

A time to decide

Information for when an abnormality 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 booklet as this is how most people choose to describe their situation.

Deciding what to do

Diagnosis

On diagnosis you will have many questions why me? Has a mistake being made? There may be shock or denial. You may feel numb or overwhelmed by anger, disbelief, guilt, pain, sadness and grief. Whatever you are feeling is natural and normal.

You will be offered the skills of specialists and support agencies (e.g. The Downs Association, Heart Children, etc) to help you work towards making a thoroughly informed decision. You will be supported, listened to and will not be judged. Accept as much or as little of this support as you wish.

Support and Guidance

The specialist Obstetrician who has talked to you about the condition of your baby will provide practical information and guidance. You can ask for medical terms to be clarified, discuss the diagnosis, and talk about details of your options and procedures.

Despite possible feelings of shock and disbelief at this time, it is helpful to find out as much information as you can from your specialist. What exactly is wrong with my baby? Why did this happen? What tests can I have to fill in the picture?

You may ask for written information, to read about your baby's condition and prognosis. If appropriate, your specialist will arrange contact with other specialists including Paediatrician, Geneticist, and radiologist or support services.

Counselling

Counselling services are available through Women's Clinic's - Te Mahoe. A counsellor can help guide you through the decision making process and the emotions you will experience.

Chaplaincy support

You may wish to talk with your own minister or the hospital chaplain for spiritual support, and pastoral care/counselling. The hospital chaplain is available to you at any stage of your decision-making or afterwards. Please ask a staff member to contact the hospital chaplain for you.

Kaiawhina and Kaumatua support

There are a range of services available to provide help and support for parent/s and /or their whanau who identify as Maori. A Whanau Care Service – Information for patients and whanau brochure is available.

Pacific Health Unit

There are a range of services available to provide help and support for parent/s and /or their whanau who identify as Pacific. Please ask a staff member to make a referral for you.

Maternal Fetal Medicine (MFM) Midwife

You will meet the MFM midwife at the time of your consultation with the specialist MFM doctor.

She will provide you with any additional information as you need it and will be happy to

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discuss results and the plan for your care, keeping you informed of appointments. She will liaise with the doctors, your Lead Maternity Carer, your General Practitioner and will refer you to other health professionals and support people as you wish.

She is able to explain procedures and what to expect as the pregnancy progresses, or if your labour is to be induced, she will discuss what will be involved.

You can contact her on 04 385 5999 ext 80774 or pager 2654.

Support from others

You might also find it helpful to talk with other people, including parents of children with the same or a similar abnormality or with those who have experienced a termination of pregnancy. Women, parents and families who have been through this experience can be contacted through Sands Wellington-Hutt Valley on 021 776 436 or 027 710 5130 or through sandswgtnhutt@gmail.com or www.sandswellingtonhutt.org.nz. Your local social worker can also arrange meeting with other support people and agencies.

Continuing With Your Pregnancy

After careful consideration, you may decide to continue with the pregnancy.

You will have thought about:

- Your baby's future quality of life.
- Your own coping skills.
- Your own particular family situation and lifestyle.
- The effect on your existing children, the effect on your relationship.
- Your baby may die after a few hours or days.

- Your extended family and friends' responses to the diagnosis and the assurance of support.
- 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:

- Discuss the baby's prognosis with a neonatal specialist.
- If you decide to continue your pregnancy you may find it helpful to talk with the Neonatal Unit social worker to explore the implications of parenting a child with special needs.
- Discuss the situation with a minister of religion, hospital chaplain or priest.
- Gain practical information from relevant support groups.
- Explore educational opportunities for children with disabilities.
- Talk with family and friends.

Some couples may make the decision to continue the pregnancy knowing their child will die at or shortly after birth. The decision to let nature take its course allows more time with the baby while you are pregnant and may be the most acceptable for you.

You may grieve the loss of the normal, healthy baby you thought you were expecting. Making this adjustment can be emotionally very draining. It involves a long process of gradually adapting to the reality of the disability, its limitations on the life of your baby and the prospect of a family life vastly changed from the one you had planned. Coming to terms with the change can eventually be positive. In meeting the challenges of your baby's

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disabilities, you may discover the potential to strengthen and enrich your family life.

Ending Your Pregnancy

The Decision

This may be the most difficult time you ever experience. The decision may need to be made without the certain knowledge of the extent of your baby's disabilities. Deciding to end your pregnancy is traumatic. If you decide to end your pregnancy, the following considerations may be helpful.

Medical or Surgical

The medical term for ending a pregnancy is "mid trimester termination of pregnancy".

There are two methods available, medical or surgical. A medical termination means that labour is induced. A surgical option is available in some circumstances up to 18-19 weeks gestation.

Preparing for the birth of your baby

The reality of the situation is unpleasant. You will experience labour. Although a daunting prospect, it has proven to be an extremely important and precious part in forming memories. The MFM midwife can discuss the induction process and what to expect during the labour. It is difficult to prepare for your baby's birth and death together, this emotional time may be intense.

Your labour will be induced. A Mifegyne tablet will be given 48 hours before you are admitted to hospital. Once you are admitted to hospital Misoprostol tablets will be used to soften the cervix and start the contractions. A further brochure with details and contact information will be given to you when the medication is started.

You usually remain in the same room throughout your labour, baby's birth, and until you go home. You may wish to bring you things you find

comforting e.g. personal family photos with you into hospital. Your partner / support person is able to 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.

If your pregnancy is over 23 weeks you would need to labour on Delivery Suite.

Your baby is usually stillborn. Sometimes babies can show some signs of life, e.g. a weak heartbeat and some small reflex movements. In this situation we would normally wrap baby to keep him/her warm and very soon the baby's heartbeat will stop.

Your baby will have very little body fat and his/her skin may look quite red and translucent. There may be some bruising caused by the delivery. In reality the abnormalities are quite often less than you have imagined. Your baby may look perfect.

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

Occasionally not all the placenta is delivered after your baby's birth. A D&C (Dilation and Curettage) operation is then advised to avoid infection. This is a brief operation performed under general anaesthetic.

You will be offered a post-mortem of your baby. There is a Post-mortem brochure 'PANUI for post-mortem exam (PMMRC)' available for you to read and keep.

You may choose whether you want a funeral or not, see the last page for legal requirements. If you choose to have a funeral or burial you may wish to use a Funeral Director.

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Saying Hello

Here are some options to consider following your baby's birth. Some parents are unsure about seeing their baby. This choice is yours. This may be an important part of coming to terms with what has happened, and later you may be thankful for all the early moments you were able to spend with your baby.

Cocoon yourself with your baby

Even though your baby has died, this is a special time in which you can parent your precious baby. You can be involved with your baby's care as much or as little as you wish. Specially made pre-term gowns and other items are donated to the hospital and are yours to keep. It is your choice on how much contact you have.

Parents are encouraged to bring their own camera to take their own photos. The hospital can provide photos of baby, and the Hospital staff will make a memory card for you to take home. It will include a photo, foot and handprints. Otherwise the card can remain in your Hospital records.

Name your baby

To help you acknowledge baby as a person, it often helps to give your baby a name. You can then talk to your baby using her/his name.

The family

It is important to tell your other children that something has gone wrong. Children are very perceptive and are likely to sense that their parents are upset. They need to be reassured that this is not the because of them. At some time, (not necessarily now), you may decide to introduce your baby to siblings. They may wish to hold their tiny sister/brother. Be prepared to answer questions.

There are a small number of books available about children and grief. See useful contacts and information section at the book of this booklet.

A service

During your hospital stay the hospital chaplain can help you with a simple blessing-farewell ceremony for your baby.

Taking your baby home

Some parents 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.

Write a letter to your baby

Some parents find it helpful to write a letter to their baby.

Saying Goodbye

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

Your own writing and writings of others can help to ease the pain of saying goodbye. There are many poems and writings that offer empathy and understanding for your situation. You may like to have some reading at this time, whether or not you have a formal farewell ceremony.

Afterwards

You may find yourself spending a great deal of time thinking about your baby, and reflecting back 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 quite exhausted. These feelings are normal indications

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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 feeling will diminish.

At about 6-8 weeks after birth you will have an opportunity to meet with the obstetrician, this is a time when results be discussed and you can consider the options for the future.

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 him/her, 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.

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 Birth, 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 later 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 Birth, 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 Birth Deaths and Marriages has interpreted this to mean within two months of birth.

Further information

www.arc-uk.org/ Antenatal Results and Choices. UK charity providing non-directive support and information to parents. They can be contacted via their website.

A Gift of Time: Continuing Your Pregnancy When Your Baby's Life is Expected to be Brief. Amy Kuebelbeck & Deborah L. Davis (2011) Baltimore: John Hopkins University Press.

Baby Gone. Douche (2011), J. Random House N.Z.

A Time to Decide, A Time to Heal: For Parents Making Difficult Decisions About Babies They Love. Molly A. Minnick, Kathleen J. Delp, Mary C Ciotti (2000), Michigan: Pineapple Press

What Happened to Baby, Sids (Wgtn), Sands (Wgtn) and Skylight

Precious Lives Painful Choices: A Prenatal Decision-making Guide. Sherokee Ilse. (2005) Minnesota: Wintergreen Press.

Difficult Decisions: For Families Whose Unborn Baby Has a Serious Problem. (1998) Centering Corporation, Nevada

Waiting With Gabriel: A Story of Cherishing a Baby's Brief Life. Amy Kuebelbeck (2003) Illinois: Loyola Press.

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Acknowledgments

Canterbury DHB Fetal Medicine Unit “A Time to Decide” pamphlet

Useful contacts

Sands

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

www.sands.org.nz and
www.sandswellingtonhutt.org.nz

Women’s Clinics-Te Mahoe Counselling

Phone: 04 806 0761

Chaplaincy Service

Phone: 04 385 5999 extension 82126

NZ Downs Syndrome Association

www.nzdsa.org.nz or phone 0800 693 724

Parent to Parent

Empowering family and whanau of people with disabilities through support and information. Phone: 0508 727 228.

Registrar of Birth, Deaths and Marriages

Phone: 0800 22 52 52

MFM Midwife

Phone: 04 385 5999 extension 80774

