



# The Association of Paediatric Chartered Physiotherapists

## **APCP Information - Your Baby with Down Syndrome** Information for Parents and Carers

Down syndrome (DS) is caused by the presence of an extra chromosome in a baby's cells and affects 1 in every 1000 births. Children with Down syndrome will have a delay in their motor development but they will reach their motor milestones, just more slowly than other children. They will also have a learning disability which affects their ability to learn, but it does not mean they cannot learn.

### **The facts**

- 85% of babies with DS will sit by 10 months, on average typical infants sit by 7 months.
- Only 13% of babies with DS crawl by 12 months, 88% of typical infants crawl by 10 months, (Pereira et al, 2013).

In a study of 1500 in the BORN TO MOVE PROJECT by Kent Health Visitors (Community Practitioner, August 2016), implementing tummy time from birth resulted in increased crawling from 30% at start of study to 94% of babies in their first year. This also resulted in better speech, behaviour, learning and fine/gross motor skills at age 5.

**Hypotonia** – children with DS have low muscle tone, also known as hypotonia (floppiness). This affects each child with DS differently – some children are affected very mildly, whereas in others it can be far more noticeable.

**Increased flexibility of joints (hypermobility)** – in children with DS the ligaments that hold the bones together can be more lax than usual.

**Decreased strength** – children with DS have decreased strength in their muscles, but this can be improved through repetition and practice.

**Short arms and legs** – children with DS have shorter arms and legs in relation to the length of their trunks. This can make sitting more challenging as they are unable to prop as easily and have further to go when falling before they can save themselves.

**Medical issues** – these can affect the child's ability to engage in gross motor activities. Issues can include heart problems, stomach issues, chronic upper respiratory infections and ear infections. They can lead to fatigue and decreased stamina.

### What can I do to help?

**Low muscle tone:** Infants with DS are prone to low tone, hypermobility and Frog Leg Posture! If your baby continues to lie with their arms and legs splayed out when they are on their back, they may find it difficult to bring their hands up to explore their face or keep their hands together above their chest. To help them, when you hold them ensure their legs and arms are tucked in towards the midline as much as possible.

**Lying on your lap:** Bend your knees up and rest your baby in your lap, with their bent legs resting on your tummy. This position encourages them to be curled up and supports their head in the middle. Talking to your baby will stimulate them to look at you. Cup your hands behind their shoulders to help them bring their hands together, so they can see their hands and start to take them to their face. Practice clapping hands and any games to bring hands and feet towards the middle.

Bringing arms and legs to cross the middle is essential for lots of motor activities and promotes good alignment and balance.

**Tummy time:** Tummy time is really important for children with DS and should be started as soon as possible. Early tummy time will improve gross and fine motor skills and facilitate crawling. Encourage your baby to lift its head and prop through its arms. A good way to introduce tummy time is when you are reclined in a chair and they are lying on their tummy on your chest. By bringing their elbows forward under their shoulders and supporting around the chest they will be able to lift their head up whilst keeping their arms forward. Adapt the amount of assistance you provide as they gain head control.

Practice makes perfect when learning a new skill. It is thought that children with DS require lots of repetition and encouragement at practicing a task before it is mastered, far more so than their peers. Many children can achieve a high level of motor skills if given the opportunity. This is often best achieved through play activities. Typically children with DS learn best visually, or by watching others. Rather than just verbally encouraging your child, show them what you want them to do.

Massage and sensory stimulation has been shown to help hypotonia (Paleg et al. 2018)



## References/recommended reading

Down's Syndrome. The Essential Guide. Antonia Chitty and Victoria Dawson ISBN: 9-781861-440839  
Need-2 Know series . Reviewed in the APCP journal (Volume 2 Number 2 May 2011)

Children with Down Syndrome A Guide For Parents and Professionals. Patricia C Winders. P.T. Wood-  
bine House 1997 ISBN: 0-933149-81-6

Down's Syndrome Association- [www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk)

Down's Syndrome Scotland- [www.dsscotland.org.uk](http://www.dsscotland.org.uk)

Down Syndrome Education International– [www.dseinternational.org](http://www.dseinternational.org)

This leaflet has been produced following a review of relevant literature and where there is lack of evidence, a consensus of expert opinion is agreed, correct at time of publication.

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