Looking after your child who has had a recent diagnosis of SMA Type 2

You can also read this guide on our website at smauk.org.uk/lk8q where you can follow all the links we give to further information.

Who this is for

This guide is for parents and carers whose child:

- has had a diagnosis of Spinal Muscular Atrophy (SMA) Type 2 ***and***
- is having difficulty with standing and / or walking.

In this guide

This guide tells you more about:

- Treatment & Care
- Your child's healthcare team
- Vaccinations
- Posture, mobility and exercise
- Breathing and diet
- Emergency care
- Financial and emotional support

These pages tell you more about some of the practical side of caring for your child. They combine information about the healthcare your child may need, along with tips and suggestions that have worked for other families. You may also want to read our information guide: **Hearing Your Child's Diagnosis of Spinal Muscular**

Atrophy > This covers the emotional aspect of receiving the diagnosis and some suggestions of who can provide support.

As all children respond to treatment and develop differently, you may find only some of the sections in this guide helpful. Your child's clinical team can advise you on this. You might find some sections in **Looking After Your Child who has SMA Type 3 >** more helpful.

1. Treatment and Care

Since 2016, new disease-modifying drug treatments have had positive results for many children, young people and adults who have SMA Type 2.

The impact of SMA Type 2 and how children respond to any drug treatment varies greatly from child to child and may change over time.

In the UK, the NHS currently funds two possible treatments for children, young people and adults who have SMA Type 2. Your child's medical team will talk you through what is known about each one, the benefits and any risks. They will decide with you on the best option 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 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 'sitter' – able to sit but not able to walk 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. The number of people in this team can feel a bit overwhelming, but they all have an important role to play. Over time, you may have contact with hospital and community specialists, including in:

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

Our Guide Who's Who of Professionals › tells you more about these specialists. Roles within a team may though 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 to promote their health, well-being and independence. 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.

3. Vaccinations

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

4. Posture, Mobility and Exercise

Children with SMA who can sit but who have difficulties standing, need specialist support for their posture and mobility. Your child should have a specialist neuromuscular physiotherapist (physio) who is familiar with the impact of SMA Type 2. They will design a personal exercise routine for your child and support you with this. It may include exercises to help to:

- encourage good posture
- encourage active movement to improve ability to manage their day to day activities and increase independence
- maintain and strengthen muscles
- maintain and further develop their range of motion
- reduce any discomfort
- stretch any tight muscles

If muscles are permanently tight, the joint becomes rigid and stiff (contractures). Regular gentle **stretching exercises** can help. Your physio will advise you. If the contractures are causing pain, it is important to talk to your child's clinician and physio.

Children often enjoy the additional freedom of movement provided by water. Your physio may suggest exercises when in the bath, swimming or hydrotherapy pool. Hydrotherapy is not available in many areas but speak to your child's team about your local facilities and what might be suitable for your child.

Your child's physiotherapy programme should also include **active exercises**. The programme may be carried out by family members or an assistant at school or nursery once they have been trained by the physio.

Regular moderate exercise will help with your child's fitness and energy levels. Activities like swimming and horse riding can be adapted to suit your child and are a fun way to exercise. As fatigue is also common in SMA, your child should not be pushed too hard. Their specialist physio will be able to advise.

Your OT will advise you on the best seating for your child. It should support them comfortably to help them play with toys, eat independently, and join in at home and school. Some children may need a spinal brace to help support them if they get tired when they have to sit for a long time. This would be organised by your physio and orthotics.

Your physio or OT will provide any equipment needed to support your child's standing and positioning. This may include a standing frame. Some children may be assessed as needing splints (sometimes called orthoses) for support. These would be made to measure specifically for your child by an orthotist. They would explain how to use them and how they can help.

Supported standing is good for many things including breathing, blood circulation, bladder, bowels, bones and joints. Your physio will advise you how often and for how long and with what equipment or orthoses (such as a brace or splints).

Children with SMA who are able to sit and are as young as 14 months can often manage to use a 'Wizzybug'. Driving one of these 'first wheelchairs', with their fun practical design, means they can explore and join in with other children and members of the family. Later, depending on their motor development, they may need to use a lightweight manual wheelchair or a small, powered wheelchair. Self-propelling a light-weight wheelchair is useful on flat surfaces for short distances. It promotes independence and provides arm and aerobic exercise.

This will make a big difference to joining in at nursery or school and when going out. These are all important and positive ways to encourage your child's independence. Your child's physio and OT will be able to advise you what will work best for your family.

Find out more about Wizzybug and first powered mobility >.

Your OT may suggest your child has a sleep system. This can assist with 24 hour postural support and help to preserve good body shape. It uses foam or fibre wedges and rolls to support the back, arms, and legs maintaining a straighter, more comfortable position.

Your OT can also advise you on adaptations and equipment to help your child with daily home and school tasks, like writing, playing, washing, dressing, and eating.

You may find this guide useful: Toys, Play & Activities for Babies and Young Children who have Spinal Muscular Atrophy >.

As your child gets older, your team will monitor the impact their SMA and muscle weakness is having on their posture when they sit or stand. 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 'S' shape it is called a **scoliosis.**
- When the spine bends forwards it is called, a **'kyphosis'.**

It is good practice for your child to be referred for spinal advice and monitoring early. If there are signs of curving, they may be provided with a spinal brace. Your child may already have one to help with sitting.

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.

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 and orthotist will explain when, and how often, your child should wear their brace.

If your child's spine is curving beyond a certain point, a spinal consultant should be monitoring their spinal posture. If needed, surgery may be suggested and will be discussed fully with you.

5. Breathing

- ## Why breathing (respiratory) difficulties are common for children and adults with SMA Type 2

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 children, young people and adults who have SMA Type 2. This can cause breathing problems, especially during sleep. This is a known as **sleep-disordered breathing** and is a leading cause of health issues,

If children do have problems, it is often due to having a weak cough and only being able to take in smaller breaths. Every child is affected differently, but the main problems caused by weak breathing muscles are that:

- It 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'.** Some of the symptoms for this are:
    - Breathlessness
    - Daytime sleepiness or sluggishness
    - Dizziness
    - Fatigue
    - Headaches
    - Loss of appetite
- It may make it difficult to take in enough oxygen while asleep.

• Support from a respiratory specialist

If your child has breathing problems, their team will include a respiratory consultant and a respiratory physio. They know what impact SMA can have on breathing. They will monitor how it is affecting your child and discuss the best management options with you. You can talk to them about any worries you have about managing your child's breathing and what to do in an emergency.

• Regular respiratory checks

Though breathing problems occur less often than for children who are unable to sit, the **2017 Standards of Care (SoC) section on Breathing for Sitters >** still recommend

that children should have a physical examination at least once every six months. At this appointment, they should have their breathing checked. If they can understand how to use it, they will use a machine called a spirometer. This measures the amount of air your child can breathe out in one second and the total volume of air they can exhale in one forced breath. These measurements will help show how well their lungs are working and the strength of their cough.

If your child has poor sleep quality, headaches, or daytime sleepiness these may be symptoms of night-time breathing difficulties. You would expect them to have an overnight sleep study. Sleep studies should anyway be routine to pick up possible hypoventilation before any symptoms appear.

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 done at your home, your child will have a small clip on a finger, which will record information. If this is done in the hospital, small sensors are attached to your child's face, head, arm and chest and they are monitored overnight. As home studies are only able to monitor oxygen and sometimes carbon dioxide, in-hospital sleep studies are more thorough.

All these tests help the clinicians, and you decide on the best options for managing any difficulties your child may have with breathing.

• Possible options for managing breathing

If your child has a weak cough, it can at times make it difficult for them to clear their secretions. This increases their risk of chest infections. There are a number of options

to help manage this, which you can discuss with your child's respiratory specialist and clinical team. Not all of them will be appropriate for your child.

Even if your child's breathing is usually fine, they may struggle to deal with a chest infection compared to children without SMA. One or more of the following options may be needed to support them whilst unwell.

Options that may be discussed 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 how often is best for your child. You may be trained and supported to do chest physiotherapy yourself.

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

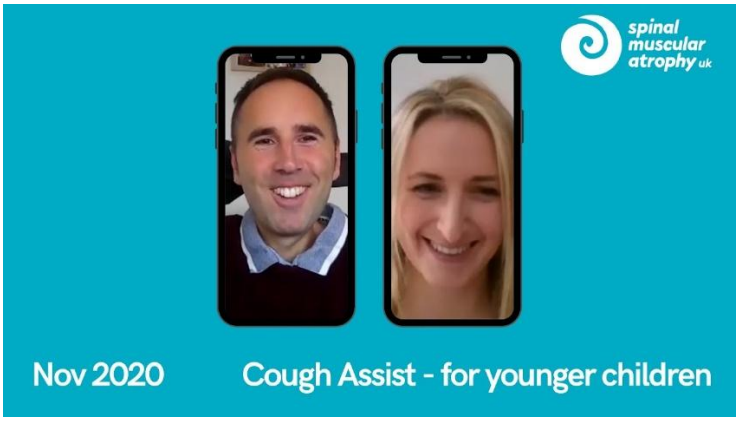
- **Cough assist.** This is the name often given to a mechanical insufflation – exsufflation machine. It helps to clear secretions from your child's lungs and create a more effective cough. Your respiratory specialist will assess if it would be helpful for your child. They often advise that cough assist is used routinely. This means your child is used to it and it is more effective if they become unwell.

- **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.

- **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.



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.

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.

- **Medication.** These are called **mucolytics**. They work by thinning mucus, making it less thick and sticky. They can be taken orally or administered via a nebuliser.
- **Antibiotics** may need to be prescribed quickly for your child if they are at risk of, or to treat, a chest infection. Your child's team may talk to you about whether or not they recommend antibiotics are taken regularly as a way of trying to prevent chest infections (prophylactic use).
- **A nebuliser.** This is a small machine that turns liquid medicine 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.

• 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 >

6. Eating, Drinking and Diet

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

Due to their muscle weakness, your child may have difficulties with chewing food and find eating tiring.

Eating difficulties can mean children do not get enough food and may become underweight. However, some children can become overweight because their muscle weakness makes it difficult to exercise. Extra weight can increase the stress on muscles, bones and joints, making positioning, physical activity and breathing even more difficult.

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

- consultant
- dietitian
- speech and language therapist (SALT)

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

• Regular checks

If your child is having difficulties chewing and swallowing food, you may find that mealtimes take longer. You will be able to discuss any concerns with your clinical team at your child's regular clinic checks. To help them gain a clearer picture, you will be asked if your child has:

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

The 2017 Standards of Care (SoC) on Nutrition, Growth and Bone Health › recommend that all children who are able to sit have their diet checked soon after diagnosis. For younger children this should then be every 3 – 6 months, then annually once older.

If your child has choking or coughing episodes when feeding or eating this may be a sign that they are struggling to swallow safely. This should be investigated. They may be **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. Aspiration can be silent, meaning there are no outward signs. If your child has frequent colds or respiratory infections this may be a sign of silent aspiration.

If needed, a swallowing assessment would be carried out by a Speech and Language Therapist (SALT). The test recommended to assess swallowing is called a Video Fluoroscopic Swallow Study. This uses a type of x-ray and swallowing of a special drink.

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.

- ## 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.

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 and coughing. A fibre-rich diet may be recommended along with extra fluids. Changing position, including standing as much as possible, can also help. Your child may also be given medications.

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

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.

• Making Eating Easier

If your child has had difficulties, your team will talk to you about the best positions for eating and drinking. They may also suggest which foods to avoid that are more difficult to chew and to swallow.

Pureed food or a semi-solid diet can help with chewing difficulties and can reduce the length of mealtimes. Thicker liquids such as milkshakes might help avoid aspiration.

Children who struggle to feed themselves can dislike not being able to be in control and having to depend on others. Long mealtimes due to eating difficulties can also put pressure on other family members and activities. Your physio and OT will be able to suggest positioning and seating options and orthotic devices if your child needs help to eat more independently. Mobile arm supports, or similar aids, are helpful for some children, so may be recommended by your child's OT or physio.

Some families have found it helpful to use valved straws which reduce the effort of drinking. They keep the liquid at the top of the straw.

• If Eating Is More Difficult

If your child is unable to swallow safely and/or is not gaining enough weight, your team may suggest additional ways for them to take in enough food safely. Some of these are covered below. You should be given time to discuss options and ask questions so that you understand the reasons for any suggestions and the possible benefits and any risks.

Whichever option is agreed, you will be provided with training and support so that you can give your child food 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
- **Nasojejunal (NJ) tube.** This goes through the nose into the middle part of the small intestine (the jejunum)

A longer-term option could be a:

- **Gastrostomy tube.** This is also called a **PEG Tube** (percutaneous endoscopic gastrostomy). It is placed in the stomach via a surgical procedure. Children who have a PEG tube to help them gain weight are usually encouraged to also eat some food by mouth.

• Looking After Teeth

Because of their muscle weakness it may be difficult for your child to open their mouth wide. This can cause problems with eating and with teeth cleaning and dental care. Regular dental check-ups are important. Your team can suggest ways to manage difficulties and help prevent complications.

7. Emergency Care

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

Your child's team should 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. 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.

8. 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 our Community Support Team 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 ›.**

9. Car Travel

Your child may be able to use a standard car seat. Ask your child's physio or OT for their advice. If it is too upright for them, or if they are uncomfortable a standard car seat may not be suitable. Talk to your physio or OT about your concerns. They may know of suitable alternatives that provide recline options and enough support. A small neck support and extra head support may also be useful.

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

Some children may need equipment when they travel and / or some may need a carer beside them to monitor how they are. Your physio, OT and respiratory team are the people to talk to about how to meet your child's individual needs. If travel is hard for you and your child, ask your clinical team about hospital transport for your appointments.

If you need a wheelchair accessible vehicle (WAV) later, you can lease one through the **Motability Scheme.** This is possible if a child is **over** 3 years old and gets the enhanced (higher) rate mobility component of Disability Living Allowance (DLA).

The **Family Fund Mobility Support scheme** is for families with a child **under** 3 with complex needs, who meet eligibility criteria. It aims to provide access to a lease car tailored to their mobility needs.

Some parents purchase their own vehicle. Others secure their child and wheelchair 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.

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 >.**

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 >.

10. Emotional Support

The emotional impact of a diagnosis of SMA Type 2 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 Child'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.

11. Support and Resources

SMA UK >

Phone: 01789 267 520
Email: office@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.

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

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 > .**

Contact >

Phone: 0808 808 3555

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

Muscular Dystrophy UK ›

Phone: 0800 652 6352

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

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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