

Grandparents

A guide for families in England, Northern Ireland, Scotland and Wales



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, siblings and other relatives may look to you for information and support. This may happen 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. You will also find a few ideas to help you if you are unsure how best to support the parents 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 someone to spend time with, and share experiences and fun times. Also, you can enjoy the pleasure of being with children and young people without many of the responsibilities being a parent.

Many families today face a range of pressures, such as demanding jobs and financial constraints. Often, grandparents who may be of working age themselves are involved in providing childcare and support, and some become full-time carers.

If your grandchild is born or diagnosed with a disability or has a long-term health condition, you may feel increased pressure to help and support your family.

What is increasingly clear from research 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. When they were growing up, many grandparents may have had little contact with disabled children as, in the past, 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 grandparents.

The role of grandparents

Most of the grandparents who helped us plan this guide felt that their roles as grandparents were varied, and there were more worries if their grandchild has a disability. Grandparents shared their concerns about how involved they should be and what help they should offer.

Most grandparents we spoke to said that just being there was important but that you need to be sensitive about the level of input you should give. Some grandparents were juggling work and supporting their families. Others said they were at a stage in their life where they were able to offer their time and support.

Most grandparents felt that having a disabled child in the family had helped them to be more understanding and to learn more about disability. One grandparent said that having a disabled grandchild had brought the whole family closer.

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

Feelings

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. ”

Difficult relationships

Not all families have good relationships. Sometimes the arrival of a disabled child, or the realisation that an older child has a disability adds to already strained relations.

Grandparents go through the same emotions as parents (including anger, grief and denial), and some find it hard to move on and accept the situation.

Every family is unique. Parents want the best for their child and it may take them a long time to accept their child's disability. Many families describe their initial feelings as a kind of grieving process which sometimes leads on 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 more 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 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 your son or daughter and their partner. What is important though, is agreeing a consistent approach with the child. Problems can often be avoided by



everyone responding to the child in a similar way, particularly for children with behaviour that challenges. 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.

i See 'Further sources of support' on page 13).

Support for grandparents

It is helpful to make use of your support networks of friends and relatives. If the child has other grandparents, it may be useful to talk about how you can best work together to offer practical and emotional support. Try to be realistic about the kind of help you can offer and remember that you have needs too, including thinking about your health.

Grandparents' groups have been set up in response to grandparents' need for support. No-one we spoke to had met other grandparents in a similar position before and everyone felt it was a valuable experience. Many were keen to speak as well as listen and learn from other grandparents. If you have a disabled grandchild, there are national support groups and online forums that can give you expert support and advice.

 See 'Further sources of support' on page 13, or call our freephone helpline on **0808 808 3555**

Benefits and national insurance credits for grandparents

If you have not taken over the responsibility for looking after a disabled child, but are helping his or her parent by providing a substantial amount of care, you might still be able to claim certain carers' benefits (for example, Carer's Allowance). However, your chances of getting benefits as a carer will depend

on a number of factors, such as your income and whether anyone else is already claiming as a carer for that child. If you provide a significant amount of care and are under state pension age, you may also be able to help protect your pension entitlement by getting national insurance credits.

Information

Learning about your grandchild's condition can help you feel empowered and will mean you are better able to support the whole family. It can also be a relief for parents to know that, at least within their family, there is someone who has knowledge and understanding.



Our website has information on hundreds of conditions and support groups:

www.contact.org.uk



Our helpline has experts who can help and support you, and provide information on support groups.

0808 808 3555 or email

helpline@contact.org.uk



What is helpful for grandparents to know?

- Every family is unique. Each family member takes time to find their way.
- You may feel afraid and not know how to help. If you are flexible and prepared to think around the situation, there may be something you can do which can make life easier for your family. Sometimes it is the little things that matter like making a meal, doing shopping or babysitting so the parent can take a break.
- Try not to assume that help has been offered from social services, or a GP. Parents may feel unsupported even if services are in place. Some parents might need support to apply for benefits. You may not have money to share with your family, but information is very important too.
- There may be some particularly difficult times for parents, such as around the time of diagnosis or when no medical diagnosis can be given. Finding a school, changing schools and transition to adult services can be stressful times and extra support may be welcome.
- Often parents have to deal with a range of services, including health, education and social services and can feel exhausted. Help with phone calls, support at meetings, or offering to care for grandchildren while the parent goes to meetings can ease the pressure.

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 extra pressures siblings face at home mean grandparents can play an important role by taking siblings out for a treat. 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, for example.

Equally supportive, where possible, is taking care of the disabled child, even if only for a short time, so that siblings can have some precious time with their parents.

 We have a free **Siblings** guide, with further information and useful organisations for siblings, available from our freephone helpline or to download at www.contact.org.uk





Tips from grandparents

- Accepting your grandchild's disability may take a long time for you and their parents.
- Be led by the parents. They will tell you what they need.
- Don't give advice, it won't always be welcome – listen!
- You can't generalise about disability.
- Don't be over sensitive. Sometimes parents need someone to let off steam to.
- Try not to offer your opinions when your adult children are upset.
- Just be there.
- Offer help. Don't wait to be asked.
- Focus on the child, not their diagnosis.
- Information is very important to find and share.
- Don't neglect the other grandchildren in the family, siblings need support too.
- Don't forget to get support for yourself.

When grandparents take on full-time care

Some grandparents find themselves taking on the full-time care of the grandchildren. This may happen if your son or daughter has physical or mental health problems, for example. You might suddenly, or without much warning, be asked to take your grandchildren into your home and a temporary measure can become permanent.

However much you love your grandchildren and know you can care for them and support them as they grow up, becoming their full-time carer may not always be easy. An unexpected start to living together may have an effect on all of you. If there is uncertainty about how long your grandchildren will live with you this may have its own effects.

Before they come to live with you, your grandchildren may have experienced difficult situations. These experiences may have long-term effects on some children's emotional wellbeing and behaviour. Try to find support services for your grandchildren. Call our freephone helpline for advice.

You may need to make changes in your life if grandchildren come to live with you. If you are working, you might want to cut your hours or give up work altogether so you can look after them. Children's services may require you to give up work before they will agree to you caring for your grandchildren full-time. There are likely to be wide ranging financial implications for you whether or not you have to give up work.



Call our freephone helpline on **0808 808 3555** to get advice about your options.

If your grandchildren's parents are still around, you might find that negotiating relationships and contact between your grandchildren and their parents bring their own difficulties. Some children's services departments will give advice and support with these issues and you can call our freephone helpline for advice.

Your legal position and financial support

Grandparents and others who take on the full-time care of children when their parents are unable to do so are often called 'kinship carers' or 'family and friends carers'. Some organisations also say 'connected person'.

There are different types of kinship carers because kinship care can be arranged in different ways. The type of kinship carer you are may change over time. It can be an informal arrangement decided between you and the parents. It can come about if a parent dies and has arranged for you to be a 'testamentary guardian'. A testamentary guardian is someone appointed by a will or other legal deed to be the guardian of a child after a parent dies.

Your grandchildren might be 'looked after' by the local authority. There may be an order from court or, in Scotland, from a children's hearing. Alternatively,

the local authority might be looking after your grandchildren with the agreement of, or at the request of their parents. Your grandchildren might be placed with you by a local authority worker, usually a social worker from the children's services department.

This can be a difficult situation. Children's services sometimes argue that the arrangement is a private arrangement between you and the children's parents even when it is children's services that placed your grandchildren with you. If you are in this situation it is important to get legal advice. Call our freephone helpline if you want us to help you find legal support.

Alternatively, you might have a residence order from a court, or a child arrangements order, or a special guardianship order in England or Wales.

These different situations are grounded in different legal principles. This means that the financial and other help you might get is different in each situation. In some cases, you will be eligible for benefits and tax credits. In some situations, the local authority may also have a legal duty or a power to give you financial support.

If the local authority has a duty to give you financial support it means they are legally bound to do so. If your local authority has the power to give support it means they can make a decision to do so. In either case, the local authority will have written policies about financial support and you can ask to see these policies.



These legal and financial issues are complicated and you need to get expert advice as soon as possible.

If you take on the full time care of your grandchild you will also be able to access help from social services in the same way as a parent would, for example equipment, or help as a carer yourself. See our guide *Getting social care services when your child has additional needs*.



Call our freephone helpline for information on how to access support.



There is also a list of useful organisations on page 13 of this guide.

The grandparents' story

It came as a shock to realise our grandson Danny 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.

We quickly tried to adopt a supportive role. 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! One minute he'd be happily paddling with us at the water's edge, the next he was swimming out to sea!

Sam has more complex needs and has always needed full-time care, so it has been harder for us to directly help as much with him.

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 support. We have willingly helped financially when we can to relieve the pressure of money worries. We've also have been involved in setting up trusts to protect our grandsons financially in the future.

Now our grandchildren are almost grown up. Danny lives away from home and Rowena hopes to go to university. We are in our 80s and live further away, so our involvement is inevitably more remote.

Being grandparents to two boys with additional needs has led to us broadening our experiences. We have helped at a club for disabled people, done a Makaton signing course, and been to talks 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

Further sources of support

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 you and your family.

GENERAL SUPPORT

> The Grandparents' Association


Support and information for grandparents on many issues including contact with grandchildren, an advice line, an email advice service, publications, and support groups.


 www.grandparents-association.org.uk

 Helpline 0845 434 9585

> Young Minds

Young Minds focuses on improving the emotional wellbeing and mental health of children and young people. They have a helpline for parents and carers, an email advice service and a website with information for children and young people as well as their carers

 www.youngminds.org.uk

 Parent carers helpline
0808 802 5544

> Children 1st - Scotland

Scotland helpline for anyone concerned about or caring for a child. Free helpline and email advice service. Children 1st offers many local services in Scotland including advocacy for children, befriending and family support.

 www.children1st.org.uk

 ParentLine Scotland advice line
0800 282 233

> Family Fund

The UK's largest provider of grants to low-income families raising disabled and seriously-ill children and young people. Funding may be offered for essential items such as washing machines, fridges and clothing but the Family Fund can also consider grants for sensory toys, computers and family breaks.

 www.familyfund.org.uk

 01904 621 115

> Family Lives

Helpline, message boards, email service, live chat and parenting/relationship support groups.

 www.familylives.org.uk


 Advice line 0808 800 2222

LEGAL HELP

> Coram Children's Legal Centre

Legal advice and information in England on the website on all aspects of family, child and education law plus limited free legal advice over the phone.

 www.childrenslegalcentre.com

 **Child Law Advice Line**
0300 330 5480

> Parenting NI

Free helpline for parents, carers and families Northern Ireland facing difficulties. There is also an email service plus free face-to-face appointments in some areas.

 Parentingni.org

 **Helpline 0808 8010722**

> Scottish Child Law Centre

Free legal advice in Scotland for and about the law relating to children.

 www.sclc.org.uk

 **Advice Line 0131 667 6333**

Free calls for under 21s from land lines on 0800 328 8970 and on 0300 330 1421 from mobiles

HELP FOR KINSHIP CARERS

> Citizens Advice Scotland

Gives advice on anything to do with being a kinship carer in Scotland. All Citizens Advice Bureaux in Scotland can also give advice on all aspects of kinship care.


 www.cas.org.uk

 **Kinship Care helpline 0808 800 0006**

> Family Rights Group

Information, advice (including legal advice) and support for families in England and Wales when social services are involved with, or should be involved with children. Also has details of support groups and an online discussion forum for kinship carers.

 www.frg.org.uk

 **Advice line 0808 801 0366**

> Grandparents Plus


Advice for kinship carers via phone and email. In 2015, they published the second edition of The Kinship Care Guide for England. They promote the role of kinship care and care by grandparents at all levels, particularly in cases of family breakdown, single parenthood or other difficult circumstances.

 www.grandparentsplus.org.uk

 **Advice line 0300 123 7015**

> Kinship Care Northern Ireland

Kinship Care Northern Ireland works to help and support kinship carers.

 www.kinshipcareni.com


 **Helpline 0800 022 3129**

> Mentor

Mentor published Kinship Care: Children cared for by family and friends. This is a guide to kinship care in Scotland. The guide can be downloaded from their website or you can order a hard copy by email from.

 www.mentoruk.org.uk

 **0131 334 8512**

 admin-scotland@mentor.org.

How can Contact can help



Contact has a team of advisers who can help you find information about individual disabilities or conditions. You can also phone us about any issues that affect your family, such as education or benefits. We are here to listen and talk through any of your concerns about your grandchild's disability.

 **0808 808 3555**  **helpline@contact.org.uk**



Parents often find that they gain most support from other parents with disabled children. Whilst advice won't always be welcome, encouraging your son or daughter to access this support may be good for the whole family. Our helpline also has 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 our free website.

www.makingcontact.org



Contact also produces a range of parent guides and publications. A full list of our guides is at the link below. All our publications are free to family members who call our helpline, and free to download.

 **www.contact.org.uk/publicationslist**

 **0808 808 3555**

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 020 7608 8700

 info@contact.org.uk


 www.contact.org.uk


 www.facebook.com/contactfamilies

 www.twitter.com/contactfamilies

 www.youtube.com/contactfamilies

Free helpline for parents and families:

 **0808 808 3555** (Mon–Fri, 9.30am–5pm)

 helpline@contact.org.uk (Access to over 200 languages)

Our free family linking service

 www.makingcontact.org



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