



York and Scarborough
Teaching Hospitals
NHS Foundation Trust

Information for Supporting You When Your Baby Dies Before, or Shortly After Birth

Information for patients, relatives and carers

① For more information, please contact:

Maternity Services

Please see our contact details on page 25

Introduction

When a baby has died, parents often feel overwhelmed by their sadness. We extend our sympathy to you and appreciate that the days and weeks following the death of your baby can be bewildering and difficult. It is especially hard that there are important decisions that have to be made at a time when you probably feel quite unable to think calmly or clearly about anything.

There is no right or wrong way to do things. Take your time. You do not necessarily need to make any decisions immediately. Try to take things one step at a time.

This leaflet deals with your immediate care and the birth of your baby.

What happens next?

Following a detailed discussion with your obstetrician, an appropriate plan of care will be agreed on together, which will include the mode of delivery to include both vaginal delivery and delivery by caesarean section. Home births are not medically recommended.

You may go home to prepare for the delivery of your baby and consider the choices available, providing that you are well enough to do so.

It is safest for you to go through labour to deliver your baby. Whenever possible we will adhere to your plans for your labour. We will explain all options and procedures to you as often and as thoroughly as you wish.

The onset of labour

You may wait at home for the onset of natural labour. If you change your mind and you wish to begin the process of induction of labour, please contact the hospital.

If you do not wish to wait for the natural onset of labour, we will plan with you when it is appropriate for your labour to be started (induced).

This is only the beginning of your journey.

Prior to your admission, as part of the induction process, you may have been given prostaglandin tablets called Mifepristone to swallow. This helps to soften the cervix and can make induction of labour easier and reduce the time you are in labour. It also blocks progesterone, a hormone essential for maintaining pregnancy. Parents can then go home and return when they are in labour, or 48 hours later for further induction.

Some parents are medically unfit to go home or may not want to go home. Please discuss this with the midwife who is caring for you in order to make the best plan of care for yourself.

There are four places that are available for delivering your baby. These are:

- Bereavement room in York located just off labour ward.
- Labour ward in York.
- Bereavement room in Scarborough located on the labour ward.
- Labour ward in Scarborough.

Parents are requested to contact the nominated ward for delivery at 08:00 hours on the date booked to ensure that this is still available. If this is unavailable further options for care will be discussed with you or admission may need to be delayed.

When you return to the Hospital ward you and your family will be shown to your room. A midwife will be allocated to care for you.

You will need to bring into hospital with you:

- An overnight bag and toiletries.
- Nightwear and comfortable clothes.
- Underwear.
- Slippers and dressing gown (optional).
- Sanitary towels.

You may like to bring things with you for your baby, for example clothes, toys, mementos. You may also bring a camera for you and your family to take pictures of your baby.

Whilst at home take your time to re-read all the information given to you and you may want to start filling out the plan of care booklet with your wishes for delivery and immediate care of your baby.

There are a number of voluntary support groups, helplines and websites that you can also view, located in the back of this booklet.

Some parents experience passive movements of their baby before delivery, it can occur when you move or change position. This can be very distressing, as it can feel as if your baby is moving even after the death has been confirmed, if this happens, please discuss this with the medical staff or midwife that is caring for you.

When should I return to hospital?

The midwife will have arranged a day and time for you to return, however you may need to return sooner in certain circumstances:

- If you experience symptoms such as abdominal pain, vaginal bleeding or have any concerns about your well-being please contact labour ward for advice.
- You may go into labour before your scheduled appointment to return.
- If you no longer wish to remain at home.

Please telephone the Labour Ward using the telephone numbers at the back of this booklet.

Will I be offered any investigations to find out why my baby died?

There are many investigations that we can offer regarding you and your baby. The medical team and midwives will be able to discuss them with you and may give you more information, so you can decide if you would like to have these undertaken.

These can include.

- Bloods from the mother.
- Swabs from mother and baby.
- Genetic testing of baby's cord or placenta.
- Postmortem of baby.
- Placental examination by a specialist doctor.

The results of these investigations will be shared with you by the consultant in your follow up appointment.

What is the induction process?

Your midwife will continue the induction process by giving you further prostaglandins. These tablets can be given either under your tongue, in your cheeks or vaginally or both; this depends on how many weeks pregnant you are and what the medical staff have prescribed. The medicine will be repeated every three or four hours until your baby is born. The prostaglandin misoprostol will be repeated until you are in active labour or deliver your baby and placenta.

You may feel some pain and discomfort, similar to that of period pains and some backache. You may also feel sick, and your temperature may rise. Induction can take some time so please be prepared to be in hospital for several days. (93% of women deliver within 48 hours from commencement of misoprostol).

As part of the induction process, or to speed up your labour, you may also need a “drip” placed in your arm. This will contain a hormone called oxytocin which increases contractions and can also increase the pain you have in labour.

The doctor and midwife will explain which of these options would be most suitable for you.

It may take some time to induce your labour. You and your partner are welcome to invite family and friends to support you.

Will I be given any pain relief?

Induction and labour can sometimes be a long, painful process. Pain relief is always available.

In early labour you may like to consider coping options such as warm baths, pain relieving tablets (e.g. Paracetamol) or a TENS (transcutaneous electrical nerve stimulation) machine.

Stronger methods of pain relief are available whenever you need them. Your midwife or doctor will answer any questions you may have about this.

Pain relief options

- ❖ PCAS – (Patient Controlled Analgesia Systems)
A Morphine pump which enables you to control your own pain relief.
- ❖ Epidurals are available when you are in labour.
- ❖ Entonox (“gas and air”).

Injections of opioids are not recommended as they may cause drowsiness and affect your ability to understand what is happening and remember the events in the future which may add to your distress.

What happens when I am ready to give birth?

Towards the end of your labour, you may feel pressure in your bottom and an urge to push. Your midwife may need to examine you to see if your baby's birth is imminent. When she is sure you are ready, she may then encourage you to push to give birth to your baby. With your permission she will give you an injection to help deliver the placenta. This will usually be delivered soon after the baby. Sometimes the placenta can take longer to deliver, and you may need surgical intervention if this occurs.

The midwife will discuss with you if you need any stitches and perform this procedure when you have enough pain relief.

Once your baby is born, we will carry out your wishes according to your plan of care. You can change your mind about anything at any time.

What happens after I have delivered my baby?

You and your partner are welcome to stay as long as you need. Throughout your stay you are welcome to invite family, friends and children to support and help you through this difficult time.

You will be offered opportunities to meet and hold your baby and create memories. Parents often find making memories following the death of their baby valuable and sharing these memories may be beneficial to the grieving process in the future.

The midwife will be guided by you at this time and what you may have decided prior to delivery on your plan of care. You may change your mind at any time and decline any or all mementos that are offered to you.

If you have any particular requests do not hesitate to talk to the staff, no one will think any request is unusual or strange.

You need to be aware that your baby's body will alter following the birth. Keeping the environment cool and the special "cold cot", "cold plate" or "cold mattress" which your baby will be in/on when not being held significantly slows this process. This means that the baby can be with you as long as you wish.

Will I have to make any decisions about my baby?

When a person dies, those who were closest to them usually have a store of memories to help them remember and remain connected to them. Parents can find making memories and having keepsakes following the death of their baby valuable and sharing these memories may be beneficial to the grieving process.

The staff caring for you will suggest a range of things you could do. Take time to think about what is right for you, you can accept or decline any offers that are made to you or you may have other ideas about what you want to do.

There is more information about the issues below within the following:

- Sands bereavement support book.
- “Information to help you following the loss of your baby,” booklet.

Seeing and holding your baby

You may want to see and hold your baby straight away or you may want time to decide. Many parents find the idea of seeing and holding their baby strange and a bit frightening, but for many parents the time spent with their baby becomes their most precious memory.

Whether you see or hold your baby is your choice and you will be supported in which ever decision you make, you can of course change your mind at any time before your baby's funeral.

Bathing and dressing your baby

Depending on your baby's size and condition, you may want to wash and dress them yourself. Or you could ask the midwife to do this for you. You may want to bring something from home for your baby to wear.

If your baby is very small or premature, the hospital can supply suitable clothing for you to choose from.

Blessing or baptism

Your midwife will contact the hospital chaplain if you would like them to, or you may ask your own minister to come to the hospital.

There is a Book of Remembrance at York and Scarborough hospital sites. If you wish, your baby's name can be entered into this, the bereavement service officer can advise you about this.

Photographs

Your midwife will offer to take photographs of your baby, which can include family photographs. If you are unsure whether to have photographs taken, discuss this with your midwife. We recommend that you keep the SD card with your photographs on even if you do not want any pictures developed and are not ready to see them initially.

The maternity unit no longer has paper medical notes therefore images cannot be stored safely, so these may not be available if you decide to collect them in the future. You can of course take your own photographs, but please discuss the development of these with your midwife.

Depending on your baby's gestation and the availability of the photographer it may be possible for your midwife to contact a member of the `Remember My Baby` team to come and take some photographs of you and your baby. Please ask for further information if this is something you would like.

Hand and footprints

Equipment is available for you to take hand and footprints of your baby, or you can ask the staff to do this on your behalf. Sometimes this is not possible due to the size or condition of your baby. Clay prints and casts may also be available to use to create additional memories of your baby.

Mementos

Parents and other relatives are very welcome to bring any mementos at all that they would like to give to the baby. The hospital can also offer mementos and you can choose to keep these, or to leave them with your baby. A small box can be provided in which you may keep any mementos, such as wristbands, blankets etc. A memory book can be completed on your behalf.

A Post Mortem

The midwife and doctor will discuss the reasons that a post mortem examination may be useful with you and your partner. It may help to find out why your baby died or help you to make decisions about future pregnancies. There will be plenty of time for you to find out about this procedure and think about it. Both of you would be asked to sign a consent form if you wish to go ahead. These take place at Leeds Hospital.

If a coroner decides that a postmortem is required, then they do not need your consent to do this, but they will keep you informed of the results.

Does my baby's death need to be investigated?

Stillbirths require no legal investigation to review why the stillbirth occurred.

Neonatal deaths. Death certification laws have changed, it has become law that all deaths are scrutinised by either a Coroner or Medical Examiner. The coroner will need to be notified if the baby is born alive and dies unexpectedly/unnaturally, if the cause of death is unknown or if a doctor did not see the baby alive.

The coroners may decide to investigate or refer back to the Medical Examiners Service to do this. If the coroner is investigating, then your baby's body will be under their care and can not be removed from the hospital without their authority. They may impose other caveats around what can be done with regards baby and these need to be adhered to.

The coroner's officers or Medical Examiners will contact you directly to keep you informed with what is happening. Both of these services are independent and not related to the hospital.

Does the hospital undertake a review of my care?

The hospital undertakes a review of your care during pregnancy, delivery, postnatal and bereavement care to try and understand why your baby died.

Prior to your discharge you should be given a leaflet "The hospital review Understanding what happened to me and my baby" which will explain the process to you. Other reviews/investigation may be undertaken but the staff will keep you informed of these if they are required. There are many different types of review, and you may be asked if you would like to contribute to the process. Any relevant Information following the review will be discussed with you via the consultant and/or senior midwife.

Registration of a stillbirth

The midwife or doctor who attended the delivery of your baby will complete a Medical Certificate Of Stillbirth, which will be forwarded to the register office by Bereavement Services.

You will need to register your baby's death within 42 days of the delivery, this is required before a funeral can take place. Upon registration you will be issued with a white certificate, to hand to the funeral director or Bereavement Officer.

Registration of Neonatal deaths

In England and Wales all births, and deaths have to be registered by the Registrar of Births and Deaths.

Registration of death must be completed before a baby can be buried or cremated if they were born alive and then died.

Registering your baby's birth

You need to register your baby's birth before registering their death. If you have not done this already, you may be able to do both at the same time. You will need to book a double appointment to cover both registrations. All births in England, Wales and Northern Ireland must be registered within 42 days of the child being born.

You should do this at the local register office for the area where the baby was born. If you cannot register the birth in the area where your baby was born, you can go to another register office. They will send your details to the correct office.

When do I register my baby's death?

Every neonatal death in England, Wales and Northern Ireland must be registered in the district in which it takes place, within five days once the cause of death has been agreed by the medical examiners team.

There may be a delay if there is a coroners post-mortem. If your baby's death is being referred to a coroner, you will not be able to register your baby's death until they give authorization. If this is the case, the Coroner's Officer will tell you what you need to do next. The coroner may issue a special certificate to enable registration and the funeral, burial or cremation to take place.

For further information about registration please refer to the booklet "Information to help you following the loss of your baby".

Can I take my baby home?

There is no legal reason why parents should not take their baby home to make their own arrangements for the funeral unless the death is to be investigated by a coroner.

For your protection and to avoid misunderstanding there is some important paperwork which will be given to you to complete. If you would like to do this, please have a look at the 'Taking Your Baby Home' leaflet.

If you have consented to a postmortem you can still take your baby home following this procedure.

Some families also opt to have the baby at home the night before the funeral. Please discuss this with the bereavement officer who can guide you through this procedure.

Can I visit my baby at the hospital after discharge?

It is important that you have every opportunity and time to create memories with your baby. All parents can visit their baby in our hospital after they have been discharged home, before the funeral occurs. If you have agreed to a postmortem and your baby or babies are in Leeds for the procedure, then this will not be possible. However, once they return to our mortuary you can arrange to visit again. In York viewings are held in the family room in the mortuary. This is arranged by contacting the mortuary directly to arrange a suitable day and time.

In Scarborough most viewings are held in the bereavement suite on labour ward. This is arranged by contacting the staff on labour ward.

If the coroner is investigating the cause of death, then visiting will need to be agreed by them and may have some caveats to how this occurs.

Funeral, Cremation or Burial

Every baby that is born after 24 weeks must legally be buried or cremated. A member of Bereavement Services will discuss this with you following the birth either whilst you are in hospital or via phone after discharge.

All parents need to discuss with the bereavement officer their wishes about what happens to their baby.

Parents can choose to arrange their own funeral and appoint their own funeral director to make the arrangements.

How will my body react after the delivery of my baby?

You may start to produce breast milk following the birth of your baby. Your midwife will offer you medication that could prevent this, though you may experience some side effects such as dizziness, headache or nausea. Please ask your midwife for the booklet `lactation after baby loss` if you require any further information. You can expect a moderate amount of vaginal bleeding, which reduces slowly over the first week but may last three to four weeks before disappearing.

Your uterus should gradually return to its non-pregnant size. This can take up to 10 days. During this time you may experience painful period type stomach pains or `after pains` these may be relieved by Paracetamol.

Your perineum may be bruised and painful, even if you do not have stitches. A daily bath and careful hygiene is advised for this and Paracetamol will help with this discomfort.

If you have any other problems or complications your midwife or doctor will explain these to you as needed and answer all your questions. Please do not hesitate to ask your GP or community midwife if you are worried about anything.

Who visits me once I have gone home?

When you leave hospital your GP, community midwife and health visitor will be informed of your loss and transfer home. Your community midwife will phone you the following day and arrange a visit. Your partner will need some time off work too. Please ask someone to inform their GP if you are not registered at the same practice.

Do I have any further appointments?

You and your partner will be sent an appointment to see your consultant when the results from all investigations undertaken are available. This may be sixteen weeks or even longer, you may be offered an interim meeting to discuss your care before all the results are available. If this is something you would like, please contact the bereavement midwives who can organize this for you. We understand that it may be difficult to return to the hospital, but it will give you the opportunity to discuss what has happened. You will have plenty of time to ask questions. Do keep a list of things you would like to ask.

Who will contact me after discharge?

The midwife who specializes in bereavement will contact you via telephone to guide you through the bereavement process. You will also receive a letter following your discharge home with further support information and contact details for voluntary groups.

The bereavement midwives will also give you more information about how you can participate in the hospital review and send you further information in the post.

If you would like to see them or discuss anything with them at any point, please contact them via email at yhs-tr.bereavement.midwives@nhs.net and leave a message. They will contact you on their next working day.

Bereavement services can also arrange this for you. All contact details are in the back of this booklet.

The bereavement team will also send you a questionnaire to allow you to feedback on any aspect of your care. If you would like a response to this please include your details on the questionnaire, otherwise it is anonymous.

If you have not met the bereavement officer during your stay they will contact you after a few days. Alternatively, you may want to contact them. Once discharged home the bereavement officers can keep you informed about your baby or funeral arrangements.

Where can I go for emotional support?

Reactions to grief are very important. You and your partner may experience differing emotions/feelings at the same time. The Sands bereavement support booklet lists some possible effects of grief.

If this is not available at the hospital, it can be accessed via the Sands web site www.uk-sands.org. This book is available online in different languages.

Please contact your midwife or GP at any time if you need to talk to them. We recognise that people need different amounts of support. If you feel that it would be helpful to speak to someone who has suffered a similar loss the telephone number for the Sands phone number is provided. Your midwife will make this call if you find it difficult. Your GP may be able to arrange professional counselling for you. You can also self-refer to IAPT (improving access to psychological therapies). The bereavement midwives also have information around charities that also offer counselling for families which they can share with you.

Included within the booklets you have received from the hospital there are a range of national support group contact details and useful telephone numbers you may need in the future, which you can contact at any time for support and further information.

We recognise that nothing we offer can alleviate your grief, but we hope that this information explains what will be happening to you, and the services we are able to offer, help as you begin to cope with your loss.

Useful telephone numbers

Patient Advice and Liaison
Service (PALS) 01904 726262

York Hospital

Labour Ward: 01904 726869 (option 3)

Community Midwife: Contact via Maternity
Medical Records during office hours: 01904 726720

Registrar's Office: 01904 654477

Bereavement Support Midwife: 07776 633807
Email: yhs-tr.bereavement.midwives@nhs.net

Bereavement Services: 01904 725445

Chaplaincy 01904 725579
(Office hours/voicemail)

Mortuary 01904 726083

Scarborough Hospital

Labour Ward: 01723 236869 (option 3)

Bereavement Services 01723 385178

Bereavement support midwife 07823 548628
Email: yhs-tr.bereavement.midwives@nhs.net

Chaplaincy 01723 342500

Switch board 01723 368111

Stillbirth and Neonatal Death (SANDS)

National helpline open Monday to Friday 10am to 4pm:
020 7436 5881, web site: www.sands.org.uk

British Association for Counselling And Psychotherapy

01455 883300

Miscarriage Association

A national organisation set up by parents who have
been through the pain of miscarriage.
www.miscarriageassociation.org.uk

Helpline:

01924 200 799

(IAPT)

Improving access to psychological therapies.
www.northyorkshireiapt.co.uk

Twins Trust

Bereavement Support Group
For parents who have lost one or both twins or more
from multiple birth.
www.twinstrust.org
Helpline: 01252 332 344.

Tell us what you think of this leaflet

We hope that you found this leaflet helpful. If you would like to tell us what you think, please contact:
Bereavement midwives, York Hospital, Wigginton Road,
York, YO31 8HE or telephone 01723 385374.

Teaching, training and research

Our Trust is committed to teaching, training and research to support the development of health and healthcare in our community. Healthcare students may observe consultations for this purpose. You can opt out if you do not want students to observe. We may also ask you if you would like to be involved in our research.

Patient Advice and Liaison Service (PALS)

PALS offers impartial advice and assistance to patients, their relatives, friends and carers. We can listen to feedback (positive or negative), answer questions and help resolve any concerns about Trust services.

PALS can be contacted on 01904 726262, or email yhs-tr.patientexperienceteam@nhs.net.

An answer phone is available out of hours.

Leaflets in alternative languages or formats

If you would like this information in a different format, including braille or easy read, or translated into a different language, please speak to a member of staff in the ward or department providing your care.

Patient Information Leaflets can be accessed via the Trust's Patient Information Leaflet website:
www.yorkhospitals.nhs.uk/your-visit/patient-information-leaflets/

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