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

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.

Who this is for

This guide is for parents and carers whose infant:

- has had a diagnosis of Spinal Muscular Atrophy (SMA) Type 1 ***and***
- is having difficultly trying to sit or roll independently.

In this guide

This guide tells you about some of the practical sides of caring for your infant. It is designed to be used alongside medical advice. This must always come from your child's medical team. It tells you more about:

- Treatment & Care
- Your child's healthcare team
- Vaccinations
- Posture, mobility and exercise
- Breathing and eating
- Cognition and communication
- Emergency care
- Activity and exercise
- Bath time and night-time
- Financial and emotional support

We cover information about the healthcare your child may need, as well as tips and suggestions that have worked for other families. 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 with 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. You might find some sections in **Looking After Your Child who has SMA Type 2 >** more relevant and useful.

1. Treatment and Care

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.

There are now three drug treatments currently funded by the NHS 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 is available and suitable for your child.

You may find it helpful to read our page on Drug Treatments for Children who have 5q SMA >. This tells you about the treatments, how they work, and which children may have access. There are links to pages with more details.

Your child's medical team will also discuss your child's healthcare and support needs with you. This will vary from child to child. It will be based on the clinical team's assessment of your child and a full discussion of this with you.

SMA REACH UK > **is the national clinical and research network set up to understand more about SMA. Information about a child's progress is vital to help with this. Children receiving treatment and care are assessed every six months when they attend their clinic appointment. Your Centre will tell you more.**

Your team may refer to the 2017 International Standards of Care for SMA (SoC) > and the Family Guide to the 2017 SoC >. These were written before the new disease-modifying drug treatments became more widely available. Even then, recommended standards of care for children, young people and adults varied and were based on:

- **whether they could sit, stand or walk**
- **whether their breathing was affected by their SMA**
- **what other daily living activities they could manage.**

This guide reflects the standards of care for a child who it describes as a 'non-sitter' – unable to sit or roll independently. The guide recognises that, with drug treatment, this may change over time.

A 3-year project is now underway to update these standards for the UK. Clinicians and patient reps are reviewing all aspects of care and management. You can find out more and keep up to date with recommendations at SMA Care UK >.

2. Your Child's Healthcare Team

Your child should 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. Some will be based at the hospital; others will be in the community. You may have contact with specialists in:

- neuromuscular conditions
- paediatrics
- breathing (respiratory) care
- physiotherapy
- orthotics
- occupational therapy
- dietetics
- speech and language therapy
- palliative care (see below)
- general practice and community health care

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

Our Guide Who's Who of Professionals > tells you more about these specialists. Roles within a team may overlap. For example, a task or assessment may be performed by either a nurse, physio or doctor. Roles may also vary between centres. For example, a nurse in one centre may carry out different tasks to a nurse in another centre.

The aim of everyone involved in your child's care is for your child to stay healthy and enjoy a good quality of life. Different members of the team will meet you regularly. This will be to monitor changes in your child's health and development and to 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.

At every appointment with your child's medical team, you should have time to ask questions. You can then decide jointly on the best support for your child.

2. Vaccinations

Children who have SMA should have all recommended vaccinations. This includes pneumonia vaccine. Flu and covid vaccines should also be added.

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. In the UK, to access the NHS-funded RSV palivizumab vaccine to prevent infection, babies and children with SMA must need routine non-invasive ventilation at home.

On 1st September 2024, a new **RSV pregnancy vaccination for infant protection programme >** was introduced. All women who are at least 28 weeks pregnant should now be offered a single dose of Pfizer's ABRYSVO vaccine. This will help protect babies against RSV from birth through the first 6 months of their life.

If your child is over 6 months old and vulnerable to breathing difficulties (respiratory compromised), but does not need long term ventilation, talk to your specialist clinicians about any concerns you have.

Though it is impossible for you to prevent your baby catching all possible viruses, you may want to try to avoid direct contact with others who have coughs and colds.

3. Safe and Comfortable Positions

The wide variation in how SMA affects children and how they respond to drug treatments makes it hard to advise on safe, comfortable positions.

Your physiotherapist (physio) or Occupational Therapist (OT) will advise you on the best options for your child. The following, more general points may be helpful. Not all will apply to your child:

- All babies begin by lying flat. Progressing to supported sitting or lying semi-reclined will depend on how easy it is for your baby to breathe. It also depends on how their muscle strength and head control are developing.
- It is important not to sit a child upright too soon if they are weak. This can encourage the development of a spinal curve. Your physio may advise that a spinal brace (an orthosis) will help with sitting. They 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.

If your child is a 'tummy breather' this means that they may be more dependent on their diaphragm muscle. This muscle sits at the bottom of the chest and above the stomach. It is pulled down in order to inflate the lungs and so the tummy moves outwards as this movement occurs. This means that being in some positions may make breathing harder work. Please follow the advice provided by your physio.

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

- Deeper breathing is important as it can help to prevent secretions building up in your child's lungs. Your child also needs to be in a position to be able to swallow safely and manage any saliva and secretions. Your child's Speech and Language Therapist (SALT) will advise you. (See the section below on **Diet, Nutrition and Swallowing**).

- It is 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 is also important to seek advice on best positioning in general from your physio, OT or respiratory team, especially before putting your child in a more upright position. You may need specialist advice from a Speech and Language Therapist (SALT) for safe positioning for your child when feeding.
- If your child does dribble a lot due to difficulties with swallowing saliva, your Speech Language Therapist will give you advice about how to manage this. Some families have found that a face cloth, muslin square or breast pad under their child's head has helped to soak up saliva. This can easily be changed when it gets wet.
- If your child is lying on their side, it is important to check that their arm and shoulder are not trapped and that their ear is flat. You may find that a rolled-up blanket against your child's back will 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 and can also be used in their buggy. However, sheepskins can make children hot, so do keep an eye on their temperature and whether they are getting sweaty.

- If your child is lying on their back and their legs tend to roll outwards, you may find it helps to use a small wedge or rolled up blanket on either side of their hips, or a small roll under their knees. You can also try using rolled up towels and soft toys as positioning aids. Again, your physio or OT can advise.
- Sometimes, for older infants, your physio or OT may advise a sleep system. This uses wedges and rolls (usually made of foam or fibre) to provide 24-hour postural support to help protect body shape while your child is sleeping.

If needed, your community physio or OT may be able to provide wedges or foam inserts which are 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 have any concerns, contact your community children's nurse or health visitor as soon as possible 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.
- As your child gets older, they will want to see more of what is going on around them. If your child struggles to change position, they will 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 can advise and may provide foot or knee or hand splints to help with this.

Even with drug treatment, SMA can weaken the muscles which support the spine. Without this support, the spine can be pulled by gravity, and curve.

- When the spine starts to curve sideways into a 'C' or an 'S' shape, it is called a **scoliosis.**
- When the spine bends forward it is called a **kyphosis.** This can affect the shape of the chest.

Your child may be prescribed a spinal brace to assist with sitting and head control. Your child's spine will be monitored for any sign of a curve.

It is widely agreed that spinal bracing may delay the progression of scoliosis, but it will not prevent it developing. Your child's team will monitor your child carefully. They will suggest any interventions based on your child's individual needs and situation. Your child will be referred to the spinal team for advice.

If your physio assesses that your child needs an individually fitted spinal brace or jacket, they 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.

Your OT or physio can assess your child's seating needs and provide advice on seating, including car and bath seats, which offer appropriate support for your child. Your OT or physio may also see if your baby would be comfortable in a seat that will give a lot of support when they are semi-upright. If this works for your child, you may find it is easier for them to play.

3. 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 – which is attached to the base of the breastbone (sternum), the lower parts of the rib cage, and the spine – contracts. This 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 causes these intercostal muscles to be weakened. This can result in a 'bell shaped' chest and poor inspiration. This results in reduced lung volume. SMA does not impact so much on the diaphragm itself.

When we breathe out (expiration), we get rid of waste gas (including carbon dioxide) from the lungs. This does not need particularly strong muscles as it is a passive movement. However, coughing requires strong muscles to be able to clear secretions.

Weak breathing muscles are common for infants with SMA Type 1 who are unable to sit as well as those who can sit but are unable to walk unaided. 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 cannot get rid of enough of the waste gas produced by breathing – which includes carbon dioxide. This is known as **'hypoventilation'.**
- It may make it difficult to take in enough oxygen while asleep. This is known as sleep-disordered breathing and is a main cause of ongoing respiratory issues.

It is important that a respiratory clinician and specialist respiratory physio is involved in your child's care as soon as possible after diagnosis.

• Regular respiratory check-ups

The **2017 Standards of Care (SoC) Section on Breathing ›** advises that all infants with SMA who are unable to sit should have a physical examination in clinic as soon as possible after diagnosis. This should then be repeated regularly, at least after 3 months and then at least every 6 months. Your child should also have regular 'sleep studies' so that their overnight breathing can be tested.

Any updates to this advice will be published once this area of care has been reviewed by the SMA Care UK › project. Your child's clinician will be up to date with any changes.

Since the covid-19 pandemic, more studies are done at home, though hospital versus home practice varies across the UK. If the sleep study is at home, your child may have a small clip on a finger which will record information. Depending on the hospital that has coordinated this, they may also have a sensor to measure the waste gas, carbon dioxide. As home studies are only able to monitor oxygen and sometimes carbon dioxide, in-hospital sleep studies 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 are monitored overnight.

'**Sleep disordered breathing'** for infants who have SMA Type 1 often does not show with just a sleep study alone as it is more complex. Your child's team will explain if any other observations or assessments are needed.

All these tests will help the clinicians, and you decide what are the best options for managing your child's breathing and keeping them as comfortable as possible.

• Possible options for managing breathing

Though each child is different, it is 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.

The options you may learn about, and use will depend on your child's breathing support needs. They may include:

- **Chest physiotherapy.** This is to help keep your child comfortable and clear secretions from their chest. How often children need this varies. You will be advised what is best for your child and may be trained and supported to do chest physiotherapy yourself.
- **Medications – such as glycopyrrolate.** These may be prescribed as they can reduce the volume of your child's secretions and / or saliva. They must be used carefully. Too high a dose can dry out the secretions too much. This then makes them harder to remove. Your medical team will monitor and change the dose as needed. Again, your child's team will talk to you about this.

If your child is assessed as needing any of the following equipment, you will be given training and support to use it:

- **A nebuliser.** This is a small machine that turns liquids into a mist that can be easily inhaled. It is often used with a salt (saline) solution or other prescribed medication 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. It can also be used with antibiotics. If a nebuliser is needed, your child's team will talk to you about when to use it and with which medication.

- **A suction machine.** This is used to help remove your child's excess secretions and / or saliva. Your physiotherapist or another member of your medical team will talk to you about when and how to do this.

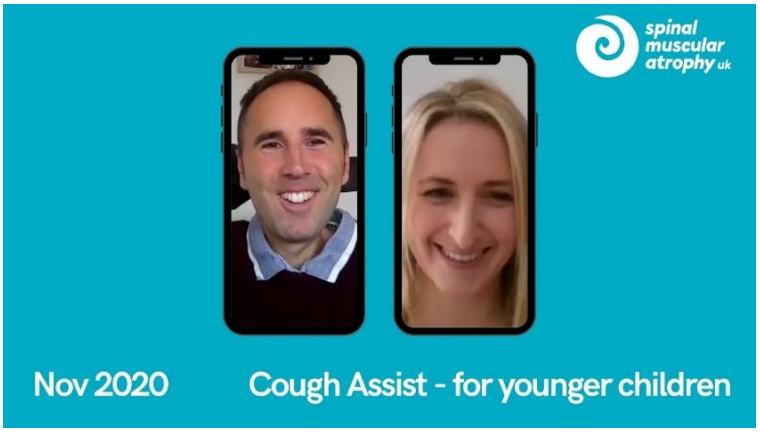
- **Cough assist.** This is the name often given to a mechanical insufflation – exsufflation machine. It helps to clear secretions from your child's lungs and create a more effective cough. Your respiratory physiotherapist will assess if it would be helpful for your child.

- **Antibiotics.** These may need to be prescribed quickly for your child when they are at risk of, or to treat, a chest infection. Your child's team may discuss using antibiotics regularly to prevent chest infections (prophylactic use).

- **Non-invasive ventilation (NIV).** This uses a machine with a mask to provide gentle pressure to enhance breathing and expand the chest with each breath. This can help your child get rid of carbon dioxide and take in more oxygen, making breathing easier. The mask is individually fitted for your child by a respiratory specialist. When your child's breath triggers the ventilator, it delivers a supported breath in. As they start to breathe out, the machine cycles into exhalation, allowing them to breathe out normally. There are a number of different products available. BiPAP is one example.

  Every child is different and the timing to start NIV is based on individual assessment. Your child's respiratory specialist will talk with you about if, when and why your child may benefit from starting to use NIV.

Information from your child's 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.



Our November 2020 video about cough assist ,chest physio and ventilation for younger children may be helpful.

Our February 2021 video about non-invasive ventilation for younger children may also be helpful.

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 ventilation such as 'continuous positive airway pressure' (CPAP) are no longer recommended for most individuals.

- **Oxygen.** This is not used regularly. Your respiratory specialist will be able to advise you if or when your child should use it.
- **Short-term invasive ventilation.** This may be used if your child has a medical emergency. A flexible plastic tube (endotracheal tube) is passed through the mouth or nose into the windpipe.
- **Tracheostomy.** This may be considered for some children when NIV does not work. This is surgery that creates an opening in the windpipe to allow breathing through a tube rather than the mouth. This would be long-term and a big step that does not suit everyone. If this is something that might need to be considered for your child, it is helpful if your clinical team has early discussions with you. Ideally this would be while your child is well and before any episode of acute ill health.
- **Pain relief.** Now children receive disease-modifying 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 who are exposed to second-hand smoke are more likely to contract a serious respiratory infection that requires hospitalisation. Children with SMA who have respiratory challenges are especially vulnerable.

Advice on how to quit smoking is available from the NHS Better Health website >

4. 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 (sometimes called pocketing). 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, or other material accidentally enters the airway and lungs instead of being swallowed into the stomach. It can happen while swallowing or when food 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

There are a number of healthcare professionals who will give you advice and support on feeding, swallowing and nutrition. These include your:

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

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

- ## Regular Checks

The **2017 Standards of Care (SoC) Section on Nutrition, Growth & Bone Health** > recommends that all children who are unable to sit should have a swallow study shortly after diagnosis. This should be repeated if they show other signs of difficulties.

The test most often used to find out what is going on during swallowing is a **Video Fluoroscopic Swallow Study.** This will be organised with a Speech Language Therapist. This uses a type of x-ray. You will also be asked if your child has:

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

This section of the SoC also recommends that a dietician reviews feeding and diet every 3 – 6 months for younger children and annually for older children.

Any updates to this advice will be published once this area of care has been reviewed by the SMA Care UK > project. Your child's clinician will be up to date with any changes.

• Possible Options for How to Give Food

If your child has unsafe swallowing or is not gaining weight, your clinical team may suggest other ways to feed your child.

There are several possible options. You should be given time to discuss and ask questions about the reasons for any that are suggested to you so that you understand the possible benefits and risks for your child. If you 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 speech and language therapist, 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:

- **Gastrostomy tube.** This is also called a **PEG Tube** (percutaneous endoscopic gastrostomy). It is 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**.

- ## Guidance for Diet

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

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

Currently, professional opinions are divided on the Amino Acid diet. It is based on an elemental formula. Some doubt its benefits. Professionals do all agree that the type of diet and how it is given should be based on each child's reactions and should be regularly reviewed.

You may find our webinar: New Research Findings – The Amino Acid Diet interesting.

It is very important that your child has plenty of fluids, especially if they are unwell. You will 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 should include sugars and protein.

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

5. Cognition and Communication

SMA does not usually affect a child's intelligence or thinking. However, there is increasing awareness that some children with SMA Type 1 struggle with their general development, learning or understanding. This shows how important it is to spot and address concerns early. Strategies can then be put in place to support individual development and educational attainment.

Our webinar with experts covers research, developmental signs, communication aids and recommended strategies that may be needed to help. They also talk about how local and specialist teams can provide support.

We have listed a number of useful resources that were suggested in the Support and Resources section below.

6. Emergency Care

It is important that you know how to access medical care in case your child has a respiratory emergency. Your medical team can arrange open access to your local children's ward.

Your child's team, including your respiratory physio, should work with you to develop an **Emergency Health Plan (EHP)** (Note this is not the same as England's **EHCP**. This is an **Education and Health Care Plan >** which is all about funding care and support).

An **EHP** records the treatment you wish your child to receive if there is an emergency or if their health deteriorates. Although these discussions can be difficult, they are 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.

The plan can be reviewed at any time. You can change your mind about what intervention the EHP records that there should be.

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

Often, staff in Accident and Emergency (A & E) have never come across SMA. We have 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.

7. Activity and Exercise

You should have the support and guidance of a specialist neuromuscular physio who is familiar with the impact of SMA Type 1. They will be able to give you advice on simple exercises to support and progress your child's development. Programmes are likely to include stretching exercises to help prevent your child getting stiff muscles. If muscles are permanently tight, the joint becomes rigid and stiff (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 is 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 is best not to take your child into a non-warm pool before they are six months old as they may have trouble regulating their temperature.

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 will need a second person to lift your baby in and out.

You should also 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.

If your child is six months old or older, and, with supervision, is safe and comfortable lying on their side, they may have an easier time bringing their hands together and passing toys between them to play.

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

You may find this SMA UK guide useful:

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

8. 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 will have your hands free for washing and playing. Your OT will advise which one is best for you and your child. Having a towel laid out ready with a head roll for after the bath will help keep your child well supported while you are 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 is probably best to feed your child after the bath, not before. They might not like being handled with a full tummy.

9. Night-Time

It is 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 do not get stiff and uncomfortable during the night.

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

It is usually best for your child to sleep on a baby mattress as these are more comfortable than ones for an adult. There are also specialist mattresses available for babies and young children made of memory foam which mould to the body. Some parents have found these helpful for their child with SMA.

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

Some families have told us that they find it helpful to use a paediatric hospital cot which can be height adjusted. Others whose children have had difficulties moving have said that they have used an alternating pressure air mattress to help prevent pressure sores and for increased comfort.

It can help to have plenty of mattress covers, bedding and facecloths so that 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 is 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.

10. A Comfortable Temperature

Babies with reduced movement are likely to become hot as they cannot 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 are 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 is not 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 are 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 is 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 are out and about.

As you child grows you may want to look at clothing to make changing easier. You can find some suggestions of where to look on this page: **Bathroom, Toilet, Clothing ›**

11. 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 and 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 is possible to organise access to hospital transport.

• Buggies

Your child will need an adjustable buggy to allow their position to be changed. It is better for them to sleep flat. It is 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 is more information in the Buggies section >

- ## 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 Deisgnability. You can self-refer for your child to be assessed for one by them. 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
- do not need to have joystick skills or be able to 'drive'.

Find out more about Wizzybugs >

- ## Car travel

If your child has respiratory needs, your child's respiratory team should talk you through what your child needs to be safe when they are travelling in a car (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 is 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 is unable to sit, they are 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 and enough support for your child, 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 is 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 are in a particular car seat. A car seat challenge may be completed or considered as part of the respiratory team's risk assessment.

As your child grows, if you have difficulty finding a suitable car seat, ask your OT or physio for advice. You can also ask SMA UK's Community Support Team what car seats have worked for other families and about possible sources of funding.

Your physio or OT may refer you to a **Regional Driving Assessment Centre (RDAC)**. They will 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 ›**

If your child needs to lie flat to travel, but cannot use a car seat safely and comfortably, a possible option might be an **E-Z-On Harness**. This allows a child to be strapped in while lying flat along the length of the back seat of a car. Ask your physio or OT for more information.

The In-Car Safety Centres › have information on car seats. The E-Z-On Harness > is also available from them. They are in Milton Keynes, Essex and Belfast. If you need help with funding, SMA UK may be able to provide a FlexiGrant >.

If your child is older and has to lie flat, another alternative to a car seat is to secure a specialist lie-flat buggy in a wheelchair accessible vehicle (WAV). Your physio or OT may be able to advise you on a suitable buggy that has been crash tested for travel when secured in a reclined position. Sometimes they are 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.
- For families whose child is **under** 3 years, has complex needs and meets eligibility criteria, the **Family Fund Mobility Support Scheme** aims to give access to a lease car tailored to their individual mobility requirements.
- 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 in the Car Travel section of Living with SMA/ Transport & Holidays ›

Any buggy secured in a WAV or accessible taxi must be a model that has been crash tested.

If your child cannot 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 will need to carry this document at all times in your car. For more information on this, visit: Seatbelts: the law ›

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 in certain cases. This is for children with medical conditions that need bulky medical equipment. It is also for those who must stay near their vehicle to access treatment.

To find out more about these special circumstances and how to apply visit **Gov.Uk/Blue Badge ›**

12. Palliative Care

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

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

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. 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 and 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.

13. Financial Support

Families living in the UK may be eligible for a number of 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: **Financial Support & Benefits ›** .

Your health visitor, community nurse, neuromuscular care advisor, family support worker, social worker or outreach worker may be able to help you with applications for financial benefits.

There are also a number of 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.**

14. 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 and organising family, home and work life around this. The 24 hour-a-day responsibility of caring for your child 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.
- **Children's emotional and psychological mental health and well-being ›** may be useful over time.

Even though you will be focused on your child, it is 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 Covid jabs is important.

15. Support and Resources

Resources to support the development of cognition & communication:

- **When do Babies Start Talking? >**
- **Child's Progress Checker Signs & Symptoms >**
- **Other Ways of Speaking >**
- **Enabling Better Lives for People with communication & swallowing needs >**
- **Augmentative & Alternative Communication >**

SMA UK

Phone: 01789 267 520
Email: office@smauk.org.uk
Website: www.smauk.org.uk

Our small, experienced **Community Support Team** offers a UK-wide service for anyone affected by SMA. We are flexible in how we can support you and can be in contact by email, phone, text or virtual meetings (such as on Zoom or Microsoft Teams). We are also able to home visit if you would find it helpful to talk something through in person. Though we do not 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 Services Team. It covers a whole host of topics, including: equipment, homes, nursery and school, transport, leisure, holidays, financial, and 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.

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 is 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

Provide information and support to families who have a disabled child, including information on benefits and grants.

Muscular Dystrophy UK

Phone: 0800 652 6352

Website: www.musculardystrophyuk.org

Provide information, support, advocacy services and grants towards specialist equipment for people affected by a range of neuromuscular conditions.

Children's hospices

Located throughout the UK, these also 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.

Version 15

Author: SMA UK Information Production Team

Last updated: June 2025

Next full review due: November 2026

Links last checked: November 2024.

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

Find out more about ***how we produce our information>.***

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