



Antenatal Results & Choices ●

Help for Grandparents

*Supporting you through
difficult family times*

Introduction

Grandparents-to-be often have their own very special hopes and dreams as their children begin families of their own. When an unborn baby is diagnosed with a significant condition or anomaly, the news can have a huge impact on the whole family. Care and attention will naturally be focused on the baby's parents, but grandparents and other family members can also experience powerful and confusing emotions. Many are desperate to help their children in some way, while also struggling with shock and distress themselves.

This leaflet explains a little more about the choices that are available to pregnant women and their partners. It talks about some of the emotions and issues other grandparents have experienced, and has suggestions on how to help yourself and your son or daughter, at this difficult time.

Antenatal testing

All pregnant women are offered ultrasound scans at around 12 weeks and 20 weeks to check the growth and development of their baby, as well as a screening test at 12 weeks to estimate the chance of the baby having Down's syndrome, Edwards' syndrome and Patau's syndrome, the three most common chromosomal conditions.

For most expectant parents, antenatal screening will provide reassurance and scans will be happy and exciting events. But for those who are given the difficult (and often completely unexpected) news that their baby has a significant condition or structural anomaly, the results usually come as a great shock.

Although some of the conditions and structural defects detected in pregnancy are treatable and curable, many are not, and expectant parents are then faced with what for many is an agonising decision between continuing with the affected pregnancy, knowing that their baby may not survive birth or will have a significant disability or health condition, and ending their pregnancy.

Some couples are aware that they have an increased chance of passing on an inherited condition, and do their best to prepare for this possibility. Even so, the reality of a diagnosis can still be very distressing, for the parents and the family.

ARC provides on-going emotional support for women and their partners and families, throughout decision-making and whatever decision is made. This booklet is written for grandparents whose children have chosen to end a much-wanted pregnancy or who continued knowing that their baby would die at birth or soon after. It deals with some of the issues related to the loss of a baby.

We are here for emotional support in the antenatal period for those continuing an affected pregnancy too, whatever the diagnosis or prognosis. But in our experience, many of those couples are looking for very specific advice and information about the condition diagnosed in their baby and what to expect when the baby is born. We can signpost to other organisations better placed to provide this information and who may be able to put them in touch with other families in similar situations.

Choosing to end the pregnancy

You will probably be as shocked and confused as your children when you know what is happening. ARC produces a handbook for women and couples considering or facing termination, which explains what will happen when they end the pregnancy. This includes information about hospital procedures and covers other decisions they may face, such as deciding whether to see their baby, whether to have tangible mementoes such as photos and footprints, whether to have a post-mortem or other testing, information about funerals and cremations and coping with the physical and emotional after-effects of a termination.

There are different ways of ending a pregnancy and expectant parents should be offered a choice of method. However, this may depend on the stage of pregnancy or the particular circumstances and on whether the necessary expertise is available at their hospital. Most of the expertise for later surgical terminations (i.e. after 12–14 weeks) is now in the independent sector. This is partly because independent providers, such as bpas and MSI now provide the majority of termination services in the UK.

Although it is possible to get a referral to a clinic for a later surgical procedure and have it funded by the NHS, many women will go through an induction and delivery of their baby. It is hard to predict how long this might take but it will involve an overnight stay in hospital. Some couples appreciate having their parents with them or visiting them at the hospital. Some may need help with child care. Every family is different but the offer of practical or emotional support is often very much appreciated.

Details about the actual process of termination may be very hard to discuss, and you may find it helpful to know a little about what may happen. You can download a copy of our booklet on ending the pregnancy from our website, or call us if you would like us to send you a copy.

Choosing to continue the pregnancy

There are conditions in pregnancy where the outcome is certain, others where the prognosis is uncertain and others where it is known that the baby will die before or soon after birth. Continuing with the pregnancy can be a very anxious and uncertain time. ARC has a Handbook which deals with some of the practical and emotional issues which parents may face. This includes organisation of antenatal care, where appointments take place, what extra care the baby may need during the pregnancy, preparing for the birth and the needs of the baby after birth. You can download a copy of our booklet on continuing the pregnancy from our website, or call us if you would like us to send you a copy.

Helplessness

"I felt so helpless, you can make things better for your child when they are small, but there was nothing I could do. I felt I had let her down."

"I would rather go through this myself than see her going through it. I'd do anything to take this pain away"

People whose children have gone through this experience often say they felt helpless, and that they were worried and confused about how to support their children, about what to say or do. Although you can offer support and suggestions, you cannot make their decision for them, and you cannot take the pain away.

Watching your child suffer is perhaps the hardest thing of all. You may feel that you should be able to stop it hurting, and be furious at your own lack of power and control over the situation. These feelings are very common. There is no 'right' way to behave in a situation like this. You may find it will help you if you can acknowledge your feelings to yourself and talk to someone else about them. ARC regularly hears from grandparents and we're here for you too.

Losing your expected grandchild

"While shopping every woman seemed to be pregnant, every woman of my age was pushing their grandchild in the pram. I was so envious and, ashamed to say, jealous."

It is important to recognise that you too have experienced a loss, the loss of your anticipated grandchild. You may need time to grieve too. The sadness may hit you very hard, and this may be even more difficult if you are trying to support your children through their own hurt.

Feeling jealous of other families is a very common reaction. You may feel a lot of sadness for what might have been. Talking to someone who will understand can be a comfort and a relief.

Feeling guilty and blaming yourself

The need or desire for an explanation as to why a condition or anomaly occurred is natural. The parents should receive as much information as is available about what was detected in their baby and what, if any, underlying cause there might have been.

In most cases, the condition or anomaly is a 'sporadic event', i.e. not inherited or passed on through the family. But a small number of couples may find out that they carry a genetic condition and that they have an increased chance of having a baby with problems.

The baby's parents often have feelings of guilt about what has happened, but grandparents too sometimes feel that they are somehow to blame, or at fault. This feeling can be even stronger with inherited genetic disorders, despite the fact that no-one is to blame for their genes, and there is usually nothing that could have been done to avoid the condition or anomaly.

Different ways of grieving

Each of us reacts differently to bereavement, and every situation is unique. Grief is a naturally isolating and painful experience. The loss of a baby in pregnancy or soon after can be a particularly poorly understood and isolating bereavement, and a diagnosis and a difficult decision often adds complex layers to parents' grief. There are broad patterns in any normal grieving process. If you know about these, you may find that it makes your own feelings easier to cope with, and that you can give more help to the baby's parents.

Shock and numbness, intense sadness and crying, anger, guilt, anxiety and confusion are all very normal reactions to any loss. In time, the vast majority of bereaved parents find a way to cope with their loss and grief. But this may not happen quickly, and 'recovery' does not happen in a neat, linear way. The bereaved often talk about the rollercoaster of grief, or waves of pain and sorrow that hit them in an unpredictable way. This may happen for grandparents too, depending on how emotionally invested they have been in their child's pregnancy. Some may have had their own difficult experiences in pregnancy and/or have lost a baby. While this might help them understand what their child is going through, it can also bring back their own pain and grief. They may have dealt with their own loss very differently. Times have changed and they may not have been offered the same information and choices.

Everyone goes through this process in their own time. There is no right or wrong way to grieve or to behave at this time and everyone copes differently. Anyone who is struggling, who feels 'stuck', or simply wants someone to talk to, can contact ARC's helpline for specialist help and understanding. There are other organisations that can help too.

Remembering the baby

The parents will never forget their baby. For some, the memory is all they need, but others will choose to have a funeral and burial or cremation and/or tangible mementoes of the baby. These can become a focus for their grief and their memories.

It is not necessarily right for everyone, but many do need a focus for their grief and many also find that significant dates such as when the baby was due, anniversaries of the loss, and traditionally family times (eg Christmas, Mother's Day and Father's Day) can bring sadness for years to come. Some bereaved parents have found it helpful to name their baby, have a service or blessing for them or plant a tree or bush in their memory.

It is not morbid to want to remember a much-wanted baby for the parents, or for their family. It is not dwelling unnecessarily on what has happened, or failing 'to get over it'. In fact, many bereaved parents appreciate their baby being remembered by others around them. It can help the parents if you remember significant dates and acknowledge that there are times that may be painful for them. Do try and take your cue from your child and if you're unsure, you can ask them what they would find helpful.

At these difficult times you can simply talk about the baby, visit a memorial, send a 'thinking of you' card or have a simple, appropriate act of remembrance such as lighting a candle. Some families like to make a donation in memory of the baby, to ARC and other causes close to their hearts. Whatever ways you choose to remember the baby can give everyone comfort.

Another Pregnancy

Subsequent pregnancies are often difficult and anxious for the parents and sometimes for grandparents too, even when a recurrence of a condition or anomaly is very unlikely. Again, you can help by simply being there to listen, and by encouraging the mother to raise her anxieties with the medical staff caring for her in the next pregnancy and to seek support if she needs it.

It's natural to want your child to feel positive and hopeful, but it can be helpful for them (and for you if you are also anxious) to have anxieties acknowledged, rather than being told not to worry. It is not unusual to remain quite anxious until the baby is born and it can help to have someone to offload to, for example the ARC Helpline and other bereaved women and couples.

While no-one can guarantee the success of a pregnancy, most women and couples ARC has contact with do find that everything goes well the next time, and that there is hope for the future.

For your son or daughter

- Be there – let them know that you are there if they need you.
- As often as you can, ask how things are for them – they can then tell you if they are struggling.
- Allow them to talk and cry whenever they need to. But make sure you have support too if you need it.
- Allow them not to talk if they prefer not to.
- If you live near enough, offer practical help with things like shopping, care of any other children and housework.
- Give them ARC's details, or contact us on their behalf.
- Try not to feel rejected if they don't notice the things you have done.

For yourself

- Take time for your own feelings and grief.
- Talk to your partner or a friend.
- Seek help from your GP if you feel you aren't coping and don't hesitate to contact ARC. Our Helpline number is **020 7713 7486** and email **info@arc-uk.org**

Books you may find helpful

Empty Cradle, Broken Heart by Deborah L. Davis

Chapters specifically about decisions following a diagnosis and about the impact on fathers, grandparents and other family members.

A Silent Sorrow; Pregnancy Loss: Guidance and Support for You and Your Family by Ingrid Kohn and Perry-Lynn Moffitt

Chapters on prenatal diagnosis and the burden of choice, and about family and friends.

Unspeakable Losses: Healing from Miscarriage, Abortion & Other Pregnancy Loss by Kim Kluger Bell

Chapters about the dilemma of choice, men's experience of pregnancy loss and an appendix for family and friends whose loved ones are dealing with a reproductive crisis.

Other useful organisations

SANDS (Stillbirth and Neonatal Death charity)

Helpline 0808 164 3332 www.sands.org.uk

Also provides support and information to bereaved parents who have lost a baby in pregnancy, at birth or soon after, and has a booklet for bereaved grandparents

<https://www.sands.org.uk/support/bereavement-support/information-and-support-grandparents-when-grandchild-dies-during-or-shortly-after-birth>

<https://www.sands.org.uk/grandparents>

The Samaritans

Samaritans

116 123 jo@samaritans.org

How can I help ARC?

ARC is the only national charity offering specialised support and information to parents who are considering antenatal testing, waiting for test results, or facing the decision to continue or end their pregnancy due to an abnormality in their unborn baby. ARC provides on-going support to parents whatever decision is made about the pregnancy, and support for other members of their families.

As a charity, we rely entirely on voluntary contributions to fund our work. Your donation will help us to continue our work, and to improve the support and information we can provide.

You can donate here: <https://arc-uk.charitycheckout.co.uk/donate#!/> or call us on 0207 713 7356 to discuss other ways of giving.

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