

Paediatric Occupational Therapy

Advice sheet for parents/carers and education staff regarding Down Syndrome

What is Down Syndrome?

A congenital disorder arising from a chromosome defect, causing intellectual impairment and physical abnormalities including short stature and a broad facial profile. It arises from a defect involving chromosome 21, usually an extra copy (trisomy-21).

What Causes Down Syndrome?

Down Syndrome is usually caused by an extra chromosome in a baby's cells. In most cases, Down Syndrome is not inherited – it is simply a one-off genetic change in the sperm or egg cell.

Types of Down Syndrome

There are 3 types of Down syndrome.:

- Trisomy 21 - 3 copies of chromosome 21 in all of the cells in the body
- Translocation – Part of chromosome 21 attached to one of the other chromosomes in the body.
- Mosaicism - Only some cells have an extra copy of chromosome 21

The following characteristics of Down Syndrome influence the development of functional skills:

- Low muscle tone
- Relatively short limbs, including hands, fingers, and thumbs
- Mild to moderate intellectual disability
- Developmental delays

Main areas of difficulty:

- Fine motor skills and play
- Gross motor skills
- Self-care
- Dressing
- Sensory processing
- School tasks e.g. handwriting, scissors skills

Developmental Milestones for Down Syndrome:

There is no such thing as a typical child who has Down syndrome. Children who have Down Syndrome are as different from each other as are all children. However, their development is generally slower than most children. The chart below gives the usual

developmental progress of children who have Down syndrome. All children progress at different rates and these milestones are given as a guide.

This information has been collated using a range of resources, including: Fine motor and self-care milestones for individuals with Down syndrome using a Retrospective Chart Review (<https://doi.org/10.1111/jir.12176>), <https://www.healthforallchildren.com/wp-content/uploads/2020/02/A5-Downs-charts.pdf>

	Motor Milestone	Age Range
Fine motor:	Raking grasp	9 – 12 months
	Transfers objects between hands	12 – 18 months
	Pincer grasp	22 months – 5 ½ years
	Intentional release of objects	22 – 36 months
	Threading beads	6 years – 12 years
Pencil skills:	Holds crayon and scribbles	22 – 36 months
	Traces pre-writing shapes	5 years – 10 years
Scissors:	Snipping paper	5 years – 8 years
	Cutting a straight line	7 years – 12 years
Mealtimes:	Hold bottle independently	16 months – 2 ½ years
	Finger feeding	20 – 28 months
	Feeds with spoon	3 ½ years – 6 years
	Drinks from cup	12 – 39 months
	Feeds with fork	5 ½ years – 7 ½ years
Dressing:	Undressing	29 months – 6 years
	Dressing	3 ½ years – 8 ½ years
Toileting:	Bladder control	20 months – 7 years
	Bowel control	28 months – 7 ½ years

General strategies I can use to support my child:

- **Have realistic Expectations:** Know what stage your child is working at, and what comes next within their development. You will know whether the activity is either too challenging, physically or intellectually, or isn't challenge enough by the child's responses. Remember persisting with skills that are beyond your child's current developmental readiness will result in frustration for you and your child.
- **Build on Success:** Use activities that you know your child has had success with. Build on that success by adding difficulty to an already accomplished task. Remember success and accomplishment are motivating to children, therefore your child will continue to want to engage in learning.
- **Break down Activities into small steps:** Grading (breaking down tasks) is a method of modifying how an activity is performed to make it more manageable or achievable. These strategies are important for all children but especially for those who are experiencing difficulties in the development of their skills.

- **Make it fun!:** The more exciting an activity is the more likely your child will be motivated to engage and participate. Be aware of your voice and body language as these are powerful tools to initiate tasks with your child.
- **Be aware of the environment:** Learning new skills requires attention and focus. Be aware of distractions that may interfere with your child's attempts at an activity. Think about physical space, hunger, time of day, interruptions, background noise and lighting. These can all impact upon skill acquisition.
- **Try out different activities:** If an activity is not successful the first time, try again using a different method. For example there are many ways to develop mark making, instead of using a pen and pencil why not try messy play and remember to do this in different environments so your child can generalise their skills.
- **Repetition:** Children with Down Syndrome tend to need more repetition to learn new skills.
- **Copying:** Children with Down Syndrome tend to be visual learners and learn from copying what you do. Take your cue from the child and imitate simple actions and sounds such as blowing raspberries, making funny faces, mouthing 'oooooh' or sticking out tongues. Play games such as peek-a-boo, looking in a mirror and making faces and noises and encourage copying. Show your child how to do an activity and then use the hand over hand method and say the action as it takes place. For instance, guide the child's hand to build a tower of bricks and say, "pick up the brick" followed by, "put it on top". Reduce support and guide from the forearm and then the elbow.

Activity ideas:

- **Exploring objects:**
 - Provide toys that are large and easy to handle to begin with, then gradually reduce the size.
 - Provide a wide variety of toys and other objects that have many different properties, for instance, textures, shapes, colour, and those that make a variety of sounds.
 - Use kitchen utensils, fabrics and containers filled with different materials such as liquids, powders, sand, or coloured beads.
 - Provide percussion instruments, drums and home-made rattles made from clear and opaque containers filled with a variety of materials such as rice, dried peas marbles and coins.
- **Object permanence:**
 - Play games such as peek-a-boo and hide and seek.
 - Hide toys and objects partially, then fully, then reveal. Follow this by encouraging the child to hide objects and involve peers in finding them.
 - Hide objects under clear pots first, then under opaque ones.
 - Roll cars and marbles. through tunnels or down tubes and play at crawling through tunnels, disappearing from view and reappearing at the other end.
- **Cause and Effect:**
 - Provide a wide variety of experiences of different objects and toys with various effects.
 - Ensure the toys and objects respond easily to a light touch.
 - Use books with lift-up flaps or windows to peek through.
 - Introduce toys that pop up, have push or slide buttons that light up and make interesting sounds.

- Create opportunities to drop objects into different containers or onto a hard surface such as a tray so that it makes a rewarding noise.
 - Make use of simple computer games or apps with easy point and click activities.
- **Mark-Making:**
- Use a multisensory approach:
 - Try making patterns using paint, chalk, etch-sketch/white board, shaving foam, rice, sand, play dough etc. Ask your child to imitate your shapes using his/her index finger or a long stick.
 - Try 'writing' on aluminium foil, construction paper of different colours, different kinds of paper, standard paper or colouring books.
 - Use special colouring books in which the colour appears when children paint with water.
 - Try drawing with scented markers.
 - Add a few drops of bubble bath or scented oil to finger-paint.
 - Use a musical or electric toothbrush to paint.
 - Attach bells to the end of a paintbrush.
 - Try finger painting in whipping cream on a flat pan of jelly.
 - Try drawing on a frosted cake to decorate it.
 - Allow the child to explore different drawing and painting tools such as wax crayons, coloured chinks, pastels, felt pens, dry wipe pens, paint brushes and soft 'B' pencils.
 - Provide lots of activities involving random scribbling beginning with A2 paper or bigger. Gradually develop control by reducing the size of the paper and increasing the level of accuracy, for example, from A3 – A4 – A5 - 10 cm and lastly 5cm squares.
 - Using water and paintbrushes paint lines and shapes on the pavement for your child to copy.
- **Fine motor skills:**
- Construction Toys: Lego, Duplo, Octons etc.
 - Puzzles, Inset Puzzles.
 - Posting toys.
 - Threading.
 - Play dough, space putty, plasticine.
 - Tweezer games: operation, feed the animals, avalanche fruit salad, bed bugs, crocodile teeth, using tweezers to sort objects / balls into colours, number, containers.
 - Sticker books.

For more ideas, please see the following leaflets on our website:

www.cambscommunityservices.nhs.uk/BedsandLutonOT

In the 'Additional Information' section at the bottom of the page:

- Fine Motor skills
- Hand writing skills
- Developing functional skills
- Dressing skills

In the 'Development of everyday skills' section on the left hand side of the page:

- Development of cutlery skills
- Development of pencil skills
- Development of scissor skills

