



Understanding Chromosome & Gene Disorders

Young Carers



rarechromo.org

Index

What is a young carer?.....	Page 3
Young carers rights.....	Page 5
Books.....	Page 7
Links.....	Pages 8-11



“My unaffected daughter helps to care for her sister. She does all sorts of things for her; that she is unable to do for herself ; as she cannot walk or talk, dress or feed herself. She spends hours playing with her and entertaining her and making sure she is safe; as she has no sense of danger. When we go out to parks and soft plays she always makes sure she takes her sister down the slide lots of times, as she loves it and cannot go down them on her own.”

Young Carers guide

What is a young carer?

A young carer is usually someone aged 18 or under who helps look after a relative who has a condition, such as a disability, illness, or mental health condition. Young carers help with jobs in and around the home, such as cooking, cleaning, tidying, helping someone to get dressed and move around, or looking after brothers and sisters. Some children give a lot of physical help to a brother or sister who is disabled or ill. Some start caring at a very young age and don't realise they are 'carers'.

Sibling relationship

The relationship between brothers and sisters is usually very close. Obviously, there are going to be occasions when you fight with each other, argue and fall out, but the bond between you usually remains for life. Children that grow up with a brother or sister who have a chromosome or genome disorder are often disadvantaged because of the additional care their parents need to give to the child with the disorder. Many children find it easy to offer help to mum/dad because they love their brother/sister and your parents and want to help. But for some siblings it can place an enormous strain not only on your relationship with your brother or sister and your parents but also on your own emotional well-being.

This guide has been created to address the needs of Young Carers like you and where to go to get help and support.



Young Carers

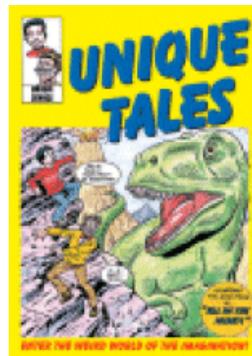
It is really important that first and foremost, your parents are able to discuss with you how it might affect the family in general. Sometimes parents find it difficult to discuss this, but it is really important to talk to them, so that you both understand and you don't feel left out. Often one or both parents might have to spend time with the affected child in hospital, or at appointments and may have to leave you with another relative or a friend. If your parents haven't been able to talk to you about this, ask them to explain. It will probably help them to know that you want to be as supportive as possible and to understand how they feel too.

If you are aged between 5 and 12 you might find reading a copy of our Unique Tales comic book helps to explain that sometimes things don't always go to plan. It is available to download from our website:

<https://www.rarechromo.org/families/>

in English, Italian and German.

If you live in the UK, you can ask us to send you the English version by post.



Embarrassment

Sometimes you might feel embarrassed about your brother or sister because they look different or behave differently to other children and attract attention when out in public. This is hard to deal with, especially if you are at a sensitive age. Young carers react in different ways to this, they either ignore any stares or comments, or stare right back, or explain that the child has a rare disability. Try to stay calm and don't allow other people to upset you. It might help you to talk to your parents, other relative or friend about this, as they might help you to decide how you might react.

Feeling left out

A child with any disability can take up a lot of time and it can mean that there is less time available for the rest of the family. You may realise your parents are busy and not want to bother them. Make sure they give you the chance for some time on your own with them. There is a service called Short breaks, your mum/dad will be able to ask for an assessment for services like this; that assessment must take into account the needs of all the family, especially brothers and sisters of the affected child. Short breaks might be where your brother or sister go to a special facility for 1,2,3 or more nights at a time. Or, it might just be a service where they go away from home for the day, or, a caring professional comes into the home to look after your brother or sister, which then allows your parents to spend more time with you.

Young carers' rights



The law has changed for young carers, and since April 2015 a social worker from your local authority must visit to carry out a “young carers needs assessment” to decide what kind of help you and your family might need, if you or your parents request this. If the local authority has already carried out one of these assessments before, they must carry out another one if you or your parents feel that your needs or circumstances have changed. A young carer’s needs assessment must decide whether it is appropriate for you to care for someone else – and this includes taking into account whether you want to be a carer. The local authority must also look at your education, training, leisure opportunities and your views about your future. When assessing a young carer they must always ask about your wishes and involve you, your parents and anyone else you or your parents want to be involved. All of these people should receive a written record of the assessment. This should include whether the local authority thinks you need support, whether their services could provide you with that support, and whether they will give you that support. It should also explain what you can do if you or your parents disagree with the assessment. Provided that you both agree, the local authority can assess both your needs as a young carer and the needs of the person you care for, at the same time. If you’re 16 or over, and you’re not in full-time education you may be eligible for help finding work as well as help with your family’s finances, for instance through benefits such as Carer’s Allowance. Your assessment is the best place to find out about what is available in your situation. Young Carers have the same needs as all children.

Carers UK have a very useful factsheet on assessments on their website:
<http://bit.ly/2zRVAWR>

NHS choices also has a link to young carers rights on their website:
www.nhs.uk/conditions/social-care-and-support/young-carers-rights/

Support

Joining a young carer’s group or sibling support group to meet other young carers, can help you to feel more confident and less isolated. Sometimes you will feel angry, sad, or fearful, but it is OK to feel like that, it is perfectly natural. If you find you can’t talk to your parents, there will be other people that you can talk to, maybe through your school welfare officer or a teacher.

As a young carer, you might find school a place where you can forget about your caring responsibilities and feel "normal" for a while. But it can also be a place where you're under extra pressure or where people don't understand what your life is like outside school. It can sometimes be hard to juggle all of your responsibilities as a young carer with the demands of teachers, friends and homework. You might not want your school to know you're caring for someone. But if they don't know about your situation, it might be difficult for your teachers to understand - if you struggle to keep up in class or don't do your homework. It's a good idea to let at least one teacher you feel able to trust, know that you are a carer. You might find it difficult to talk about your home life with a teacher, so you could ask someone in your family to write a letter to the school, perhaps to the head of year. Some young carers find it easier to talk about their situation if they keep a diary, or a list of all the jobs and tasks they have to do. If you're having trouble with school or homework, your teachers may offer:

- ◇ Extra time for school work when you have to give more help to the person you care for
- ◇ Help for your parents to travel to parents' evenings, if they have trouble leaving the house to talk to you privately about your home life .
- ◇ Homework clubs

The school could also put you in touch with your local young carers service, or get a young carers support worker to talk to you. Some schools run lunchtime groups or homework support groups for young carers. If your school doesn't do this, you could suggest the idea to your teachers. Socially, it can be difficult to have the same opportunities as other young people, inviting your friends over to your house for example, might not be possible. Whatever your situation, you are special too and it is important not to hide your feelings, but to talk about them.



Meet other young carers

Meeting up with other young carers is a great way to make new friends, have some fun and share some of your worries with people in similar situations to your own. The Children's Society runs services for young carers in many areas. These can help you to have a break from home, and meeting other young carers can help you to relax. Young carers projects may offer evening clubs, weekends away, days out and even holidays as well as friendly advice

and information for you and for your family.

See: www.childrenssociety.org.uk/in-your-area Local Carers support services often have separate groups for young carers. They will involve meeting and talking to other young carers like yourself. If you need any assistance finding your nearest service, please email: marion@rarechromo.org and she can help with this.

BOOKS



A Draw It Out Guidebook
For Kids Dealing With
A Special Needs Sibling

AVAILABLE IN
ENGLISH & SPANISH

The Other Kid workbook was designed to give siblings a way to open up and talk about their feelings and concerns.

It is available in English and Spanish.

www.theotherkid.com/book.html

The following titles are some of the many available from Amazon and other good booksellers.

- ◆ Being the Other One: Growing Up with a Brother or Sister Who Has Special Needs (Paperback) by Kate Strohm
- ◆ Don't Call Me Special: A First Look at Disability (First Look at Books) (Paperback) by Pat Thomas
- ◆ Everybody is Different: A Book for Young People Who Have Brothers or Sisters with Autism (Paperback) by Fiona Bleach
- ◆ Guidebook for Young Carers (Children who provide care) Paperback by Mike Raynor (Author)
- ◆ Living with a Brother or Sister with Special Needs: A Book for Sibs (Paperback) by Donald J. Meyer and Patricia F. Vadasy
- ◆ Oh, Brother!: Growing up with a Special Needs Sibling (Paperback) by Natalie Hale
- ◆ Siblings by Kate Strohm www.e-bility.com/books/siblings.php
- ◆ Sibling Slam Book: What It's Really Like to Have a Brother or Sister with Special Needs (Paperback) by Donald J. Meyer
- ◆ Sibling Stories: Reflections on Life with a Brother or Sister on the Autism Spectrum (Paperback) by Lynne Feiges and Mary Jane Weiss
- ◆ Special Brothers and Sisters: Stories and Tips for Siblings of Children with Special Needs, Disability or Serious Illness: (Paperback) by Annette Hames and Monica McCaffrey
- ◆ Views from Our Shoes: Growing Up with a Brother or Sister with Special Needs (Paperback) by Donald J. Meyer



LINKS

- ◆ **Action for Children** <http://bit.ly/2yDOiV1>
01923 361500

Action for children offer services providing practical and emotional support to young carers.

- ◆ **Barnardo's** <http://bit.ly/Wj4NP5>

Barnardo's runs services across the UK, which work to support young carers and their families

- ◆ **Carers National Association** www.carersonline.org.uk

for information, advice and support for carers, including young carers

- ◆ **Carers Trust** <http://bit.ly/2vMBy9i>

Know your Rights: Support for Young Carers and Young Adult Carers in England. This free guide explains what those rights are. It also tells you what should happen when you talk to the council about being a young carer or young adult carer.

- ◆ **Carers UK** www.carersuk.org

⇒ Carers England: 020 7378 4999

⇒ Carers Wales: 029 2081 1370

⇒ Carers Scotland: 0141 445 3070

⇒ Carers Northern Ireland: 02890 439 843

Support and information for all carers, including a Young carers factsheet: <http://bit.ly/1BOTOLE>

- ◆ **CCHF** (Formerly known as Children's Country Holidays Fund)

www.cCHF-allaboutkids.org.uk

01903 339155

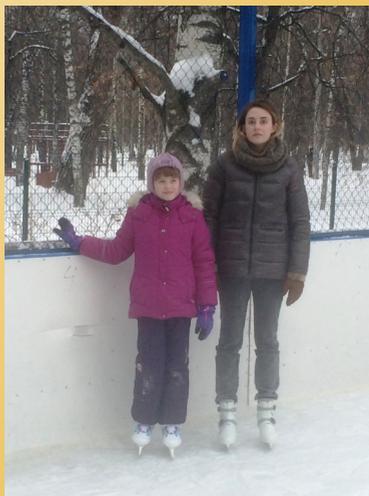
CCHF All About Kids provide a range of residential activity and respite breaks that allows children aged 7-11 to escape the traumas of their everyday life and simply become children again.

- ◆ **Childline** www.childline.org.uk/

Freephone: 0800 1111

There is also an online 1 to 1 chat service.

Childline is a free 24-hour counselling service for children and young people up to their 19th birthday in the United Kingdom provided by the NSPCC.



- ◆ **Children's Society** <http://bit.ly/2maoSqU>

0300 303 7000

Support and information for young carers.

- ◆ **Connects and Co.**
www.connectsandco.co.uk

01603 405328

A local Norfolk charity for young carers

- ◆ **Facebook groups for young carers**

There are many local groups on facebook for Young carers. Just go to facebook and search for young carers followed by your town and/or county



- ◆ **KIDS** www.kids.org.uk/young-carers

⇒ KIDS London: 0207 359 3635

⇒ KIDS East Midlands (KIDS Strut): 0152 254 2937

⇒ KIDS South East: 0132 931 2312 Email: southeastadmin@kids.org.uk

⇒ KIDS South West: 0117 947 6111

⇒ KIDS West Midlands: 0121 355 2707

KIDS Yorkshire and The Humber: 0148 246 7540

Kids provides support to young carers under the age of 18, whose lives are restricted in some way. It allows the young carer to take time out for themselves, socialise and cope with the demands placed on them as carers. Kids run regular clubs where young carers can safely talk about how they feel, meet other young carers, get support, advice and information as well as have some fun away from their caring responsibilities They also provide holiday activities and occasional weekends away. The services also provide accessible links to youth counselling and other agencies who can give expert advice and information on all issues that affect young carers.

- ◆ **Kidscape** www.kidscape.org.uk

for support and advice on dealing with bullying and teasing

- ◆ **Kooth** <https://kooth.com/>

Kooth, from XenZone, is an online counselling and emotional well-being platform for children and young people, accessible through mobile, tablet and desktop and free at the point of use. For more information about XenZone, please visit XENZONE.COM. If you're a parent looking for more information about Kooth, please email PARENTS@XENZONE.COM

◆ **Honeypot** www.honeypot.org.uk/
020 7602 2631

Honeypot works to enhance the lives of young carers and vulnerable children aged 5 – 12 years old. They provide respite breaks and on-going outreach support. Honeypot gives young carers a break from demanding and stressful responsibilities at home and provides a safe, nurturing environment where children at risk can develop their full potential.

◆ **Law stuff** <https://lawstuff.org.uk/>

LawStuff gives free legal information to children and young people. It is run by Coram Children's Legal Centre, which provides more detailed information both over the phone and online. Easy use website. Please be aware that the information on this website is strictly applicable to England.

◆ **Over the Wall** www.otw.org.uk/
02392 477 110 Email: info@otw.org.uk

Over the Wall is a national UK children's charity and a member of the International SeriousFun Children's Network. They provide free of charge Therapeutic Recreation camps to help children with life-limiting illnesses and their families reach beyond the perceived limitations of illness to rediscover a whole new world of possibilities.

◆ **Siblings Australia**
www.siblingsaustralia.org.au

Siblings Australia is committed to improving the support available for siblings of children and adults with chronic conditions including disability, chronic illness and mental health issues. This website will allow you to access information about sibling support – services, resources, research and policy – whether you are a sibling, parent, worker or researcher.



◆ **Sibling Support project** www.siblingsupport.org

The Sibling Support Project is a national program dedicated to the life-long and ever-changing concerns of millions of brothers and sisters of people with special health, developmental, and mental health concerns. They've published books for and about brothers and sisters, hosted online groups for teen and adult siblings, and presented workshops on sibling issues internationally and in every state of the U.S.A

◆ **SIBS** www.sibs.org.uk

Facebook group: [www.facebook.comSibsCharity](https://www.facebook.com/SibsCharity)

Advice line 01535 645453

Sibs exists to support people who grow up with or, have grown up with a disabled brother or sister. It is the only UK charity representing the needs of over half a million young siblings and over one and a half million adult siblings.

◆ **SSAFA Adventure Holidays** www.ssafa.org.uk

The Soldiers, Sailors, Airmen and Families Association (SSAFA) provide new experiences and holidays for children and young people from services families. It runs short break holidays for children and young people aged 8 to 16 years. All children applying must be descendants of current serving regular or reserve military personnel. The full costs of the holidays are covered by the SSAFA.

◆ **Tros Gynnal Plant** www.trosgynnal.org.uk

Tros Gynnal work with children and young people in Wales to promote and realise their rights.

◆ **Young Carers Initiative** www.childrenssociety.org.uk/youngcarers or www.youngcarer.com

Part of The Children's Society the Young Carers Initiative provides a support network, newsletter, and runs projects for young carers.

◆ **Young Carers together** www.youngcarerstogether.org.uk/

Email: info@youngcarerstogether.org.uk

Providing activities and fun days for Young Carers to have the chance to have a break from their caring role and have some fun.



Inform Network Support

Understanding
chromosome
disorders

Unique

Rare Chromosome Disorder Support Group
The Stables, Station Road West, Oxted, Surrey,
RH8 9EE, United Kingdom.
Tel: +44(0)1883 723356
info@rarechromo.org | www.rarechromo.org

Join Unique for family links, information and support.

Unique is a charity without government funding, existing entirely on donations and grants. If you can, please make a donation via our website at www.rarechromo.org Please help us to help you!



ST. JAMES'S PLACE
CHARITABLE FOUNDATION

The publication of this guide was made possible thanks to the generous support of the St James Place Charitable Foundation.
www.sjfoundation.co.uk/

Our thanks to all of our parents for their contributions to this guide.

This guide was compiled by Unique .

Please note: We also have a separate guide for Siblings and a separate guide for carers (Carers wellbeing), some links contained within this guide might also be included in those guides.

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