



Grandparents

Information for families

UK

Incorporating **The Lady Hoare Trust**

Introduction

Having a disabled child in the family has an effect on everyone, not just parents and siblings. As a grandparent, you may sometimes find yourself in an unfamiliar and sometimes difficult situation. The child's parents, brothers, and sisters and other relatives may look to you for information and support. And this may be at a time when you are trying to come to terms with the news that your grandchild has a disability.

We hope that this guide will help you identify with some of the feelings and needs of other grandparents, as well as give a few ideas to those of you who are unsure how best to support the parents/carers of a disabled child.

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Spotlight on grandparents

For those of us lucky enough to grow up knowing our grandparents, most of us found it a unique, rewarding and enriching relationship. As their grandparent, children may see you as a person with whom they can spend time, share experiences and fun times. Similarly, you can enjoy the pleasure of being with children and young people without many of the responsibilities of your own child-rearing years.

Increasingly, families today face a range of pressures, such as demanding jobs and financial constraints. As a result, grandparents who may be of working age themselves are involved in providing childcare and support. If your grandchild is born or diagnosed with a disability or health condition, you may feel increased pressure to provide help.

Research on 'special grandparenting'

What is increasingly clear from research on grandparents of disabled children is the amount of support grandparents

provide. Grandparents who are less supportive tend to be those who find it difficult to accept their grandchild's disability. What may also be important is the fact that the disability movement has changed social attitudes significantly in a grandparent's lifetime. Many grandparents may have had little contact with disabled children in their formative years as, at that time, many disabled children were cared for away from home.

Research shows that changes in attitudes towards disability and the move towards inclusion of disabled children in mainstream schools and activities can challenge the original experiences and assumptions of the older generation.



Freephone helpline: **0808 808 3555**
www.cafamily.org.uk

How does it feel to be a grandparent of a child with a disability?

Here, some grandparents describe their feelings when they heard the news that their grandchild had a disability:

- "It was hard coping and fighting, if only I was ten years younger"
- "I was very angry. Why our boy?"
- "It was hard to know how to support my daughter and husband - I tried to give them space"
- "It was very difficult to accept. I wanted to do more to help"
- "It was a double whammy – concerned for the child's parents but also worried about the child."

The role of grandparents

Most of the grandparents who attended Contact a Family's grandparents' workshop felt that their roles as grandparents were very varied and that there were additional worries if their grandchild had a disability. Grandparents shared their concerns about how involved they should be and what help they should offer.

Many common themes emerged during the workshop. Most felt that just being there was very important but that grandparents needed to be sensitive as to the level of input they should give. A

number of grandparents felt they were at a stage in their life where they were able to devote their time and attention and offer support. In return, they felt having a disabled child in the family had helped them to be more understanding and to learn more about disability. One grandparent felt that the effects of having a disabled grandchild had brought the whole family closer.

Many grandparents report that their involvement in their grandchild's life is greater if they were the child of the daughter, rather than of the daughter-in-law. Also, relationships with the child's parents remain good if they had been getting on well before the child was born. Similarly, if the parent does not have a partner involved with the disabled child, then grandparents are often more involved in providing support.



Difficult relationships

Of course, not all families have good relationships and sometimes the arrival of a disabled child adds to already strained relations. It has been reported that grandparents go through the same emotions that affect parents (including anger, grief and denial), but some find it hard to move on to an acceptance of the situation.

Many families describe these initial feelings as a kind of grieving process which sometimes leads to looking for someone or something to blame. Questions and ideas like, 'whose side of the family is to blame?' or, 'You can always have another child' can cause additional pain and distress.

Equally, some grandparents are overwhelming in their offers of support and advice, and sometimes find it hard to know when to back off. There is a strong need to care for your own child but it is important to really listen to the parents and acknowledge their needs, as well as addressing your own feelings.

As a grandparent, you may not always share the same ideas about parenting as those of your son or daughter and their partner. What is important, however, is a consistent approach with the child. Difficulties can often be avoided by everyone responding to the child in a similar way, particularly for children with behavioural problems. The situation can often be helped by a feeling that you are all pulling in the same direction.



If parents' relationships break down there can be all kinds of implications for grandparents. You may be concerned about continuing to have contact with your grandchildren and want to know your legal rights. There are organisations that can offer help and advice (see 'Useful organisations' on page 10).

When parents are no longer able to care

Some grandparents find themselves in the position of taking on the full-time care of the grandchildren. This may happen if your son or daughter is unwell. In cases of bereavement, or if for some reason the parents are unable to look after their children, grandparents may suddenly be asked to take their grandchildren into their homes and a temporary measure can become permanent. In such situations, the legal and financial issues are complicated and you need to get expert advice as soon as possible. Phone our freephone helpline for information on how to access support.

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What is helpful for grandparents to know?

Every family is unique. Parents take differing lengths of time to find the right direction for them and their family.

- Try not to assume that help has been offered, for example from social services, a GP or consultant. Many parents feel unsupported even if services are in place. Some parents might need support in asking for help such as a short break (a break away from their caring role) or applying for benefits. Often, there are support groups for specific conditions offering useful leaflets for families. Contact a Family can provide details of support groups, both locally and nationally.
- There may be some particularly difficult times for parents, such as around the time of diagnosis or when no medical diagnosis can be given. Also, finding a school, moving to secondary school and transition to adult services can be stressful times when extra support may be welcome.
- Often parents have to deal with a range of services, including health, education and social services and the process can be exhausting.
- Help with phone calls, support at meetings, or offering to care for grandchildren while the parent goes to meetings can ease the pressure.
- Parents often find that they gain most support from other parents with disabled children. Encouraging your son or daughter to access such support may be good for the whole family, including grandparents.

Siblings

Siblings of disabled children may feel that, because of the additional care needs of their brother or sister, their parents have less time for them. There may be little or no time for family activities. The additional pressures siblings face at home mean grandparents can play an important role by offering to take siblings out. Involving siblings in activities they would otherwise miss out on can make a big difference, as can giving them a quiet place where they can do their homework or just have time out. Equally supportive, where possible, is taking care of the disabled child, even if only for a short time, so that the other children can have some precious time with their parents. Contact a Family has produced a guide, *Siblings* with further information.

Support for grandparents

Grandparents groups have been set up in response to grandparents' need for support. At a Contact a Family workshop



for grandparents, none of those attending had met other grandparents in a similar position before and all felt this was a very valuable experience.

Many were keen to speak as well as hear and learn from other grandparents. If you have a disabled grandchild, there are local and national support groups and online forums that can give you support and advice. Phone our freephone helpline on 0808 808 3555 for more information.

It is also helpful to make use of your own support networks of friends and relatives. If the child has other grandparents, it may be useful to pool ideas and work together in offering support. You should be realistic about the kind of help you can offer and remember that you have needs too, including thinking about your own health.

Information

Many grandparents feel excluded from information networks available to parents and feel that professional workers should include them when information is shared. They often look to the child's parents for information and this can leave the parents feeling unsupported. Grandparents should not feel afraid of looking for information to help them understand the situation and learn about the child's condition. Local libraries, health centres or GP surgeries can be helpful sources of information.

Parents often find it frustrating explaining time and again to professional workers about their child's condition and it can be a relief to them to know that at least within their family, there is someone who has some knowledge and understanding.

How can Contact a Family help?

Contact a Family has a team of advisers and information officers who can help you find information about individual disabilities or conditions as well as issues that may affect the family, such as education or benefits. We are here to listen and talk through anything you are concerned about in relation to your grandchild's disability. We also have details of local and UK-wide support groups.

Where a condition is very rare and there is no support group, we try to link individual families through MakingContact.org. We also produce a range of parent guides and publications.



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“Be led by the parents – they will tell you what they need.”

Tips from grandparents

Grandparents often feel afraid and do not quite know how to help or get involved. Sometimes it is easier to back off, but if you are flexible and prepared to think around the situation, there might just be something you can do which can make life easier. Sometimes it is the little things that matter like making a meal, doing shopping or babysitting so the parent can take a relaxing bath in peace.

As well as providing direct help, getting involved in fundraising for a local group may make family members feel useful.

Tips from grandparents:

- be led by the parents – they will tell you what they need
- listen. Be a sponge
- accept that advice won't always be welcome from you
- just be there
- try to understand the impact of the disability
- remember that the caring goes on after you are no longer around
- if what you want to say won't help, don't say it
- don't be oversensitive – sometimes parents will need someone to let off steam to

- offer help, don't wait to be asked, but be sensitive
- focus on the child, not on the diagnosis
- respect that parents want the best for their child and it may take them a long time to accept their child's disability
- encourage the child to have age-appropriate dress and appearance
- information is very important to find and to share
- jump in with both feet
- you can't generalise about disability
- don't neglect the siblings – they have needs too
- if you have money, give them money to buy help now, don't wait to leave it to them in your will.



The grandparents' story

It came as a shock, when he was around three, to realise that Danny, our handsome grandson, had autism. When his younger brother Sam was born with multiple disabilities we felt demoralised and began to ask why, and wonder what or who was responsible. Self-questioning raised the fear that some hereditary factor might be the cause.

We quickly tried to adopt a supportive role. This was easier when we lived nearer and when both the grandchildren and ourselves were younger. We could help by taking Danny and his sister Rowena out, perhaps to the seaside for a picnic, or take all the children for a local walk.

On visits, we were also able to help with gardening, the inevitable mountains of washing and other chores. We've always tried to treat the boys as precious individuals with some unique characteristics. More than once we've been caught out underestimating Danny's capabilities and understanding – often to his own advantage! On one outing, one minute he was happily paddling with us at the water's edge, the next he was swimming out to sea!

Sam has always needed full-time care and it has been harder for us to directly help as much with him. As we now only see the family two or three times a year, it's difficult to build up a relationship with Sam. Fortunately, we all share a love of music, and different

sorts of music are something we can all enjoy together.

Over the years, we have been glad to see the children thriving and happy in their different ways but have realised that this was largely at the expense of their parents – the main carers. Much depends on parents being able to build a team of reliable helpers to manage all their commitments with each of the children – something which needs careful organisation.

It is a comfort for us, to see that our daughter and her family are getting some support. We have willingly helped financially when we can, to relieve the pressure of money worries, and have been involved in setting up trusts to protect the grandsons financially in the future.

Now our grandchildren – aged 20, 18 and 15 – are practically grown up. Danny now lives away from home and Rowena hopes to go to university. We are now in our 80s and live further away, so our involvement is inevitably more remote. However, being grandparents to two boys with special needs has also led to us broadening our experiences. We have helped at a club for disabled people, been on a Makaton signing course, and attended seminars about autism and genetics. All this has helped us come to terms with the situation, even though it was very upsetting at the beginning.

Gwen and George

Useful information

Our guide *When your child has additional needs* gives an overview of the services and support available to families of children with a disability or health condition, including rare disorders.

There are many national and local organisations that support families who have a child with a disability or health condition. If your grandchild has a diagnosis, it could be worth finding out if there is a specific organisation for their condition and what help they can offer. The Contact a Family freephone helpline can offer information and advice and put you in touch with local and national organisations.

Useful organisations

BeGrand.net

Tel: 0845 423 5565

<http://begrand.net>

Provides information, advice and an online community for grandparents.

The Grandparents' Association

Tel: 01279 428 040

Helpline: 0845 423 55 65

www.grandparents-association.org.uk

Support and information for grandparents including an advice line, publications, groups and mediation.

Grandparents Plus

Tel: 020 8981 8001

www.grandparentsplus.org.uk

Promotes the role of kinship care and care by grandparents at all levels, particularly

in cases of family breakdown, single parenthood or other difficult circumstances.

Family Rights Group

Tel: 020 7923 2868

Advice line: 0808 801 6368

www.frg.org.uk

National organisation providing advice and support for families whose children are involved with social services.

The organisation has a database for grandparent carers to make contact with each other in the UK.

Parentlineplus

Tel: 0207 284 5500

Helpline: 0808 800 2222

www.parentlineplus.org.uk/grandparents

National parenting charity with information for grandparents and how to support your children and grandchildren.

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Twitter

twitter.com/contactafamily

Podcasts

You can download podcasts from our website at: www.cafamily.org.uk/news/podcasts.html

iTunes users can listen to our podcasts at:

www.cafamily.org.uk/itunes

Videos

You can watch videos on our YouTube channel at:

www.youtube.com/cafamily

Freephone helpline: **0808 808 3555**
www.cafamily.org.uk

Getting in contact with us

Free helpline for parents and families

0808 808 3555

Textphone

0808 808 3556

Open Monday–Friday

Access to over 170 languages

www.cafamily.org.uk
www.makingcontact.org

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Language Line
services

Other information booklets available

This guide is one of a series produced for parents and groups concerned with the care of disabled children. A full list of Contact a Family publications is available on request or can be downloaded from our website www.cafamily.org.uk

- Concerned about your child? ^(UK)
- Understanding your child's behaviour ^(UK)
- The tax credits guide ^(UK)
- Working ^(UK)
- Siblings ^(UK)
- Disabled children's services in England and Wales ^(England & Wales)
- Getting direct payments for your disabled child ^(England & Wales)
- Dealing with debt ^(England & Wales)
- Preparing for adult life and transition ^(England & Wales)
- Relationships ^(UK)

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