



## Little one we love

Practical information for parents





Little one we love
Little one we love, you don't go away
You walk beside us every day,
Unseen, unheard, but always near,
Still loved, still missed and very dear.

(author unknown)



Your baby did not have the chance to carry on growing and have a life of its own. Expectations have been dashed, and holding on and letting go are very closely bound up with each other. We realise the distress and bitter disappointment that this has caused you.

We hope that you will be able to make space for your feelings and reactions. Be sure to take the time to do so. During the first few days, we may be able to go a few steps of the way together – because you are not alone at this time.

This leaflet provides information about the various forms of support that are available during and after your stay in hospital. We briefly present all the relevant members of hospital staff, and we also explain the different options for your baby's burial.

We hope that this leaflet will be of help to you and provide answers to various questions. Obviously, it is not comprehensive. If you would like more information about anything, do not hesitate to contact one of the relevant hospital staff members.

Please accept our condolences during this difficult time.



## SUPPORT BEFORE THE HOSPITAL STAY

At the prenatal appointment, the gynaecologist responsible for fetal medicine will inform you clearly and honestly about the diagnosis and consequences of the defect(s) detected in your baby. If there is a referring gynaecologist, he or she will be contacted and informed of the findings. The gynaecologist and the case manager will provide initial psychosocial support.

A multidisciplinary prenatal staff meeting is held every Monday at which every pregnancy with a prenatal diagnosis and a request for termination is discussed. After the discussion, the patient is contacted by the gynaecologist or case manager and informed of the decision that has been made.

Ideally, an appointment is scheduled prior to admission. During this consultation, the case manager will explain in detail how the termination will proceed. You will also be told more about any additional tests that are required. The administrative formalities will be dealt with and an admission date will be set.

If you wish, your GP can be informed of the diagnosis and the decision to terminate the pregnancy.



## **TESTS**

Parents who decide to terminate a pregnancy because their baby has serious defects tend to have a lot of questions after an initial period of grief. It is important to know the cause of certain defects. If you still wish to have children, it is also important to find out whether there is a risk of such problems recurring.

Many congenital defects occur 'by chance'. Others are genetically determined. Genetic defects may themselves be caused by chance if an error creeps into the genetic material during development. On the other hand, they may be transmitted by one or both parents.

If additional information is required to confirm the presumed diagnosis, a number of additional tests will be recommended. These tests can be performed either during the pregnancy (such as amniocentesis or a blood test for one or both parents) or after the delivery of a stillborn baby. The results of these tests will be discussed by the gynaecologist in charge in the hospital during a scheduled consultation about six weeks after the delivery.

A number of imaging tests (such as NMR and RX) and an autopsy are usually recommended.

These tests should preferably be carried out within a certain period of time. This may be from four to 20 hours after the delivery. The case manager will always discuss this with you beforehand.

## **DURING YOUR STAY**

During your stay in hospital, you will come into contact with a number of health care providers. The team consists of:

- Gynaecologists
- Case manager
- Midwives
- Social worker
- Psychologist
- Pastoral worker

## GYNAECOLOGISTS AND MIDWIVES

Initially, you will be surrounded by a medical team on the obstetrics ward. A midwife will receive you. Your stay may last several days, so bring comfortable clothing with you. You can also bring personal reading matter with you. Your partner is always free to stay the night. If you wish, you can bring your own camera along to capture some memories. In principle, visitors are not allowed. However, this can be permitted if the matter is discussed within the team of doctors and you also agree.

Once you have been assigned a room, a doctor will come by to talk to you. He/she will also administer the medication. This medication can cause menstruation pains for which various kinds of painkiller are provided, ranging from oral medication to an epidural anaesthetic. The doctor will discuss progress with the midwife at regular intervals and administer further medication if necessary. The case manager will also talk to you during the day.

After the delivery, you will be given the time and space to say goodbye to the baby. The midwife will take photos of your baby and make handand footprints if the stage of pregnancy permits this (usually from 18 weeks). You can also obtain a few photos from the non-profit association Boven De Wolken along with a USB stick so that you can take a digital copy of the photos home with you.

In addition, the Berrefonds will offer you a 'treasure chest' containing a series of ideas and materials to create a few last, very tangible memories of your child. You can also bring in your own keepsake.

After the delivery, it is best to spend one night in the Hospitalisation Women B unit. The obstetric parameters will be checked during this time. Your partner is also free to stay.

# SOCIAL WORKER, PSYCHOLOGIST AND PASTORAL WORKER

Psychosocial support can be provided by the social worker, the psychologist and the pastoral worker. In the gynaecology and obstetrics department, they set aside the time and space needed to listen to your personal story and help you come to terms with it.

Parents often experience a range of different feelings and it is important to express them. During the discussions, the psychologist, social worker and pastoral worker will raise the following subjects among others:

- coming to terms with a medical diagnosis and the subsequent treatment;
- working through loss and grief;
- · communicating with relatives, friends and acquaintances;
- · relationship and family problems.

The social worker, psychologist and pastoral worker will also give you the opportunity to talk about how you want to say goodbye to your baby in the hospital. We often find that parents have difficulty in seeing or holding the baby. However, we encourage this as it is an important step in working through grief.

#### **SOCIAL WORKER**

The social worker will also look at social and legal issues with you. First of all, he or she will explain the possibilities for burial or cremation in more detail. He or she will make the necessary arrangements in consultation with you and refer you to specialised health care providers (psychologist, pastoral worker or representative of another faith, etc.).

The social worker will also take the time to discuss practical and organisational matters such as the arrangements for taking time off work, insurance, questions about your discharge from the hospital and so on.

The social worker will come and see you while you are in hospital in any case. He or she can also be contacted before and after your stay in hospital. If necessary, the social worker can also provide a referral to a specialised service.

#### **PSYCHOLOGIST**

In the discussion with the psychologist, extra time and space will be allowed to consider the significance of the loss of your pregnancy. The sudden loss is often overwhelming and the psychologist can help you articulate the complex emotions you are experiencing. Expressing feelings is an important step in the grieving process.

The psychologist will also consider the relationship aspect. Loss and saying goodbye are an individual grieving process, but they are also something that you go through as a couple. The psychologist can help you stay connected as a couple while respecting the unique way in which each partner deals with this loss. This means that feelings of grief, anger, helplessness and so on can be experienced together.

The contact with the psychologist can vary depending on your own needs. Prenatal psychological support can be provided around the time when the bad news is received. The psychologist can provide support during any decision-making process after the prenatal diagnosis.



The psychologist can come and see you in the delivery room or on the ward at your request. Sometimes this proves to be enough to enable people to carry on. Upon request of the parents, we make appointments at that time for psychological support after you have been discharged. This may be either at UZ Leuven (perinatal psychiatry) or via a referral to a professional health care provider in your own neighbourhood.

It is possible to receive postnatal psychological support for up to one year after the delivery and even longer in the event of any subsequent pregnancy. These discussions take place in the perinatal psychiatry department.

#### **PASTORAL WORKER**

You can ask the pastoral worker to come and talk to you at any time. These conversations cover topics such as questions about why this has happened, guilt feelings, dealing with loss, saying goodbye and so on. A conversation can also give rise to requests for (farewell) ceremonies, a desire for a reassuring gesture to express the love that you feel for your child. A moment like this is part of your experience and takes shape with the help of targeted questions, poetry, texts, music, symbols and so on. The ceremony can take place in total privacy in the delivery room before or immediately after the delivery. It can also be arranged afterwards, in the Hospitalisation Women B unit, or a few days later in the hospital chapel. The pastoral worker can be reached before, during and after your stay in hospital. He or she can be contacted at any time of



day or night. If you wish, representatives of other recognised faiths can also be contacted at any time for a talk, blessing or (farewell) ceremony.

Once a year, we hold a memorial service for all the babies who have died. If you would like to receive an invitation to this, please inform the pastoral worker, either by calling 016 34 86 20 or by sending a message to pastorale\_dienst@uzleuven.be. An invitation will then be sent out in good time.

## **PAYING RESPECTS**

After the death, the baby will be laid out in the UZ Leuven mortuary. If you wish, you can pay your last respects shortly after the death — having consulted the mortuary staff. To find the mortuary, follow the grey arrows on the second floor on the Gasthuisberg campus. People wishing to pay their respects can go to the mortuary at the following times:

Working days:

2.00 to 5.00 pm (please arrive by 4.45 pm at the latest)

Weekends and public holidays: from 9.00 am to 12.30 pm (by appointment only, call 016 34 46 60)

## POSSIBILITIES FOR YOUR BABY'S BURIAL

The law specifies various possibilities if you wish to bury your baby, but it makes a distinction.

- ✓ A stillborn baby delivered before 180 days of pregnancy may not be buried in the usual fashion. However, the law makes provision for various possibilities for burial or cremation:
  - (Anonymous) burial in Leuven cemetery (the 'Little Stars Garden', see map below)
  - (Anonymous) burial in the cemetery of the municipality of residence
  - Cremation



The 'Little Stars Garden' in Leuven

- A stillborn baby delivered after more than 180 days of pregnancy must be buried in accordance with the generally applicable rules. This means that you have to contact a funeral director to arrange for the baby's burial. The law specifies various possibilities for burial or cremation:
  - Burial in Leuven cemetery (children's area)
  - Burial in the cemetery of the municipality of residence
  - Cremation

## **Visiting Leuven cemetery**

Leuven City Cemetery Nieuwe Kerkhofdreef 3001 Leuven

Opening hours: Monday to Friday: 8.00 am to 3.45 pm

Saturday and Sunday: 8.00 am to 5.00 pm

## Legislation

✓ Stillborn baby delivered between 140 and 179 days:

For a stillborn baby delivered between 140 and 179 days of pregnancy, as of 31 March 2019 a certificate of stillbirth can be drawn up, without any obligation, at the city of Leuven civil registry (place where your child was born).

## What does this mean in practice?

 Your child may officially be given a first name (a surname is not possible).

- You are not entitled to any social benefits related to a birth: for example, no maternity allowance, no maternity leave, and so on.
- This does not affect the possibilities for burial and cremation (see pages 14 and 15).

### How can you request this?

- Make an appointment with the Leuven civil registry (www.leuven.be/afspraak).
- Go to the civil registry, taking with you a medical certificate + your identity card(s). (If you are not married, you have to go together).
- It is best to do this as quickly as possible (within a fortnight, for example)

## ✓ Stillborn baby delivered after 180 days:

The registration of stillborn children has been modified as of 31 March 2019.

## What does this mean in practice?

- Your child may officially be given a surname. The funeral director will take care of this together with the certificate of death.
- You are entitled to the social benefits related to a birth: for example, maternity allowance, maternity leave, and so on.
- This does not affect the possibilities for burial and cremation (see pages 14 and 15).

## **CONTACT DETAILS**

Case manager tel. 016 34 26 58
Maternity ward tel. 016 34 36 04
Hospitalisation Women B tel. 016 34 43 00
Social worker tel. 016 34 86 20

Psychologist tel. 016 34 28 60 (Th-Fri)

or 016 34 14 28 (Mon-Tues-Wed)

Pastoral worker tel. 016 34 86 20 Mortuary tel. 016 34 46 60

Alternatively, you can find support outside UZ Leuven:

## Met lege handen vzw (Empty-handed)

Met lege handen is a non-profit association for parents who have lost a baby. Via support groups made up of fellow sufferers, we offer a listening ear to parents confronted with the grief of losing their baby. Met lege handen organises support groups in Leuven, Antwerp, Ghent and Roeselare.

We also put parents in contact with one another via a closed Facebook group for fellow sufferers and a public Facebook page. Our magazine, 't Lichtpuntje, is published quarterly.

www.metlegehanden.be



#### Fara vzw

Fara is a non-profit association that listens, informs and provides support with pregnancy options. Are you finding it difficult to opt for a termination for medical reasons? At Fara, someone listens to your story and questions, anonymously, every weekday between 9 am and 4 pm.

You can also contact us for counselling (alone or with your partner) on loss and working it through or if you would like to be put in contact with fellow sufferers.

www.fara.be tel. 016 38 69 50 e-mail vragen@fara.be

## **Boven De Wolken vzw (Above the Clouds)**

Boven De Wolken is a non-profit association that offers bereaved parents a professional photo report of their deceased baby free of charge. These photos provide a beautiful, tangible memory of their little star and can make a big difference in working through the grieving process. This is done in a very serene manner, with respect for you and your baby.

www.bovendewolken.be

#### **Berrefonds**

Berrefonds is a warm-hearted organisation that wants to be there for parents who lose a baby during pregnancy or a child up to the age of 12 years.

By offering a memory box or 'treasure chest', we hope to support these parents in their loss.

www.berrefonds.be

## Flemish professional organisation of midwives

If becoming and being pregnant have not gone as planned, you can turn to the midwife for advice. If complications arise during the pregnancy, the midwife cares for you and supports you with expertise and empathy. Find your midwife on www.vroedvrouw.be.

## Kind en Gezin (Child and Family Agency)

Just like other parents, you can contact Kind en Gezin. Kind en Gezin can help you place the loss of your child within your family. Some parents may not need additional support immediately. Depending on your needs and at a time that you decide yourself, Kind en Gezin aims to support and assist you, for example by a visit to the maternity clinic, a home visit, providing contact details, etc.

If you have not been contacted by Kind en Gezin, do not hesitate to contact them by calling 078 150 100. If your family already receives

assistance from Kind en Gezin, then careful account is taken of your new situation when further support is provided.

www.kindengezin.be/zwangerschap-en-geboorte/anders-dan-verwacht/verlies-van-een-kind/

NOTTIES		

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Please send comments or suggestions relating to this brochure to communicatie@uzleuven.be.

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