When a little child dies

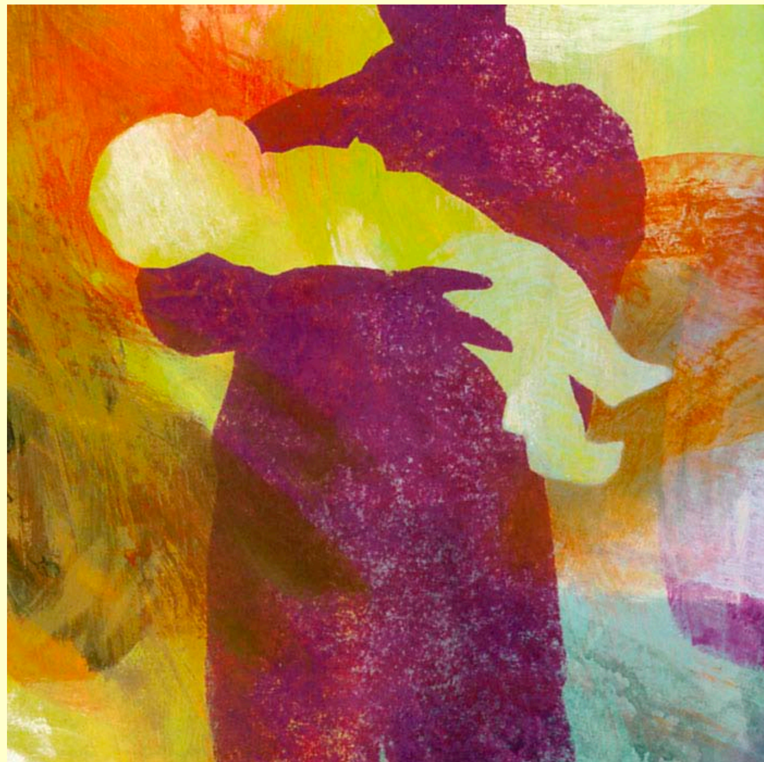
In the mother's womb, at birth, or during the first years

To lose a child is possibly the biggest tragedy that can happen to a person.
That a child dies is meaningless, it creates terrible pain and is completely unreal.
Children should not die. Hours and days in shock and chaos will follow - dreams and expectations are suddenly destroyed. The death marks the beginning of a painful time where emptiness, longing and anger are normal feelings.
Experience shows that it is important to let yourself react and express these strong experiences.
It will take time and effort to work through the grief over the 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] with Camilla Emilie Hatleskog as the main author.
Many thanks to the parents, the association's advisors and to other expert advisors, for their important help and insights.
Thanks for the economic help from Inge Steenslands Foundation.
Illustrations: Anne Kristin Hagesæther. Layout Holtmann Reklamebyrå
Originally printed in August 2008, print run of 6000
Note about the translation;
Where appropriate the Norwegian word has been left in the text and surrounded with [brackets]
A suggestion for additional references to the SANDS (UK) website and forum have been added to the English version (marked in green on page 17)
Translation into English by Julie and Colin MacKenzie, June 2009

CONTENTS

When the unthinkable happens	3
When a child dies	3
When a child dies in the mothers womb	4
When a child dies during birth or soon after	5
When a child dies during the first years	6
Autopsy [Obduksjon]	7
Making a final farewell	8
The funeral or cremation	10
The mothers body after a birth	11
Returning to daily life	13
WebPages, literature and brochures	16-17



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 in an otherwise chaotic and difficult time. It will be an intense experience, with much to organize and with many important decisions to be taken in the upcoming period. At the Landsforeningen uventet barnedød we have experienced that it can be helpful to know what others have gone through, what was important to them, and what can provide support for similar situations. This brochure shares these experiences.

Whether the child dies in the mother's womb, at birth, or during the child's first years, there are many aspects of grief that will be similar. Likewise are all situations totally different. To start with, we describe the facts and experiences tied up with how the child died; as stillborn, during birth or other kind of unexpected child death. The other parts 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]. 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 register 2008). The registration is however inadequate, especially regarding the earliest miscarriages. Most stillbirths occur during the third trimester before the birth process begins. A stillbirth can affect anyone, and we still understand little of why apparently healthy children die inside their mother's womb. In recent years there has been steadily 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 in the mother's womb

"Sorry, there is no life"

The final confirmation that a child is dead must be taken by two doctors. To find out that the child's heart has stopped beating is terribly painful. Many parents experience physical reactions including trembling, nausea, vomiting, heart palpitations and dizziness. There are many questions: "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 take in the information you are given.

After the traumatic message of the child's death, it is important to take time to sort out your thoughts amongst the chaos. It can be difficult to make decisions. It is therefore important to have a good dialogue with the health personnel. They have experience with stillbirths and can give good advice. If you do not have Norwegian as a first language, please ask for an interpretation. In crisis situations the right words can be hard to find, and it can be difficult to understand all the information and express oneself in a foreign language.

Why must the child be born?

Some mothers have a strong reaction when they hear they are expected to give birth naturally to their child. To have a dead child in their womb can be terrifying. Even if it is not considered dangerous from a medical perspective, many will 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 includes when the child is dead.
- A cesarean section is a large stress for the body, and it takes a longer time to recover from.
- 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?

To make a trip home for a while before the birth is induced, can be good for some. For others it is better or necessary for practical reasons to stay put 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 also brought their camera. If you do not have this possibility, you can speak with the hospital staff if they can arrange for clothes and a camera can 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 testing amniotic fluid from the womb. This is done to try and establish an answer as to what has gone wrong.

To induce the birth, a hormone pill is inserted into the woman's vagina. It can proceed quickly, but it can also take many days before the birth actually starts. Many find this time spent waiting to be a strain; however it can also give you the time you need to get prepared for the birth and to meet with your dead child. During this waiting period, it can be important to consider different issues such as what you think both about having a birth, and what the child might look like. Talk with each other and 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 your questions, so that you are well prepared for this question when it is asked (see also the section about autopsy).

A birth is never pain free, however the midwife will do everything she can to make the mother comfortable and provide the pain relief 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 they are still warm. Many parents are very grateful that the child was laid up on the mother’s chest just after the birth. For some parents their most valuable memories are a picture of the mother and father together with their newly born child.

When the child dies during birth or soon after

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

- About half of children that die, do so because of some factor with 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 10% die of breathing and heart interruptions, nearly 5% die from a chromosome deficiency and only 1% die from infections.
- Around 4% die from poorly defined or unknown reasons.
- About 6% die from other reasons than stated above.
- There are more boys than girls that die during birth.
  (The Medical birth registry 2008)

"Sorry, there is nothing more we can do"

When children die during birth or soon after, the death can happen under dramatic circumstances. The child may be hurriedly swept away right after the birth to undergo emergency lifesaving treatment. Parents may hardly get to see their child before receiving the news that there is nothing more that can be 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 with anger, desperation, anxiety, indifference or apathy. To hold your dying child is unbearable. All the same, other parents have felt that exactly; to hold, hug and smell their child is important. This is how they 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 on a respirator, it is extremely difficult when the life cannot be saved and the respirator must be turned off. Some children pass away quietly and peacefully while sleeping on their parent’s chest, once the news has been given that the child will not live. Many parents that have held their dying child and stayed with them until they died, whether it was only for a few minutes or hours have afterwards 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 years

Every year around 200 children die in Norway during their first 4 years, usually because of illness. 50 to 60 of these children die suddenly and unexpectedly, among them 15 to 25 from cot death. Others die in accidents or with a sudden illness such as viral or bacterial infections. (The central bureau for statistics 2008)

When a child dies suddenly and unexpectedly during their first years, it is normal that the child is delivered to a hospital, regardless of whether or not an attempt at revival is conducted. The hospital is obligated to notify the police, as such deaths are deemed unnatural, and because they occur outside the hospital (doctor’s law §41). It is therefore desired that a forensic autopsy of the child is carried out (you can read more about autopsies on page 10). The hospital should offer parents an examination of the place of death[1]. This is important for putting into place a certain diagnosis, and to provide parents with information as to what can have happened. Before the child is sent to autopsy, a number of tests will be taken of the child. The parents and possibly brothers or sisters will have the possibility to spend time with the child. At the hospital, the parents and other family members should be offered support during the sudden crisis in the wake of a death.

Those of you, who have lost a child suddenly and unexpectedly, have experienced a massive shock. Many have strong and painful memories of the time when their child was found dead. That a child dies so unexpectedly is traumatic and can create strong grief and crisis reactions. It can take a long time for these frightening images to be erased from 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 planned to become law in 2009.

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 n 1989 with 145 children including those

over 1 year old. Since 2000 the number of cot deaths has been between 15 and 25 per year.

There has been much research done about cot death. We therefore know a good deal about the risk factors and provoking factors, yet still there is a mystery as to what cot death actually is. No one can know that it will happen, and no one can be blamed for when it does occur. Current research into cot death suggests that there are several factors that when combined can provoke a cot death: There are probably both inherited and environmental factors working together that can create the conditions for 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, coma and death.

What we know about cot death

- That most children die while sleeping and have no suffering before they die.
- They do not suffocate due to bed clothes or vomit.
- It occurs most frequently during the child's first month after birth, but can occur as late as 2 to 3 years of age.
- It affects children who sleep on their front more often and in families where there are smokers. But it can also affect children who have never slept on their fronts, or been exposed to cigarette smoke.
- It is presumed that genetic factors play a part, which makes individual 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 with a thorough doctor’s examination right before the death.

Autopsy [Obduksjon]

Whether the child has died in their mother's womb, during the birth or has lived for some time after the birth, the question of having an autopsy will be raised. An autopsy can give information regarding illness or deformations as a reason for death, and also provide information that may be significant to future pregnancies. Autopsy is in many cases an absolute necessity in arriving at a sure diagnosis, regardless of how or when the child died and especially in cases where the death was unexpected.

With hospital autopsies [sykehus-obduksjon] parents have the right to refuse an autopsy. With 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 it is the police who will take the final decision and in such cases it is not possible to refuse the autopsy.

What is an autopsy?

An autopsy can be considered as a comprehensive surgical operation. All the internal organs are taken out and examined and tissue samples taken for microscopic examination. Amongst the smallest children many of the inner organs are so small that the whole organ is taken out for microscopic examination. With a forensic autopsy firstly a thorough external examination is carried out and 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. At the back of the head a cut is also made to allow the brain to be examined. Sometimes a cut will also be made at 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 to work that the funeral or cremation will have taken place before the examination is completed. These organs will be incinerated, cremated or buried later. If you wish for more information regarding this, you can contact the doctor or department that carried out the autopsy (the pathology department at the hospital or at the forensic institute).

The autopsy should take place a short time after the death. This ensures the best possible examination and the best chance for an answer as to what has happened. In the larger hospitals it is not unusual for parents to get their child back on the same day, after the autopsy. With other hospitals the child must be sent away for autopsy and it can take some days before the parents get to see their child again.

The child after the autopsy

The child will be treated with the greatest of 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 to appear as a wound from an operation. There can be a little leakage of fluid from the wounds; this can be stopped with clean tape. Staff at the ward can help to assist you, should you need help.

Please speak with the health 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 and find that their child looks fine.

The autopsy report

With hospital autopsies it takes about 3 to 4 months before the autopsy report is ready. You will then be contacted to come in for a meeting at the hospital. Forensic examinations can take a longer period of time. Here the 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, will receive a copy of the autopsy report. The hospital will contact the parents to come in for a meeting. Normally the parents can also get the autopsy results by making an enquiry to the doctor who carried out the autopsy or the doctor responsible for the hospital ward. Some parents have chosen to have the pathologist present at the meeting regarding the autopsy report and have felt this was a positive thing to do.

Making a final farewell

Both with still born, and for other sudden child deaths, the short time you can spend together with your child is extremely precious. Use it well and take good time to make your farewells. The staff at the hospital can support you here. Those parents, who do not speak Norwegian as a first language, can use an interpreter to help you make the decisions that are right for you. 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 minority of people will have seen a dead child before, and some think this 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 larger children worry about injuries or other changes so that they will not be able to recognize their child. Some are frightened to touch the child or to hold them; "What if the skin falls away?" It is easy to think that the less time one spends with the child, the easier it will be to bid them farewell. This can seem like a natural way to protect ourselves. At the same time it is important for parents to know that the pain will be no greater if they spend time together with their dead child.

Create memories and experiences

Spending time with the child is understood to be 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 them and hug them. You can also clean and change the child yourselves, dress them in their own clothes and talk with them, or sing for them. This is important regardless of how big or small the child is. If there is something that is difficult to do, the hospital staff or priest 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 has been born dead, this is the only opportunity you have to create a relationship with the child. It is no less important for the father, who has not had the same closeness that the mother will have experienced with the child in her womb. Remember that you are still the child's parents, even though that child is no longer alive. Become known with how your child looks, both dressed and without clothes. Touch the child, examine and play with their hands and feet. Also with other kinds of unexpected child death, it is important to see the child again and again. Now you will be prepared for the child being dead and you will relate to the child in another way than when you first discovered the child was dead. Some choose to take the child home to say farewell and spend the most time possible together.

Clothing and other items

Parents of stillborn children have found that it can be good to have 2 changes of clothes for the child, so that they can keep hold of one set of clothes as a keepsake. You may also wish to keep hold of a teddy bear or soft toy that the child has had with them in the hospital. For older children, clothing, the baby's dummy, a soft toy or other personal effects can help form important memories of the final time together with the child.

Pictures, hand and feet prints, and other memories

Take lots of pictures of the child, both on their own and when you are holding and caressing them. Be sure to take family pictures also, including brothers or sisters, grandparents or other family members. You can take pictures of the child both dressed and undressed. Pictures in black and white hide any discoloring that may develop. If it is too hard to take pictures of the child yourselves, you can get help from someone else to do it. In most hospitals there is a routine to take pictures of the child, together with hand and feet prints. You can also take a clipping of the child's hair and make a remembrance book with the date of birth, length and weight.

Siblings, family and friends

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 can take their own photos of their brother or sister? Invite the grandparents, other family and close

friends to say their farewells. To create shared memories and moments together with the child can help in future for them to understand what you are going through. This should make it easier for them to relate to you and the dead child in the times that follow. Remember that they can be important in offering you support in the future.

Name

You should give the child a name if they are stillborn. This gives the baby an identity. It is best to use the name that you have been thinking of previously. Only children that are living 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 child blessed.

Funerals and Cremations

The first days after the death can often seem unreal. Some people feel that they are not quite there in what is happening. Some just wish to be together with the child, whilst others focus more on the practical arrangements. Making plans for the final farewell, funeral or cremation, is one of the last things that you can do for your child. Give good consideration as to how you would like the ceremony and burial to be. Will you use a funeral director, or will you organize the arrangements yourself? More information is given in the brochure [Gravferdsveiledning] - for parents that have lost a little child.

Casket burial or burial of the ashes urn

You must make a decision if the child's casket shall be buried or cremated. With a cremation, the ashes will be collected in an urn which can then be buried in a graveyard some time after the funeral service.

Casket

Make the decision yourselves over which casket the child should have. Many parents feel that it is good to have laid the child into their casket themselves. Choose the clothes the child will be wearing. Maybe you will want the child to have some soft toys with them, a baby's dummy 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 child. In this way the farewell can be personal for those that are involved. You can also consider if you will have an open casket for the ceremony.

Burial place

There are many different burial places to choose between. You can have a traditional grave with a gravestone and planting. Some graveyards have a special place for children, or perhaps you may prefer to use a family grave. Some parents choose to have use an anonymous grave or memorial place 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 will 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

With an application to the local NAV office, parents can receive financial support up to 17 952 kronor (in 2008) to use for the funeral of a child under 18 years and for children that die before or during birth. The funeral directors can assist with this. There is no lower limit as to how long the pregnancy has gone. The social welfare services [Folketrygden] covers practical expenses to the funeral such as flowers, a gravestone and a casket. Expenses to any further memorial get-together are not covered.

The mother's body after a birth

During pregnancy the mother undergoes large physical and mental changes. After birth the body should return to same state as before the pregnancy. When you lose a child during birth, the 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 with multiple births. It is OK to ask for painkillers if you suffer a lot from after-birth contractions. It takes about 6 weeks before the mother's womb will return to a normal size. To lie on one's stomach in the times after the birth can help the womb to contract more quickly.

Breast engorgement pains

The production of breast milk is triggered by giving birth, even if the child is stillborn. The hospital should give you tablets that will stop the breasts producing milk. However a little milk may be produced by the breasts during the first weeks and you may experience some breast engorgement pains. It can be soothing to alternate between using a cold compress and standing in a warm shower. You can also take painkilling tablets. If you suffer a lot from breast pains, it can be a relief to use a breast pump or milk by hand to reduce milk production. You should do this with caution however because it can also stimulate milk production. Some women pack their breasts with tight clothing round them. It is important to know what the different methods are and do what is right for you. Use a good supporting bra during this time.

Bleeding

There will be an area in the uterus wall where the placenta was attached, which will give a bloody discharge in 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 be different for different women. The majority experience heavy menstrual bleeding for the first 3 to 4 days, which then gradually decreases. The bleeding will become browner later on as the bleeding decreases. If the bleeding continues to be heavy in the weeks after the birth, or if you bleed for more than 6 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, and if you have stitches it can sting. It is normal if you do not have a bowel movement for several days, especially if you have been given an enema. Many women get hemorrhoids during the birth and these can be painful when you go to the toilet. If the pain continues, you should contact the hospital where the birth took place. 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 vanish by itself. You may experience some tightness and stinging during first days after receiving stitches. A gentle rinsing with lukewarm water dried only by air, can give some relief to painful stitches.

Clenching exercises

During birth the muscles of the pelvic floor are weakened and it is important to get these back into condition. Weakened muscles of the pelvic floor can lead to urine leakage and involuntary bowel movements under serious circumstances. Conditioning these muscles also has implications for a continued sexual life. It is recommended that women who have given birth undertake clenching exercises 3 times daily.

Weight

Pregnant women normally gain between 10 and 20 kilograms during pregnancy. Right after birth as much as 10 kilos can be lost, however it takes time for the rest of the extra weight to be lost, especially when you are not breast feeding. During a time when you are stricken by grief it can be especially difficult to motivate oneself to be active. Gentle physical activity during this time after the birth is good both for the body and for the soul. Some women lose their appetite, while other women will comfort eat. Try and keep a routine to meal times all the same.

Psychological changes

A postpartum (postnatal) woman will often be easily prone to tears. There are large hormonal changes that take place in the body after a birth, and many are 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 to wait with intercourse until the bleeding has totally stopped. 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 death. Men and women will often wish to recover their sex life at different times. In the meantime, some find comfort and intimacy from 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 sex can act as a way to vent strong feelings and their grief. It is important to talk about sex and to respect each other's different reactions and needs. In this way it may be possible to find new ways to satisfy 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 "Parforhold og sorg ved tap av barn").

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 after about 6 to 8 weeks after a stillbirth. Many wish to be pregnant again as quickly as possible, while others will wish to wait until the shock and grief have been more resolved. There is no correct answer as to what is the right thing to do. It is however important to understand that a new child can never replace the child that has died. (More can be read on this subject in the brochure "Nytt svangerskap etter tapet av et barn").

Returning to daily life

To grieve 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 appear and not to push them aside. Grief is demanding, but must be faced. It is a myth that time heals all, however a healthy grieving process can help the wounds to heal, although there will always be a car. The sense of loss and melancholy will always be there, but after a while the good memories will be more prominent.

Normal reactions

Grief has many different sides. Grief is more than just feelings. It is also everything that you deal with, what you do and what you think. Grief can also express itself as 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 the birth or the time spent with the child after they have died. These kinds of thoughts can often appear during the evenings, or can take the form of nightmares during the night. It can therefore be difficult to get to sleep. Please seek help if you have trouble getting enough sleep over a long period of time.

Many experience guilt and blame themselves. "Can I have done something to prevent the death?" To lose a child suddenly and unexpectedly is also for many associated with disgrace. Thoughts such as "I couldn't even manage to

give birth to a living child" and "I wasn't able to look after my child" are 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 loose all their energy. Grief is all-consuming and it is normal to have concentration issues and memory problems. Feelings of anxiety and aggression are normal. Grief can affect all of our senses, and 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 that they will lose all sense of reason. These experiences are normal, especially early on, 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, the fear that something will happen to them can be strong. Many also feel additional fears of loosing other family members, or that something painful will happen to them. Grief takes time, and many experience it passing in waves. Some days or periods can be especially heavy, especially after a while, when the social expectations are for you to be "back to normal". Special occasions such as birthdays, anniversaries of the death, and celebrations with others can be tough for several years. Through establishing contact with other parents who have lost a child (For example with Landsforeningen uventet barnedød) your feelings will find confirmation such that you can understand they are normal reactions, also after a long time. You will however begin to notice that, after a while, there will be longer periods between how often you feel really down.

To lose a child in stillbirth has been called "the lonely grief". The people you meet with will most likely not have met the child and therefore 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 at other parents that have had children that are living. These are difficult feelings that 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 would expect. Some feel that time is standing still, while time moves on for other people. It is not unusual that relationships to family and friends can be strained or altered for some periods of time. Many people around the affected parents are unsure of the situation and will withdraw themselves away or come out with hurtful comments. Often the basis for a lack of support is that people are unsure of what they should say or do and how they can show help and support. Many will not dare to name the child because they are scared of "opening up" the grief. Please pass on the brochure "plutselig dødsfall - hvordan kan du hjelpe?" to important people in your network of family and friends. Here they will find good advice on bereavement support. Perhaps you will find that you are not given support from people you had expected to come forward and offer support for you. It can be painful to be feeling less than understood or 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. The most important support for many is that they receive from family and friends, still it is not unusual to experience that more distant friends are those that become the more important support for you.

Relationships and grief

To lose a child is a huge strain to 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. Some days, one person will have a good day, while the other can fell 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 the majority of their feelings, they would rather cry alone than in the company of others, and occupy themselves more with work or physical activities, than women.

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 it like this, however for the most part we all experience the loss and express this differently. We often know little about each other's way to express the grief and reactions. It is important to speak together about how different ways of grieving can present themselves and come to 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 "Parforhold og sorg ved tap av barn").

"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).

To be alone in grief

Single parents can feel themselves extremely lonely in their grief. Where many can find support from their partner, must you as a single mother (or father) live alone with your grief for the child? You are alone to take 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 practical things that need to be organized in connection with funeral arrangements and the times that follow. Your social network becomes especially important for those who are alone. Try and involve other people near to you with the farewell to the child and in the grieving, then they will be able to understand more and be better prepared to support and help you in the difficult times that are ahead. It is also important to take up offers of help and support both from professional support services and from your network, but at the same time be clear what you need and what you do not have need for.

Siblings (brothers and sisters)

It is important that you include siblings in the grieving process and let them take part in and understand what has happened and what is still happening. They have lost a sister or brother that they have connected with or looked forward to. In addition they have also lost the everyday routines that they know, and are secure with.

Children often become scared when someone close to them dies, and it is important that you are there to give them comfort and love. Explain why you cry. Be open and honest to children. Do not try to protect them by holding back information or use phrases like "went to sleep", "travels" and so forth. Then children will make up their own explanations and fantasies about what has happened, that are often much worse and more frightening than the reality. Talk to children about what they have been through. In this way the loss is something you go through together and not something that you must work through only for yourselves. Accept that children also grieve and relive that grief in their everyday and through their play. They will often play deaths or funerals. It is important that you do not stop this kind of play so that children get the chance to work through their shock and grief. It can be difficult for parents, who themselves experience a loss of energy to match their other children's increased need for care and attention. You can have good use for help and advice from your network and help services. (read more in the leaflet

"sma barns sorg, skolebarn og sorg og ungdom og sorg).

When should children return to kindergarten and school? Most children find it a comfort to get back into everyday routines. Routines provide the structure for their every day. In a period when parents are especially vulnerable it can be good if others whom the children feel safe and secure around, can help out. It can be a teacher, a grandmother, an uncle or a neighbor. They can give the child some fun in an otherwise painful time and additionally give you important information about how your child is coping when you are not around. Nursing staff at the hospital can be supportive with informing the healthcare center, kindergarten or school about the death, and help to establish further follow-ups.

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 for people who are grieving and it can take a very long time before one regains one's normal working capacity. It is important that the workplace accepts this so that it is possible to come back to work without feeling the pressure to give 100%. Often it is seen that men return to work faster than women. A return to work provides the possibility to think about something else and the feeling to manage something. This is considered by many as a positive experience as part of going further through the grieving process. (More information is available in the brochure ”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 NAV office can explain to you what your entitlements are. The main rules are as follows (2008):

- When a child is stillborn after the 26th week of pregnancy, the mother has a right to parental welfare [foreldrepenger] for six weeks after the birth, so long as she has worked enough to have built up the right to the parental welfare payment. 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 valid also if the child was born alive before the 27th week of pregnancy.

- The father has a right to 2 weeks 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 (worked up through employment) and there is still at least 6 weeks of the original permission left. Assuming that the death did not occur during the first 6 weeks after the birth (the period of permission reserved for the mother), the parents are free to divide the six weeks between them. If they return to work before the 6 weeks are over, the parental welfare is stopped.

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

- Mothers who are employed by the state or local authority 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 leave with pay,

potentially up until 6 weeks of the remaining period of leave. Other employers may have similar agreements.

Who can help?

It is important to speak with somebody about the difficult feelings. To find someone that you trust, and speak openly with, can provide 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 grateful for it afterwards. Bereavement support groups and individual support for affected parents and possibly also siblings is available through many hospitals.

Nursing staff at the hospital can be of help in informing the healthcare authority, local hospital and other available health services to establish further support. Accept the help and support that is being offered. Over time can new needs and questions arise and then to have contact with the hospital or another support organization be important. Hospital chaplains [sykehusprest] and ordinary priests can be good to talk with regardless of which belief you have. They often experience people dealing with grief. The health center [Helsestasjonen] in your district should also be able to offer support if you need their help. Should the grieving process become long drawn out and complicated, it can be possible to contact a psychologist.

Healthcare personnel can also assist you with coming in contact with parent's organizations where you can get support and fellowship with other effected affected parents. Some of these voluntary organizations, including Landsforeningen uventet barnedød (The national association of unexpected child death), offer bereavement support groups and individual bereavement support.

You can also find meeting places on the internet for parents who have lost a child, including the secure forums at www.engelsiden.com (based in Norway, written in Norwegian) **and www.sandsforum.org (based in the UK, written in English).** Many parents feel it is good to meet other people with similar experiences and views in a forum where it is easy to make contact with each other. 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 is possible to remove or delete again, it should be possible for you and others to read what you wrote there also many years in the future. Pay special attention as to how you might refer to other children in the family.

Landsforeningen uventet barnedød (The national association of unexpected child death) is an organization for collective support and help to those who have lost a child suddenly and unexpectedly, this includes children that have been alive a while or died during birth or in pregnancy. A nationwide network of voluntary parents who have themselves lost a child, offer affected families help and support with bereavement. We also publish information relating to grieving. In addition, research and prevention of unexpected child death are important work undertaken by the organization. Read more at 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" (Organization "we who have a child too few)

www.ffhb.no Landsforeningen for hjertesyke barn (The national association for children with heart problems)

www.engelsiden.no Engelsiden (angel pages)

www.sandsforum.org Stillbirth and neonatal death charity in the UK

Literature

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

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

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

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

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

Pelle og de to hanskene. Eo bok om døden.
(Barnebok) Vinje, K. og Olsen, V.S.
Luther forlag, 1999.

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

Brochures available from Landsforeningen uventet barnedød

(NORWEGIAN SIDS AND STILLBIRTH SOCIETY)

Gravferdsveiledningen - for foreldre som har mistet et lite barn
Kjære besteforeldre
Parforhold og sorg ved tap av barn
Plutselige dødsfall - hvordan kan du hjelpe?
Nytt svangerskap ved tap av barn
Når barnet dør - en brosjyre for helsestasjonen
små barns sorg (pedagogisk forum) - information og veieldning til foreldre
Skolebarn og sorg
Ungdom og sorg
Når sorgen rammer en av dine ansatte
DVD: *Samtale om sorg ved tap av barn*

Look to www.lub.no for more information

This booklet is intended for the help and support of parents that have lost a small child suddenly and unexpectedly.

The booklet can also be of assistance and help to healthcare personnel and other professional people in contact with the affected parents.

LANDSFORENINGEN
UVENTET BARNEDØD

Ole Fladagers gate 1A, 0353 Oslo
Tlf: 22 54 52 00. Faks 22 54 52 01
E-mail: post@lub.no - www.lub.no

ISBN978-82-91154-19-0 (norsk versjon)