only by people who have lost a child, but also by others who feel the topic is important.
This makes her feel that the topic is less of a taboo than she initially thought.
Initially Eve felt like Stories is meant for mostly mothers, but the range of content makes it feel that she is welcome.

Eve likes that Stories are made by people who care. It makes her feel like the family is not alone in their loss.

Appendix 7: Mother's HR manager's (Evelyn) journey

Design concept experience



Evelyn opens Stories in order to gain a better understanding how the company can best support Helena in returning to work.

Her main focus is on content about returning to work and she feels supported by people's experiences and suggestions of experts.

Evelyn has access to various content available to public, not just content related to workplaces. It gives her a better understanding of the situation and makes her able to better relate to Helena's loss.

As Evelyn has never needed to deal with a similar situation in a workplace setting, she feels better knowing that Stories is curated and therefore has "a stamp of approval" from the actual community and people who know what they are talking about.

Evelyn receives different perspectives as she gets information from posts from different people.

As the content is composed by people who care, it sets an example also to Evelyn.