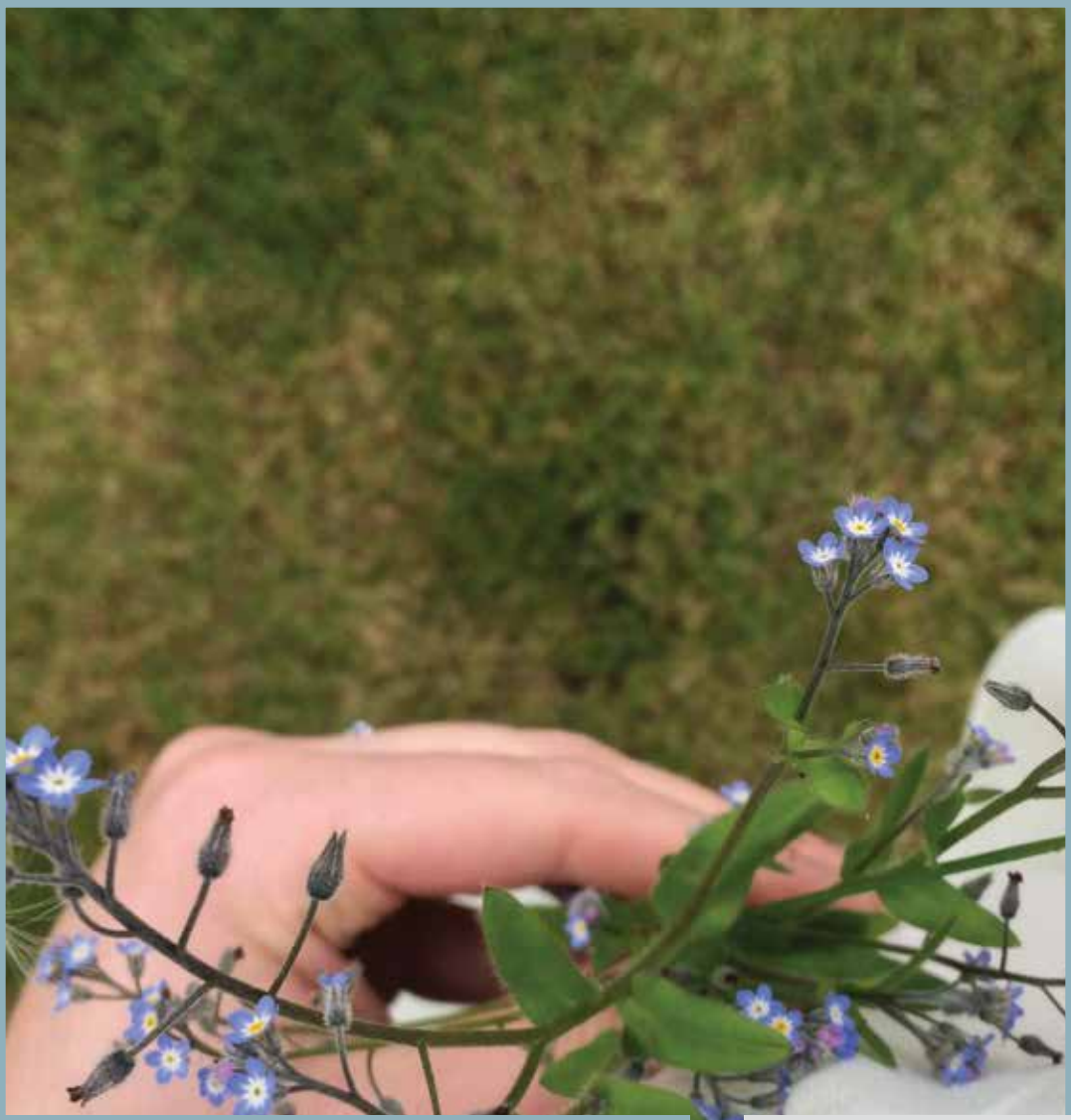

WHEN JOY TURNS INTO SORROW

GLEYM-MÉR-EI
STYRKTARFÉLAG

EDITORS:

Anna Lísa Björnsdóttir, mother
Bjarney Hrafnberg, midwife LSH
Ingileif Malmberg, hospital priest LSH
Þórunn Pálsdóttir, midwife LSH

THANKS / CONTENT / ADVICE & PROOFREADING:

Everyone who shared the stories of their children
Translator: Edythe Laquindanum Mangindin
Layout: Jónas Bergmann Björnsson
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WHEN JOY TURNS INTO SORROW

Each pregnancy comes with hopes and dreams. We envision a new life. We allow ourselves to look ahead. We start preparing for having a baby. We allow ourselves to look forward to it. These dreams and hopes most often arise when the pregnancy has become a reality.

When a baby dies in the womb or in the hospital after birth, these dreams, hopes and expectations die with the baby, and the parents are left grieving their loss.

Some people in your life may feel that the shorter the pregnancy and the smaller the baby, the less and lighter the sorrow. Experience shows that usually this is not the case. Grief needs to run its course; regardless of what stage in pregnancy you were in or the reason behind your loss. The mourning is always deep.

No two individuals experience sorrow the same way. No one can say that one behavior is right and another wrong in what you are or are not feeling. This brochure aims to guide and support you and your family through grieving after the loss of your baby.

Your mind may be filled with questions and reflections, and you will want to share these thoughts and questions with the specialists who will be taking care of you at the hospital. Please do not hesitate to ask them any questions that you may have.

FEELINGS THAT OFTEN ACCOMPANY GRIEF

When expecting parents are faced with the reality of having to say goodbye to their baby, they will likely feel a level of grief and sorrow unimaginable before that moment. Finding out that your baby has died in the womb, or that you must make the difficult decision to induce labor, e.g. due to serious fetal defects, is a horrible shock. No two individuals will respond the same because sorrow is always a personal experience. This is also true for you and your partner. You may react in different ways. When your baby has died, no one reaction is more correct than others and no two situations are the same.

Grief is accompanied by a range of feelings that most people (mothers, fathers, friends, relatives) feel and experience in one way or another. Many people are initially shocked. Thoughts like "This can't be true" clash with the painful reality.

Some people show strong emotions right from the start, crying, asking, looking for answers… others show different reactions, both of which are normal. As reality becomes clearer, you will have to deal with a range of emotions and thoughts.

– *Deep disappointment:* Disappointment that this should have happened. "I was really looking forward to it."

– *Helplessness:* Not being able to do anything to save the baby. You may even feel like you have lost control of your body. "How did this happen? I took such good care of myself."

– *Fear:* It may be related to the thought that "something is wrong with me." Or "Maybe I can't have children. Maybe we are incompatible."

– *Anxiety:* "Will this happen again?" Anxiety can affect your daily life after experiencing loss. At times, everyday tasks can even become overwhelming, and you may worry about taking on the simplest tasks.

– *Guilt:* “Was this somehow my fault?”
“Did I do something wrong during pregnancy?” Remember that feelings of guilt are usually entirely unfounded.
– *Anger:* You may feel anger towards yourself or your family. It may be directed towards the hospital, hospital staff or other people who cared for you during pregnancy. Anger may also be directed at higher powers.

Remember that all of these feelings are normal when grieving and often emerge with the loss of a baby.

PHYSICAL REACTIONS TO GRIEF

Physical exhaustion is common at the start of the grieving process. You may experience shortness of breath, the need to gasp for breath, an increased heart rate, abdominal pain, a loss of appetite, or the feeling of heaviness in the arms. You may have difficulties sleeping, which can occur alongside difficult dreams or nightmares. There are medications available to help you battle insomnia. In the past, sedatives were used to lessen the sorrow, but relying on such medication can delay the natural process of grieving and postpone the pain that you will have to deal with sooner or later. Allow yourself to express your feelings and talk about what you are going through with your partner and/or your relatives and close friends. Experience has shown that putting your feelings into words can be of great help to your well-being. Expressing yourself can work against stress and reduces the risk of sleep disorders. Also, take advantage of the support and advice that is available to you.

POSSIBLE CAUSES

When a baby dies in pregnancy, the first reaction often is to search for explanations. What happened? Your first response may be the thought that you possibly did something wrong, but this is almost never the case. The following are a few explanations of what could have caused the death of your baby.

Miscarriage

Miscarriage occurs in about 15% of confirmed pregnancies. It is estimated that one in three women will lose a fetus at some point during their period of fertility. Miscarriages are most common during the first 12 weeks of pregnancy, but late miscarriages are less frequent. There are diseases that occur in the fetus during the fetal development and placental disorders that lead to illness or death of the fetus and the abnormal development of the placenta and umbilical cord. Serious diseases in the mother, such as diabetes and preeclampsia, which impact the growth and development of the fetus can also be possible causes.

Serious fetal defects

In about 1.5% of cases, a serious fetal defect is detected during a prenatal ultrasound. All women are offered an ultrasound during the 12th and 20th weeks of pregnancy. The ultrasound at 12 weeks results in the diagnosis of a large proportion of fetal chromosomal abnormalities and about a third of the congenital malformations detected during pregnancy. Subsequent ultrasounds can also detect fetal malformations, about 35-40 cases each year. If a malformation is detected, it may be a good idea to look at the chromosome type of the fetus. The most common fetal defects diagnosed during pregnancy are defects in the urinary tract, heart, central nervous system or gastrointestinal tract. Some problems are so serious that the fetus will not be able to survive.

If it is certain that the baby will die shortly after birth due to the severity of the fetal defect, most expectant parents will choose to terminate the pregnancy. During the second half of pregnancy, gastrointestinal tract can be detected which can lead to the death of a baby during pregnancy or shortly after birth.

Multiple pregnancies

Premature births in multiple pregnancies occur for a variety of reasons, and pregnancy related problems are more common in multiple pregnancies, such as hypertension, toxemia, diabetes, blood transfusion between twins (Twin to Twin Transfusion Syndrome), growth delays, among others. Cervical incompetence is more common in multiple pregnancies. Due to uterine distension it is quite common for contractions to start early, thus starting birth, even if the pregnancy is not far advanced.

Cervical incompetence (CI)

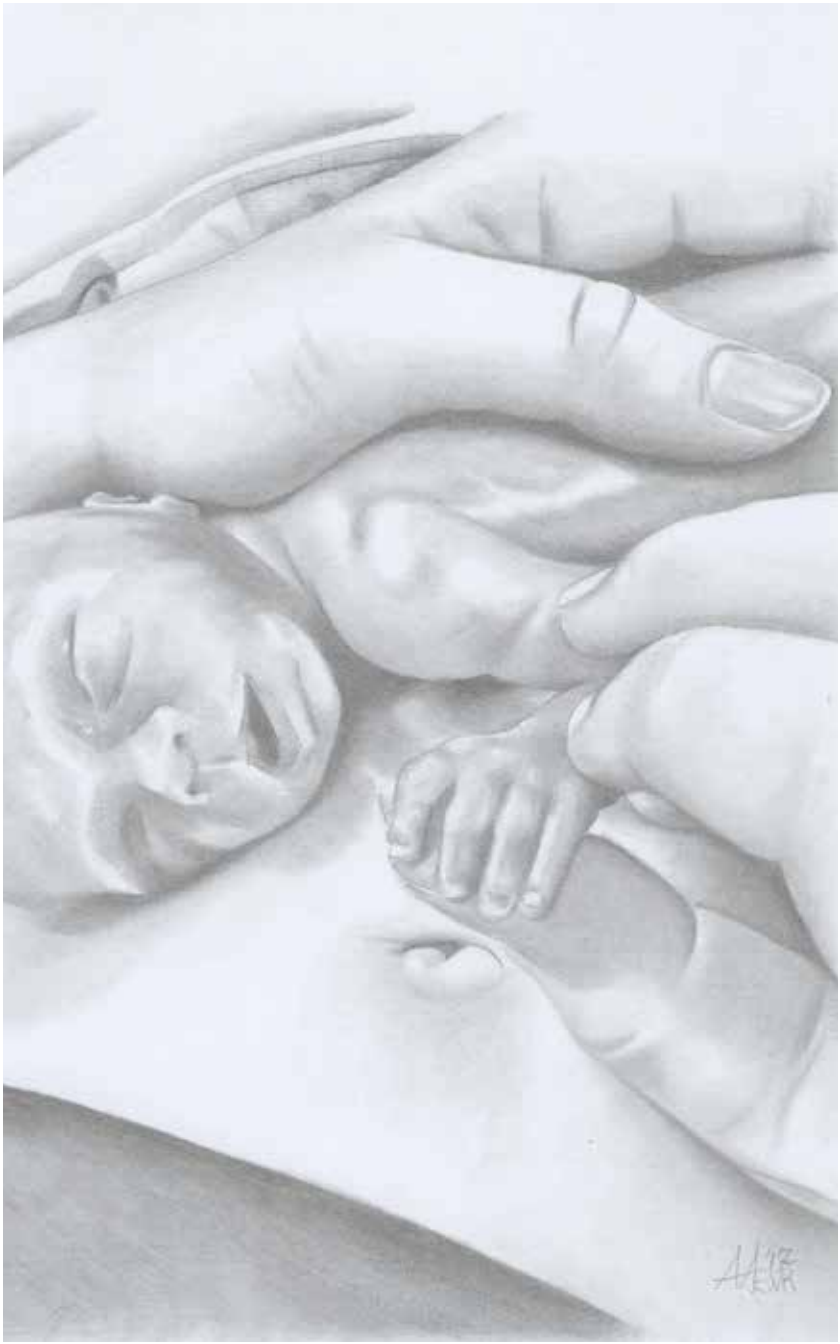
The cervix keeps the baby secure in the womb throughout pregnancy and opens once labor starts. Occasionally, cervical incompetence (CI) can occur, and its symptoms are bleeding or discharge, without contraction or labor pains. In rare instances, a mother may have a congenital defect in the cervix, which may be linked to a prevalent weakening of connective tissues, or there may be a congenital defect in the uterus and/or the cervix of the mother; sometimes, the cervix is naturally too short. Cervical incompetence may also be the result of cervical injury in previous births or after a D&C (dilation and curettage) procedure. Cervical operations, such as conization, can also increase the risk of cervical incompetence. A short cervix may lead to a smaller mucus plug, which protects against infections, containing antibodies (IgA) and other substances that actively protect against infections; therefore, a small mucus plug can lead to easier access for bacteria to enter the uterus and cause infection. Usually, by the time a woman experiences symptoms, it is too late to prevent the baby's birth.

Infection

Infection can travel to the uterus either from the vagina through the cervix or through the mother's blood. An infection in the fetal membranes and uterus is always serious and may lead to a very serious illness in the mother. Administering antibiotics to the mother only partially reaches the fetal membranes, fetus, and uterus, ultimately forcing the medical team to induce the birth of the fetus and placenta to eliminate the infection. Infection in the uterus typically arises following cervical incompetence. When the cervix is normal, infection can also occur if the mother has weak defenses or reduced function of the immune system.

Umbilical cord/Placenta

Umbilical cord complications can occasionally cause the death of a baby, especially when the cord is very long and/or thin, or if it has prolapsed into the mother's vagina. This often has accompanying factors, such as growth restriction due to placental insufficiency. Placental insufficiency can cause the flow of oxygen and nutrition from the placenta to be reduced, which may lead to growth impairment and even to the death of the baby in the uterus. Usually this is due to underlying diseases in the mother, such as toxemia or chronic serious hypertension. The placenta can also come loose from the uterus during pregnancy, with or without visible bleeding, which can even lead to the baby's death.



Drawing by Esther Viktoria

WHEN A BABY IS DIAGNOSED AS DECEASED

Babies are usually diagnosed as deceased in prenatal care appointments or in the maternity ward because movements have been different from normal or have not been felt for some time. The doctor or midwife will start out by listening for fetal heartbeat, and if it is not found, they will do an ultrasound to confirm that the baby has no heartbeat. It is common that you may have thought you felt movements because the baby moves about in the surrounding amniotic fluid even though the baby has died. This can be very distressing. After the death of the baby has been confirmed, the doctor and midwife will speak with you about your pregnancy, your health before the pregnancy, and how the birth will be arranged. After the doctor and midwife have explained and discussed with you the background and possible causes of your baby's death, various tests are performed to assess the mother's condition to try to find an explanation for the baby's death. If labor has not yet started, induction of labor is recommended. If your vital signs and blood tests are within normal limits and you wish to go home, you can do so. However, it is recommended that you return to the hospital within 24 hours as it is not considered preferable to prolong birth longer than this time. For some it can be helpful to go home to reflect upon all that has happened, or deal with obligations at home before starting the birthing process.

WHEN THERE ARE NO ANSWERS

In some instances, the cause for the baby's death is unknown. When that happens the hospital will do an autopsy, chromosome tests, or specific blood tests to help explain or reveal the reasons for the baby´s death. Even the most thorough investigations do not always pinpoint the reason for the death of a baby, and it can be hard to come to terms with not finding an explanation of what happened.

In search of answers, the following tests can be done:

It is up to you what you decide to do. Your doctor will always explain why each test is considered important, but you must feel comfortable with that choice. The recommended tests vary depending on the mother's health, family history, gestational age or previous history of loss.

- *Detailed and accurate story*
  Recent trauma, injury, unexplained symptoms or infections may be helpful in reaching a conclusion.
- *Physical examination of the baby*
  This is a traditional pediatric examination that looks for abnormalities in the baby´s appearance.
- *Samples from the mother*
  Signs of infection, blood type incompatibility between mother and baby, autoimmune diseases, diabetes, drugs/substances that can affect the baby as well as other factors that affect the mother's health are most often researched.
- *Placental and umbilical cord problems*
  The placenta should always be examined if the pregnancy ends in miscarriage as the placenta is the main organ that helps the baby to develop and thrive in the womb. The umbilical cord is the baby's lifeline and carries oxygen and nutrients to the baby, and abnormalities of the umbilical cord can reduce the flow of oxygen and nutrients to the baby. A pathologist will examine the placenta, its size, weight, whether there are signs of coagulation defects, damage or poor blood flow. In addition, small fragments are taken from the placenta and from the umbilical cord, which are examined under a microscope. The specialist will also evaluate the umbilical cord, among other things, with regard to abnormal development or attachment of the cord to the placenta, abnormal rotation, knots or cysts.
- *Chromosome tests*
  Chromosome tests are offered and can provide important information. Samples are taken from the baby, placenta and umbilical cord to detect possible abnormalities in the number of chromosomes of the baby, and further studies of the genome are sometimes performed.

AUTOPSY

When an autopsy is performed, a pathologist examines the baby carefully and assesses factors such as appearance and examines the baby internal organs. Samples are taken for tissue analysis and examined in more detail. The tests recommended by doctors to get the most accurate results may vary. It is generally believed that the most useful research is an accurate collection of information about the course of the pregnancy, a detailed pathological examination of the baby, placenta, umbilical cord and autoimmune tests. If you decline an autopsy, it is possible to perform an X-ray of the baby, but the results will not be as accurate.

Duration of testing

Most tests should not take longer than 1-2 days, but the most extensive tests can take several weeks up to a month to obtain complete results since samples often have to be sent abroad. Parents are invited to an interview with an obstetrician when all of the results are available.

Common concerns

There are various reasons why parents choose not to have the cause of the baby's death investigated further, and the most common are the following:

- *Cultural and/or religious reasons.*

If parents have cultural and/or religious traditions that require their baby to be buried within a certain time, it is important to inform healthcare professionals. In many cases, it is possible to complete the tests that needs to be done within this specific time.

- *Lack of information to make an informed decision.*

- *Concerns about how the baby will be treated.*

An autopsy is always performed with the utmost respect for the deceased baby and his or her relatives.

- *The feeling that the results of the tests will not change anything.*

Although the cause of death of a baby is not always found, it is important to know what did NOT cause his or her death, especially when/if the parents decide to have another baby.

Parents are usually content with the decision to have an autopsy performed or have the recommended tests taken in order to obtain results on what caused the baby´s death. When the results are available, they may be able to answer the questions that have caused the parents concern. For parents who want to have more children later, the knowledge that the tests provide can guide them and their healthcare providers in regard to their care during later pregnancies. However, at the same time, the results may lead some parents to decide not to have more children.

It is important to take the time to talk to your partner, family or friends about the options available. It is also important to know that there are no right or wrong decision, but it is important to have all the information so that the family can make the decision that is right for them.

Parents often find a certain comfort in the results of the tests taken on their baby, whether to learn more about what lead to his or her death or to prevent other families from having to go through the same experience.

ARRIVING AT THE MATERNITY UNIT

Birth

Upon arrival at the unit, the midwife will greet you and your partner and accompany you to the room where you will be staying. You will stay in a private room and can have your closest relatives and friends with you as much as you would like. The midwife will discuss the birth process with you in detail, seek to answer any questions you may have and honour your requests during the entire process. The hospital will try to arrange it in such a way that as few healthcare professionals as possible provide care for you during your stay. You will be offered to talk to a priest or minister employed at the unit. If you wish to see a representative from your religion, the staff will assist you in getting in touch with him or her.
When you are admitted to the unit, the midwife will discuss the main points related to labor and birth, such as what can be expected regarding the birth and the baby. Your vital signs will be measured and blood tests will be taken. Women without a Rhesus factor (Rhesus negative) are given an intramuscular immunoglobulin injection to prevent the formation of antibodies, since blood may have been mixed between mother and fetus. To induce labor, medication in the form of tablets is often used to stimulate contractions in the uterus. The most common side effects of this medication are diarrhea and nausea. It is safe for you to have some food at the start of the process, but once labor pains start you will not be able to eat but will be given intravenous fluids. When your cervix is examined for the first time, vaginal stroke cultures are taken and sent to the research lab. Sometimes intravenous medications are given. In addition, rupturing of the amniotic sac may be required, and the amniotic fluid is usually green or brown. The length of this process varies from woman to woman. It often begins with contractions that are tight and close together. When you begin to feel pain during contractions, you may need pain-relieving medication. When the pains have become stronger and have developed

into labor contractions, labor has begun. Induction of labor and the length of time each birth takes varies. In active labor, contractions are often 2-5 minutes apart, with a period of rest between them. Pains are usually strongest above the pubic bone through to the small of the back. During labor, you will be able to use all pain relief options that are available if your situation allows. When dilation is complete, your baby will be born. Stroke cultures will be taken from the baby's skin and sent to the research lab. If appropriate, a blood sample from the umbilical cord will also be taken and sent. Before the umbilical cord is cut, it is recommended to take pictures of the baby that will be sent to the pathologist. Shortly after childbirth, you will be given contraction stimulating medication through an intramuscular injection. After the placenta is delivered, samples will be taken and sent to the lab. You will be able to see the placenta and examine it closely it if you would like. After giving birth, the midwife needs to monitor your uterus in regard to how well it contracts and how much bleeding occurs. If the placenta is not delivered withing 30-60 minutes, it may need to be retrieved. This is done under general anesthesia and the operation itself takes 10-20 minutes.

Seeing and touching the baby

When and whether you want to see the baby is usually discussed with you before the birth. Some of you may be filled with anxiety at this thought. Keep in mind that the picture we have in our minds may be much worse than reality. Many people find that the baby's appearance gives more comfort than a vague idea or image can. The midwife will help you make the decision you feel is best. Before the baby is born, a cooling mattress in a crib will be brought into your room. The cooling mattress enables families to spend more time with their babies. If you request to not see your baby right away, he or she will be placed in the crib. The midwife will assist you in dressing and caring for your baby. Together, you will make a hand and foot impression of your baby and cut a lock of hair (if possible) that you can preserve.

You will receive a memorial box as a gift from the Forget Me Not charity (Gleym mér ei styrktarfélag).
"Losing a baby during pregnancy or in/after birth is one of the most difficult experiences parents go through in their lives. The anticipation and expectations for the life to come are shattered. The time the family spends with the baby after birth is precious, and it is important to create as many memories as possible. These memories can be preserved for years to come as a reminder of the life that never came to be. (GME website)

It is important that you take all the time that you need to say goodbye. Although many find it valuable to use the opportunity and spend time with the baby, the circumstances may be that you make the decision not to see the baby. Everyone has different needs, and each circumstance is different. The midwifes will respect your decision and will help you say goodbye the way you choose.

Photographs

Photographs of the baby, perhaps along with ultrasound photos, snapshots, photos of your pregnancy and other things you can preserve for your memories may become precious to you as time goes by. If you feel unable to take the photographs yourselves, you can ask someone you know and trust to ask your midwife to take some photographs. At this moment, you may find it unlikely and strange that you will want to take, or keep, such pictures; however, you may change your mind later. The midwife can contact the photographer at Landspítali who will come and take pictures of the baby.

Discharge from the hospital

If everything goes well after birth, you can expect to go home within two days. If you wish to take your baby home, you will be offered to take a crib with a cooling mattress with you home. Some parents prefer to take their baby home and spend time with their loved ones. We encourage you to discuss this with your midwife. The midwife and/or pastor will then assist you with the preparation and burial of your baby.

Follow-up

A medical secretary will contact you and offer you an appointment with an obstetrician. During the appointment, the obstetrician will review the results of the tests that were taken and answer any questions that you may have. If the results of the tests are not available, you may need to return at a later date. It can be a good idea to write down any questions you would like answered or anything that you would like explained during the appointment.

COMING HOME

People will grieve in many different ways, and questions like “what should I expect?” and “when will I get better?” are common. Parents can experience alternating feelings and emotions that come and go, and it can be helpful to discuss those feelings with relatives and friends. It can also be a good idea to find different ways to get through the day such as writing down your feelings, joining a support group of parents who have experienced loss or talk to other individuals who have gone through the same thing.

There is nothing wrong with not crying

Most people in mourning have the need to cry; however, tears are certainly no indication of how much you are grieving. Some people find it hard to cry when other people are around, and do not want to be physically touched, while others feel better when they have company and will gladly accept physical contact and closeness. Both are normal. Many find a certain relief after crying. Crying can help you release grief and emotional tension. As time goes by, the need to cry will likely lessen, but this does not mean that you will stop crying altogether. There may be days that are more difficult than others, and you will break down and cry. Do not be alarmed. This is normal. Your friends and relatives will react to your grief in different ways. Some will be openly supportive; others will not mention your loss for fear of upsetting you and bringing you to tears. It can be helpful to keep in mind people mean well and are trying to help you feel better.

There is nothing wrong with being happy

It is healthy and good to experience happy moments while grieving. Happiness and laughter are not an indication that you have forgotten or that you are not mourning properly.

One day may be very different from the next. As time passes from the time of your loss, the days will be marked less and less by sorrow and sadness.

Remember that it is okay to be happy and enjoy life again.

When parents have lost a baby, it can be difficult to distinguish between postpartum depression and grief over time. If you feel as if you cannot handle the situation, have difficulty concentrating in your daily activities, have difficulty sleeping, experience anxiety, experience new health problems or have difficulty communicating with your loved ones, you should seek professional help.

Other children in the home or family

If you have older children, it is important that they be allowed to take part in what you are going through, although this needs to be done on their own terms. Your children are also grieving. Tell your children the truth according to what you feel their age and maturity allow. If you are in doubt as to how best to approach the subject with your children, our staff, such as the chaplain or minister, are experts in these matters. Keep in mind that children can have a very active imagination. When children are kept completely in the dark about sorrow and death in the family, they are quick to fill in the blanks and often create a false reality of their own. Children are sensitive to their parents' feelings. They sense that you are feeling sad.

For this reason, it is better for them to know why you are feeling upset rather than for them to make up their own explanations. Your children may want to discuss the sibling who has died frankly and openly with you. Be prepared. Clear and uncomplicated answers to their questions are the best solution. Give them information on the things they ask about and have the maturity to understand. In the box you will receive from the Forget Me Not charity is a childrens book about pregnancy loss. It can be helpful to read with your children.

Grandparents

The grandparents also mourn the loss of your baby. They grieve for the grandchild they did not get to know and watch grow. They are also grieving because you, their child, are in pain. Just as you do not want your children to suffer, your parents tend to want to protect you against the pain of grief. Allow them a part in your mourning, to relieve your burden as much as they can.

Telling people

Most people choose to tell close family and friends about their loss themselves. Regarding other people in your social circles, it may help to let the message pass from one person to another. You may want to talk to your closest relatives about how you plan to tell the rest of the family, friends and others about your loss.

You decide under what circumstances, with whom and at what time you will discuss the loss. Therefore, it may be a good idea to think about how you will react if people approach you in unexpected situations, such as going to the store or attending a party. Many people have found it helpful by preparing themselves with phrases like “Thank you for showing you care, but I’m not ready to discuss it here/now.”

Returning to work

Many parents dread going back to work after having been away due to pregnancy loss. You may find it difficult to face your co-workers because you fear their reaction as well as your own. You may find it uncomfortable when attention is directed at you. Some people may even avoid talking to you. You can also expect that someone will approach you to share their own story with you.

Some find it helpful to establish contacts at work, who will deal with distributing information to other colleagues. Some like to go on a short visit to their workplace before fully returning to work.

Being around babies and pregnant women

After experiencing baby loss, particularly pregnancy loss, some parents have difficulties being in the company of small children and pregnant women. You may feel that there are newborn babies everywhere, all the time. The birth of a baby to friends or family, children's birthday parties, or other gatherings with children may exacerbate your discomfort and sorrow, so it is understandable that you may try to avoid such circumstances to begin with. In the long run, it is not advisable to avoid children and expecting parents or other situations you find painful. Try to deal with the circumstances you find most difficult one step at a time. As time passes, you will be able to be around small children and expecting parents without being overcome with pain every time.

Please keep in mind that new or expecting parents may find it difficult to meet you after your loss. They fear causing you discomfort and may even avoid meeting you. Try to remember that people mean well.

Words of advice to partners

With loss, you may experience similar feelings as the mother. You also need to have the opportunity to grieve for your baby and learn to live with what has happened. Your life and feelings have changed course due to the expected arrival of your baby and his or her death is a big shock to you. Many know how to take on a supportive role for the mother and set their own grief aside. You may experience concerns about your partner's health and what to expect the future. Feel free to share your feelings with your partner, relatives/friends, seek out support groups, talk to other people who have similar experiences or write down your thoughts /feelings. Many find comfort in having enough work to do and often return to work earlier than the mother, but it is important to give yourself time. It can also be good to participate in activities that calm the mind and nourish the body and soul.

If your feelings and thoughts are beginning to have a negative effect on your daily life and your relationship with your partner and/or if you are experiencing thoughts of hurting yourself, please do not hesitate to see the help of a professional. Realizing that you and your partner do not grieve in the same way can be a helpful step towards understanding and supporting one another. Everyone grieves in their own way. Grief is a lot of work and requires a lot of energy from a person. Show kindness.

THE FINAL FAREWELL

Wake/funeral

One of the things you will be faced with is the wake and funeral for your baby. Although the thought of your baby's funeral is distressing, it will help you put your experience and grief behind you. Most stillborn babies are buried in their own coffin, often in a relative's grave or in a grave of their own. Cremation is also an option; the baby's urn is buried in the same way as stated above. Many parents elect to mark the baby's grave by name, date of birth and date of death. The stillborn baby's name will then be entered into parish registers, along with the names of the parents.

Cemetery in Fossvogur Cemetery

In Fossvogur Cemetery in Reykjavík, there is a special memorial cemetery for fetuses up to the 22nd week of pregnancy. After the autopsy, if one is conducted, the baby will be sent from the research laboratory to the chapel at Fossvogur chapel where the cremation will take place. The idea of the memorial garden in Fossvogur Cemetery is that the baby rests within the walls of the cemetery in sacred soil. The purpose is also to provide you with a peaceful place to visit.

It is important that you and your partner take the time you need to decide how you want to say goodbye to your baby. Talk and listen to each other. The hospital chaplain, minister or midwife can also assist you and your family and give you the guidance you need. You can also turn to your own vicar or representative of the religious or philosophical organization you belong to.

Memorial of life

In the square in front of Fossvogur Cemetery in Reykjavík is a monument to life. The monument is an arched wall with an image of an angel. The words from Psalm 139 of David are engraved on it: "Your eyes have seen my unformed substance." The monument is a symbolic acknowledgment of your gried and loss. It is also, like the memorial garden, thought of as a place of remembrance,

Preserving memories

It may become extremely precious for parents who lose their baby during pregnancy to hold on tightly to their memories of their baby. These memories can be of various kinds. The suggestions mentioned below are all meant to help you process your experience and grief.

Here are some examples on how to honour the memory of your baby:

- Write a letter or a poem
- Keep a diary of your feelings
- Hold a memorial service
- Prepare a plot in your garden with stones/rocks, plants or other things you find appropriate
- Light a candle in the baby's memory
- Use the memorial box you are given for things that remind you of the baby, such as photos from the pregnancy, ultrasound pictures and/or any existing pictures of the baby

Naming the baby

Most parents choose to name their baby. You do not have to do this right away and you may choose not to; take your time in deciding what you want to do. Whatever decision you make is the right one.

Important dates

The day when the baby was born, the day of your loss, and the day when the baby should have been born are important to you. Other members of the family may forget these days as time goes by. Try not to take this too close to heart and remind your loved ones of the dates you hold dear.

Memorial service

October 15th is International Day of Pregnancy and Infant Loss. On this day every year, Forget Me Not charity(Gleym mér ei styrktarfélag) holds a memorial service.

More information can be found on the website:
www.gleymmerei-styrktarfelag.is.

The Grief Center (Sorgarmiðstöð)

The Grief Center (Sorgarmiðstöð) is a collaborative project of grassroots organizations on subject of grief processing. The goal is to support those who are mourning and those who work towards the well-being of those in mourning.

More information can be found on the website:
www.sorgarmidstod.is.

GENERAL RECOMMENDATIONS

It is important to pay close attention to your own well-being. Rest and sleep as well as a healthy and diversified diet are essential for your body. It is also important to try to maintain a routine in daily life and find a suitable physical activity or exercise to your liking, e.g. starting with short walks.

Breast discomfort

You may feel engorgement of the breasts, especially if you have breastfed before or if you are around small children. You can reduce lactation in the following ways: wearing a bra that constricts the movement of the breasts, avoiding stimulation of the nipples, and keeping hot water off your chest. Cold compresses on your breasts may also reduce this engorgement; alternatively, you can use a rag, after first wetting and freezing it. Chilled white cabbage leaves, or other cold compresses on your breasts, are also quite healing. Taking painkillers may also give relief. If you are producing a lot of milk, it can be helpful to hand express a small amount of mile to release some pressure, but the sooner you stop hand expressing, the sooner your body will stop producing milk. It is important to contact a midwife or doctor if you have symptoms such as redness or heat in your breasts and/or if you have a fever of 38.5°C. In a last stage attempt, it is possible to use a medicine (Dostinex) to prevent or reduce lactation, but this medicine is seldom used due to the side effects it may bring.

Pain

It is normal for women to experience contraction in the uterus after giving birth. These contractions can last for several days intermittently. We recommend taking pain-relief medication, using heat packs, going to the toilet regularly to urinate since a full bladder can irritate the uterus.

Postpartum bleeding (Lochia)

Postpartum bleeding is typically a few days of fresh bleeding which should decrease day by day and change in color. Women may have a brownish discharge for up to 6-8 weeks after giving birth. It is important to consult a midwife/doctor if you experience profuse bleeding after giving birth, passing large blood clots or the smell of discharge changes. It is not recommended to use a tampon or medication that is given vaginally. Your period may begin about 2-3 weeks after giving birth but it is more common that it will begin around 2-3 months later. There is a possibility that you can become pregnant even though your period hasn't started yet. It is recommended to take a shower everyday, change your menstrual pad regularly and wash your hands well both before and after trips to the bathroom to reduce the risk of infection. Women who have been sutured can experience itchiness and soreness in the perineum. Stitches will not need to be removed since they begin to absorb after about 10 days.

Urine and bowel movements

It is common for urinary output to increase after birth as the body is getting rid of the accumulated fluid. At first, the bladder does not fully empty after childbirth. It is important to go to the toilet regularly and urinate because women do not always feel the need to urinate, especially if they have had epidural anesthesia or a cesarean section. Women are often worried about bowel movements, but since bowel movements slow down after childbirth, it is common for women to not have a bowel movement for several days. To prevent constipation, it is important to move, drink plenty of fluids and eat a high-fiber diet. It may also be advisable to take laxatives.

Hemorrhoids

It is known that women get hemorrhoids during pregnancy and after childbirth. Hemorrhoid suppositories and creams can be used to reduce symptoms, but at the same time it is important to drink well and keep stools soft.

Sexual intercourse

Starting to have sex after pregnancy loss can spur some very mixed feelings. One of you may possibly feel ready earlier than the other. By openly discussing sex and your feelings with your partner, you will hopefully be able to come to a conclusion which works for both of you. Medically, we recommend that you abstain from sexual intercourse for 6 weeks after giving birth. Each woman must figure out for herself when she is ready for sexual intercourse. If you feel that you are ready before the six weeks have passed, we recommend using condoms due to the risk of infection. In some cases, we will recommend that you put off becoming pregnant again until we have received all results from your examinations; you will be advised on this by your consulting doctor. Ovulation may occur soon after giving birth, so it is important to use contraceptives if you are not planning another pregnancy. Do not hesitate to contact your midwife/consulting doctor if you have any questions.

Cesarean section

Having to go through the process of birth is a difficult thought, and many people ask whether a caesarian section is not a better option. Experience and research show, however, that giving birth is a better and more natural course to take, even when the thought of it is hard. On rare occasions it may be necessary to perform a caesarian section with regard to the mother's health.

After a cesarean section, it usually takes longer to recover physically due to the invasive abdominal surgery. To help your digestive tract return to normal, it is important to drink plenty of water and eat regularly. A highprotein, high-fiber diet is recommended. Physical mobility is important because it stimulates the function of the digestive tract and reduces the risk of various complications after surgery, such as blood clots. Avoid heavy lifting and exercise during the first 4-6 weeks. It is important to listen to your body and act accordingly. After a cesarean section, some women need to take blood thinners, but this is assessed on a case-by-case basis.

A midwife in home care will remove the surgical staples from your incision and the bandage 5-6 days after surgery. The sutures in the incision will dissolve on their own.
The incision must be assessed daily for infection. Contact a midwife or doctor if there are signs of infection such as fever, redness, inflammation and/or fluid leaking from the incision. It is also important to contact us if an incision opens or ruptures or if you experience increased swelling around the incision.

Contact us

If you have any of these symptoms, we suggest you get in touch:
– fever
– acute abdominal pain
– foul-smelling discharge
– heavy bleeding (more than usual menstrual bleeding)
– large blood clots passing from the uterus
– difficulty urinating
– problems with your breasts

Within 2 weeks from birth:

- *Your homecare midwife will refer you to a specialist as needed.*
- *If a problem arises immediately, contact the Antenatal Clinic at Landspítali 543-3253.*
- *If you have an urgent problem during the evening, night or weekend, contact the switchboard at Landspítali 543-1000.*
- *For emergencies, contact 112 at any time.*

After more than 2 weeks from birth:

- *Your Primary Healthcare Clinic during weekday working hours.*
- *Læknavaktin in the evenings from 16:00, s. 1770.*

SUPPPORT SERVICES

Pastoral counselling

The chaplain and deacon at Landspítali University Hospital are consecrated servants of the National Church, and all have further education in pastoral counselling. Their services are available to everyone, to you as well as your relatives, regardless of your religion or life views. Should you so choose, you may receive your own pastor or representative to the unit. The hospital chaplain or deacon can assist you in establishing the connections you prefer. If you do not live near the hospital, our staff may be able to assist you in finding the appropriate resources where you live. The goal of pastoral counselling is to assist people who are dealing with grief and feelings of loss related to traumas in life. When parents lose a baby during pregnancy, the role of the chaplain/ deacon is to support the parents through the initial shock and be of support in their sorrow. He or she does this by talking to the parents, giving advice, and being of assistance regarding any responsibilities they must undertake after their loss. The hospital chaplain or deacon will meet you either before or after the birth, in accordance with your wishes. He or she will seek to answer your questions and give you guidance concerning your other children and relatives, for example. The chaplain, deacon or midwife will inform you of the follow-up care the hospital offers.

Social counselling

Social counsellors at the Women's Hospital at Landspítali will offer you and your partner social counselling and advice, as well as information on maternity leave or other rights. During the week, we will try to respond quickly and see you before you leave the hospital should you so wish; otherwise, we will be in contact once you have returned home, and you and your partner are offered a consultation.

Psychological services

If the grieving process is unusually long and/or difficult and the services mentioned above are not sufficient, an appointment with a psychologist at the Women's Hospital can be arranged. We would like to also point out that it is often possible to get subsidy for psychological services from your trade union and insurance company.

Home care services

If your pregnancy was longer than 22 weeks, you have a right to receive services from a homecare midwife. Often this can be the midwife from your antenatal clinic or the midwife that has provided care during your time at the unit. It is your choice.

Interpretation services

The hospital will provide you with an interpreter.

Maternity/paternity leave

According to Article 12 of the Laws on Maternity/Paternity and Parental Leave no. 95/2000:

Right to maternity/paternity leave in the event of stillbirth and miscarriage "Parents have a joint right to maternity/paternity leave of up to three months in the event of a stillbirth after 22 weeks of pregnancy. In the event of a miscarriage after 18 weeks of pregnancy, the parents have a joint right to maternity/paternity leave of up to two months."
www.althingi.is/altext/stjt/2000.095.html

If a miscarriage occurs before the 18th week of pregnancy, a doctor will provide a medical certificate. The application must be submitted with along with a medical certificate stating the length of pregnancy. When a baby is born alive but dies after birth, the same rules apply as to live-born babies. A pediatrician will sign a death certificate if the baby is born alive.

PREGNANCY AFTER LOSS

Most people who go through losing their baby during pregnancy will try for another baby. You may experience a number of conflicting emotions with your next pregnancy, ranging from immense joy to severe anxiety and fear. You may feel particularly emotional or anxious when you reach the time in your pregnancy you were at when your baby passed away. You may also have difficulties forming connections with the new baby or believing that this pregnancy is going to end well. It is vital that you let other people know how you feel. These feelings may apply to everyone in the family and they are entirely normal. On the other hand, it is important to try to enjoy the pregnancy as much as possible. Keep in mind that in the vast majority of cases, the pregnancy ends with a live and healthy baby.

We are aware that the mourning process takes much longer than the few days you and your partner spend in our care. We know you will be going through a difficult time in which each and every one of you will be dealing with incredible sorrow and grief. We sincerely hope that this booklet will be of use to you and your family on your journey that you are now on and that it will be a source of support and guidance in your grief. No one can take away from you the grief you are going through. This booklet and the following stories from parents will hopefully show you that you are not entirely alone. There are many people who are both willing and able to offer help in your difficult situation.

Do not judge the cloud that blocks the sun,
for it is in the cloud's nature to hide the light.
When the liberating breeze blows it away,
only then can you appriciate how bright the
sun shines.

E.J.

PARENTS' STORIES

Big sister Rósa

Joy, excitement and anticipation are probably the words that best describe my feelings on the way to the labor and delivery ward just over six years ago. For several years, we had been trying to have a baby, so we had waited a long time for the moment that would change our lives forever. However, things did not go as planned. After a difficult birth, a full-term, beautiful little girl was born who was not able to survive and died a few hours later. We had decided on a name before she was born and gave her the name Rósa. A beautiful baptismal service was held in the neonatal intensive care unit, where the immediate family had the opportunity to meet and say goodbye to our little girl. Following her death, a funeral was held. We were advised to limit the number of guests at the ceremony. We both come from large families and have large groups of friends, and many would have come to the funeral to support us. Instead, a moment of silence was held at our church where family and friends had the opportunity to show their sympathy. In retrospect, I think it was the right decision not to have a crowded funeral since we were under a huge amount of pressure and it was demanding being on an emotional roller coaster during this time. A flood of emotions would come without you being able to control them. The mourning process itself did not really begin until after the funeral.

From the very first moment after her death, we promised each other that we would stand together and get through this great loss together. If anything, our relationship strengthened, and we got married just over three months after Rósa's death. At this time, it was a good feeling to be able to rejoice together and start a new chapter of our lives. The first few months were marked by great sadness and at times, it was difficult to get through the days when one could barely control one's emotions. So, I tried to choose the situations that I went into, e.g. I did not attend any gatherings

until I trusted myself to be able to handle the situation.

However, emotions can overwhelm a person, and it still happens today. I can get hurt in certain situations when I think of my little girl. I had a great need to spend time with my wife, and we took good care of each other for the first few months. As time went on, or about half a year, I had a great need to be alone and think things through. The best moments of solitude, when I could think of my daughter, were on short fishing trips out of town. I also visited her often, and there I could express my feelings. A while later, I felt the need to talk to a psychologist about what happened and my experience. My wife and I tried to go together once, but it did not work out, so I changed my psychologist and was very content with that decision.

As is to be expected, in this whole process, after the loss of a baby, there is a great emphasis on the mother but less on the father. The mother is the one who was pregnant and gave birth to the baby, and therefore, she goes through physical changes that take a toll on the soul when a baby is no longer present. It made me very happy to discuss things in private with a professional who focused on me, a father who had just lost a baby and a husband who had been with his wife through a very difficult time. No one can tell you exactly how to behave after losing a baby, how long it will take before you go back to school or work, or where and if you should seek help to deal with the grief. All I know is that you have to do it on your own terms and as you see fit. If you feel well and you feel strengthened, then you are doing the right thing.

Today, we remember Rósa in many ways and think warmly of her. She is a part of our family and her younger siblings get to know her story. We go on family trips to the cemetery, e.g. at Christmas and on her birthday. On her birthday, the immediate family is invited to a meal or cake and enjoys the day together. Despite her short stay, this little girl has changed our lives tremendously. She is always on our minds and even though we have not had the opportunity to live life with her, she lives with us.

Triplets

I finally became pregnant after three in vitro fertilizations, a miscarriage and one transfer of frozen embryos. It turned out that we were expecting triplets, and two of the children were identical twins. When being pregnant with identical twins, the so-called TTTS (Twin to Twin Transfusion Syndrome) can occur at any time. There is a problem in the placenta where one twin gets almost all of the blood flow and the other almost nothing. This happened rather early in this pregnancy. Despite a successful operation in Belgium, the heart of the baby who received too little blood flow gave up after almost 24 weeks of pregnancy. Now, I was carrying one dead baby and two who were alive. It was a strange time. The movements were increasing and it was hard to imagine that not all of them were kicking in my belly. I did not leet the sadness get in the way. I tried to stay calm and optimistic because there were still two living babies growing inside of me.

I ended up undergoing an emergency cesarean section in my 28th week of pregnancy due to umbilical. We had two boys and one girl. It was a strange experience. We considered ourselves so rich because we had two living babies, but they were still "just" two. Congratulations were always accompanied by condolences. All the energy now went into our 750 gram and 1,000 gram babies in the neonatal intensive care unit. However, we took the time to mourn our little angel boy twice, when we saw him and when he was buried. He had deteriorated a lot after being dead for four weeks before birth, but nonetheless, we saw that there was a perfect baby with all his fingers and toes. We decided on his name at the moment, and he was named Bjarni after my father-in-law. The funeral was a small and beautiful ceremony with our closest loved ones. He was laid to rest between my parents-in-law.

After a long and difficult time in the neonatal intensive care unit, everything was stable and the siblings were finally brought home. This is when the grief began.

Thoughts of how it would have been now with all three came up often and suddenly. I found various ways to work through the grief.

I mainly sought strength and information in foreign online forums where people had lost a child due to TTTS. I framed sonograms, and when it came to the first Christmas, I made a special commemorative candle decoration and have done so every Christmas since. I put everything related to our little boy in a baby bag. There is a book to write to him, handiwork that we received and more. Our friends who have also lost a baby shortly after birth gave us angel wings that always go up on the Christmas tree.

What I have found most difficult is that I am often asked whether his siblings are twins. This is especially difficult when strangers ask. In my mind, they are triplets, as I carried and gave birth to three babies at once. Therefore, I have a hard time answering the twin question in the affirmative. But if I say no, it calls for further explanations that one is not always ready to go into. However, it has helped a lot in the grieving process, and in this situation, I can easily talk about what happened and that there should have been three. The children we were so lucky to have alive in our arms are five years old today, and we told them very early that they were triplets and have an angel brother. They are, therefore, aware of him, and he comes up regularly in conversations. He is part of the sibling group.

Alli

Everyone was looking forward to the new family member who was expected around Christmas. The anticipation grew day by day with the older siblings, and we hoped to be able to open the biggest package on Christmas day.

But the reality of the situation was different. I was almost 38 weeks pregnant when I sensed decreased movements and discussed it in my antenatal visit, but everything seemed normal. Then, I felt more contractions and was told that it was normal that during this time of pregnancy that movements lessened as contractions increased. I took it easy but become very restless when I could not feel the small kicks anymore and went straight for an examination.

We did not believe the doctor's words when he told us that the little heart was no longer beating. The reality was bitter, and my existence collapsed in an instant. We were in shock when we went home, but the next day we had to start the birthing process. When we got home, it was very difficult to tell our children that their little brother was dead. However, we received a lot of support from family and friends who came to our house that evening.

Alli lay transverse, so an external cephalic version was attempted. It was not successful, and I ended up having a cesarean section. My husband was allowed to stay with me, and I requested to be able to stay awake and hold Alli in my arms right away. It was an amazing feeling to hold him in my arms, stroking, hugging and kissing him. He was so beautiful and handsome, resembling his big brother in so many ways. He was weighed and measured, and we got his foot and hand imprints on a piece of paper. He was immediately dressed in a suit that both of his siblings had been in. We placed a hat on his head, and we wrapped him in a blanket. That's how his siblings held him when they came to us. We took a lot of pictures that are precious to us today because this period was clouded.

Because of the cesarean section, I had to spend the night in the ward, and when it came time for Alli to go down to the morgue, the thought was unbearable. So, we had time with him that night, and he lay between us all night long, wrapped in his blanket. That time is invaluable to us and gave us the freedom to touch, cry, talk and grieve.

The next few days, we were in a trance. We received good help in planning the funeral. We got to go to the morgue and see Alli almost every day until the coffin was laid. I dressed him in beautiful knitwear and wrapped a blanket around him. He got my favorite necklace, a bracelet with his name, a poem, a picture from his siblings and a letter from me in the coffin.

Aðalsteinn Ingi was buried on a beautiful December day. Many questions came to mind, but "why" was the most common. Later, we learned that he was healthy and well-built, but it appears to have been a placental abruption without any pain or bleeding.

No one is prepared for such a shock, and the blow of the loss was very heavy. However, we were determined to stand on our own two feet and received good help from family and friends who were always ready to listen. It also helped a lot to be able to share our experience with others in the support group at Landspítali. However, Alli's death is not something that one accepts but learns to live with.

Today, Aðalsteinn Ingi is part of the family and has now also become a big brother. Not a day goes by that I do not think of Alli, and he will always be in our hearts and minds.

From a father

How was I supposed to tell people the bad news? Almost a week earlier, we went to the 20 week check-up and life was smiling on us. Everything changed in only two days. Our son was stillborn due to cervical incompetence, which we had no way of preventing. Now we were on our way home, as all physical danger had passed. It was a mild Saturday in April. I had sent an email to my employers saying that I'd be away from work for one day when it was clear that my wife would have to spend a night at the hospital. Now I had the job of telling my family, friends and coworkers about what had happened. The last thing I wanted to do at that moment was to call people to tell them the news. I started out by preparing a list of the people I wanted to tell myself. Then I called my closest relatives but sent emails to the others, describing what had happened and mentioning that we would be in touch when we felt up to it. My wife did the same. I also announced that I would be away from work for the next week, at the least. I was greatly relieved when this was done. There is never a right time for telling bad news.

We were offered support from the chaplain at the hospital, and we received information on psychological assistance after we had returned home.

I never thought that I would ever have accepted such assistance. To tell the truth, I did not think very highly of psychologists and wondered what a chaplain could say to make me feel better. However, this was not the right time for turning down offers of help. I was also worried about my wife. This was a serious blow, and I was not at all certain how she would cope. The psychologist later told me that all these thoughts were normal considering the circumstances. Neither the psychologist nor the chaplain had a magic solution but they pointed out ways for us to deal with our thoughts and questions. What did we do wrong during the pregnancy? Why do I grieve differently from my wife? When would everything return to normal? I am more content today than I had allowed myself to ever hope for, and my opinion of psychologists and the clergy has completely changed. There were like guides. They turned out to be invaluable guides to me and my wife, helping us back on track after our loss.

Oddný Guðríður

My first pregnancy went smoothly and my boyfriend and I had a wonderful daughter in May 2009. When we were expecting a baby for the second time, the pregnancy also went smoothly when we went to the 20week ultrasound. This was the week before Christmas 2010. The equipment in the rural areas is not as good in the Capital Area, and the midwife wanted to send us to an extra ultrasound in Reykjavík since she could not get a proper four-chamber view of the heart. But she was still optimistic that it was nothing serious.

The midwife who examined me at Landspítali told us that our little one had a heart defect and that she wanted a pediatric cardiologist to come and examine it a little better. Ooof… the cold truth dawned on me, and at that point my husband broke down. When the cardiologist had examined the little heart and told us that it was a very serious heart defect called hypoplastic left heart syndrome, I was devastated. I found life so unfair. At this point, it was extremely difficult to digest the information and our options. The next day we returned to LSH, and everything was explained to us again. The heart of our baby was severely damaged.

We faced the most difficult decision we had ever had to make in our lives, a decision that no parent should have to make. It was either to continue the pregnancy and put our little girl through many treatments and surgeries, which were not likely to be successful, or to end the pregnancy. Both options had their advantages and disadvantages. We did not have much time to think, as all this happened around Christmas time, and I had been pregnant for over 20 weeks, and an induced “abortion” was not allowed after the 22nd week. After much arguing, crying and anger over the injustices of life, we decided that it would probably be best to end the pregnancy and trust that the next child would be healthy.

We also had to think about our older daughter. It would not be easy to for her if we had to be far away from home for long periods of time to be at the Children’s Hospital or abroad.

On New Year's Day 2011, we took one more trip to Reykjavík to get one tablet that stops the production of the pregnancy hormone. This was definitely the hardest tablet I have ever had to swallow. On January 3rd, I was admitted. The midwives in the ward did everything for us. Around 4 o'clock that same day, our lovely angel was born 336 grams and 26 cm. We named our little girl Aníta Sif. After the birth, we were able to see our little angel who was so perfect, with her tiny beautiful fingers and toes. We had a good four hours with her and tried to enjoy it as much as possible. The hospital chaplain came and blessed her for us, and we were given a beautiful card of with her hand and foot imprints. We were also offered help from a social worker and a psychologist. Ahead of us was the period of sorrow. We were so fortunate that she was laid to rest beside her uncle in the cemetery nearby, so that we can visit her at any time. For us, it is very important, and we always talk about this little angel as our daughter. Our oldest daughter knows about her, and we often talk about her and bring candles to her grave.

Half a year later, we decided to try to have another child. I soon became pregnant. This time, we decided to have the nuchal fold thickness measured, and due to my previous history, I got more monitoring. Today, we have three children, a lovely three-year-old girl, a threemonth-old boy, and of course, the little angel girl I think about every day and how life would be different if she had come to us just over a year ago.

Kristín Guðmundsdóttir

On April 20th, 2011, I found out I was pregnant, but I already had twin daughters. I had just become an Icelandic Handball champion along with my teammates in Valur, for the second year in a row. At the end of May, I went in for my 12-week ultrasound and got the news that I was pregnant with twins again. The ultrasound also revealed that there were three amniotic sacs but one of them was empty. This meant that it was difficult to determine whether they were identical twins. In twin pregnancies, this is very important since pregnancies with identical twins are considered riskier.

Then, the horrible day came. I woke up on the morning of July 20th, then 18 weeks pregnant, and saw that I was bleeding a little again. I was not stressed about it since it was most likely that the third amniotic sac was trying to detach and could cause bleeding. However, I decided to have my husband drive me to the hospital to have it checked. I was examined and everything looked fine. I had not contractions or pain. The doctor then decided to examine my cervix, and then then the cold reality hit me. I was told that I was about 3-4 cm dilated. I was put in a wheelchair, taken to the hospital room and put straight to bed. I called my husband and told him to bring the children immediately and that the situation was bad. We were then told that we would probably lose the two boys. I did not want to believe it and had full faith that I could just glue my legs together for the next 10 weeks and that everything would work out in the end. Then, the days passed. I did everything I could to prolong the time. I did not get out of bed and did everything that was needed in bed, as fun as it may be. I was so lucky to get one of the newly renovated rooms that the LÍF sponsorship fund raied money for. However, I could not open the windows in my room because I would hear the little newborn babies and their happy parents.

After I had been at the hospital for a week, the heavy blow hit. I had been told that as soon as I got sick with an infection that I would no longer be able to cope and the pregnancy would have to come to an end.

All day, I felt that I was getting very sick. I had cold sweats and heat sweats alternately, but I still did not want to let them know because the thought was horrendous. That evening, I was examined, and my husband and I were informed that the next morning, we would have to give birth. This was terrible news, and the next few hours proved to be very difficult for us. The next morning, I had to give birth to our two boys. Since it was difficult to get the placenta out, I had to have surgery. It was really a great relief to me; I was put under general anesthesia and was able to get out of this miserable situation. Shortly after the operation, we got to see the boys. They were the most beautiful I have ever seen, just as perfect as any other child; eyes, mouth, nose, fingers, toes as everything should be. The only thing that was not completely developed was their lungs. We admired them for a while, and my mom came and saw them too, which was really nice. It's so hard to explain to people what we were going through. It's completely impossible for others to put themselves in our position. This experience is really just tangible for those of us who saw the boys. Others can never fully understand it. Our daughters were five years old at the time. Having to tell them that their brothers were dead was the hardest thing I have ever had to do. To see our children so sad is awful. They immediately asked if they could see the boys, but we refused. They asked us again the next day, and after consulting professionals, it was decided to let them decide. Our daughters thought the boys were perfect. They hugged them, kissed the, and sang for them. Then, together, we said the Lord's Prayer. We found that by seeing the boys, it all became real to them. They had become big sisters. They regularly talk about their brothers today and always include them when counting family members. The boys were buried a week later, and the hospital chaplain took care of everything. He had proved to be a great help to us in this whole grieving process.

Anna Lísa

I'm a mother. I consider myself a mother. I am a wife, a sister, a daughter, a granddaughter, a friend and a mother. But my son does not play with his cousins. He is not with me. I'm a mother with an emptiness in my arms. I think of him every day, and like other parents, my baby is never far from my heart.

I had a son after 21 weeks of pregnancy which had gone very well until the day before he was born. He died because I have cervical incompetence. I felt that I could not accept the fact that my child had died, but after I realized that I did not have to accept it, but "just" learn to live with it - then I found that I could live with this reality. I have no other choice.

When people ask, "Do you have children?" I usually say no. Not because I do not see myself as a mother or because I am in denial about my son, but because I want to answer what lies behind the question. When people ask if you have a child, they usually ask if parenting is a part of your daily life. The correct answer to that question is "no" and it took time to learn that it is okay to answer no.

A child is not a part of my daily life, but I am still a mother. It's hard for me to find that role and its purpose, and it's also hard for the people around me.

After the loss, I got to know the people around me again. The best advice I got was to forgive people who said something thoughtless or hurtful and always keep in mind that they mean well. I also had to learn how to live life anew and I am still working on it. I have a new perspective on what is important to me and how I will allow my grief to change me.

Ragnheiður Ýr

Twenty-two years old and I have two little angels. A little girl and a little boy. The first time I was told that there was no heartbeat, I was 17 weeks pregnant. I was like a ghost and thought nothing but “do I have to give birth to my dead child”. Things went quickly and we managed to spend some time with the little baby. We decided to name her and bury her. I spent many days afterwards in bed, alone. There was no desire to go out among people, let alone answer their questions. I thought it was unfair to know that she was healthy. Why did she die? This bothered me for a long time.

Five months passed and I got pregnant again. It was unexpected but everything went really well. Of course, we were excited, because why should something happen again? After I reached 17 weeks of pregnancy, I was able to breathe easier. A week later, I ended up in hospital with contractions and 3cm in dilation. Once again, we were told that nothing could be done. This time, however, there was one chance. Quickly, emergency stitching was done on my cervix. I had two weeks with my little boy. I was lying in bed and could only get up to go to the toilet. The days were bad, both physically and mentally. Every other morning, I woke up with a sharp contraction. I did everything for him. Then, one day nothing could be done, and our little boy was born after 20 weeks of pregnancy. He was as small as his sister, but more mature. He had a little hair on his head, with such little fingers and toes that I longed to touch every day, just once. As with his sister, we decided to name him and bury him.

This time I was diagnosed with cervical incompetence. The second time we lost a healthy baby, and all because I’m flawed. Once again it was the baby stuff is put away in storage. After that, I found it even harder to go out in public. We disappeared for a few weeks, but we returned refreshed and ready to face life. School and work awaited us. The days varied, and I often wanted to stay home in bed. Why stand up?

There was nothing waiting for me but my sadness. But every day I got up and dealt with everything that awaited me.

No priest, doctor, or psychologist can tell you how to deal with all the emotions that come with this life experience. No one can say how or when the next step will be taken.

For both of us, these are our children, our little angels, although the medical definition is different.

I rarely go to the cemetery, but always on birthdays and Christmas. Here at home, I have made my memories of them, but the decision to give them a name and bury them was very important to both of us. Even today, just over a year after the second loss, emotions and days are mixed. Today I am grateful that they were healthy, I am grateful that we were able to seek help. This experience has taught us to better appreciate what we have, because one day we will have a small child and be able take him or her home.

Pétur Emanúel

It's December. Christmas is just around the corner and preparations along with Christmas magic fills the air. I enjoy being on Christmas break with my beautiful pregnancy bump. I had been waiting a long time for this little miracle of mine. I was so looking forward to new projects and envisioned maternity leave full of joy and happiness. Maternity leave with my son would warm my heart so much. Countless stroller walks, visits, travels and coziness. Everything that excited mom-to-be imagines before her baby comes into the world.

This evening, I feel like my little boy has moved a lot less than usual. Tonight, he does not kick as hard as he used to. I feel worried but tell myself not to stress, the baby is definitely okay. I fall asleep but do not sleep well. When I wake up around five o'clock, I know something is wrong. It's something different. Such a strong feeling. I reach for the heart rate monitor. This device had saved my mental health before the baby started moving a lot. I had not used it for a few weeks, but by chance I checked his heart rate the day before. It was so perfect. But this morning, December 21st, there was only one heartbeat. It was mine. I searched and searched. I reminded myself that my little unborn son had often been a prankster whenever I searched for his heartbeat. But there was none. Nothing. No movement, no heartbeat.

It's about eight o'clock when I finally call the hospital. I say I'm afraid something's wrong. The sceptical midwife says I can now come for an examination anyway. Anyway. She's really going to show me she's smarter than me and find his heartbeat. Much later, far too long, she beings to turn pale. I tell her there's no heartbeat there, although I really hope that I'm wrong. Please, little baby, be alive. Please move, do it!! The midwife calls the doctor.

He turns on the sonar device. I look into his eyes and he does not have to say anything. I know my baby is dead.

Sometime later I go home. Absolutely paralyzed. Completely done.

Wow, how much life hates me. What did I do to deserve this? Why me? Why my child? I have to show up again early the next morning to give birth to my baby. My son who is dead. I do not know if I will survive this. I do not know if I will ever smile again. I sit on my bed and stroke endlessly over my little bump with my son. I eternally wish that this is a dream. A bad dream that I will wake up from as soon as possible. I call my closest friends and tell them the situation. I get stressed out about not having picked a name for my baby. Suddenly, none of the names I had in mind fit my little boy. I look on a website of names where I had tagged names that I thought were beautiful. There it is, directly opposite me. Suddenly, I was able to choose the name of my child in the blink of an eye and realized that all the rings I had gone in when trying to pick a name were unnecessary.

I took a shower and looked at my naked body in the mirror. I looked into my eyes where just a short time before had been so much joy. Now they were full of sorrow. I really enjoyed being pregnant. But now I looked at my naked pregnant body for the last time. Pregnant body with a dead child.

It's December 22nd. I'm going to the hospital and I'm starting to give birth. This is not a birth that ends with a living child. Baby crying and tears of joy. There's not much to motivate me to give birth, even though I'm looking forward to when the baby finally comes into the world. Fifteen hours later, Pétur Emanúel was born after almost 30 weeks of pregnancy. So small, so perfect. So warm and it was so nice to hold him in my arms. In the distance, I hear babies crying. I looked at my little baby and wished so warmly that I too had a crying baby. I dress Péter Emanuel in clothes and enjoy having my baby with me. I could watch him forever. I did not know it was possible to love someone so much. I am also grateful for his existence. For the time I got pregnant. For the memories of him that were created during the pregnancy. For having my little boy with me for a while.

The cradle with the cooling mattress had just arrived at the hospital.

The midwives started to get it started so I could have Pétur Emanúel with me for one night. We sleep side by side, me in bed and him in the crib next to me. When I woke up the next morning, on the Mass of St. Thorlac, right before Christmas, everything was so unreal. I reach for the cradle. Take my son up. He's cool. Ice cold. I have so much respect for this little child. The child who made me a mom. I'm going home from the hospital. Home, with no child. How do you do that? Where do you find the strength to kiss your baby goodbye and leave it? When will I see him again?

Home. The days go by so slowly and quietly. The candlelight is on indefinitely. Christmas passes without me wanting to know much about it. The tears have flowed endlessly.

It's December 30th. The day I finally get to see Pétur Emanuel again. I was looking forward to it. I found it difficult that after this day I would not see him again. There he was in the coffin he came in from the hospital. I hugged him for the last time. Had such a hard time laying him to rest on his beautiful white bed. But I must let go. I put him down and cared for my baby for the last time. Later in the day there was a small and very simple farewell ceremony. I put the lid on the coffin. I took very heavy steps out to the cemetery with the coffin containing what I love most in life. My baby. My baby in a coffin in the ground. This is so completely wrong. Should not even be a possibility. No one should have to follow in these footsteps. But life is fleeting and unfair.

But life goes on. Very slowly and very difficult the first weeks and months. Eventually things start to change, but tears can come so quickly. I went to the cemetery every single day for a long time. Even today, now that Pétur Emanúel is three years old, I find trips to his grave important.

I have made an effort to keep the memory of my son alive and will make sure that my children, whom I have been fortunate enough to have alive, get to know their brother in heaven as much as possible. There will always be one child missing in my family. Big brother living in heaven. But Pétur Emanúel will always be one of us because the footprints left by his little feet are so big in my heart.

Júlía

Last in line, but not least. Today's birthday girl - his mom's birthday girl. Today is a year since these perfect toes and soles were kissed for the first and last time. Today Júlía is one year old.

One stormy morning in December, my husband and I drove down to Landspítali. The day our third child was to be born. Words cannot describe the feelings we experienced that day, but I would like to try.

The midwife who greeted us was lovely and set the tone for the day. Professionalism was impeccable, but at the same time remarkable compassion. I found solace in seeing tears twinkle in her eyes as the end drew near.

Most of the day was calm in our own privacy. Just the two of us bringing our little girl into the world. Strangely, this birth was not different from the other two and far from being unbearable mentally. I found that with each passing moment, the anticipation of holding our little baby in my arms increased. To get to see her, hug her and kiss her.

Then she came. The midwife offered to place her directly in my arms. I shouted yes and found the question preposterous. Time stopped. She was perfect. Ten toes, ten fingers, two ears, one slightly crumpled, flat soles of the feet and the most beautiful little nose the world has ever seen. I remember the midwife asking if it was a boy or a girl. I felt my chest explode with pride when I told her it was Júlía Björgvinsdóttir. For just a few minutes, there was nothing but overwhelming love, happiness, and pride. Stunning pride. For a moment there was no need to think. There was no tomorrow, no worries. Just now. Just her and us. Our little light was so peaceful and beautiful. It was like she was asleep.

Her father walked her around the room and looked at her with the sweetest gaze. With the same expression as when he held Saga and Vilji newly born.

Mindful and surprised. But at the same time as if he had known her all his life. Just a very ordinary father with his little girl.

We spent the rest of the day with Júlía. After a shift change, my mother, our main midwife, took over. She took precious imprints of Júlía's hands and feet. She got to meet her little grandma's girl.
A hospital chaplain also came to us. She lit a candle, took Júlía in her arms and officially named her. She was wonderful and shared an unforgettable and beautiful time with us.

Little by little, an inevitable feeling began to creep in. An excruciating pain crept into my heart. In the evening it was time to say goodbye. The time had come to go home empty-handed with an empty heart. Every single cell in my body called for this moment to be postponed. Just one more kiss. Just one kiss.

We drove home along empty streets. The weather was crazy and no one was travelling. Time stood still. I crawled into bed and just wanted to sleep with my Júlía and never wake up again.

The following days were marked by complete numbness and silence. Empty bump, no kicks, no movements. Breasts full of milk that my baby would never drink. Empty heart. In addition, a new, slightly surprising twist was added. Grieving big sister. Five-year-old Þórunn Saga who thought about and loved her long-awaited little sister who only the angels would be able to enjoy.
One of the most painful feelings that comes with giving birth to a child and not being able to take her home is that the world will never know one of the most important people in our lives. This little post is primarily meant to remind all of our good friends of our invisible child.
I think these sentences from Norwegian poetry combine this so beautifully and well.
You only know our family if you know our invisible child. We are four, but at the same time we are five.

This year has been the most painful and difficult we have ever experienced, but at the same time the most rewarding. Emotions have deepened, not just the bad ones but the good ones as well. We have probably never been happier, as backwards as it may sound. There is only one thing that matters in life.

Our children and our people. Everything else is insignificant. I do not expect the wounds to heal for some time, but it is possible to learn to live with them. These are wounds we carry with pride. Even if given the opportunity, we would never wish that Júlía had not existed. She made us who we are.

We are going to spend our days as four together, but at the same time five. Allow ourselves to cry, miss Júlía, eat something terribly unhealthy and light all the candles we find in the house. We wholeheartedly believe that our angel is watching. We are also convinced that one day we will be together again.

Frigg

Dear friends. It probably has not escaped your notice that the little family and I were expecting a little girl at the beginning of March. I was due on March 5th, and we were pretty excited to have her in my arms.

On Friday a week ago, I went for check-up with our midwife, and to make a long story short we ended up in the women's ward where it turned out that there was no heartbeat from our baby. I had felt a change in fetal movements the night before, but I believed that the girl was resting before she came, and now she was finally coming.

On Saturday morning, March 5th, the birth was induced and our girl came into the world stillborn at 22:45, 13 marks and 52 cm. We were proud parents and found her beautiful and perfect.

We gave our daughter the name Frigg, since the name means, "the beloved one."

This is how Facebook status began in 2016, which my husband I posted shortly after we returned home, childless, from the maternity ward.

This time is still in a bit cloudy. The Facebook announcement was one of those things we had to do, like choose our daughter's last place to rest, cook dinner, BE STRONG, find beautiful clothes to dress her in, walk around the kitchen, choose music for the funeral, wake up in the morning, receive guests and flowers, take a shower, comfort others, choose a funeral day, read a book for our eldest daughter, 4 years old, iron shirts, sleep…. ohhhh…. sleep, it was the only thing I wanted to do and preferably not wake up any time soon and realize once again that the nightmare was the reality.

Unfortunately, we all have grief in common. We know it all too well, deep wounds - I do not need to tell you about it. That's why I want to talk about happiness.

Because then it happened one day that the everyday life took over again husband went back to work, our older child went back to kindergarten, the flowers stopped arriving and Fréttablaðið kept coming, full of news as if nothing had happened. Afterwards, I sat alone on the couch with the baby stuff unused all around me, with my eyes swollen with tears, broken down into little pieces and engorgement in my breasts - NOT SO STRONG.
At this point, I hit rock bottom. I did not have to stay long to realize that I did not want to be he here. I had to find a purpose to it all - If not for our older daughter, my husband, the marriage, the family, myself, then for our daughter Frigg… our daughter who did not get to live. For her, I understood life - that was the purpose! I felt a certain ingratitude in not living life to the fullest and enjoying all that it has to offer - I get to live while others die. But how was I supposed to live, how in hell was I supposed to get off the couch - the hell of the couch! It was so painful to face reality…. then it was just easier to shut everything down and keep sleeping.
My way was to run. I went out every day and ran, sometimes slowly, sometimes fast, sometimes smiling, sometimes tired, sometimes crazy, sometimes crying, sometimes happy. The races were my meditation. Then I was alone with myself and allowed myself to feel all the emotions - during the races I did not have to put on any masks, I did not have to stand up for anyone, just be me with myself and my feelings. And so I began to unravel the complications, little by little, one by one. I took all the unpleasant feelings and terrible memories and allowed them to come to me unhindered, little by little, one by one. For a long time, I managed to transfer all the unbearable feelings that came with the memories of Frigg and the overwhelming disappointments of what would not be, to the positive, happy and good feelings.
Thus, little by little, I was able to care for my daughter without feeling overwhelmed with sorrow and sadness - instead, I began to find my own strength, power and courage, joy, pride and HAPPINESS.

An excerpt from a sketchbook from November 2016 “I was running in the dark up Álfheimar when it suddenly occurred to me that FRIGG IS THE BIGGEST GIFT OF LIFE TO ME and completely ridiculous and it sounds like the fact is the beginning of a new and better life - HAPPIER….. I started crying - with sounds and with a sob - I could not stop crying - I felt I was one step closer to actually finding some purpose - and I started smiling - I can’t stop smiling. “

Facebook status the week of March 5th-9th, 2018. Reflections at the end of the week:

The last two years have been a non-stop emotional roller coaster ride that I think is finally coming to an end.

On Monday, March 5th, it had been two years since our Frigg was born stillborn after a full-term pregnancy. Absolutely perfect, beautiful with her black hair - like her sister. With ten fingers and ten toes, her dad’s ears and her mom’s lips. But we never got to see her eyes - some days I want nothing more than to have been able to look at them, even if only once.

On February 14th this year, our third daughter was born. Absolutely perfect, beautiful with her black hair - like her sister. With ten fingers and ten toes, her dad’s ears and her mom’s lips. And the eyes ... oh those eyes that I can forget myself in forever.

Our goal throughout the pregnancy was to take each day with stoicism and the belief that everything would go well.

Frigg is the strength in my heart, my courage and my driving force.

She did not die in vain - she is and will always be with me and help me through all the days and tasks that life offers.

Thus, I found the strength to carry another child in the shadow of fear, anguish and anxiety due to previous experiences. The strength to deal with difficult memories and the fall of excitement after birth, and last but not least, the strength to allow me to be happy, love and enjoy, and hopefully be the best possible version of myself.

GLOSSARY

Connective tissue – a type of tissue in the body's make-up.

Blood clots – When heavy bleeding occurs, the blood coagulates and forms blood clots.

Fasting – abstaining from food or drink. If anesthesia is necessary, there is the danger of stomach contents entering the respiratory tract, so a 6-hour fast is preferable before every operation.

Induced birth – When birth is initiated, usually because the pregnancy has passed the expected date of birth, or because of the mother or the unborn baby's illness.

Conization – the removal of part of the cervix due to cellular changes or cancer.

Autopsy – After death, autopsy is sometimes performed to search for the reasons for the death. An autopsy is performed by a pathologist and consists of examining the external and internal appearances; samples will be taken from internal organs and microscopically studied. Various special examinations may be performed, depending on the circumstances.

Chromosomes (chromosome test) – Most people have 23 chromosome pairs, i.e. 46 chromosomes, in addition to sex chromosomes. Women have two X chromosomes and men one X and one Y chromosome. There are various deviations in the number of chromosomes, e.g. an extra chromosome or the loss of chromosome, which may lead to the death of the fetus or later diseases in the baby. mmune response – The body develops an antibody as an answer to an unknown object in the body, both bacteria and viruses, and thus gives us protection. When the mother forms antibodies (immunoglobulin) that pass through the placenta, the antibodies can affect the baby. These are usually antibodies against the baby's red blood cells. The most common Rhesus blood group antigen is when the mother's blood group is negative, but the blood group of the father and baby is positive. When this is the case, the mother's antibodies can cause hemolysis and anemia in the fetus.

Congenital anomalies – internal organs that do not develop normally.

Curettage – Sometimes a uterine curettage needs to be performed in order to loosen the placenta or placental tissue from the uterus following miscarriage or birth.

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GLEYM MÉR EI