



Information and  
support for parents  
of a child recently  
diagnosed with a  
genetic condition

You have been given this leaflet because your child has recently been diagnosed with a genetic condition. This leaflet aims to help you find information and organisations to support you.

## Understanding your child's genetic diagnosis

Understanding your child's diagnosis can help you better identify their individual needs and get support. You may have had an opportunity to discuss your child's diagnosis with a professional already, but it can often take time to get an appointment with a specialist. We've put together some suggestions about where you can access information and support in the community in the meantime.



## Contact an organisation specialising in genetic conditions

Many UK based charities have a wealth of experience supporting a wide range of genetic conditions. These charities include Unique, Genetic Alliance and SWAN. Contact, are the main support charity for families with disabled children and provide information and resources to help families get the help they need.

A good first step would be to get in touch with these organisations to discuss your individual circumstances and access their expertise and resources. The 'Health A to Z' resource on the NHS website can also provide some helpful information.

## Make sure the information you read is of good quality

The internet can be a great resource to find information, but it can also be overwhelming. The quality of the information can vary greatly, and it can be difficult to tell what 'good' information is.

The charities mentioned at the end of this leaflet provide good and reliable information, so they are a good place to start. If they don't have what you're looking for, ask them if they know where you can look to find it. They will often be able to signpost you to other good quality information.

## Consider joining a parent support group

Other families can be an invaluable source of community, information, and practical and emotional support.

The charities mentioned at the end of this leaflet can put you in touch with a reputable family support group.

Be mindful when joining online groups (for example, Facebook groups) that they are connected to a recognised reliable support organisation. This will help you consider the quality and accuracy of their information.

## Prepare for an upcoming medical appointment

It can be helpful to think about the questions you have in advance of a medical appointment and to write them down. You may want to talk your questions through with a trusted person first, for example a friend or family member.

Take your questions along with you on the day. Also, decide if you would like someone else to go with you. You may find it helpful to include your family and friends at this time so that you can learn about your child together and so they are there to provide emotional and practical support from the earliest stages.

Unique's guide, '[A Clinical Genetics appointment](#)' provides good information about what to expect during an appointment with a genetics specialist and gives some ideas about the questions you might like to ask. Contact Unique if you would like a paper copy.

Parents can sometimes feel like their questions may sound silly, but your consultant/genetic counsellor is there to explain everything in a way that makes sense to you, so don't be afraid to keep checking the questions you have written down and ask them everything you would like to.



# Support groups

The following charities support a wide range of genetic conditions



Cerebra support children with complex needs and their families. Our resources offer comprehensive and current information and advice on a wide variety of topics, including physical, social, and legal issues. Practical support is also available via our Sleep Advice Service, the Cerebra Innovation Centre, our book and toy library and our Legal Rights Service.

Website: <https://cerebra.org.uk/>

Email: [enquiries@cerebra.org.uk](mailto:enquiries@cerebra.org.uk)

Helpline: 01 267 244 200



Contact is the main UK charity that supports families with disabled children. They run advice, information and support services (online, print and helpline). They also run workshops, events and support groups for parents/ carers of disabled children.

Website: <https://contact.org.uk/>

Helpline: 0808 808 3555

Order a free helpful guide that signposts you to lots of useful information: <https://contact.org.uk/order-your-copy-of-the-helpful-guide-for-families-with-disabled-children/>



Genetic Alliance is a charity working to improve the lives of individuals and their families affected by genetic, rare, and undiagnosed conditions. You can learn more about genetics, living with a genetic condition, finding a support group and more on their website.

Website: [www.geneticalliance.org.uk](http://www.geneticalliance.org.uk)

Email: [contactus@geneticalliance.org.uk](mailto:contactus@geneticalliance.org.uk)



The 'Health A to Z' resource on the NHS website provides some helpful information.

Website: [www.nhs.uk/conditions/](http://www.nhs.uk/conditions/)



If a genetic diagnosis cannot be made, contact SWAN (Syndromes Without A Name) UK for further advice. SWAN UK (run by Genetic Alliance) is the dedicated support network available for families of children and young adults with undiagnosed genetic conditions in the UK.

Website: [www.undiagnosed.org.uk](http://www.undiagnosed.org.uk)

Email: [info@undiagnosed.org.uk](mailto:info@undiagnosed.org.uk)



The charity UniqUe provide a wealth of information guides about rare chromosome disorders and some autosomal dominant single gene disorders associated with learning disability amongst other symptoms. They also run a telephone and email support helpline.

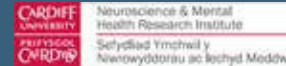
Website: [www.rarechromo.org](http://www.rarechromo.org)

Email: [info@rarechromo.org](mailto:info@rarechromo.org)

Helpline: 01 883 723356



Innovate UK



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# Working wonders for children with brain conditions

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