



Grandparents

Information for families

UK

Incorporating **The Lady Hoare Trust**

Introduction

Having a disabled child has an effect on the whole family, not just parents and siblings. As a grandparent, you may find yourself in an unfamiliar and sometimes difficult situation. The child's parents, brothers and sisters and other relatives may be looking 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 factsheet will help you identify with some of the feelings and needs of other grandparents as well as highlighting a few ideas for 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 a grandparent, children see you as a safe haven, 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, modern families are being faced with a range of pressures, such as demanding jobs and financial constraints. As a result, grandparents are involved in providing childcare and support. This may be further increased if the grandchild is born or diagnosed with a disability or health condition. You may feel increased pressure to provide help.

Research on 'special grandparenting'

Much of the research on grandparents of disabled children has been carried out in the United States although some

work is beginning in the UK. What is overwhelming in many of these studies, is the amount of support grandparents have been able to provide. Grandparents who have been less supportive, have tended to be those who have found it difficult to accept the child's disability. What may also be important is the fact that the disability movement has changed significantly in their 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.

According to the research, changes in attitudes towards disability generally and the move towards inclusion of disabled children in mainstream schools and activities, can challenge original experiences and assumptions.

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

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

A workshop for grandparents was held in Richmond-upon-Thames. Here are some quotes from grandparents, describing 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 people who attended the workshop felt that their role as a grandparent was a very varied one with some additional worries if the child was disabled. There were many 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 a very important role to play but that some sensitivity was needed about 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 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.

All families are different in their make-up, but many grandparents have reported that their involvement in their grandchild's life was greater if they were the child of the daughter, rather than the daughter-in-law. Most relationships with the child's parents remained good if they had been good before the child was born. Similarly, if the parent did not have a partner involved with the disabled child, then grandparents were often involved in providing additional support.

Difficult relationships

Inevitably, 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 lead to looking for someone or something to blame. Feelings and ideas like 'whose side 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, noting that sometimes it is hard to know when to back off. There is a strong need to care for your own child which can evoke strong maternal/paternal feelings. It is important to really listen to the parents and acknowledge their needs as well as addressing your own feelings of loss.

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. These situations can often be helped by a feeling that you are all pulling in the same direction.

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

Some grandparents find themselves in the position of taking on the full-time care of the grandchildren when families breakdown. There is a great need for support at such times, whether this is emotional or practical.



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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 or 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 respite care (a break away from their caring role) or applying for benefits. Remember also that some parents might be struggling even though they appear to be coping.
- Very often there is a support group for the specific condition with useful leaflets about individual disabilities, often written with families in mind. Contact a Family can provide details of support groups, both locally and nationally.
- There may be some particularly difficult stages for parents, such as around the time of diagnosis or for when no specific diagnosis can be given. Entering primary school, moving to secondary school and transition into adult services can all be stressful times when extra support may be welcome.
- Often parents have to deal with a range of statutory services including health, education and social services and the process can be quite exhausting.
- Help with phone calls, support at meetings, or caring for the children while these matters are dealt with can ease the pressure.
- Parents often find that they gain most support from other parents with

disabled children. Encouraging such support may be beneficial for the whole family, including grandparent to grandparent support.

Siblings

Siblings of disabled children often feel that because of the additional care needs of their brother or sister, there is a lack of time for their own needs. This can lead to limited family activities and additional pressures at home. There may be an important role to play here for grandparents who could perhaps offer some special time for siblings, or include them in activities they would otherwise miss out on.

You may be able to offer 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 factsheet 'Siblings' with further information.



Support for grandparents

A few grandparents groups are beginning to be established with the recognition that grandparents also feel isolated and in need of support. Some of the parent support networks may not always be accessible for grandparents. At the grandparents workshop we held, none of those attending had ever met other grandparents in a similar position and felt this was a very valuable experience.

Many were keen just to hear what others had to say and to learn from each other. There may be a specific role for grandparents to be involved in established local and UK-wide support groups.

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

Information

Many grandparents feel excluded from the normal information networks available to parents and feel that professional workers should include them when information is shared. They often look to parents for information and this can leave the parents feeling unsupported. Grandparents should not feel afraid of looking for information to help in

understanding the situation and becoming knowledgeable about the child's condition. Parents often find it frustrating explaining time and again to professional workers about the particular disability their child has 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.

Contact a Family can help you to locate information about individual disabilities or medical conditions and the range of issues that may affect the family. Local libraries, health centres or GP surgeries can also be helpful sources of information.

How can Contact a Family help?

Contact a Family has a team of advisers and information officers who can help. This might be information about an individual condition or disability, or on related issues such as education or benefits. We aim to give details of support networks, local and UK-wide groups.

Where a condition is very rare and there is no support group, we try to link individual families. We are also here to listen and talk through any issues you are concerned about and are happy to hear from any family members. Contact a Family produce a range of factsheets (see back cover for more details).

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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 how to get involved. It does not always mean providing physical help but perhaps getting involved in fundraising for a local group for example. 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 taking the parent out to lunch, doing the shopping or babysitting so the parent can take a bath in peace.

- 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 it doesn't help, don't open your mouth;
- 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 need to strive for the best potential of their child and acceptance of the child's disability may take a long time for the parents;
- 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 special needs too;
- if you have money, give them money now to buy help now, don't wait to leave it to them in your will.



A grandparents story

It came as a shock, when he was around three, to realise that Danny, our handsome grandson, had become autistic. 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 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 the 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 Cox

Useful information

Our factsheet '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. Available in paper and CD formats as well as on the Contact a Family website.

There are many national and local organisations that support families who have a child with a disability or health condition. And many of them are becoming more aware of the role that grandparents play in helping their children and grandchildren. If your grandchild has a diagnosis it could be worth finding out if there is a specific organization for their condition and what help they can offer. Many now offer resources and information for grandparents.

Call the Contact a Family helpline. We can offer information, advice and put you in touch with local and national organizations which may be of help.

For children without a firm diagnosis there is an organization called SWAN (which stands for Syndromes Without A Name). In fact it was set up by a grandmother who, finding there was no support group for her family, decided to start a small local group. SWAN is now a registered charity offering support to families by telephone, letter and e-mail.

SWAN,

6 Acorn Close

Great Wyrley, Walsall, WS6 6HP

Tel/Fax: 01922 701234

e-mail: info@undiagnosed.org.uk

Web: <http://www.undiagnosed.org.uk>

Useful organisations

The Grandparents' Association

Moot House, The Stow Harlow CM20 3AG

Tel: 01279 444964

Helpline: 0845 4349585

(Mon-Fri, 10.30am-3pm)

Web: <http://tinyurl.com/yrn25u>

Supports grandparents who have lost contact with their grandchildren, are caring for their grandchildren fulltime, or have childcare responsibilities for their grandchildren.

Grandparents Plus

18 Victoria Park Square, Bethnal Green, London, E2 9PF

Tel: 020 8981 8001

Web: <http://www.grandparentsplus.org.uk>

Promoting the role of kinship care and care by grandparents at all levels, particularly in circumstances of family breakdown, single parenthood or other difficult circumstances.

Family Rights Group

The Print House, 18 Ashwin Street, London E8 3DL

Advice Line Tel: 0800 731 1696

(Mon-Fri, 10am-12pm & 1.30-3.30pm)

Web: <http://www.frg.org.uk>

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

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

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Web: **www.cafamily.org.uk**

Getting in contact with us

Free helpline for parents and families

0808 808 3555

Textphone

0808 808 3556

Open Mon–Fri, 10am–4pm;

Mon, 5.30–7.30pm

Access to over 100 languages

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

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Language Line
SERVICES

Other information booklets available

This factsheet 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

- About families with disabled children (UK)
- Dealing with debt (Scotland, England and Wales, Northern Ireland)
- Fathers (UK)
- Understanding your child's behaviour (UK)
- Living without a diagnosis (UK)
- Siblings (UK)
- Holidays, play and leisure (UK)
- Aids, equipment and adaptations

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