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.

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

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.

Section	Topic	Page
1	Treatment and Care	3
2	Your Child's Healthcare Team	5
3	Vaccinations	6
4	Posture, Activity & Exercise	7
5	Mobility	9
6	Hips & Spinal Care	11
7	Breathing	13
8	Eating, Drinking & Diet	19
9	Emergency Care	25
10	Car Travel	26
11	Financial Support and Care & Support Packages	28
12	Emotional Support	29
13	Support & Resources	30

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.

The symptoms and impact of the condition on children who have SMA Type 2 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 more relevant and useful in our guide:

- **Looking After Your Child who has SMA Type 3 >**

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 2.

Children are diagnosed with SMA Type 2 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, young people and adults who have SMA Type 2. Not every treatment is suitable for every child. Children diagnosed with SMA Type 2 are not eligible for treatment with the gene therapy Zolgensma.

Your child's medical team will talk you through what is known about possible treatments 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. They range from managing the impact on mobility, 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. Some will be based at the hospital; others will be in the community. Who you see will depend on your child's symptoms.

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

- neurology
- paediatrics
- physiotherapy
- breathing (respiratory) care
- orthotics
- orthopaedics
- occupational therapy
- dietetics
- speech and language therapy
- genetics.

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.

4. Posture, Activity and Exercise

You should have the support and guidance of a specialist neuromuscular physio who's familiar with the impact of SMA Type 2. They'll be able to give you advice on simple exercises to support and progress your child's development. They will include exercises that:

- encourage good posture
- work to improve their ability to manage day-to-day activities and increase independence. These are called 'functional skills'. If appropriate they may include standing and walking with orthotics and / or equipment
- maintain and strengthen muscles
- maintain and further develop their range of motion
- reduce any discomfort
- stretch any tight muscles

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.

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

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 shouldn't 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 in a good position. For example, if they get tired when they have to sit for a long time. This would be organised by your physio and orthotics See **Section 6. Hips & Spinal Care**.

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 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. They include 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).

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. This includes activities like writing, playing, washing, dressing, and eating.

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 >**.

5. Mobility

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

It's important to remember that this is not possible for all children. Making comparisons with other children can lose sight of how differently SMA impacts each child. All children respond to treatment and develop differently.

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. 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: Living with SMA, Tab 1 Wizzybugs ›

Wheelchairs

Later on your child may need to use a lightweight manual wheelchair or a small, powered wheelchair. This will depend on their motor development.

Self-propelling a light-weight wheelchair is useful on flat surfaces for short distances. It promotes independence and provides arm exercise.

This physical activity, called aerobic exercise, also increases heart rate and breathing. It does this by making the body use oxygen to produce energy.

Being able to get around in a small wheelchair will make a big difference to joining in at nursery or school and on outings.

Find out more:

- **Living with SMA: Tab 6 Manual Wheelchairs >**
- **Living with SMA: Tab 2 and 3 First Powerchair >**

6. Hips and Spinal Care

Despite disease-modifying drug treatment, weak muscles often impact a child's hips. X-rays can show displacement of the hip joints, sometimes at an early age. This doesn't usually affect a child's day to day abilities. However, hips need to be monitored from early on by the specialist Neuromuscular team

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 will be published soon 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 balance
- to help slow progression of scoliosis by providing some correction of the curve.

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. To be most effective, this is usually for most of their upright time.

It's widely agreed that spinal bracing may delay the progression of scoliosis, but it won't prevent it developing.

There is no evidence that any type of bracing is better than any other.

Your child's team will monitor your child's spine carefully. They will be referred to the spinal team for advice.

It's important to remember that your child is an individual. Any recommendations are specific to your child.

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.

7. Breathing

Why some children who have SMA Type 2 may have breathing (respiratory) difficulties

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.

Every child is affected differently, but the main challenges for children who have SMA Type 2 and weak breathing muscles 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 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).

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.

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.

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

Even if your child's breathing is usually fine, they may struggle to deal with a chest infection compared to children without SMA.

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. Not all of them will be appropriate for your child. You'll be trained and supported so that you know what to do and when.

Secretion Clearance

Children who find it difficult to cough up mucus and other secretions are more vulnerable to chest infections.

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 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 eating
- 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.

Some 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.

Air Quality

All children can be more susceptible to the effects of poor air quality, for example cigarette smoke. Second-hand smoke makes it more likely a child will contract a serious respiratory infection that will 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. 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 don't get enough food and may become underweight. However, some children can become overweight. This is because their muscle weakness makes it difficult to exercise. Extra weight can increase the stress on muscles, bones and joints. It can make positioning, physical activity and breathing even more 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.

Support from Healthcare Professionals

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

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

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. Calcium and Vitamin D are especially important. These are needed for bone health. You will also be advised how often to give your child food.

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 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.

It's very important that your child has plenty of fluids, especially if they're 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.

If your child needs help to eat more independently, your physio and OT will be advise. They will suggest positioning and seating options and orthotic devices .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 will advise you. They will explore additional ways for them to take in enough food safely.

Whichever option is agreed, you will be provided with training and support so that you can give your child food safely at home.

- ## How swallowing is checked

If your child is having difficulty swallowing, they 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).

Options to support having enough food

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.

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. 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 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.

10. 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's too upright for them, or if they're 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 ›.**

The In-Car Safety Centres › have information on car seats.

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.

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).

Some parents purchase their own vehicle. Others secure their child and wheelchair in an accessible taxi.

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

Find out more about Wheelchair Accessible Vehicles and the Motability scheme. See: Living with SMA Tab 1 Car Travel Transport & Holidays >.

The Blue Badge scheme

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 >.

11. 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 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 ›**

12. 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. 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 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. 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 will 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 Covid jabs is important.

13. 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 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 Community Support Team. It covers a whole host of topics. They include: equipment, nursery, school, transport, 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.

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, and grants towards specialist equipment.

Treat SMA

Website: www.treatsma.uk

They offer independent information, real stories and practical support.



Version 18

Author: SMA UK Information Production Team

Last updated: August 2026

Next full review due: August 2029

Links last checked: August 2026

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 ›.***