



Information for parents of a stillborn (Little Star) baby★

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Dear parent

Sometimes life takes an unexpected turn and the unthinkable happens to you: your baby did not have the opportunity to fully develop.

Please remember that you are not facing this alone. This brochure aims to provide you with information on what is likely to happen before, during and after your admission to hospital. Which care providers will be ready to assist you? What is the task of a case manager, midwife, social worker or pastor? Which practical or administrative information should you be aware of?

We hope that this brochure can assist you and provide an answer to a number of questions you may have. In the event of doubt or other questions, please do not hesitate to contact one of the people involved in your care. Their contact details are included at the end of this brochure.

You are in our thoughts and we send you our support, solace and warmth

PRIOR TO THE BIRTH

During the **prenatal consultation** the gynaecologist who is looking after you will provide you with clear and honest information about the condition of your baby. If a serious disease or disorder has been identified, you will be told at that point in time what the diagnosis is and what its potential consequences are. If you were referred by your own gynaecologist outside UZ Leuven, he/she will also be notified. The gynaecologist and case manager (midwifery consultant) at UZ Leuven will look after you.

In the event of a prenatal diagnosis involving a request to terminate the pregnancy or in other complex situations the pregnancy will be discussed during a multidisciplinary consultation. These consultations take place each week, on a Monday. Where applicable, these discussions will also include a potential pregnancy termination. The gynaecologist or case manager will subsequently inform you of the decision that was taken.

A consultation will be arranged prior to your admission to hospital during which the case manager will provide you with more detailed information about the pregnancy termination procedure and which further examinations need be performed. Any necessary administrative formalities will be completed and the date for your admission scheduled.

If you wish we can notify your GP about the diagnosis and decision to terminate the pregnancy. At this stage you can also contact our team's social worker to obtain any information you would like.

ADDITIONAL TESTS

A pregnancy termination may give rise to many questions. It is important to be aware of the cause of certain abnormalities in your baby. Particularly if you would like to have another baby in the future, it will be good to know whether there might be a risk of a future baby developing in the same way.

Many congenital abnormalities are purely accidental, if there is a mutation in DNA during the baby's development. Other congenital abnormalities are genetic (hereditary), i.e. transmitted by one or both parents.

A number of examinations will be proposed to gain additional information about the diagnosis. These tests may be performed during pregnancy (e.g. amniocentesis, blood samples from one or both parents) or on the baby after the birth. The results of these tests will be discussed with you approximately six to eight weeks after the birth by the hospital gynaecologist who is looking after you.

The most commonly proposed tests usually include imaging tests (e.g. an NMR scan and X-rays) and an autopsy. These tests have to be performed within a specific time frame. Postnatal your baby will be looked after and kept cool using appropriate cooling technology. The case manager will discuss this procedure with you in advance.

PROGRESS OF CHILDBIRTH

You will be looked after by a medical care team in the delivery suite. You will be welcomed by a midwife who will take you to your room. You will have to stay in hospital at least one night (two days). It is advisable to bring some comfortable clothing with you. If you wish to do so, you can create your own memories using your mobile phone or a camera.

Your partner or confidant will be able to stay the night, but visitors are not allowed in the delivery suite. Visitors will be allowed on the ward where you will be staying following the birth, i.e. hospitalisation 8. Both the physician and the case manager will visit you in your room during the course of the day. Please do not hesitate to share questions or concerns with them - they are there to listen to you.

The doctor will give you medication to induce the birth. This may cause cramps, for which we can provide various types of pain relief. The doctor and midwife will continue to monitor your progress and regularly review whether new medication is needed.

You will be given ample time to get acquainted with your baby after the birth. The midwife will also take photographs of your baby. 'Boven de Wolken vzw' can also arrange for a professional photographer to take photographs that can be provided in digital format on a USB stick. You can request this in advance. Further information and contact details are included at the end of this brochure and on their website (www.bovendewolken.be). If your baby is mature enough (18 weeks or older), hand and foot prints will also be made.

You will be offered a 'Cherished Memories Case' by Berrefonds, which contains a number of items that can be used to record tangible memories of your baby as well as elements that might offer solace. The Case also contains baby clothes such as a little vest, swaddle wrap and hat. Obviously, you can also bring items yourself, such as a soft toy or comfort blanket.

OUR TEAM IS READY TO SUPPORT YOU

Our care providers are ready to support you before, during and after the birth of your baby. In addition to the gynaecologist, case manager and midwife, you can also rely on the services of the social worker, psychologist and pastor at the unit.

SOCIAL WORKER

The social worker will visit you during your stay in hospital and you can also contact them at a later date. If you would like to talk to the social worker before your admission that can also be arranged. Just ask your case manager.

The social worker primarily provides support concerning social and legal matters (for example which options are available for the burial or cremation of your baby, the right to name your baby, etc.). The social worker will make all the necessary arrangements together with the parents.

PSYCHOLOGIST

Whilst you are in hospital the psychologist can visit you in the delivery room or on the ward. This may be enough to help you move on. You can also be referred for a consultation with a psychologist in your home environment if you wish to do so. It will be up to you to decide whether you feel a need to be in contact with the psychologist – everyone perceives this differently.

It may help to consider together what is happening to you and to have the opportunity to express your feelings. If you have a partner this will be something that's affecting you both. The psychologist can provide support on an individual basis or to you both.

If you would like to talk to a psychologist before the delivery, during the period after you received disturbing news, that can be arranged also. Feel free to let us know. For example, a psychologist can provide support when you have to make decisions following the prenatal diagnosis.

The doctors in question may also consider it advisable to arrange psychological guidance before you are admitted to hospital. If that is the case it will be discussed with you in advance and scheduled as soon as possible.

PASTOR

Saying farewell is immensely difficult. It is a very personal matter which we all approach in our own way. You can talk to the pastor about the process of saying farewell or if you feel the need for a farewell ceremony to express the love you feel for your baby. The pastor can help you find a way in which to realise this. A ceremony

of this nature will be adapted to how you feel and created using poetry, text, music and other symbols.

The ritual can take place before or immediately after the delivery in the intimacy of the delivery room. It can also be arranged later on during your stay in hospital or when you are leaving to go home. Later on there will also be an opportunity to say farewell in the hospital chapel together with your family.

The pastor can be contacted day and night before, during and after your admission. The pastor is a Christian representative for everyone. Representatives of other recognised faiths can also be contacted for a meeting, blessing or (farewell) ritual if you wish to do so.

Every year we commemorate all stillborn 'Star' babies in conjunction with the pastoral service. Let the social worker or pastor know if you would like to attend this by calling +32 16 34 86 20 or sending an email to pastorale_dienst@uzleuven.be.

GREETING YOUR BABY

At some point, in consultation with the parents, the baby will be taken to the mortuary, usually when the parents leave the hospital. You can still see your baby at the mortuary though.

You are free to visit the mortuary every day (also both at weekends and on public holidays) between 2 pm and 5 pm. Please make a prior appointment by calling +32 16 34 46 60. The mortuary is accessed via Bruine straat (Brown gateway), gate 3, level 2 (BR 3.2). It is advisable to park at parking Oost.

WAYS TO SAY GOODBYE TO YOUR BABY

Several options are available to provide a final resting place for your baby, depending on the stage of his/her development. The following is a summary of these options.

IF YOUR BABY IS BORN BEFORE THE 180 DAY GESTATION PERIOD OF THE PREGNANCY (27 weeks and 4 days according to the ultrasound count)

Your baby can be buried or cremated and given a final resting place at the local community's cemetery or at the Municipal Cemetery in Leuven. Both Leuven and a large number of other cities and communities provide an area or garden dedicated to stillborn 'Little Star' babies. If you opt for a cremation, you can keep the ashes at home or scatter them in a memorable location.

You can decide whether or not to use the services of an undertaker or to take your baby to the cemetery or crematorium yourself. If you decide to work with an undertaker, you also have the option to lay out your baby at home prior to the cremation or burial.

UZ Leuven will provide a wicker basket in which your baby can be buried or cremated.

LITTLE STAR GARDEN IN LEUVEN

The little star garden is a final resting place for stillborn babies. Parents have the option to place a star with the name and date of birth, to commemorate their baby, in amongst the rose bushes. These stars are available free of charge. If it would make you feel better and give you solace a second star can be sent to your home address.

Should you prefer to bury your baby yourself at the Municipal Cemetery in Leuven, you are free to do so. Cemetery staff will provide you with the necessary support. If you would rather not be present, UZ Leuven can also arrange (free of charge) for your baby to be given a place in the little star garden.

www.leuven.be/sterretjestuin



Are you entitled to social benefits?

As a parent of a stillborn baby with a gestation period of less than 180 days you are not entitled to the social benefits associated with a birth, i.e. the start allowance (former birth premium), maternity or paternity leave. If you had already completed certain administrative formalities (e.g. applied for a start allowance or booked a place in a nursery), don't forget to cancel them.

Can you have your baby's name registered?

In many cities and towns a baby born during the initial 140 days of a pregnancy can be symbolically entered into a star register. This also applies in the city of Leuven. The Berrefonds website includes a summary of all Flemish star registers, which is updated on a monthly basis.

A baby born between 140 days (22 weeks) and 179 days (27 weeks and 4 days) of pregnancy can officially be given a first name. This is entirely up to you. After the birth you will be provided with a certificate to register your baby. To do this you need to make an appointment with the registrar of births, marriages and deaths in the city or town where your baby was born, e.g. in Leuven if your baby was born in Leuven. It is not necessary to complete this registration within a certain period of time, it can be done at a later date.

IF YOUR BABY IS BORN AFTER 180 DAYS OF PREGNANCY (27 weeks and 5 days according to the ultrasound count)

Your baby can be buried or cremated and given a final resting place at the local community's cemetery or at the Municipal Cemetery in Leuven. If you opt for a cremation, you can keep the ashes at home or scatter them in a memorable location.

If your baby had reached this stage of development, you will have to use the services of an undertaker. If you prefer, your social worker can act as an intermediary and, in consultation with you of course, make all necessary arrangements with the undertaker. You can also lay out your baby at home prior to the cremation or burial. UZ Leuven will provide a small white casket for your baby.

Are you entitled to social benefits?

As a parent of a stillborn baby with a gestation period of more than 180 days you are entitled to all social benefits associated with a birth, i.e. a start allowance (the former birth premium), maternity or paternity leave, limited leave of absence, etc.

Can you have your baby's name registered?

Babies older than 180 days can officially be given a first name and surname and registered accordingly in the city or town where your baby passed away. The undertaker will complete this registration.

CONTACT DETAILS WITHIN AND OUTSIDE UZ LEUVEN

TEAM UZ LEUVEN

- Case manager tel. +32 16 34 26 58
- Delivery suite tel. +32 16 34 36 04 (available 24/7)
- Hospitalisation 8 tel. +32 16 34 43 00 (available 24/7)
- Social worker tel. +32 16 34 86 20
- Psychologist tel. +32 16 34 75 29
- Pastoral representative tel. +32 16 34 86 20
- Mortuary tel. +32 16 34 46 60

MUNICIPAL CEMETERY LEUVEN

Address

Kerkhofdreef 7
3001 Leuven

The municipal cemeteries in Leuven can be visited 24/7.

Contact details

Tel. +32 16 27 40 40

Email: begraafplaatsen@leuven.be

The administrative department can be contacted Monday to Friday between 9 am and 4 pm.

‘MET LEGE HANDEN’ (EMPTY-HANDED)

‘Met lege handen vzw’ works on behalf of parents of stillborn babies. Via support groups in Leuven, Antwerp, Ghent and Roeselare they, being fellow sufferers, will listen and lend a sympathetic ear. This charitable organisation also puts bereaved parents in touch with one another via a secure Facebook group for fellow sufferers and a public Facebook page. Their magazine entitled ‘t Lichtpuntje’ is published every three months.

www.metlegehanden.be

FARA

‘Fara vzw’ listens, provides information and support for pregnancy choices. Would you like to talk to someone about the decision to terminate a pregnancy for medical reasons? At Fara someone will listen to you and answer your questions, anonymously, every working day between 9 am and 4 pm. You can also contact them for support meetings (on your own or with your partner) focused on loss and coping with grief, or they can put you in touch with fellow sufferers should you so wish.

www.fara.be

tel. +32 16 38 69 50

email: vragen@fara.be

‘BOVEN DE WOLKEN’ (‘UP IN THE CLOUDS’)

‘Boven De Wolken vzw’ offers parents of a stillborn baby a photographic record of their baby entirely free of charge. These photographs are a beautiful, tangible memory of their baby and can

make a huge difference when processing their loss and grief. The photographs are taken unobtrusively and serenely, respecting your and your baby's privacy. You can apply yourself for a photographic record via the 'Boven De Wolken' website. Applications are processed as soon as possible. Remember to tell the nurse and social worker when you are admitted to hospital that you would like to use the services of 'Boven De Wolken'

www.bovendewolken.be

BERREFONDS

'Berrefonds vzw' is a welcoming organisation which aims to support parents who lose a baby during pregnancy or a child up to the age of 12. Amongst other things, the organisation provides Cherished Memory Cases and its website provides a lot of information and various tools that can help or support you or provide solace. You can also contact Berrefonds if you would like to get in touch with fellow sufferers, for example during one of its introductory events.

www.berrefonds.be

FLEMISH PROFESSIONAL MIDWIVES ASSOCIATION

If becoming or being pregnant doesn't work out as expected, you can contact a midwife for advice. In the event of complications during pregnancy the midwife will guide and support you with appropriate expertise and empathy. Contact a midwife via www.midwife.be.

KIND EN GEZIN ('CHILD AND FAMILY')

Parents can also contact 'Kind en Gezin', an organisation that can guide and help you give your stillborn 'Little Star' baby a place in your family. Some parents may not need additional support straight away. Depending on how you feel and at a time you decide, 'Kind en Gezin' will provide guidance and support, for example with a visit to the maternity ward, to your home, by providing contact details, etc. If 'Kind en Gezin' hasn't contacted you yet, feel free to contact them by calling +32 78 150 100. If you are already being supported by 'Kind en Gezin', the new situation will be approached with the necessary care and consideration.

www.kindengezin.be

GLINSTERHULP

'Glinsterhulp' is an online platform for families following the loss of a baby or small child. It can put you in touch with fellow sufferers in an easy and straightforward way. Even though each loss and each story is unique, sharing your story and questions with fellow sufferers can be a particularly comforting experience.

www.glinsterhulp.be

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

Publisher
UZ Leuven
Herestraat 49
3000 Leuven
tel. 016 33 22 11
www.uzleuven.be

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