



Lived Experience Factsheet

Version 2.0

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Introduction

This factsheet has been written to summarise advice and suggestions from parents who have children with trisomies 13 and 18. The information has been collected from:

- Living with Trisomy stories (SOFT UK) - <https://www.soft.org.uk/living-with-trisomy>
- Trisomy Talks - <https://beverlyjacobson.com/page/trisomy-talks>
- Open-access blogs:
 - <https://melodysstory.com/>
 - <https://compatiblewithjoy-trisomy18.blogspot.com/>
 - <https://thativygirl.wordpress.com/>
- Other recommendations have been provided directly by the SOFT UK community. Thank you to all those who have shared their experiences and advice.

The suggestions included in this factsheet are not intended to replace any advice you have received from your child’s medical or social care team, nor do they represent recommendations from SOFT UK. Instead, they reflect the lived experience of families and are here to refer to when you feel you need some guidance or support. **Please discuss any information from this factsheet with your child’s medical team before making any changes to their care, to ensure that it is safe for your child.**

I have tried to keep this factsheet brief and easy-to-read. If you have any suggestions for improvements or other recommendations which you would like to be included in this factsheet, please let me know through the following link:
<https://forms.gle/LuLpvvSXyfMG13Le8>

Managing your child's care

Feeding

- If you are considering oral feeding, ask for a swallow study first to make sure this is safe for your child.
- If you think your child gets tired while eating orally, ask the professional who is doing the swallow study to turn off the fluoroscopy for a few minutes until your child is tired, then switch it back on.
- If your child does not like a particular flavour straight away, you could try it multiple times before ruling it out of your child's diet.
- If your child has an oral aversion, speech and language therapy may be helpful, alongside using toys and gentle touches for desensitisation (one such toy, the **z-vibe oral motor tool**, is listed in the 'Equipment, products and apps' section of this factsheet under [Feeding and Drinking](#)).
- There is a blog post with a number of helpful tips about reflux, formula and blended diet here: <https://www.soft.org.uk/living-with-trisomy/keeping-it-inside-tips-from-a-pro-on-reducing-vomiting>

Hormones

- If your child is not producing hormones, this may affect their bone density. It may be worth seeking endocrinology advice.

Scoliosis

- There are some useful suggestions on managing scoliosis here: <https://www.soft.org.uk/living-with-trisomy/dealing-with-scoliosis-and-spinal-surgeons>

Seizures

- If you think your child is having a seizure, film it and time how long it lasts so that you can discuss this with your child's medical team.
- Some children are more prone to seizures when they are unwell but may have further seizures when they are better.
- Seizures can be hormonal, so it may be useful to track them and log their timings.
- If they can respond to a flashlight or snapping fingers, it is less likely to be a seizure (but check with your child's medical team).
- If your child's eyes start looking upwards or going in a circle, this may be a sign that they are about to have a seizure.
- **Myoclonic seizures:** your child may look startled and twitch. These can be brief.

- **Tonic-clonic seizures:** your child may have stiff arms and legs with some repetitive jerking, their mouth may twitch, they may look panicked and get goosebumps on their face, they may go apnoeic.
- **Absence seizures:** your child may look vacant.
- **Tachycardic seizures:** your child may thrash around, they may have a higher-than-normal heartrate, and their SATS may drop.
- **Infantile spasms:** your child may appear startled; they may laugh or cry.

General advice


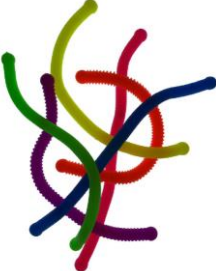

- If you are unhappy with a medical consultation, you can ask for a second opinion.
- If allowed, take an objective advocate with you to take notes during medical appointments so that you can review these later.




Equipment, products and apps

Clothing

- Smaller-sized clothing for newborns is available from clothing companies such as:
<https://cheekychumsonline.co.uk/> and <https://www.babyprem.com/>

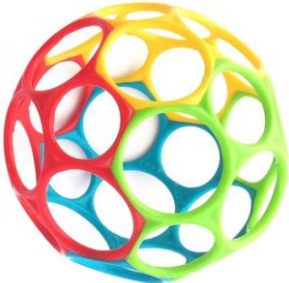


Sensory Toys

Picture	Name and Price	URL
	<p>LED fan (Product no. 2133)</p> <p>£130 excl. VAT</p>	<p>http://independent-life-technologies.co.uk/Home_page/AdaptedToys/Fans Water Toys.html</p>
	<p>Textured Stretchy Noodle Elastic Snakes</p> <p>£4.32 incl. VAT</p>	<p>https://www.sensorytoywarehouse.com/product/sensory-fidget-textured-elastic-snake/?utm_term=33687&gclid=Cj0KCQjwz8emBhDrARIsANNJjS6DZyRfFzxiFXhNanMD2wBU6Z8S8ta-EtynU3vNymuAds-tOdQzS60aAgFoEALw_wcB</p>
	<p>Crinkle Paper</p> <p>£5.50 incl. VAT</p>	<p>https://outtheboxbabygifts.co.uk/products/baby-paper-crinkle-toy-rainbow</p>

	<p>Clacking Windmill</p> <p>£107.94 incl. VAT</p>	<p>https://www.edusentials.co.uk/product/clacking-windmill/</p>
	<p>Mirror Chimeabout</p> <p>£106.80 incl. VAT</p>	<p>https://specialneedstoys.com/uk/mirror-chimeabout-visual-sensory-toy.html</p>
	<p>Switch-adapted Bubble Toys</p> <p>From £15 incl. VAT (excl. switch)</p>	<p>https://www.merushop.org/product/switch-adapted-toy-bubble-machine-2/</p>


- Children with trisomies 13 and 18 may enjoy **optic lights** and **sound toys**.
- Toys can be bought from **Rompa** (<https://www.rompa.com/>), **TFH** (<https://specialneedstoys.com/uk/sensory-toys>), and **Spacekraft** (<https://www.spacekraft.co.uk/>)
- There is a list of Christmas toys for trisomy children here: <https://beverlyjacobson.com/page/trisomy-talks> (see under Episode 6: Toys for Trisomy Tots). This was compiled for an American audience, but you may be able to find equivalent products in the UK. If you cannot find a similar product in the UK, please email Sarah at sarah.bowell@soft.org.uk who will be happy to look into this for you.

Toys for Motor Skills

Picture	Name and Price	URL
	<p>O-ball</p> <p>£3.99 incl. VAT</p>	<p>https://www.boots.com/baby-einstein-oball-classic-easy-grasp-toy-10307276</p>
	<p>V-tech crawl and learn ball</p> <p>£17.99 incl. VAT</p>	<p>https://www.smythstoys.com/uk/en-gb/toys/pre-school-and-electronic-learning/vtech-toys/vtech-infant/vtech-crawl-and-learn-bright-lights-ball/p/160373</p>
	<p>Toddler fidget spinners</p> <p>£9.88 incl. VAT</p>	<p>https://www.etsy.com/uk/listing/1327082722/baby-development-toys-sensory-toys-for-6?ga_order=most_relevant&ga_search_type=all&ga_view_type=gallery&ga_search_query=toddler+fidget+toy&ref=sr_gallery-1-4&frs=1&sts=1&organic_search_click=1</p>

	<p>Freestanding abacus</p> <p>£15 incl. VAT</p>	<p>https://www.ikea.com/gb/en/p/underhalla-abacus-multicolour-60506676/?gclsrc=aw.ds&gclid=Cj0KCQjwz8emBhDrARIsANNjS5hkUTycDyDDmC3vzckrdLVGjC7LfWpqRgh4aI7VAR1PUQtfd-To6YaAmzoEALw_wcB&gclsrc=aw.ds</p>
	<p>Activity toys</p> <p>£64.99 incl. VAT</p>	<p>For example: https://www.bigjigstoys.co.uk/products/activity-cube</p>

Other Toys

Picture	Name and Price	URL
	<p>Teepee Play Tent</p> <p>£54.95 incl. VAT</p>	<p>For example: https://www.tickety-boo.co.uk/acatalog/Teepee-Play-Tent-by-Djeco-7079.html#SID=23</p> <p>Some have fairy lights.</p>

Accessible Equipment

- **Buttons and eye gaze technology**
- **Switch-adapted toys:** You can adapt a battery-operated toy to make it switch-enabled, as long as the toy has on/off functionality only (i.e., it does not have other settings or speeds). You can do this through purchasing a battery interrupter (e.g., <https://www.liberator.co.uk/battery-device-adapters>) and inserting it between the battery and its connection. This YouTube video explains how to do this: <https://www.youtube.com/watch?v=rnoGvHPz42Q>
- Switches are available here: <https://www.merushop.org/product/switch-with-mount-and-perspex-cover/>

Apps

- **Speak for Yourself app** to help communication (<https://apps.apple.com/gb/app/speak-for-yourself/id482508198>)
- **Proloquo2go app** for communication (<https://apps.apple.com/gb/app/proloquo2go-aac/id308368164>)
- **Sensory and musical apps**

Equipment for exercise

- **Cellerciser with balance bar** (<https://cellercise.com/products/cellerciser%C2%AE-bi-fold-rebounder-w-balance-bar>)
- **Crawling track** (these can be ordered through this Estonian website: <https://ergohiir.ee/en/development-of-newborns-and-children/2280-newborn-baby-crawling-track-track-by-glen-doman-2029321113991.html> which delivers across the UK. Alternatively, there are instructions about how to make one here: <https://marathewondergirl.com/en/infant-crawling-track/> or this book which provides more information: https://www.amazon.co.uk/How-Smart-Your-Baby-Revolution/dp/0757001947/ref=sr_1_1?crid=2RUR4PIWUKHNM&keywords=How+Smart+Is+Your+Baby+%3F%3A+Develop+and+Nurture+Your+Newborn%E2%80%99s+Full+Potential+%28The+Gentle+Revolution+Series%29&qid=1691678192&srefix=how+smart+is+your+baby+develop+and+nurture+your+newborn+s+full+potential+the+gentle+revolution+series+%2Caps%2C339&sr=8-1)
- **Wingbo Tummy Time Swing** (USA) – this company is no longer in business. Second-hand swings may be available on websites such as eBay, Gumtree, Shpock, Facebook Marketplace etc. There are alternative tummy time products available (but not swings).
- **Standers** (as directed by your child’s medical team)
- **Indoor swing:** Rainy Day Indoor Playground Support Bar (<https://store.playawaytoy.com/body-define-home-fitness-system/rainy-day-support-bar>) which can be installed in a doorway and Little Tykes Swing (<https://www.adventuretoys.co.uk/little-tikes-high-back-toddler-and-baby-seat/>). If the Support Bar is not available in the UK, you could consider a bearing bar (<https://specialneedstoys.com/uk/vestibular/indoor-swings/bearing-bar.html>) or an alternative frame, such as this one: <https://specialneedstoys.com/uk/vestibular/indoor-swings/foldaway-swing-frame-only.html> (which does not come with a swing), or this one: https://www.amazon.co.uk/FUNLIO-Sandbags-Foldable-Portable-Toddlers/dp/B0C278NSQ5/ref=sr_1_34?crid=2AERUR2VQFPW1&keywords=Indoor%2BSwing&qid=1691745

[328&sprefix=indoor%2Bswing%2Caps%2C102&sr=8-34&th=1](#) (which includes a swing and can be folded away).

Safety equipment

- **Apnoea monitor** (probe or mat) – you may be able to borrow this from a hospital.
- **Bath chair and handlebars in the shower**

Feeding and Drinking

- **Z-vibe oral motor tool** can be used for oral stimulation (<https://www.tinknstink.co.uk/collections/z-vibe/products/arks-z-vibe-vibrating-oral-motor-tool?variant=44490563092780>). The probe tip, which is included with the tool when purchased through this link, has three textures and can be used to stroke around your child's lips and mouth, with the vibrate function on or off. There are a few YouTube videos demonstrating this tool, and a handbook which has been scanned in here: <https://www.scribd.com/document/477995548/zvibe#> It is recommended that you use this in conjunction with (and as directed by) your child's speech and language therapist. Food flavourings could be incorporated into these exercises; please discuss this with the speech and language therapist.
- **Training spoons with curly handles.** Made by Sassy brand in USA, but a similar spoon is available to purchase on eBay: <https://www.ebay.co.uk/itm/363909489632?hash=item54bab223e0:g:iPkAAOSw2eJi0RcU&amdata=enc%3AAQAIAAAA8C4Q91KKuVS6WTOKnbyhlcZ4fNg2Jc4TaW9qLIURWndWMVLR3ot2dnyQpcGXOiz4clgLmnU5JvgjLty9yiMSdPPsCjKRIOMv5MjG%2FitZNH0r0fptF2%2B8jY6MwEPEN%2BFZvhbHDoh7S71DBwhioBDMzK7Q6P5CUa354hPBg%2FEP5NqbGZPh4M1WjmXmOlyAbHA0iQwJpx0aqihTHNQwS3TswgdkgVkvwY8HTsloY0jiFjPKNX YB6Bzhe4k3yJWFBofHKoiEGZ5SB9Fbnk2RwC76EPjFheMmFwZgitFKTAnMmuLs4BrrBBWvuklsqugokRuvA%3D%3D%7Ctkp%3ABFBMlq3lyLxi>
- **Nipple shields** (upon medical advice).
- There are a number of drinking cups which have been recommended by parents, including:
 - **Munchkin cup:** this is a sippy cup which has been designed not to spill https://www.johnlewis.com/munchkin-miracle-360-degree-sippy-trainer-cup-7oz/blue/p110229296?s_ppc=2dx_mixed_fashion_BAU&tmad=c&tmcampid=2&gclid=Cj0KCQjwuNemBhCBARIsADp74QQ_DycgAWdbOo1-LTppR3WYqZ5PsWleYU81AE67xrzuPeVJthrdHgaAp39EALw_wcB&gclidsrc=aw.ds
 - **Honey bear cup:** this is a squeezable bottle with a straw which allows children to drink if they have difficulty with suction <https://www.tinknstink.co.uk/products/arks-bear-bottle-kit-for-straw-drinking>
 - **Provale cup:** this sippy cup dispenses a small amount of liquid at a time (although the reviews on Amazon are poor) <https://www.amazon.co.uk/PROVALE-Regulating-Individuals-Swallowing-Thickeners/dp/B07BHXPGGP?th=1>

General advice

- Don't believe everything you read and take statistics at face value.
- Focus on the near future and what you can do.
- Trust your instincts.
- Accept help from your friends.
- Advocate for your child.
- Write a list of things to pack in a hospital bag.
- If you can afford to, get additional support around dinnertime.
- If something happens in your child's life that you are not anticipating, try not to be afraid of it.
- It may be useful to look into patterning, the Doman method and horse-riding.
- If your child has sensory needs, singing to them, touching them and using high-pitched voices may help with bonding.
- Access counselling if you need to, know your triggers and anticipate them.

Version Control

Version	Author	Date	Changes
1.0	Sarah Bowell	15/08/2023	First draft
2.0	Sarah Bowell	02/11/2023	Minor changes to introduction