



Wāhi Rua
New Zealand
Maternal
Fetal Medicine
Network

A time to decide

**Information for when an unexpected
difference is diagnosed in your baby**

A time to decide

This pamphlet is to provide you with information that may help with decision making when an unexpected difference is diagnosed in your baby.

In this information, 'you' applies to both parents when both are involved or to either one when that is relevant. We use the terms parents and baby throughout the pamphlet as this is how most people choose to describe their situation.

Take time to be sure that your decision is in the best interests of your baby, yourselves and your family. Listen to others, find out all you can, but most of all, act according to your own judgement.

This pamphlet covers:

Section A: Deciding what to do

Section B: Continuing your pregnancy

Section C: Ending your pregnancy

Section D: Useful contacts



Section A: Deciding what to do

Diagnosis

When a diagnosis has been made you may have many questions. Why me? Has a mistake been made? You may feel numb or overwhelmed by anger, disbelief, guilt, pain, sadness and grief. Whatever you are feeling is natural and normal.

There are decisions to make about whether to continue with, or end, your pregnancy. To help you work towards making a well-informed decision, you will be offered the help of specialists and contacts for support agencies. You will be supported, listened to and will not be judged. It is okay to accept as much or as little of this support and guidance as you wish.

Support and guidance

The **obstetrician** or **specialist maternal fetal medicine (MFM) doctor** you meet with will provide information and guidance about your baby's condition. You can ask them questions and talk through your options and next steps.

It can feel overwhelming or hard to take everything in at first. You may find it helpful to ask questions such as:

- What is affecting my baby?
- Why has this happened?
- Are there any further tests that may help us understand more?

You can also ask for written information about your baby's condition and what it may mean for your baby and family. If needed, your

specialist may arrange contact with other teams such as paediatric, genetic, and radiology services.

You will meet the **maternal fetal medicine (MFM) midwife** at your appointment with the specialist MFM doctor. They will provide you with any additional information as you need it and are available to talk through your results, explain procedures and what to expect.

The MFM midwife will support your care planning and help to keep you informed of upcoming appointments. They also communicate with the doctors, your lead maternity carer and your GP to ensure your care is well coordinated. If needed, they can connect you with other health professionals and support people.

You can find the MFM midwives' contact phone numbers in the useful contacts section at the back of this pamphlet.

Other supports

A member of your care team can help with access to any of these supports:

Social worker/counselling services

Meeting with a social worker or counsellor can help guide you through the decision-making process and the emotions you may experience. They can see you after the birth of your baby for ongoing support also.

Spiritual support

There are hospital chaplains that are available for support. Or, you may wish to talk with your own spiritual leader for support and pastoral care / counselling.

Kaupapa Māori support

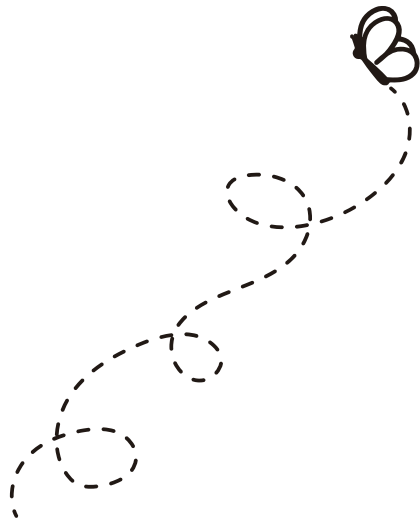
There are a range of services available to provide cultural support for parent/s and /or their whānau who identify as Māori.

Pacific peoples' support

There are a range of services available to provide cultural support for parent/s and /or their family who identify as Pacific peoples.

Support from others

You may also find it helpful to talk with other people who have been through similar experiences. This may be with parents of children with the same or a similar difference or with those who have experienced a termination of pregnancy. Support organisations such as Sands, and Parent to Parent, offer contact with others who have had similar experiences. They are listed in the useful contacts section in the back of this pamphlet.



Section B:

Continuing with your pregnancy

After careful consideration, you may decide to continue with the pregnancy. You may have thought about:

- Your baby's future quality of life
- Your own coping skills
- Your own family situation and lifestyle
- The effect on your existing children and the effect on your relationship
- The life expectancy of your baby
- Your wider support network i.e. family and friends
- The existence of appropriate medical and educational services
- Your own spiritual or religious beliefs.

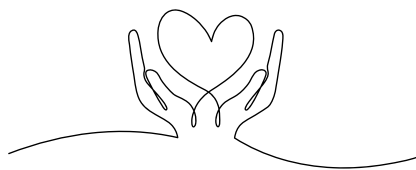
Practical steps

The practical steps which might help you with the above are:

- Discussing your baby's likely outcome with a neonatal specialist
- Talking with the counsellor or social worker to explore the implications of parenting a child with special needs
- Gaining practical information from relevant support groups
- Talking with trusted family and friends.

You may decide to continue your pregnancy, even if you know your baby may not live long after birth. This can offer precious time with your baby during pregnancy, and for some, this feels like the best option for them.

You may grieve the loss of the baby you thought you were expecting. Making this adjustment can be a challenging time. It can involve a long process of gradually adapting to the reality of the diagnosis, its limitations on your baby's life and the prospect of a family life vastly different from the one you had planned. Coming to terms with these changes can take time. As you and your family adjust and support your baby's needs, you may also find new strengths, deeper connections and meaningful ways to grow together as a family.



Section C:

Ending your pregnancy

The clinical term for ending a pregnancy is “mid trimester termination of pregnancy”.

There are two methods available: medical or surgical.

A medical termination means labour is started using medication, and you will give birth to your baby. This option can be used at most stages of pregnancy. If the gestation is over 22 weeks an additional procedure is needed beforehand that will stop the baby’s heartbeat before labour begins.

A surgical option may be available in some situations, generally, up to 19 weeks gestation. Some centres may offer this procedure up to 22 weeks.

The decision may need to be made without knowing exactly how severely your baby may be affected. Choosing to end a pregnancy can be an extremely difficult and emotional decision. If you decide to proceed, the following information may help you prepare.

Preparing for the medical birth of your baby

The MFM team can talk with you about what to expect during the induction, labour and birth.

Labour is started using medication. You will usually take a medication called Mifegyne 48 hours before coming into hospital. Once you are in hospital, another medication called Misoprostol is used to soften the cervix and start the contractions.

You will usually stay in the same room during labour, the birth of your baby, and until you go home. If your pregnancy is over 20 weeks you would need to labour on Birth Suite. You may wish to bring things that you find comforting with you into hospital e.g. personal items. Your partner / support person can stay and support you for the duration of labour and birth. Do not be afraid to ask for help from hospital staff, and to accept offers of support.

It can be very hard to prepare for your baby's birth and death at the same time, and this may feel emotionally overwhelming. Although the thought of meeting your baby may be daunting, many parents find that spending time with their baby becomes a precious and important memory.

Usually, your baby will be stillborn. Sometimes however, babies can show brief signs of life, such as a faint heartbeat or small reflex movements. If this happens, your baby will be kept warm and comfortable, and their heartbeat will stop naturally soon afterwards. Your baby may have very little body fat, and their skin may appear red and translucent. There may also be some bruising from the birth. Often, physical differences are less noticeable than parents expect, and to you, your baby may look perfect.

Sometimes the placenta does not come away naturally after birth (known as retained placenta). If this happens, a short procedure called a D & C (dilation and curettage) may be recommended under a general anaesthetic to remove the placenta safely. Having the D & C helps to avoid serious infection that can be caused by a retained placenta.

Saying hello

Some parents are unsure about seeing or holding their baby. However, this may be an important part of starting to come to terms with what has happened, and later you may be thankful for the early moments you were able to spend with your baby. The choice is up to you. Below are some options to consider following your baby's birth:

Time with your baby

The hours after your baby has passed can be a special time in which you can spend time with, and parent, your precious baby. You can be involved with your baby's care as much or as little as you wish. Again, how much contact you wish to have is up to you.

Parents are encouraged to bring their own camera to take their own photos. The hospital can provide photos of baby, and foot and handprints can be taken. This will require your consent and is not done automatically without permission. The hospital staff can make a memory card for you to take home. Otherwise, the card and prints can remain in your hospital records.

A private organisation called 'Heartfelt' offers to provide professional sensitive photographs of baby and in some centres offer castings of hands and feet of baby – this is free of charge.

Naming your baby

Whether or not you name your baby is a personal choice. You may wish to name your baby so you can talk to them by name and remember them by name later.

The family

If you have other children, it can help to think about what you may want to tell them. Children are often aware that something is worrying or upsetting their parents, even if they do not fully understand why. Reassuring them that they are loved and that they are not the cause of what is happening can help.

In time, when, and if it feels right for your family – you may choose to introduce your baby to their siblings. They may want to see, touch, or hold their baby brother or sister. Children are likely to have questions, and answering them honestly and gently can help them feel included and supported. Further information can be found at <https://wheturangitia.services.govt.nz/>

A service

During your hospital stay there are hospital chaplains who can offer a simple blessing or a farewell ceremony for your baby if you wish. Or you may prefer to have support from your own religious or spiritual network.

Taking your baby home

Some parents may like to take their baby home. Others want to spend time with baby at the hospital. As parents, you can decide what is best for you. Discuss with a hospital midwife, nurse or doctor the practical implications of taking your baby home.

Breast comfort and milk production

Your milk may 'come in' a few days after baby's birth. This can be painful but wearing a firm fitting bra and taking regular pain relief as needed will help. A tablet to suppress milk production can be prescribed and should be started within 24 hours of delivery.

Saying goodbye

You will know when it is time to bury or cremate your baby. You do not need to hurry this step. Everybody reacts differently and has different needs. It is important to do whatever suits you.

You will be offered a post-mortem of your baby. The brochure 'Pānui/information for whānau/families about post-mortem examination (PMMRC)' explains more and is made available for you to read and keep.

You may choose whether you want to hold a funeral or not. If you choose to have a funeral or burial, you may wish to use a funeral director. Refer to the Legal requirements section further on in this pamphlet.

Your own writing and the writings of others can help to ease the pain of saying goodbye. Some parents find it helpful to write a letter to their baby. There are many poems and writings that offer empathy and understanding for your situation. You may like to include some readings at this time, whether or not you choose to have a formal farewell ceremony.

Afterwards

You may find yourself spending a great deal of time thinking about your baby and reflecting over the past days and weeks. You may want your baby so much that your arms ache, and you imagine you hear your baby crying. Your sleep may be disturbed, and you may have vivid dreams. You may feel exhausted. These feelings are normal indications that you are grieving the loss of your loved baby. This is a time of grief, when the ordinary demands of life may be overwhelming, and when you may need to be cared for by others.

The process of grief can be long and difficult. In this situation, your grief may be intensified by feelings of guilt, and/or depression. With time and with support these feelings will diminish.

At about 6-8 weeks after birth, you will have an opportunity to meet with the maternal fetal medicine specialist, or your local obstetrician. This is a time when results are discussed and you can consider the options for the future (where to from here).

Legal requirements

If your baby is stillborn before 20 weeks of pregnancy and weighs less than 400 grams, the baby's birth is not registered, and there is no legal requirement to bury them, although you are able to have a funeral if you wish. If you do not wish to arrange a funeral yourself, the cremation of your baby can be arranged by the hospital. This service is free. It is important to know that your baby may be cremated with one or other babies and that the ashes will not be returned to you. They are scattered in a special area.

There is a legal requirement if a baby is stillborn after 20 completed weeks of pregnancy, and /or weighing more than 400 grams to have their birth registered and to be buried or cremated in an appropriate manner. The death is not registered, but a medical certificate is completed at the hospital. A birth certificate is available to you on request and on payment of the prescribed fee, from any Registrar of Births, Deaths and Marriages (Call free 0800 22 52 52).

If your baby suffered a neonatal death (that is when the baby was born alive at any gestational age and then died) the baby's birth must be registered and the baby must have a burial or cremation.

The baby's death must also be registered (usually by the funeral director). A birth and death certificate will be issued on request by Births, Deaths and Marriages.

The law requires the parents of the child to register the birth "as soon as is reasonably practicable". The Registrar-General of Births Deaths and Marriages has interpreted this to mean within two months of birth.

Parental leave

If you are eligible for primary carer leave and parental leave payments, and your baby dies before or after the birth, you are entitled to parental leave. Please check Employment New Zealand for further information:

www.employment.govt.nz/leave-and-holidays/parental-leave.



Useful contacts

MFM Midwifery Team

- **Auckland:** Ph: 021 983468
- **Counties Manukau:** Ph: 021 784 825 or 09 250 9800
- **Wellington:** Ph: 021 199 8223 or 04 385 5999 extension 80774
- **Christchurch:** Ph: 03 364 4557 extension 85557

Chaplaincy Service

- **Auckland:** Ph 09 3074949, hold for the operator and ask for the on-call chaplain.
- **Wellington:** Ph: 04 385 5999 extension 82126
- **Christchurch:** Ph: 03 364 0640 extension 89555
- **Other hospitals:** Call your nearest hospital or speak with your nurse/midwife/doctor.

Counselling and Social Work support

- **Auckland:** Please discuss with your midwife/nurse/doctor.
- **Wellington:** Women's Clinic Te Mahoe Counselling
Ph: 04 806 0761
- **Christchurch:** The counselling services handout will be provided by the Fetal Medicine midwives at the time of your consultation/appointment.
- **Other hospitals:** Call you nearest hospital or speak with your nurse/midwife/doctor.

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Parent to Parent

Empowering family and whānau of people with disabilities through support and information. www.parent2parent.org.nz
or phone: 0508 236 236

Sands

An organisation that supports parents and families following the death of baby, at any age and under any circumstance.
www.sands.org.nz

Whetūrangitia

A NZ government website with information for whānau experiencing the loss of a baby or child. Contains information on termination of pregnancy & stillbirth, including decision making, support services, memory making & financial information/entitlements
<https://wheturangitia.services.govt.nz>

Registrar of Births, Deaths and Marriages

Phone: 0800 22 52 52

**For more information please contact your
nearest NZ MFM unit**

Auckland

Auckland Hospital
2 Park Road
Grafton, Auckland 1023
Phone: 09 367 0000 extn 24951

Wellington

Wellington Hospital
Riddiford Street
Newtown, Wellington 6021
Phone: 04 806 0774

Christchurch

Christchurch Women's Hospital
2 Riccarton Ave, Christchurch 4711
Phone: 03 364 4557

Health New Zealand
Te Whatu Ora

About Wāhi Rua:

<https://www.healthpoint.co.nz/public/wahi-rua-new-zealand-maternal-fetal-medicine/>

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