



Understanding Chromosome & Gene Disorders

Communication



rarechromo.org

Communication guide

Communication isn't just about speech. We communicate in lots of different ways. Speech, signing, pointing, eye contact, body movements, expressions etc. It can and is used by everyone, every day.

This guide was written to help parents whose child has a rare chromosome or gene disorder, and includes ideas to help them to teach communication skills and to learn how to communicate with their child who has a developmental delay. Speech is a skill that children begin to develop as babies. Infants start by communicating through crying, then they move onto develop babbling speech which contains no real words. This can carry on for some time. For most children, their first words are made up of simple vowel sounds like 'da da', 'ma ma' or 'ba ba'. Gradually children begin to use these sounds to form language but this can come at very different ages. As children begin to develop more complicated language, they produce longer words and can string words together to form a sentence. By the time they start school; most children have speech that is easily understood. However, some children take longer to develop their speech to a level where everything they say can be understood. Some children do not learn to speak at all and have to find other methods of communicating their wants and needs.

Speech – the oral sounds that are made
Language - the use of words or gestures
Receptive skills - understanding language
Expressive skills - producing language

If your child has a developmental delay, speech will often also be delayed, or not develop at all. There maybe many reasons for this, such as hypotonia (low

muscle tone) which can affect the muscles in the mouth, hearing loss, neurological disorders, brain injury, and/or physical impairments such as cleft lip or palate. Frequently, however, the cause is unknown.

A child's communication is considered delayed when the child is noticeably behind his or her peers in the acquisition of speech and/or language skills or when their level of understanding significantly exceeds their ability to express themselves but this is not always the case.

How can you help your child's speech and language

- Read to your child when they are a baby. Children acquire vocabulary and speech sounds gradually. Very often children tend to like the same book(s) read to them over and over. Words become familiar and the more they hear those words, the more likely they will remember and use those words and make sentences with them.
- Use the 'say what you see' strategy. It is thought that language develops through play, therefore watch how your child plays and add words to their actions as they play. For instance, if your child is banging bricks together rather than building them, you say "bang bang bang".
- Try not to ask too many questions, i.e. 'what's that?', 'what colour is that?', etc. Provide a model for what your child should be saying in a given situation, e.g. 'bird, a bird singing'.
- When you do not understand what your child says, try and encourage

your child to try and tell you again. When your child pronounces a word incorrectly, repeat the word clearly and accurately, then carry on with what you were both doing before. Children learn correct speech by listening to you talk and read correctly.

- Imitate your child - copy sounds, gestures, actions if your child isn't yet able to speak or communicate clearly with pictures/signs. It's amazing how you can get a rich two-way communication going back and forth with children who have limited or no language ability.
- Give your child a choice of two options, e.g. dresses, t-shirts, puddings, toys, books.

Consult your family doctor (GP) or paediatrician if you have any concerns about your child's speech or language. They should be able to refer you to a speech and language therapist (SALT) if further evaluation is necessary.

Speech and Language Therapy (SaLT or SLT)

Speech and Language Therapists work with parents to assess if a child has speech and/or language difficulties, communication or eating, swallowing and drinking difficulties. The therapist will consider the difficulties the child has and the impact these will have on his/her life. The therapist can decide how the child can be helped to reach their full communication potential. Anyone including parents can refer to Speech and Language Therapy but the referral must always be made with the parent's consent.

Speech and Language Therapists can work in a variety of settings such as homes, nurseries, schools, clinics and other locations in the community.

Assessment

An assessment may include information gathering from parents, families and others involved in the child's life and building on what is already known about the child from other agencies such as education and social services. A speech and Language Therapist will assess the child's:

- ability to focus on an activity (sometimes known as Attention and Listening skills).
- understanding of spoken language and body language
- expression through speaking and body language
- production and use of sounds
- ability to use language in a social context
- eating, drinking and swallowing
- play skills

This may include formal and informal assessment such as observation. The decision whether to offer further support from Speech and Language Therapy is based on the outcome of assessment and the impact of the difficulty on the child's life. Following assessment the outcome will be discussed with the parent and a written report will be sent to the parent and the referrer. The therapist may need to share this information with other people for the child's benefit; this should be discussed with the parents.

Interventions

There is a range of possible ways of supporting a child. These will always involve working with parents and others such as nursery assistants, classroom assistants, class teachers and learning support teachers. Possible ways of supporting the child may include one or more of the following:

- Training and advice for parents/carers and other service providers (health, social services, education)
- Provision of programmes of work and ways of supporting the child in different environments and by different people
- Assessment and provision of communication aids and resources
- Direct therapy with child individually or in a group
- Following the agreed period of support the child's progress will be reviewed in partnership with parents/carers and others and further recommendations and actions will be adopted according to the child's changing needs.

Independent Therapy

Independent speech and language therapists can usually offer an appointment for assessment without delay, followed by therapy to suit the client. Many therapists will carry out assessment/therapy in schools, homes or hospitals if required. Because this is a private service, charges are made. General information about Speech and Language Therapy is available from:

■ **The Royal College of Speech and Language Therapists**

Website: www.rcslt.org

Telephone: 020-7378-1200

Speech and Language Therapists are graduate health professionals who must be registered with the Health Professions Council which is the regulatory body for all Allied Health Professions. You can check registration of any Speech and Language Therapist via The Health and Care Professions Council website: www.hpc-uk.org Telephone: 0300 500 6184

■ **The Association of Speech and Language Therapists in**

■ **Independent Practice**

Website: www.helpwithtalking.com Telephone: 01494 488306

Funding for private speech therapy (UK)

Website: <https://www.treeofhope.org.uk/therapy-for-children/>

Ideas to encourage speech

Finger and hand puppets can be used as a method to assess and promote language development. They can be both educational and fun. Some puppets are also used to sign.

Website: <https://livingmadeeasy.org.uk/category/leisure-and-play/learning-toys-and-activities/toys-to-encourage-speech>

Sign Language

What is sign language?

Sign language is a visual way of communicating using hand gestures, facial expressions and body language. Visual communication methods have been around for thousands of years and nowadays there are hundreds of different types of sign languages in use across the world.

Within Britain the most common form of Sign Language is called

■ **British Sign Language** (BSL) Website: www.bslcentral.co.uk/

You can learn BSL online. Sign language evening classes are offered all around the country. You can find a course near you through the

Signature website: <https://www.signature.org.uk/>

Telephone: 0191 383 1155

■ **Makaton Vocabulary Development Project**

Website: www.makaton.org

Telephone: 01276 606 760 Email: info@makaton.org

Makaton is an internationally recognised communication programme, used in more than 40 countries worldwide. Most Makaton users are children and adults who need it as their main means of communication. But everyone else who shares their lives will also use Makaton. These include the families, carers, friends and professionals such as teachers, speech and language therapists, social workers, playgroup staff, college lecturers, instructors, nurses, and psychiatrists.

■ **Paget Gorman** Website: www.pagetgorman.org/

Paget Gorman Signed Speech is an accessible signing system which supports the education and communication of children with Speech, Language and Communication Needs.

■ **Signalong** Website: www.signalong.org.uk

Telephone: 01634 727087 Email: info@signalong.org.uk

Signalong is a sign-supporting system based on British Sign Language, designed to help children and adults with communication difficulties, mostly associated with learning disabilities, autism and other special needs. User-friendly for easy access.

“ My little boy aged 3, is using Signalong. We have been teaching him since the end of last year - since we started seeing a SALT. He was initially taught the sign ‘more’, this took a little while for him to learn. However since I went on the Signalong course he is learning the signs at a very fast rate. He now knows about 40 signs and is able to use 2 and sometimes 3 signs together. The SALT says he is learning the signs and using in the same way you learn to speak. This communication system has allowed him to express himself and for us to explain what is happening or is going to happen. He still gets frustrated; but the way he is communicating now gives me hope that even if he cannot speak; he has an effective way to talk to us, which can only keep improving. The whole family has embraced Signalong - even our 5 year old. ”

“ We registered national sign language as our child's mother tongue in the hopes of securing the rights to an environment where signing is understood. No problem with hearing. ”

Pictures/symbols and visuals

Many children with limited or no speech, find using pictures or photographs of objects help them to express themselves. Many that use pictures or sign language often go on to develop speech and some children use a mixture of both.

■ Pyramid Educational Consultants UK Ltd

Website: <https://pecs-unitedkingdom.com/>

Telephone: 01273 609555 Email: pyramiduk@pecs.com

The Picture Exchange Communication System (PECS) was developed over 20 years ago as a unique augmentative, alternative training package that allows children and adults with autism and other communication difficulties to initiate communication. First used in the United States, PECS has received worldwide recognition for focusing on the initiation component of communication. PECS begins with teaching students to exchange a picture of a desired item with a teacher, who immediately honours the request. For example, if they want a drink, they will give a picture of 'drink' to an adult who directly hands them a drink. Verbal prompts are not used, thus encouraging spontaneity and avoiding prompt dependency. The system goes on to teach discrimination of symbols and how to construct simple "sentences." Ideas for teaching commenting and other language structures such as asking and answering questions are also incorporated. It has been reported that both pre-school and older students have begun to develop speech when using PECS. The system has been successful with adolescents and adults who have a wide array of communicative, cognitive and physical difficulties.



“ PECS works for my daughter as well as some sign and coded vocals. Meaning I know what she wants; although no one else does. One way or another she gets her point across. ”

Flash cards

Free online PECS pictures to download.

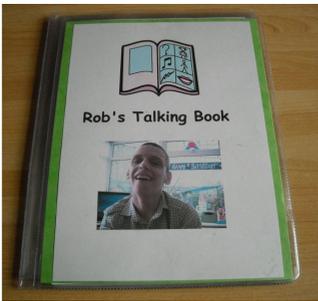
- Website: <https://trainland.tripod.com/pecs.htm>
- Website: www.do2learn.com/picturecards/printcards/index.htm
- Website: <https://www.sparklebox.co.uk/special-needs/communication-language/#.UZlwbqLBN8F>

Symbols software to purchase

Boardmaker, PCS, Widgit, Clicker.

- Website: www.cricksoft.com/uk/home.aspx
- Website: www.sensorysoftware.com/

You could make your own 'talking book' or 'communication passport' using pictures or photographs



Objects of Reference

This refers to the use of objects to support and develop communication. Objects of Reference can be used to signal what is about to happen and to offer choices. Also some children may find pictures difficult to understand and may need to see or feel the object to understand what is happening next. They may also act as a solid link to language, by allowing learners through representations of things and events. For example: Rob has no speech, he wants to go swimming whilst he is at school, so he gives the swimming float to his teacher, who then takes him swimming. Other examples include giving a cup for 'drink', or a spoon, fork or bowl for 'eat'.



Body Language

Of course speech isn't the only method of communication.

Communication can be:

- Tone of voice
- Pitch of voice
- Facial gesture
- Body movement – part or whole, fine or gross
- Body gestures
- May use other people's body parts to indicate what they want – e.g. taking someone's hand/arm and showing it should be placed around somebody else, to indicate their affection for that other person
- Whole person is a 'communication aid'
- Pointing – using fingers, whole hand or eye-pointing
- Crying and other vocal noises

■ On-body signing

Website: <https://bit.ly/2Gdbf6k> is mainly used for children and adults with little or no sight. It is a tactile communication, using hands, fingers, chin, mouth, etc. An example of on-body signing is the.....

■ Canaan Barrie technique

Website: www.ssc.education.ed.ac.uk/canaanbarrie/ which signs involve touching on the body or hands. The Canaan Barrie technique was developed by a teacher at a school for the blind over 25 years ago.

“ We use the Canaan Barrie system. So for goodnight - running our hand over his face as if closing his eyes, hello - shake his hand and finished tapping hands together and then spreading them out to indicate the item has gone. We combine this with objects of reference for other things like shake keys for going out, nappy for nappy change, etc.”

“ A lot of the Canaan Barrie signs are adapted for the individual's mobility and understanding. For G we learn a few signs at a time. For her milk she taps her mouth (to teach her this we used to put her hand to her mouth before feeding her; she will now do this herself. She will also tap her leg (or tray if she's sitting in her chair) for more; again this was taught by first us doing it, using her hands -bubbles was what motivated her to do it the first time. She banged on that tray until she got more. It was a massive breakthrough for us. She's recently learnt happy, she does this by rubbing her chest, she will do this sign for when she wants us to sign 'happy and you know it'. Sometimes she will lose the ability to sign and we have to start the process again but it's lovely when she's doing it. Not all the signs have worked for her, it's a real trial and error.”

Technology

In these modern days of assistive technology there is a huge variety of communication products available, they come in all shapes and sizes and the costs vary greatly from a few pounds up to several thousand pounds. The types of technology available include switches to operate toys and everyday objects i.e. a food blender. Speech output devices are a way of communicating automated speech by pressing buttons with fingers or by mouth operated tools or eye movements. Communication Software is a range of disks that you put into a computer; it allows you to print signs and pictures. Touch screen computers, allow you to touch the screen with your fingers or a tool to communicate. The list below gives you an idea of some of the technology available:

■ **Light Tech** e.g. Big Mack, Talking Buddy

Buttons, Step-by-step communicators

■ **Mini speech output** e.g. Allora, adVOCate, GoTalk, LEO, PortaCom, VocaFlex

■ **Speech output** e.g. Dynamo, DynaVox V/V

Max, DynaWrite, Eco-14, FuturePad, LEO, Lightwriter, Say-it Sam, SM1, MightyMo, MiniMo, Motion Tablet, Pathfinder, Springboard, Tellus 3 & Mobi, Vanguard, Vantage



■ **Communication software** e.g. Boardmaker, Communicate series, Day Planner, Eurovocs suite, EZ Keys, Grid & Grid Mobile, Memory Message, Mind Express, PCS & Widgit symbol libraries

■ **Vocabularies** e.g. CALLtalk, ExpressTalk, Ingfield Express, Picture Wordpower, Wordpower

■ **Eye Gaze** e.g. My Tobii, Other devices e.g. environmental controllers, switches, amplifiers

■ **Touch screen** e.g. Computers, ipod touch, ipad, kindle fire, Samsung and other tablets.

Communication aid suppliers

■ Website: <http://uk.dynavoxtech.com>

■ Website: www.inclusive.co.uk

■ Website: www.liberator.co.uk

■ Website: www.logan-technologies.co.uk

■ Website: www.ability-world.com

Specific Funding for communication aids

■ **The Sequal Trust** Website: www.thesequaltrust.org.uk

Telephone: 01691 624 222 Email: info@thesequaltrust.org.uk

The Sequal Trust provides relief to children and adults who are severely disabled and depend on electronic communication aids and adaptations.

Apps.

Many people and schools are using devices such as the iPad and other tablets, to help with communication and learning. There are many apps available, some of which are either free or less than £5. Gift vouchers to buy apps can be purchased easily in many shops and supermarkets. So this can make a great gift for a person with a learning disability.

■ Flash card apps

Website: <http://a4cwsn.com/flash-cards/>

■ Proloquo2GoX

Website: www.assistiveware.com/product/Proloquo2Go
Proloquo2Go™ is an Augmentative and Alternative Communication (AAC) solution for iPad, iPhone and iPod touch for people who have difficulty speaking or cannot speak at all. This app. is quite expensive but users report it to be very good.



“My son loves his iPad - he finds it easy to use.”



Useful organisations and online resources

■ Afasic

Website: www.afasicengland.org.uk

Parents' Helpline: 0300 666 9410 during opening hours – Monday &

Wednesday: 10.30am to 4.00pm. Email: info@afasic.org.uk

Afasic seeks to raise awareness and to create better services and provision for children and young people with speech and language impairments.

■ British Stammering Association (BSA)

Website: www.stammering.org

Helpline: 020 8880 6590 Email: info@stammering.org

BSA is the national organisation for adults and children who stammer, run by people who stammer.

■ Communication Matters

Website: www.communicationmatters.org.uk

Telephone: 0845 456 8211

Communication Matters is the UK Chapter of the International Society for Augmentative and Alternative Communication (ISAAC) which focuses on the needs of people with complex communication needs who may benefit from AAC systems to maximise their opportunities and enhance their life. Augmentative and alternative communication (AAC) systems includes eye pointing, gesture, signing, using symbol/word boards, and electronic speech devices.

■ The Communication Trust

Website: www.thecommunicationtrust.org.uk

The purpose of The Communication Trust is to highlight the importance of speech, language and communication across the children's workforce and to enable practitioners to access the best training and expertise to support the communication needs of all children.

■ The CReSTeD Register

Website: www.crested.org.uk/about.html

Email: crested.admin@crested.org.uk

Helping parents and those who advise them to choose schools for children with Specific Learning Difficulties (SpLD). i.e Dyslexia and Dyspraxia etc.

■ Cued Speech Association

Website: www.cuedspeech.org.uk

Cued Speech Association UK provides information about and training in Cued Speech, a simple system which uses eight handshapes in four positions around the mouth, together with the lipshapes of normal speech, to totally clarify lipreading for deaf babies, children and adults.

■ **The British Dyslexia Association**

Website: www.bdadyslexia.org.uk/parent

Helpline: 0333 405 4567

■ **Dyspraxia foundation** Website: www.dyspraxiafoundation.org.uk

Helpline: 01462 454 986

The Dyspraxia Foundation was founded by two mothers who after being told that their children had Dyspraxia were astonished to discover that no facilities existed to help parents and children with the condition.

■ **Find A Voice** Website: www.findavoice.org.uk

Telephone: 01233-640443 Email: speak@findavoice.org.uk

Supporting people of all ages who have severe speech, language and communication needs by providing access to life enhancing advice, equipment and training

■ **The Hanen Centre** Website: www.hanen.org

Early language intervention for children with language delays. Hanen has developed several research-based programs and resources specifically for parents of children from birth to five years of age to show them how they can make the most of every interaction they share with their child. Workshops, books and DVD resources are available.

■ **ICAN** Website: www.ican.org.uk

Helpline: 020 7843 2544 Email: info@ican.org.uk

UK charity that helps children with speech and language difficulties throughout the UK

■ **Intensive Interaction** Website: www.intensiveinteraction.co.uk/about/

Intensive interaction is an approach to teaching the pre-speech fundamentals of communication to children and adults who have severe learning difficulties and/or autism and who are still at an early stage of communication development.

■ **Mencap** Website: www.mencap.org.uk

Telephone: 0808 808 1111

The learning disability charity has many resources on communication issues.

■ **Murdoch Institute (USA)**

Website: <https://www.geneticsofspeech.org.au/resources/>

■ **Oxfordshire Total Communication** Website: www.oxtc.co.uk

Telephone: 01865 228041 Email: total.communication@oxfordhealth.nhs.uk

Resources and training.

■ **TACPAC** Website: www.tacpac.co.uk

Telephone: 01865-772213 Email: info@tacpac.co.uk

Tacpac is a sensory communication resource using touch and music to help communication and social skills

■ **Talking Point** Website: www.talkingpoint.org.uk

An information resource for parents and professionals, focusing on speech, language, and communication difficulties in children

■ **Total Communication** Website: www.totalcommunication.org.uk/

Lots of useful resources, including videos of signed nursery rhymes

■ **Us in a Bus** Website: www.usinabus.org.uk

Telephone: 01737 764774 Email: info@usinabus.org.uk

Us in a Bus is an independent organisation that enables adults with profound learning disabilities and/or complex needs to connect with others through interaction, play and self-expression.

Theatre

Drama companies such as:

■ **Oily Cart** Website: www.oilycart.org.uk

Telephone: 020 8672 6329

■ **Heart & Soul** Website: www.heartnsoul.co.uk

Telephone: 020 8694 1632

(who both visit schools)

■ **Bamboozle** Website: www.bamboozletheatre.co.uk

Telephone: 0116 255 2065

■ **Chicken Shed** Website: www.chickenshed.org.uk

Telephone: 020 8292 9222

All of the above are theatrical production companies that communicate from and to all, using all means available.



Personal Passports or Portfolios

There are a variety of templates available on the internet to create a personal communication passport for your child. Examples can be found at:

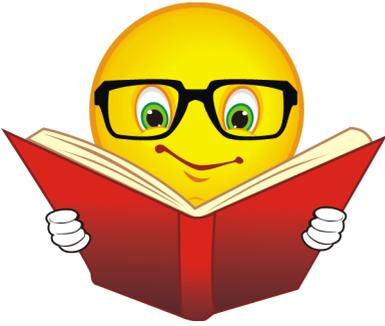
Website: www.communicationpassports.org.uk

Many hospitals now use passports especially for adults with learning difficulties who cannot communicate their needs easily. You can download one from

■ **Easy Health** Website: <https://bit.ly/2Gd4Pny>

Some hospitals have a learning disability liaison nurse. This service is currently only available to people with learning difficulties, who are aged 16 and over.





Books

There are lots of resources on the internet to help families whose children have a rare chromosome or gene disorder. There are many different ways of helping your child to communicate. Another idea that many of our families have used successfully is using social stories.

What is a social story?

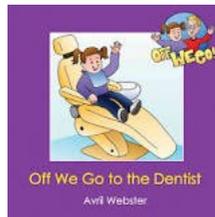
Social Stories are a concept devised by Carol Gray in 1991 to improve the social skills of people with autism spectrum disorders (ASD). Social stories are used to educate and reward children's efforts. Social stories model appropriate social interaction by describing a situation with relevant social cues, other's perspectives, and a suggested appropriate response. Taking the form of short narratives, the stories take children step-by-step through basic activities such as brushing your teeth, taking a bath and wearing a safety belt in the car. Books are available from Amazon, kindle and from other booksellers.

There are also sensory stories, similar to social stories and great for children with Profound and Multiple Learning Difficulties (PMLD). One of our Unique mums has successfully written the

■ **Off We Go!** Series of books by Avril Webster

- ⇒ which includes the following titles:
- ⇒ Going to a Birthday Party
- ⇒ Going to the Cinema
- ⇒ Going to Buy Clothes
- ⇒ Going to the Dentist
- ⇒ Going to the Doctor
- ⇒ Going to the Hairdresser
- ⇒ Going to the Optician
- ⇒ Going to the Restaurant
- ⇒ Going to Buy Shoes
- ⇒ Going to the Supermarket
- ⇒ Going Swimming

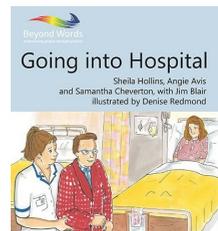
All available from Amazon Website: <https://amzn.to/2GiWxGA>



■ **Books beyond words**

Website: <https://booksbeyondwords.co.uk/>

Books beyond words are a series of picture books with no words at all, and designed particularly for adults with learning difficulties.



There are websites that give you templates to help you to make your own sensory stories for your child or you can make your own, using scrapbooks

■ **Twinkl** Website: <https://bit.ly/2Gyik0A>

Design your own sensory story. Lots of other SEN resources available to download from the website.

■ **Bag books** Website: www.bagbooks.org/

Telephone: 020 7627 0444 Email: office@bagbooks.org

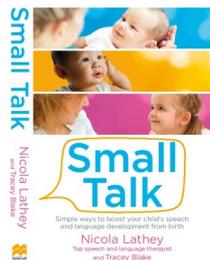
For children with a rare chromosome disorder who also have severe to profound learning difficulties. Multi-sensory books offer accessible stories for those who cannot benefit from mainstream books. They are told interactively, through actions and emotions rather than words and pictures, so they are perfect for anyone with severe learning difficulties (SLD), profound and multiple learning difficulties (PMLD) and those on the autistic spectrum (ASD).

■ **Small Talk**

Website: www.smalltalktime.com

Email: Nicola@smalltalktime.com

A book written by Nicola Lathey, a Speech and Language Therapist which explains in intricate detail, the development of speech and Language skills between the ages of Birth to 4 years. It also has a chapter on weaning and covers others issues such as dummies, bilingualism, glue ear and tongue tie.



■ **Speech Teach UK**

Website: www.speechteach.co.uk

Free Speech and Language Therapy Resources for Parents and Teachers.



Inform Network Support



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. rarechromo.org
Please help us to help you!

Our thanks to our parents for their contributions towards this guide.

This guide was compiled by Unique and reviewed by Nicola Lathey, Speech and language therapist, author of Small Talk and director of the Owl Therapy Centre, Oxford.

Version 2 (MM)

Copyright © Unique 2018

Rare Chromosome Disorder Support Group Charity Number 1110661
Registered in England and Wales Company Number 5460413