

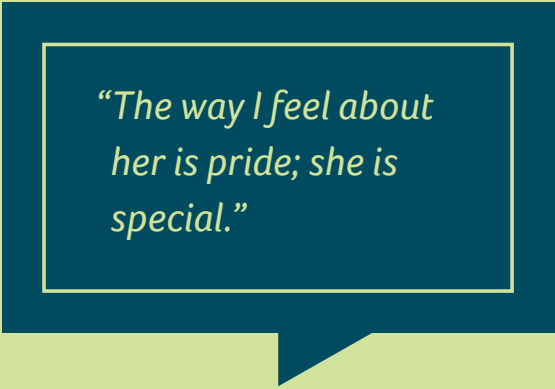
GRANDPARENTS



INFORMATION FOR GRANDPARENTS OF DISABLED CHILDREN



contact



*“The way I feel about
her is pride; she is
special.”*

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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.

"We've always tried to treat the boys as precious individuals with some unique characteristics.

Grandparent carer

SPOTLIGHT ON GRANDPARENTS

For those of us lucky enough to grow up knowing our grandparents, most of us will have 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.

SUPPORTING YOUR GROWN UP CHILDREN

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.

CHANGING ATTITUDES TOWARDS DISABILITY

Grandparents who are less supportive tend to be those who find it difficult to accept their grandchild's disability. The disability movement has changed social attitudes significantly in the last 50 years. When they were growing up, many grandparents may have had little contact with disabled children as, in the past, 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.

BRINGING THE FAMILY TOGETHER

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 very difficult to accept. I wanted to do more to help"

Grandparent

"It was hard coping and fighting, if only I was ten years younger."

Grandparent

"It was a double whammy — concerned for the child's parents but also worried about the child."

Grandparent

"It was hard to know how to support my daughter and husband — I tried to give them space."

Grandparent

"I was very angry. Why our boy?"

Grandparent

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.
- **Parents often 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.
- **Parents often gain most support from other parents with disabled children.** Whilst advice won't always be welcome from you, encouraging your son or daughter to access such support may be good for the whole family.



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.

COMING TO TERMS WITH THE SITUATION

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.

A CONSISTENT APPROACH WITH THE CHILD

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 THE PARENTS’ RELATIONSHIP ENDS

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 — see ‘Further sources of support’ on page 24).

SUPPORT FOR GRANDPARENTS

It is helpful to make use of your support networks of friends and relatives. If your grandchild 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 24, 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.



We have an **A-Z medical directory** with **reliable medical information** on more than 440 medical conditions including rare disorders, plus contact details for UK support groups. All entries are approved by a medical expert.

CONNECTING WITH GRANDPARENTS ONLINE

Reaching out to others online may be particularly useful for grandparents, as you may know few people in your situation.

You may find that someone else's experience helps you to deal with issues you too are experiencing. By talking to others you may find out about treatments, new therapies or research projects that are being conducted to learn more about the condition your grand child is affected by. Contact the condition-specific support groups in our A-Z medical directory above.

Facebook may also be a good way to meet other grandparents — there are lots of online support groups for specific conditions and there is the option of closed or private groups. You can set up your own group if there isn't one, and then other grandparents can find you. But do remember to check if there is already an established group you can contact — they may already have useful information and advice to share.



We have a **closed (private) Facebook group** with more than 18,000 members you are welcome to join, or **follow our Facebook page** to get up-to-date news and information for families with disabled children.



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.



WHEN GRANDPARENTS TAKE ON FULL-TIME CARE

Some grandparents find themselves taking on the full-time care of their 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.

ADJUSTING TO THE NEW SITUATION

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 on **0808 808 3555** for advice about support, and read how to get **practical support** both in the home and outside it.

Possible lifestyle changes

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.

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.

Types of kinship care

- **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 would like us to help you find legal support.
- **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.

Financial support from the local authority

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 may make a decision to do so, but are not legally bound to.

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.

Practical support from the local authority

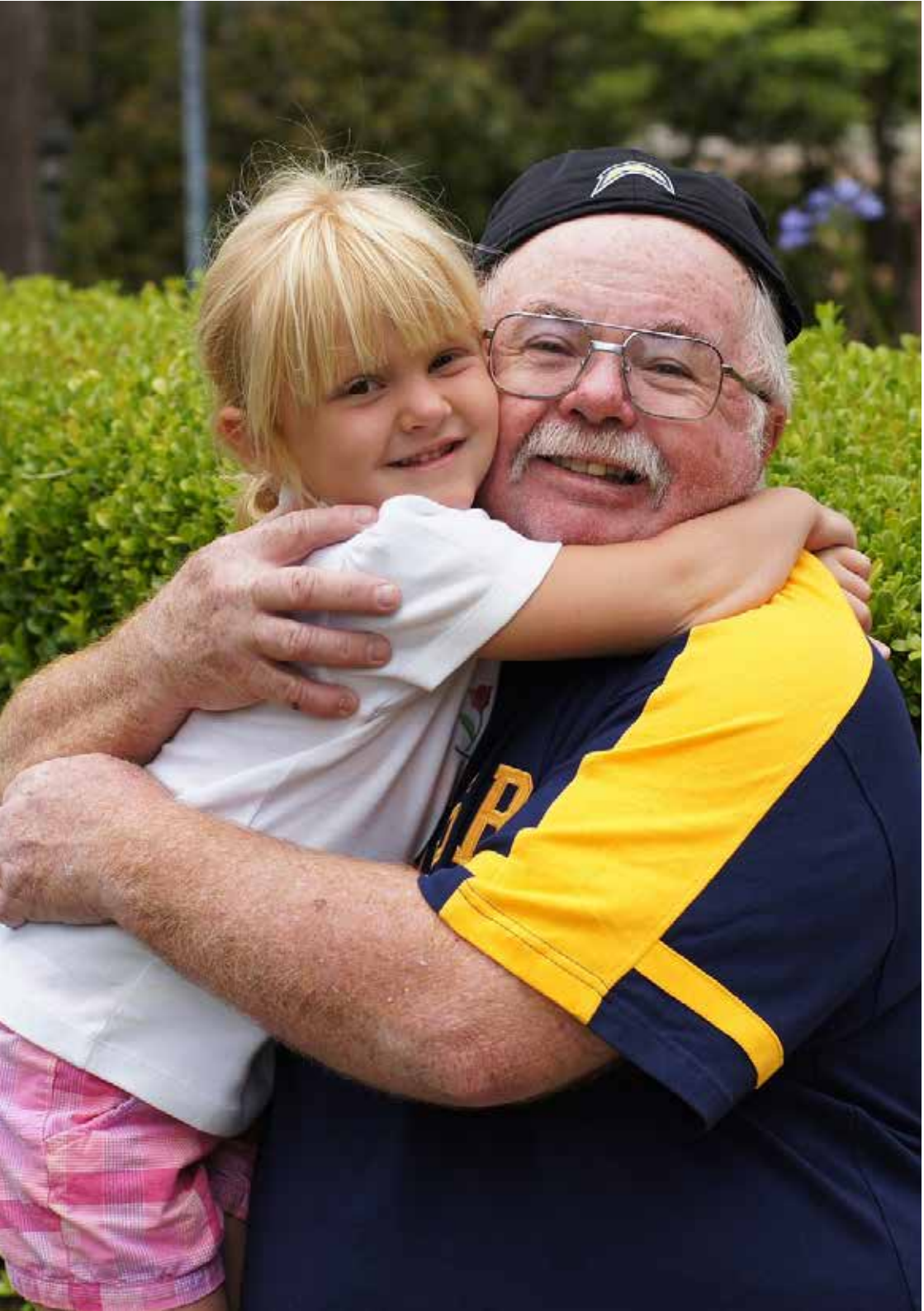
If you take on the full time care of your grandchild you will also be able to access help from social services in the same way as a parent would, for example equipment, or help as a carer yourself.



Call our freephone helpline on **0808 808 3555** for advice about support, and read how to get **practical support** both in the home and outside it

TOP 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.
- **Have someone to talk to yourself.**
- **Don't be over sensitive.** Sometimes parents need someone to let off steam to.
- **Keep calm and be open to advice.**
- **Keep positive** and enjoy every moment.
- **Be available** when you are needed.
- **Be patient** and look at the positives.
- **Listen** – be at the end of the phone.
- **Keep up your own interests too.**
- **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.
- **Reliable, accurate 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.**



A GRANDPARENT'S STORY

GETTING THE DIAGNOSIS

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.

A HELPING HAND

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.

OUR UNIQUE BOYS

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!

FINDING COMMON GROUND

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.

CARE FOR THE CARERS

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.

LOOKING TO THE FUTURE

Now our grandchildren — aged 20, 18, and 15 — are almost 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.

BROADENING OUR EXPERIENCE

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, 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

Family Lives

Support and information for grandparents on many issues.

Helpline: 0808 800 2222

familylives.org.uk

Children 1st — Scotland

Helpline for anyone caring for a child, including grandparents and kinship carers. Local family hubs in Scotland providing advocacy, befriending and family support.

ParentLine: 0800 28 22 33

children1st.org.uk

Parenting NI

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

Helpline: 0808 8010 722

parentingni.org

Family Fund

Grants for low-income families raising disabled and seriously-ill children and young people.

Tel: 01904 550055

familyfund.org.uk

LEGAL HELP

Coram Children's Legal Centre

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

childrenslegalcentre.com

Scottish Child Law Centre

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

Free Advice Line: 0300 3301 421

sclc.org.uk

HELP FOR KINSHIP CARERS

Kinship — England and Wales

Online information, advice and support hub for kinship carers.

Helpline: 0300 123 7015

kinship.org.uk

Kinship Care — Scotland

Advice on anything to do with being a kinship carer in Scotland.

Helpline: 0808 800 0006

kinship.scot

Kinship Care — Northern Ireland

Works to help and support kinship carers.

Helpline: 0800 022 3129

kinshipcareni.com

Family Rights Group — England and Wales

Free specialist legal and child welfare practice advice service for parents and kinship carers 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.

Free Advice Line: 0808 801 0366

frg.org.uk



HOW CONTACT CAN HELP

Our team of advisers can help you find information about individual disabilities or long-term health 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

GUIDES FOR GRANDPARENTS

We have a range of free guides and factsheets to download from our website, including:

- ***Siblings***
- ***Claiming Disability Living Allowance for children***
- ***Claiming Child Disability Payment (Scotland)***
- ***Money Matters – a checklist of financial help available***
- ***Money Matters (Scotland) – a checklist of financial help available***
- ***Sleep***
- ***Toilet Training***
- ***Understanding Behaviour***

WORKSHOPS AND ACTIVITIES

We run workshops, which usually take place online. Many of our workshops are tailored to different child age groups, and needs. We also run a series of general workshops appropriate for carers of children of all ages.

Better Together is our series of fun and engaging activities. Popular with families with disabled children who might not always have had the opportunity to take part. A Better Together session could be focused on nature, art, music or sport but is not restricted to these. Better Together activities are a great opportunity for parents and carers to meet each other and our friendly team.

Details of our workshops and events are available on our website:



0808 808 3555



contact.org.uk

GET IN CONTACT

Our helpline advisers can support you with any issue about raising your disabled child: help in the early years, diagnosis, benefits, education and local support.

-  0808 808 3555
-  info@contact.org.uk
-  www.contact.org.uk
-  twitter.com/contactfamilies
-  facebook.com/contactfamilies
-  youtube.com/contactfamilies

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We are Contact, the charity for families with disabled children.

We support families with the best possible guidance and information.

We bring families together to support each other.

We help families to campaign, volunteer and fundraise to improve life for themselves and others.

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