



Being a grandparent to a heart child

The aim of this fact sheet is to give grandparents of heart children information about heart conditions and how best to help their grandchild's parents.

My grandchild has a heart problem

One in 133 children is born with some kind of heart defect. The majority of these defects do not need treatment or can be corrected so that the heart works properly.

In the past, many children died as a result of heart problems. Thankfully, there have been huge medical advances in recent years. More and more heart children are now surviving and leading normal lives. Today, over 95% of children who have open heart surgery survive.

If you want to know more about your grandchild's condition, do get in touch with us. We are happy to talk to you on the telephone and we also have a range of fact sheets explaining different conditions and how they are treated.

Family problems

Having a seriously ill child can lead to increased tension within the family. Grandparents often experience the same emotions, such as anger, grief and denial that affect parents on learning of a diagnosis and it can be difficult to move on.

A common source of tension within families is family members trying to advise parents on how best to look after their heart child. However well meant the advice is, it can upset parents as their child may need special treatment, for example a different diet.

One grandparent contacted us after she saw her daughter feeding her son cream. She was shocked as she thought that cream was bad for the heart and too rich for babies. In fact, a dietician had recommended a high calorie diet for the baby so that he could put on weight before his next operation.

The best way to avoid misunderstandings like these is to find out as much as you can about your grandchild's condition. Often, parents will be grateful for your interest and happy to explain any special treatment.

Supporting each other

Whilst there may be the occasional row or misunderstanding, many families are drawn even closer together. We often hear about grandparents playing a vital role in supporting the parents of heart children.

Offering help

It is important that everyone who wants to help is led by what the parents want and need at the time. You may have ideas about what you could do to help but try to be as flexible as possible. If parents tell you they do not need help now, let them know that they can always ask you again in the future.

Grandparents help in many ways, for example: babysitting, cooking meals, helping with the housework and giving lifts to appointments.

Some grandparents become very knowledgeable about their grandchild's condition and accompany parents to appointments with cardiologists. This can be useful as there is often a lot of information to take in and two sets of ears can be better than one.

Often the most important thing grandparents can do to help is to listen. Many parents turn naturally to their own parents as people they know they can talk to and whose support they can depend on.

Too far away?

If you live far away, try and stay in touch by short telephone calls or cards. Looking after a heart child can also mean extra financial burdens so any offers of financial help that you can make may also be gratefully received.

Other grandchildren

The brothers and sisters of heart children can often find themselves overlooked by relatives anxious about the ill child. Parents too can find it hard not to make their heart child the centre of their attention. Grandparents can help by giving other children time and attention. They might also be able to look after the heart child so that the parents can spend time alone with their other child or children.

Help for you

The Children's Heart Federation can provide you with information about heart defects – just call the helpline number **0808 808 5000** or visit our website **www.chfed.org.uk**

If your relationship with your children and grandchildren has been affected by a family disagreement, you can contact the

Grandparents' Association. This is a national charity which works to improve the lives of children by working with and for all grandparents. They have an advice line **0845 434 9585** and there is also lots of information on their website **www.grandparents-association.org.uk**

From the post bag

"Often on the ward we see grandparents sitting with children while parents take an hour or two to sleep, or work, or see to other members of the family. And off the ward, at fundraising events or social occasions, again it is often grandparents on the stall, baking the cakes, selling the tickets."

"When our son was periodically very ill it was his grandma who rescued us from having to look after the other children, brought delicacies into hospital for Mum and Dad as well as making the fruit juice jellies which were the patient's staple diet."

"I discovered that my daughter was desperate and did not think I cared – I had made the mistake of thinking that they were coping well..."

"I send cards, sometimes flowers to celebrate every small triumph - like when she took more than a few mls of milk, the day she didn't vomit.... And the day she sat up was champagne!"

"She has always been a source of strength and love, even at those benighted times when we were anguished and surly – we acknowledge what she did for us at much sacrifice to her own comfort."