



Children with Down Syndrome

Information for Parents and
Caregivers, Benefits of
Physiotherapy

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What is Down Syndrome?

Down Syndrome, also known as Trisomy 21, is a genetic condition that results in the presence of an additional copy of chromosome 21.

Most children are born with 23 pairs of chromosomes and 46 individual chromosomes in total. In Down Syndrome, there are 47 chromosomes due to the extra copy at 21. (1)

This extra genetic material can cause children to develop differently than their peers and may impact their everyday life.

Each child with Down Syndrome will have different abilities. A child may experience difficulties with communication and physical impairments, and may struggle with vision and hearing loss. (1) Other physical and cognitive signs include:

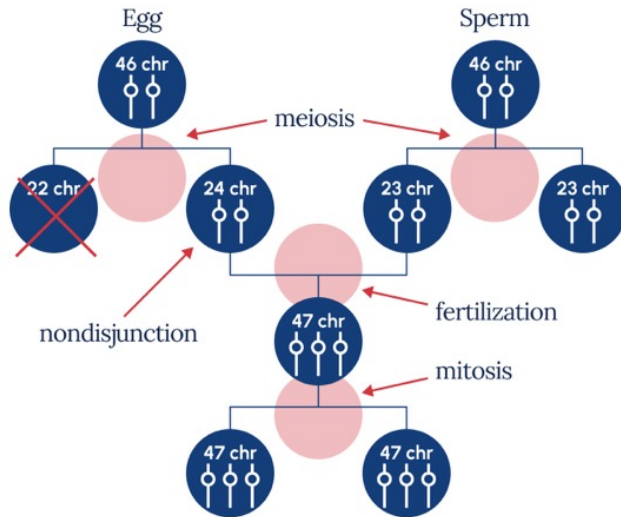
- Weakness and low tone
- Reduced mobility and functional ability
- Poor balance
- Shorter height
- Smaller facial features, hands and feet
- Sleep apnea
- Heart defects

The NHS provides guidance on how to care for a child with Down Syndrome.(2)
Please watch the video on the NHS for more information:
<https://www.nhs.uk/conditions/downs-syndrome/>

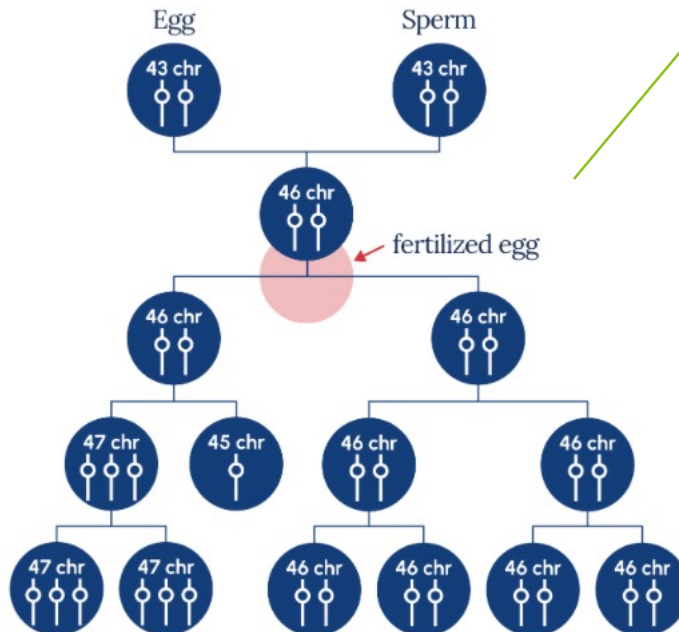


(3) National Down Syndrome Society (NDSS)

Types of Down Syndrome



(3) National Down Syndrome Society (NDSS)



▶ Trisomy 21 (Nondisjunction)

- ▶ 95% of all Down Syndrome cases
- ▶ Prior to or at conception, a pair of 21st chromosomes in either the sperm or the egg fails to separate.
- ▶ As the embryo develops, the extra chromosome is replicated in every cell of the body. (3)

▶ Mosaicism

- ▶ 2% of all Down Syndrome cases
- ▶ Diagnosed when there is a mixture of two types of cells, some containing the usual 46 chromosomes and some containing 47. (3)

Translocation

- ▶ 3% of all Down Syndrome cases
- ▶ Total number of chromosomes in the cells remains 46; however, an additional full or partial copy of chromosome 21 attaches to another chromosome, usually chromosome 14. (3)

Risk Factors

- ▶ The incidence of births of children with Down Syndrome increases with the age of the mother. (5)
- ▶ However, due to higher fertility rates in younger women, the probability of having a child with Down Syndrome increases with the age of the mother and more than 80% of children with Down Syndrome are born to women under 35 years of age. (5)

- ▶ The chances of having a child with Down Syndrome increase with maternal age, as seen on the right.
- ▶ Testing for Down Syndrome can be done prenatally and at birth.
 - ▶ Screening tests are done through ultrasound or a blood test.
 - ▶ Diagnostic tests are done through amniocentesis and chorionic villus sampling (CVS)
- ▶ Speak to your doctor if you suspect that your child may have the characteristics of Down Syndrome.

Maternal Age	Incidence of Down syndrome
20	1 in 2,000
21	1 in 1,700
22	1 in 1,500
23	1 in 1,400
24	1 in 1,300
25	1 in 1,200
26	1 in 1,100
27	1 in 1,050
28	1 in 1,000
29	1 in 950

(3) National Down Syndrome Society (NDSS)

Physiotherapy Treatment of Down Syndrome in Children

- ▶ Treatment should include:
 - ▶ Improving low tone, strength, promoting postural alignment, development of motor skills, balance and sensory processing
- ▶ Guidelines exist for the best practice with children with Down Syndrome for physiotherapists and all healthcare professionals. Three are listed below:
 - ▶ (7) Health Assessment of Children and Young People with Down Syndrome (Specialist Children's Services, NHS)
 - ▶ (8) Learning Disability: Care and support of people growing older (NICE Guidelines)
 - ▶ (9) Down's Syndrome Association

▶ Treatment Methods:

- ▶ “A combination of sensory integration therapy, neurodevelopment treatment, perceptual-motor therapy and traditional strength and conditioning programmes.” (9)
- ▶ Examples include...
 - ▶ Neurodevelopmental Treatment
 - ▶ Sensory training
 - ▶ Perceptual-motor therapy
 - ▶ Balance and gait training
 - ▶ Physical activity and strength training
 - ▶ Hydrotherapy
 - ▶ Treadmill or bicycle training
 - ▶ Gym ball therapy
 - ▶ Play!

Developmental Milestones

- ▶ Because children with Down Syndrome experience issues with communication and motor skills, it is common for them to experience delays in their developmental milestones.
- ▶ This is often due to poor balance, low tone, ligament laxity, poor postural control, smaller brain size and slow reaction time.
- ▶ The greater multidisciplinary team will be involved to help progress developmental milestones (pediatricians, nurses, audiologists, ophthalmologists, psychologists and physiotherapists).

Milestone	Range for Children with Down Syndrome	Typical Range
GROSS MOTOR		
Sits Alone	6 - 30 Months	5 - 9 Months
Crawls	8 - 22 Months	6 - 12 Months
Stands	1 - 3.25 Years	8 - 17 Months
Walks Alone	1 - 4 Years	9 - 18 Months
LANGUAGE		
First Word	1 - 4 Years	1 - 3 Years
Two-Word Phrases	2 - 7.5 Years	15 - 32 Months
SOCIAL/SELF-HELP		
Responsive Smile	1.5 - 5 Months	1 - 3 Months
Finger Feeds	10 - 24 Months	7 - 14 Months
Drinks From Cup Unassisted	12 - 32 Months	9 - 17 Months
Uses Spoon	13 - 39 Months	12 - 20 Months
Bowel Control	2 - 7 Years	16 - 42 Months
Dresses Self Unassisted	3.5 - 8.5 Years	3.25 - 5 Years

(6) Developmental Milestone Range for Children with Down Syndrome

Communication

- ▶ Children with Down Syndrome may experience cognitive and physical symptoms that limit communication. (4)
 - ▶ These symptoms include changes in:
 - ▶ Gross and fine motor skills
 - ▶ Language development skills
 - ▶ Learning and cognition
 - ▶ Play (social and emotional skills)
 - ▶ A speech and language pathologist should help develop communication skills with children with Down Syndrome.
- ▶ Communicating with Children with Down Syndrome (2)
 - ▶ Use praise when they learn something new
 - ▶ Speak clearly and calmly
 - ▶ Play, sing songs and read books to help with sounds and words
 - ▶ Provide demonstrations with instructions
 - ▶ Find new ways to help them communicate

Down Syndrome International



**International Guidelines for
the Education of Learners
with Down Syndrome**



Education

For children with Down Syndrome, educational adaptations should be in place to enhance the child's learning in school.

Down Syndrome International (DSi) provides guidelines for educators of children with Down Syndrome to facilitate learning in schools and how to account for all of their needs.

The link to this document can be found below.

<https://workdrive.zohoexternal.com/external/8CkAlci1QBB-Jxfap>

Living with Down Syndrome

- ▶ Please watch the videos below to better understand the lifestyle of a family with a child with Down Syndrome, and how it can impact Activities of Daily Living (ADLs).



Parent, Care-giver and Public Top Tips

DO...

- ▶ Remember that each child is an individual and has their own likes and dislikes (2)
- ▶ Remember Down syndrome is a condition or a syndrome, not a disease (3)
- ▶ Set routines so they feel settled (2)
- ▶ Encourage them to be healthy and active (2)
- ▶ Watch for changes in mood and behaviour as they may not be able to communicate their feelings (2)
- ▶ Take them from regular hearing, eyesight and health checks (2)

DON'T...

- ▶ Talk down to someone with Down Syndrome, as they should be treated like their age (2)
- ▶ Only talk to parents and caregivers- speak directly to the person with Down Syndrome (2)
- ▶ Use outdated or offensive language when speaking to someone with Down Syndrome (2)
- ▶ Use the term “normal”, the term “typical” is more polite (3)
- ▶ Use any derogatory terms to describe a child who has Down Syndrome! (3)

Funding for Children with Down Syndrome

▶ Down's Syndrome Association

- ▶ For people with Down Syndrome, their parents and caregivers
- ▶ Phone: 03331212300
- ▶ Website: <https://www.downs-syndrome.org.uk/>
- ▶ Email: info@downs-syndrome.org.uk

▶ Mencap

- ▶ For people with learning disabilities and their families
- ▶ Phone: 08088081111
- ▶ Website: <https://www.mencap.org.uk/>
- ▶ Email: helpline@mencap.org.uk

▶ Down Syndrome UK

- ▶ Empowers parents and professionals for the care of people with Down Syndrome
- ▶ Phone: 03301112121
- ▶ Website: <https://downsyndromeuk.co.uk>
- ▶ Email: <https://downsyndromeuk.co.uk/about-dsuk/contact-us/>

▶ Down Syndrome Development Trust

- ▶ Delivers support services and interventions to improve the lives of people with Down Syndrome
- ▶ Phone: 01323893323, 07897373839
- ▶ Website: <https://downsyndromedevelopment.org.uk/#/events>
- ▶ Email: hello@downsyndromedevelopment.org.uk

References

- ▶ 1. Centers for Disease Control and Prevention: <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome.html#:~:text=What%20is%20Down%20Syndrome%3F,during%20pregnancy%20and%20after%20birth>
- ▶ 2. NHS: <https://www.nhs.uk/conditions/downs-syndrome/>
- ▶ 3. National Down Syndrome Society: <https://ndss.org/about>
- ▶ 4. Cleveland Clinic: <https://my.clevelandclinic.org/health/diseases/17818-down-syndrome>
- ▶ 5. Kazemi, M., Salehi, M. and Kheirollahi, M. (2016) Down Syndrome: Current Status, Challenges, and Future Perspective. Int J Moll Cell Med, 5:3, pgs. 125-133. Found at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5125364/>
- ▶ 6. Kim, H. et al. (2017) Motor and Cognitive Developmental Profiles in Children with Down Syndrome. Ann Rehabil Med, 41:1, pgs. 97-103. Found at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5344833/>
- ▶ 7. Specialist Children's Service Guidelines: <https://www.clinicalguidelines.scot.nhs.uk/media/3314/guidance-for-the-assessment-of-cyp-with-downs-syndrome-reviewed-jan-2022-1.pdf>
- ▶ 8. NICE Guidelines on Learning disability: Care and support of people growing older: https://www.nice.org.uk/guidance/qs187?_ga=2.70194448.185602388.1686571362-484693031.1686571362
- ▶ 9. Down's Syndrome Association: <https://www.downs-syndrome.org.uk/about-downs-syndrome/>