



What do we do now?

Practical information for when a baby dies



Your contacts

If you have any concerns during business hours (Monday to Friday 9am to 5pm) please contact your bereavement worker.

Bereavement worker name:

Contact telephone number:

After hours you will need to telephone the hospital switchboard and ask them to put you through to the ward/area that was caring for you:

Contact telephone number:
(03) 8345 2000

When you are in need of urgent medical care:

If you need urgent care you can:

- telephone or attend your nearest emergency department
- telephone or attend the Women's Emergency Department any time day or night - (03) 8345 3636
- dial 000.

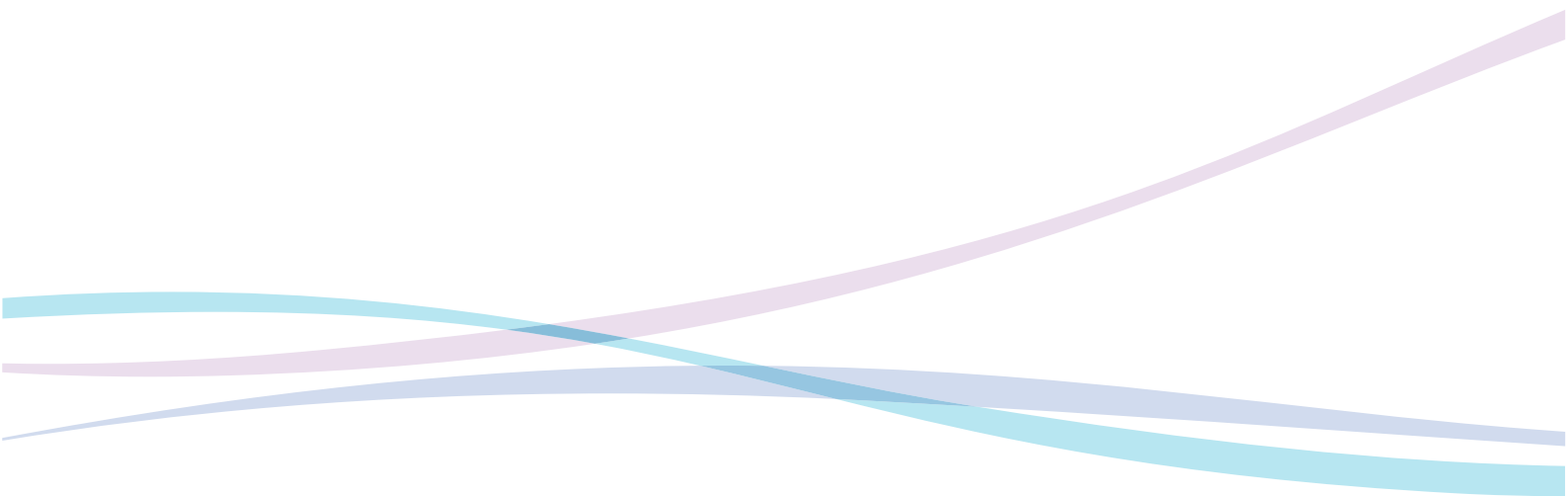
Your carers:

- midwives or nurses
- doctors - including specialists such as paediatricians, obstetricians, gynaecologists and geneticists
- bereavement worker
- anatomical pathology staff



*Have you become a star
in some undiscovered galaxy...
Or are you a breath or a breeze
In the in-breathing and out-breathing
of the universe?*

From *End and Beginning* by Marjorie Pizer



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Introduction

No one can tell you how you should be feeling, because grief and loss affects everyone in different ways. We offer this information in the hope that it will answer any questions you may have.

Our role is to help and support you.

This booklet aims to give you *practical* information to help you with decisions in the first days and weeks after your baby has died. You may have further questions or you may need other information which is not in this booklet. Please feel free to ask us any question, even if you think it is trivial. From pages 32-37, we have included the details of hospital supports, other organisations, books and brochures to give you further opportunities to seek information or support if you need it. We can also help to put you in touch with organisations in your community if you wish.

There can be many things to think about in the next few days and weeks. Take your time and remember there are no right or wrong decisions; just decisions that have to be made. Talking things through can also be helpful.

Some women will, for various reasons, have surgery to end their pregnancy. While this booklet may be helpful with some issues, it will not give you all the

information you need and it will not always be relevant to you.

If you are having surgery to end your pregnancy please ask for more information.

Things you may like to know now:

- After the birth your baby is treated with care and respect.
- In many cases your baby will be in your room with you. If you prefer, your baby will be in the mortuary.
- If the baby is not in the room with you, you can ask to see your baby as often as you like.
- You will be offered the services of a bereavement worker. You can still contact the bereavement worker after you go home.

Explaining the role of the bereavement worker

Each bereavement worker at the Women's comes from a different professional background, including social work, pastoral (spiritual) care and genetic counselling. You can ask for a bereavement worker who you feel comfortable with. While all workers offer a range of practical and emotional support, each has particular expertise and experience that may be more suitable for you. Your midwife or nurse can help you to decide.

Legal issues

All bereavement workers offer:

- grief and loss support
- funeral information
- practical assistance
- referral to community support organisations.

This booklet offers information to women and their families whose baby has died before or soon after birth. When you receive this booklet you may still be pregnant or you may have recently given birth.

The booklet includes information about pregnancy loss; when a baby dies during pregnancy, during labour, at birth or afterwards. Staff use all kinds of expressions to describe the time at which a baby dies like 'miscarriage', 'fetal death in utero', 'stillbirth', 'perinatal' death, 'neonatal' death or infant death. In this book we will simply refer to the death of your baby.

A baby's birth must be registered with the Victorian Registry of Births, Deaths and Marriages when it meets the following criteria. This is a legal requirement.

A birth *must be registered* if:

- the baby shows signs of life at birth
- the baby does not show signs of life at birth but the gestation is 20 weeks or more.

A birth *cannot be registered* if:

- the baby shows no signs of life at birth and is less than 20 weeks gestation.

Sometimes it's not clear when your baby died, or how many weeks pregnant you were. In this case the doctor will look at other things, like your baby's weight, to estimate the age at the time of death.

Registered births - important things to know

- You need to complete a registration form which is due at the Victorian Registry of Births, Deaths and Marriages within 60 days of your baby's birth. The nurse or midwife caring for you will give you this form.
- You can request a copy of the birth certificate from the Registry. This certificate will include details of stillbirth if this applies to your baby. There is an order form attached to the birth registration form, and a small fee to pay.
- Funeral arrangements must be made with a private funeral company (the hospital can support you with this) (see p.13 for further information).
- You may be able to make a claim for a bereavement payment from Centrelink. Depending on your circumstances, payments such as the baby bonus, maternity immunisation allowance and the family tax benefit may be available and are means tested. To discuss eligibility for these payments, contact Centrelink on 13 61 50.
- A death certificate is signed by a doctor and registered with Births, Deaths and Marriages. You can get a copy from the Registry at any time in the future.

You do not need to do anything to register your baby's death. The attending doctor completes a medical (death) certificate.

The Coroner

Sometimes a live-born baby's death has to be reported to the State Coroner for further investigation, particularly if a doctor is unable to record a cause of death. If this should affect you, the doctor will discuss it with you.

The Coroner is not able to investigate a stillbirth or a birth which can't be registered.

Unregistered births - important things to know

If gestation is less than 20 weeks and the baby showed no signs of life at birth, the birth cannot be registered with the Victorian Registry of Births, Deaths and Marriages. If there is no registration of birth there is also no registration of death.

- For families who would like one, a *Recognition of Life* certificate can be produced by the hospital.
- If you wish
 - you can take your baby home to be buried; or
 - the hospital offers respectful communal cremations (at no cost); or
 - you can ask for a hospital arranged funeral service, and your baby can either be buried or cremated (there is a small cost which the staff can discuss with you); or
 - you can organise a private funeral.

Overview

- Some babies that die during pregnancy are too small or too young to have their births legally registered.
- This will affect your funeral and burial or cremation options.
- The doctor will tell you if your baby's birth can be registered.

Your time in the hospital

Your baby's birth

If you are still pregnant and your baby has died, the doctor will talk to you about your baby's birth. They will usually recommend an induction (starting labour with medical assistance). For some women it will be possible to wait for labour to start without medical assistance, but for others there will be medical reasons as to why that is not possible. The doctor will discuss your particular situation with you.

The doctor and midwife can talk with you about what is going to happen during your labour, how your pain can be managed, and any other concerns or fears that you may have. The aim is to prepare you and to support you throughout your labour and afterwards. After the birth, you may need to stay in hospital for a number of days.

A caesarean will only be recommended in very specific situations. It may seem like the least unpleasant way to give birth, but caesareans can lead to longer hospital stays, more pain, and potentially more problems in future pregnancies than vaginal births.

Some women who are less than 18 weeks pregnant may have surgery to end the pregnancy.

After your baby is born

The staff are always saddened by the death of a baby and will *always* treat your baby with the greatest of care and respect.

You may be able to keep the baby with you in your room. If you prefer, your baby can be cared for in the hospital mortuary until you have made the funeral arrangements. Some families will want to see their baby a number of times before the funeral. We can arrange for you to spend time with your baby in the hospital viewing room.

Some families do not wish to see their baby again and we respect your decision.

Creating memories

Overview

- If you are pregnant the doctor or midwife will talk with you about giving birth.
- Most women will be offered an induction of labour.
- You will be offered lots of support during the labour and birth.
- After the birth your baby will be treated with great respect.
- It is your choice whether you want to see and spend time with your baby.
- Some women who are less than 18 weeks pregnant may have surgery to end the pregnancy.

How you would like to remember your baby is a personal choice based on what's important to you and your family. We respect your choices and decisions and will offer support and guidance as you need it.

The memories you have of your baby can play an important part in helping you with your grief. While you are in hospital there are a number of ways that you can spend time with your baby or to create memories if you wish, including:

- seeing, holding or dressing your baby
- bathing your baby
- photographs
- naming or other personal rituals
- creating a memory folder and keeping special mementoes such as teddies
- religious rituals such as baptism.

Spending time with your baby

It is very important that the decision to spend time with your baby is made by you and your family. We will respect your decision.

If you are unsure about seeing your baby, it may help to think about why that is, or to think about how you might feel later on. Some families have regrets about not seeing their baby, while others say they are fearful because they don't know what to expect or how they will react. We can discuss your concerns with you and hopefully answer your questions. We can also help to prepare you for what to expect.

It is also possible to spend time with your baby without actually looking at your baby. For example, you can have the cot in your room but your baby can remain covered.

You may simply need more time to think about your decision and we understand that.

What will my baby look like?

The way your baby looks will depend on gestational age at the time of death and how long it has been since your baby died. It may also depend on the extent of physical problems or abnormalities. Sometimes it is hard to know if the baby is a girl or a boy. A post mortem examination may be able to find this out (see p.17 for more information about post mortem examinations).

Your baby may look different to how you imagined, in size, skin condition or features.

There may be bruising or skin discolouration, the lips may be dark red in colour while the rest of the body is bluish, the skin may have started to break down, and the body will be cool to touch soon after death.

Some parents have said that the fear of seeing their baby's physical problems or abnormalities was much worse than the reality.

Dressing and bathing your baby

If it is possible and if you want to, the midwife or nurse can help you to dress your baby. You can provide your own clothes or wraps, or we can give you clothing that has been handmade by volunteers and donated to the hospital. It may also be possible to bathe your baby - the warm water can feel soothing and the ritual of bathing can feel very nurturing.

Photographs

You may take your own photos or we can organise our professional photographer to take them during business hours (free of charge). Some families believe it is very important to have photos taken of their baby while others are not so keen at first, but regret not having done so down the track. It is your choice and we will support any decision you make.



If you are concerned about how your baby will appear in the photographs, the photographer can help you with suggestions. Photos can be in colour or black and white. You may also consider being in the photo with your baby.

If you are uncertain, and with your permission, we can take photos of your baby and store them for you to collect at a later time.

Naming

There is no legal requirement to name a baby who has died, but some parents find naming an important part of acknowledging and recognising their baby's life. If your baby's birth can be registered, the name can be included on the birth certificate. If the birth is not registrable it can be included on the *Recognition of Life* certificate provided by the hospital. Some families like to have a naming ceremony. Your bereavement worker can discuss ideas with you.

Rituals

Some families find that ritual helps them to move through the grief; others feel it's an opportunity to publicly acknowledge and mourn their baby. Ritual can also be helpful for other children who may not be old enough to fully comprehend the meaning of death, but are aware that something has happened. Some families feel that this time is a deeply private one and will want only a few close family or friends to attend. Others will feel comforted and supported by a large gathering of friends and family.

Our pastoral care workers can arrange support and appropriate ceremonies from most faiths and traditions, or they can arrange a non-religious ceremony which can be written to meet your specific needs. They can provide a simple naming ceremony, blessing, candle lighting or ritual to honour your baby; or you can do this privately with your family.

Your own religious representative is also welcome to visit you at the hospital and to participate in these events.

Memory folders

With your permission, we can help you to put together a memory folder which can include information about your baby; including the cot card, birth weight, length, hand and footprints, and a lock of hair if you like. You can also include photos, the ultrasound images, medical results, or other information. If you are unsure, another option is for us to make a memory folder and keep it at the hospital so that if you change your mind it will be here to collect later. This will also need your permission.

Taking your baby home

Some families like the opportunity to take their baby home for awhile before the funeral and, in many instances, it is possible. If this is something you would like to do, your bereavement worker can give you more information, which includes health and safety issues to consider. When you are ready you can return your baby to the hospital, or organise for the funeral director to collect your baby from your home.

A baby whose birth cannot be registered with Births, Deaths and Marriages (because the baby is too young and shows no signs of life at birth) can be buried at home if you wish. The midwife, nurse or bereavement worker can give you more information about what you need to consider if you decide to do this.

Overview

- You can choose whether or not you want to see and spend time with your baby.
- The staff can talk with you about what to expect when you see your baby.
- Some families like to have a special ceremony to name the baby or to mark their birth or death. Your bereavement worker can help you to think about things you want to do.
- We can make a memory folder with you.
- Our photographer can take photos of your baby during business hours (free of charge). Another option, if you don't want a photo now, is for us to take some and put them in your hospital record so that if you change your mind you can come and get them later.
- If you want to, you can take your baby home for a short time before the funeral. Your bereavement worker will give you some more information.

Funerals and ceremonies

Your options for funerals, burial or cremation depend on whether your baby's birth can be registered or not.

A baby's birth must be registered with the Victorian Registry of Births, Deaths and Marriages when it meets the following criteria. This is a legal requirement.

A birth *must be registered* if:

- the baby shows signs of life at birth
- the baby does not show signs of life at birth but the gestation is 20 weeks or more.

A birth *cannot be registered* if:

- the baby shows no signs of life at birth and is less than 20 weeks gestation.

Funeral options for a baby whose birth has been registered

A private funeral service for registered births

There is a legal obligation to place your baby in the care of a registered funeral director for burial or cremation. Your bereavement worker can help you to organise this.

Private funeral companies can offer an individual funeral or memorial service, as well as a burial or cremation to suit your family's needs. The cost of this service will vary depending on your preferences, but there are

reasonably priced options available. Your bereavement worker can give you a list of accredited funeral directors including options which are specific to your religious or faith beliefs.

If you are concerned about cost, remember that you may be entitled to a bereavement payment from Centrelink.

Funeral options for a baby whose birth is not registrable

There are a number of options for your baby's funeral or cremation:

- a) private burial or cremation
- b) hospital arranged funeral service
- c) hospital arranged burial
- d) hospital arranged individual cremation
- e) hospital arranged communal cremation (at no cost to you)
- f) home burial

a) A private funeral service for an unregistered baby

A private funeral company can provide an individual funeral or memorial service, as well as a burial or cremation to suit your family's needs. The cost of this service will vary depending on your preferences, but there are reasonably priced options available. Your bereavement worker can give you a list of accredited funeral directors including options which are specific to your religious, cultural or faith beliefs.

b) Hospital arranged funeral service

The hospital offers a non-religious funeral service for all families who have had a pregnancy loss before 20 weeks gestation (and the baby cannot be registered). The ceremony is held in the hospital's Sacred Space. The burial or cremation happens on the same day, and families can attend the cemetery afterwards if they choose. There is a cost for this service and an account will be sent two months after the service.

c) Hospital arranged burial

If you choose a hospital arranged burial, your baby will be buried in an individual name-plated coffin. The coffin is buried in a communal grave for infants in the public burial section at Fawkner Crematorium and Memorial Park. It is possible for you to arrange for a memorial plaque to be placed where your baby is buried, by contacting the Fawkner Cemetery. There is a fee for this service.

d) Hospital arranged individual cremation

You may choose an individual cremation, and collect the ashes from the crematorium. Some families like to keep the ashes at home, while others prefer to scatter them in a place of importance to them. There is a fee for this service.

e) Hospital arranged communal cremation (free)

If you would prefer to not be involved in burying or cremating your baby, the hospital can arrange for a communal cremation provided at Altona Memorial Park. The ashes are scattered on the memorial garden. This service involves the cremation of all 'products of conception' which are collected by the hospital. There is no fee for this service.

If you do not tell us what you want to do within three months of your baby's death, we will organise for your baby to be cremated as part of the hospital's communal cremation service.

f) Home burial

If you were less than 20 weeks pregnant when your baby died, and your baby showed no signs of life at birth you have the option of burying your baby at home if you wish. Some families hold a special ceremony with family and friends, and then bury their baby in their garden. If you choose to do this, your bereavement worker can give you information about health and safety, and help with the necessary arrangements for you to take your baby with you. It is important to know that while you can bury a baby on your own property, human tissue cannot be buried in a public place.

Overview

- There are different funeral, burial and cremation options.
- Your bereavement worker can tell you what is available for you and help you to organise a funeral that is best for you and your family.
- If your baby's birth is not registrable the hospital can take care of everything without your involvement if you wish.
- If your baby's birth is registrable you must employ a private funeral company.
- If your baby's birth is registrable, you *may* be entitled to financial help from Centrelink.

Finding out why your baby has died

We aim to give you as much information as possible about why your baby died. While there are many explanations as to why babies die during pregnancy, birth or soon after, your circumstances will be unique. If there is anything you don't understand from the explanations you are given, please ask again.

It is possible that there will be no explanation for your baby's death but the doctors will do as much as you will allow, in terms of investigations and tests, to find one.

Common causes of death include:

- a fetal abnormality or birth defect
- bleeding from the placenta
- the placenta not working properly
- problems with the umbilical cord
- complications during labour
- prematurity, and complications related to this
- infections.

In some cases (especially when a baby dies during pregnancy), the cause of death cannot be found. This is often referred to as an Unexplained Fetal Death in Utero.

Following the death of your baby, a number of tests may be suggested, to try and find the cause of death. These tests may include:

- blood tests for the mother
- examination of the placenta
- x-rays and other imaging techniques
- post mortem examination of your baby.

Post mortem



What is a post mortem examination?

A post mortem examination, sometimes called an autopsy, is a medical examination of your baby which may or may not involve surgery. A post mortem examination aims to find out as much as possible about why your baby died. The examination is done by a specialised medical practitioner—a pathologist. Your baby is treated with the utmost respect and care during this procedure.

It is your decision how detailed the post mortem will be. If you are concerned about your baby having surgery after death you can give consent for the doctors to do an external examination only. Or you can provide permission for your baby to have surgery and specify which organs you wish to be tested or examined (limited post mortem).

A post mortem cannot be done without your consent. The only exception to this is when the baby's death has been reported to the Coroner (see The Coroner on page 5). When you have made a decision about what you want, we will ask you to sign a form to say whether or not you want a post mortem examination to be done on your baby.

A post mortem examination may:

- Provide information on the cause of death or what to exclude as cause of death
- Confirm the gestational age of your baby
- Confirm the sex of your baby
- Provide approximate time of death
- Explain the impact of genetic or physical problems
- Provide information to help mothers and babies in the future through research

Options for a post mortem examination

There are several levels of post mortem examination, none of which can be done without your consent. (We also need your consent *not to* do a post mortem.) The amount of information that we can get from a post mortem depends upon how complete and detailed the examination is, and the particular problems that have occurred. However, even in a full post mortem examination the cause of death may not be found. It is important that you discuss the advantages and disadvantages carefully with your doctor, and take your time in making your decision.

The levels of post mortem are:

- a) full post mortem examination
- b) limited post mortem examination
- c) external examination
- d) no post mortem examination.

a) Full post mortem

This is a detailed operation during which the pathologist will carefully remove all of the baby's internal organs, and examine them very thoroughly. The pathologist will also take specimens of body fluids and tissue samples. This type of post mortem provides the most detailed information.

b) Limited post mortem

The pathologist will only remove and examine specimens of body fluids, tissues and organs in the areas that you specify.

c) External examination

An external examination involves careful observation of the body and may include x-rays, MRI (Magnetic Resonance Imaging - which gives a more detailed internal image) and photographs. No specimens of body fluids, tissues or organs are taken in this examination.

d) No post mortem

You can decline to have any type of formal examination of your baby.

The doctor (obstetrician or paediatrician) may still gently examine your baby with you present and will attempt to answer all your questions as best as possible.

Advantages and disadvantages of a post mortem examination

Here is a list of possible advantages and disadvantages of a post mortem examination for your baby.

Advantages

- A post mortem will usually give you more information about why your baby has died.
- Information from a post mortem may help with your future pregnancies.
- During a full post mortem the doctors can investigate every organ in great detail and carry out a range of tests and investigations.
- Any tissue collected during a post mortem must be stored by the hospital for 23 years. These will be available to researchers (with hospital ethics approval) who are seeking to improve outcomes for babies in the future. This may be an advantage for some and not for others.

Disadvantages

- Sometimes even the most detailed post mortem will provide very limited information. It is also possible that the post mortem will provide no further information at all.
- A full post mortem can delay funeral arrangements. (Although doctors are aware of religious considerations and for that reason will attempt to complete the post mortem a timely manner.)
- During a full post mortem organs are removed from your baby's body. Usually all organs are returned to the body before the funeral, but sometimes additional or more complicated testing is needed which may delay this.
- After a surgical post mortem your baby will have a scar from an incision on the back of the head and another down the front of the body. The scars won't be noticeable with clothing.
- Some families notice a difference in the way their baby feels after a full post mortem.
- If you consent to a surgical post mortem the hospital is legally required to store collected tissue for 23 years.

Legal requirement to store tissue from a post mortem examination

There is a legal requirement for hospitals to keep any tissue collected from a post mortem in storage for 23 years. If you agree to a post mortem you are also agreeing for any tissue, which is collected during the post mortem, to be stored and later used for research. The baby's details remain anonymous and any research that is done must first be approved by the hospital's ethics committee. Research using stored tissue and organs can help in the diagnosis and treatment of future mothers and babies and add to the body of knowledge which will progress medicine in this area.

At this point in time it is not possible to consent to a post mortem examination without also agreeing for tissue to be stored for 23 years and available to researchers (with ethics approval) during that time.

Your decision

A doctor will talk with you about a post mortem examination and offer you the opportunity to ask questions or to express your concerns. It is important that all of your questions are answered before you decide to give or withhold your consent.

Consent for a post mortem examination is a personal decision based on your family's values and beliefs. Your doctor will provide you with information to help you make this decision.

Other things to consider

- The post mortem is carried out as soon as possible after the death of your baby.
- You do not have to pay to have a post mortem examination on your baby.
- Your baby's body is usually released to the funeral director on the day of the post mortem unless there is more detailed testing required.
- For some specific tests, tissues may not be able to be returned to the body in time for release to the funeral director. If this is the case for your baby you will be informed of this at the time you give consent to the post mortem, and will be able to decide whether to proceed with these tests or not.
- After a full or limited post mortem - both which involve surgery - a technician will take great care to prepare your baby to reduce obvious differences in the way your baby looks and feels.
- Post mortem results typically take 8 to 12 weeks.
- *Your baby will be treated with respect and care throughout all examinations.*

After the post mortem examination

The post mortem examination is usually completed within one to two days following death. If you decide to have a full or limited post mortem, it is still possible to see and maybe hold your baby after the procedure is completed.

The post mortem report is usually completed within 8 to 12 weeks, depending on which tests have been requested. An opportunity to discuss your baby's results is made in a follow-up appointment with a senior doctor (see follow-up appointments on p.24).

In certain circumstances a post mortem may be performed by the Coroner without your consent, however this is very unusual (see The Coroner on p.5).

Your health after the birth

Overview

- A post mortem can provide more information about why your baby died.
- A post mortem will not be done without your written consent unless it has been referred to the Coroner, but this is unusual.
- You can decide how detailed you want the post mortem to be.
- You also need to agree in writing if you don't want a post mortem.
- Post mortem results take 8 to 12 weeks and are discussed at your follow-up appointment with a senior doctor.

Bleeding

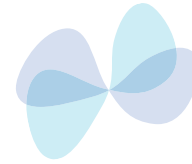
After giving birth, you will have vaginal bleeding for approximately 5-10 days; it may be even longer if your baby was born at or close to full term. Initially, this loss will be dark red, becoming lighter over the next few days. It is recommended you use pads rather than tampons to reduce the risk of infection.

See your general practitioner (GP) if you experience any of the following symptoms:

- prolonged or heavy bleeding
- blood clots
- severe lower abdominal pain
- changes in your vaginal discharge or offensive smelling discharge
- fever or flu-like symptoms.

Breast changes

Following the birth of your baby, you may experience some breast changes. Your breasts may show signs of producing milk as early as 16 to 18 weeks when you are pregnant. Your breasts may become tender. You may notice they are larger and there may be some milk leakage. This is not unusual; it is your body responding normally to pregnancy.



Painful breasts may be relieved by:

- avoiding handling or stimulating your breasts
- wearing a firm comfortable bra day and night (you may need a larger size)
- using cold compresses to decrease swelling (cold wet face washers or gel packs are useful)
- pain relief such as paracetamol
- small hand expressions of milk (for comfort only as expressing milk will cause more milk to be produced)
- wearing breast pads to help soak up the milk
- if you have been expressing milk for some time you will need to decrease the frequency and duration of expressing gradually over time. Discuss this with the midwife.

Your breasts will become more comfortable and softer within the first week after birth. There is no need to restrict your fluid intake or to take fluid tablets - milk production will stop as your body adjusts.

Sometimes medications are used to stop breast milk. Medications work by stopping your body from making prolactin, which is the hormone that makes milk.

If your breasts become red and sore or you develop flu-like symptoms (such as fever or body aches and pains) you may have developed mastitis. It is important

to contact a doctor or the hospital to avoid your symptoms getting worse.

If you have any concerns you can contact the following:

- the lactation consultant at the hospital (ask your midwife or nurse)
- Breastfeeding Education and Support Services (BESS) at the Women's
- the Australian Breastfeeding Association 24 hour helpline on 1800 mum2mum or 1800 6862686
- your local Maternal and Child Health Service or the Maternal and Child Health 24-hour helpline on 13 22 29.

Professional care at home

When you are ready to go home we will refer you to health services in your community. Some families may benefit from ongoing support and your bereavement worker can assist you.

A hospital midwife or local health care worker (if you live outside the hospital catchment area) may visit you at home if requested. If you have any concerns, contact your local maternal and child health nurse, GP or hospital emergency department.

Sex and intimacy

It may be some time before you start thinking about resuming a sexual relationship with your partner. There are many reasons for this, apart from the

complications of grief and loss. If you have suffered any discomfort, tearing or injury to your perineum, or you have had a caesarean section, sex can be uncomfortable and painful for some time afterwards. Even women who have had a straightforward vaginal birth can find sex in the weeks after childbirth painful or unpleasant.

If you do feel comfortable, pain free and ready; and assuming you don't have any medical reasons not to, then there is no reason why you cannot have sex when you want to.

But if you don't feel ready it's okay to wait. It is a very individual decision.

Your sexual needs and your partner's sexual needs may be very different for awhile. It can be helpful to keep talking to each other about your thoughts and feelings. If you find it hard to talk to each other you might consider talking with a health professional or a counsellor.

Contraception

After giving birth, it is common for women to not think about contraception until after they have their first period. It is important to remember that ovulation happens before your period and it is possible to ovulate and become pregnant within weeks after a birth.

If you do not want to become pregnant again straight away talk to the doctor or midwife about contraception.

Overview

- You may bleed for 5 to 10 days after the birth.
- Your breasts will change as they prepare to make milk. This will settle with time.
- After you go home, a visit from a hospital midwife or local health care worker can be organised if you wish.
- You will know when you are ready to have sex again - it's your choice.
- It is possible to get pregnant within weeks of giving birth - talk to your doctor about contraception.

Things to consider when you go home

Support after hospital

Your bereavement worker is available for short-term support following your baby's death. They will also give you information about supports in your local community and, with your permission, can refer you to other services.

Follow-up appointments

All women who give birth are advised to see a doctor (GP or obstetrician) six weeks after the birth.

If you gave birth at the Women's hospital and your baby died you will be offered an appointment to see a senior doctor from the team caring for you while you were in hospital.

- If you have *not* requested a post mortem examination, your appointment will be in approximately six weeks.
- If you *have* requested a post mortem examination, your appointment will be in approximately 12 weeks (but you should also see a GP or obstetrician at six weeks).
- If you are waiting for post mortem results and you have an appointment before 12 weeks, the post mortem results may not be available at that appointment and a further appointment will need to be made.

At this appointment the doctor will be concerned about your recovery and will aim to answer any questions you may have. In the time before your appointment, if you have any questions, it might be helpful to write them down.

If you live in a rural area, or if it is more convenient for you to visit a local GP instead of coming to the Women's, the post mortem results can be sent through to your GP.

If your baby was not born at the Women's you will need to organise an appointment with your GP, obstetrician or the hospital in which your baby was born.

If your baby spent time in Newborn Intensive and Special Care at the Women's, you will be offered a follow-up appointment to meet with a senior paediatrician and discuss your baby's death and answer any questions you may have.

When you go home, think about writing your questions down; it may help you to make the most of your appointment with the doctor. You can also contact your bereavement worker during this time.

Future pregnancies

The doctor will talk with you about your particular situation and whether there are risks to future pregnancies or health issues. If you are not clear about this, or you need more information, there are many opportunities to ask. We are keen to answer your questions to the best of our ability.

Annual hospital memorial service

Once a year, Pastoral Care and Spirituality Services at the Women's, holds a memorial service to remember the babies who have died. The service is held in the Sacred Space. Unless you tell us otherwise, you will receive an invitation to the service and you and your extended family are welcome to attend. Your bereavement worker can give you more details. *Please let your bereavement worker know if you do not want to receive an invitation to this service.*

Centrelink payments

If your baby's birth is registered (see p.4) you may be able to make a claim for a bereavement payment from Centrelink. Depending on your circumstances, payments such as the baby bonus, maternity immunisation allowance and the family tax benefit may be available and are means tested. To discuss your eligibility for these payments, contact Centrelink on 13 61 50.



Overview

- Your bereavement worker can still be contacted after you go home.
- All women should see a doctor six weeks after giving birth.
- If you gave birth at the Women's you will be offered an appointment at the Women's in approximately six weeks if there was no post mortem, and approximately twelve weeks if there was.
- At your appointment at the Women's, the doctor can talk with you about future pregnancies.
- If your baby spent time in Newborn Intensive and Special Care you will also be offered an appointment with a doctor who specialises in caring for babies (a paediatrician).
- The hospital has an annual memorial service to remember babies who have died. We will invite you to come. If you don't want an invitation, please tell us.

Grief

Every parent, couple or family will have their own reaction to a baby's death. If the baby died early in the pregnancy it may be that you were still coming to terms with being a parent. Even when a death occurs later in a pregnancy, feelings can vary from ambivalence in one person to profound grief in another.

This chapter offers a brief insight into grief. The information will be useful for some people but not everyone. If you need further support or information please see the back of this booklet for recommendations.

Acknowledging your grief

Society has not always acknowledged the close bond that can form between parents and their expected baby, nor the intensity of the grief that can follow. Sometimes a long-awaited pregnancy may produce a strong bond from the earliest stages of conception. As well as grieving for the loss of your baby you may also be grieving for the loss of your parenting dreams.

Feelings and physical reactions

Grief, and the way we express it, is influenced by so many things, such as our values, beliefs, culture and upbringing. This is why people deal with their loss and grief in so many different ways. It is also why there is no right or wrong way to behave or respond. Some people find themselves overwhelmed by a number of feelings,

including shock, sadness, denial, guilt and anger. Others might experience physical reactions like nausea, headaches, loss of appetite, sleeplessness, fatigue, difficulty concentrating as well as generally feeling unwell. Others again, may feel numb and unable to cry, but feel that they should.

Some people find that it takes weeks or months before they start to feel 'normal' and able to return to daily activities. Occasions such as the baby's expected birth date, the anniversary of the miscarriage or birth, a subsequent pregnancy or other significant family events, may bring back more intense feelings of grief.

It may be helpful to anticipate occasions that might remind you of your baby's death. Try putting some rituals in place with your family and loved ones so that the grief is acknowledged. Some families have a place where they can put flowers or light a candle each day; some have a special place in the garden where they can sit and remember, and others choose a time in the week where they can spend time remembering together. How you remember your baby will be unique to you and your family.

If you find your grief is overwhelming or is stopping you from doing the things you need to do, or doesn't diminish with time, it may be useful for you to speak with a trained counsellor or another parent who has gone through a similar experience (see community support contacts on p.34).

It can be helpful to contact support organisations early so that you know where to get help should you need it. Your bereavement worker can help refer you.

Individual differences

Many parents are concerned that their emotional and physical reactions to grief are different from their partner's. This can be especially difficult if you feel that your partner doesn't understand, or care about what has happened. Different people deal with grief in different ways. It can be hard to look after your relationship if you are overwhelmed by your feelings of grief and loss, but it may help to keep talking, openly and honestly about how you feel, and what both your needs are at this time. It is also important to listen; this may be very hard at first but will eventually become easier. Sometimes it is not possible for you or your partner to meet each other's support needs, and speaking with other friends, family or professional supports may be helpful.

Other children

It is often hard to know how children are affected by death because their reactions can be so very different to those of adults. A child can seem to be upset one minute and then be happy to go and play the next. It's important to remember that children use play to understand the world they live in and to make sense of things.

Children's grief may come out in their behaviour: some may become more clingy or unsettled, and others may be aggressive or disruptive.

What can you do?

- Many families tell us that being open and honest with their children was helpful.
- You can include your children in activities to remember your baby (see p.8). This gives them the opportunity to acknowledge the baby and respond and grieve in their own way.
- If you're not sure how to talk with your children about death, your bereavement worker can provide advice and other resource material.

Reactions from family, friends and colleagues

Family and friends may respond in different ways to your loss. They may feel upset and powerless to know how to help you. Sometimes they don't know what to say or they will make comments that you find unhelpful and hurtful. Friends and family can be very helpful for the first few weeks, but some will expect you to return to normal soon after. This can be very upsetting, and at this time you may need to remind them that things are still difficult for you. Professional support organisations can help, and have useful information to give to your family and friends (see p.34)

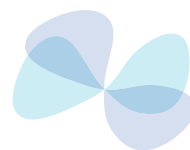
Multiple pregnancy

When there has been a multiple pregnancy, parents can be divided between mourning and making funeral arrangements for the baby or babies who have died, and keeping vigil at a sick baby's cot. Sometimes joy at the birth of a healthy baby, and sadness at the loss of another baby occur at the same time which can be a very confusing and distressing time. Complications in a multiple pregnancy are emotionally demanding and exhausting, and parents can be left with feelings of guilt and helplessness.

The staff will support you through the day to day while you are in hospital and your bereavement worker will stay in contact with you for a time after you go home. You may have a lot of questions about what happened and why your baby or babies have died. There will be many opportunities to talk to medical staff who will ensure that you are kept informed and involved throughout your care and the care of your babies.

When you are single

Even with a high level of support from family and friends, it can be a very isolating experience to be grieving the death of your baby on your own. It is important that you are able to share your thoughts and feelings with someone you trust. There are professional supports available to you, some of which are available twenty four hours a day (see community support contacts on p.34).



Overview

- There is no right or wrong way to feel or behave when you are grieving; everyone grieves in their own way.
- Grief can cause physical and emotional reactions.
- The way you deal with grief might be different from that of your partner. Be patient with each other, or ask for help if you are finding it hard.
- Children may have different responses to grief than adults - look out for behaviour that is not normal for them and try to keep them involved if you can.
- Family and friends can find it hard to know how to respond and will sometimes say hurtful things without intending to. Professional and community organisations have information which is especially for families and friends.

Who will care for you at the Women's?

The Reproductive Loss Service at the Women's is provided by a team of professionals committed to the care of women and families when their baby dies. Your care team will provide care that is respectful of your values and beliefs, and the decisions that you make.

The people caring for you are:

- midwives or nurses
- doctors
- bereavement worker
- anatomical pathology staff

Midwives or nurses

Depending on where you are admitted to hospital, you will be cared for by either a midwife or nurse. A midwife has specialist qualifications in pregnancy care. Nursing staff may have specialist qualifications in gynaecology, or caring for babies. Where possible, the same midwives or nurses will care for you and your baby until you leave the hospital.

Doctors

You may see a number of doctors during your time in hospital. The doctors caring for you and your baby include obstetricians, who specialise in pregnancy care or gynaecologists, who specialise in women's health. A doctor who specialises

in the newborn babies is called a neonatal paediatrician and may be involved in the care of your baby. The doctors' responsibilities include providing medical care, completing legal documentation, discussing possible reasons for your loss and answering any questions you may have.

Bereavement worker

A worker from the bereavement support services team (pastoral care, social work or genetic counselling) will be notified of your loss. The bereavement worker will meet with you and your family to provide emotional support and information about grief. They can also advise on practical matters such as funeral arrangements, and referrals to community support organisations.

Your bereavement worker can be a pastoral care worker, social worker or genetic counsellor - it's your choice.

- A social worker can provide short-term grief counselling and assistance with other concerns such as financial, housing or relationship issues.
- A pastoral care worker can provide support and counselling and assist with spiritual and religious needs, including rituals, naming or blessings.

Important contact details

- A genetic counsellor can assist if your baby had a genetic abnormality. You may have already seen one of the genetic counsellors if the diagnosis occurred before your baby was born. If you require additional support from one of the other professions, this will be organised by the midwife or nurse or your bereavement worker.

Anatomical pathology staff

Anatomical pathology staff will care for your baby's body whilst in hospital. They will perform the post mortem examination if you have given consent (see p.17). Your baby's body will be treated with respect and dignity at all times by hospital staff.

Royal Women's Hospital

Located: corner of Flemington Road and Grattan Street, Parkville VIC 3052
Tel: (03) 8345 2000 (hospital switchboard)
Web: www.thewomens.org.au

Women's Social Support Services (social work)

A free and confidential service to women who are patients of the Women's.
Located: Women's Counselling and Support, ground level south
9am to 5pm Monday to Friday
Tel: (03) 8345 3050 or (03) 8345 3051
Email: social.support@thewomens.org.au

Pastoral Care and Spirituality Services

Located: Women's Counselling and Support, ground level south
9am to 5pm Monday to Friday
Tel: (03) 8345 3021

Genetic Counselling Service

Located: Outpatient department, level one
9.00am to 5.00pm Monday to Friday
Tel: (03) 8345 2180
Fax: (03) 8345 2179

Breastfeeding Education and Support Service (BESS)

Located: Level 4 south
Education and support to families who are patients of the womens experiencing breastfeeding problems.
Tel: (03) 8345 2000 (ask for BESS)

Outpatient appointments

Located: corner Flemington Road and Grattan Street, Parkville VIC 3052
Tel: (03) 8345 3032 or (03) 8345 3033



Patient Enquiries

Tel: (03) 8345 3030

Women's Health Information Centre (WHIC)

The WHIC is on the ground floor of the Women's, near the front entrance.

It offers a range of information to borrow or to take free of charge. The midwives are information specialists who can help you to locate information and community resources that are useful and appropriate for your needs. You can drop in, telephone or email.

Open 9.00am to 5.00pm Monday to Friday

Tel: (03) 8345 3045

Regional/rural callers: 1800 442 007

Email: whic@thewomens.org.au

Aboriginal Women's Health Business Unit (AWHBU)

Located: ground floor (next to the Women's Health Information Centre)

Tel: (03) 8345 3047 or (03) 8345 3048

FARREP (support for women who have experienced female genital mutilation)

Located: ground floor in Women's Social Support Services

Tel: (03) 8345 3058

Email: Farrep.Program@thewomens.org.au

Sacred Space

Located: ground level north

This space is on the ground floor of the hospital. It is provided for families who may need quiet time away from the rest of the hospital.

Viewing room

A viewing room is available for families to spend some quiet time with their baby after death. Speak with your bereavement worker about accessing this room.

Accommodation

Accommodation may be available for parents from the country. Please speak with your bereavement worker.

Interpreters

For parents who speak little or no English, there are interpreters available in the hospital during standard working hours. The telephone interpreter service is available at other times.

Tel: (03) 8345 3054

Child Care Centre

The Child Care Centre is located on the ground floor of the hospital, next to the main entrance on Flemington Road. It is open 9am-5pm, Monday to Friday (closed on public holidays). Please telephone (03) 8345 2098 to book.

Consumer Advocate

The Consumer Advocate welcomes your comments, both positive and negative about all aspects of your care. Your complaints are handled confidentially and with concern, and will not reflect on your care now or in the future.

Located: First floor south

Tel: 8345 2290

Email: consumer.advocate@thewomens.org.au

Community support



The following organisations provide support for parents and families when a baby dies. You may wish to make contact with them now or in the future.

Australian Centre for Grief and Bereavement

McCulloch House, Monash Medical Centre
246 Clayton Road, Clayton VIC 3168
Tel: (03) 9265 2100
Fax: (03) 9265 2150
Freecall: (Australia wide) 1800 642 066
Email: info@grief.org.au
Web: www.grief.org.au

The Australian Multiple Birth Association (AMBA)

AMBA has a special club for bereaved parents who have had a baby or babies die, called the Multiple Birth Association Bereavement Support Group (M-BABS). More information is available on the AMBA website or you can email them.
Email: bereavement@amba.org.au
Web: www.amba.org.au

Bonnie Babes Foundation

A free grief counselling service for families that have experienced the loss of a baby through miscarriage, stillbirth or prematurity and related issues.
PO Box 407, Canterbury VIC 3126
Tel: (03) 9803 1800
Fax: (03) 9803 2699
Email: enquiry@bbf.org.au
Web: www.bbf.org.au

GriefLine

An anonymous telephone counselling service.
12.00 noon to 3.00am seven days a week
Tel: (03) 9569 7799
Web: www.griefline.org.au

Lifeline

24 hour crisis telephone counselling service
Tel: 13 11 14
Web: www.lifeline.org.au

Open Leaves Bookshop

Provides a comprehensive collection of books on death and bereavement.
79 Cardigan Street, Carlton VIC 3053
Tel: (03) 9347 2355
Email: openleaves@openleaves.com.au
Web: www.openleaves.com.au

OzMOST

(Aussie Mums of surviving twins)

An internet based support group for families who have experienced the death of a baby in a multiple pregnancy.

Email: OzMOST@tpg.com.au

Web: www.OzMOST.com.au/

SAFDA (Support after fetal diagnosis of genetic abnormality)

Genetic counselling service at the Women's (in partnership with SIDS and Kids).

Tel: (03) 8345 2180

Web: www.gsnv.org.au/SAFDA/

SANDS (Stillbirth and Newborn Death Support) (Vic)

Suite 208/901 Whitehorse Road,
Box Hill VIC 3128

9.30am to 3.00pm Monday to Friday

Tel: (03) 9899 0217 (administration);

(03) 9899 0218 (support line)

Fax: (03) 9899 0219

Email: info@sandsvic.org.au

Web: www.sandsvic.org.au

SIDS and Kids Victoria

1227 Malvern Road, Malvern VIC 3144

Tel: (03) 9822 9611

Fax: (03) 9822 2995

Email: melbourne@sidsandkids.org

Web: www.sidsandkids.org/vic/

The Compassionate Friends (includes the Bereaved Parent Centre)

24 hour grief support

Tel: (03) 9888 4944

Free call: 1800 641 091 (ask for local contact)

Web: www.compassionatefriendsvictoria.org.au/

Victorian State Coroner's Office

57-83 Kavanagh Street, Southbank VIC 3000

Tel: 1300 309 519 (all hours)

Victorian Registry of Births, Deaths and Marriages

595 Collins Street, Melbourne VIC 3000

Tel: 1300 369 367

Web: www.vic.gov.au/law-justice/births-deaths-marriages.html

Suggested reading

Lactation suppression (2005)

Australian Breastfeeding Association

Multiple birth - bereavement care for parents

(2008) OzMOST

Email OzMOST@tpg.com.au

Always a part of me: surviving childbearing loss

(2002) Amanda Collinge, Sue Danial, Heather Grace Jones, ABC Books, Sydney, Australia

Coping with grief

(1995) Mal McKissock, ABC Books, Sydney, Australia

Your baby has died

(2002) Rosemary Crowther and Penny Brabin SANDS (Vic), Australia

Empty arms - coping after miscarriage, stillbirth and infant death

(1990) Sherokee Ilse, USA

The grief of our children

(1998) Diane McKissock, ABC Books, Sydney, Australia

Shattered multiple dreams

(2005) Multiple Birth Association Bereavement Support Group (M-BABS)
Email: bereavement@amba.org.au

Pregnancy after loss

(1996) J and M Warland, Adelaide

Web: www.unisanet.unisa.edu.au/staff/homepage.asp?Name=Jane.Warland

Our baby died

(1994) Jane Warland, Melbourne JBCE (Uniting Education)

Web: www.unisanet.unisa.edu.au/staff/homepage.asp?Name=Jane.Warland

SIDS and Kids publications

- Choices in arranging a child's funeral
- Always your child
- To family and friends - you can make a difference
- Grandparent to grandparent
- Treasured babies
- Another baby? The decision is yours
- Miscarriage: information for parents and families (NSW).

SANDS publications

- Your baby has died (2003)
- Our babies have died - stories of miscarriage, stillbirth and neonatal death (2008).

Websites about loss and grief

www.grief.org.au - The Australian Centre for Grief and Bereavement provides information about grief and bereavement, counselling supports, education services and resource materials.

www.bereavementcare.com.au - general information about grief and bereavement including an interactive site for children who have experienced the death of a family member.

www.grieflink.asn.au - an information resource on death-related grief for the community and professionals.

www.stillbirthalliance.org - the International Stillbirth Alliance (ISA), a non-profit coalition of organisations dedicated to understanding the causes and prevention of stillbirth.

www.compassionatefriendsvictoria.org.au - a worldwide organisation offering friendship and understanding to families following the death of a child or sibling.

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The Mater Mother's Private Hospital (2004) *Telling other children*

SANDS (2003) *Your baby has died*

OzMost (2002) *Multiple loss bereavement care: important information for care providers*

Schott J, Healey A, Kohner N (2007) *Pregnancy loss and the death of a baby - guidelines for professionals*, 3rd edn, SANDS, Great Britain

Terms you may hear

Autopsy - also called a post mortem (see below).

Caesarean section (delivery) - when the baby is delivered by surgery. A doctor cuts an opening through the abdomen and into the uterus.

Cervix - the entrance of the womb or narrow lower end of the uterus that opens into the vagina.

Conception - when the ovum or egg is fertilised by the male sperm.

Coroner - the State Coroner has a legal responsibility under the *Coroners Act 1985* to investigate reportable deaths to find out what happened and why. The Coroner is usually a magistrate (who is a lawyer).

Doctor - a medical practitioner registered under the *Health Professions Registration Act 2005*.

FDIU (Fetal Death in Utero) - medical term used when a baby dies during the pregnancy. An 'Unexplained' FDIU is where there is no apparent reason for death.

Funeral director - professional employed by the family of the deceased for the purposes of carrying out a lawful burial and cremation.

Genetic - inherited, hereditary.

Gestation - the duration from the first day of the last menstrual period to the date when the baby is born, or in the case of stillbirth, the duration from the first day of the last menstrual period to the date when the fetus is known to have died. If the first day of the last menstrual period is uncertain, the gestational age is established by ultrasound.

Induction of labour - when a midwife or doctor encourages the start of labour. This can be done in a few ways including 'breaking the waters' or with synthetic hormones delivered via a drip.

Infant death - is the term used when a baby dies more than 28 days after birth, and before the first birthday.

Midwife - a health professional who, in partnership with women, provides care, education and support. The midwife works with women, partners and families during the prenatal, pregnancy, birth and the postnatal periods.

Miscarriage - when an egg and sperm join, they rapidly develop new cells. These cells are the very early stages of a pregnancy, and in a successful pregnancy the cells continue to grow and develop to form a baby. A miscarriage occurs when the cells stop developing and the pregnancy comes

to an end prior to 20 week's gestation. At this stage, the tissue from the pregnancy is passed out of your body and you will experience bleeding and some pain.

Neonatal death - is the term used to refer to a baby who is born alive, and dies within 28 days of birth.

Obstetrician - a specialist doctor with extra qualifications and training in pregnancy and birth.

Perineum - the area between the anus and the opening to the vagina.

Perinatal death - the term used to describe:

- a. the death of a live-born child within 28 days after the birth; or
- b. a stillbirth after 20 weeks gestation.

Post mortem - a post mortem examination is performed after death to find out as much as possible about why your baby died.

Postnatal - the term used to describe the six week period immediately following the birth of the baby.

Products of conception - the contents of the uterus during pregnancy, including the placenta, baby and amniotic sac.

Registrable birth - when the baby shows signs of life at birth or when the gestation is 20 weeks or more, the birth must be registered under the *Victorian Births, Deaths and Marriages Act 1996*.

Stillbirth - is the term used to refer to a baby who has died prior to birth or who dies during birth and who has reached 20 or more weeks gestation. If a baby is born without any signs of life and the gestation is uncertain, he or she is also considered to be stillborn if the birth weight is 400 grams or greater. A stillborn baby who meets this criterion requires registration.

Ultrasound - a test to view the internal organs of the baby in the uterus. It uses sound waves that echo off the body to create a picture of the baby.

Unregistered birth - if the baby shows no signs of life at birth and gestation is less than 20 weeks, (and the baby weighs less than 400 grams if the dates are not known;) the baby's birth is not registrable under *Victorian Births, Deaths and Marriages Act*.

Uterus - a muscular organ in which the baby grows.





We welcome your comments

The Royal Women's Hospital has taken great care to produce this booklet. We have consulted widely with families and carers to ensure that it is useful, relevant and sensitive to your needs at this time. However, we are aware that there may still be gaps in the information and that there are always ways that we can improve this very important information booklet. We genuinely welcome your comments and your feedback - both negative and positive.

Please forward your comments to Women's Consumer Health Information.

Postal address:
Locked Bag 300
Parkville VIC 3052
Tel: (03) 8345 3040
Email: rwh.publications@thewomens.org.au

Thank you to the Taplin Family for sponsoring this edition of **What do we do now?**

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*I was alone
In my distress and desolation.
But as I sat sadly on the ground,
The sun reached out his hand to me
And touched my face
And so my healing began*

From *End and Beginning* by Marjorie Pizer

