

Diagnosis of abnormality in an unborn baby

The Impact, Options
and Afterwards





THE IMPACT, OPTIONS AND AFTERWARDS...

This title has been chosen from the words
of a parent describing her experience:

“There is a price we have to pay, be it physical, emotional, social or spiritual. Each of us has had to decide which cost we are willing to be responsible for. The cost gets paid in the “afterwards” and sometimes that “afterwards” seems to go on for such a long time. There is the near afterwards, the far afterwards and the bit in the middle. Each “afterwards” brings its own kind of learning, sometimes easy, sometimes hard.”

* Although some health professionals and parents may use the term “fetus”, the authors have, based on feedback from parents, chosen to refer to the “baby” irrespective of gestational age, throughout this booklet. In addition the authors intend that “you” may refer to a single parent, both parents or any “significant others” throughout the text.

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THE SAFDA STORY

SAFDA was formed by a network of professionals who offered support and information for people who experienced the diagnosis of a problem in their unborn child.

SAFDA was successful for many years and had fulfilled its aim of providing support and raising awareness of needs after the diagnosis of a fetal abnormality. Due to an increased work load and the restructuring of services, SAFDA no longer exists. This booklet however will remain as a testament to the invaluable work many people put into setting up SAFDA.

The Association of Genetic Support of Australasia (AGSA) whilst not trying to emulate SAFDA, has received funding to follow on SAFDA's work by providing counselling and, where possible, contact with other individuals in like circumstances. A qualified Genetic Counsellor who is also a Registered Psychologist has been employed by AGSA to counsel individuals on a needs basis, free of charge. For referral please phone AGSA (02 9211 1462) to arrange a counselling session.

THE IMPACT

FINDING OUT...

For most parents, the news that an abnormality has been identified in their unborn baby is completely unexpected. A problem or abnormality identified in the developing baby generally comes as a shock and is often the beginning of a very difficult, perhaps devastating sequence of events.

The baby's problems may have been seen through an ultrasound examination offered as a routine screening test early in pregnancy or in the more detailed scan around 18 weeks. Perhaps the diagnosis may have been made by prenatal diagnostic procedures such as CVS (chorionic villus sampling) in the first trimester of pregnancy or by amniocentesis in the second trimester. Whatever way the diagnosis is made, most people are quite unprepared for the reality.

Some couples, who considered CVS or amniocentesis, may have had a screening test, which indicated that there was an increased risk of a problem. Others may have had prenatal diagnostic testing without this prior screening. Before having the diagnostic tests, some couples may have had the opportunity to discuss their feelings with a genetic counsellor and concerns about the possibility that the test result could reveal a problem in the developing baby. Other couples may have given thought to the possibility because they have a family history or a previous child with a particular disorder for which the pregnancy is at risk.

"I anticipated that it would be really sad to have this happen, but I had no idea how emotionally devastating it would be." *

In the light of the technologies available to monitor pregnancy, more and more abnormalities are being identified through “routine” examinations such as ultrasound. Often then the parents have never given consideration to the chances that such a routine test would find something wrong with their unborn baby.

“My husband and I never discussed the possibility of what we would do if it turned out badly. I guess we didn’t want to jinx ourselves.” **

You may have received the news by telephone or in person from your doctor, a genetic counsellor, or another health care worker. Quite often, the person who tells you such painful and personal news, is a stranger to you and sometimes it may not have been gently and thoughtfully given. You may relive the experience of hearing the results for some considerable time. Many parents describe a sense of unreality after hearing the diagnosis.

This kind of news is painful and shocking regardless of how it is given or who tells you.

You, with or without your partner, are faced with making one of the most difficult and painful decisions possible, regarding the future of your pregnancy.

It is important to give yourself as much time as you need to make the decision.

“The “pain” felt was I think, often caused, not because of the emotions felt e.g. anger, fear etc but because of there not being any clear and definite “right” decision to make, too many options and yet not enough information about the available resources.”



FEELINGS...

Like many others, you may be feeling numb, very frightened, alone, or out of control. Your decision may be made in the midst of emotional confusion and this confusion and other strong and varied feelings can continue for a long time after the decision is made.

“when we got the bad news, I immediately rejected the baby as “other”, “alien” ... only later did I again begin to feel love for and attachment to my what-was-to-have-been baby.” *

The numbness and sense of unreality that you may feel is part of the shock reaction. Some people have physical reactions as well, such as nausea, shortness of breath, rapid heartbeat, and feeling faint. Often parents cannot believe what they have heard and will want frequent reassurance that the diagnosis is correct. It is normal to not want to believe such unhappy news and it is perfectly acceptable for you to question the accuracy of the result that you have been given. In some cases, parents may seek a second opinion about the diagnosis.

Parents say that learning that their unborn baby has serious problems means the end of all their hopes and dreams about having a healthy, normal baby.

“it feels like a bad dream” **

Once the feeling of numbness subsides, parents describe feeling intense anger and sadness about knowing that their baby has a serious problem and about the prospects that lie ahead. It is normal to ask “why me?” even though there may be no answer for this question. Finding out that your unborn baby has an abnormality is one of life’s most unjust events and it is very difficult to accept.

“I remember feeling very bad and alone at this time. It was as if I was being punished for being bad and rebellious.”

The sadness you experience may be overwhelming and take many forms. Sleeplessness, loss of appetite, apathy and depression are some of the possible reactions. You may shed many tears, for months and possibly even years, down the road.

“I couldn’t eat, I couldn’t sleep, I couldn’t concentrate. I went around with a grinding feeling in the pit of my stomach that something was “terribly wrong.” Sometimes I almost felt that I couldn’t breath.”

It is not unusual for parents, particularly the mother, to have feelings of guilt. Regardless of the cause of the baby’s problems, you may wonder if you could

have possibly contributed to the abnormality or if anything could have been done to prevent it from happening. Sometimes, a parent feels guilty because they have had ambivalent feelings about the pregnancy.

Whatever the cause of your unborn baby's problem, it is unlikely that there was anything that you or your partner did or did not do that made it happen. Many of the problems found in a developing baby are "chance" events. Even if the problem has a genetic basis, no one can control which genes a baby might inherit from its parents. It may be helpful to remind yourself that neither you, nor your partner is to blame for your baby's problem.

You may experience many other, sometimes out of control, feelings which are common emotional responses to the impact of such shocking news. It is not uncommon for a parent, particularly the mother, to experience an intense mixture of feelings about the pregnancy. Some women describe a need to distance themselves from the baby as they consider the options. The feelings of anger about the diagnosis may be directed towards the baby.

"and now I could take any medications I wanted; after all I'd be killing this fetus in a few days, so it didn't matter. It was a horrible switch: to go from being protective of this new life to deciding to end it."*

Occasionally emotional reactions can be quite complicated and difficult to accept as normal grief responses. Professional help is available – your doctor or a social worker can provide you with more information about available services.

WHAT IS IMPORTANT FOR YOU AT THIS TIME...

It is important to allow yourself time to experience and accept your emotions both now and in the days, weeks, and months ahead.

It may help to involve your partner and share your feelings and thoughts with each other as much as possible. It is important to consider that the impact of the diagnosis of an abnormality in your unborn baby may be felt by both parents in different ways. The ways of grieving may be different for each partner and this can place a strain on relationships.

The other parent may be ill-equipped to provide the support needed at this time. If you are not in a relationship, seek support from someone who is close to you.

You may want to involve other family members, friends, or seek support and guidance from professionals such as the genetic counselling team, social workers or clergy. It is often very difficult to reach out and share your grief with others.

WHAT TO TELL YOUR CHILDREN...

If you have other children, they may be aware of the unhappiness and the stress that you are under. You and your partner will need to decide what to tell them about the pregnancy. Some parents choose to inform their other children that the developing baby is not strong and healthy.

Depending on the age, many children need reassurance that nothing bad is going to happen to them. Also, children may feel somewhat responsible – it is especially important to offer reassurance that nobody caused the baby to have problems.

Talk to your children at their level of understanding. It is important to listen carefully to your children – they have an uncanny ability to let you know what they need, even at a young age. Parents can seek guidance from professionals such as social workers, school counsellors, or teachers about how and when to tell their children.

It may also be that parents themselves must be the bearers of the news to other family members who may also be unable to comprehend or believe the information. This can result in a lack of support from the usual and expected sources within the family at just the time it is so badly needed. As with partners, their form of grieving may be at odds with that of the parents and cause further distress.



OPTIONS AND DECISIONS

You are faced with having to make a decision about the future of your pregnancy. This decision is a highly personal one. It is a decision that will be made on the basis of the information you receive about your baby's problem, your religious and moral beliefs, and your relationships and family structure. Your decision will usually involve consideration of the short and long term impact of each of the options available to you.

Well-meaning friends, family members, even your doctor may suggest what you should do in the situation. It is very important to remember that only you and your partner will have to cope with the impact and the consequences of the decision. That is why the decision needs to be made by you, the baby's parent/s.

It is important that your decision is an informed one, meaning that you have obtained all the information that you want and taken as much time as is possible to make a considered decision.

However it is important to remember that there are medical/legal considerations surrounding termination of pregnancy which may impact on the amount of time available to make a decision. These may vary in different states and health areas. Your doctor, genetic counsellor or social worker will be able to discuss the legal and medical considerations of this option with you. You are entitled to know how much time there is in which to make your decision without affecting the options available to you.



WHAT YOU ARE ENTITLED TO...

Ask questions. As the sense of unreality and numbness begins to fade, you may not remember all the information that was shared with you at the time of diagnosis. Many parents need repetition of basic information as they absorb the impact of the diagnosis. Obtaining as much information as possible in written form often proves valuable. You may need information about some or all of the following issues:

- the abnormality found in your baby
- any risks for the mother associated with the abnormality diagnosed in the unborn baby
- the range of ability and disability that is associated with the particular condition
- an assessment of future quality of life for the baby and the family
- any anticipated potential medical/genetic breakthroughs for the condition diagnosed
- any implications that may affect future pregnancies
- all the options, alternatives or choices that may be available.

Occasionally the diagnosis of an abnormality is not clear-cut. Some parents may be faced with making a decision based on test results which can indicate only a possibility or risk of a serious effect. This situation intensifies the dilemma for parents, as there may be very little information available on which to base a decision. You may wish to see another health professional to review the results and to obtain more information. In order to get the most reliable information, you may want to see a specialist in **genetic counselling**. In addition to providing you with as much information as is available about your baby's problem, such specialists are also trained to provide support and resources to parents through their decision-making process. The genetic counselling team will not make a decision for you but will help you to access the information that you need to make your decision.



Allow yourself time to seek information from all available sources. Try not to let anyone rush you into making a decision. This is a decision that you will live with forever – you are entitled to take as much time as is possible to reach the appropriate decision for you and your partner.

The single most important thing that empowers you during the decision making process and afterwards is non-judgemental support. The support of friends, family, and professionals at this time is of great importance to many parents. It is important also to ascertain the ability of health professionals to remain supportive in the light of your decision.

IF YOU DECIDE TO CONTINUE THE PREGNANCY...

The knowledge that your baby will be born with serious problems affects the joy and hopeful anticipation that many expectant parents experience as the pregnancy progresses. It is normal to grieve for those lost feelings and the health and normality of the baby.

There may be uncertainty about the seriousness of the baby's problem. It is often not possible to predict the degree of severity of the condition, nor the extent of any disability. Many parents find that they can better cope with the feelings of uncertainty and being powerless by preparing themselves. Information is the most important component of the preparation process.

You and your partner, with help from your doctor, midwife, genetic counsellor or social worker can plan for the birth of your baby in terms of support persons to be present, medications, and methods of delivery etc.

Preparation may also include consideration of some of the following issues:

- how the baby will be after delivery?
- is the baby likely to die at or after birth?
- will the baby need surgery soon after birth?
- what say do parents have in the medical management of the baby?
- can the parents make decisions about whether to proceed with life-saving measures?
- what resources are available to families with a special-needs child?
- how can we access services?

You may find it helpful to contact parents whose children have or had a similar abnormality. There may be a parent support group in your area. Sometimes a condition is so rare that there are no other parents nearby who have had a similarly affected baby. However there may be families in other areas or internationally with whom you might correspond. A Genetic Counselling unit can provide more information about particular parent support groups (see Resources on Page 21) or contact the Association of Genetic Support of Australasia (AGSA) – see Other Support Services on Page 26.

There may also be other groups, which could be of some comfort and support before and after the birth of the baby in particular circumstances. Such groups may offer support to parents whose babies are chronically ill, have had surgery or require long-term hospitalisation. There are also support groups for parents whose babies die shortly after birth (see Other Support Services on Page 26).

If you have other children, you will need to prepare them for the birth of their sibling, especially if the baby is likely to die or to require surgery or long term hospitalisation.

If it is certain that the baby will die soon after birth, you, your partner, and your children may want to discuss issues such as a name for the baby, spending time with the baby, baptism, a funeral, memorial service, ways to commemorate your baby's birth and death, and any keepsakes, such as a lock of hair, footprints, or a photograph that you would like to have. Inform the hospital staff of your wishes and plans for the baby.

MEMORIES OF YOUR BABY ARE AN ACKNOWLEDGMENT OF THE REALITY OF YOUR BABY'S BRIEF LIFE.

Another thing to consider is whether you want to have an autopsy or post-mortem examination performed on your baby. The cause of the baby's problems may not be known and such an examination may or may not provide additional information. However as it may provide information relevant to future pregnancies, you may want to discuss the reasons for undertaking this procedure with your doctor, genetic counsellor, or social worker who can also reassure you about many of the sensitive concerns which surround this issue.

You and your partner need non-judgemental support and caring comfort during the months of pregnancy and after the baby is born.



IF YOU DECIDE TO TERMINATE THE PREGNANCY...

The procedure for ending a pregnancy will vary depending on how advanced the pregnancy is, and on the policy of the particular hospital or clinic.

There are many questions that you need to ask. Even though you may feel vulnerable and grief-stricken, it is important that you are informed about:

- what you can expect to feel before, during, and after the procedure
- the types of procedures used to terminate a pregnancy
- the risks and possible complications of each procedure
- whether you have a choice of procedure
- how the baby will be after delivery
- seeing and spending time with your baby after delivery
- care for your baby afterward eg photographing, need for postmortem
- the guidelines about birth/death certificates
- funeral arrangement/memorial service
- your partner or other support person remaining with you throughout your stay
- all aspects of your care while in hospital
- legal considerations.

You may have many other questions which are painful to ask and have answered, however most parents say that they feel less vulnerable and less out of control when they are fully informed.

For example you may want to consider whether you want to have any remembrances of your baby such as a photograph, an ultrasound picture, or a blanket. Depending on the procedure used for the termination of pregnancy, you may be able to see and hold your baby. It is important to discuss this ahead of time with your doctor, genetic counsellor or social worker. Where it is possible, seeing and holding the baby gives some parents a sense of reality and allows parents to say goodbye.

Many parents feel that by acknowledging their baby and their loss, the healing process can begin. Even where it is not possible to see and hold the baby there are ways to acknowledge and remember. Having a celebrant organise a naming ceremony for the baby, holding a memorial service or funeral, planting a tree in your garden as a memorial and in some cases having the baby baptised.

WHAT YOU ARE ENTITLED TO...

You are losing your baby and you deserve to be treated like any other parent/s who has/have lost their child. You may find that you feel numb or detached while in hospital, but going home empty-handed can be very hard. You may experience after-birth contractions, breast discomfort and some breast milk production after the procedure. Many parents, who are not anticipating these physical reactions, can be distressed by them.

The hospital staff caring for you should make any necessary follow-up arrangements for post-hospital nursing assistance, further support or genetic counselling.

"I couldn't cope with leaving the hospital and not signing something or saying goodbye. Staff said to just leave when I wanted to. I felt very empty-handed, nothing to acknowledge."

Hospital staff should at all times be non-judgemental about the painful decisions involved and sensitive to your grief. If you encounter a staff person who is having difficulty in accepting your situation, you are entitled to have another staff person assigned to care for you. It may be difficult for you to make a request for a change in staff – your partner, or other support person or your social worker may be able to act on your behalf. You, your partner and family, and your baby are entitled to be treated with respect and dignity.

A SPECIAL SITUATION ... TWINS

Some families may encounter a most difficult circumstance when there is a twin or multiple gestation pregnancy and one of the unborn babies is found to have an abnormality.

If this occurs, the parents may have an additional option available to them apart from either continuing or terminating the pregnancy. They may, in some cases choose a procedure called "selective termination." Individual circumstances and medical considerations will necessitate lengthy consultation and counselling in these cases.

A couple choosing the latter option takes the risk of losing the healthy twin as a result of the procedure as well as the risk of medical complications for the mother. The emotional aspects of this particular situation are somewhat complicated and confusing for the parents. The uncertainty associated with the risks to the mother and the developing baby can bear heavily on the parents. The parents may still grieve for the baby that they lost and, at the time of delivery, there can be a mixture of joy and sadness about what the parents have gained and lost.

ANOTHER OPTION... ADOPTION

Some parents feel they could not cope with raising a child with special needs, nor coping with terminating the pregnancy. For these couples, continuing the pregnancy and then giving the baby up for adoption may be a possible option. Exploring this option is best done with guidance from a genetic counsellor and/or another appropriate health professional such as an adoption caseworker or a social worker with experience in this area. Parents choosing this option may be faced with feelings of loss and uncertainty. Additionally, there will be the anticipatory grief associated with releasing their baby at birth for adoption.

AFTERWARDS

Regardless of whether you have decided to continue your pregnancy or to end the pregnancy, you will need time to grieve and to allow the healing process to begin. Allowing yourself to grieve is fundamental to the healing process. This process follows no particular timetable – it is highly individual.

You may experience shock, disbelief, anger, depression, sadness, or guilt, among other emotions, at different times – these are all normal grief reactions. The intensity of these feelings can vary as well.

You may find that you and your partner or other family members will grieve and heal in different ways. Sharing your feelings and maintaining open communication with loved ones may help in understanding how each of you is coping. Each of you is entitled to experience your grief and healing at your own pace and in your own way.

“at the deepest level, grief is so lonely. No one can share this pain, not even my husband.”

Many parents find solace and comfort in contact with or meeting with other parents who have opted to terminate a pregnancy. Such meetings provide participants with opportunities to acknowledge their grief in a safe non-judgemental environment, and find reassurance that their reactions are common to others and reduce the sense of isolation which is often experienced. A listing is provided at the end of the booklet to help you to access the appropriate continued support.

“Listening to their reactions, bizarre thoughts and grief confirms that I’m not crazy for feeling the way I do. There in the group I don’t have to explain or justify anything.”

"The meeting has helped me not to feel as alone and different to other couples with children. I also feel less guilt and regret about the decision we made. Even though other couples at the meeting were strangers, I feel that they are a great source of support."

"We didn't feel alienated if we wished to talk about our daughter."

You may find that people, even close friends, will say things that hurt. They may not be able to understand the difficulty of your decision, nor be able to acknowledge your baby or the pain of your loss. People probably do not intend to be hurtful or judgemental and in time, you may be able to let people know what is helpful for you.

"I felt that everyone was against me for putting "them" through the pain "they" were feeling. It was like I was the culprit. How dare I? Nobody seemed to realise that all the feelings of anger, hurt, frustration, fear, pain they were feeling, were the same feelings I had."

Special days, such as holidays and Mothers and Fathers Days, can be particularly difficult, especially for those couples who have lost their baby. Also the baby's due date and the anniversary of the birth date can be especially sad days for the parents. Often the time leading up to the special days can be very trying.

Anticipating the difficult days and perhaps planning something special for the day may help in coping with the memories and emotions of your experience.

"and still sometimes it hits me all over again, fresh, like a nauseating punch in the stomach. All over again, I cry in shock and disbelief, "This isn't the way it's supposed to be! I'm supposed to be pregnant now." *



For some couples, it can be very painful to see pregnant women, or to see new mothers with their babies, or hear the sound of a baby crying ... this is a normal response and you will find ways to accept and cope in time.

Remember, no matter what decision you make, you do not have to feel alone. Reach out to friends, family, other parents, or professionals for empathy, compassion and support.

For those who continue their pregnancy, there is both grieving and a healing process involved as they come to accept their child and let go of the concept of the child they had anticipated. Regardless of whether the baby survives, it is normal to grieve for yourself and for your baby with special needs.

Support groups may provide the opportunities to share feelings and thoughts with others that have had similar experiences. This often helps reduce the feeling of isolation that many parents may feel.

As time goes on, the pain of the loss will start to diminish. The memories, the emptiness and the sadness may remain for months or years, but the heartache will ease in time. You will find that, little by little, healing begins and it is possible to experience enthusiasm and find your energy directed in a positive manner again.

THE FUTURE ...

You and your partner may have already discussed a possible future pregnancy. However for some, this may not be possible. Your doctor can advise you about how long you should allow for physical recovery after a full term delivery or after a pregnancy termination. Only you will know when you are ready emotionally to consider becoming pregnant again.

Such a decision may benefit from a discussion with a genetics counsellor for a review of:

- the abnormalities found in your baby
- the risks of recurrence
- any measures which may reduce the risk of recurrence
- options for future prenatal testing, their risks, benefits and limitations.

After experiencing the diagnosis of your baby with a serious problem, you may feel vulnerable and apprehensive about another pregnancy. You may find little comfort even where the chances are statistically low of the same problem occurring again. Prenatal testing may or may not be reassuring to you.

“My perception of risks has changed. When one looks at a group of a hundred or a thousand women of a certain age, it makes sense to say, ‘About 1% of these women will get a bad outcome on an amniocentesis, but, for me as an individual woman, facing another pregnancy, the risk at the emotional level is simply 50%. That is, a bad outcome either will happen again or it won’t.” *

It is important to reflect on the loss of your baby and to discuss any possibility that the same or a similar problem could occur again. Sadly, some parents are faced with a high risk of abnormality in future pregnancies.

Undertaking a subsequent pregnancy involves many personal considerations. It is the experience of many parents that allowing time to sufficiently acknowledge the grief of a previous experience is important in reducing the complexities faced in a future pregnancy.

Many parents feel a mixture of emotions during a subsequent pregnancy.

There is a strong feeling of hope yet there are painful memories and fear as well. It is normal for the parents to “hold back” their enthusiasm about the developing baby for fear of being hurt again. Some parents may find that they are still holding back their emotions even after the baby is born. It may take time to accept the reality of a healthy baby.

Some parents will not experience another pregnancy, nor the birth of a healthy child and there is the associated and particular grief of their experience to be acknowledged.

We, the parents who have made the difficult decisions about our babies’ futures and the professionals who have offered their support to us wish you courage and strength to face what is ahead of you. We hope that, in time, you will have peace of mind and heart about your decision.



RESOURCES

Centres for genetic counselling and prenatal diagnosis testing and counselling throughout NSW and other Australian states and territories are listed. Additional support organisations and resources are also included to meet continuing needs.

PRENATAL TESTING AND GENETIC COUNSELLING SERVICES

Prenatal testing services within NSW

CAMPERDOWN	King George V Hospital Fetal Medicine Unit Ph: (02) 9515 6042
KOGARAH	St George Hospital Women's & Children's Health Ph: (02) 9350 3635
LIVERPOOL	Liverpool Hospital Fetal Medicine Unit Ph: (02) 9828 5631
NEWCASTLE	John Hunter Hospital Prenatal Diagnosis Unit Ph: (02) 4921 4694
PENRITH	Nepean Hospital Fetal Medicine Unit Ph: (02) 4734 3362
RANDWICK	Sydney Children's Hospital Department of Medical Genetics Ph: (02) 9382 1704 Royal Hospital for Women Centre for Fetal Medicine Ph: (02) 9382 6098
ST LEONARDS	Royal North Shore Hospital Fetal Medicine Unit Ph: (02) 9926 6478
WESTMEAD	Children's Hospital at Westmead Department of Genetics Ph: (02) 9845 3273

GENETIC COUNSELLING SERVICES WITHIN NSW

For enquiries and appointments, please contact the genetic counselling service below.

CAMPERDOWN	Royal Prince Alfred Hospital Molecular and Clinical Genetics Unit Ph: (02) 9515 5080 Fax: (02) 9515 7595
KOGARAH	Genetic Counselling Services St George Hospital Ph: (02) 9350 3635 Fax: (02) 9350 3901
LIVERPOOL	Liverpool Health Service Clinical Genetics Unit Ph: (02) 9828 4665 Fax: (02) 9828 4650
NEWCASTLE	Hunter Genetics Regional Medical Genetics Unit Ph: (02) 4985 3100 Fax: (02) 4985 3105
PENRITH	Nepean Hospital Clinical Genetics Department Ph: (02) 4734 3362 Fax: (02) 4734 2567
RANDWICK	Sydney Children's Hospital Department of Medical Genetics Ph: (02) 9382 1704 Fax: (02) 9382 1711
ST LEONARDS	Royal North Shore Hospital Ph: (02) 9926 6478 Fax: (02) 9926 7880
WESTMEAD	Children's Hospital at Westmead Department of Clinical Genetics Ph: (02) 9845 3273 Fax: (02) 9845 3204

NSW OUTREACH CENTRES

BATHURST	Community Health Centre PO Box 1479 BATHURST NSW 2795 Ph: (02) 6339 5677 Fax: (02) 6339 5655
BROKEN HILL	Broken Hill Community Health Centre PO Box 457 BROKEN HILL NSW 2880 Ph: (08) 8088 1554 Fax: (02) 8088 1611
COFFS HARBOUR	Mid-North Coast Health Service Locked Mail Bag 812 COFFS HARBOUR NSW 2450 Ph: (02) 6656 7000 Fax: (02) 6656 7687
FORSTER	Forster Community Health Centre Breeze Pde FORSTER NSW 2428 Ph: (02) 6555 1800 Fax: (02) 6554 8874
GOSFORD	Central Coast Health PO Box 361 GOSFORD NSW 2250 Ph: (02) 4328 7994 Fax: (02) 4328 7925
GOULBURN	Child Development Unit Locked Bag 15 GOULBURN NSW 2580 Ph: (02) 4827 3951 Fax: (02) 4827 3958
KEMPSEY	C/- Port Macquarie Community Health Ctr Ph: (02) 6588 2882 Fax: (02) 6588 2800
MUDGEES	Mudgee Community Health Centre PO Box 29 MUDGEES 2850 Ph: (02) 6378 6236 Fax: (02) 6372 7341
MUSWELLBROOK	Muswellbrook Community Health Centre PO Box 120 MUSWELLBROOK NSW 2333 Ph: (02) 6542 2050 Fax: (02) 6542 2005

NORTH COAST	Child and Family Health Centre 37 Oliver Avenue GOONELLABAH NSW 2480 Ph: (02) 6625 0111 Fax (02) 6625 0102
PORT MACQUARIE	Port Macquarie Community Health Centre Morton Street PORT MACQUARIE NSW 2444 Ph: (02) 6588 2882 Fax: (02) 6588 2800
TAMWORTH	Tamworth Community Health Centre PO Box 83 TAMWORTH NSW 2340 Ph: (02) 6766 2555 Fax: (02) 6766 3967
TAREE	Mid-North Coast Area Health PO Box 35 TAREE NSW 2430 Ph: (02) 6592 9703 Fax: (02) 6592 9607
WAGGA WAGGA	Wagga Wagga Base Hospital PO Box 159 WAGGA WAGGA NSW 2650 Ph: (02) 6938 6666 Fax: (02) 6921 5632
WOLLONGONG	Northern Illawarra Maternal and Paediatrics Service Wollongong Hospital Crown Street WOLLONGONG NSW 2500 Ph: (02) 4253 4267 Fax: (02) 4222 5477

New services are continually being developed.

For information on services in other areas and newly developed services, please contact:

The Centre for Genetics Education
PO Box 317
ST LEONARDS NSW 1590
Ph: (02) 9926 7324 Fax: (02) 9906 7529
Email: genetics@med.usyd.edu.au
Internet: <http://www.genetics.com.au>

SERVICES OUTSIDE NSW

AUSTRALIAN CAPITAL TERRITORY	The Canberra Hospital PO Box 11 WODEN ACT 2606 Ph: (02) 6244 4042 Fax: (02) 6282 2844
NORTHERN TERRITORY	C/- South Australian Clinical Genetics Services Women's and Children's Hospital NORTH ADELAIDE SA 5006 Ph: (08) 8161 7375 Fax: (08) 8161 6088
QUEENSLAND	Queensland Clinical Genetics Service Royal Children's Hospital and District Health Service HERSTON QLD 4029 Ph: (07) 3636 1686 Fax (07) 3636 1987 Mater Mother's Hospital SOUTH BRISBANE QLD 4101 Ph: (07) 3840 1593
SOUTH AUSTRALIA	South Australian Clinical Genetics Services Women's and Children's Hospital NORTH ADELAIDE SA 5006 Ph: (08) 8161 7375 Fax: (08) 8161 6088
TASMANIA	Tasmanian Clinical Genetics Service C/- Royal Hobart Hospital GPO Box 623 HOBART TAS 7000 Ph: (03) 6222 8296 Fax: (03) 6222 7961
VICTORIA	Royal Women's Hospital 132 Grattan Street CARLTON VIC 3053 Ph: (03) 9344 2121 Fax: (03) 9344 2066 Monash Medical Centre 246 Clayton Road CLAYTON VIC 3168 Ph: (03) 9594 2026 Fax: (03) 9594 6022

Genetic Health Services Victoria
Royal Children's Hospital
PARKVILLE VIC 3052
Ph: (03) 8341 6201 Fax: (03) 8341 6390

WESTERN
AUSTRALIA

King Edward Memorial Hospital for Women
374 Bagot Road
SUBIACO WA 6008
Ph: (08) 9340 1525 Fax: (08) 9340 1678

OTHER SUPPORT SERVICES

THE ASSOCIATION OF GENETIC SUPPORT OF AUSTRALASIA
(AGSA)
66 Albion Street, Surry Hills NSW 2010
Tel: (02) 9211 1462
Fax: (02) 9211 8077
Email: agsa@ozemail.com.au
www.agsa-geneticsupport.org.au

An umbrella organisation with a client database representing over 500 genetic conditions and a rare chromosomal abnormalities contact register.

DOWN SYNDROME ASSOC. OF NSW INC.
31 O'Connell Street
Parramatta NSW 2150
Ph: (02) 9683 4333
Email: admin@dsansw.org.au

The Down Syndrome Association provides a parent support network, information and resources and peer support for families and people with Down syndrome. Resources are available in many languages.

NALAG (NATIONAL ASSOCIATION FOR LOSS AND GRIEF)
PO Box 379
DUBBO NSW 2830
Ph: (02) 6882 9222
Fax: (02) 6884 9100

An organisation which provides assistance to those suffering the effects of loss and grief and promotes community education in these areas.

THE CENTRE FOR GENETICS EDUCATION
PO BOX 317
ST LEONARDS NSW 1590
Ph: (02) 9926 7324 Fax: (02) 9906 7529

A state wide service of the NSW Genetics Service which aims to raise the awareness of the contribution of genetics to family health, both for health professionals and the public. The program can be contacted regarding availability of and access to a range of genetic services, information and resources. Referral to metropolitan and outreach genetic clinics and genetic support groups is available.

IFFA-INDUCTION FOR FETAL ABNORMALITY
PO Box 39
WARATAH NSW 2298
Ph: (02) 4967 7413

A local parent support group for families who have interrupted a pregnancy.

SIDS and KIDS NSW
Bld 301, Rozelle Hospital Campus
Balmain Road,
ROZELLE NSW 2039
Ph: (02) 9818 8400 Fax: (02) 9818 4555

SIDS and KIDS NSW is sensitive to the specific issues facing individuals experiencing a prenatal diagnosis of abnormality and its consequent decisions. It also has had experience in offering support to families who are grieving following the sudden loss of a child from the time of conception to 6 years and maintains an excellent library of grief literature.

SPINA BIFIDA GROUP OF NSW
The Northcott Society
PO Box 4055
PARRAMATTA NSW 2151
Ph: (08) 9890 0100
Fax: (08) 9683 2827
Email: enquiry@northcott.com.au
Web: www.northcott.com.au

The Northcott Society provides support, information and a peer support network for families and people with spina bifida.

FURTHER READING

- “The Tentative Pregnancy”*** Barbara Katz Rothman
Penguin Books, NY USA 1987
- “Coping with Grief”*** Mal MCKissock
- “Ended Beginnings”*** Claudia Panuthos and Catherine Romeo
- AVAILABLE FROM: CAPERS BOOKSTORE
PO Box 412
RED HILL QLD 4059
Ph: (07) 3369 9200 Fax: (07) 3369 9299
- “Letter to a Genetic Counsellor”*** Rose Green
- AVAILABLE FROM: Journal of Genetic Counselling
Vol. 1, No. 1, 1992
Human Sciences Press, Inc.
233 Spring Street
New York, N>Y> 10013-1578

GENETIC INFORMATION SHEETS

- Available in plain English
- Genetic Conditions
 - Patterns of inheritance
 - Genetic Counselling
 - Prenatal Testing and Screening For Fetal Abnormalities
 - Genes and Chromosomes

AVAILABLE FROM: THE CENTRE FOR GENETICS EDUCATION
PO Box 317
ST LEONARDS NSW 1590
Ph: (02) 9926 7324
Fax: (02) 9906 7529
Email: genetics@med.usyd.edu.au
Website: www.genetics.com.au

“Footprints”

AVAILABLE FROM: IFFA-INDUCTION FOR FETAL ABNORMALITY
PO Box 39
WARATAH NSW 2298
Ph: (02) 4967 7413

GLOSSARY

ABORTION

See Termination of Pregnancy

AMNIOCENTESIS

A procedure for obtaining fluid for prenatal diagnosis. Using a sterile needle, gently inserted through the mother's abdomen a sample of amniotic fluid is removed from the uterus; the amniotic fluid contains cells from the fetus which can be analysed to determine if the fetus has a specific disorder.

AMNIOTIC FLUID

Fluid in which the fetus floats in the uterus; fetal cells are found suspended in this fluid.

CHORION

The chorion develops into the placenta and chorion cells have the same genetic composition as the cells of the fetus. Cells of the chorion are sampled during a prenatal diagnostic test called CVS (chorion villus sampling)

CHORIONIC VILLUS SAMPLING (CVS)

A procedure for obtaining the chorion cells to enable testing of the fetus for specific abnormalities. It is usually carried out in the 11th-13th week of pregnancy.

FETUS

A term used by health professionals to describe the product of conception after the eighth week of pregnancy to the moment of birth. The term embryo may be used prior to eight weeks gestation.

GENES

The basic unit of heredity; a segment of DNA which contains the information for a specific characteristic or function.

GENETIC COUNSELLING

Diagnosis, information and support provided by health professionals, with specialised training in genetics and counselling.

GESTATION

Stage of pregnancy development.

INHERITED

The transmission of genetic information from a parent to a child.

POSTMORTEM

This is a surgical procedure which examines the external parts of the body and the internal organs to document any abnormalities and possibly to determine the cause of the baby's death. Two incisions are made to examine the baby's internal organs. Following the procedure the incisions are usually stitched.

PRENATAL DIAGNOSIS

The detection of fetal abnormalities during pregnancy.

TERMINATION OF PREGNANCY

Intervention to ensure a pregnancy does not continue: interruption of pregnancy.

TRIMESTER

Three month period used to describe stages of pregnancy.

ULTRASOUND

The use of sound waves for visualising the body tissues and structures. In pregnancy, some structural abnormalities in the fetus can be detected.

References

* Green R. 1992 "Letter to a Genetic Counsellor"
Journal of Genetic Counselling 1:55-70

** "Courage" Newsletter of the National MPS Society, USA, Spring 1993

