



Understanding Chromosome & Gene Disorders

Mental Health and Wellbeing



rarechromo.org



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Mental Health and Wellbeing

Most people will experience a mental health issue at some point in their lifetime, whether it is anxiety, depression or just feeling a bit low. There will be 'dark days' and for some it will be very difficult to manage or get the right help, or even know where to go to get that help. In this guide, we have included as many sources of support as we can, for as many mental health issues as we can. We hope this guide can provide some helpful information and reassurance that if you are suffering with a mental health problem, you are not alone in feeling the way you do. It can be incredibly hard to know how 'just a bad day' can turn into many bad days. This may impact your daily mood, feelings, thoughts and behaviour. It is a known fact that before the Covid pandemic hit, there were long waits to access NHS mental health services in the UK, sadly people trying to access support since the pandemic has increased ten-fold. This guide is aimed at parents, children, and adults affected by a Mental Health condition.

What is Mental Health?

Mental health is all about how we feel, how we act and how we think. When life gets difficult because of stress, anxiety, depression or trauma, this increases the risk to our mental well-being. Some people cope well with small or temporary problems using self-help and talking to their family and friends; but for others, they can need more help. There could be a whole range of reasons why people are struggling or experiencing difficulties with their mental health and day-to-day life. For example, they could be suffering from Post-traumatic stress disorder (PTSD), bipolar disorder, schizophrenia, eating disorders, depression, anxiety, suicidal thoughts and many other thoughts or feelings that are becoming intrusive and impacting their life. Many people find it difficult to ask for help, or if indeed they recognise that they actually need help and just suffer alone.

The Mind website is very helpful with trying to understand mental health issues: <https://www.mind.org.uk/information-support/types-of-mental-health-problems/>

Information and training on mental health

◆ **Every mind matters** <https://www.nhs.uk/every-mind-matters/>
NHS campaign dedicated to mental health matters covering anxiety, low mood, stress and sleep.

◆ **Health talk** <https://www.healthtalk.org/>

On healthtalk.org you can find out about what it's like to live with a health condition, by watching other people share their stories. These stories are collected by academic researchers who interview people in their own homes, using their own words.

Counselling

◆ **Counselling Directory** <https://www.counselling-directory.org.uk/>
Counselling falls under the umbrella term 'talking therapies' and allows people to discuss their problems and any difficult feelings they encounter in a safe, confidential environment. Counselling is a process people seek when they want to change something in their lives or simply explore their thoughts and feelings in more depth.

◆ **The British Association For Counselling And Psychotherapy** (BACP) <https://www.bacp.co.uk/>

01455 883300

Email: bacp@bacp.co.uk

BACP can provide a list of accredited counsellors in your area.

◆ **UK Council for Psychotherapy (UKCP)**

<https://www.psychotherapy.org.uk/>

020 7014 9955

You can search for accredited Psychotherapists in your area, and learn what their expertise is which may suit you.

Self-care for parents

Most people experience some stress in their lives but when you have additional responsibilities of caring for someone, whether your child, partner, close friend or relative, this can increase your stress levels and give you symptoms like headaches, fatigue, pain, tummy ache. It can make it difficult to concentrate and can make you feel overwhelmed and worried. It can affect your sleep and eating habits and make you irritable around those you love, sometimes without realising. We often forget that we need to look after ourselves as well, but if we don't, it then makes it difficult to care for our children and our loved ones. There are lots of things that you can do to help ease stress. Make sure to have some 'me' time, even if your only escape is having a bath, ten minutes in a quiet room or the garden. Don't feel alone or isolated, there is lots of support out there.

**Taking care of myself
doesn't mean 'me first',
it means
'me too'!**

As well as talking therapies, there are also pet therapies, music therapy, laughter therapy. Also just going for a walk, meeting a friend for a coffee or changing your scenery for just a short while can be great stress busters.

We have a separate guide on **Therapies** and we have a separate guide on **Carers wellbeing** on our website, these guides includes more information on how to look after yourself and de-stress.
<https://rarechromo.org/disorder-guides/>

◆ **Dudes and Dogs** <https://dudesndogs.co.uk/>

Dudes & Dogs is a Community Interest Group created to get men out in the fresh air together for a walk and talk.

◆ **Meditation and mindfulness** is really good for easing stress, there are some useful apps here:
<https://www.nhs.uk/apps-library/category/mental-health/>

◆ **Mental Health support group on facebook**
<https://www.facebook.com/groups/857290524405180/>

◆ **Mind** <https://tinyurl.com/3uj3haex>

InfoLine: 0300 123 3393

Email: info@mind.org.uk

Mental health charity Mind provide a list of practical self-care suggestions on their website, which includes finding time for relaxing activities, learning a new craft or skill, talking to others and getting active. Local Mind services include talking therapies, crisis helplines, drop-in centres, employment and training schemes, counselling and befriending:
<https://www.mind.org.uk/information-support/local-minds/>

◆ **Mindful** <https://www.mindful.org/>

◆ **Mindful Life** <https://www.themindfullife.co.uk/>
Mindfulness for carers.

Carers support services

We are great advocates of carers support services. Every area of England (and possibly other countries in the UK) will have a local carers support service.

Your local service may provide individual support or group support with other carers. They can help you obtain a carers grant (usually around £250-£300)

towards something that you as a carer can benefit from, it might be towards a weekend away or gym membership or a laptop, etc. This may involve you having a carers Assessment, which just involves answering questions. See: <https://tinyurl.com/3vb49dkb>. You can find out more about your local Carers Support service by visiting your county council website or by contacting:

◆ **Carers UK** <https://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.



◆ **Carers Trust** <https://carers.org/>

0300 772 9600

Email: info@carers.org

◇ Scotland 0300 772 7701 Email: scotland@carers.org

◇ Wales 0300 772 9702 Email: wales@carers.org

Carers Trust is a major charity for, with and about carers. They work to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.

◆ **Time to Change**

<https://www.time-to-change.org.uk/mental-health-and-stigma/help-and-support>

Email: info@time-to-change.org.uk

Information for carers experiencing mental health problems.

◆ **AFFINITY HUB** <https://www.affinityhub.uk/1/>

Blog: <http://www.affinityhub.uk/blog/>

Publications/resources: <https://www.affinityhub.uk/4/Publications.html>

This website is an excellent source of information and signposts to emotional support for parents and carers of children with special needs. Many parents of disabled children or children with special needs face additional associated challenges in practical, physical and emotional terms. Joanna Griffin, Counselling Psychologist, owns the website and has written a book, which you can find out more about here:

<https://www.amazon.co.uk/Day-Emotional-Wellbeing-Disabled-Children/dp/1911383531>

◆ **Care For The Family** <https://www.careforthefamily.org.uk/>

029 2081 0800

Email: mail@cff.org.uk

Care for the Family is a national charity which aims to promote strong family life and to help those who face family difficulties.

◆ **Social care and support guide**

<https://www.nhs.uk/conditions/social-care-and-support-guide/>

This website explains your options as a carer and where you can get support.

◆ **Family lives** <https://www.familylives.org.uk/>

Free and confidential helpline offering information, advice, guidance and support on any aspect of parenting and family life, including bullying.

Relationship Support

Having a child with a chromosome or gene disorder, or a disability, can put a huge strain on your relationships, not only with your child - but with your spouse or partner. This has a big impact on our mental health. It is very important to talk to each other about your family situation as much as possible and work on supporting each other. Having a supportive partner that can help you with some of the caring can be a lifeline for so many of our families, particularly as your child gets older, bigger and stronger. Just coming to terms with having a child with a chromosome or gene disorder can be so difficult for parents, but also for grandparents and siblings too. Initially it can come as a sense of loss. For the parents; the loss of their longed for 'typically functioning child' and for the grandparents the loss of their longed for 'typically functioning grandchild' - but also their grief at seeing their own child having to go through that loss. It is not meant to sound like a bad thing, because for so many parents it isn't a bad thing to have a child with a chromosome or gene disorder, it is just different and it takes time getting used to. It is important to not look at what you have lost, but to appreciate what you have. If it's possible to do so, it is important for everyone in the family to sit down and talk to each other to discuss things and not bottle things up or, end up shouting at each other. Your child won't necessarily know they are different whilst young, and it isn't theirs or your fault. Just try to live and enjoy life the way you would have been doing, as much as possible. Take each day as it comes.

Get as much help as is offered by local services. There are some very supportive professionals like doctors, nurses, and therapists out there to help you.

◆ **RELATE** <https://www.relate.org.uk/>

0300 100 1234

The UK's largest provider of relationship support.

Services include:

- ⇒ Relationship Counselling for individuals and couples
- ⇒ Family Counselling
- ⇒ Mediation
- ⇒ Children and Young People's Counselling

They also provide informal workshops for people at important stages in their relationships.

◆ **One Plus One** <https://www.oneplusone.org.uk/>

07818 137443

Email: info@oneplusone.org.uk

A relationships charity. One-Plus-One has over 50 years' experience in creating evidence-based resources to support the development of healthy relationships.

Anxiety

Everyone feels worried or anxious at times. Feeling anxious before speaking in public, having medical tests or going to a job interview is perfectly normal. Some people find it hard to control their worries. When feelings of anxiety are more frequent, they can start to affect our day-to-day life. The symptoms of anxiety and stress can manifest themselves in lots of different ways.

Generalised anxiety

◆ **Anxiety Care UK**
<https://anxietycare.org.uk/>

◆ **Anxiety UK**
<https://www.anxietyuk.org.uk/>
03444 775 774 (helpline)
07537 416 905 (text)
Advice and support for people living with anxiety.

Phobias, Panic and Obsessive Compulsive Disorder (OCD)

◆ **Triumph over Phobia**
<https://www.topuk.org/about-top-uk/>
TOP UK runs a network of weekly self-help groups for people phobias, obsessive compulsive disorder and other related anxiety disorders

◆ **No More Panic** <https://www.nomorepanic.co.uk/>
Provides information, support and advice for those with panic disorder, anxiety, phobias or OCD, including a forum and chat room.

◆ **No Panic** <https://nopic.org.uk/>
0300 7729844
Provides a helpline, step-by-step programmes and support for people with anxiety disorders.

◆ **OCD Action** <https://ocdaction.org.uk/>
0300 636 5478
Information and support for people affected by OCD and hoarding, including online forums and local support groups.

◆ **OCD UK** <https://www.ocduk.org/>
03332 127890
Charity run by and for people with OCD.



Post-Traumatic Stress Disorder

◆ **PTSD UK** <https://www.ptsduk.org/>
Information for those suffering from post-Traumatic stress disorder that some people develop after experiencing or witnessing a traumatic life-threatening event or serious injury.

EMDR (Eye Movement Desensitisation and Reprocessing) therapy

◆ **EMDR Association (UK)** <https://emdrassociation.org.uk/>

◆ **EMDR International Association**

<https://www.emdria.org/about-emdr-therapy/>

EMDR is best known for treating post-traumatic stress disorder (PTSD) and it can also help with a range of mental health conditions in people of all ages.

Depression and low mood

Everyone goes through ups and downs, but people who are depressed can feel low for weeks and months at a time. Depression affects people in different ways, some of the symptoms include feelings of unhappiness, hopelessness, losing interest in things you used to enjoy, feeling tired and having no appetite. Sometimes depression can have a trigger, such as a stressful life-changing event, but in other cases there's no obvious reason.

◆ **Depression UK**

<http://depressionuk.org/>

Depression UK promote mutual support between individuals, affected by or at risk from depression.



Bereavement

We have a separate guide on **Bereavement** on our website:

<https://rarechromo.org/practical-guides-for-families/>

Eating disorders

People with eating disorders use control of their food and eating habits to cope with their feelings. Some symptoms can include worrying about weight and body shape, eating very little food, avoiding eating in public, exercising too much or having strict routines around food.

◆ **BEAT** <https://www.beateatingdisorders.org.uk/>
BEAT charity run a national helpline to support people living with an eating disorder access support.

◇ **England** Helpline: 0808 801 0677
Email: help@beateatingdisorders.org.uk

◇ **Scotland** Helpline: 0808 801 0432
Email: Scotlandhelp@beateatingdisorders.org.uk

◇ **Wales** Helpline: 0808 801 0433
Email: Waleshelp@beateatingdisorders.org.uk

◇ **Northern Ireland** Helpline: 0808 801 0434
Email: NIhelp@beateatingdisorders.org.uk

◆ **Eating disorders support** <https://eating-disorders.org.uk/>
Run by National Centre for Eating Disorders. Provides information about all aspects of eating disorders. Also offers practical steps to recovery and provides access to a network of professional counsellors.

Addiction

◆ **Help guide** <https://www.helpguide.org/home-pages/addictions.htm>

◆ **Talk to Frank**
<https://www.talktofrank.com/get-help/find-support-near-you>

Psychosis

◆ **Hearing voices network** <https://www.hearing-voices.org/>
Email: info@hearing-voices.org

International

USA <http://www.hearingvoicesusa.org/>

Other countries:

<https://www.intervoiceline.org/national-networks#content>

Support for people that hear voices, see or experience unusual things.

LGBTIQ Support



These organisations offer mental health advice, support and services for LGBTIQ people.

- ◆ **Gendered Intelligence** <http://genderedintelligence.co.uk/>
Runs youth groups in London, Leeds and Bristol for trans, non-binary and questioning young people.
- ◆ **Imaan** <https://imaanlondon.wordpress.com/>
Email: imaanlgbtq@gmail.com
Imaan is a charity that supports LGBTQ Muslims, providing an online forum where people can share experiences and ask for help.
- ◆ **LGBT Foundation** <https://lgbt.foundation/>
Helpline: 0345 3 30 30 30
Email: info@lgbt.foundation
The LGBT Foundation offers information, advice, and support services, including a Talking Therapies Programme to LGBT people.
- ◆ **London Friend** <https://londonfriend.org.uk/>
020 7833 1674
Email: office@londonfriend.org.uk
Counselling and social support group for LGBT people living in and around London.
- ◆ **Mind LGBTQ** <https://tinyurl.com/54byvsf3>
Information about mental health support for people who are LGBTIQ.
- ◆ **Pink Therapy** <http://www.pinktherapy.com/>
07971 205323
Email: admin@pinktherapy.com
Pink Therapy has an online directory of therapists who work with people who are LGBTIQ)
- ◆ **Switchboard LGBT+ Helpline** <https://switchboard.lgbt/>
Switchboard provides a listening service for LGBT+ people over the phone, via email and online chat. It can provide you with contact details of an LGBT-friendly therapist.

Resources specifically for children and young people

One of the most important ways parents can help, is by asking your child how they're feeling, listening to them and taking their feelings seriously. Most of the time children and young people's negative feelings pass without intervention. But it's a good idea to get help if you are worried about your child's mood and behavior, especially if they are unable to communicate. Signs of mental health problems in children can include lasting sadness or worry, trouble sleeping or eating, and problems at school. If your child is having problems at school, a teacher, school nurse, school counsellor or educational psychologist may be able to help. Otherwise, you can speak to your GP or paediatrician. They can refer a child to further help if necessary. Different professionals often work together in Child and Adolescent Mental Health Services (CAMHS). For a child over 18, ask to be referred to Adult Mental Health Services (AMHS).

Emotional Support

◆ **Kooth** <https://www.kooth.com/>

Children and young people aged between 11 and 19 can access 24/7 immediate online support. This service is free, confidential and anonymous. They can also access an extensive selection of self-help information and guidance.

◆ **Youth Access** <https://www.youthaccess.org.uk/>

Free youth advice and counselling throughout England. Use their online directory to find local counselling options.

◆ **Young Minds** <https://www.youngminds.org.uk/>

Provides free, 24/7 text support for young people across the UK experiencing a mental health crisis.

◆ **The MIX** <https://www.themix.org.uk/>

Information and support on a wide range of issues facing young people, including drugs and alcohol related issues. Website contains a live chat room, articles, and a database of local, regional and national organisations offering advice and support.

◆ **A place to be** <https://www.place2be.org.uk/>

Place to be is a mental health charity which provides support in schools through one-to-one and group counselling.

◆ **Childline** <https://www.childline.org.uk/>

0800 1111

Information and advice for children and young people.

◆ **Teen Mental Health – A Guide for Parents**

<https://www.mytutor.co.uk/blog/parents/teen-mental-health-a-guide-for-parents/>

0203 773 6025

Email: schools@mytutor.co.uk

Useful tips and advice for parents to help their teens overcome body image issues, academic anxiety, peer pressure, and cyberbullying, including links to other important teen mental health resources - all of which can be helpful in these uncertain times.

Worry Monster

Some children find comfort in having a worry monster. It is a cuddly toy with a mouth that unzips. A worry monster is designed to help your child discuss what is bothering them and help them reduce their worries. Children write or draw their worry onto a piece of paper and then feed it to their worry monster. Once the monster has 'eaten it', the worry can then be discussed and shared with an adult. You can buy worry monsters from Amazon, The works and other suppliers.



Purrble (USA based) <https://www.purrble.com/>

Purrble is a cuddly, interactive tool that helps people to find calm in moments of stress, overwhelm, and other big emotions.

Support for young people with caring responsibilities

◆ **SIBS** <http://www.sibs.org.uk>

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. They have extensive online resources for supporting young and adult siblings.

◆ **Sibling Support** <https://www.siblingsupport.co.uk/>

◆ **Our Time** <http://www.ourtime.org.uk>

Our Time provides support to young people whose parent/carer has a mental health issue. There is an estimated 3.4 million young people that are affected by having a parent with a mental health issue, that at present receive no attention or support. Our Time is campaigning for and supporting these young people to ensure they get the right help early on and to prevent them from becoming patients themselves. They hold workshops monthly across the UK and have resources online.

Urgent help

Some people might need more help than others, so it is important that this guide includes information to help everyone, including those who cannot see a way out of their situation. If your life or someone close to you is at risk right now. If you or they are having suicidal thoughts, feelings or have made plans to harm yourself/themselves call 999 for an ambulance or go to your nearest hospital A&E. If you aren't at that stage but still feel unsafe make an urgent appointment with your GP or contact 111 (England and Wales only). Mental health emergencies are serious. You won't be wasting anyone's time. You deserve help. If you are outside of the UK call your usual emergency number for emergency services.

◆ **Samaritans** <https://www.samaritans.org/>

Call 116 123

Email: jo@samaritans.org (emails answered within 24 hours)

Samaritans is a well-known organisation that provides a listening ear and emotional support without judgment to people going through any relationship and family problems, loss and bereavement, financial worries, stress, loneliness, depression and pain, addictions etc.

Samaritans also have a lot of useful links on their website which you might find helpful: <https://tinyurl.com/28pnmtf6>

◆ **National Suicide Prevention helpline (UK)**

<https://www.spbristol.org/NSPHUK>

0800 689 5652

◆ **Shout** <https://giveusashout.org/>

Shout is a 24/7 text service, free on all major mobile networks, for anyone struggling to cope and in need of immediate help.

Text SHOUT to 85258

The helplines above are free and confidential and open 24 hours a day, every day, 365 days a year.

◆ **CALM** <https://www.thecalmzone.net/>

0800 58 58 58 (daily 5pm-midnight)

CALM, the Campaign Against Living Miserably is a suicide prevention charity that offers free, anonymous and confidential support via their helpline and web-chat for anyone who is in crisis.

◆ **The Listening Place** <https://listeningplace.org.uk/>

The Listening Place is somewhere individuals can talk openly about their feelings without being judged or being given advice.

◆ **Papyrus HOPELine UK** <https://www.papyrus-uk.org/hopelineuk/>
0800 068 41 41

HOPELine UK offers confidential support, practical advice and information to young people under the age of 35 considering suicide, and can also offer help and advice if you're concerned about a young person you know that could be thinking about suicide.

◆ **SOS Silence of Suicide** <https://sossilenceofsuicide.org/>
0300 102 0505

SOS Silence of Suicide provides a listening service for children and adults who need emotional support, understanding, compassion & kindness.

Self-Harm

Sometimes people can find it very difficult to talk and express their emotions, for some the only way they can cope is to physically hurt themselves. This can be by a variety of methods which causes them physical injuries, most commonly cutting themselves. If you or someone you are supporting has made plans to harm themselves, please seek support as soon as possible.



◆ **Harmless** <https://harmless.org.uk/>
Harmless is an organisation who works to address and overcome issues related to self-harm and suicide.

◆ **National Self Harm Network**
<https://www.nshn.co.uk/>

Online forum providing support and empowerment for individuals who self-harm as well as information regarding professional help. Supports friends, families and carers of individuals who self-harm.

Specialist support for children and young people

◆ **Self-harm** <https://www.selfharm.co.uk/>

Runs a website for young people impacted by self-harm, providing a safe space to talk, ask any questions and get information about self-harm. There's an online forum where you can view videos, share thoughts and feelings with other young people who self-harm. Free online support for 14- 19 year olds.

Other sources of help

◆ **Born at the right time** <https://www.bornattherighttime.com/>
01702 963019 Email: admin@bornattherighttime.com
Twitter/Facebook: [@bornatRightTime](https://twitter.com/bornatRightTime)

Rachel Wright, Founder, is a qualified nurse and parent of a son with complex disabilities and life-limiting epilepsy. She's an award winning blogger and the author of two books, works towards bridging the gap between families of children with complex conditions and the practitioners who support them.

◆ **Breathing Space (Scotland)** <https://breathingspace.scot/>
0800 83 85 87 (Mon-Thu 6pm-2am, weekends 24 hours).
Offers a confidential phone and web based service for people in Scotland experiencing low mood, depression or anxiety.

◆ **Community Advice & Listening Line (Wales)**
<https://www.callhelpline.org.uk/>
0800 132 737 (24/7) or text "help" to 81066
Community Advice & Listening Line offers emotional support and information on mental health and related matters to people in Wales.

◆ **Lifeline (Northern Ireland)**
<https://www.lifelinehelpline.info/index.html>
0808 808 8000 (24 hours a day)
Lifeline provides support to people suffering distress or despair in Northern Ireland, regardless of age or district.

◆ **NAC Wellbeing** <https://www.nacwellbeing.org/>
Supporting mental health and emotional care and wellbeing for people with severe and profound intellectual disabilities. NAC offers affordable online training courses for families and professionals.

◆ **Nightlines** <https://nightline.ac.uk/>
Nightlines are confidential, anonymous, non-judgmental support services run by students for students. If you're a student, you can search for your institution's Nightline details via the website.

◆ **The Zero Suicide Alliance**
<https://www.zerosuicidealliance.com/training>
Free suicide prevention training, which can be done in stages.

National Guidance

Future in Mind report: promoting, protecting and improving our children and young people's mental health and wellbeing by the Department of Health and NHS <https://tinyurl.com/evt5c4xc>

Public Health England

Promoting children and young people's emotional health and wellbeing: a whole school and college approach <https://tinyurl.com/59xnchfn>

NHS Children and young people's mental health services (CYPMHS)

<https://tinyurl.com/4dkptfm2>

Information and support for coping with anything relating to a child's mental health or wellbeing.

Transforming Children and Young People's Mental Health Provision: a

Green Paper by the Department of Health and Social Care and the Department of Education <https://tinyurl.com/2dva8x7t>

Building Children and Young People's Resilience in Schools by Public Health England and UCL Institute of Health Equity

<https://tinyurl.com/3yyak696>

A public health approach to promoting young people's resilience report by the Association for Young People's Health and funded by Public Health England <https://tinyurl.com/45s4a2r8>

Five Year Forward View for mental health, report from the NHS independent taskforce <https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf>

Mental Health and behaviour in schools guidance from the Department of Education

<https://www.gov.uk/government/publications/mental-health-and-behaviour-in-schools--2>

Emotional Wellbeing and Mental Health Strategy for Children and Young People in Hampshire 2019 – 2024 <https://tinyurl.com/r59afctz>

Department for Education Teaching about Mental Wellbeing Guidance

<https://www.gov.uk/guidance/teaching-about-mental-wellbeing>

Supporting Young Carers in Schools: <https://tinyurl.com/32ceezu6>

A Step-by-step Guide for Leaders, Teachers and Non-Teaching Staff by the Carers Trust.

Staff Mental Health in Education toolkit

<https://www.mentalhealthatwork.org.uk/toolkit/staff-mental-health-in-education/>

Books

◇ **What's Going On Inside My Head?:**

Starting conversations with your child about positive mental health Hardcover by Molly Potter



◇ **Breathe Out** by Fiona Rose

A guide for Teenagers

◇ **Good Enough** by Jen Petro-Roy

Written by an eating disorder survivor and activist, Good Enough is a realistic depiction of inpatient eating disorder treatment, and a moving story about a girl who has to fight herself to survive.

◇ **Mental Health Journal:** Self Care Diary workbook, Anxiety Journal, Complex PTSD and Depression by Holly Books

◇ **Looking After Your Mental Health** by Alice James

Lots of practical advice, this lively, accessible guide explains why we have emotions, and what can influence them. Covering everything from friendships, social media and bullying to divorce, depression and eating disorders, this is an essential book for young people.

◇ **Don't Worry, Be Happy: A Child's Guide to Dealing with Feeling Anxious** by Poppy O'Neill

◇ **Be Strong: You Are Braver Than You Think: A Child's Guide to Boosting Self-Confidence** by Poppy O'Neill

◇ **The Unworry Book** by Alice James

◇ **Doodle Your Worries Away: A CBT Doodling Workbook for Children Who Feel Worried or Anxious** by Tanja Sharpe

◇ **This Book Will Change Your Mind About Mental Health: A journey into the heartland of psychiatry** by Nathan Filer

◇ **It's OK Not to Be OK: Good Advice and Kind Words for Positive Mental Well-Being** by Claire Chamberlain

◇ **An Introduction to Child and Adolescent Mental Health** by Maddie Burton

- ◇ **The Parent's Guide to Self-Harm: What parents need to know**
by Jane Smith
- ◇ **Mental Health Emergencies: A Guide to Handling and Recognizing Mental Health Emergencies** by Nick Benas
- ◇ **5-Minute Stress Relief: 75 Exercises to Quiet Your Mind and Calm Your Body** by Elena Welsh
- ◇ **Mindfulness for Stress Management: 50 Ways to Improve Your Mood and Cultivate Calmness** by Robert Schachter
- ◇ **Recovery from Complex PTSD: From Trauma to Regaining Self Through Mindfulness & Emotional Regulation Exercises**
by Don Barlow
- ◇ **Mind Over Mood: Change How You Feel by Changing the Way You Think** by Dennis Greenberger
- ◇ **Saving Ourselves from Suicide - Before and After: How to Ask for Help, Recognize Warning Signs, and Navigate Grief**
by Linda Pacha
- ◇ **Self-Compassion: The Proven Power of Being Kind to Yourself**
by Kristin Neff
- ◇ **The Compassionate Mind** by Paul Gilbert

All of the above titles are available from online booksellers.

Apps

◆ **distrACT**

The distrACT app is a free app which gives you easy, quick and discreet access to information and advice about self-harm and suicidal thoughts. The content has been created by doctors and experts in self-harming and suicide prevention. Suitable for anyone over the age of 17 who's concerned about self-harming. The distrACT app aims to help you better understand urges to self-harm, and encourages you to monitor and manage your symptoms. It can also help reduce the risk of suicide. There's advice and support information, including emergency contact numbers, how best to work with healthcare professionals, and safer alternatives to self-harming.

◆ **Expert Self Care** <https://www.expertselfcare.com/>
free-to-use mobile self-help apps

◆ **Moodtools app** <https://www.moodtools.org/>

◆ **NHS apps**
<https://www.nhs.uk/apps-library/category/mental-health/>

◆ **Sidekick** (Apple only)
<https://www.sidekick.org.uk/>

Apps aimed specifically at children and young people

◆ **Clear fear** (Android, iPhone, iPad)
Suitable for age: 11-19. Younger users can use the app with the support of a parent, carer or teacher. Uses mindfulness, relaxation and breathing techniques to help young people learn ways to reduce their physical responses to threat.

◆ **MindShift** (Android, iPhone, iPad)
MindShift app is based on to help young adults cope with anxiety, by acting as a portable coach that guides users through challenging situations. Designed in collaboration with Anxiety Canada, this app teaches users how to relax and helps them identify active steps to directly face and take charge of their anxiety.

Chatting with other Unique parents

Sometimes all you need to do is to talk to someone who understands.

Many of our parents can be good to talk to; so if you haven't already joined our private Facebook groups for registered Unique family members you would be very welcome. Everyone on our private groups are registered with Unique as a member, or the partner or parent of a member. Our main group (Unique Chromosome Network café) is for families anywhere in the world and the most used but we also have regional groups in the UK, USA and around the world. If you would like to be added please email: marion@rarechromo.org



It's good to talk!

International support

Australia

◆ **Health Direct Mental health: where to get help**

<https://www.healthdirect.gov.au/search-results/mental%20health>

◆ **NDIS** (National Disability Insurance Scheme)

Mental health and the NDIS <https://tinyurl.com/2yuyby25>

1800 800 110

National contact centre open Monday to Friday 8am to 8pm (local time)

Email: enquiries@ndis.gov.au

◆ **Beyond Blue** <https://www.beyondblue.org.au/>

1300 22 4636

Facebook: <https://www.facebook.com/beyondblue>

Beyond Blue provides information and support to help everyone in Australia achieve their best possible mental health, whatever their age and wherever they live. In response to the COVID-19 outbreak and for anyone who is seeking support, they have a dedicated Coronavirus Mental Wellbeing Support Service funded by the Australian Government, this free service is available around the clock.

Canada

◆ **Kids Help Phone** <https://kidshelpphone.ca/>

1-800-668-6868 (toll-free) or text CONNECT to 686868.

Available 24 hours a day to Canadians aged 5 to 29 who want confidential and anonymous care from trained responders.

◆ **Hope for Wellness**

Help Line 1-855-242-3310 (toll-free) or connect to the online Hope for Wellness chat.

Available to all Indigenous peoples across Canada who need immediate crisis intervention. Experienced and culturally sensitive help line counsellors can help if you want to talk or are distressed. Telephone and online counselling are available in English and French. On request, telephone counselling is also available in Cree, Ojibway and Inuktitut.

New Zealand

◆ **Mental Health Foundation** <https://mentalhealth.org.nz/>

Resource & Info: 09 623 4812

Information for anyone going through a difficult time, for people supporting someone they care about, and those interested in mental health and wellbeing, living in New Zealand.

◆ **Ministry of Health New Zealand Mental Health Services**

<https://www.health.govt.nz>

0800 855 066

◆ **I am Hope** <https://www.iamhope.org.nz>

I AM HOPE aims to promote positive attitudinal societal change around mental health throughout New Zealand, and fund private care and counselling for young people stuck-in-the-mud on waiting lists.

USA

◆ **Mental Health America** <https://www.mhanational.org/>

Toll Free (800) 969.6642

Facebook: <https://www.facebook.com/mentalhealthamerica>

Mental Health America (MHA) is the nation's leading community-based non-profit dedicated to addressing the needs of those living with mental illness and promoting the overall mental health of all.

◆ **NAMI** (National Alliance on Mental Illness)

<https://nami.org/Home>

Helpline: 800 950 6264 M-F 10am -10pm ET

In a crisis text NAMI to 741741 for 24/7 for confidential, free crisis Counselling. Local chapters in different states of America.



Parent Quotes

“ One quote I use often is 'when being judged they have only one finger pointing at you but three back at them'. Another thing I always tell my son is; that differences are ok, we all have some sort of difference, it is just that some have more special differences that we learn to be stronger with.”

“ So, I can't talk yet for my daughter who is only 3 years and 9 months but I can talk for me, a single mother (by choice). As an MD with a good academic career AND good at sport, I had always thought my Children would be clever and maybe even advanced at school like me, and would excel at sport etc. These kinds of thoughts were so stupid; I realise it now. However, the mourning of the perfect child is hard to do, for every parent, but even more with a disabled child, implying limited possibilities in their life and a major anxiety for the present and the future. Having said that, I have had a very hard time after the diagnosis. I was very angry at the entire world and also towards my daughter. I had the feeling she was not doing enough effort to make progress. I wanted my perfect life, perfect child and my dreams back. It can be very hard to find the right support. The Unique Facebook group, a close friend with a disabled child too and seeing a psychologist helped.”

“ As a parent with 16p11.2 and children who have been diagnosed with the condition, my 11-year-old is suffering from depression and anxiety related issues. Refused school. Refused to sleep. She was discharged from the paediatrician's care back to GP care. When I was at breaking point myself I explained to the GP that I couldn't take any more of her issues and something needed to give. The GP altered her sleeping meds and gave her Sertraline and also wrote to CAHMS for intervention. CAHMS declined and advised school counselling not to give medication for depression and anxiety. We struggled for a few more months until the point she was not smiling any more. The Doctor went against CAHMS and have put her on sertraline 25mg. All I can advise is to fight for your child, we are their voice. Sometimes paediatricians don't know your child as well as they think they might.”

“ As parents we all feel like failures at times, but we are all doing a good job, its often other people (that don't understand what it's like) that make us feel anxious and can lead to our mental health problems, it would be helpful if they understood better and think about what they are saying before they speak.”

“ We found out very early on that our baby, who we tried for 13 years to have, was missing 19 million lines of DNA. She will be profoundly mentally disabled, physically delayed, non-verbal, have a host of medical issues, and will need lifelong caretaking. I was devastated at first but eventually realized I had not only returned to feeling myself, but felt joy again. What really helped me, were six things.

- 1. I began writing publicly to help process my grief. Often times, friends and family would offer words of support which helped me not feel alone.*
- 2. I started intentionally networking with other parents who had kids with a similar deletion. I asked a lot of questions about their kids at our daughter's age and that helped me form a much clearer picture of what to expect. As a result, I quickly stopped comparing our daughter to her neuro typical peers and, instead, began seeing her progress in context to kids with deletions like hers and realized she was doing really well.*
- 3. In our country, the primary caregiver gets 1.5 years of paid leave. We made the decision a few months in, to have my husband also take off work. Because of the amount of issues we've encountered due to our daughter's deletion, it has helped tremendously to have two of us to do full-time caregiving.*
- 4. A friend sent me a few podcasts (like Mama Bear Podcast and The RARE life) of other families raising kids with rare chromosome disorders. It helped, again, made me feel less alone, and that parenting a kid with problems could still be a joy-filled life.*
- 5. A fellow parent of a disabled child said that she's made a practice of going to therapy regularly. So I got plugged in with a therapy that works for me early on and it's helped tremendously.*
- 6. I've been learning to identify stress-relieving activities, and making sure I find some way to squeeze them in every day so I can take care of myself.”*

Notes



Notes

Inform Network Support



Understanding Chromosome & Gene Disorders

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!

This guide was compiled by Unique.

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