UNEXPECTED CHILD DEATH
SOCIETY OF NORWAY

When a small child dies

During pregnancy, at birth, or during its first years

To lose a child may well be the greatest tragedy that a person experiences. The death of a child is meaningless. It creates terrible pain, and feels completely unreal. Children should not die. Hours and days of shock and chaos ensure. Dreams and expectations are suddenly dashed. Death marks the beginning of a painful period of time when emptiness, longing and anger reign. Experience shows that it is important to let yourself react and express these strong emotions.It will take time and effort to work through grief over a lost child, but it will not always be so painful.

This booklet is prepared and published by the National Association of Unexpected Child Death [Landsforeningen uventet barnedød, LUB], and Camilla Emilie Hatleskog its primary author. Many thanks go to the parents, the association's advisors and to other expert advisors, for their important insight and contributions. LUB is grateful for the financial support of the Inge Steenslands Foundation. Illustrations: Anne Kristin Hagesæther. Layout: www.studiosju.no. Originally printed in August of 2008. Print run of 6000. Note about the translation: Where appropriate, some Norwegian words have been left in the text and enclosed in [brackets]Translation into English by Julie and Colin MacKenzie, June of 2009

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When the unthinkable happens

This brochure is written for all parents who suddenly experience the loss of their precious, little child. This brochure provides no right or wrong answers as to what you should do, but it can give advice and guidance during an otherwise chaotic and difficult time. It will be an intense experience. A lot will have to be organized and many important decisions will need to be made in the near term. At LUB we have experienced that it can be helpful to know what others have experienced, what was important to them, and what can provide support in similar situations. This brochure shares these experiences.

Whether the child dies in its mother's womb, at birth, or when the child is young, there are many aspects of grief that will be similar. Likewise, all situations are very different. To start with, we describe the facts and experiences associated with how the child died; as stillborn, during birth, or from another kind of unexpected child death. The other sections of the brochure will cover topics such as autopsy [obduksjon], saying a final farewell, and funerals or cremations, along with grieving and working through bereavement. These topics are relevant for all grieving parents, regardless of how the child died.

When a child dies

What is a stillbirth?

A stillbirth [dødfødsel] is defined as the birth of a child with no visible signs of life (Heart activity, breathing or muscle activity) from and including the 22nd week of pregnancy (The World Health Organization, WHO). If the child is born dead before this period, this is termed a late miscarriage [senabort]. The fact that the definition of stillbirth is set at 22 weeks does not mean that it is any easier to loose a child at an earlier stage of pregnancy; experiences of loss, grief and pain are individual.

Every year around 250 children die as stillborn in Norway (approximately 3 for every 1000 children born). About 200 late miscarriages between the 12th and 22nd week of pregnancy have been registered every year for the past few years (The Medical Birth Registry, 2008). Registration is, however, inadequate, especially regarding the earliest miscarriages. Most stillbirths occur during the third trimester before the birth process begins. Anyone can have a stillbirth, and we still understand little about why an apparently healthy child dies inside its mother's womb. In recent years there has been more and more research, and today we know the following:

- Common reasons for stillbirth are placenta deficiency, placenta loosening (abruption), infections, deformation, chromosome anomalies, and umbilical cord complications.
- Approximately half of children have a growth restriction and/or have had an illness.
- In about 25% of stillborn cases in Norway, no cause of death is found.
- More boy than girl babies are still born.

When a child dies during pregnancy

"Sorry, there is no life."

The final confirmation that a child is dead must be made by two doctors. Discovering that the child's heart has stopped beating is terribly painful. Many parents experience physical reactions including trembling, nausea, vomiting, heart palpitations, and dizziness. Many questions arise. "What happens next?" "What will that involve?" "Must there be a child birth?" The whole situation can prove completely chaotic, and it can be difficult to absorb information imparted.

After receiving the traumatic message about the child's death, it is important to take time to sort out your thoughts amidst the chaos. It can be difficult to make decisions. It is therefore important to maintain a good dialogue with health personnel. They have experience with stillbirths and can give good advice. If Norwegian is not your native tongue, please ask for an interpreter. In crisis situations the right words may be hard to find, and it can be difficult to understand all the information you receive or express yourself in a foreign language.

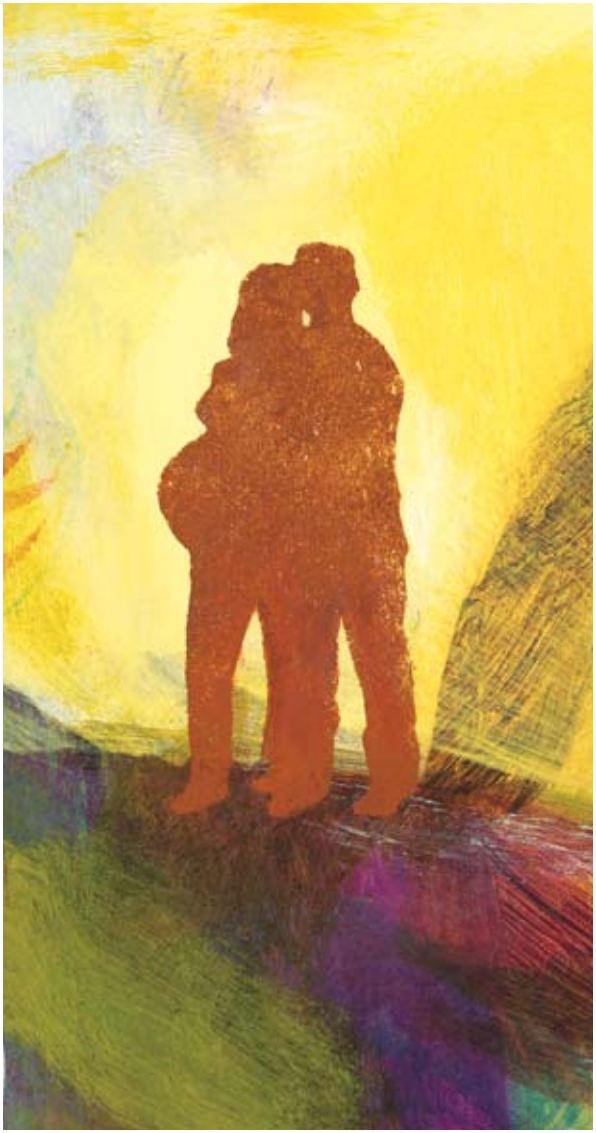
Why does the child have to be born?

Some mothers react strongly when they hear they are expected to give birth naturally to their child. To bear a dead child in their womb can be terrifying. Even if it is not considered dangerous from a medical perspective, many may feel an immediate need to deliver the child by cesarean section. Normally a cesarean section is not recommended. There are many important reasons to go through with a normal birth:

- Parents say afterwards that they are both thankful and relieved that they went through with, and managed a natural birth.
- A birth is natural and strengthens the bond between a mother and child, and this also the case when the child is dead.
- A cesarean section causes major stress on the body, and it takes a longer time to recover from the operation.
- If the child has died form an infection, there is a greater risk of passing on the infection to the mother with a cesarean section.

Should we go home?

Some may find it beneficial to make a trip home for a while before the birth is induced. For others, it is better or necessary for practical reasons to remain at the hospital. Many parents are thankful afterwards that they went home to collect clothes and perhaps a teddy bear for the baby, and they are glad that they also brought their camera. If you do not have this option, you can speak with the hospital staff to see if they can arrange for clothes and a camera to be made available



The quiet birth

Before the birth is induced [settes i gang], both the midwife [jordmor] and doctor [lege] will speak with you. They will explain what will happen and can answer your questions. In addition they will need to take different tests, such as a blood test and a test of the amniotic fluid from the womb. This is done to try and determine what has gone wrong.

To induce the birth, a hormone pill is inserted into the woman's vagina. The birth may proceed quickly, but it can also take many days before the birth actually starts. Many find that this time spent waiting is a strain. However, it can also give you the time you need to prepare for the birth and experience the encounter with your dead child. During this waiting period, it may be important to consider different issues such as what you think about having a birth, and what the child might look like. As a couple, you should discuss this with each other and speak with the staff about what the midwife will do, right after the baby is born. It is important to think through how you will spend this time with your child before you part. Will you agree to an autopsy? Please ask the doctor or the midwife questions, so that you are well prepared for this question when it is asked (Also, see the section about autopsy.).

A birth is never painless; however, the midwife will do everything she can to make a mother comfortable and provide pain relief as needed. It can be a huge ordeal having to push, whilst giving birth to a dead child. "Where will the energy come from?" "What is there to be joyful for, when the child is born?" Even though the child has died, it is still your child that will be born; it is now that you will get to see and get to know your child.

Parents have found that the first moment they see their child is very precious. It is important to get to know the child. Hold, cradle and hug the child while it is still warm. Many parents are very grateful that the child was laid up on the mother's breast just after the birth. For some parents their most valuable memories are a picture of the mother and father together with their newborn child.

When the child dies during birth or soon after

Every year around 50 children die during the first week after birth. Some die right after the birth, while others die after a short or longer period in a respirator, and after attempts at resuscitation. There are many different reasons why a child may die during the first week after birth:

- About half of children that die, do so because of some factor related to the mother, such as pre-eclampsia or eclampsia (poisoning), diabetes, the waters breaking too early, placenta praevia (covering the cervix) and abruption (loosening). Also, there can be complications during the pregnancy, the birth, or delivery.
- Over a quarter of deaths are caused by some form of deformation.
- About ten percent die of breathing and heart interruptions; nearly five percent die from a chromosome deficiency; and only one percent die from infections.
- Around four percent die from poorly defined or unknown reasons.
- About six percent die from reasons other than those stated above.
- More boys than girls die during birth

(The Medical Birth Registry, 2008)

"Sorry, there is nothing more we can do."
When children die during birth or soon afterwards, death can occur under dramatic circumstances. The child may be hurriedly swept away right after the birth to undergo emergency life-saving treatment. Parents may hardly get to see their child before receiving the news that there is nothing more that could have been done to save the child's life. If the child dies under such dramatic circumstances, it can be extra difficult to accept what has happened. It is not unusual to react in anger, desperation, anxiety, indifference or apathy. To hold your dying child is unbearable. All the same, other parents have felt exactly that to hold, hug and smell their child was important. This is how people come to know the child that they are about to lose. Some also wish for the child to be baptized.

If the child is lying in a respirator, it is extremely difficult to recognize that its life can no longer be saved and the respirator must be turned off. Some children pass away quietly and peacefully while sleeping on their parent's chest, after the news has been broken to the parents that the child will not live. Many parents who have held their dying child and stayed with it until it died, whether it was only for a few minutes or for hours, have later been grateful for the time they had together with their baby. It is important to take pictures of the child, both alone and together with the parents and brothers or sisters, while the child is still alive. This creates a shared history during the child's short life and will provide precious memories.

When a child dies during its first few years of life

Every year around 200 children die in Norway during their first four years of life, usually because of illness. Fifty to 60 of these children die suddenly and unexpectedly, among them 15 to 25 from cot death. Others die in accidents or from a sudden illness, such as viral or bacterial infections. (The Central Bureau for Statistics, 2008)

When a child dies suddenly and unexpectedly during its first few years of life, it is normal that the child is delivered to a hospital, regardless of whether or not an attempt at revival is made. The hospital is obligated to notify the police, as such deaths are deemed unnatural, and because they occur outside the hospital (See Norwegian "doctor's law", §41). It is therefore preferable that a forensic autopsy of the child be conducted (You can read more about autopsies on page 10.). The hospital should offer parents an examination of the place of death1. This is important in implementing a particular diagnosis, and to provide parents with information as to what may have happened. Before the child is sent to have an autopsy, a number of tests will be taken of the child. The parents and possibly brothers or sisters will have the opportunity of spending time with the child. At the hospital, the parents and other family members should be offered support during this sudden crisis, in the wake of a death.

If you have lost a child suddenly and unexpectedly, you have experienced a massive shock. Many have strong and painful memories just when their child was found dead. A child dying so unexpectedly is traumatic and can create a strong sense of grief and crisis reactions. It can take a long time for these frightening images to be erased from one's memory. Therefore, it can help to see the child again many times, both before and after the autopsy.

[1] An obligatory offer to examine the place of death, when an unexpected death occurs with newly born and young children, is expected to become a legal right in 2010.

What is cot death?

An apparently healthy child dies suddenly and unexpectedly without any warning. Even with a thorough autopsy and a detailed examination of the circumstances surrounding the death, no explanation can be found as to why the child has died. This is called cot death or sudden infant death syndrome (SIDS).

In the 1980s there was an epidemic of cot deaths in Norway. This peaked in 1989 when the number rose to 145 children, including those over one year old. Since the year 2000, the number of cot deaths has been between 15 and 25 per year.

There has been considerable research done into cot death. Therefore, we know a good deal about the disease's risk and causal factors. Yet, it is still a mystery as to what cot death actually is. No one knows if and when it will occur. Nobody can be blamed for it, when it does happen. Current research into cot death suggests that there are several factors that, when combined, can cause cot death. There are probably both inherited and environmental factors working together that can create the preconditions for the occurrence of a cot death. The mechanics of such deaths are still not understood, but it is thought to involve a slower, irregular breathing pattern and / or heart performance, leading to insufficient oxygen intake, coma and death.

What we know about cot death

- Most children die while sleeping and do not suffer before they die.
- They do not suffocate because of their bed clothes or vomit.
- Cot death occurs most frequently during the first month after the child is born, but can occur as late as two to three years of age.
- It affects children more often if they sleep on their stomach and in families where there are smokers. But it can also affect children who have never slept on their stomachs, or ever been exposed to cigarette smoke.
- It is presumed that genetic factors play a role, which makes some children vulnerable to risk factors that otherwise are not dangerous.
- It affects boys more often than girls.
- About half of the children had a slight infection such as a cold, just before they died.
- It has not been possible to foresee that a child would die, even if the child had a thorough doctor's examination right before the death.

Autopsy

Whether the child has died during pregnancy, during the birth, or has lived for some time after the birth, the question of having an autopsy will be raised. An autopsy can provide information regarding illness or deformations which could have caused death, and also provide information that may be significant in connection with future pregnancies. An autopsy is in many cases an absolute necessity in arriving at a reliable diagnosis, regardless of how or when the child died and especially in cases where the death was unexpected.

In the case of hospital autopsies [sykehusobduksjon], parents have the right to refuse an autopsy. In the case of a sudden and unexpected death of a child after birth, the police have the right to request a forensic examination [rettsmedisinsk obduksjon]. In such cases according to the law, the next of kin must be informed and given the opportunity to comment. However, the police make the final decision. If the police want an autopsy, it is not possible to refuse.

What is an autopsy?

An autopsy can be considered to be a comprehensive surgical operation. All the internal organs are taken out and examined, and tissue samples taken to examine under a microscope. Amongst the smallest children, many of the inner organs are so small that the whole organ is removed for that kind of examination. In the case of a forensic autopsy, first a thorough external examination is carried out, and then the body is x-rayed.

During the autopsy it is normal to make a cut in the middle of the torso from the top of the chest to the abdomen. A cut is also made at the back of the head to allow the brain to be examined. Sometimes a cut will also be made in the thigh in order to take samples of the thigh muscles.

Most of the organs that are removed during an autopsy are placed back again after being examined. Some organs (such as the heart and brain) must be treated in a special fluid before a sample can be taken. This procedure takes so long, that the funeral or cremation will have taken place before the examination is completed. Hence, these organs are incinerated, cremated or buried later. If you wish for more detailed information, you can contact the doctor or department that conducted the autopsy (the pathology department at the hospital or at the forensic institute).

The autopsy should take place soon after the death. This ensures the best possible examination and the best chance to obtain an answer as to what has happened. In larger hospitals it is not unusual for parents to get their child returned on the same day, after the autopsy. At other hospitals, the child may have to be sent away for an autopsy, and so it can take several days before the parents get to see their child again.

The child after the autopsy

The child will be treated with the utmost respect during the autopsy, and there is great consideration given to making the child look as good as possible after the examination. You can be together with and care for the child after the autopsy. You can also take the child home if this is practically possible. The cuts made by the pathologist or forensic examiners will be sewn and taped so as to appear like a wound from an operation.

There may be a little fluid leakage from the wounds; this can be stopped with clean tape. Staff at the ward can assist you, should you so require.

Please speak with the healthcare personnel that have seen the child after the autopsy so that you will be well prepared for how the child will look. Most parents think that it is good to see their child again after the autopsy. They find that their child looks fine.

The autopsy report

In the case of hospital autopsies, an autopsy report requires about three to four months before completion. You will then be contacted to come in for a meeting at the hospital. Forensic examinations can take longer. In the latter case, results are sent to the police, who decide who will be allowed to know the autopsy results. In most cases the hospital where the child was in care, will receive a copy of the autopsy report. The hospital will contact the parents to arrange a meeting. Normally, parents can also obtain the autopsy results by making an application to the doctor who conducted the autopsy or the doctor in charge at the hospital ward. Some parents have chosen to have the pathologist present at the meeting about the autopsy report, and have felt this was a positive thing to do.

Saying your final farewell

In the case of a stillborn, or another sudden infant death, the short time you can spend together with your child is extremely precious. Use it well. Take the time you need to say your farewells. The staff at the hospital can support you in this regard. Parents, who do not speak Norwegian as their native language, can use an interpreter to help make the decisions that they feel are right for them. As parents it is good to be able to look back at the experiences you shared with your child and know that you did everything possible together. Afterwards, these will become good memories. Parents seldom regret what they did with their child, but more likely regret what they did not do.

The majority of people have not seen a dead child before. Some think it sounds terrifying. Many are anxious as to how the child will look. With stillbirths they can wonder if the child will look deformed. Parents with older children worry about injuries or other changes that make them unable to recognize their child. Some are frightened about touching the child or holding it. "What if the skin falls off?" It is easy to think that the less time one spends with the child, the easier it will be to bid it farewell. This may seem like a natural way to protect ourselves. At the same time, it is important for parents to know that this pain will be no greater if they spend time together with their dead child.

Create memories and experiences

Spending time with the child is considered important for the grieving process. It creates a unique relationship to the child, which in the long run will be very precious. You can look at the child, hold it, and hug it. You can also clean and change the child yourselves, dress it in its own clothes, and talk with it, or sing for it. This is important regardless of how big or small the baby is. If there is something you find difficult to do, the hospital staff or chaplain can help you. Feel free to see the child again and again, over many days, right up to the funeral or cremation. This is dealing with the reality of the loss. If the child was born dead, this is the only opportunity you have to create a bond with the child. It is no less important for the father, who has not experienced the same degree of closeness that the mother will have experienced, having borne the child in her womb. Remember that you are still the child's parents, even though that child is no longer alive. Become familiar with how your child looks, dressed and naked. Touch the baby, examine and play with its hands and feet. Also, in the case of other kinds of unexpected child death, it is important to see the child again and again. In that way, you will be prepared for the fact that the child is dead, and you will relate to the child differently than when you first that discovered the child was dead. Some choose to take the child home to say farewell and spend as much time as possible together.

Clothing and other items

Parents of stillborn children have found that it is useful to have two changes of clothes for the baby, so that they can keep one set of clothes as a keepsake. You may also wish to keep a teddy bear or soft toy that the child has had with it in the hospital. For older children, clothing, the baby's pacifier, a soft toy or other personal effects can help form important memories of those last moments together with the child.

Pictures, hand and footprints, and other memories

Take lots of pictures of the child, both on its own and when you are holding and caressing it. Be sure to take family portraits also, including brothers or sisters, grandparents or other family members. You can take pictures of the child both dressed and undressed. Black and white photographs are better at camouflaging any discoloration that may have developed. If it is too hard to take pictures of the child yourselves, you can get help from someone else. Most hospitals have a routine of taking pictures of the child, together with hand and footprints. You can also take a lock of the child's hair, and make a scrapbook with the date of birth, length and weight of the baby.

Siblings, friends, and family

If you have other children, it is important that they also get the chance to say goodbye to their brother or sister. Prepare your other children well, and let them take part in creating memories and the farewells that will take place. Perhaps they could take their own photos of their brother or sister? Invite the grandparents, and close friends and family to say their farewells. Creating shared memories and moments together with the child can help in future, so that they understand what you are experiencing. This should make it easier for the others to relate to you and the dead child afterwards. Remember, they can be important in offering you support in the future.

Name

You should give the child a name if it is stillborn. This gives the baby an identity. It is best to use the name that you may have been thinking of previously. Only children that are alive can be christened or baptized. However, it is possible to hold a ceremony in connection with the naming of the dead child. If you wish, the hospital chaplain can be part of the ceremony, and you can have the baby blessed.

Funerals and cremations

The first days after the death can often seem unreal. Some people feel that they are not quite present, in the situation in which they find themselves. Some just wish to be together with the child, whilst others focus more on practical arrangements. Making plans for the final farewell, funeral or cremation, is one of the last things that you can do for your child. Consider carefully how you would like the ceremony and burial to be. Will you use a funeral home, or will you organize the arrangements yourself? More information is provided in the brochure - for parents who have lost a small child *[Gravferdsveiledning]*.

Casket burial or burial of the ashes in an urn

You must decide whether the child's casket shall be buried or cremated. In the case of a cremation, the ashes will be collected in an urn, which in turn can be buried in a graveyard at some time after the funeral service.

Casket

Make the decision yourselves regarding which casket the child should have. Many parents feel that it is good to have placed the child into its casket, themselves. Choose the clothes the child will be wearing. Maybe you will want the child to have some soft toys with it, a baby's pacifier, or a toy? Siblings and others can also contribute with drawings, poems, farewell letters or other items that have been made or chosen to give to the baby. In this way, the farewell can be personal for those who are involved. You can also consider whether you want an open casket for the ceremony.

Burial place

There are many different burial places to choose among. You can have a traditional grave with a gravestone and planting. Some graveyards have a special area for children. Perhaps you would prefer to use a family plot. Some parents choose to have an anonymous grave or memorial site for their child.

Announcements of the death

An announcement can be placed in the newspaper, either before or after the funeral. If you wish to have an open ceremony, the newspaper announcement can be a good way of informing when and where it will take place. If the ceremony is to be private, an announcement is also a good way to let the world around you know that you have lost a child and are grieving.

Financial support

Ved henvendelse til det lokale NAV-kontoret kan foreldre få dekket inntil 17 952 kroner (2008) til gravferd av barn under 18 år og barn som dør før eller under fødsel. Begravelsesbyrået kan bistå med dette. Det finnes ingen nedre grense for hvor langt svangerskapet var. Folketrygden dekker faktiske utgifter til gravferder som blomster, gravstein og kiste. Utgifter til en eventuell minnestund dekkes ikke.

The mother's body after a birth

During pregnancy, a mother undergoes significant mental and physical changes. After birth her body should return to same state as it was before the pregnancy. When you lose a child during birth, these physical changes can be especially demanding.

After-birth contractions

The womb expands during pregnancy. In the first days following the birth, the womb will contract quite quickly. This can cause pain or so called after-birth contractions, especially in the case of women who had multiple births. It is acceptable to ask for painkillers if you suffer a lot from after-birth contractions. It takes about six weeks before the mother's womb returns to its normal size. Lying on one's stomach after the birth can help the womb to contract more quickly.

Breast pains, when heavy with milk

Giving birth triggers the production of breast milk, even if the child is stillborn. The hospital should give you tablets that stop your breasts from producing milk. However, a little breast milk may be produced during the initial weeks after the birth, and you may experience some breast engorgement pains when your breasts become heavy with milk. It can be soothing to alternate between using a cold compress and standing in a warm shower. You can also take painkillers. If you suffer a lot from breast pains, it can be a relief to use a breast pump or milk your breasts by hand to reduce milk production. However, you should do this with caution, because pumping can also stimulate milk production. Some women pack their breasts by wrapping clothing tightly around themselves. It is important to know about the different methods and to do what you feel is best for you. Use a good support bra at a time like this.

Bleeding

There will be an area in the uterus wall where the placenta was attached, which will produce a bloody discharge during the first weeks after the birth, sometimes called "cleansing". This consists of blood, vaginal discharge (slime), and secretion from the healing wound which is left after the placenta. The amount of bleeding, and how long it continues, will vary for different women. The majority of women experience heavy menstrual bleeding for the first three to four days, which then gradually decreases. Bleeding will become browner later, as bleeding subsides. If the bleeding continues to be heavy during the weeks after the birth, or if you bleed for more than six weeks, you should contact your doctor or midwife.

Digestion and genitalia

It can be painful to go to the toilet after a birth. Genitals can be sore. If you have had stitches, they can sting. It is normal not have a bowel movement for several days, especially if you have been given an enema. Many women get hemorrhoids during birth, and these can be painful when you go to the toilet. If the pain continues, you should contact the hospital where you gave birth. If you experience any ripping or were cut, you will receive stitches after the birth. These stitches will not be removed, as the thread used will disintegrate and eventually disappear by itself. You may experience some tightness and stinging during the first few days after having stitches. Gently rinse the area with lukewarm water,

dried only by air, and this should give you some relief from that pain.

Clenching exercises

During birth, the muscles of the pelvic floor are weakened, and it is important to get these back into shape. In serious cases, weakened muscles of the pelvic floor can lead to urine leakage and involuntary bowel movements. Conditioning these muscles also has implications for your continued sex life. It is recommended that women who have given birth do clenching exercises three times a day.

Weight

Pregnant women normally gain between ten and 20 kilograms during pregnancy, which is equivalent to about 22 to 44 pounds. You may lose as much as ten kilos right after the birth. However, it takes time to lose the rest of the extra weight, especially when you are not breastfeeding. At a time when you are stricken by grief, it can be especially difficult to motivate yourself to be active. Gentle physical activity during this stage after the birth is good for the body and soul. Some women lose their appetite, while other women eat more, seeking comfort. Try to maintain a routine and regular meal times, all the same.

Psychological changes

A postpartum (postnatal) woman will often be easily prone to tears. There are major hormonal changes that take place in the body after a birth, and many women become extremely exhausted. In a postpartum woman without a child, these physical and psychological changes are often stronger. Grief and longing over not having a newborn baby with you, demands a lot, and you may experience a loss of energy.

Sex

After a birth, it is recommended that couples postpone intercourse until the woman's bleeding has totally subsided. For grieving couples, it can take a long time before their sex life returns to normal. For many, it is completely unthinkable to consider sex during the first weeks or months after the baby's death. Men and women will often wish to resume their sex life at different times. In the meantime, some find comfort and intimacy by engaging in sex. Many women feel less than attractive after a pregnancy, and some do not want to have sex because it reminds them of how the dead child was conceived. For some men, the act of sex allows them to vent their grief and strong feelings. It is important to talk about sex and to respect each other's different needs and reactions. This way, it may be possible to find new ways of satisfying each other's needs. Other forms of intimacy and care can be an alternative during a period when sex can be difficult. (More information is available in the brochure "Relationships and grieving after the loss of a child").

Menstruation and new pregnancies

The natural hormonal protection that prevents women from getting pregnant right after a birth disappears when the mother's milk is gone. Ovulation and menstruation normally return about six to eight weeks after a stillbirth. Many wish to be pregnant again as quickly as possible, while others may want to wait until the shock has subsided, and grief has been resolved. There is no correct answer as to what is right. It is, however, important to understand that a new child can never replace the baby that has died. (Read about this subject in the brochure: "A new pregnancy after loss of a child" *[Neste svangerskap etter tapet av et barn]* – so far only available in Norwegian).

Returning to everyday life

Grieving over one's dead child is a healthy and natural reaction. Grief is a process that takes a long time, and everyone reacts differently. However, it will not always be so painful. It is important that you accept the emotions that surface and not to push them aside. Grief is demanding, but must be faced. It is a myth that time heals all wounds. However, a healthy grieving process can help heal wounds, though there will always be a scar. A sense of loss and melancholy will always remain; but after a while your good memories will come to the fore.

Normal reactions

Grief is many-facetted. Grief is more than just feelings. It is also everything that you deal with during a period of grieving, what you do and what you think. Grief can also express itself in the form of physical ailments, such as tiredness and pain. It is normal to relive what has happened, receiving the tragic news, or finding the child has died at birth or the time spent with the child after it has died. These kinds of thoughts can often occur during the evening, or can take the form of nightmares at night. It can, therefore, be difficult to get to sleep. Please seek help if you have trouble getting enough sleep over an extended period of time.

Many experience guilt, and blame themselves. "Could I have done something to prevent the death?" For many people, losing a child suddenly and unexpectedly can also be associated with disgrace. Thoughts arise, such as, "I couldn't even manage to give birth to a living child." "I wasn't able to look after my child." This is normal. To lose a child is absolutely nothing to be ashamed of!

After losing a child, many experience a strong sense of longing, emptiness, and sadness. Most people experience powerlessness and lose all their energy. Grief is all-consuming. It is normal to have problems concentrating or experience memory problems. Feelings of anxiety and aggression are normal. Grief can affect all of our senses. It is not unusual to both "see" and "hear" the child that has died. These are terrifying experiences that one knows, deep down, are not real. Many are scared all the same, feeling that they may lose all sense of reason. These experiences are normal, especially early on in the grieving process; but these will pass after a while.

After a while, as time passes, many experience an increased sense of anxiety. If you have other children, you may develop a strong fear that something will happen to them. Also, many experience additional fears of losing other family members, or become afraid that something painful will happen to them. Coping with grief takes time, and many experience it as coming and going, in waves. Some days or periods can be particularly heavy-going, especially after a while, when the social expectations are that you get "back to normal". Special occasions such as birthdays, anniversaries of the death, and celebrations with others can be tough, for several years. By establishing contact with other parents who have lost a child (For example through LUB), you will have the opportunity of verifying the normalcy of your feelings, and you may accept that these are normal reactions, even after a long time. You will, however, begin to notice that, after a while, your feelings of depression will occur less and less frequently.

To lose a child in stillbirth has been called a “lonely grief”. People you meet will most likely not have met the child, and therefore they will tend to find it difficult to relate to your loss. It is extremely painful for parents when their loss is trivialized. A normal feeling amongst mothers (and fathers) can be envy, that other parents have children who are alive. These are difficult feelings with which to cope, and are completely normal amongst parents who have lost a child.

The people around you

Grief often takes a much longer time than we, ourselves, and others might expect. Some feel that time is standing still, while time moves on for other people. It is not unusual for relationships with family and friends to become strained or altered at times. Many people around the affected parents are unsure of the situation. They might withdraw or may utter hurtful comments. Often the reason for a lack of support is that people are unsure of what they should say or do, as well as how they can show support and provide help. Many will not dare to name the child because they are scared of “opening” the wound, your grief. Please share within your network of friends and family the brochure on sudden death and how you can help, called (in Norweigan) “Plutselige dødsfall - hvordan kan du hjelpe?”. This pamphlet provides good advice regarding bereavement support. Perhaps you will find that you are not given support from people you had expected to come forward to offer you help. It can be painful to feel that you are not fully understood or that you are isolated in your grief. You can help relieve the situation by being open and taking the initiative yourself to tell others how you are feeling and what your needs are. Many people find that the most important support they get is from friends and family. Yet, it is not unusual to experience that relatively distant friends may be those that become more important sources of support.

Relationships and grief

Å miste et barn er en stor påkjenning for et
To lose a child is a huge strain on a relationship. Grief affects the life you share together, communication, intimacy and sexuality. Couples often find that they grieve differently and are out of step with each other. At times, one person will have a good day, while the other can feel very low. It can be difficult to find the energy to help each other.

Men and women often have different ways of grieving, and this can lead to misunderstandings and a breakdown in communication. A typical pattern is that women have a stronger and longer lasting emotional reaction than men, and that they want to talk about their feelings over and over again, throughout the grieving process. Many men hold back most of their feelings. They would rather cry alone than in the company of others, and they occupy themselves more with work or physical activities than women do.

These differences can result in women often feeling that men “do not grieve enough”, while men often

think women “grieve too much”. Not everyone experiences this. However, for the most part, we all experience the loss of a child differently and express it in different ways. We often know little about how the other person expresses grief and reactions to loss. It is important to speak together about how different ways of grieving can surface and be expressed, so that we can learn to recognize and come to terms with these differences. Then, a relationship can become a source of strength during the grieving process. (More information is available in the brochure “Relationships and grieving after the loss of a child”).

“It has been incredibly tough, but we have been forced to understand and respect each other. What we have been through has strengthened our relationship” (Parents that lost their son to cot death).

Being alone in grief

Single parents can feel that they are extremely lonely in their grief. Where many can find support from their partner, do you as a single mother (or father) have to live alone with your grief for the child? You are alone and taking care of any other children who are grieving for their brother or sister, and you are alone with all the difficult choices and all the practicalities that need to be organized in connection with funeral arrangements and the period thereafter. Your social network becomes especially important for those of you who are alone. Try and involve other people near to you in the farewell to the child and in the grieving process. Then, they will be able to understand more and be better prepared to support and help you in the difficult times that lie ahead. It is also important to accept offers of help and support from professional support services and from your network, while simultaneously being clear about what help you need and what you do not.

Siblings (brothers and sisters)

It is important that you include siblings in the grieving process. Let them participate in and understand what has happened, and what is still happening. They have lost a sister or brother with whom they have developed a relationship or looked forward to. In addition, they have temporarily lost out on the daily routines with which they are familiar and feel secure.

Children often become scared when someone close to them dies, and it is important that you are there to give them love and comfort. Explain why you cry. Be open and honest with children. Do not try to protect them by holding back information or by using phrases like “went to sleep”, “went away”, and so forth. If you do, children will make up their own explanations and fantasies about what happened, and these may often be much worse and more frightening than reality. Talk to children about what they have been through. In this way the loss is something you experience, together, and not something that you must work through alone. Accept that children also grieve and relive that grief in their daily lives and when they play. They will often play games about deaths or funerals. It is

important that you do not stop this kind of activity, because this is the way children get an opportunity to process their shock and grief. It can be difficult for parents, who themselves experience a loss of energy, to meet the increasing demands of their other children's needs for care and attention. You are likely to benefit from help and advice from your network and support services. (Read more about this in the brochure "Grief in young children" and the brochures published in Norwegian called " Skolebarn og sorg" and "Ungdom og sorg")

When should children return to kindergarten and school? Most children find it comforting to return to their everyday routines. Daily routines provide structure in their lives. During a period when parents are especially vulnerable, it is beneficial to get assistance from others with whom the children feel safe and secure. This can be a teacher, a grandmother, an uncle or a neighbor. They can provide the child some enjoyable experiences at an otherwise painful time, and furthermore provide you with important information about how your child is coping when you are not around. Nursing staff at the hospital can be supportive in providing information to the healthcare center, kindergarten or school about the death, and can help to establish additional follow-up.

Back to work

When is the right time to go back to work after having lost a child? Both concentration and memory problems are normal side effects people have when they grieve. It can take a very long time before one regains one's normal working capacity. It is important that this situation is accepted at your workplace, so that it is possible to come back to work without feeling the pressure of giving your all or working 100 percent. Men tend to return to work sooner than women. Returning to work provides one with the opportunity of thinking about something else and feeling that one is able to cope. This is considered by many as a positive experience, and as part of progressing through the next stage of the grieving process. (More information is available in the brochure published in Norwegian *"Når sorgen rammer en av dine ansatte").*

Maternity and sick leave

When you lose a child you will either be granted maternity leave or sick leave. Your local social security welfare office (NAV) can explain to you what your entitlements are. The main rules (as of 2008) are as follows:

- When a child is stillborn after the 26th week of pregnancy, the mother has a right to parental welfare payments [foreldrepenger] for six weeks after the birth, so long as she has worked long enough to have built up the right to the parental welfare payment benefits. If she has not worked long enough to receive this entitlement, then the mother is entitled to a one-off benefit [engangstønad]. These benefits are also valid if the child was born alive before the 27th week of pregnancy.

• The father has a right to two weeks of unpaid leave in connection with the birth. This is also valid if the child was stillborn or died right after the birth.

• If the child dies later on after the birth, one has the right to parental welfare [foreldrepenger] for six weeks after the death, so long as this entitlement has been earned (by virtue of sufficient prior employment) and there is still at least six weeks of the original leave of absence remaining. Assuming that the death did not occur during the first six weeks after the birth (the period of the leave of absence reserved for the mother), the parents are free to divide the six weeks between themselves. If they return to work before the six weeks are over, the parental welfare payment is stopped.

• If the child was stillborn before the 27th week of pregnancy or died after the end of maternity leave, parents can get a note entitling them to sick leave [sykemelding] from their own doctor or the hospital doctor. This is also the case under other circumstances in which the mother and/or father are not fit for work.

• Mothers who are employed by the state or local authorities and have a stillbirth in the 27th week of pregnancy or later, or who lose their child during the period of maternity leave, have a right up to 33 weeks of leave with pay, potentially up until six weeks of the remaining period of leave. Other employers may provide similar benefits.

Who can help?

It is important to speak with somebody about your difficult feelings. Finding someone that you trust, and speaking openly with him or her, can provide you with necessary help and support. Use each other, a good friend or someone in the family, who is willing to listen. This can create a better relationship and lasting friendship.

Very many feel that it is good to talk with others who have experienced the loss of a child. Some get help from going to bereavement support groups [sorggrupper]. Most parents, who choose to make use of such services, are glad they did, afterwards. Bereavement support groups and individual support for affected parents and possibly also siblings are available through many hospitals.

Nursing staff at the hospital can be of assistance in informing the healthcare authorities, the local hospital and other available health services in order to establish additional support. Accept the help and support offered. Over time, new needs and questions may arise. Then, being in contact with the hospital or another support organization may prove important. You may find it helpful to speak with the hospital chaplains [sykehusprest] and ordinary priests, regardless of your religious preference. These professionals have experience dealing with the bereaved. The local health clinic [helsestasjonen] in your district should also be able to provide support, should you need their help. Should the grieving

process become long, drawn out, and complicated, it may be possible to contact a psychologist.

Healthcare personnel can also assist you in coming into contact with parent organizations where you can get support and experience fellowship with other affected parents. Some of these volunteer organizations, including LUB (The Norwegian SIDS and Stillbirth Society), offer bereavement support groups and individual bereavement follow-up.

You can also find meeting places or chat rooms on the internet for parents who have lost a child, including the secure forums at www.engelsiden.com (based in Norway, and written in Norwegian) and www.sandsforum.org (based in the UK, written in English). Many parents feel that it is beneficial to meet other people who have had similar experiences and viewpoints in a forum where it is easy to make contact. Some also make memorial pages on the internet. Be aware of how you use the internet. Use the correct level of etiquette (nettiquette). Think about what you write and the pictures that you post. Not everything can be removed or deleted, later. It should be possible for you and others to read what you wrote there, many years in the future. Pay special attention to how you might refer to other children in the family.

LUB is an organization established to provide collective support and help to those who have lost a child suddenly and unexpectedly. This includes children who were alive for a while or died during birth or in pregnancy. A nationwide network of parent volunteers, who have themselves lost a child, offer affected families help and support in their bereavement. LUB also publishes information relating to grieving. In addition, the organization conducts other important work, like research and the prevention of unexpected child deaths. Read more at the LUB website; www.lub.no.

Relevant web pages

www.lub.no Landsforeningen uventet barnedød (Norwegian SIDS and Stillbirth Society)

www.etbarnforlite.no Foreningen "Vi som har et barn for lite" (The Norwegian Organisation for families who have lost a child)

www.ffhb.no Landsforeningen for hjertesyke barn (Norwegian Association for children with congenital heart disease)

www.engelsiden.no Engelsiden (angel pages)
www.sandsforum.org Stillbirth and neonatal death charity in the UK

www.fsid.org.uk The Foundation for the Study of Infant Deaths (FSID)

Literature: The reference materials below are available in Norwegian

Barnet som ikke ble.
Wold, K.
Emilia forlag, 2008.

Små føtter setter dype spor. Teigen, J.
Commentum forlag, 2007.

Sorg.
Bugge, K., Eriksen, H. and Sandvik, O.
Fagbokforlager, 2003.

Sorg hos barn. En håndbok for voksne.
Dyregrov, A.
Fagbokforlaget, 2006.

Sosial nettverksstøtte ved brå død. Hvordan kan vi hjelpe?
Dyregrov, K. and Dyregrov, A.
Fagbokforlaget, 2007

Pelle og de to hanskene. En bok om døden.
(a children's book) Vinje, K. and Olsen, V.S.
Luther forlag, 1999.

Det kan ikke være sant. Når et lite barn dør.
Myhre, A.M. Selvbiografi (an autobiography).
Universitetsforlaget, 1992.

Brochures available from Landsforeningen uventet barnedød

(Norwegian SIDS and Stillbirth Society)

Available in English:

A funeral for your child: your options and some guidelines (Gravferdsveiledningen - for foreldre som har mistet et lite barn)

Relationships and grieving after the loss of a child (Parforhold og sorg ved tap av barn)

Grief in young children – information and guidance for parents (Små barns sorg - informasjon og veiledning til foreldre) (Pedagogisk forum)

Brochures in Norwegian:

Plutselige dødsfall - hvordan kan du hjelpe? (A sudden death - how can you help?)

Den doble sorgen. Å miste et barnebarn (Grandparents and grief - coming in 2010, will then replace "Kjære besteforeldre")

Nytt svangerskap ved tap av barn (A new pregnancy after the loss of a child)

Når barnet dør - en brosjyre for helsestasjonen (When a child dies - a brochure for health personnel)

Skolebarn og sorg (School children and grief)

Ungdom og sorg (Youths and grief)

Når sorgen rammer en av dine ansatte (When grief affects one of youremployees)

DVD: Samtale om sorg ved tap av barn (A conversation about grief after the loss of a child)

Check www.lub.no for more information.

This booklet is intended to help and support parents who have lost a small child suddenly and unexpectedly. The booklet can also be of assistance and help to healthcare personnel and other professionals who come in contact with the bereaved parents.

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