



**RARE**  
resources  
S C O T L A N D



## **4 Support and information for parents and carers**



Rare Resources is a collection of information guides for families who have recently received a diagnosis of a genetic or rare condition, are on the journey to a diagnosis, or have been told their child's condition is so rare they might not get a diagnosis.

The Rare Resources guides have been developed in collaboration between Genetic Alliance UK and families in Scotland. The guides provide links to reliable sources of information and support, and contain 'top tips' from other families.

Rare Resources contains the following guides:

1. Genetic, rare and undiagnosed conditions explained
2. The journey to diagnosis
3. Using NHS Scotland
4. Support and information for parents and carers
5. Support and information for your child
6. Information directory detailing support services available in Scotland

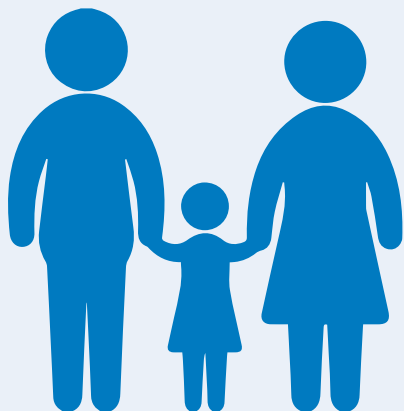
The Rare Resources guides can be downloaded from [bit.ly/rrgeneticallianceuk](https://bit.ly/rrgeneticallianceuk)

If you have an questions about our Rare Resources guides, please contact us on 0300 124 0441 or [contactus@geneticalliance.org.uk](mailto:contactus@geneticalliance.org.uk)

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# 4.1 Parent carers



**You are a carer if you provide care for another person for a reason other than because of their age. You can be a carer even if you are related to the person that you care for.**

Parents to children and young people who have a genetic, rare or undiagnosed condition, are also typically carers. They are often referred to as 'parent carers'.

As a parent carer to a child with a genetic, rare or undiagnosed condition, it is natural to put the needs of your child ahead of your own.

**However, it is important to recognise that your needs are also important – think of what they tell you on aeroplanes – you need to fix your own oxygen mask before attending to anyone else!**

**'I've been a carer to both my wife and child, but who cares for the carer?'**  
Workshop participant

Being a parent carer can sometimes feel stressful and overwhelming, but there is support available to you.

**'I think people are starting to recognise just how valuable carers are. There is more and more help out there, it's just knowing where to find it - and that's the hard part.'**  
Workshop participant

## Top Tips From Parents

**Meet other parent carers** – It can be very beneficial to meet others who are experiencing, or have experienced what you are going through.

**Understand your rights as a carer** – Many parents are unaware that they are also carers for their child, and as a result miss out on the practical, emotional and financial support available to them.

**Don't be afraid to ask for help** – Remember it is completely normal to feel overwhelmed from time to time. Don't be afraid to ask for help when you need it.

**Make time for yourself** – This can be a little time each day, or a couple of hours a week.

**Remember who you are** – You are not only a parent carer. Try to make time for yourself and the things that you enjoy even if it is just for a few minutes. If this isn't possible then try and find ways to fit in small things that can help while you are doing other tasks – for example, use going to the bathroom as a chance to stop and count ten deep exhalations to relax you.

# 4.2 Your rights and needs as a carer



**In Scotland, carers have rights under the Carers (Scotland) Act 2016. As a carer in Scotland, you are entitled to an Adult Carer Support Plan which is an assessment of your needs by your local council.**

Your local council may be able to arrange practical help for you. This may include:

- Information and advice.
- Support from other carers or carer organisations.
- A break from your caring responsibilities
- Emotional help.
- Carer training courses.
- Help applying for financial benefits.

Local carer centres provide information on your rights and needs as a carer.

[bit.ly/rrlocalcarerscentresscot](http://bit.ly/rrlocalcarerscentresscot)

## What is an Adult Carer Support Plan?

An Adult Carer Support Plan looks at seven areas of your life: your caring role, how you are feeling, time for you, your health, how you manage at home, your finances and your work situation.

Each local council has its own local eligibility criteria which it uses to decide what support you are entitled to. You can request an Adult Carer Support Plan by contacting your local council.

The plan will set out what support you might need to help you in your role as a parent carer. The plan should set out your needs and how they will be met.

## Rights for Working Carers

Parents and carers who also work may be entitled to in-work benefits or tax credits.

Speak to a benefits advisor before returning to work. They can provide you with advice and support on how returning to work will affect your entitlement to benefits.

You may be able to get support from your employer to balance your caring needs with work. This could include flexible working options, and paid or unpaid leave. Contact your local carers centre for advice.

## Carer's Allowance

Carer's Allowance is the main welfare benefit for carers and is for anyone who spends at least 35 hours per week providing regular care to someone.

You may be entitled to Carer's Allowance if your child receives the middle or high rate care component of Disability Living Allowance. Carer's Allowance is not means tested, but what you earn may affect how much you are entitled to.

## Top Tips From Parents

It is a good idea to prepare for your Adult Carer Support Plan conversation. Spend some time considering the points listed above. You can obtain advice on the Adult Carer Support Plan by contacting your local carer organisation.

## 4.3 Support for carers

**There are a number of carers organisations that provide information, advice and support to carers in Scotland.**

These include:

Care Information Scotland  
0800 011 3200  
[bit.ly/rrcareinfoscotland](https://bit.ly/rrcareinfoscotland)

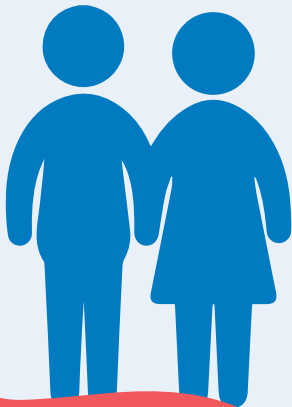
Carers Scotland  
[bit.ly/rrcarersscotland](https://bit.ly/rrcarersscotland)

Coalition of Carers in Scotland  
[bit.ly/rrcarersinscotland](https://bit.ly/rrcarersinscotland)

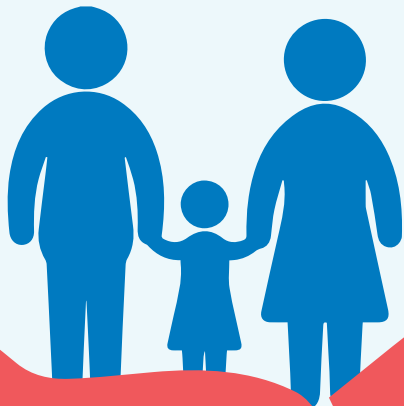
Carers Trust Scotland  
[bit.ly/rrcarerstrustinscotland](https://bit.ly/rrcarerstrustinscotland)

The Samaritans provide emotional support to anyone struggling to cope, through their telephone helpline and website  
**116 123**  
[bit.ly/rrsamaritans](https://bit.ly/rrsamaritans)

Local Carer Centres  
Each local council must provide an information and advice service for carers. You can find out more about the service in your area by contacting your local council.  
[bit.ly/rrlocalcarerscentresscot](https://bit.ly/rrlocalcarerscentresscot)



# 4.4 Find support from other parents and carers



**It can be comforting and helpful to talk to someone with, or who has a child with, the same condition – someone who has experienced the same things that you are facing.**

Having a rare condition (which most genetic conditions are) can feel extremely isolating because there aren't many other people living with the condition. The same goes for being a parent, carer or family member to someone with a genetic, rare or undiagnosed condition.

The best way to try and find other parents and families is through a support organisation for your child's condition. Support organisations exist to support children, families, individuals and carers. They are experts in understanding their specific conditions and at providing the support that you need.

Genetic Alliance UK can help you find support. On the Genetic Alliance UK website, you can use the 'search' function on the members' page to find groups that may be relevant to you in the UK. [geneticalliance.org.uk](http://geneticalliance.org.uk)

## Online forums

The internet is home to a wealth of virtual areas for people to meet and talk about their experiences with genetic, rare and undiagnosed conditions. Some trusted resources include:

### Facebook

As a free, informal platform Facebook is home to a number of online support

groups. You don't need to have a Facebook account to search for groups, although if you do find a relevant group you will need to sign up to join and talk to people. If there isn't already a Facebook group for the condition you can always set one up for the next person who is searching for one. It can be a great way to connect with others directly.

### Contact

Contact is an online forum set up by the organisation Contact for parents of children with disabilities. Just enter your condition into the search function on the Making Contact website and you'll be able to see how many people have registered under the condition name. Don't forget to register yourself, even if there isn't anyone else registered, so that anyone who is newly diagnosed can find you. [bit.ly/rrcontact](http://bit.ly/rrcontact)

### Rare Connect

Rare Connect is a free online platform with condition specific communities and general discussion groups. The platform was set up by EURORDIS: an alliance of rare disease patients in Europe. Discussions are translated across six languages (English, French, German, Italian, Spanish and Portuguese). [bit.ly/rrrareconnect](http://bit.ly/rrrareconnect)

# 4.5 Managing relationships



**Our relationships with others can play a big part in our lives and can provide comfort, encouragement, help and support, both emotionally and practically.**

For many parents, their relationships with others can make a difference to their health and wellbeing.

However, caring for a child or young person with a genetic, rare or undiagnosed condition can bring new challenges and pressures, and sometimes this can put strain on relationships.

## Your relationship

For some couples, the experience of raising a child with a genetic, rare or undiagnosed condition can be overwhelming.

Some couples report that the experience brings them closer together, whilst for others, the experience can put a strain on their relationship. Every person, and every couple, is different and it may also change over time.

## Single parents

Being a single parent to a child with a health condition can bring additional responsibilities.

There is support available to single parents from organisations such as One Parent Families Scotland and Parenting Across Scotland.

## Families and friends

Telling family members and friends about the diagnosis of a genetic, rare or

undiagnosed condition can be a difficult conversation.

You may be worried about what your family members might say, whether or not they will be understanding or whether they will be upset.

**The important thing to remember is that telling your family members is your decision to make, and it is up to you how you choose to do it.**

## What if we need help?

We all hope that our relationships are strong enough to help us overcome some of the challenges in our life. For some, the challenges of having a child with a health condition can strengthen their relationships.

Unfortunately, this is not always the case and some relationships can change. It may be that it would be helpful to seek some independent, professional advice.

This can be in the form of counselling or mediation services.

There are organisations that can provide advice and offer support:

- One Parent Families Scotland [bit.ly/rroneparentfamiliesScotland](https://bit.ly/rroneparentfamiliesScotland)
- Parenting Across Scotland [bit.ly/rrparentingacrossscot](https://bit.ly/rrparentingacrossscot)
- Relationships Scotland [bit.ly/rrrelationshipsScotland](https://bit.ly/rrrelationshipsScotland)
- Scottish Mediation Helpline 0131 556 8118





# 4.6 Taking a break



**There will be times when your caring responsibilities can become exhausting and it might be good for you, or you and your partner, to have a short time away from your caring role.**

This is sometimes called a short break or respite care.

Short breaks or respite can be an essential part of the overall support that families need, they can provide a break from routine, time to rest and recharge, and opportunities to spend time with others or pursue your own interests.

Short breaks and respite care can come in many different forms including:

- Holiday or activity breaks
- Care for your child at a day centre
- Specialist play schemes or after school clubs
- Funding for you to do something you would like to do, such as relaxation therapies or going to the cinema

You may be able to access a short break or respite care through your local council. You will have a discussion about your respite needs as part of your Adult Carer Support Plan discussion.

There are also charities and third sector organisations that provide respite or grants for short breaks.

## Top Tips From Parents

Take a Break is Scotland's short breaks fund for carers of disabled children, young people and their families. Take a Break grants can be used for a break away, towards leisure activities or outings; sports equipment and much more. Find out if you may be eligible to apply and how to make an application at [bit.ly/rrtakeabreakscotland](https://bit.ly/rrtakeabreakscotland)

Shared Care Scotland provides a directory of short break and respite services across Scotland, with details of how to access them. [bit.ly/rrsharedcarescotland](https://bit.ly/rrsharedcarescotland)

## 4.7 Help with finances

Caring for a child with a genetic, rare or undiagnosed condition may have an impact on your family's finances and you may wish to try to access financial support.

As a carer, you may be entitled to welfare benefits. Benefits and tax credits are payments from the government. They may be given to meet specific needs or to people on a low income.

**Most benefits are subject to eligibility criteria and based on your own personal circumstances.**



It is a good idea to seek advice from a social security advisor to obtain information on what type of financial support you may be eligible for.

Information on available benefits and details of eligibility criteria can be found on [bit.ly/rrmygov](https://bit.ly/rrmygov)

You can access a welfare benefits advisor through your local Citizen Advice Bureau [bit.ly/rrcas](https://bit.ly/rrcas)

Your local carers centre can provide information on available welfare benefits and provide information on how to claim.

Turn2us is a national charity that helps people in financial hardship to gain access to welfare benefits, charitable grants and support services  
[bit.ly/rrturn2us](https://bit.ly/rrturn2us)

## 4.8 Health and Social Care Standards

The Health and Social Care Standards set out what we should expect when using health, social care or social work services in Scotland.

The Standards can be applied to a diverse range of services from child-minding and daycare for children in their early years, housing support and care at home, to hospitals, clinics and care homes.  
[bit.ly/rrnewcarestandardsscot](https://bit.ly/rrnewcarestandardsscot)





# Your Notes

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