

Looking after your child who has had a recent diagnosis of SMA Type 1

You can also read this guide on our website at smauk.org.uk/8x63 where you can follow all the links we give to further information.

This guide is for parents and carers whose infant:

- has had symptoms of Spinal Muscular Atrophy (SMA)
- has had a diagnosis of SMA Type 1
- is having difficulty trying to sit or roll independently

We hope it's useful for parents and carers who are finding positioning, handling, feeding and playing challenging. It introduces you to some of the management and care options your child may need. It doesn't give medical advice. This must always come from your child's medical team. It includes tips and suggestions that have worked for other families.

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You may also want to read our guide:

- [Hearing Your Baby's Diagnosis of Spinal Muscular Atrophy >](#).

This covers the emotional aspect of receiving your child's diagnosis and some suggestions of who can provide support.

The symptoms and impact of the condition on children who have SMA Type 1 varies greatly. Also, all children respond to treatment and develop differently. This may mean that only some of the sections in this guide are relevant to your child. Your child's clinical team can advise you. If your child is stronger, you might find some sections more relevant and useful in our guide:

- [Looking After Your Child who has been recently diagnosed with SMA Type 2 >](#)

1. Treatment and Care

There is no cure for SMA. But since 2016, new disease-modifying drug treatments have had positive results for many children who have SMA Type 1.

Children are diagnosed with SMA Type 1 at different times. They will have different symptoms and be at different stages of development when treatment starts. Each child will respond differently to treatment, and this may change over time.

The NHS funds disease-modifying treatments for children who have SMA Type 1. Not every treatment is suitable for every child. Your child's medical team will talk you through what is known about each one and the benefits and any risks. They will help you decide according to what's available and suitable for your child.

You may find it helpful to read our pages on

- [**Drug Treatments for Children who have 5q SMA – England, Wales & Northern Ireland >**](#)
- [**Drug Treatments for Children who have 5q SMA – Scotland >**](#)

These tell you about the treatments, how they work and which children may have access.

Your child's medical team will also discuss your child's healthcare and support needs with you. This will depend on your child's symptoms and the impact their SMA is having on them.

The way SMA impacts on children, young people and adults has changed since treatments started. This has meant that the way the condition is managed and the care needed has also changed.

This is why expert clinicians and patient representatives are now agreeing on new guidelines for care.

There are many areas to think about – from managing the impact on breathing, spine & hips to nutrition, play and interaction with others. When a new guideline is agreed and published, we will link to it in the relevant section.

For more information see: [SMA Care UK >](#)

2. Your Child's Healthcare Team

Your child will receive care and support from a multidisciplinary healthcare team. This can feel like an overwhelming number of people, but they all have an important role to play. Who you see will depend on your child's symptoms.

You may have contact with specialists at the Neuromuscular Centre in:

- neurology
- paediatrics
- breathing (respiratory) care
- physiotherapy
- orthotics
- occupational therapy
- dietetics
- speech and language therapy
- palliative care (see Section 15)
- general practice and community health care

Other specialists may also be involved depending on your child's needs.

You may also have contact with local general practice and community health care professionals. This may include, for example, community paediatrician, physiotherapist (physio) and occupational therapist (OT).

Our Guide [Who's Who of Professionals](#) > tells you more about these specialists.

Everyone involved in your child's care aims for your child to stay healthy and enjoy a good quality of life. Members of your child's team will monitor changes in your child's health and development. They will offer advice and interventions at the right time. They will consider your home and family circumstances as well as your child's medical and physical needs.

3. Vaccinations

Children who have SMA should have all vaccinations recommended in the UK. But check with your child's specialist team for any new guidance and when your child should have them. Recommended vaccinations include protection against flu and covid where eligible. Consideration for the 23 valent pneumococcal vaccination is also recommended. Families and close carers are also encouraged to keep their vaccinations up to date to help reduce infection risk.

The routine vaccination schedule may need to be altered for infants receiving Zolgensma™. No vaccinations should be given in the 2 weeks before and after treatment. No live vaccination should be given until steroids have been discontinued for 3 months. Your infusion centre will advise you on this.

Respiratory syncytial virus (RSV) is a common respiratory virus that can cause serious lung infections.

Anyone more than 28 weeks pregnant should have been offered a single dose vaccine. This helps protect babies against RSV from birth through the first 6 months of their life.

Talk to your specialist clinicians about any concerns you have if your child is:

- over 6 months old
- vulnerable to breathing difficulties (respiratory compromised)
- does not need long term ventilation.

It's impossible for you to prevent your baby catching all possible viruses. But you may want to try to avoid direct contact with others who have coughs and colds.

4. Safe and Comfortable Positions

Every child's needs are different. Your physiotherapist (physio) or Occupational Therapist (OT) will advise you on the best options for your child as they grow and develop.

The following, more general points may be helpful:

- All babies begin by lying flat. Being able to progress to supported sitting or lying semi-reclined will depend on:
 - how easy it is for your baby to breathe
 - how their muscle strength and head control are developing.
- If a child is weak, it's important not to sit them up too soon. Doing so can encourage the development of a spinal curve. See **Section 5: Hips & Spinal Care** for how this is managed.

If your child is a 'tummy breather' this means that they may depend more on their diaphragm muscle to breathe. This muscle sits at the bottom of the chest and above the stomach. It's pulled down to inflate the lungs and so the tummy moves outwards with this movement. This means that being in some positions may make breathing harder work.

Tummy time is though important for all babies. It helps them develop muscle strength. Your physio will advise the best and safest way to do this. It must ALWAYS be with supervision.

Please always follow your physio's advice.

Deeper breathing is important. It can help to prevent secretions building up in your child's lungs. Your child needs to be in a position to be able to swallow safely and manage any saliva and secretions. Their Speech and Language Therapist (SALT) will advise you. See **Section 8: Feeding, Nutrition and Swallowing**.

It's important for your child to strengthen their neck and back muscles. Your physio will advise on positioning and any exercises you can encourage and supervise to help with this.

It's important that any exercises are 'little and often'. Fatigue is recognised as being one of the impacts of SMA. Your child will tire quickly.

Your physio, OT or respiratory team will give you general advice about best positioning. They will especially advise you before putting your child in a more upright position. It's important not to do this too soon.

You may need specialist advice from a SALT for safe positioning for your child when feeding, playing and interacting with others.

Your child may dribble a lot due to difficulties with swallowing saliva. Your SLT will work with your child's clinical team to advise you how to safely manage this. A face cloth, muslin square or breast pad under your child's head can help to soak up saliva. It can easily be changed when it gets wet.

If your child is lying on their side, it's important to check that their arm and shoulder are not trapped and that their ear is flat. A rolled-up blanket against their back may help support them. Avoid always lying them on the same side.

A baby's sheepskin blanket can be very comfortable for your child to lie on. It can also be used in their buggy. But sheepskins can make children hot. If you use one, keep an eye on their temperature and if they're getting sweaty.

If your child is lying on their back, you may find their legs tend to roll outwards. A small wedge or rolled up blanket on either side of their hips, or a small roll under their knees can help. Rolled up towels and soft toys can also be used to help with positioning. Again, your physio or OT can advise.

Your community physio or OT may be able to provide wedges or foam inserts shaped to promote good postural support.

If your child has a limited range of comfortable positions, look out for any red or sore 'pressure' areas on their skin. Early intervention is important. If you're concerned, contact your community children's nurse or health visitor as soon as possible for advice.

As your child gets older, they'll want to see more of what's going on around them. If your child struggles to change position, they'll need help to do this. Changing position can also help relieve any pressure and can reduce stiffness in their joints.

If your child is developing tightening of their muscles or joints (contractures) and discomfort, your OT or physio will advise. They may provide foot or knee or hand splints to help.

Your OT or physio can assess your child's seating needs and provide advice on seating. This includes car and bath seats which offer appropriate support for your child. They may also discuss having a seat that will give a lot of support when your child is semi-upright. If your child is comfortable, it may be easier for them to play.

Your child's pram or moulded seat will be designed to provide them with the right amount of head and neck support. If you face them in different directions, you can help encourage them to turn their head safely which helps strengthen their muscles. For example, so that they turn their head to watch you cooking.

See Section 13: Night Time, for safe and comfortable positions at night.

5. Hips & Spinal Care

Despite disease-modifying drug treatment, weak muscles often impact a child's hips. It's important that this is monitored from early on in life.

There are lots of different ways to manage hip care. These are currently being reviewed by the SMA Care UK project. New guidelines for hip care have been agreed and published for clinicians. An SMA Community Guide will be published soon. We will provide a link here as soon as it's available. In the meantime, your child's specialist neuromuscular team will guide you about the best hip care pathway for your individual child. They will work with orthopaedics.

Even with drug treatment, SMA can also weaken the muscles which support the spine. Without this support, the spine can be pulled by gravity, and curve. This ultimately affects the shape of the chest.

- When the spine starts to curve sideways into a 'C' or an 'S' shape, it's called a **scoliosis**
- When the spine bends forward it's called a **kyphosis**.

Your child may be prescribed a spinal brace to assist with sitting and head control. Your physio will make a referral to the orthotics department where this will be custom-made. Your physio will explain when, and how often, your child should wear their brace.

It's widely agreed that spinal bracing may delay the progression of scoliosis, but it won't prevent it developing. Your child's team will monitor your child's spine carefully.

It's important to remember that your child is an individual. Any recommendations are specific to your child. There is no evidence that any type of bracing is better than any other

Your child will be referred to the spinal team for advice.

If your child wears a spinal brace or other orthosis, look out for any red or sore 'pressure' areas. Marks from splints should disappear in 20 minutes. Contact your physio or orthotist straight away if you have any concerns.

6. A Comfortable Temperature

Babies with reduced movement are likely to become hot as they can't adjust position so easily. Children can be very sweaty with flushed faces and hot or cold hands. This can make it difficult to judge if their temperature is OK. If you're not sure, you can check with a small digital thermometer. You can get ones that you hold under your child's armpit, or ones that you put in their ear. You can buy these from any chemist.

Please see: [How to take your baby's temperature >](#) on the NHS website.

Changing clothing isn't easy with any small baby, but especially if your child is weak, tired or uncomfortable. Front-fastening clothes allow you to avoid lying them on their tummy.

When they are little, roomy vests, baby grows or onesies that have large neck-openings are easier to get on and off. Make sure that they're loose enough not to dig into your child's skin. Watch out for tight cuffs or feet that are too small and will cramp toes.

Thin, loose layers of clothing work well as you can remove a layer if your child's hot. If their feet and hands get cold, you can add an extra layer of warmth with booties or soft slippers and mittens.

You may find that baby or small sleeping bags, which are warm but loose and roomy, are useful when you're out and about.

As your child grows you may want to look at clothing that would make changing easier. You can find some suggestions of where to look on this page: [Bathroom, Toilet, Clothing >](#)

7. Breathing

Why breathing (respiratory) difficulties are common for infants who have SMA Type 1

When we breathe in (inspiration):

Certain muscles act as bellows to expand our lungs and enable oxygen to be pulled in:

- The diaphragm contracts. It's attached to the base of the breastbone (sternum), the lower parts of the rib cage, and the spine. So, when the diaphragm contracts it increases the length and diameter of the chest cavity and expands the lungs
- The muscles between the ribs (intercostal muscles) help move the rib cage to also assist in breathing
- SMA weakens these intercostal muscles. This can result in a 'bell shaped' chest and poor inspiration. This then results in reduced lung volume
- SMA does not impact so much on the diaphragm.

When we breathe out (expiration):

We get rid of the waste gas carbon dioxide. This does not need particularly strong muscles as it's a passive movement. However, coughing requires strong muscles to be able to clear secretions.

Weak breathing muscles are common for infants who have SMA Type 1. This results in breathing difficulties which are a leading cause of health problems.

Every child is affected differently, but the main challenges for children are that:

- This makes it difficult to cough and therefore clear mucus (secretions) from the lungs
- The lungs can't get rid of enough of the waste gas produced by breathing – carbon dioxide. This is known as '**hypoventilation**'
- It may make oxygen levels to fall while asleep. This is known as **sleep-disordered breathing**. This is an important cause of ongoing respiratory issues

- Children may have a less effective cough to clear any food and drink from their mouth or throat (pharynx). If food or drink isn't effectively swallowed or cleared it can lead to respiratory infections. This is due to a small amount of food or drink entering the airway (aspiration).
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Regular check-ups & sleep studies

As soon as possible after diagnosis your child should be seen by a specialist doctor and physiotherapist in respiratory care. They will look for any problems early on rather than waiting to see if a child starts to struggle with their breathing (proactive care). They will also organise regular respiratory check-ups.

Your child's team may want to monitor your child's breathing when they're asleep. Sleep studies should ideally measure both oxygen and carbon dioxide levels overnight. Oxygen monitoring alone may miss night-time breathing problems.

These studies are often done at home, though this depends on where you live in the UK. If your child has a home study, they may have a small clip on a finger which will record information. They may also have a sensor to measure the waste gas – carbon dioxide.

Studies in hospital are more thorough. If a sleep study is done in a hospital, small sensors are attached to your child's face, head, arm and chest and they're monitored overnight.

'Sleep disordered breathing' for infants who have SMA Type 1 is complex. It often doesn't show with just a sleep study. Your child's team will explain if any other observations or assessments are needed.

These tests will help the clinicians, and you, decide on the best way to manage your child's breathing and keep them as comfortable as possible.

Possible options for managing breathing

A specialist respiratory team experienced in SMA should make decisions about breathing support. They'll discuss which of the following options your child needs to support their breathing. You'll be trained and supported so that you know what to do and when.

- **Secretion Clearance**

Though each child is different, it's very common for children who have SMA Type 1 to have difficulty coughing up mucus and other secretions. This makes them more vulnerable to chest infections.

Chest physiotherapy. This is to help keep your child comfortable and clear secretions from their chest. How often children need this varies. You may be trained and supported to do chest physiotherapy yourself. One technique is chest percussion. You would be shown how to cup your hand, fingers down, and clap your child's chest in a steady rhythmic pattern.

Saliva medications – such as glycopyrronium bromide. These can reduce the volume of your child's secretions and / or saliva by making them thicken up. They must be used carefully. Too high a dose can dry out the secretions too much and this makes them harder to remove. Your medical team will monitor and change the dose as needed.

Nebulisation. Medication can be given via a nebuliser. This is a small machine that turns liquids into a mist that can be easily inhaled. It's often used with a salt (saline) solution or other medication prescribed to help loosen secretions. Your child will breathe the mist through a connected mouthpiece or facemask. This allows the medicine to enter the lungs directly. Some antibiotics can be given this way.

A suction machine. This is used to help remove your child's excess secretions and / or saliva.

Cough assist. This is the name often given to a mechanical insufflation – exsufflation machine. It helps to clear secretions from your child's lungs and create a more effective cough. It does this by giving a big breath in using positive pressure. It then mimics a cough by using negative pressure to pull secretions out.

Antibiotics

Children with SMA can become unwell quickly during a chest infection. This is because weak breathing muscles make it harder to clear mucus from the lungs.

If your child has signs of a chest infection, their respiratory team may recommend starting antibiotics promptly. Antibiotics are often used in combination with increasing ways to clear their airway. For example chest physiotherapy, suction and cough assist.

Some children who experience frequent chest infections may be prescribed regular (prophylactic) antibiotics. Your child's respiratory team will advise whether this is appropriate.

Contact your respiratory team if your child develops:

- increased coughing
- more mucus or secretions
- difficulty clearing secretions
- increased work of breathing
- fever
- reduced feeding
- unusual sleepiness or lethargy
- changes from their usual breathing pattern.

The team will advise on appropriate intervention. If they suspect that aspiration is causing frequent chest infections, they may also suggest a swallow assessment. Food, liquid, saliva and stomach contents should go through the oesophagus. This is the muscular tube that connects your throat to your stomach. If they accidentally go into the airway and lungs, they cause aspiration. See Section 8. Feeding, Nutrition & Swallowing below.

• **Breathing Support**

Non-invasive ventilation (NIV). This uses a machine with a mask which is individually fitted by a respiratory specialist.

The machine provides support to your child's breathing and helps expand the chest with each breath. This can help a child get rid of carbon dioxide and take in more oxygen. This makes breathing easier.

When a child's breath triggers the ventilator, it delivers a supported breath in. As they start to breathe out, the machine cycles into exhalation.

A specialist respiratory Multi-Disciplinary Team (MDT) should make any decision to start NIV. They must have expertise in the management of SMA and work in partnership with a family. They will consider the child's symptoms, current health, prognosis and quality of life.

Some babies and young children may struggle to tolerate NIV at first. This is normal. Regular respiratory check-ups ensure a child is getting the right support tailored to their needs. Talk to your respiratory team about any concerns you have with NIV tolerance.

If your child is using NIV, information from their sleep study or an acute illness may indicate a need for changes in NIV settings. Your child's respiratory specialist will advise you. Settings should only be changed if advised by your child's specialist team.

NIV may be recommended before obvious breathing problems appear. This is particularly where there are concerns about:

- a child's growth
- how hard it is to breathe
- secretion clearance
- chest shape or capacity.

NIV is sometimes used to manage any new and often sudden (acute) infection or to correct night-time hypoventilation. Other ways of giving non-invasive breathing support are not recommended for most individuals. For example, 'continuous positive airway pressure' (CPAP).

Oxygen. This isn't used regularly. It may be needed in some situations, but it should be used carefully. Rate and depth of breathing and carbon dioxide levels should be monitored. Oxygen alone does not treat weak breathing muscles.

Short-term invasive ventilation. This may be used in a medical emergency. A flexible plastic tube (endotracheal tube) is passed through the mouth or nose into the breathing tube. This is done by respiratory specialists. They will also plan for when and how the tube will be removed. This will be done in an intensive care setting. Immediate NIV and cough assist support will be given if appropriate

Tracheostomy. This may be considered for some children when NIV doesn't work. An opening is made in the windpipe to allow breathing through a tube rather than the mouth. This is a long-term decision and a big step that doesn't suit everyone.

Pain relief. Now children receive drug treatments for SMA this is not commonly needed for breathing difficulties. It can though be used for any child in pain or distress because of their breathing.

Air Quality

All children can be more susceptible to the effects of poor air quality, for example cigarette smoke. Children exposed to second-hand smoke are more likely to develop a serious respiratory infection. This would need hospital care. Children with SMA who have respiratory challenges are especially vulnerable.

Advice on how to quit smoking is available from the [NHS Better Health website](#) >.

8. Feeding, Nutrition and Swallowing

Good nutrition is vital for the well-being of any child who has SMA.

Your child's muscle weakness may cause a weak suck. They may have trouble chewing or opening their mouth. Food may get stuck in your child's cheeks. This is sometimes called **pocketing**. Food residue may also build up in their throat (pharynx) due to weak muscles. This can make feeding and swallowing difficult.

Safe swallowing is one of the most important aspects of care. Children with a weak swallow are at risk of **aspirating**. This is when food, liquid, saliva or other material accidentally enters the airway and lungs. It should be swallowed into the stomach. It can happen while swallowing or when food, vomit or reflux comes back up from the stomach. This can cause choking and chest (respiratory) infections. It can also have more serious consequences like difficulty in breathing.

Feeding can be tiring for your child. Mealtimes can take longer. They may also be using a lot of energy and effort breathing. This can result in your child not gaining weight, or even losing weight.

Support from Healthcare Professionals

You may have advice and support on feeding, swallowing and nutrition from your child's:

- health visitor
- consultant
- speech and language therapist (SALT)
- dietitian
- community nurse.

Occupational therapists (OTs) and physios may also advise you on positioning and seating to help with feeding.

How swallowing is checked

Your child should have a clinical swallow assessment. This would include:

- asking you about your child's feeding and swallowing
- directly observing your child's feeding and / or swallowing

It may result in recommendations or modifications to:

- the pace of giving your child food
- your child's positioning
- the consistency of food and drinks given.

A **Video Fluoroscopic Swallow Study** is commonly set up after this. These studies won't be appropriate for all children. The clinical assessment will decide if it is. If one is done, it's organised by a SALT. The test uses a type of x-ray.

You'll also be asked if your child has:

- been bringing back up what they've swallowed (gastroesophageal reflux)
- had difficulties passing their bowel motions (constipation)
- been sick (vomiting).

Possible Options for How to Give Food

If your child has unsafe swallowing or isn't gaining weight, your clinical team may suggest other ways to feed your child.

The clinical team will make sure that you understand the possible benefits and risks for your child of any options suggested.

They will explain the ways the risks associated with swallowing difficulties can be reduced. They will discuss if these might work for your child so that they can continue oral feeding. This may involve trialling different **pacing, positioning, and food consistencies**.

Another option may be **fortification**. For example, food with higher calorie but a lower volume ratio. This would help with growth but reduce the pressure caused by volume and the impact this has on fatigue.

If your child does need any of these options, you will be provided with training and support so that you can feed your child safely at home.

Short-term options may include giving nutritional liquid food through a:

- **Nasogastric (NG) tube.** This is a thin flexible feeding tube passed through the nose into the stomach. Some children may have most of their nutrition through a tube. But, if advised by a SALT, they may be allowed 'tastes' by mouth
- **Nasojejunal (NJ) tube.** This goes through the nose into the middle part of the small intestine (the jejunum).

A longer-term option is a:

- **Gastrostomy tube.** This is also called a **PEG Tube** (percutaneous endoscopic gastrostomy). It's placed in the stomach via a surgical procedure. Another procedure which helps to reduce any reflux may be done at the same time. This is called a **Nissen Fundoplication**.

There are often options for mixed feeding e.g. some amount of oral feeding plus tube top-up.

Many children can still have tastes or small amounts of oral intake for pleasure alongside tube and PEG feeds. It's not all or nothing in many cases.

- **Blended diets**

These give real food blended to a consistency to be delivered via a gastrostomy tube. Blended diets can be used in the nutritional management of SMA from an appropriate weaning age. Check with your dietitian. Potential benefits include:

- improved gastrointestinal tolerance – less reflux and vomiting
- better stool patterns
- whole-food variety

They do though require careful planning with a clinical team to manage:

- feed thickness (viscosity)
- micronutrients, **and**
- food safety.

Blended diets must be designed with a registered dietitian. They must be specialised in the delivery of liquid food using a feeding tube (enteral nutrition). This will ensure a child who has SMA has adequate nutrition to sustain their expected growth.

Due to feeding tubes bypassing the mouth there are strict food safety guidelines. These include requiring:

- appropriate food preparation
- storage, **and**
- correct tube size or bore compatibility.

All this is needed to avoid tube clogging or bacterial contamination.

Due to the increased thickness of the blended formula, they can't be given through standard feeding pumps. Blended diets are therefore restricted to children who are fed by a syringe that gives liquid food or formula through a feeding tube. They have set amounts several times a day. This is called syringe bolus feeding. There are new generation feeding pumps on the market that can be purchased privately. Ask your dietitian for advice.

Blended diets aren't recommended for children who are fed into their small bowel (jejunal/ duodenal feeding). This is due to the increased risk of microorganism contamination. For the same reason, children who have a compromised immune system are also not recommended to have a blended diet.

Guidance for Diet

A dietitian should work out what calories your child needs. SMA-specific growth charts aren't available yet, so this may be based on standard growth charts for children. Your dietitian will take account of other individual measurements for your child.

Your child's diet will be adjusted so that they're getting the right calories, fluids and macro and micro-nutrients. Calcium and Vitamin D are especially important. These are needed for bone health. You'll also be advised how often to give your child food.

It's very important that your child has plenty of fluids, especially if they're unwell. You'll be advised about correct amounts and how often.

If your child is acutely unwell, experts suggest they should never go without food for longer than six hours.

This is especially important during respiratory infections or hospital admission. Food should include sugars and protein.

Due to reduced activity, it's common for children to become constipated. This can cause discomfort and reduce the movement of the diaphragm. This then restricts breathing. You'll be advised what medications to use to help this.

Oral hygiene

This is important not only for comfort but also for health.

Keeping your child's mouth clean can help keep their lungs healthy too. If food, drink, or saliva goes down the wrong way ('aspiration'), bacteria from the mouth can get into the lungs and make them unwell with a chest infection. In more serious cases it can develop into aspiration pneumonia.

Brushing teeth and cleaning the mouth every day helps remove this bacteria. This can reduce the risk of aspiration related illnesses. Advice is to:

- Brush teeth with fluoride toothpaste at least twice daily
- Clean the tongue as well as teeth and gums
- Remove food residue after meals
- Manage any 'dry mouth' (xerostomia), which can increase bacterial growth
- Support children who are unable to manage oral care independently.
- Continue oral care even for children who are tube fed or are not to have food, liquids, or medications orally (nil by mouth).

9. Cognition and Communication

SMA doesn't usually affect a child's intelligence or thinking.

As for any baby, playing and interacting with them is recommended from the early days onwards. For example, talking to them, reading and singing. You'll find ideas for play on our page:

- **[Toys & Play activities for babies and young children who have SMA >](#)** .

You may also want to ask for one of our [Multisensory Toy Packs >](#) .

[Tiny Happy People >](#) also offer useful resources.

There is though increasing awareness that some children with SMA Type 1 struggle with their general development. This can affect their learning or understanding or their ability to interact and communicate.

Children struggling in this way can be supported with their individual development and access to education. It's important to spot and address concerns early.

[Our webinar with experts >](#) may be of interest. It covers research, developmental signs, communication aids and recommended strategies. The panel also talk about how local and specialist teams can provide support. The resources they suggest are listed in **Section 18: Support and Resources**.

10. Emergency Care

It's important that you know how to access medical care and what early treatment there should be during any illness. This would include:

- **increased airway clearance**
- **early contact with the respiratory team**
- **early antibiotics where appropriate**
- **careful monitoring**
- **escalation to specialist respiratory or Intensive Care support if needed.**

Your medical team can arrange open access to your local children's ward.

Often, staff in Accident and Emergency (A & E) have never come across SMA. We've worked with clinical experts to produce:

- **Essential Information for Emergency Services when Assessing and Caring for a Child who has Spinal Muscular Atrophy >.**

You can give them this information sheet. Download it, have it ready on your phone or ask us to send you a printed copy information@smauk.org.uk

Always insist that A & E staff contact your child's specialist neuromuscular team. Treatment and management in SMA may be different compared to the general population of children. This includes treatment and management of fractures and severe injuries

Your child's team, including your respiratory physio, should also work with you to develop an **Emergency Health Plan (EHP)**. This records the treatment you wish your child to receive if there is an emergency or if their health deteriorates. For children at risk of breathing difficulties, it should include:

- specific respiratory information such as cough assist and any NIV settings
- airway clearance routines
- antibiotic plans
- emergency contact details.

Although these discussions can be difficult, they're important and should be had before a child is unwell. The team will discuss possible respiratory problems and the different ways that these can be managed.

An EHP can be reviewed at any time. You can change your mind about what it says.

With your permission, your child's EHP can be shared with professionals supporting your child. This can include ambulance services. Everyone is then aware of your wishes. You should have a copy so that you can give it to hospital services if you're away from your home area.

Note an **EHP** is not the same as England's **EHCP**. This is an **Education and Health Care Plan** > which is all about funding care and support.

11. Activity and Exercise

You should have the support and guidance of a specialist neuromuscular physio who's familiar with the impact of SMA Type 1. They'll be able to give you advice on simple exercises to support and progress your child's development.

Programmes are likely to include **stretching exercises**. These support the delay of your child getting stiff muscles. If muscles are weak, the joint becomes stiff, which leads to contractures. To make these exercises fun, you can try them to music or songs. Moving will help to maintain and develop a range of movement in your child's joints. It's also good for their circulation.

Appropriate exercises and activities may change with time and abilities. An individual programme is important as children start and progress differently.

Children often enjoy the additional freedom of movement provided by water. Your physio may suggest exercises when in the bath, swimming or hydrotherapy pool.

It's best not to take your child into a non-warm pool before they're six months old as they may have trouble regulating their temperature.

Their vaccinations must be up to date.

Speak to your child's clinical team about your local facilities and what might be suitable for your child.

You could be in the bath with your baby for exercise and fun. You'll need a second person to lift your baby in and out.

If your baby has a lot of difficulty with head control you may find a swim ring for their head will help. Ask your physio.

Encourage your child to make movements themselves. For example, if you position toys carefully and your child is comfortable, encourage them to try reaching out.

Children who are six months or older often like to play by passing toys between their hands. With supervision, and if it's safe and comfortable, your child may be able to lie on their side to enjoy this.

Your physio may show you how to use slings to encourage active movement without gravity.

You may find these SMA UK resources useful:

- [**Toys, Play & Activities for Babies and Young Children who have Spinal Muscular Atrophy >**](#)
- [**Physiotherapy through Play – Webinar with Experts >**](#)

12. Bath Time

Warm water helps with buoyancy, so bath time provides not only a fun playtime but also a good opportunity for exercise.

If you have a bath support for your child, you'll have your hands free for washing and playing. Your OT will advise which one's best for you and your child.

A towel with a head roll laid out ready will help keep your child well supported while you're drying them.

Though fun, bath time can also be tiring for your child. If they get upset after bath time you may need to keep it brief and follow it with a nap.

It's probably best to feed your child after the bath, not before. They might not like being handled with a full tummy.

13. Night Time

It's recommended that all babies sleep in their parents' bedroom for the first six months. You may need to do this for longer so that you can check on your child regularly. A baby monitor will help with this. There are many options available. Ask your health visitor or community nurse for advice.

You may need to reposition your child so that they don't get stiff and uncomfortable during the night.

Try to avoid having a room that's dry, stuffy, or too warm. This can make your child's secretions sticky and hard to remove. It's good to have some air circulation in the room but avoid any draughts.

It's usually best for your child to sleep on a baby mattress. These are more comfortable than ones for an adult. Specialist mattresses are also available for

babies and young children. They're made of memory foam which mould to the body. Some parents have found these helpful for their child with SMA.

Sleep systems may sometimes be provided to support your baby's limbs in an appropriate postural position at night time. These are wedges and rolls usually made of foam and fibre. Your OT and / or community nurse will be able to provide you with more information on sleep systems and suitable mattresses.

Some families have found it helpful to use a paediatric hospital cot which can be height adjusted. If their child has had difficulties moving, some have used an alternating pressure air mattress. This helps prevent pressure sores and for increased comfort.

Plenty of mattress covers, bedding and facecloths can be helpful. You can change and wash them when they get damp.

Several thin, light covers on top of your baby are useful so that you can add or remove a layer if your child gets cold or hot.

If you have any questions or concerns, speak to your community nurse.

It's important that you get rest and sleep. If your child needs a lot of help overnight, your local health services may be able to provide some night care to give you a break. Ask your health visitor, paediatrician or community nurse.

14. Getting Out and About

Many families find it challenging to find safe comfortable ways to get out and about with their child. Some children:

- find it hard to tolerate travelling for a long time and may get hot and sweaty
- need equipment with them to help their breathing and / or a portable suction machine
- need a carer beside them to monitor how they are.

How you get out and about and what equipment you need will depend on your situation. This includes your child's health, stage of development and motor abilities.

Your physio, OT and respiratory team are the best people to advise you.

If travel to get to and from appointments is difficult, ask your clinical team if it's possible to organise 'access to hospital' transport.

Buggies

Your child will need an adjustable buggy to allow their position to be changed. It's better for them to sleep flat. It's essential that you always take with you any equipment that your respiratory team has advised your child may need – such as a suction machine.

A strong and stable carrying basket or storage tray can be useful.

Your OT or physio should be able to help you find out about a make and model of buggy that will work well for you and your child. SMA UK can also let you know what models have worked well for other parents.

There's more information in the [Living with SMA Buggies section](#) >

Your Child's Mobility

SOME children are able to progress to using walking aids. These are usually orthoses. This decision must be made with the specialist physiotherapist. The type of walker and timing is crucial. It's important that this is ONLY started after careful assessment and discussion. Not all walking aids are appropriate.

• Wizzybug

This is a small powered 'wheelchair' for children under the age of 5 and weighing up to 20 kgs. With adult supervision it can be used indoors and outdoors and is easy to control. It may be suitable for children as young as 14 months. In time, one may be recommended for your child. Your OT or physio will advise you if one would be appropriate for your child.

Wizzybug is loaned to families free of charge by the charity Designability. After you have had a discussion with your physio or OT about this possibility for your child, you can self-refer. Your child will then be assessed further by a Designability OT. To be accepted onto the scheme, children:

- must have good, sustained head control
- need to be able to maintain a sitting position with the harness, headrest, lap-belt and chest (thoracic) supports provided
- don't need to have joystick skills or be able to 'drive'.

Find out more in the Living with SMA: [Wizzybugs >](#)

Car travel

If your child has breathing difficulties, their respiratory team should let you know what you need to do to travel safely in a car. This is **a risk assessment**. For some children, this may include:

- an adult always being with them in the back of the car
- being on non-invasive ventilation (NIV) or oxygen saturation (SpO₂) monitoring while travelling.

It's essential that you always follow the advice of your respiratory team. You must take with you any equipment they have advised and be able to use it when needed.

If your child's unable to sit, they're likely to need a rear-facing car seat and possibly additional head support. They may be able to use a standard car seat, but this may be too upright for them. Ask your physio or OT to check that your car seat has suitable recline or lie flat options. Your child needs enough support, including for their neck and head.

Weaker children should have a '**car seat challenge**'. This is carried out by the physio or OT to check that travel is safe. It's an observational assessment to make sure that your child's breathing is safe in a car seat. Your child's breathing pattern, oxygen saturation levels and heart rate are monitored. They look out for your child showing any signs of respiratory distress when they're in a particular car seat. A car seat challenge may be completed or considered as part of the respiratory team's risk assessment.

The [In-Car Safety Centres](#) > have information on car seats.

Your physio or OT may refer you to a Regional Driving Assessment Centre (RDAC). They'll work closely with a child's therapist to offer advice on car seats. You can find details of this service and where the centres are on the [RDAC website](#) >.

You can also ask [SMA UK's Community Support Team](#) > what car seats have worked for other families.

If you need help with funding, SMA UK may be able to provide a [FlexiGrant](#) >.

If travel is hard for you and your child, ask your clinical team about hospital transport for your appointments.

Car seats with a lie-flat facility are generally designed to carry younger children who are both lighter and shorter. So, you may find your child outgrows their seat. It can then be challenging to find a car restraint that's both safe and comfortable for an older bigger child. Ask your physio or OT for advice.

A specialist lie-flat buggy that goes directly into a wheelchair accessible vehicle (WAV) can be an option for older children. It must be one that has been crash tested for travel when secured in a reclined position. Your physio or OT may be able to advise you on a suitable one. Sometimes they're available through wheelchair services.

WAVs: can be leased through the **Motability Scheme** if:

- a child is **over** 3 years old **and**
- receives the enhanced (higher) rate mobility component of Disability Living Allowance.

Some parents purchase their own vehicle. Others secure their buggy in an accessible taxi.

Find out more about Wheelchair Accessible Vehicles and the Motability scheme.

The Blue Badge scheme is run by local authorities. This entitles people with severe mobility problems to parking concessions.

The minimum age for Blue Badge applications is 3 years. But you can apply for children under 3 who:

- need bulky medical equipment **and**
- must stay near their vehicle to access treatment.

Find out more about these special circumstances and possible Road Tax concessions.

Go to Living with SMA: Tab 1 Car Travel [Transport & Holidays](#) >

If your child can't use a car seat for medical reasons, you can contact your GP for a certificate which will explain why. This is a 'certificate of exemption from compulsory seatbelt wearing'. You'll need to carry this document at all times in your car.

Find out more at: [Seatbelts: the law](#) >.

15. Palliative Care

Palliative care is often associated with end-of-life care. Though this is one aspect, unless needed it is not a focus for these services which provide support and respite to families at any stage of a child's life.

Palliative care may be offered as an option during discussions about treatments. Services vary across the UK. They may be in hospitals, children's hospices and at home. They're provided by different healthcare professionals. They work together as a team aiming to actively support the physical, emotional and practical needs of any child and family.

Palliative care includes providing information and practical support. This includes the management of symptoms, and the provision of short breaks from caring. The overall aim is to achieve the best quality of life for a child, whichever medical options are chosen.

Services offered may include [children's hospices >](#). These support families, both practically and emotionally. As well as offering nursing care, they provide a range of services. These may include physiotherapy, complementary therapies and play and music therapy.

Palliative care services can support a family to make decisions about their baby's ongoing care. They can also discuss a family's wishes for their child's future care should they become very unwell. Your child's consultant, care advisor or specialist nurse can advise you about services available in your area.

16. Financial Support and Care & Support Packages

Families living in the UK may be eligible for financial benefits to help towards the cost of providing the extra care their child may need. This depends on your individual circumstances. For further information, see: **Living with SMA: [Financial Support & Benefits](#)** >. This page also has a section on **Cost of Living Support**.

Your child may also be eligible for health and social care support and how this links in with education support. Our website section on this discusses what assessment route would be best for your child. It also covers what you can do to get ready for any assessment. See: **Living with SMA: [Children, Support Packages](#)** >.

There are a number of people who may be able to help you with applications for financial benefits. They include your health visitor, community nurse, neuromuscular care advisor and social worker.

There are also charities that may assist you with the cost of general household goods, specialist equipment and holidays or days out. For more information, please contact **[SMA UK's Community Support Team](#)** >

17. Emotional Support

The emotional impact of a diagnosis of SMA Type 1 comes with the need for rapid decision making about drug treatment and care. Family, home and work life need to be organised around this. If you have other children, you will be keenly aware of their needs. Managing all these responsibilities 24 hour-a-day can be physically, emotionally and psychologically exhausting.

- **[Hearing your Baby's Diagnosis of Spinal Muscular Atrophy >](#)** talks about the impact of this and what support is available
- **[Family and Friends / Challenges and Support >](#)** may also be helpful. It includes Siblings and Grandparents and gives links to resources and support
- **[Children's emotional and psychological mental health and well-being](#)** may be useful over time .

Even though you'll be focused on your child, it's important to look after yourself as well. Remembering things like keeping up to date with your own health checks and getting the 'flu' and any other jabs is important.

18. Support and Resources

Resources to support the development of cognition & communication:

- [When do Babies Start Talking? >](#)
- [Child's Progress Checker >](#)
- [Signs & Symptoms >](#)
- [Children Communicating in Different Ways >](#)
- [Enabling Better Lives for People with Communication & Swallowing Needs >](#)
- [Augmentative & Alternative Communication >](#)

SMA UK

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Our small, experienced [Community Support Team >](#) offers a UK-wide service for anyone affected by SMA. We're flexible in how we can support you and can be in contact by email, phone, text or virtual meetings (such as on Google Meet or Microsoft Teams). We're also able to home visit if you'd find it helpful to talk something through in person. Though we don't give medical advice, we can discuss with you the support you and your family can access.

[Multisensory toy packs >](#) We have two different packs suitable for infants living in the UK who are:

- aged up to 12 months or
- 12 to 24 months of age.

Each family may have one of these packs free of charge.

The [Living With SMA area of our website >](#) gives useful information and ideas. It builds on knowledge and advice from the SMA Community and SMA UK's Support Team. It covers a whole host of topics. They include: equipment, homes, nursery, transport, leisure, holidays, finances, emotional and social support.

We offer a number of ways for you to [Connect with the SMA Community >](#)

We have a number of [Grant Schemes >](#) that may be useful.

We work with [Rareminds >](#) to offer a counselling service.

Any family affected by SMA and living in the UK, can request a free copy of **Our SMArt World**. Written for children age 7 – 11, it's all about SMA and living with the condition. **Smasheroo** is another free book written for younger children. You can order these and other items through [our shop >](#)

Other resources that may be useful are listed in our [Resource Hub >](#)

You can keep up to date about events, new research developments and much more by [signing up for our monthly E-news >](#).

Contact for Families with Disabled Children

Phone: 0808 808 3555

Website: www.contact.org.uk

They provide information and support to families who have a disabled child. This includes information on benefits and grants.

Muscular Dystrophy UK

Phone: 0800 652 6352

Website: www.musculardystrophyuk.org

They provide information, support, advocacy services and grants towards specialist equipment.

Treat SMA

Website: www.treatsma.uk

They offer independent information, real stories and practical support.

Children's hospices

These are located throughout the UK. They offer a wide range of services and support to eligible children and families; some also offer short breaks. More information and details of hospice services are available from [Together for Short Lives >](#)

Thank you to the parents and families affected by SMA Type 1 who have passed on their tips and suggestions.



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This page, and its links, provide information. This is meant to support, not replace, clinical and professional care.

Find out more about [how we produce our information >](#).

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