



Understanding Chromosome & Gene Disorders

Therapies



rarechromo.org

THERAPIES

Being the parent of a child with a rare chromosome or gene disorder, when you think about therapies you probably automatically think of the three obvious ones, Physiotherapy (PT), Occupational therapy (OT) and Speech and Language therapy (SALT). However, there are so many other therapies that can help your child to develop and achieve goals you might never have dreamed possible. The purpose of this guide is to inform parents of the different types of therapies available. Many of the therapies mentioned in this guide have been suggested by our member families, who may live in the UK, USA or another country, so some therapies might be known by other names depending on the country you live in and some therapies might not be available in all countries. Links to useful websites have been included where possible, so that you can find out more information about a particular therapy.

You should always consult with a medically qualified clinician before trying any of the therapies in this guide.

It is worth mentioning that support groups and organisations; whether local or national, can also be therapeutic. Talking to other parents can be of great benefit to your mental health. Unique has private Facebook groups designed for this purpose. You have to be a registered member of Unique to join our private groups, so if you are a registered member and have not yet joined our Facebook groups and would like to, please email marion@rarechromo.org to be invited (you will need to provide the email address that you use for Facebook).

There are parent carer forums local to you and also Carer support services that run local parent carer groups both of which often run coffee mornings, where you can meet and chat with other parents.



Some of the independent therapies listed can be quite expensive and may not be as helpful as hoped. There are some charitable organisations that will help fund the cost of some of the therapies available. We do have a separate guide on Grants and funding, which is available to download from our website:

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

There may be local funding support from charities within each health board, so it is worth consulting with your therapist/paediatrician.



The information in this guide is the best available at the time of publication. For ease of use, the therapies have been categorised into alphabetical order.

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ART THERAPY

Art therapy is a form of psychotherapy that uses art as its mode of expression and communication. Within this context, art is not used as diagnostic tool but as a medium to address emotional issues which may be confusing and distressing. Art therapy has been in development for over 50 years.

- ◆ **The British association of Art Therapists**
<https://www.baat.org/About-Art-Therapy/Find-a-therapist>



AUDITORY INTEGRATION TRAINING (AIT)

Auditory integration training (also known as AIT) involves a person listening to a selection of music or other sounds which have been electronically modified. AIT is based on the idea that some people, including some people on the autism spectrum, are hypersensitive (over-sensitive) or hyposensitive (under-sensitive) to certain frequencies of sound.

Please Note: The National Institute for Health and Care Excellence (NICE) made the following recommendations: 'Do not use auditory integration training to manage speech and language problems in children and young people with autism.' (NICE, 2013)

- ◆ **Sensory Education** <http://auditoryintegrationtraining.co.uk/>

COGNITIVE BEHAVIOURAL THERAPY (CBT)/ TALKING THERAPIES

CBT is provided by a trained psychotherapist, who can help you to make sense of overwhelming problems by breaking them down into smaller parts. This makes it easier to see how they are connected and how they affect you. Talking therapies are a free NHS service offered by most NHS trusts. They are open to anyone and give support to those struggling through a difficult time. Talking therapies can help with anxiety, depression, stress, phobias, addictions, adjusting to difficult life events and more. Each NHS trust offers a slightly different service, but the options may include one-to-one counselling, guided self-help or therapeutic groups. You can ask your GP what is available in your area or you could look online. You can self-refer to many of the service, but there can be a bit of a wait. You could do an online search for 'NHS talking therapies' along with your location, or you could follow this link for more information:

<https://www.nhs.uk/conditions/stress-anxiety-depression/>

This website also has links to a wide range of different resources including practical information, tools and videos that you may find helpful.

On the NHS talking therapies include:

- ◆ cognitive behavioural therapy (CBT)
- ◆ guided self-help
- ◆ counselling
- ◆ behavioural activation
- ◆ interpersonal therapy (IPT)
- ◆ eye movement desensitisation and reprocessing (EMDR)
- ◆ mindfulness-based cognitive therapy (MBCT)



COMPLEMENTARY THERAPIES

Complementary or alternative therapies are therapies that aren't usually part of conventional medical therapies. They are often used alongside conventional medical therapies.

◆ NHS:

<https://www.nhs.uk/conditions/complementary-and-alternative-medicine/>

◆ **British Association for Behavioural and Cognitive Psychotherapies** <https://www.babcp.com/Default.aspx>

◆ **Therapy Directory** <https://www.therapy-directory.org.uk/>

This website helps you to find a class near you: acupuncture, aromatherapy, massage, reflexology, etc.

Complementary therapies are covered in more detail in our guide on Carers Wellbeing, which you can find on our website:

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

DANCE THERAPY

Dance/movement therapy (DMT) in USA and Australia or dance movement psychotherapy (DMP) in the UK is the psychotherapeutic use of movement and dance to support intellectual, emotional, and motor functions of the body.

◆ **Association for Dance Movement Psychotherapy UK (ADMP UK)**

<https://admp.org.uk/>

◆ **American Dance Therapy Association**

<https://adta.org/>

◆ **The Dance Movement Therapy Association of Australasia (DTAA)** <https://dtaa.org.au/>



DOLPHIN THERAPY (Swimming with Dolphins)

Dolphin therapy was started in the early seventies by an educational anthropologist who noticed the therapeutical effects of dolphins on her disabled brother. The aim of Dolphin therapy is to increase sensory activities. Programmes take place in a pool with dolphins and therapists who assist the children, children are asked to swim, touch, feed or pat the animals. Therapists work on specific areas such as speech, behaviours and motor skills and programmes are customised to the needs of the children.

Please note: Dolphin therapy has proved to be controversial over the years for its ethical treatment, so be sure to do plenty of research, if planning to try it.

- ◆ Europe <http://www.dolphinswim.net/en/>
- ◆ Florida <https://islanddolphinscare.org/>
- ◆ Israel <https://www.dolphinreef.co.il/>
- ◆ USA <https://www.dolphins-world.com/dolphin-assisted-therapy/>

DRAMA THERAPY

Drama therapy is the use of theatrical techniques to help with social and therapeutic goals.

- ◆ **British Association of drama therapists** <https://badth.org.uk/>
Find a therapist

- ◆ **North American drama therapy association**
<https://www.nadta.org/what-is-drama-therapy.html>

EYE MOVEMENT DESENSITISATION AND REPROCESSING (EMDR) AND ADAPTIVE THERAPY.

EMDR was developed by an American clinical psychologist in the 1980s. The therapy involves the identification of unprocessed traumatic or other distressing experience.



- ◆ **APA.org**
<https://tinyurl.com/y3yoqo25>
- ◆ **Psycom.net**
<https://tinyurl.com/y5hzsof6>
- ◆ **The British Psychological Society**
you can read more about EMDR here:
<https://tinyurl.com/wcgonf4>

HORSE RIDING THERAPY

Also known as Hippotherapy, Equine assisted therapy or Riding for the Disabled. Horse riding as a therapy is used to help improve a person's strength, balance and co-ordination. It can also be calming and help with relationships/responsibility.

UK

◆ Riding for the disabled

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

RDA National Office

01926 492915 Email: info@rda.org.uk

Ireland

Sensational Kids

<https://www.sensationalkids.ie/childrens-services/hippotherapy/>

- ◆ KILDARE: 045 520900 email: info@sensationalkids.ie
- ◆ CORK: 023 887 8208 email: Clonakilty@sensationalkids.ie
- ◆ MAYO: 094 9357005 email: Claremorris@sensationalkids.ie

AUSTRALASIA:

◆ (QLD) Equine Assisted therapy Australia

[http://](http://www.equineassistedtherapyaustralia.com.au/)

www.equineassistedtherapyaustralia.com.au/

Jane Faulkner, email: admin@eata.net.au

◆ (ACT) PEGASUS [http://](http://www.pegasusact.com.au/hippotherapy.html)

www.pegasusact.com.au/hippotherapy.html

02 6254 9190 email: admin@pegasusact.com.au

◆ (WA) Embrace therapy

<https://embracetherapy.com.au/hippotherapy/>

Mobile: 0490175252

email: Info@embracetherapy.com.au

New Zealand

◆ Riding for the disabled association

<https://www.rda.org.nz/>

USA

◆ The American Hippotherapy Association

<https://americanhippotherapyassociation.org/>

(970) 818-1322

email: info@theahainc.org



HORTICULTURAL THERAPY

This type of therapy is gardening, using planting and gardening techniques to improve mental health and physical skills. It can help anyone regardless of age.



- ◆ **Horticultural therapy trust**

<https://horticultural-therapy-trust.org/>

Deb Hoskin 07507 675 344

email: deb@horticultural-therapy-trust.org

Supports people of all ages who experience mental/physical disability, through gardening, growing vegetables, wildlife conservation etc.

- ◆ **Pop gardens** <https://popgardens.co.uk/>

07738 414 056 email: talk@popgardens.co.uk

Provide training in horticultural therapy to groups.

- ◆ **Thrive** <https://www.thrive.org.uk/>

0118 988 5688 email: info@thrive.org.uk

Thrive support and work with people who have a physical or learning disability; people with mental health support needs; people who may have sensory loss or autism; people with age-related conditions such as dementia, heart problems, diabetes or stroke survivors and also young people who have social, emotional or behavioural difficulties.

HYDROTHERAPY, AQUATIC OR WATER THERAPY

A Physiotherapy programme given in water, by a qualified Physiotherapist .

- ◆ **The Aquatic Therapy Association of Chartered Physiotherapists (ATACP) UK**

Find a therapist

<https://atacp.csp.org.uk/>

- ◆ **Physiofunction**

<https://tinyurl.com/szqjaaf>

- ◆ **Hydroworx USA based**

<https://tinyurl.com/ycq52stt>

- ◆ **Moveability**

(South Australia)

<https://tinyurl.com/u6xu3g9>

0413 493 722

email:

hayley@moveability.com.au

- ◆ **Hydrotherapy Brisbane**

<https://tinyurl.com/vh8n8ta>

(07) 3263 1515

email: info@hydrotherapybrisbane.com.au



LAUGHTER THERAPY

Laughter therapy is used to promote health and wellness. It aims to use the natural process of laughter to help relieve physical or emotional stresses or discomfort. It is a therapy that not only increases happiness, but it also strengthens the immune system, and helps to lower stress. Laughter relaxes the whole body. There are many Laughter clubs, or Laughter Yoga clubs popping up all over the country. Type Laughter Yoga into a search engine online and you will see lots of links.

- ◆ **Laughter Therapy**

<https://laughtertherapy.org.uk/>
0115 772 2062 Mobile: 07545 347 462

- ◆ **Laughter Yoga**

www.laughteryoga.co.uk/
07736 341 717
email: info@laughteryoga.co.uk



LEGO® THERAPY

I must confess, I hadn't heard of this type of therapy before, but several Unique members have mentioned it, so I have included links below.

Lego® therapy is a program for children with social communication difficulties or autism. It uses the child's love of playing with **Lego®** to help them develop communication and social skills. The therapy was developed by a licensed paediatric neuropsychologist.



- ◆ **Autism Bricks UK**

<https://tinyurl.com/wboegxt>

- ◆ **Network Autism UK**

<https://tinyurl.com/wtsjh4t>

- ◆ **Raising children Australia**

<https://tinyurl.com/wuejs2y>

- ◆ **Lego Therapy**

<http://www.legotherapy.com/>

LIGHT THERAPY or PHOTOTHERAPY



This is used to treat SAD (Seasonal Affective Disorder) by exposing yourself to artificial light such as a light box. SAD is a type of depression that usually occurs during the winter months when there is less natural sunlight. You sit in front of a light box for 15-20 minutes or what suits you best.

MUSIC THERAPY

Music therapy is used to help children and adults to relax and de-stress. It can help with emotional, behavioural and social difficulties.

◆ **British Association for Music Therapy** <https://www.bamt.org/>
Find a music therapist:
<https://tinyurl.com/rrmjlse>
020 7837 6100
Email: info@bamt.org

◆ **Music as Therapy International**
<http://www.musicasterapy.org/>
020 7735 3231 Facebook: musicasterapy
Email: info@musicasterapy.org
A UK registered charity which devises and delivers innovative, high-impact music therapy projects around the world.



OCCUPATIONAL THERAPY (OT)

Occupational therapy is available via the NHS or social services in the UK. An OT can do an assessment on your child to see what help they can provide to help them towards independence. Things like equipment, which might include items like seating, positioning, bathing equipment, or adaptations to the home, i.e. wet room, bed, hoist, handrails, ramps etc. An Ot can also provide help and guidance on the most effective ways of achieving certain tasks e.g. wiping your own bottom! An OT will be able to assess not just in the home environment, but at school/college/day care/ respite/, etc. An OT can also liaise with other professional services including how to access sensory processing therapy.

◆ NHS UK

<https://www.nhs.uk/conditions/occupational-therapy/>

Not everyone can get the help they might need via the NHS or Social care and there can be long waiting lists.

◆ Independent OT's

There are independent OT's that you can pay to offer support: Find a therapist via the Royal College of Occupational Therapists:

<https://rcotss-ip.org.uk/find>

◆ Griffin Occupational Therapy

<https://www.griffinot.com/>

07413 330 566 Facebook:

<https://www.facebook.com/GriffinSensoryOT/>

Griffin OT offers affordable and easily accessible online occupational therapy solutions for schools and parents. This includes an online Sensory Processing Disorder training course. All Griffin OT programmes offer you more than a list of

activities/strategies to try. Their primary aim is to help school staff and parents to understand why they're doing these activities or using specific

strategies. **What they do:** If you want to learn more about Sensory Processing Disorder, how it affects children and how to help, their online

course 'Sensory Processing: What's the Fuss?' could be a good solution for you. If your child has gross or fine motor skill delays, struggles with their pencil grip or finds using scissors really tricky, then their online motor skill development programmes may be relevant.

◆ Inclusion.Me

<https://www.inclusion.me.uk/>

01892 320334 Email: info@inclusion.me.uk

Inclusion.Me offers nationwide coverage for private OT and has a disability access audit service.



PETS AS THERAPY (PAT)

Pets as Therapy (PAT) or Animal Assisted Therapy (AAT) is usually visits by dogs, but sometimes other animals. Trained volunteers can visit people in various locations with their own pet. You can also apply for your own therapy dog to assist your child with everyday tasks in your home.

◆ **Assistance dogs UK** <https://www.assistedogs.org.uk/>
Assistance Dogs UK is a coalition of eight assistance dog charities.

◆ **Canine Partners**
<https://caninepartners.org.uk/>
Facebook: caninepartners

◆ **Dogs for good**
<https://www.dogsforgood.org/>
01295 252600

◆ **Pets as Therapy**
<https://petsastherapy.org/>

◆ **Support Dogs**
<https://www.supportdogs.org.uk/>

◆ **Therapy Dogs nationwide**
<http://www.tdn.org.uk/>

A national Charity where visiting volunteers take their own dogs into establishments to give comfort, distraction, and stimulation.

IRELAND

◆ **Irish therapy dogs** <https://irishtherapydogs.ie/>
01 544 6198 Email: info@irishtherapydogs.ie

◆ **Dogs for the Disabled Ireland** <https://dogsfordisabled.ie/>
021 431 6627 or Email: info@dogsfordisabled.ie

USA

◆ **4Paws for Ability** <https://tinyurl.com/rhh3nng>
937 374-0385 email: karen@4pawsforability.org

◆ **Assistance dogs International**
<https://tinyurl.com/tw5hxkn>
Email: info@assistedogsinternational.org
Programs that train and place Assistance Dogs for disabled people.

◆ **Service Dogs for America**
<http://www.servicedogsforamerica.org/>
Email: info@servicedogsforamerica.org
Trains and certifies service dogs for individuals with disabilities.

◆ **Pet Partners** <https://petpartners.org/>
Pet Partners teams visit patients in recovery and people with disabilities.

AUSTRALIA

◆ **Therapy Dogs - Australia**
<https://therapydog.com.au/>
Email: info@therapydog.com.au



NEW ZEALAND

◆ **Therapy dogs – New Zealand** <https://therapydogs.co.nz/>
022 515 4886 Email: wendy@therapydogs.co.nz

PHYSIOTHERAPY(PT)

A physiotherapist treats the whole body. They provide a tailored exercise plan to help with mobility, tight muscles, balance, movement and strength and improve health generally. Sometimes physiotherapy can be provided in water, this is known as Hydrotherapy (see page 8)

◆ NHS

<https://www.nhs.uk/conditions/physiotherapy/how-it-works/>

Waiting lists for physiotherapy on the NHS can be long. Some people choose to pay for an independent physiotherapist assessment, or additional therapy on top of what the NHS provides.

◆ Chartered society of Physiotherapy – find an independent physiotherapist

<https://www.csp.org.uk/public-patient/find-physiotherapist>



PLAY THERAPY OR THERAPEUTIC PLAY



Play therapy or therapeutic play, is play using art, crafts, imaginative or role play, puppets, music and touchy feely items like shaving foam, sand, playdoh etc. It can help children to overcome fears, anxiety and trauma and can also help with behavioural, social and communication issues. Find a therapist.....

◆ **Association for play therapy (USA)**
<https://www.a4pt.org/>

◆ **British Association of play therapists**
<https://www.bapt.info/>

◆ **Play Therapy UK**
<https://playtherapy.org.uk/>

◆ **Psychology today - blog about play therapy**
<https://tinyurl.com/yaphquhu>

REBOUND THERAPY

Rebound therapy is an exercise therapy which uses a full sized trampoline to provide movement and recreation for people with additional needs. This type of therapy is not suitable for everyone, so please check with your GP, physician or paediatrician as to whether it would be a suitable therapy for your child.

◆ **UK:**
<https://www.reboundtherapy.org/>

◆ **USA:**
<http://www.reboundtherapy.org/fbt-usa/>
Rebound therapy training courses

◆ **Physio UK**
<https://tinyurl.com/vxl9gop>
Clinics in NW England

◆ **Physiopedia**
https://www.physio-pedia.com/Rebound_Therapy
Rebound therapy training courses



SENSORY THERAPIES

Sensory therapies are covered in our guide on Behaviour and sensory, which can be found on our website.....

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

SPEECH AND LANGUAGE THERAPY (SALT OR SLT) AND FEEDING THERAPY

Speech and Language therapy provide assessment and treatment for children with delays in speech/ language, or communication, and feeding/ swallowing difficulties. This therapy can be provided in the home or at school. There can be a wait for home speech therapy. Speech and Language Therapists work with parents, teachers, nurses, and doctors in a variety of settings. In some areas SALT for children/young adults is provided through small 'communication groups' of individuals with similar levels of ability. You can also pay privately for an independent therapist.

AAC

Augmentative and Alternative Communication (AAC) is a range of strategies and tools to help people to communicate. This could be using pictures or assistive technology devices. Speech therapists can do an assessment on a child at school to see if a communication device is appropriate and discuss funding if necessary.

♦ **Afasic** <https://www.afasic.org.uk/>

Helpline: 0300 666 9410

Afasic seeks to raise awareness and to create better services and provision for children and young people with speech and language impairments. It works in partnership with local and national government, professional and statutory bodies and other voluntary organisations. They provide information and training for parents and produce a range of publications.

♦ **CLAPA (Cleft Lip and Palate Association)** <https://www.clapa.com/>

020 7833 4883 Email: info@clapa.com

CLAPA is a charity offering support and information to parents whose children were born with a cleft.

♦ **Communication Matters** <https://communicationmatters.org.uk/>

Communication Matters is a UK-wide organisation that supports people of all ages who find it hard to communicate because they have little or no speech. They run conferences and study days, and provide information about AAC.

♦ **Help Kidz Learn** <https://www.helpkidzlearn.com/>

Information on a variety of apps that can help children to communicate.

♦ **I Can Talking Point** <https://ican.org.uk/i-cans-talking-point/>

Enquiry line: 020 7843 2544

Email: enquiries@ican.org.uk

Working with families to help their children to communicate

♦ **I communicate**

<https://www.icommunicatetherapy.com/>

Speech, language and communication resources.





◆ **Makaton** <https://www.makaton.org/>
01276 606760 Email: info@makaton.org
MAKATON is a language and communication programme which provides signs and symbols to support speech, for children and adults with communication and learning difficulties. Makaton provides a national network of tutors offering training and advice throughout the UK and produces a wide range of resources,.

◆ **Michael Palin Centre for stammering**
<https://tinyurl.com/r9pzsVK>
020 3316 8100 Email: mpc.admin@nhs.net
Offering assessment and therapy programmes to

children and adults who stammer.

◆ **PECS UK (Picture Exchange and Communication System)**

<https://pecs-unitedkingdom.com/>
01273 609555 Email: pyramiduk@pecs.com

PECS is a communication system using pictures. Starting with a picture of an individual item, 'the teacher' honours the exchange by passing the object to the child.

◆ **PECS USA** <https://pecsusa.com/>
1-888-732-7462 Email: pyramidus@pecs.com

◆ **PECS style pictures free to download**
(USA based)

<http://trainland.tripod.com/pecs.htm>

◆ **Signalong**

<http://www.signalong.org.uk/>
Sign language training and resources to assist those with communication difficulties and English as an additional language.

◆ **Speech Teach**

<http://www.speechteach.co.uk/>
Speech therapy resources for parents and professionals.

◆ **STAMMA** <https://stamma.org/>

Freephone 0808 802 0002

Email: help@stamma.org

Support and information for people who stammer.

◆ **The association of speech and language therapists in**

Independent practice <https://www.asltip.com/>
0203 002 3704 Email: office@helpwithtalking.com

Find an independent speech therapist.

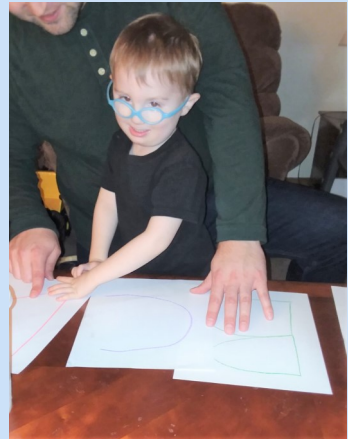
◆ **The Communication Trust**

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

Email: enquiries@thecommunicationtrust.org.uk

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

The Communication Trust is a coalition of over 50 not-for-profit



organisations working together to support everyone who works with children and young people in England to support their speech, language and communication.

- ◆ **The Ed Psych** <https://www.theedpsych.com/>
Enquiries & Appointments 078 3344 7356 / 079 9053 8654
Email: Office@TheEdPsych.com

An independent practice based in London, consisting of Educational Psychologist, Therapists, Occupational Therapists, and Speech Therapists who work closely with Families, Nurseries, Primary and Secondary Schools, Colleges, Paediatricians and other professionals to support children and young people for whom there are concerns about learning, emotional well-being, and developmental progress.

- ◆ **The National Deaf Children's Society** <https://www.ndcs.org.uk/>
0808 800 8880 Monday to Friday 9am – 5pm
Free from all UK landlines and major UK mobile providers
SMS: 0786 00 22 888 (SMS) Monday to Friday 9am – 5pm
BSL Interpreter: BSL Interpreter Now Monday to Friday 9am – 5pm
Contact them via a free video call with a BSL interpreter. Information and support on a range of topics across the UK related to childhood deafness, including Communication options and support and Technology and equipment to support deafness.

.....FEEDING THERAPY

Feeding therapy is usually taught by a specially trained speech and language therapist. They work with children and their parents to determine the source of the child's difficulties and develop very specific therapies to make the entire process of eating, safer, easier and more enjoyable.



- ◆ **Eating and drinking management clinic at Chailey Heritage school – a useful guide of what to expect**
<https://tinyurl.com/snjgfk5>

- ◆ **Great Ormond Street Children's Hospital (GOSH)**
<https://tinyurl.com/v2ymzrp>

The National Feeding and Eating Disorders Service at GOSH specialises in the assessment and treatment of children with feeding and eating difficulties of a psychological nature, often associated with co-occurring health conditions and usually quite complex presentations.

- ◆ **The children's feeding clinic, London**
<https://www.childrensfeedingclinic.com/>

VISION THERAPY

Vision therapy is a supervised program of visual activities designed to correct vision problems and visual skills.

- ◆ **All about vision** <https://tinyurl.com/ryer3k2>
- ◆ **Amblyoplay** <https://tinyurl.com/wfwpyh4>
- ◆ **Vision Therapy** <https://www.visiontherapy.org/>

WHOLE CHILD THERAPY

- ◆ **Brainwave** <https://www.brainwave.org.uk/how-therapy-works>

⇒ North West Centre (Manchester)

01925 825547 Email: enquiriesnw@brainwave.org.uk

⇒ South East Centre (Essex)

01376 505290 Email: enquiriesse@brainwave.org.uk

⇒ South West Centre (Somerset)

01278 429089

Email: enquiries@brainwave.org.uk

⇒ Scotland 01925 825547

Email: enquiriesnw@brainwave.org.uk

⇒ London 01376 505290

Email: enquiriesse@brainwave.org.uk

Brainwave is a charity that exists to help children with disabilities to achieve greater independence by aiming to improve mobility, communication skills and learning potential through a range of educational and physical therapies.

- ◆ **BIBIC** <https://bibic.org.uk/>

01458 253344

Email: info@bibic.org.uk

BIBIC is a national charity and exists to maximise the potential of children and young people with conditions affecting their social, communication, sensory, motor and learning abilities.

- ◆ **Conductive Education**

The National Institute of Conductive Education UK

<https://conductive-education.org.uk/>

Founded in the 1940s by Hungarian Professor Andras Peto, Conductive Education programmes are not medically based, but task orientated.

- ◆ **The Movement Centre** www.the-movement-centre.co.uk

Robert Jones and Agnes Hunt Hospital, Oswestry SY10 7AG

01691 404248 Facebook: TMCOSwestry Twitter: @TMCOSwestry

The Movement Centre is a UK charity which offers a therapy called Targeted Training, aimed at helping children with a wide range of movement disorders. It can be delivered in addition to the child's existing physiotherapy programme. They work closely with families and the course



of therapy is tailored to each child's specific needs. Targeted Training Therapy is an intensive intervention. It facilitates a daily provision of physiotherapy. Close liaison with the child's physiotherapists, consultants and other clinicians ensures a co-ordinated and integrated overall therapy input.

◆ **Whole Child Therapy** www.wholechildtherapy.com/
020 3441 6810 Email: enquiries@wholechildtherapy.com

Whole Child Therapy are a team of occupational therapists, osteopaths, a body work specialist, a naturopath, a nutritionist, a play therapist and speech & language therapists, working together as one whole team for children. Their therapy is designed to be fun, sometimes challenging, with achievable goals. Their objective is that every child leaves feeling more positive and confident in their abilities.

Their Experience with Rare Chromosome Disorders

One of the biggest problems that they say they see for children with rare chromosome disorders is that they have been treated like a child with Autistic Spectrum Disorder (ASD) or with developmental delay. Often the diagnostic process is not clear enough and specific needs are overlooked, or even miss treated. Appropriate help is delayed and more harm than good can result from even the best intentions. Even with a diagnosis of a rare chromosome disorder, one child's picture is not the same as another's with the same diagnosis. The difference between RCD and ASD is that with RCD, there is a cellular disruption - a deletion or a duplication.



Much like stroke rehab, neural plasticity needs to be improved. That is the process by which the brain can learn new things through experience. It is an essential part of achieving long-lasting functional change and mental compensation, where necessary. This is different from treating a developmental delay or ASD, which would use repetition and transference of strengths across different functional areas, rather than creating new ways for the brain to do something. Treatment of a child with a rare chromosome disorder requires a good level of neural and developmental knowledge and an ability to explore how neural or developmental pathways may work cross-functionally. They use their knowledge of neurology, development, sensory functions, environment and education to make sure that a child is given a tailored assessment and programme. Whole Child Therapy is in itself unique. They don't have a 'one size fits all' approach. Working across home and school, they make sure that a child is seen and recognised for who they are, and not just their condition. They make sure they treat each and every child as unique and work with families across their whole team to ensure they are as informed as possible.

Wilderness therapy

Wilderness therapy is a program of alternative support for troubled young people. Outdoor activities can really benefit youngsters with mental health issues. There are intensive wilderness therapy programmes available for young people struggling with emotional challenges.

Adventure therapy <https://adventuretherapy.org.uk/>
01271 865285 Email: enquiries@adventuretherapy.org.uk

Venture Mor <https://venturemor.co.uk/>
Email: info@venturemor.co.uk

Wilderness Foundation <https://wildernessfoundation.org.uk/>
0300 1233073 Email: info@wildernessfoundation.org.uk



PARENT QUOTES

“We use a lot of sensory play. Soap on marble/granite work tops, paint on tarpaulin in the garden, orbeez in the pool, face-painting all over the body. We also use our lazy spa a lot.”

“Our Trampoline has been the best release, sensory-wise.”

“Horse riding with the RDA has been great therapy for my son.”

“My sons school does Lego therapy. It builds confidence, team work etc. but also fine motor skills, hand-eye coordination, as well as the maths skills.”

“We have done brainwave therapy (they have UK centres that do speech, physio and occupational therapy altogether), snowdrop therapy, conductive education, talk tools for feeding and speech, and have just started movement lessons. I've also trained in rebound therapy. Other therapies we've looked into are hydrotherapy, RDA riding, Cranio-osteopathy. So many! I think they all help and have their place, but it's definitely a case of trying different things and seeing what works for your child. Most will create programmes you then follow at home. These are great, but my advice would be to say that you can't do everything every day! Do what you can and give both yourself and your child a break too! Also the NHS usual physio, speech, OT is useful but are often woefully sparse and they rarely know about more alternative therapies.”

“Balance Pods were our best investment, so cheap and great to use!”

“My son has extremely weak core muscles and struggles with movements involving turning his upper body round. He also struggled to balance when sitting on his bottom with his legs crossed, or in front of him. He was told by an occupational therapist to use a peanut workout ball to sit on. He could sit on it straddled, or sit on it as a chair with both feet in front. When he was sat straddled we could peg clothes pegs to the back of his shirt and encourage him to try and remove the pegs, without falling off or wobbling on the peanut. He was encouraged to use the peanut as a desk chair and gently bounce on it. After 2 years of this, I am pleased to say he can now clean himself in the bathroom 80% of the time.”

.....Continued

“My son has really benefited from Sensitivity OT. His practitioner focusses on Proprioception and his sensory needs, which involves lots of swinging, climbing, stretching through restrictive fabrics and tactile messy play. Since starting, we have gained a far greater understanding of his behaviours, he is more physically able and can tolerate sensations and textures that he wouldn't even approach before.”

“ We used the Dévény method - a Hungarian well known therapist, who worked with babies and children born with any disorder. The therapist died not long ago, but she taught many therapists to practice her therapy. It is based on a special massage to all parts of the body, to stimulate the nerves in the brain. I took my daughter to see one of her therapists for 18 months and it helped a lot.”

“CBT has been really difficult to access for a young adult in our area. Some NHS/CHUMS services consider a child up to 16 and some up to 18. By the time we needed to access it for our daughter she was 16 and not eligible, but adult services wouldn't see her either because of her learning difficulties and the need for the techniques therapists use with young children. She is now on a long waiting list to see the only psychologist in our area who provides help for adults (she is now aged 19) with learning disabilities.”

“I would specify an OT or PT that specializes in vestibular and proprioceptive systems, and put in a few things like sensory processing delays (SPD) Q&A. It is one that sometimes appears to be autism but is not. Sensory has been huge in our behaviour journey. My guy is 9, and we are finally getting more good days than bad.”

“J wants to jump. But he couldn't use a trampoline. His physiotherapist used something called a jumper-roo and a roller board against the wall. After a long time of practicing, he's finally making small jumps on a children's trampoline.”

“A Squeeze vest and clothing has helped my son's nervous system to calm. He was always in fight and flight. Everyone seems to think weighted is best, but he hated weighted with his low tone, so deep pressure was extremely helpful.”

Equipment

I'll touch briefly on equipment in this guide. There are so many different types of equipment and different manufacturers that sell these specialised items, too many to list here. We will create a separate guide in the near future. The types of equipment relevant to this guide would be items like:

- ◆ feeding equipment
- ◆ specialist seating
- ◆ bathing and toileting equipment
- ◆ therapy items including therapy balls, mats, etc
- ◆ mobility aids like grab rails, gait trainers, prone standers, rollators, walking frames, sticks, stairlifts, specialist buggies, wheelchairs
- ◆ specialist cots/beds.
- ◆ shoes/boots



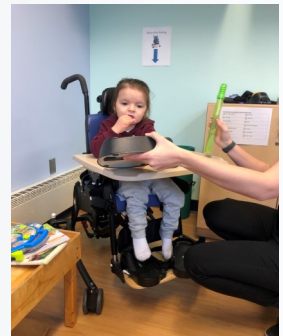
Some of these items are available on loan via the NHS equipment services in the UK, but many are not. An Occupational Therapist can help with assessing your child for equipment and if it isn't available on the NHS, they should be able to enquire about funding an item, on your behalf, or suggest where you might go to get funding. Council housing depts. administer a Disabled Facilities Grant (DFG) following an assessment, but cannot necessarily cover the whole cost of relevant bedroom/therapy room/bathroom conversion in your home. DFG's are available in England, Wales and Scotland and are not means tested for children

but they are for adults.

Find out more here: <https://www.gov.uk/disabled-facilities-grants>

Scotland: <https://tinyurl.com/sxxla7s>

“Equipment we have used: corner seat, standing frame, gait trainer, adapted buggy, standing ladder, therapy bench, wedge, exercise balls, specialist seating, piedro boots/memo shoes, Z vibrate for oral exercises.”



Inform Network Support



Understanding Chromosome & Gene Disorders

Rare Chromosome Disorder Support Group
The Stables, Station Road West, Oxted, Surrey RH8 9EE,
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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!

Our thanks to all of the parents that contributed towards this guide.

This leaflet is not a substitute for personal medical advice. Families should consult a medically qualified clinician in all matters relating to genetic diagnosis, management and health. The information is believed to be the best available at the time of publication.

It was compiled by Unique and reviewed by Lisa Bryson, Paediatric registrar, Royal Hospital for Children, Glasgow.

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