



Guiding Conversations

with your health care team
when your baby dies



This guide comes with our heartfelt thoughts, as a message of support to you at this difficult time. We know the intense grief that parents experience when their baby dies. The shock and emotional distress can be overwhelming.

There are often difficult decisions to make and things to plan. These include making choices about care for you and your baby while you are in hospital and finding support when you return home.

Through this guide we want to give you the best possible evidence about what can be helpful for parents around the time of their baby's death. It adds to the information and support you will receive from your health care team and may help support the discussions you have with them.

There are many types of pregnancy loss that can happen at different stages, for many different reasons and in many different circumstances. Every loss is unique and not all the information in this guide will be relevant to all situations. We hope that some of what you find here may be helpful.

This guide aims to help you think about what is important for you as a parent of your baby, the questions and concerns you have, and to work out what may be right for you.

How this guide was developed

This guide is based on the Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death, which was developed in 2020 by the Centre of Research Excellence in Stillbirth (Stillbirth CRE) and the Perinatal Society of Australia and New Zealand (PSANZ). The Clinical Practice Guideline is the most current and comprehensive guideline to assist health care professionals in providing the best possible care for parents when their baby dies or is expected to die.

This parent version has the same information adapted for families. It draws on the experiences of parents and health care providers, along with best available research, and it has been designed to be sensitive to parents and their families at the time of loss. The focus is on stillbirth and neonatal death, and much information may also be relevant for parents who have had other types of pregnancy loss.

This guide has been funded by Stillbirth Foundation Australia, who have worked in partnership with the Stillbirth CRE to develop this parent version.



Design and distribution funded by the Sydney 2 CAMberra Charity Ride, which was created after a young Sydney couple lost their son Cameron through stillbirth. The tragic event heavily impacted their life and touched many of their family members and friends. In recognition of Cameron, the Ride raises significant funds, awareness and support of families affected by stillbirth and SIDS.



We acknowledge the Traditional Owners of this land and their ongoing custodianship. We pay our respects to their Ancestors and their descendants, who continue cultural and spiritual connections to Country.

We acknowledge the diversity across Aboriginal and Torres Strait Islander cultures, language and practices and that it is vital that all health care services respectfully manage protocol and provide a culturally positive health care experience for Aboriginal and Torres Strait Islander people when going through sorry business.





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How to use this parent guide

This guide is designed to help you think about what is most important at this time and to help you find the information and support you need. You can use this guide in different ways. Some topics may be relevant straight away, others may matter to you later and some may not be relevant to you at all. The guide is written for parents, but you could share it with members of your family or support network.

It can be hard to find the right words or to know what questions to ask. There are spaces for you to write down or highlight any topics or questions that you would like to discuss with your health care team. Your health care team may include your midwife, doctor, social worker or others who are involved in your care while you are in hospital and after, when you go home.

Parents often find it helpful to hear from others who have faced a similar loss. These pages include quotes from parents who share some of the things they found helpful.

You may find that this guide covers topics you have not thought about yet. Not all topics will be relevant to you. Please turn to the topics that are most helpful for you and skip over those that are not. If at any time you find any topic distressing, please remember that support and further information is always available from your health care team.

There are links to more information and support organisations at the end of this guide.

Some helpful contact numbers are listed on the last page and you can add to these. Many parents find it helpful to have a main contact person who can help to answer their questions. You may wish to ask your health care team to add their details so you can get in touch when you need to.



When my baby died, I had no idea what I needed to know, or what was possible. It was such an overwhelming time. What I really needed was to know the options I had so that we could make decisions that were right for us.







A note about grief when your baby dies



From the start my partner and I handled our baby's death completely differently. I thought he should be upset, but he looked like he was okay. One of the most helpful things I read was that the biggest strain on relationships isn't that you've lost a child, but that you aren't able to accept each other's ways of grieving. Then I just thought to myself 'All right, we are not going to grieve the same way.'



A note about grief when your baby dies

There is no right or wrong way to grieve, there is no timeframe, and there are no set stages to go through.

It is normal to feel overwhelmed by emotions when your baby dies. Parents describe feelings that may include deep sorrow, sadness, shock, numbness, anxiety, guilt, fear, anger, and blame. These feelings may be intense, confusing and frightening. But they are normal for parents who are grieving the loss of their baby. Grief can affect all aspects of ourselves – our emotions, our thoughts, our bodies, the way we relate to others and our spiritual beliefs.

Each person will have their own way of grieving. Some find it helpful to express their feelings by talking with others, while others need to go inward or express their grief by doing something practical. It is common for partners and family members to grieve in different ways. Over time, people's ways of grieving may change.





Making decisions for your baby

Making decisions for your baby

Along with the stress and grief, there are often difficult decisions to make and things to plan. Parents often say they are glad to have had the chance to be involved in decisions. The decisions you may need to make will depend on your situation. Making decisions at a time of grief and overwhelming emotions can be hard. Parents or other family members may also have different views, and this can add challenges.

The support and information you need will depend on your personal and family situation, your beliefs and values, and on the decision itself. Your needs may also change over time.

There is no one 'right' way to respond at a time like this. It is important to have the support and information you need so that you can be involved in decisions to the extent that you choose and to sort through different options.

To help with making decisions

- A member of your health care team is your first point of contact. This may be a midwife, obstetrician, social worker or another health care professional who is involved in your care at this time. *You might use this guide to help the conversations you have with them.*
- You may wish to involve other people, such as family members or trusted friends, your general practitioner (GP), another parent who has had a similar experience, or a spiritual leader or elder.
- Stress and grief can make it more difficult to take in and remember information. You may need to repeat your questions and ask for information to be explained again. Please ask your health care provider as many times as you need so that you have the information you are seeking. *Parents often find it helpful to have a support person with them to help with questions or take notes.*
- You might also find that you are asked the same question several times by members of your health care team. This may feel difficult, unnecessary or frustrating. But it gives you a chance to think about your options, to check your understanding, and time to ask more questions.
- Sometimes talking to your health care team is enough, but at other times you may want more information. Parents often find it helps to receive information in different ways, such as written or online information and from parent support organisations. You will find some links to information in this guide.

You may feel that some things are out of your control, but as your baby's parent, you can decide what feels right for you and your baby.



There were so many decisions to make at such a devastating time. It's very hard to make decisions in the midst of grief. You don't know what you want and you don't know what you need. The team at the hospital helped us work out what we needed to do next, and how much time we had to think about what to do. They also let us know about other places we could find information we could trust.



Questions you might have about making decisions

Talking with your health care team

- Who are the main people on your health care team, and how can you contact them?
- What things might your health care team need to know to help you? (such as any spiritual, cultural, religious or other personal needs)
- Where will you stay while in hospital? Will you have the privacy you might need? Will your partner or support person be able to stay with you?
- What questions would you like to ask your health care team?

To work out what is most important to you, it may help to write down some of the questions you have. You can use the spaces provided to write down your questions and any other notes.

Involving other people

- Are there other people you would like to have with you to support you with your decision-making?
- Is there someone else you might like to talk to?
- Would you like your health care team to contact someone for you? (such as a family member or friend, a spiritual leader, elder or interpreter, or another parent who has had a similar experience)

Types of information

- What forms of information would be most helpful for you? (such as booklets or brochures, reliable online information, information from parents who have had similar experiences)
- Would you like to have any information explained again?
- Are there any decisions that need to be made quickly?

What information and support is most important to you right now?

What are your main concerns?

What other information or support do you need?





Preparing for your baby's birth

Preparing for your baby's birth

When you are given the news that your baby will not be born alive, or may live for only a short time, one of the decisions that may need to be made is how your baby will be born. There may be time to prepare for your baby's birth and to think about what is most important to you about how this takes place.

There may be no rush to birth your baby, or it may be that your baby needs to be born quite quickly. The timing of your baby's birth may depend on your health and some other factors to do with the pregnancy. Ask your doctor or midwife to explain your birth options and how much time you have to make decisions.

If you have already prepared a birth plan during your pregnancy it can be hard to re-think your needs and wishes. Yet many parents in this situation later say that they were glad they had the chance to prepare a plan that included their needs and wishes for their baby.



I had prepared for a natural birth and calm birthing and still wanted my birth plan. We were able to follow that plan as much as we could. It helped me feel I had done the best for my baby.





Birthing your baby

In most cases vaginal birth is likely to be a safer option for the mother than a caesarean birth. A vaginal birth can also provide both physical and emotional benefits, compared with a caesarean birth, including for future pregnancies. There are reasons why a caesarean may be recommended as the safest option, such as if you have a specific medical condition. Having your partner, another family member or support person with you when discussing the birth with your health care team is usually helpful, as they know what is important to you and can often take in information and ask questions that you may forget to ask.

If your baby is still living, but not expected to survive for long after the birth, decisions may centre on being able to meet and care for your baby while they are alive.

It may seem to you that caesarean section is your obvious choice, but it is really important to consider the pros and cons and to discuss your wishes and concerns with your midwife and obstetrician.

When a baby is expected to be born alive, decisions about planning medical care may also be needed. You can make a palliative care birth plan with staff who will care for you and your baby during and after birth.

Think and talk about what is most important for you and your baby, what might happen around the time of birth, preferred treatments or tests, ways to keep your baby comfortable and where to care for your baby if they live long enough to leave hospital. This won't be a one-off conversation: keep talking with people in your health care team about what is important for you and your baby to help your baby have a good life, even if it is a very short life. It is also okay to change your mind as time passes. Just let your health care team know what you are thinking.

Please ask your healthcare provider if you need any information repeated or explained. You may also wish to ask for written information or to be directed to appropriate websites and support services.

If there is enough time, some of the things you might wish to think about are:

Preparing for birth

- What information do you need to help you prepare for the birth of your baby? What might help you to develop a birth plan? What is most important to you?
- How would you like to birth your baby? What are your main worries or concerns?
- What are the potential benefits and risks of vaginal and caesarean birth in your situation?
- What are the options for where and when you will birth your baby?
- What would help to create a supportive atmosphere? (such as lighting, sound, scent, special items, privacy, space for family or support persons)
- Who would you like to have with you during the birth? Would you like to involve family members or other members of your support network? When might you want them there?
- Would you like to have photographs or video taken? Do you want photographs of your time in labour as well as when your baby is born?

When your baby is born

- How would you like to meet your baby for the first time? What will your baby look like?
- Would you like skin-to-skin contact with your baby as soon as they are born?
- Who would you like to cut your baby's umbilical cord?
- Are there cultural, spiritual or other rituals that are important to you and your family at the time of your baby's birth, or death?

If your baby is expected to be born alive

- What would help you to develop a plan about the medical and health care your baby might need? What is most important to you?
- What are the options for medical care for your baby to keep them comfortable while they are still alive?
- What are the options about where you can care for your baby if they live long enough to leave hospital, for example hospice care or at home?

Timing of birth

Depending on the situation, you may be able to decide when your baby's birth will take place. This could be as soon as possible, or you may prefer to go home for a while beforehand. For some parents, having time at home can help them to process what has happened, to discuss the information they have been given and to think about what they might want to happen around the time of the birth.

It may also be a time for you to gather with family members, including any other children, to talk about your baby.

Things to consider may include:

- Would you like the birth to take place as soon as possible, or would you like to continue the pregnancy without intervention?
- Will tests and monitoring be needed while waiting for the birth?
- What might happen to your baby if you delay the birth?
- What might happen to you if you delay the birth?
- Will delaying the birth affect the results of tests that might be done on your baby to understand the cause of death?
- Who do you contact if you change your mind or are worried?

Options for managing pain

Some women will prefer to be as aware as possible during the birth. Others will choose different pain management options depending on their situation, or may be unsure. It is important to discuss pain relief options for labour and birth with your health care team.

Things to consider include:

- What questions do you have about pain relief options?
- Would you like to consider pain management options such as ‘the gas’, morphine or an epidural, or would you prefer to avoid medication during labour?
- Would you like to be upright, mobile and active during your labour?
- Would you like the option of labouring in water?
- What physical position would you like to be in when you give birth?

Discussing your concerns with your health care team, midwife or obstetrician can help you decide what is best for you. Many women change their choices during labour and birth.

What are your main concerns?

What other information or support do you need?





Honouring your baby



At first I was really afraid when I thought about spending time with our baby. I talked with my midwife, who was able to tell me what other parents have found helpful and to make some suggestions. The memories we have, like the photographs and time spent with our baby, mean so much.



Honouring your baby

Right now, it may feel hard to think about making memories with your baby. But parents often find how important those memories become and that they carry them close to their hearts. These include mementoes and keepsakes of your baby (such as photos, hand and footprints, and other special items) as well as memories made spending time with your baby. Looking back, many parents say that being able to parent their baby, even for a short time, is something they cherish.

Finding ways to parent your baby and gathering mementoes is a way of honouring your baby. These memories can also be important to share with others, to show that your baby is part of your family.

Your health care team can help as much or as little as you wish as you think about ways to create memories with your baby.

Remember, there is no single right approach. Most parents find it hard to know what to do.

It is okay to take time to think it over before deciding. Sometimes decisions need to be made quickly but often you don't need to rush to make important decisions. Take the time you need. It is also okay to change your mind as the days pass.


Spending time with your baby

There are many ways to make memories and to be a parent to your baby. You may feel unsure or anxious about some of the ideas – many parents do at first.

Talking about your baby with a member of your health care team or with someone else you trust is a good place to start if you are not sure.


These are just a few ways of creating memories of your baby:

- Naming your baby and saying your baby's name aloud.
- Gently talking, reading or singing to your baby and telling them about the family they belong to.
- Gathering mementoes such as hand and footprints, locks of hair, baby's identification bracelet. You may wish to keep the mementoes you collect in a memory box.
- Photos and/or video that 'tell the story' – such as photos taken around the time of birth, before and after baby is born – and photos of others with your baby.

Professional photography services, including local volunteer services such as **Heartfelt** , may be available.

- Planning a naming ceremony, blessing or some other ritual for your baby.
- Spending time with your baby in ways that you choose, for example holding, bathing, dressing and undressing your baby, seeing all your baby's features.
- Dressing your baby in clothes that you have chosen for them. You may have had some clothes ready for your baby, or you may want to find a special outfit. Volunteer services such as the **Red Nose Treasured Babies Program**  and **Angel Gowns Australia**  handcraft beautiful clothing to give to parents for their baby.
- Inviting siblings and other family members, such as baby's grandparents, aunties, uncles and cousins, and others who are special in your life, to meet and spend time with your baby.

 **heartfelt.org.au**

 **Treasured Babies Program:**
<https://rednosegriefandloss.org.au/support/article/treasured-babies-program-seeing-holding-and-dressing-your-baby>

 **angelgownsaustralia.org.au**

- A 'cuddle cot' (a special bassinet or basket with a small cooling unit inside) may be available for you to keep your baby close to you for an extended period of time after they have died.

When a baby has died, some parents feel they would like to have some time with their baby outside the hospital environment. This might be a place that has meaning for you and your family, such as the family home or somewhere outdoors in nature, even in the hospital grounds or garden. Ask your health care team about how they can support you to take your baby outside the hospital, including transport options and the use of a cuddle cot.

Parents of twins, triplets or other multiple births

Parents of twins, triplets or other multiple births may experience conflicting emotions when one or more babies die and one or more survive. You may be torn between spending time with a baby who has died and devoting time to your surviving baby or babies. This can be a difficult situation and it is important to share your concerns with your health care team and others.

Some further information about pregnancy loss with twin, triplet or multiple babies can be found here:

 tinyurl.com/GCTwinLoss

If you feel you are not quite ready to think about gathering mementoes or keepsakes, you might ask someone you trust to help store these for you until you are ready. Your health care team may be able to guide you on this.

Sometimes parents find they are unable to create memories around the time of their baby's birth. There are many ways of honouring your baby at any time, even many years later. Parent support organisations, such as those at the end of this guide, can help you with ideas and information.

Some parents choose to not spend time with their baby, and this too will be respected.



I just didn't feel able to spend time with my baby. But a midwife told me how she cared for him and how he looked. She described how she carefully wrapped our son and placed him in a cot, and the details of his face and hands. I am so grateful to the midwife for allowing me to see my baby through her eyes.



Questions you might have

- What would you like to know before you spend time with your baby? What are your concerns? What are your hopes? Are there things you are fearful about?
- What will your baby look like?
- How would you like to spend time with your baby?
- Who would you like to have with you? Do you want time alone with your baby?
- How would you like to start gathering mementoes of your baby? Are there family members and/or other people special to you that you want to involve?
- Would you like to talk to your health care team about taking your baby somewhere outside of the hospital?
- How can you involve your other children, or other family members or friends?

When you think about ways to make memories with your baby, what is most important to you?

What are your main concerns?

What other information or support do you need?





Saying goodbye
to your baby



My social worker said to us that there is no right or wrong way to honour our baby. We decided to have a funeral service, but a friend – who very sadly has also had a stillborn baby – chose not to. Their family wanted a different way of saying goodbye.



Saying goodbye to your baby

Saying goodbye to your baby is hard. There may be a series of goodbyes, such as the last time you see or hold your baby, when you leave hospital, or at a funeral service for your baby. Having time to think about how and when you will say goodbye to your baby is important. You may feel under pressure to make decisions, but take the time to help work out what is most important to you.

You will likely need to think about burial or cremation of your baby's body as this is required by law. These arrangements need to be made with a registered funeral or cremation service. Your health care team will be able to tell you about options and help you to contact relevant services in your area. A funeral director will be able to guide you through options for funeral arrangements. Costs will depend on your choice of funeral service. Some funeral services offer reduced costs to families whose baby has died.

Organising a funeral or other service for your baby can be daunting and overwhelming. But having some form of commemoration that is meaningful to you and your family is another way for you to honour your baby. The type of funeral service – and whether you have a funeral – is up to you. There is no rush to decide and you can change your mind about arrangements at any time before the funeral. You can wait until a later time to commemorate your baby if you wish.

When planning a commemoration for their baby, many parents have included words, songs, images, clothing and other special items that have meaning for them and their baby.

Questions you might have

Saying goodbye

- Is there someone you would like to talk with about how to say goodbye to your baby?
- Where will your baby be? When will you be able to see or spend time with your baby?
- Who will be taking care of your baby?
- How will your baby travel to the funeral home? Are you able to travel with your baby to the funeral home?
- Would you like to take your baby to your home before the funeral?

Holding a funeral service or other ceremony

- What are the options for holding a funeral service or other type of commemoration to honour your baby?
- Is there something that you would like to have happen? (such as special clothing, toys or other items for your baby, or reading a message, poem or letter)
- How might your other children, family members or friends be involved in a funeral service or ceremony for your baby?
- Would you like to involve a spiritual leader or elder in the commemoration of your baby? Are there any customs or rituals linked to your culture, spirituality or faith you would like to include?
- Where would you like your baby's final resting place to be? What options are there for a burial spot for your baby? If your baby is cremated, what options are there for your baby's ashes? This could be a special urn, within a piece of jewellery, or placing the ashes somewhere that is meaningful to you. There is no rush to make these decisions.

You may feel under pressure to make decisions, but if you can it's important that you take the time to help work out what is most important to you.

Please talk to your health care team about where you can find the information you need.

What is most important to you as you think about saying goodbye to your baby?

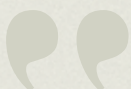
What are your main concerns?

What other information or support do you need?





Understanding why your baby died



I wanted the doctor to tell me only the most important information because there was too much to take in, but my partner wanted much more detail and to find out everything. We both needed time to think about things.



Finding answers

Finding answers is often of great concern to parents when a baby has died. There are a number of tests (investigations) that your health care provider will undertake to help understand the cause of death. You are likely to be asked about an autopsy for your baby because it offers the best chance of finding answers. These can be difficult discussions for all involved. You may have conflicting thoughts: a strong need to find answers as well as a strong need to protect your baby.

Clear and balanced information will help you to make the decision that is right for you and your baby. It is important that you get the information you need and to know when and how you will receive the results of any investigations.

Investigations

Whether to have an autopsy (sometimes called a post-mortem) for their baby is a confronting decision for many parents.

An autopsy is where the baby's body is medically examined to help understand the cause of death. An autopsy can help explain why a baby died or rule out a suspected cause. Understanding whether a problem could arise again may also help guide any future pregnancy.

There are different levels of autopsy, such as a full autopsy, partial autopsy or other less invasive investigations for your baby. A full autopsy offers the most detailed level of examination of your baby's body and combines these findings with a review of clinical notes and medical investigations of the mother and the placenta. An autopsy does not always uncover a cause of death. This can be very difficult for parents. Even when a cause is not found, possible causes may be ruled out and there can be important information to help with understanding or for future pregnancy care.

Some parents will feel certain about going ahead with an autopsy. Others will feel that it may not be right for them or their baby. Often parents will feel unsure and will have concerns or fears. This is normal and it is important to discuss your questions and concerns with your health care team.

Your health care provider can provide information about other investigations that may help to find the cause of death (such as MRI or CT) if you choose not to have an autopsy examination.

You can find more information to help with the decision about autopsy in a brochure that has been prepared by the Perinatal Society of Australia and New Zealand/Stillbirth CRE.

 tinyurl.com/GCAutopsyConsent

Sometimes it's hard for parents to put into words their concerns about an autopsy or other investigations. Your concerns may include:

- Needing to know that your baby is being taken care of and protected.
- Needing to know where your baby will be taken.
- Whether you will be able to see your baby again and how your baby may look.
- Possible delays for funeral arrangements.
- The amount of time you can spend with your baby, and whether you can still bring your baby to your home if you wish.

It is important that you have the information you need and enough time to make the decision that is right for you. Your health care team will be able to give you more information including written information for you to keep.





We made some decisions on our own, but there were times when it helped to ask questions and talk to others. It was exhausting and overwhelming, but in the end we feel comfortable with our decision. We felt reassured to know that our baby would always be treated with care and respect.



Finding out the results of investigations

You may find out the results of some investigations or tests before going home from hospital. Other results may take longer. Parents can find that the wait for the results is difficult. It can be helpful to think that the time it takes for a thorough investigation means you will have the best possible information about the reasons for your baby's death. Parents often find it helps to know when and how they will receive the results that are not available at the time of discharge.

Parents are usually offered a follow-up appointment within about 12 weeks of their baby's death. These appointments are led by a senior health care professional and are an opportunity to talk about medical and emotional aspects of your care.

You may wish to find out the process and expected timeline for getting the results of tests, including when your follow-up appointment will be held.

Questions you might want to ask your health care team may include:

- How will you get the results of investigations?
- When will the results be available?
- Will the results be presented in a way that is suitable for you to read as your baby's parent?
- Who will help explain the results?
- Who do you contact if you have questions?
- When will your follow-up appointment take place? Where will it be held? (some parents prefer that it is at a time and place where they won't have to wait with pregnant women or babies, if possible)
- How are the autopsy results used by the health system to help understand reasons for pregnancy loss?



I remember feeling that I couldn't follow everything the doctor was saying about the possible reasons our baby died. I was able to ask her to explain it again in a way that made sense. And it was good to have the short summary that didn't use all the complicated medical words.



Hospital committee review to understand causes of a baby's death

When a baby dies, many hospitals do a formal review of the care mother and baby received to help understand the events leading up to the baby's death. This is sometimes called a 'perinatal mortality audit' or 'perinatal mortality and morbidity review'. In some specific cases a much more in-depth investigation may be conducted by the hospital such as a root cause analysis or external review, and this may take some time to complete.

As part of the process to understand why your baby died, a health care professional will prepare a summary of what happened during your pregnancy (a clinical history) and may ask you some questions to help with that summary.

As your baby's parent, you might be asked to give input to a hospital committee review.

- What would you like to ask your health care team about the hospital's perinatal mortality review? Will there be a review? When will it take place? Who will attend?
- Is there anything you would like to tell your health care team about your care, or about you or your baby, to help the hospital understand why your baby died?
- What feedback will you receive from the review? Who will give you this feedback? When will you receive the feedback?

Questions you might have

About autopsy or other investigations


- What are the reasons for having an autopsy? What will an autopsy tell you?
- What types of autopsies and investigations are possible?
- How soon do you have to decide about whether you agree to an autopsy?
- Who would perform the autopsy?
- What tests might be done on the placenta?
- How long does it take to get an autopsy report?
- Who pays for investigations?
- Where can you find more information to help with your decision?

Care for your baby around the time of autopsy

- When will you be able to spend time with your baby if they have had an autopsy?
- How will your baby look when they return from the autopsy?
- Who will be taking care of your baby? Where will your baby be taken and how will your baby get there? Who will go with your baby? Can you go with your baby?
- How long will your baby be away? Will an autopsy delay the funeral?
- Are there any special items, such as a blanket, message, toy, or other keepsakes that you would like to stay with your baby?

There is space at the end of this guide to write down the details of your follow-up appointment and any questions you might want to ask.

What information and support is most important to you as you think about possible investigations for your baby?



What are your main concerns?

What other information or support do you need?





Leaving hospital



Once we left hospital it was a long journey. I guess in a way leaving hospital is just the start of a difficult road. What I really needed to know was what to expect ... it helped to know that support was out there when I needed it. The hospital gave me some contact details and made a follow-up appointment for me to see them.



Leaving hospital

Leaving hospital can be a time of mixed emotions. Some parents want to leave as soon as possible, other parents feel they are leaving a place that holds many precious memories of their baby.

Most parents find that leaving hospital without their baby is a very painful moment in time. It may feel like the start of a new phase of grieving. It may be when the reality hits as you return home to a life that is so different than the one you had planned. It is a time to be gentle on yourself and to know that deep sadness and many intense emotions are a normal part of grieving for your baby. It is important that you leave hospital knowing that support is available if needed.

Please ask your health care provider to write contact details for 24-hour follow-up support on the last page of this guide. Your health care team may also arrange a follow-up phone call or visit to your home soon after you return from hospital.

There is also 24-hour phone support available to you through Red Nose (1300 308 307).

Your physical recovery

While in hospital, your health care team (for example, your midwife or obstetrician) will be able to give you information and support to manage your physical health. This should include things to watch for and when to seek medical care as well as other relevant information.

Your physical health care is important, just as it is for any woman who has given birth. Vaginal bleeding and breast milk production (lactation) are normal, but these and other physical reminders can be upsetting for women when their baby has died.

Breast milk/Lactation

There are different options for managing lactation. Some mothers choose to stop their body making breast milk with medication, while others choose to continue lactating. Some mothers may want to donate their breast milk to help another baby via a Milk Bank, if this option is available.

Your decision relates to both your physical and emotional wellbeing and it's important that you have support for the decision that is right for you.

Please discuss with your midwife or doctor the different ways to stop, slow down supply, or use the breast milk your body makes so you can make the decision that is right for you.

This resource from the Australian Breastfeeding Association provides helpful information:

 <https://tinyurl.com/GCLactation>

Medical follow-up

It is important that you receive the health care you need once you leave hospital. As for all women who have given birth, a post-natal check with your general practitioner (GP) or obstetrician should be scheduled soon after birth. Your health care team can advise your GP or obstetrician of what has happened so that they have the relevant information before the appointment.

Parents can find it upsetting to receive reminders about appointments that are no longer needed. Your health care team can help to cancel appointments and make any new appointments that may be needed.



I wasn't expecting to feel so emotional about all the changes in my body after the birth. Having an appointment with my GP helped to reassure me.



Emotional support

Facing the future

Going home from hospital without your baby can be an intensely emotional time. You may find you have unanswered questions about the reasons your baby died. It can be daunting to think about facing people and telling others about what happened. It can be helpful to prepare for interactions with others, and to realise that family and friends might not know how to respond. You may also have concerns about how others in your family are managing or about the effects on your relationships.

For many parents certain days and anniversaries can be especially hard. Times that would usually call for celebration such as your baby's due date, family gatherings, religious or cultural events and other holidays may instead be painful reminders of your loss. Hearing of others becoming pregnant or babies being born can be a time of mixed emotions. These reactions are a normal part of grief following the loss of a baby.

Feelings of grief often continue over a long time and getting the support that best suits you is important. It is common for parents to seek extra support, especially in the early stages of their grief. Different types of support are helpful at different times. Some examples are:

- Written or online information about the grieving process to refer to as needed.
- Connecting with other parents who have experienced the death of their baby. This kind of peer support is widely available through parent-based organisations listed on the back page of this guide. Your health care team can help you to contact these organisations if you wish.
- Talking with your GP or other health care professional, such as a skilled grief counsellor who specialises in supporting parents after their baby dies. You may be able to get help with costs through Medicare. Grief counselling is available at no cost to parents through organisations such as Red Nose.
- Spending time with trusted family members, friends and others who understand.
- Seeking support from spiritual leaders or elders.
- Taking care of yourself in ways that are right for you, such as physical activity, rest, music, art, yoga, spending time in nature, writing in a journal.
- If you have other children, getting guidance about how to best support them or others who may be very affected by your baby's death.

You may feel you need more support if you have other life stresses or if you have experienced anxiety, depression or other mental health problems in the past. Your health care team may also suggest referral to a service or health care professional experienced in supporting parents and families whose baby has died.



Practical support

There may be practical issues to consider. Some, such as registration of your baby's birth or other paperwork, will need to be completed by most parents. Others will depend on your own personal situation.

Parents often have questions about medical certificates, parental leave or possible sources of financial assistance, such as the Centrelink claim form for bereavement payment.

Your family may be eligible for bereavement payments, including Parental Leave Pay. You can find information at Centrelink. A social worker or other member of your health care team can help with further information.

Exploring options about returning to work may be important. Parents may be entitled to different types of paid or unpaid leave. Some parents find it helpful to talk with their employer (or another trusted colleague) when they feel ready. You may want to discuss how you would prefer to let others know about your loss and any steps that could be taken to help with a return to work.

Other practical issues might include help with the care of other children, additional caring responsibilities you may have, and other day-to-day activities. Do talk with your health care team about practical tasks that need to be organised. Family members or friends may also be able to help with some everyday tasks.



I found online support meant I could communicate with people without having to go through the emotions face-to-face. I connected with people who understood. One of the ideas I learned from other parents was to have a ‘go-to’ statement so I could more easily talk about our baby to family and be ready with a response to some of the questions people might ask.



Questions you might have

About your physical recovery

- What do you need to know about your physical health when you leave hospital?
- Do you need extra information about specific issues related to you, your loss or your health?
- Would you like your health care team to contact your GP or other health professionals about what has happened?
- Do you need help to cancel any appointments?
- Would you like your health care team to help arrange new follow-up care appointments such as your post-natal check with your GP or obstetrician?
- How will a member of your health care team contact you after you leave hospital?



About your emotional support needs

- What kinds of support might be helpful when you leave hospital?
- Do you have contact details for the support you might need? Do you have a follow-up meeting arranged with someone from your team at the hospital?
- Would you like someone to help you make contact with an organisation that supports parents, such as Red Nose?
- How do you want to tell your friends and community about what has happened? Do you need help with this and who could support you?

About your practical support needs

- What kinds of practical support might you need as you return home?
- Do you need any practical support such as financial support or accommodation if you are away from your home?
- What paperwork might you need to follow-up, such as birth registration, medical certificates, or Centrelink forms?
- What help might be available to care for your other children at this time?
- Would it be helpful to contact your employer?
- Do you have contact details for the support you might need?

What is most important for you as you think about leaving hospital?

What are your main concerns?

What other information or support do you need?



Looking back, there are things that I might have done differently. But given the circumstances, I feel that I did the best I could at the time. I have been able to honour my baby, and to get support that helps me feel less alone. Each year the anniversary of my baby is hard, but I have found ways to make this day meaningful ... and it does get a little easier with time. On my baby's anniversary my thoughts also go out to the families who have experienced a similar loss.



Closing note

There is no set time frame or single pathway for grieving the loss of your baby. Please know that for many parents, finding ways to keep a connection with their baby as part of their family is important.

Each year, parents throughout Australia and the world mark International Pregnancy and Infant Loss Remembrance Day on 15 October. This is a time for all bereaved parents, together with their family and friends, to remember their babies with love and to know that much support exists.

Some parents seek ways to create a legacy for their baby. For some, this includes being part of a parent community that helps to shape better care and support for parents when a baby dies. This guide includes the voices of many parents who have participated in research on what was important to them around the time their baby died. If you would like to hear about future research projects, you are invited to register your interest with the Stillbirth Foundation Australia.

Your follow-up information

Who can you contact for support at any time?

- Red Nose, 24-hr Support:
1300 308 307
- Hospital contact person
Please ask your health care provider to write in details here:

- Other support person
Please write in details here:

- **Follow-up about your health care**
Contact and appointment details:

**Your follow-up review meeting to discuss investigations
about your baby’s death and your well-being**

- Who do you contact if you have questions before the follow-up review meeting? *Name and contact details:*

- *Any questions or notes you may have for the meeting:*

- *Other information that may be important for you:*

Information and resources

You may have other questions now or in the future. There are links to sources of information and support on specific topics in the relevant sections of this guide. These organisations all support families who experience pregnancy loss. You may find additional information and support on their websites.

Stillbirth Foundation Australia

Research, education and advocacy to reduce the incidence and impact of stillbirth.

(02) 9557 9070

stillbirthfoundation.org.au

Stillbirth Centre of Research Excellence

Research, resources and information to reduce the number of stillborn babies and provide best possible support for parents and families when a baby dies.

stillbirthcre.org.au

Red Nose

Supporting families whose babies have died through peer support and professional counselling services.

1300 308 307 (Available 24 hours)

rednose.org.au

Bears of Hope

Leading support and exceptional care for families who experience the loss of a baby.

1300 11 HOPE

bearsofhope.org.au

Still Aware

Supporting a safer pregnancy through education and awareness programs nation-wide.

stillaware.org

Pink Elephants Support Network

Providing the latest resources, information, and peer support for anyone impacted by early pregnancy loss.

pinkelephants.org.au

Read this guide online at: bit.ly/GuidingConversations

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