



RARE
resources
S C O T L A N D



5 Support and information for your child



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

If you have any questions or comments about our Rare Resources guides, please contact us on 0300 124 0441 or contactus@geneticalliance.org.uk.

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5.1 Supporting your child

If your child has a genetic, rare or undiagnosed condition it is likely that they will be entitled to some kind of support. This can include practical help such as aids and equipment, or support to access play and fun opportunities.

Sometimes, when a child has a very rare condition, or if a child is undiagnosed, the people who care for them can be worried that they may find it difficult to access the services their child needs.

This is not the case – in Scotland, you should be able to access support based on your child's needs, not their diagnosis.

In this section you will find information about support available, how to access it and details of where further information can be found.




5.2 Talking to your child about their genetic, rare or undiagnosed condition

Families often worry about the impact that having a child with a genetic, rare or undiagnosed condition may have on them and their siblings.

If appropriate, you may wish to talk to your child and their siblings about their genetic, rare or undiagnosed condition.

On the next page, we have provided some tips you might find helpful, but you will be the expert in your child's condition and how it affects them and their siblings and will know the best way to talk to your children. Do what feels right for you.





Top Tips From Parents

Take your time

Before you talk to your child, allow yourself time to understand the condition and what it means. Think about what you would like to tell your child and consider what questions they might have, so that you can think about how you would like to answer them.

Use resources

Many patient organisations have produced information for children.

If there is not a condition specific resource for your child's condition, looking at others may be helpful to give an idea of how you can provide easy to understand information.

There are many books and leaflets that explain genetics and genetic conditions in a fun and easy to understand way. Search online for children's books and check reviews from other parents.

When your child doesn't have a diagnosis

If your child doesn't have a diagnosis you might find it helpful to watch SWAN UK's video, 'Ellie's Story' with your child. bit.ly/elliessstory

Ellie's story, which is in the form of an animation, explains why children can be undiagnosed. SWAN UK also has information leaflets that parents can use as a guide to help explain what it means to be undiagnosed.

Let your children lead the conversation

Your child may feel confused or overwhelmed by their condition. They may have questions about the condition or have said something to you or someone else that might prompt a conversation.

You might find it easier to have shorter conversations with your child or their siblings when they ask a question or raise a concern. Trying to tackle everything about their condition in one conversation may be overwhelming for you and for your child.

You might find it helpful to reassure your child that they can talk to you at any time about any worries or concerns they might have. It may be helpful to encourage your child to ask questions.

Advice from others can be helpful but remember, you know your child best and what and when is best for them.

Talk to and meet other families

Talking and meeting up with others who are in a similar situation might be able to offer tips on what has worked for them when talking to their children about their condition.

It can also be helpful for children to have a chance to meet or talk to other children or siblings so that they can have someone that they can relate to.

Seek advice

If your child has a diagnosis you may be seeing a genetic counsellor. Genetic counsellors can advise you on how you might talk to your child and their siblings about their condition. This might include your child being present at an appointment where the diagnosis is explained.

Genetic counsellors will be able to help gauge the level of information needed for your child. They might also be able to provide you with resources and signpost to support groups which can be an excellent source of information, advice and resources.

5.3 Supporting siblings



Research from Rare Disease UK's report 'Understanding children and young people's experiences' shows that siblings typically understand a great deal about their brother's or sister's care, and develop skills in empathy and compassion.

Being the sibling of a child with a genetic, rare or undiagnosed condition can be difficult. Siblings can face both practical and emotional challenges.

As well as worrying about their brother or sister, siblings also worry about their parents or carers because they know they can feel 'stressed' or 'scared' too. It is not uncommon for siblings to have to spend a lot of their time in hospitals, or staying with other family members. It can mean that siblings miss out on precious time with their parents and brother or sister, and on special occasions and events, like birthdays and holidays.

'He has to go into hospital all the time. This time we have lived there for eleven months. I stay by his side. When my dad is at work I sleep on the floor in the hospital. Life is hard. It's hard going to hospital every day I get travel sick travelling to and from school every day.'

And I have to get up really early so I can get to school on time because it's a long way from the hospital. It's hard because mum and dad get sad sometimes because of stress.'

Sibling of a child with a rare condition

For parents or carers, it can be hard to balance the needs of their child with a genetic, rare or undiagnosed condition and the needs of their siblings.

'My son recently told me that he had missed out on a birthday party years ago because his brother was in hospital. It really bothered him, but I didn't realise at the time.'

Parent of a young person with a rare condition

Siblings as carers

Your child may be considered to be a 'young carer' if they provide care for a sibling who has a genetic, rare or undiagnosed condition, are under the age of 18 or still in school.

5.4 What support is your child entitled to?



What is GIRFEC?

In Scotland, the [Getting It Right For Every Child \(GIRFEC\)](#) policy is the Scottish Government's approach to improve outcomes and support the wellbeing of children and young people, as well as support them and their parent(s) to work in partnership with the services that can help them. It offers the right support at the right time from the right people.

Children with genetic, rare and undiagnosed conditions may need more specialist support to address particularly significant, complex or multiple needs.

Such needs will be identified and considered by those involved in the care of your child, working in partnership with children, young people and families. This intends to provide a consistent approach to planning support which can lead to the offer of a Child's Plan.

'It's so important to know your child's rights under GIRFEC – I found it a real struggle to understand at first, but it helped when my child was having some problems at school.'

Workshop participant

GIRFEC is intended as a single planning framework that all services may use to build solutions with children and their families to coordinate specialist teams or support from multiple services. Under the GIRFEC approach,

each child should have someone who is responsible for ensuring they get the support that they need.

You can find information on the GIRFEC policy on the Scottish Government website bit.ly/rrgirfec

Top Tips From Parents

The Health and Social Care Alliance Scotland (the ALLIANCE) provides information and support to those who want to find out more about GIRFEC policy. The ALLIANCE has produced a helpful resource pack to explain GIRFEC.

bit.ly/rralliancescotland

Child's Plan

A Child's Plan must be available for children who require extra support that is not generally available to address a child or young person's needs and improve their wellbeing.

'It took me a long time to get a plan in place for my child – we had a real struggle to get the school to listen to our needs. Now we have a lead professional involved and things are a bit better.'

Workshop participant

Every plan should include and record:

- information about the child’s wellbeing needs including the views of the child and their parent(s)
- details of the action to be taken
- the service(s) that will provide the support
- the way in which the support is to be provided
- the outcome that the plan aims to achieve
- when the plan should be reviewed

A Child’s Plan should also record who will coordinate the support.

This person is known as the Lead Professional for the plan and works with the child and their parent(s) to keep them informed.

Overall responsibility for delivering a Child’s Plan sits with an organisation, such as a health board or local council.

Community Care Support

Practical help for your child is generally provided by your local council. It is important that you always check with your own local council about the services that your child may be entitled to.

Different local councils provide their services in different ways and there can be significant variation across Scotland.

What support and services might be available from my local council?

Every child will have their own unique needs. Your local council has responsibility for providing information on the services that they offer and working with your family to identify what services you need. Services that your child may be entitled to from your local council include, but are not limited to:

- **Care and support in your home** - for example, help with washing and making meals
- **Equipment and adaptations for your home** -for example, equipment that will make day-to-day living easier. You may also be able to get your home adapted to suit your child’s needs
- **Day care and support** - your local authority may provide a range of recreational, occupational and educational activities for your child

To understand your child’s needs, your local council will require you to have your child’s needs assessed before they provide care services for you.

What if the needs of my child change?

You can ask for a reassessment of your needs at any time if you feel the services you are getting no longer meet your child’s needs. Depending

on the outcome of the reassessment, the local council may increase, change or reduce the services you are provided with.

Who else can help with aids and equipment?

Your local council is responsible for providing aids and equipment for daily living and non-medical needs. To find out what you may be entitled to, contact your local council.

Your local health board is responsible for providing equipment to meet nursing or medical needs.

To find out what you may be entitled to, contact your GP or specialist clinician responsible for your child’s care. You may also be able to access support from charities and third sector organisations to pay for aids and equipment. Contact your local carers’ centre for information.

Who can help me make adaptations to my home?

It may be necessary to make some adaptations to your home to make it more accessible for your child. You may be able to access financial support towards the costs of doing this.

In Scotland, the [Scheme of Assistance](#) provides ‘mandatory grants’ if you are a homeowner

or private tenant and require adaptations to meet the needs of your child. The grant can cover 80% of the cost of the work, with the remaining 20% being means tested. bit.ly/rrschemeofassistance

You may be eligible for assistance if you are a local council or housing association tenant. Speak to your local council.

Further information

Scottish Government Key Facts bit.ly/rrscottishgovernmentkeyfacts
Find out about GIRFEC in your area bit.ly/rrgirfecinmyarea
Enquire is an organisation that provides bit.ly/rrenquire

Where to find support

There are many organisations that can provide advice on grants that may be available for home adaptations.

Family Fund: bit.ly/rrfamilyfundscot

Shelter Scotland: bit.ly/rrshelterscot

Living Made Easy: bit.ly/rrlivingmadeeasy

AskSARA: bit.ly/rrasksara

5.5 School and education

Whether your child is already attending school, or will be starting soon, it is important to think about your child's needs and whether they require any additional support. This is known as Additional Support Needs (ASN).

Your child may be entitled to help if they have difficulties reading, understanding or talking, or if their condition affects their behaviour or physical skills.

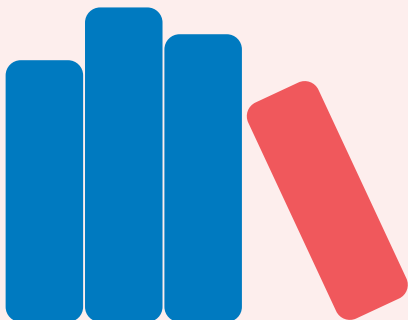
Enquire is the Scottish advice service for additional support for learning. bit.ly/rrenquire

In Scotland, there is a duty for education authorities to identify and meet the additional support needs of their pupils. Schools must also provide support to children with health conditions when they are at school – this might mean help with personal care or taking medication.

If you think your child needs, or will need, additional support for learning, it is a good idea to speak to your GP or specialist clinician and/or someone in their school.

Most schools will have an Additional Support for Learning Assistant responsible for coordination services for additional support needs.

It is a good idea to familiarise yourself with what additional support learning is and to get advice on what it means to you and your child.



5.6 Travel

Families with a child with a genetic, rare or undiagnosed condition may be able to access help to make travelling with their child a little easier.

Public Transport

Local councils can provide free or discounted bus passes or vouchers for a disabled child. In some council areas, carers can also be entitled to free or discounted travel. What is available to you will depend on the local council you live in. Contact your local council to find out what is available in your area.

You may also be able to get help with the costs of train travel with a Disabled Persons Railcard.
bit.ly/rrdisabledpersonsrailcard

The Blue Badge Scheme

You can apply for help with parking if you care for a child with a health condition.

You may be eligible for help with parking through the blue badge scheme. You can find out whether you are eligible, and if so how to apply, on the Citizen's Advice Website.
bit.ly/rrcitizensadvicebluebadge

Your local Citizen's Advice Bureau can also provide guidance on how to complete the application.

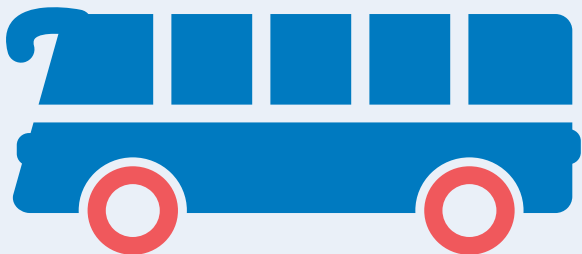
The Motability Scheme

You may be able to lease a car or qualify for a driving lessons grant under the motability scheme. You may be eligible if your child receives disability living allowance or personal independence payments.
bit.ly/rrmotabilityscheme

Getting to school

Local councils may provide free transport if your child has certain additional support needs. They may also provide free transport if your child has a health issue, for example a mobility issue.

Contact your local council to find out if they can support you.
bit.ly/rrfindyourlocalcouncil



5.7 Childcare

There are many options when it comes to childcare. All childcare facilities should include and feature facilities that cater for children with health conditions. Depending on your child's needs you may wish to consider specific specialist childcare services.

The **Scottish Family Information Service** provides free, impartial advice on childcare availability in your area including: nurseries, childminders, playgroups and out of school care. bit.ly/rrscotfamilies

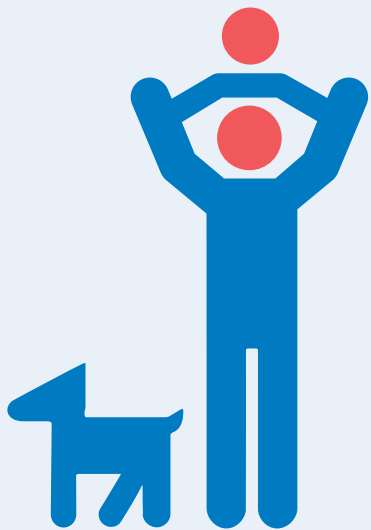
Do I have to pay for childcare?

You can get help from the government to pay for any type of 'registered' childcare. This means childcare provided by individuals and organisations registered with the Care Inspectorate. These include nurseries, playgroups, childminders and out of school care providers. Visit your local council's website to find out what is available in your area.

You can find more advice and information on help with childcare costs on the mygov.scot website bit.ly/rrmygovscot



5.8 Play, fun and taking a break



Play is an essential part of every child's life. Sometimes, for a child with a genetic, rare or undiagnosed condition, it can be difficult to find accessible play and fun opportunities. However, your family may be entitled to get help.

What play and fun activities are available to my child?

In your local area there may be a number of sport and hobby clubs that your child might be able to access. It is a good idea to get in touch with the club that you think your child might enjoy and explain your child's needs.

Quite often, reasonable adjustments can be made by those in charge of running a club so that your child can participate.

You can contact your local council, or visit your local library or leisure centre to find out more about what is on offer in your area.

You may wish to access a club that is specifically for children with additional needs. Your local council and your local carers' centre can provide details of those in your area.

Day trips and places to visit

There are a number of initiatives and facilities that provide opportunities for play or days out across Scotland.

Many visitor attractions in Scotland provide discount schemes or accessible tours to families who require them.

Visit Scotland (Scotland's national tourist board) provides information on its website and in its local branches about accessible visitor attractions and days out across Scotland.

The CEA Card is a national card scheme developed for UK cinemas by the UK Cinema Association. The card enables a person with a disability to receive a complimentary ticket for someone to go with them when they visit a participating cinema. bit.ly/rrceacard

5.9 Holidays

Families with children with health conditions may be entitled to help from local councils. Some councils may give grants towards holiday costs, others may offer holidays at places of your own choice.

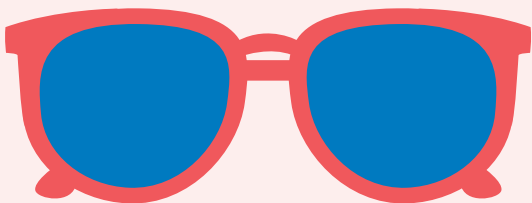
PAMIS Breaks – The organisation PAMIS can provide advice on planning holidays and respite. They also have two holiday facilities that you can apply to use.
bit.ly/rrpamisbreaks

Family Fund – Family Fund may be able to help towards holiday costs. Grants are a contribution towards family holidays with or without the child.

Family Fund works with a range of providers, so that families can choose the best holiday for themselves and their family. Family Fund may be able to help with other grants to help children and young people access play and leisure activities.
01904 550 055
bit.ly/rrfamilyfundorg

Euan's Guide – Euan's Guide lists access information for venues across the UK and beyond. Including information about accessible toilets, wheelchair access, hearing loops and multiple other access features.
0131 510 5106
bit.ly/rreuansguide

Contact – Contact has produced a helpful booklet on holidays, play and leisure with general information and details about funding and local facilities. It can be downloaded from their website.
bit.ly/rrcontactholidays





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