



# The Lived Experience: Physiotherapy and your baby with Down syndrome

[www.downsyndromeuk.co.uk](http://www.downsyndromeuk.co.uk)

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**At Down Syndrome UK, we work hard to ensure expectant and new parents have access to accurate, relevant information to support their baby's development and well-being. This document has been prepared to encourage and support parents with some early physiotherapy activities that can be implemented from birth, that will help baby's development.**

**We value the importance of early physiotherapy input for our babies and strongly advocate Tummy Time, starting from in the Delivery Room if possible!**



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## Importance of Tummy Time

### Why is it so important and why start immediately after birth?

Tummy time helps to:

- **STRENGTHEN** your baby's back and neck muscles in preparation for crawling.
- **ENCOURAGE** your baby to learn to roll which helps to develop balance and to learn how big they are in relation to their surroundings (spatial awareness)
- **DEVELOP** the brain and strengthen link between the right and left sides (60% of brain development happens in the first year of life). Tummy time is important for this.
- **ENCOURAGE** crawling. Babies spending more time on their tummies are more likely to be crawling by 10-12 months old.
- **PREVENT** a condition called Plagiocephaly - a flattening of one side of the skull which can develop if babies spend too much time on their back.

Babies with Down syndrome tend to have low tone so they need to experience antigravity and extension positions to stimulate movement and strength.



## Frequency

### How long should I aim for each day?

A study by Erin Wentz in 2017 revealed that if tummy time was initiated shortly after birth and before 11 weeks it reduced motor delay in babies with Down syndrome. The study recommended that baby has at least 90 minutes per day. The study found that all infants with Down syndrome achieved pincer grip, unilateral reaching, block stacking, sitting to play with toys, 4-point crawling, standing and walking alone significantly earlier than infants not engaging in Tummy Time.

## Early Weeks

### Tummy time positions for first 3 months

A good way to introduce Tummy Time is when you are reclined in a chair and baby is 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 baby gains head control.



**New babies don't do their tummy time on the floor; they get extra cuddles = Tummy Time!**



**Forearm carrying = Tummy Time**



**Baby burp position = Tummy Time**

**Everyone can enjoy Tummy Time - great opportunity for bonding and talking to your baby.**



**Tummy Time can be enjoyed  
anywhere and everywhere!**



**Changing Mat = Tummy Time Use Toys/cot mobile to stimulate your baby**



**Even if baby is in hospital you  
can still do Tummy Time.**



## Free play

As with everything in life, anything in excess isn't advised. This is the same with Tummy Time. As well as Tummy Time, awake time should be spent allowing your baby to move and explore and learning body awareness through free play on their back and supported side lying. Free play is essential on the floor lying on the back. Ensure stimulation to encourage reaching, kicking and turning head. Babies will begin to find their feet with your help. Engage your baby on the floor by using toys, mirrors, you!





## Side Lying

This can be carried out on your lap or on the floor – with support and supervision. Gravity will help bring both of baby's arms and legs together. They will be able to watch their hands easily in this position. A rolled towel positioned behind baby may be required to stop them rolling backwards and give them added support if they are on the floor. Placing a toy in front of them will give them something to look at and explore.

## Lap activities

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 and interact. 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. Allow your baby to experience gentle movement whilst feeling supported and secure by slowly moving them backwards and forwards. As their head control improves you can reduce the amount of support you offer.



## Common issues

Infants with Down syndrome are prone to low tone, hyper mobility and 'Frog Leg Posture'!

It is important that baby is checked by a qualified health care professional for hip dysplasia.

Assuming baby does not have hip dysplasia, if they 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. Bringing upper and lower limbs to cross the midline is essential later on for everyday living activities and promotes good alignment and balance.

To help them, swaddle them when asleep and handle them ensuring legs and arms are held towards the midline as much as possible.

Practice clapping hands and any games to bring hands and feet towards the midline. Whilst supervised, to help them you can

position a rolled-up towel around them, under their shoulders and around their thighs. This will support them in a curled-up position with their head in middle. As they get more active and stronger, they will need less support and will no longer require the rolled-up towel. You must not use any such supports while baby is sleeping.

Following the successful Back to sleep Campaign in 1996 to combat SIDS (Sudden infant death syndrome), new mums are not putting their babies on their tummy even when they are awake. This means that an infant may be asleep on their back for approximately 18 hours/day including naps. When awake they may be in a bouncer or being held. This can lead to Container Baby Syndrome which can limit and slow your baby's development.



# Container Baby Syndrome

## What is Container Baby Syndrome?

Container Baby Syndrome is when a baby is placed in a container for an excessive amount of time during the day.

This can lead to increased risk of:

- Head shape abnormalities and/or torticollis
- Developmental delay
- Difficulty with sensory processing
- Attention and/or social deficits
- Childhood obesity

## What is a container?

- A device intended to keep your baby in one spot
- A piece of equipment that may alter or delay development if overused
- A toy intended to entertain baby
- A piece of equipment that limits freedom of movement

## Examples

- **Bouncers • Swings • Infant Seats (Bumbos)**
- **Loungers • Rockers • Jumperoos • Baby walkers • Car seats**



## How can you prevent Container Syndrome?

- ✓ Limit the amount of baby containers you buy so that they are not as accessible.
- ✓ If you have a bouncer/walker limit to 15 minutes/day.
- ✓ If you bring baby in from the car remove from car seat immediately to reduce time spent.
- ✓ Ensure baby spends most of their awake time on their tummy, side play or free play on their back.



### Baby walker or Jumperoos

- Can encourage physical independence before cognitively ready
- Promotes jumping in children who structurally and developmentally shouldn't be jumping until c20 months old
- Can promote tip-toe walking
- Banned in some countries due to injuries • Links to delayed independent walking
- The design prevents visual access to the infant's moving limbs (Visual access to feet when standing is vital for spatial awareness and proprioception and helps with co-ordination and balance)
- Creates unnecessary stress on the hip joints, which can cause hip dislocation and leg alignment issues. This is because hips are immature, and joints are shallow prior to 7 months so excessive weightbearing is discouraged



### Push walker

- Allows for Baby to walk when they are ready
- Encourages upright posture
- Promotes typical walking and muscle activation
- Increases confidence with independent mobility

## Playtime ideas

### 3 words that are vital for your new baby... **STIMULATION, STIMULATION, STIMULATION!**

Your baby will benefit from all sorts of sensory stimulation in the early few months.

Sense of:

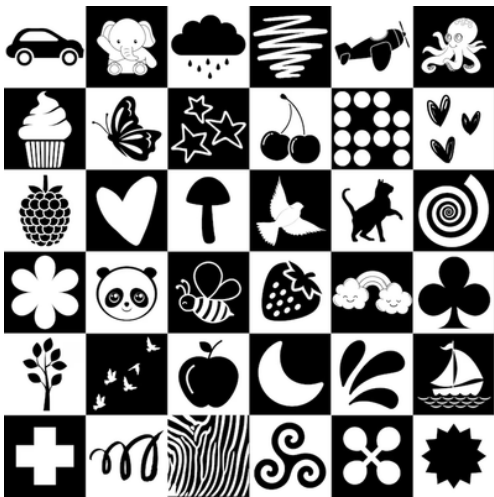
- **Touch** – tactile, light and deep pressure, tickles and massage. Give particular attention to baby's hands and feet to gradually integrate the grasp and plantar reflex.
- **Sight** – stimulate vision with black/white images initially and moving objects across their visual field to track and look at.
- **Hearing** – exposure to all sorts of noises from your own voice to music etc.
- **Proprioception** – knowing where they are in space and body awareness. Floor time, rocking and connections between right and left side reinforce this sense.
- **Vestibular** - the ability to balance and move in a controlled way. Rocking/rolling and changes of positions all help this sense develop.



Another Study of the Effect of Activation of preferred Stimulus on Tummy time Behaviour, found that it **increased head lift** in an infant with Down syndrome. (Boutot et al 2018.) In other words, find what interests or motivates your child and put it in front of them when on their tummy. Your voice or face is usually an excellent stimulus also. Or use a light up toy, baby mirror etc.



## Suggested toys for babies of 0-6 months



### Black & White baby book or pictures/cards

These visually stimulate and engage baby.



### Baby gym mat

Essential for floor time play.



### Baby mirror

The bigger the better! Mirror wall tiles placed above skirting level can be invaluable as baby grows.



### Emergency Foil Blanket

As well as being great for playing on, on back or tummy, a foil blanket is also good for sensory and fine motor skills.



### Baby grasp toys

Must be of size/weight to enable baby to grasp and soft if they drop them.



### Tummy time pillow

In the early days a small rolled up towel will do until baby is stronger.



### Tummy Time Water Mat

A new addition in the last couple of year by very useful.



### Light up wand

Great for encouraging baby and helping with visual tracking.

We always encourage supporting local businesses, but if you do order from Amazon please go via Amazon Smile and choose DSUK, a small percentage is donated to us – no cost to you!



## General advice

### Ways in which you can help

Practice makes perfect when learning a new skill. In general, children with Down syndrome require lots of repetition and encouragement at practising 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 Down syndrome 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 have been shown to help hypotonia (Paleg et al 2018).

Hand and Foot massage is really beneficial to integrate the infant grasp and plantar reflex and any form of touch or massage is useful to stimulate all your baby's senses.



### Play with your baby and talk directly face to face

Allow baby to experience changes of body position by playing 'aeroplanes' and giving baby up/down and rocking motion. This is particularly useful for the vestibular system and helps babies refine their balance reactions.





## The facts

- 85% of babies with Down syndrome will sit by 10 months, 100% of typically developing infants sit by 7 months (not such a dramatic difference).
- However only 13% of babies with Down syndrome crawl by 12 months in comparison to 88% of typically developing infants who achieve crawling by 10 months. (Pereira et al, 2013).
- The main things to work on are tummy time and crawling. These will then improve gross and fine motor skills.
- Achieving crawling has been shown to improve cognition, behavioural issues, spatial awareness, fine and gross motor skills.
- A study on infants who did and didn't crawl using virtual cliff edge technology, showed that the infant who crawled anticipated the cliff edge and had better spatial awareness.
- Learning to crawl is particularly important for a child with Down syndrome as it promotes stability in shoulders and the pelvis, it also releases the palmar reflex to enable fine motor skills and pencil grasp.
- Crawling stimulates both sides of the brain and strengthens the link between right and left through the corpus Callosum.
- In a study of 1,500 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, behavior, learning and fine/gross motor skills and School Readiness at age 5.

This information has kindly been compiled by **Donna Murphy** (Chartered Physiotherapist) of **Carn Physiotherapy**

## References

In a study by Tudelia et al 2011 they emphasized activities in the prone position at early stages for children with Down syndrome to help develop suitable toning.

In other words, find what interests or motivates your child and put it in front of them when on their tummy. Your voice or face is usually an excellent stimulus also. Or use a light up toy, baby mirror etc.

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