



Toys, Play & Activities for Babies and Young Children who have Spinal Muscular Atrophy

Practical tips and suggestions for parents and carers, including ideas shared by parents of children who have SMA.

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Babies and children who have SMA are generally bright, alert and eager to engage with people. They want to play but their reduced muscle strength and movement may make this challenging for them. We hope that the suggestions in this booklet will give you some ideas that you can use and enjoy with your child.



SMA UK provides free multisensory toy packs for infants up to 12 months of age who have been newly diagnosed with SMA. If your child is older, we may be able to help you access other suitable toys. For more information, please go to:

smauk.org.uk/9nxt

Toys and Safety

Look out for small, lightweight toys or ones that need minimal pressure to get them to work. You can also provide your child with a fun sensory experience with household objects such as wooden spoons, pots, containers and cardboard boxes – just check and throw away any with sharp edges, splinters or staples.

You might find that some toys designed for older children are suitable for your child because they're light, but please satisfy yourself of the safety and suitability of any toy you give your child. There are some links to more information about safety at the end of the booklet.

Please always:

- ❖ read any instructions that come with the toy or activity
- ❖ make sure it's safe and suitable for your child
- ❖ supervise your child when they're playing
- ❖ check toys regularly to make sure they aren't broken or unusable

Your child's comfort and safety

The great variation in how children are individually impacted by SMA, and also in how they respond to drug treatments, makes it difficult to give general advice about safe and comfortable positions. Your physiotherapist (physio) or Occupational Therapist (OT) will advise you on the best options for your child. These general points may be helpful:

- All babies begin by lying flat. Progressing to supported sitting or lying in a semi-reclined position will depend on how easy your baby is finding it to breathe and how their muscle strength and head control are developing.
- If your child is a 'tummy breather' (see our Looking After guide: smauk.org.uk/7h1h), being in some positions may make breathing harder work. Please follow the advice provided by your physio.

As your child gets older, your OT or physio can assess your child's seating needs and provide advice. If your child can sit comfortably and safely, supportive seating and other equipment may help them play and join in with activities.

If your child is using specialist seating or a wheelchair, you may want to use a table with a rim to stop toys sliding off or a non-slip mat to help keep toys in place.

A height-adjustable table, or a table on blocks can be useful. Your OT or physio will be able to help you with best positioning and different options.



Your physio or OT will also have ideas about how you can use play as a way to help your child exercise, stretch and move their muscles as much as possible. They may also be able to suggest suitable toys and play opportunities such as playgroups, parks or toy libraries in your area.

Noise and Colours

Before babies learn how to grasp objects, they respond to things they can look at and listen to. Bright colours or high contrast colours like black and white are easiest to see. Babies particularly like objects that make a noise when moved.



Some ideas

- ❖ Brightly coloured musical mobiles and baby play gyms
- ❖ Unbreakable mirrors
- ❖ Helium balloons which can be attached to your baby's wrist
- ❖ Wind chimes, coloured ribbons, balloons, windsocks and sensory scarves in the garden
- ❖ Tinsel and fairy lights (securely out of reach)
- ❖ Sensory toys, fibre optic lights, lava lamps, disco balls, bubble tubes
- ❖ Space blanket - these are often shiny and make a sound when scrunched up; they can also be used for playing 'peek-a-boo'
- ❖ Blowing bubbles
- ❖ Music – YouTube and nursery rhymes
- ❖ Talking and singing with your baby
- ❖ Lullaby projector lightshows
- ❖ Bath time fun with music and toys that make a noise or light up

"Bubbles are great. We blow them over our daughter when she is lying on the floor and she tries to catch them"

Mum of 3-month-old



Exploring Using Mouth and Hands

As babies get older, they learn to explore using their mouth and by grasping at their toys. If your baby finds it tiring to use their arms and hands, you can follow your physio / OT's advice to support your child in a comfortable and safe sitting or lying position. Lying your baby on their side with support may help them to use both their hands together.

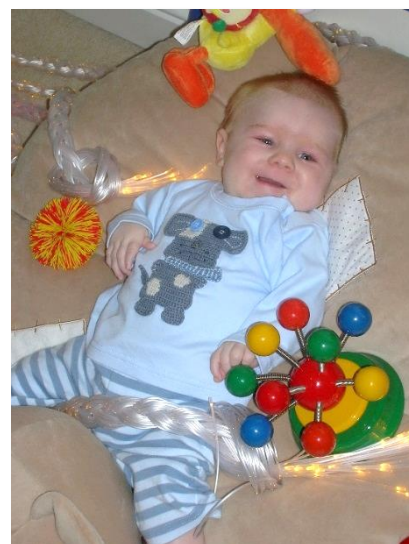
As your baby grows, your OT and physio will discuss and review their seating and positioning with you.

"We play catch indoors with a balloon as this is much lighter than a ball"

Dad of 5-month-old

Some ideas:

- ❖ Activity centre, play mat or vibrating mat for when your baby is lying down
- ❖ Lightweight rattles and bells
- ❖ Squeaky rubber toys
- ❖ Colourful teething rings
- ❖ Bangles and pegs which are brightly coloured and light to hold
- ❖ Reading to your child using colourful boards or fabric books with textured pages
- ❖ Action songs, for example, 'Round and Round the Garden' (see below) and 'This Little Piggy'
- ❖ Finger puppets that are lightweight and colourful
- ❖ Small soft toys which can be held easily



*"Round and round the garden,
like a teddy bear.*

One step...

Two step...

Tickle you under there!"



Holding Objects

Over time, your child may start to pull objects towards them and pass them from one hand to the other. They may also begin to pick up small objects between their forefinger and thumb (using a 'pincer' grasp).

They might enjoy having their toys in front of them on a tray with a rim so that they don't easily slide off.

You can also use non-slip mats to help keep toys in place.

"Our son enjoys playing with small blocks and animals on a tray"

Dad of 8-month-old

Some ideas:

- ❖ Building blocks made of cloth or lightweight plastic e.g. Duplo. These are light and encourage reaching and stretching. You can also get magnetic blocks which make building easier
- ❖ Books with different textures to touch and feel
- ❖ Soft toys with bells inside
- ❖ Lightweight shape sorters
- ❖ Stacking cups or rings
- ❖ 'Treasure Baskets' - fill a tray or basket with things for your baby to explore



Movement and Interaction

Your child may enjoy movement and interactive games such as tickling and peek-a-boo. As they get older, they may begin to imitate what they see around them, start to recognise words and the names of familiar objects.

"Our daughter loves to move shapes along a string. It encourages her to stretch and makes her laugh"

Mum of 1-year-old

Some ideas:

- ❖ Gentle baby massage
- ❖ Gentle swinging in a hammock
- ❖ Movement to music and acting out nursery rhymes
- ❖ Toys that move. If needed, some battery or switch operated toys can be adapted so that they can be worked by a large button or flat pad which requires minimal pressure
- ❖ Toy telephones with buttons that need little pressure to work
- ❖ An arm sling attached to a baby gym can support your child's arm when they're playing. Ask your physio for advice – you might be able to make your own
- ❖ Look in your local library for storytelling or rhyme sessions
- ❖ Lightweight plastic musical instruments which need minimal pressure to work
- ❖ Finger and hand games such as 'Incy Wincy Spider' and 'The Wheels on the Bus'
- ❖ A sand box to feel the texture with hands and feet
- ❖ Perhaps introduce a computer or tablet and games that encourage play and learning. Your phone is very likely to have been noticed and be of interest! You might want to try different ways of positioning the screen so that your child can use it comfortably.



More ideas:

- ❖ Going to a local music group, sometimes held at your local library
- ❖ Visiting a local wildlife centre, zoo, or aquarium to see the animals
- ❖ Joining a baby sign language class or baby sensory class (either in person or online)
- ❖ Going to the park and feeding the ducks
- ❖ Take a bucket and collect leaves, pinecones and other interesting items for your child to see and feel
- ❖ A trip to the seaside and making sandcastles - look for small lightweight buckets and spades or plastic sandcastle moulds
- ❖ Swimming or, if you have one, hydrotherapy pool activities. The buoyancy and warmth of the water makes it easier to move. There are various floatation aids available if you need them. Ask your child's team about your local facilities and what might be suitable for your child.



Cause and Effect

As your child becomes interested in what happens when they do something, you can introduce new toys and ideas to provide fun and learning.

Some ideas:

- ❖ Magnetic books, jigsaws or games
- ❖ Building towers with blocks, cubes, or plastic cups
- ❖ Playmobil and Duplo figures are lightweight and washable
- ❖ Messy play using sand, water or jelly. Your child may be able to sit in a wooden sand pit or try a corner seat. Some standing frames have a bowl within the tray for messy play.
- ❖ Games of hide and seek like hiding under the towel at bath time
- ❖ Toys controlled using a joystick can be fun and develop skills that will be useful later on if your child uses a powered wheelchair
- ❖ Drawing or painting. It can help to stick paper down with blue tack to hold it still. Try light-touch thicker pencils, felt tip pens or Crayola Twistables which glide on easily. Pencil grips can also help make the pencil easier to hold. Finger painting or printing using shapes is also fun
- ❖ Stickers to make cards and pictures
- ❖ Magnetic drawing boards are easy to use and wipeable too
- ❖ Helping with baking, mixing, and decorating cakes and biscuits

“We saved empty yoghurt pots to build into towers. We also made it into a competition to guess which way up they would land before they were knocked over”

Dad of 18-month-old



More ideas:

- ❖ If you have a garden, children enjoy the motion of a swing. You will need a seat that gives back, side and head support and has a harness – check with your OT or physio
- ❖ Make a 'Mud Kitchen' outdoors for pretend and messy play by "cooking" with mud, sand, water and food colouring
- ❖ Tablet and other touch-screen devices offer various apps for play and learning. You can use a stand to hold or support the device
- ❖ Miniature skittles using a sponge ball
- ❖ Throwing and catching games using light sponge balls or balloons
- ❖ Helping in the garden: planting seeds; smelling flowers; growing vegetables; or caring for small pets like rabbits and guinea pigs
- ❖ Having a picnic. Use plastic lightweight crockery and plastic foods to encourage imaginative play
- ❖ Watching a puppet show or children's play
- ❖ Visiting a fairground or theme park to enjoy the sights, sounds and smells
- ❖ In some areas of the country there are inclusive cycling projects which have adapted cycles so that children with disabilities can join in with their families. Search websites of local parks for more information.



Hands On

If you need to help your child to enable them to move and explore for themselves, it can take some creativity, and some trial and improvisation. Working with your child's current abilities can help avoid them feeling frustrated or upset if they find an activity difficult to manage by themselves.

"We found dressing up in full outfits could be difficult so we focused on using lots of wigs and hats"

Mum of 2-year-old

Some ideas:

- ❖ Playdough. Rolling, squeezing, and cutting out shapes. Fresh homemade playdough is softer and easier to manage (see below)
- ❖ Dressing up using hats, wigs, costumes, and face paints
- ❖ 'Fuzzy'-Felt and sticker activities
- ❖ Trains and cars on tracks or slides. Magnetic trains are easier to join together
- ❖ Magnetic tiles or blocks and magnetic fishing games
- ❖ Large piece wooden jigsaws and puzzles
- ❖ Toys that use the pull of gravity like cars or marbles sent down ramps. This encourages reaching and stretching
- ❖ Pom poms are light and soft and come in different shapes and colours



Recipe for soft homemade playdough

- 2 cups of salt
- ½ cup oil
- 3 dessert spoons of cream of tartar
- Food colouring
- 6 cups of boiling water
- 5-6 cups of flour

Dissolve all the ingredients except the flour in the boiling water. Add the flour and stir thoroughly. It's a wet mixture but dries out when cool.

Becoming more independent

Your child's physio or OT will tell you about powered wheelchairs if your child needs one to explore, take part in activities and play with their friends more independently.

Wizybug is a powered wheelchair for children under the age of 5. It can be used both indoors and outside and is easy to work so can be suitable for children as young as 14 months old. Talk to your OT or physio about whether this may be a suitable option for your child. Wizybugs can be loaned or purchased from Designability: designability.org.uk

As your child gets older, they may need different wheelchairs. Your OT or physio will be able to advise you.

"Soft sponge balls are good for playing football. Our son goes in goal and uses his wheelchair to stop the ball when he is playing with his able-bodied friends"

Dad of 4-year-old

Computers and Assistive Technology

If your child wants to use a computer for playing games and for schoolwork, they may need some adaptations so that they can use a computer independently, for example a light touch mouse.

For more information on computer adaptations you can contact the following organisations:

AbilityNet – offer advice and training on computer technology for disabled people: abilitynet.org.uk

Everyone Can – help disabled people speak, live independently, control their environment and have fun, through training and assistive technology: everyonecan.org.uk

Inclusive Technology – online retailer specialising in computer access equipment: inclusive.co.uk

Special Effect - enable you to find out about and try adapted gaming controls. For more information, please see: specialeffect.org.uk

Smartbox Assistive Technology - combine computer technology with communication software: thinksmartbox.com



"iPads are great as they are small and easy to manage"

Dad of 5-year-old

Where to get toys and help with play ideas

➤ Borrowing Toys

Toy libraries run loan schemes where you can borrow toys at a very low cost. It's a good way of giving your child variety so that they don't get bored. It's also a good way of testing which toys your child enjoys most before you buy anything. Your local authority website or your local library should give you details of your nearest toy library. Your health visitor may also be able to tell you if there's a Snoezelen Centre (multi-sensory environment) in your area.



In Scotland, Smart Play Network supports toy libraries, play services and play providers: smartplaynetwork.org

Newlife – a charity for Disabled Children – loan toys through their play therapy pod service. Phone: 0800 902 0095 - newlifecharity.co.uk

➤ Centres and Schemes

Children's Centres provide activities and play ideas for children under the age of 5. To see if you have a local centre please see: gov.uk/find-sure-start-childrens-centre

The Portage Scheme is a national home-visiting educational service for pre-school children with additional support needs and their families: portage.org.uk

Children's hospices offer play facilities for children with life-limiting conditions and their siblings, including multi-sensory rooms and music rooms. Some hospices employ play workers who work both in the hospice and in the community, visiting families at home to offer support and advice. To find your local hospice, visit: <https://www2.togetherforshortlives.org.uk/portal/public/volunteer/>



➤ **Buying Toys**

Specialist suppliers include:

- ❖ **Dycem** – supply non-slip mats: dycem-ns.com
- ❖ **Explore your Senses** – sensory toys: exploreyoursenses.co.uk
- ❖ **Hope Education** – educational resources: hope-education.co.uk
- ❖ **Liberator** – switch adapted toys: liberator.co.uk
- ❖ **Living made easy** – information about play equipment and suppliers: livingmadeeasy.org.uk – from the tabs at the top, choose ‘leisure and play’
- ❖ **Meru** – device holders, sensory and switch-adapted toys: merushop.org
- ❖ **Rompa** – sensory and developmental toys: rompa.com
- ❖ **Sense Toys** – sensory toys: sensetoys.com
- ❖ **Sensory Toy Warehouse**: sensorytoywarehouse.com
- ❖ **Spacekraft** – sensory resources: spacekraft.co.uk
- ❖ **Special Needs Toys** – range of toys: specialneedstoys.com

Charity shops, eBay and Facebook Marketplace can be good for buying second-hand toys.

➤ **Funding for Toys**

You can apply to the Family Fund for financial assistance towards the cost of toys: familyfund.org.uk

SMA UK may have information on other potential sources of funding. Our contact details are at the end of this booklet.

➤ Safe Play

The charity Sense has a play toolkit for parents that includes tips and suggestions: [sense.org.uk/information-and-advice/life-stages/childhood-and-school/how-to-play-with-a-child-with-complex-disabilities/#toolkit](https://www.sense.org.uk/information-and-advice/life-stages/childhood-and-school/how-to-play-with-a-child-with-complex-disabilities/#toolkit)

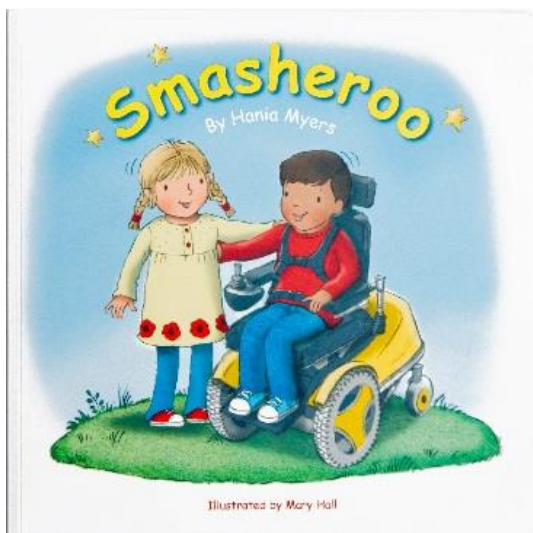
For toy safety in general: [rospa.com/home-safety/advice/product/toy-safety](https://www.rospa.com/home-safety/advice/product/toy-safety)

➤ Wish Granting Charities

Wish granting charities may be able to arrange a memorable wish or experience; for suggestions see this page: [smauk.org.uk/3tu1](https://www.smauk.org.uk/3tu1)

SMA UK Children's Books

The following book is available via our website: [smauk.org.uk/kw8l](https://www.smauk.org.uk/kw8l)



Smasheroo: 'A person or thing of superlative quality or importance etc. a 'smash-hit'.

Written by Hania Myers, whose daughter has SMA Type 3, with illustrations by Mary Hall, this uplifting story highlights that everyone is different and everyone is special in their own way.

Any family affected by SMA, living in the UK, can request a free copy from SMA UK



Acknowledgements and Disclaimer

This leaflet has used the knowledge and experience of parents and grandparents of children with SMA and Spinal Muscular Atrophy UK staff who have spent time with families.

Our thanks to the writers and reviewers who assist us in our information production. A list of who this includes may be requested from information@smauk.org.uk

We make every effort to provide information that is complete, correct and up to date. We signpost to recommended and trusted organisations where relevant. We cannot, though, guarantee we always get it right.

Our healthcare information is not intended to replace that provided by your healthcare team. Medical advice for any individual should always come from their own medical team

If you have any feedback about this information, please do let us know at: information@smauk.org.uk



Patient Information Forum

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