

Palliative care for your baby

This information is for families of babies who have a serious condition and may die during pregnancy, during birth (stillbirth), or after birth. It includes babies who are not yet born, babies who die before or during labour, and babies who are born alive and need palliative care.

IMPORTANT: You may find it helpful to read this information with a support person or loved one. Please feel free to put this document aside and return to it when you feel ready. Your team is available to discuss any section in person as many times as needed.

What is palliative care?

Palliative care is gentle, special help for babies who have very serious illnesses. It's a way of caring for your baby and making them comfortable before they die.

Palliative care does not mean shortening a life. It means trying to give your baby the best life possible. It can start before your baby is born or at any time after.

Your baby can have palliative care at the same time as other treatment that may help to improve a condition or symptom. This means your baby can get both kinds of care together

Palliative care helps your baby:

- feel comfortable and not in pain
- have the best life possible, for as long as possible.

Palliative care helps you and your family:

- make choices about your baby's care
- spend time together
- remember your baby
- get support before, during and after your baby dies.

Who will look after you and your baby?

A special team works together to look after your baby and support your family. The team might include:

- doctors
- nurses
- midwives
- social workers
- Aboriginal and/or Torres Strait Islander health workers
- cultural liaison officers
- psychologists
- palliative care coordinators
- chaplains
- spiritual carers
- other allied health (e.g., music therapist, physiotherapist).

What choices can you make?

You might need to make some important decisions. Your healthcare team can help you understand what is happening and what choices you have.

Before your baby is born, you might need to make decisions such as:

- whether you will continue the pregnancy
- what tests you want to have
- how often to see the doctor or midwife
- where and how you want to have your baby.

During labour and birth, you might choose:

- what kind of monitoring you want
- what type of pain relief you want
- where and how you want to have your baby.

After your baby is born, you might choose:

- what treatments your baby receives (like help with breathing, medicines or feeding)
- what you would like to do if your baby's heart or breathing stops (resuscitation decisions)
- where your baby is cared for (hospital, home or hospice)
- whether you want:
 - treatments that try to cure or give more time
 - comfort-focused care only
 - or a combination of both.

Your healthcare team will support you with these decisions. Talk with them as often as you need to.

What will your baby's care look like?

Care can change according to what your baby needs and what is important to your family. The focus is comfort. Your healthcare team can use medicines and other gentle methods if your baby is uncomfortable. You can ask your team anytime about comfort management. You might like to:

- cuddle, bathe, or change your baby's nappies
- do skin-to-skin ("kangaroo") care
- talk, sing, read, or play music to your baby
- involve siblings, grandparents, or others.

Your team supports you wherever you are (hospital, home, or hospice).

For Aboriginal and/or Torres Strait Islander families, share who and what is important to you (extended family, Elders, community, and Connection to Country). Your team will support cultural/spiritual practices around birth and death.



How can you create memories?

There are many things you can do to create lasting memories. Some families want many. Others prefer very few. There is no right or wrong choice.

Memory creation can be things like:

- taking photos or videos
- collecting hand and footprints or locks of hair
- bathing and dressing your baby
- having friends, family and community visit.

Memory boxes are special boxes to store memories. They are free and available wherever you are.

If you're not ready now—that's okay. You can change your mind any time while baby is with you.

- Your team can store items until you go home
- Ask about options when leaving hospital:
 - If you're not ready, you can ask a family member to keep them safe for you.

For Aboriginal and/or Torres Strait Islander families: talk to your team about cultural protocols around taking photos and keepsakes. They will follow your guidance and respects your wishes.



Footprints and a teddy in a memory box

What about breastfeeding and breast milk?

If you cannot feed your baby, no matter the reason, it's normal to feel uncomfortable and sad. If you have been expressing milk for your baby, stopping can bring grief, but your team can help.

Your healthcare team, midwife and/or lactation consultant can:

- help you express milk if needed
- explain what to do with expressed breast milk (EBM)
 - use for your baby for comfort care like mouth swabs or drops.
- explain your choices:
 - continue expressing for a short time if it feels right
 - discard in a way that feels okay; or
 - donate to a human milk bank in some cases.
- guide how to safely decrease or stop your milk (lactation suppression)
- support you emotionally with milk coming in after loss.

What if you have requests that are important to your family?

Talk with your healthcare team about what you want.

You might want to have:

- a baptism, christening, or naming ceremony
- blessings
- cultural/spiritual ceremonies or rituals
- video call with extended family/community unable to attend
- involvement of Elders/community leaders important to you.

Ask your healthcare team if these (or any other events) are important to you and your family.

When might your baby die?

It is not always possible to know exactly when death will happen. Most babies with life-limiting conditions will die peacefully.

Some babies die before birth, during birth, or after birth. This may happen very quickly (within minutes), or it may take hours or even days.

Every baby and every family's experience is different. You will not be alone.

Your healthcare team will keep you informed as things change. They will support you every step of the way.

What might your baby look like?

As your baby becomes weaker, you may notice some changes in how they look or act. Your baby may:

- have breathing that becomes uneven, slow, or noisy
- take irregular breaths, or gasp
- sleep more
- move less
- feed less.

These are natural dying changes and do not mean your baby is in pain. Their hands or feet may feel cool, and their skin may look pale or bluish. These changes are a natural part of the body slowing down.

If you are concerned at any stage that your baby may be uncomfortable, talk with your healthcare team. They will focus on keeping your baby as comfortable as possible.

What happens after your baby dies?

After death, the team will treat your baby's body with great care and respect.

Some babies, especially those who are stillborn, may have very soft or fragile skin. You can hold your baby as much, or as little, as you want. You can change your mind anytime about this.

Your care team can support you to:

- hold, cuddle, or dress your baby (if you wish)
- take photos, handprints, or footprints
- understand how your baby may look and feel.

It is normal to feel many emotions, including sadness, fear, or confusion.

What support is available for you?

Support is available to you and your family before, during, and after your baby's death. Support can be flexible and can depend on what feels right for you.

The following table shows what types of support there are, and who you might look to for help if you need it.

Type of support	Who it is	What is it for
Counselling	<ul style="list-style-type: none"> • Counsellors • Psychologists 	Emotional and psychological support for family
Peer support groups	<ul style="list-style-type: none"> • Other families who have experienced baby loss • Bereavement networks 	Sharing experiences and grief support
Community services	<ul style="list-style-type: none"> • Paediatric Palliative Care Service • Hummingbird House 	Specialist palliative care and family support
Rural or remote	<ul style="list-style-type: none"> • Telehealth services • Local outreach programs 	Access to specialist care closer to home
Aboriginal and Torres Strait Islander support	<ul style="list-style-type: none"> • Aboriginal and Torres Strait Islander health workers • Cultural liaison officers 	Culturally safe care respecting traditions
Siblings and other children	<ul style="list-style-type: none"> • Your healthcare team 	Age-appropriate emotional support and communication
Practical support	<ul style="list-style-type: none"> • Social workers • Community services 	Help with financial, transport, and other needs

Support and Information:

Queensland Clinical Guidelines: Parent information. <https://www.health.qld.gov.au/qcg>

13HEALTH: (13 432584) free confidential phone service providing health advice. <https://www.qld.gov.au/health/contacts/advice/13health>

Lifeline: (13 11 14) Telephone crisis support service. <https://www.lifeline.org.au>

Red Nose Australia Grief and Loss Support Line: (1300 308 307—support line is available 24/7) for anyone affected by the loss of a pregnancy, stillbirth or death of a baby or child. <https://www.rednosegriefandloss.org.au>

Paediatric Palliative Care Australia: information, resources, and educational tools for health professionals, families, and carers. <https://www.paediatricpalliativecare.org.au>

Precious Wings: supplies memory boxes (free of charge) for families who lose a baby in pregnancy or a child up to 18 years of age. <https://www.preciouswings.org>

Preterm Infants Parent Association (PIPA): (1300 773 672) support organisation for parents of premature babies <https://www.pipa.org.au>

Bears of Hope Pregnancy and Infant Loss Support: (1300 11 4673) provides support for families who experience the loss of their baby including cuddle cots. <https://www.bearssofhope.org.au>

Angel Gowns Australia: supplies angel gown garments for families who experience the loss of their baby. <https://www.angelgownsaustralia.org.au>

Harrison's Little Wings: high risk pregnancy support service. <https://www.harrisonslittlewings.org.au/>

Australian Breastfeeding Association: (1800 686 268 - Helpline available 24/7) provides evidence-based information, resources and peer support counselling for parents about breastfeeding. <https://www.breastfeeding.asn.au>

Perinatal Depression and Anxiety Australia (PANDA): (1300 726 306) supports the mental health of parents during pregnancy and throughout the first year of parenthood. <https://www.panda.org.au>

1300MHCALL: (1300 642 255) is a confidential mental health phone triage service who can link you to your nearest public mental health service in Queensland. <https://www.qld.gov.au/health/mental-health-and-wellbeing/how-to-get-help/1300-mh-call>

Gidget foundation: (1300 851 758) national service to support the emotional wellbeing of expectant and new parents through online resources, phone, telehealth and face to face counselling. <https://www.gidgetfoundation.org.au>

Rural Health Connect: (1800 841 045) Support for anyone impacted by perinatal loss. <https://ruralhealthconnect.com.au/perinatal-loss/>

Centre of Perinatal Excellence (COPE): provides information, mobile applications, education and a directory of services for perinatal mental health. <https://www.cope.org.au>