Looking after your child who has SMA Type 1

Information for parents and carers of babies and infants who have had a recent diagnosis

Includes

- Healthcare teams who support you
- Safe & comfortable positions
- Breathing, feeding and movement
- At home and out & about
- Support and resources

Spinal Muscular Atrophy Support UK
Help for today • Hope for tomorrow
What’s in this guide?

This guide is for parents and carers whose infant has had a recent diagnosis of Spinal Muscular Atrophy Type 1 (SMA Type 1). It explores options that aim to manage symptoms, reduce complications of muscle weakness and maintain the best quality of life. It combines information about the healthcare your child may need, along with tips and suggestions that have worked for other families.

The guide is designed to be used alongside medical advice which should always come from your child’s medical team. Their medical care should be guided by the 2017 International Standards of Care for SMA (SoC). This outlines best practice and management for the three more common childhood onset forms of SMA – Types 1, 2 and 3. The information in these pages refers to the sections in the SoC headed ‘non-sitters’.

Am I reading the right guide?

Treatment with nusinersen

If you and your child’s medical team have agreed that this treatment is appropriate, and it is available for your child, you may potentially find some sections of our other ‘Looking after your child’ guides helpful. Your medical team will be able to advise you which parts of which guide will be most useful to refer to.

A later diagnosis

Symptoms of SMA Type 1 usually begin and are diagnosed before six months of age. For a number of reasons, however, some children may not be diagnosed with SMA Type 1 until they are around one year old. These children are likely to have a different experience from children who are diagnosed much younger. Their diagnosis is sometimes referred to as ‘strong Type 1’ or ‘SMA Type 1 / Type 2’. These children may reach the physical milestone of being able to sit independently and have experiences more similar to children who have SMA Type 2. Our guide ‘Looking after your child who has had a recent diagnosis of SMA Type 2’ that refers to the SoC information relating to ‘sitters’ may be relevant to you. Your medical team will be able to advise you which parts of which guide will be most useful to refer to.

The impact of SMA Type 1 varies greatly between individuals and may change over time.

You can find out more about nusinersen in our guide: ‘Nusinersen for children with SMA Type 1 – Information for families.’

A later diagnosis

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You can find out more about nusinersen in our guide: ‘Nusinersen for children with SMA Type 1 – Information for families.’

The most common form of spinal muscular atrophy (SMA) is also known as 5q SMA due to its genetic cause. 5q SMA includes SMA Type 1. For more information about this please see:

- What is Spinal Muscular Atrophy?
- Symptoms, diagnosis & effects of 5q Spinal Muscular Atrophy
- The Genetics of 5q Spinal Muscular Atrophy

You can find these at: www.smasupportuk.org.uk/about-sma
Who will be in my child’s medical healthcare team to support us?

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. You may have contact with specialists in:

- neuromuscular conditions
- hospital or community paediatrics
- breathing (respiratory) care
- physiotherapy
- occupational therapy
- dietetics
- speech and language therapy
- palliative care
- general practice and community health care.

The aim of everyone involved in your child’s care is that your child will stay healthy and enjoy a good quality of life. Different members of the team will meet you regularly both to measure any change in your child’s health and to offer advice and interventions at the right time. As well as looking at your child’s medical needs, when they talk with you about options for care of your child, they will also want to be aware of your family’s social, cultural and spiritual needs.

You should be given time to ask questions at every appointment with your child’s medical team and then jointly, with the team, decide what support is best for your child.

What vaccinations should my child have?

The SoC recommend that all with SMA should have the ‘standard’ immunisations plus the pneumococcal vaccine and, at age over 6 months, the annual influenza (flu) vaccination. They also recommend that children up to the age of 2 years are protected against a common virus called respiratory syncytial virus (RSV) which can cause breathing problems. These vaccinations are only given once a month during bronchiolitis season (October – March).
What positions will keep my child safe and comfortable?

As with all babies, babies with SMA Type 1 begin by lying flat. They may progress to supported sitting or lying in a semi-reclined position; this will depend on how easy it is for them to breathe and how strong they are. As they get older they may have less movement than other children so will need more help to be able to look at and enjoy their surroundings.

If your child is too upright or lies on anything that sags or is curved, their chest may concertina or ‘hunch up’ which makes it more difficult for them to take deeper breaths. Deeper breathing is important as it can help to prevent mucus building up in your child’s lungs.

Your child may find it easier to breathe more deeply when they are lying on a firm, flat surface though that may mean they can’t look around very easily. They may also have difficulty swallowing their saliva and other secretions, which may make them sound chesty or make them cough. When you’re lying your child down, it can help to place their head to the side to avoid their chin tucking under or resting on their chest. This allows them to swallow more safely and for saliva to dribble out of their mouth.

With help and advice from your occupational therapist (OT), physiotherapist (physio) and community nurse, you’ll be able to find the best position for your child. They’ll talk to you about how your child will let you know if they aren’t comfortable, or if breathing or managing saliva is difficult. In general, if your child is breathing in the same way as when they’re lying down or isn’t dribbling any more than is usual for them and looks happy, then they are comfortable.

During the day you’ll need to change your child’s position every hour or so. This will help to relieve pressure to ensure that their joints don’t become stiff and will give them a change of view. You may find that over time they’re not as happy in a position that had previously worked well. This may be because the position is now causing breathing problems. If this happens, it’s worth trying one of the other positions your OT, physio or community nurse has suggested, or asking them for further advice.

Children with SMA Type 1 are ‘tummy breathers’ and are more dependent on their diaphragm muscle. This muscle sits at the bottom of the chest and above the stomach. It’s pulled down in order to inflate the lungs and so the tummy moves outwards as this movement occurs. Due to this, children with SMA should never be laid on their tummies as this makes it harder for the diaphragm to work properly and so harder to breathe.

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 side, it’s worth checking that their arm and shoulder aren’t trapped and that their ears are flat. If they’re in their buggy, you may find that a rolled-up blanket against their back will help support them.

Also, because your child’s neck muscles may be weak, a small neck roll, or a rolled-up piece of muslin or a small facecloth may steady their neck in a more comfortable position and help with breathing. Your physio may suggest and provide a collar to help. A small neck roll and soft toys can also help to support other parts of their body comfortably.

Your physio or OT will be able to advise you about good positioning and may be able to provide wedges or foam inserts which are shaped to promote good postural support. If your child is experiencing tightening of their muscles (contractures) and discomfort, they may provide foot and hand splints to help with this.

SMA commonly causes what is called a ‘scoliosis’ which is when the spine starts to curve sideways into an ‘S’ shape because of the weakening of supporting muscles. Your child will be monitored for this and if there are signs that this is happening they may be provided with a spinal brace to wear during the day. It would be custom-made and fitted by a specialist called an orthotist so that it goes right round your child’s body helping them to sit and breathe more comfortably.

As your child will have a limited range of comfortable positions, they are at risk of developing pressure sores. Do look out for any red or sore areas on their skin. Early intervention is important so if you have any concerns, contact your community children's nurse or health visitor as soon as possible for advice.

Your OT or physio can assess your child’s seating needs and provide advice on seating, including bath seats, which offer appropriate support for your child. Some seats fit on a base for use indoors, and then transfer to a buggy base for use outdoors. This can save on space required to store equipment.

Your OT or physio may see if your baby would be comfortable in a seat that will give a lot of support when s/he is semi-upright. If this works for your child, you may find it’s easier for them to play.
What can be done to help my child’s breathing?

When we breathe in, certain muscles act as bellows to expand our lungs; these are called inspiratory muscles. They enable oxygen to be pulled into the lungs. The most important inspiratory muscle is the diaphragm. SMA causes the inspiratory muscles to be weakened, resulting in a reduction in lung volume.

Breathing out the waste gas (carbon dioxide) from the lungs is known as expiration. This doesn’t need particularly strong muscles, but coughing does.

Weak breathing muscles are common for infants with early onset SMA who are unable to sit. This results in breathing problems (sometimes called ‘insufficient’ breathing) which are a leading cause of health problems. The main problems for children are that:

➢ It makes it difficult to cough and therefore clear mucous (secretions) from lungs.
➢ Lungs can’t 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.

The SoC advise that a specialist ‘respiratory doctor’ should become involved in your child’s care as soon as possible after diagnosis.

- Regular respiratory check-ups

The SoC advise that all infants with SMA who aren’t able 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. If your child has difficulties breathing, it’s important that their carbon dioxide levels are checked at the end of a breath (this is called ‘end tidal carbon dioxide’). They should also have regular ‘sleep studies’ so that their overnight breathing can be tested. A sleep study involves attaching small sensors to your child’s face, head, arm and chest and monitoring them overnight.
- **Possible options for managing breathing**

As it’s very common for children who aren’t able to sit to have difficulty coughing up mucous and other secretions, they’ll be more vulnerable to chest infections. There are a number of options to help you manage this that are described below, though not all options will be appropriate for your child.

The options you may learn about and use include:

- **Chest physiotherapy** to keep your child comfortable and help clear secretions from their chest. How often children need this varies. You’ll be advised what is best for your child and may be trained to do chest physiotherapy yourself.

- **A suction machine** to help remove your child’s excess secretions. Your physiotherapist or another member of your medical team would talk to you about this and give you training so that you felt confident about using it.

- **Medications** that can break down your child’s secretions (such as glycopyrrolate) may be prescribed. These must be used carefully as too high a dose can dry out the secretions too much, which then makes them harder to remove. Your medical team will monitor and change the dose as needed. Long-term use of these medications isn’t recommended.

- **Pain relief** may be advised if your child is in pain or distress because of breathlessness.

- **Antibiotics** which need to be prescribed quickly for your child when they’re at risk of, or to treat, a chest infection. They aren’t recommended by the SoC as a way of trying to prevent chest infections (prophylactic use) for all children.

- **Cough assist** is the name often given to a mechanical insufflator – exsufflator machine. This helps to clear secretions from your child’s lungs. Your respiratory specialist will assess if it would be helpful for your child and show you how to use it.

- **Oxygen** isn’t used regularly but your respiratory specialist will be able to advise you if / when your child should use it.
Non-invasive ventilation (NIV), a machine with a mask providing gentle pressure to breathe against, helps to keep the lungs inflated longer. This can help your child get rid of carbon dioxide and take in more oxygen making breathing easier. This is individually fitted for your child by a respiratory specialist. When your child’s breathing 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.

The SoC guidelines recommend really proactive use of NIV for all infants with symptoms of ‘insufficient’ breathing and that they start using NIV early before signs of breathing problems start. This is so that your child is familiar with it and so won’t be distressed when they need it to relieve their breathing problems.

Short term invasive ventilation may be used if your child has a medical emergency. This is when a flexible plastic tube (endotracheal tube) is passed through the mouth or nose into the windpipe.

Tracheostomy may be considered for some children when NIV doesn’t 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 doesn’t suit everyone. Early discussions with your medical team about this option are helpful, while your child is well and before any episode of acute ill health.

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 Smokefree website: www.nhs.uk/smokefree
What advice is there on feeding, nutrition and swallowing?

- **Professional Support**

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, dietitian and community nurse. Occupational therapists and physiotherapists may also advise you on positioning and seating to help with feeding.

- **Regular Checks**

Due to their muscle weakness, your child may have difficulties with feeding and swallowing. Safe swallowing is one of the most important aspects of their care as children with a weak swallow are at risk of inhaling (aspirating) their feed which can cause choking and chest (respiratory) infections.

You may find that your child’s suck is weak, and mealtimes are taking longer. Food may be getting stuck in your child’s cheeks (sometimes called pocketing) or they may be finding it harder to open their mouth. You will be able to discuss any concerns like this with your medical team at your child’s regular clinic checks.

The SoC recommend that all children who aren’t able to sit have a swallow study shortly after diagnosis and again 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 which 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), or been sick (vomiting).

Your child’s glucose levels will be checked so that their diet can be corrected if the level is too high (hyperglycaemia) or too low (hypoglycaemia).

Feeding can be tiring for your child. On top of this, they may be using a lot of energy and effort breathing. This can result in your child not gaining weight or even losing weight so the Standards of Care recommend that a dietician reviews feeding and diet every 3 – 6 months for younger children and annually for older children.
- **Possible Options for How to Give Food**

If swallowing becomes unsafe, or if your child is not gaining enough weight, your medical team may suggest alternative ways to feed your child.

You should be given time to discuss and ask questions about the reasons for any of the following suggestions so that you understand the possible benefits and risks for your child.

Short-term options may include feeding through a:

- **Nasogastric (NG) tube** - a thin flexible feeding tube passed through the nose into the stomach
- **Nasojejunal (NJ) tube** - through the nose into the middle part of the small intestine (the jejunum)

A longer-term option is:

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

- **Guidance for Diet**

A dietician should work out what calories your child needs. SMA-specific growth charts aren’t available yet, so this may be based on standard growth charts for children, but your dietician will also take account of other individual measurements for your child. Their diet will be adjusted so that they are getting the right calories, fluids and macro and micro nutrients – especially calcium and Vitamin D which are needed for bone health. You’ll also be advised how often to give your child food.

It’s very important that your child has plenty of fluids, especially if they’re unwell. You’ll be advised about correct amounts and how often. If your child is acutely unwell, experts suggest they should never go without food for longer than six hours.

Your child is quite likely to become constipated due to their muscle weakness and not being able to move around. This can cause discomfort and reduce the movement of the diaphragm, which in turn restricts breathing. If needed, you’ll be advised what medications to use to help this.

Whatever the decision about which option is best, you’ll be provided with training and support to enable you to feed your child safely at home.

Currently, professional opinion is divided about whether the Amino Acid diet, which is based on an elemental formula, is beneficial. Professionals do, though, all agree that the type of diet and how it is given should be based on each child’s individual reactions and should be regularly reviewed.
**Should I help my child move around and exercise?**

You should have the support and guidance of a physio who will be able to give you advice on simple exercises, which include ‘stretches’ to support your child or give you tips on massage techniques. You can try ‘ride your bicycle’ movements with their legs, gently moving them at the hips and doing ‘hand jives’ with their arms to music or songs. As well as being fun, this will help prevent your child getting stiff muscles (contractures) and will also help to maintain a range of movement in their joints. Moving is also good for your child’s circulation.

Your physio may suggest exercises for in the bath, swimming or hydrotherapy pool as children often enjoy the additional freedom of movement provided by warm water. It’s 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 medical team about your local facilities and what might be suitable for your child.

You can also encourage your child to make movements themselves. If you position toys carefully and your child is comfortable, encourage them to try reaching out. If your child is six months old or more, and is safe and comfortable lying on their side, they may be able to bring their hands together more easily and pass toys between them to play.

**What’s the best way to manage bath time?**

It will help a lot if you have a bath support for your child so that you can have your hands free for washing and playing. Your OT will advise you which one is best for you and your child. You might also find it helpful to have a towel laid out ready with a head roll for after the bath, to help with keeping your child well supported while you are drying them.

Though fun, bath time can also be tiring for your child. If s/he gets upset after bath time you may need to keep it brief and follow it with a nap. It’s also probably best to feed your child after bath time rather than before as they might not be comfortable being handled so much when they have a full tummy.
I worry about night-time. What tips are there for this?

It’s recommended that all babies sleep in their parents’ bedroom for the first six months. You may need to do this on an ongoing basis so that you can check on your child regularly and reposition them so that they don’t get stiff and uncomfortable during the night.

It’s best to have a room that isn’t dry or stuffy or too warm as this can make your child’s secretions become sticky and difficult to remove.

It’s usually best for your child to sleep on a baby mattress or pillow as these are more comfortable than an adult mattress. 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 (equipment to aid postural support) may sometimes be provided to increase comfort and to support your baby’s limbs in a comfortable 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.

It helps 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 your child coughs a lot during the night you can try to improve the air circulation in the room, but make sure they aren’t in a draught. If you have any questions or concerns speak to your community nurse.

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

It’s important that you get rest and sleep. If your child needs a lot of help overnight, your local health services may be able to provide some night care to give you a break - ask your health visitor, paediatrician or community nurse.
How can I help my child stay at a comfortable temperature?

As mentioned before, SMA can make children very sweaty with flushed faces and hot or cold hands. This can make it difficult to judge if their temperature is ok. If you aren’t sure, it’s worth checking with a small digital thermometer that you can hold under your child’s armpit, or one you can put in their ear - you can buy these from any chemist.

Changing clothing isn’t easy, especially if your child is tired or uncomfortable. You can avoid having to lie your child on their tummy when changing them if they have front fastening clothes.

It’s worth choosing roomy vests, baby grows or onesies that have large neck-openings which make them easier to get on and off and that 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.

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

How can I get out and about with my child?

Your child is likely to enjoy getting out and seeing things, however they may need a lie-flat buggy.

Longer term, you may need to carry a suction machine and other equipment with you so a buggy that has a strong and stable carrying basket or storage tray can be useful.

If your child is lying on their side in a buggy, you may find that a rolled-up blanket against their back will help support them. A small neck roll and soft toys can also help to support other parts of their body comfortably. Your physio or OT will be able to advise you about good positioning and may be able to provide wedges or foam inserts which are shaped to promote good postural support.

For how to take your child’s temperature please see:


Thin, loose layers of clothing work well as you can remove a layer if they are hot.

If your child’s feet and hands get cold you can add an extra layer of warmth with booties / soft slippers and mittens.

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

Children who aren’t able to sit are likely to need rear-facing car seats and possibly additional head support. Your child may be able to use a standard car seat, but this may be too upright for them. If they’re uncomfortable in their car seat, you can ask your physio or OT for their opinion of any suitable alternatives that provide recline / lie-flat options and enough support. A small neck support and additional head support may also be useful.

If your child can’t use a car seat safely and comfortably then a possible option might be an E-Z-On Harness which enables a child to be strapped in whilst lying flat along the length of the back seat of a car.

Another alternative to a car seat, particularly for older children, 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. Sometimes specialist buggies 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. Currently this option is not available to children under the age of 3, so some parents purchase their own vehicle. Others secure their buggy in an accessible taxi.

The Blue Badge scheme is run by local authorities. This entitles people with severe mobility problems to parking concessions. Although the minimum age for Blue Badge applications is 3 years, in certain circumstances it is possible to apply for children under 3 years old with medical conditions which require them to be accompanied by bulky medical equipment, or if they need to remain near their vehicle in order to access treatment. To find out more about these special circumstances and how to apply for a Blue Badge visit the GOV.UK site: [www.gov.uk/blue-badge-scheme-information-council](http://www.gov.uk/blue-badge-scheme-information-council)

Even if your child is dependent on suction and other equipment, it may still be possible to get out and about and visit enjoyable places like the zoo and the seaside. Ask your community nurse or physio about a portable suction machine which you can take out with you. You might also want to keep spare equipment such as suction catheters in the car.

It may be difficult to find a suitable car seat for your child as they grow; ask your OT or physio for advice. SMA Support UK can also help with information on car seats and possible sources of funding.

More information on car seats and the E-Z-On Harness is available from the In-Car Safety Centre: [www.incarsafetycentre.co.uk](http://www.incarsafetycentre.co.uk) In Car Safety Centres are located in Milton Keynes, Essex and Belfast.

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

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. For more information, please see: [www.gov.uk/seat-belts-law](http://www.gov.uk/seat-belts-law)
**What should I do if my child’s health deteriorates or there is an emergency?**

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 they can be difficult, these discussions 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, and you can change your mind about the contents of the EHP at any time.

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

**What care and support can other members of our health team offer?**

Palliative care services vary across the UK and may be provided by a number of different healthcare professionals in a variety of settings including hospitals, children’s hospices and at home. They work as a team aiming to actively support the physical, emotional and practical needs of your child and family and should be involved with you early on, from the point of diagnosis. They are careful to take account of any cultural and spiritual needs you may have.

Your child’s consultant, care advisor or specialist nurse can advise you about services available in your area. This may include children’s hospices which support families, both practically and emotionally. Palliative care is often associated with end of life care. Though this is one aspect, unless needed it is not a focus for palliative care services which provide support and respite to families at any stage of their child’s life. As well as offering nursing care, they provide a range of services that may include physiotherapy, complementary therapies and play and music therapy. They can support you to make decisions about your baby’s ongoing care and wishes for their future care should they become very unwell.

It’s important that you know how to access medical care in case your child has a respiratory emergency.

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

You can upload a copy of your child’s latest EHP to your mobile using our app. Find out more: [https://ehpapp.com](https://ehpapp.com)

Palliative care includes the management of symptoms, information and practical support, 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.

Many families find hospices to be happy and positive environments where they can spend time together with siblings doing activities as a family.
What about 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 does depend on your individual circumstances. For further information visit the website: www.gov.uk

There are also a number of charities that may assist you with the cost of general household goods, specialist equipment and holidays / days out. Please contact SMA Support UK for more information or see our online SMA Type 1 Route Map (more details at the end of the booklet).

I know I ought to look after myself

The impact of a diagnosis of early onset SMA Type 1 on families is enormous. It often comes as a shock and you may experience feelings of disbelief, confusion, anger and sadness. You may find it difficult to take everything or anything in. The 24 hour-a-day responsibility of caring for a child with complex medical needs that follows can be physically, emotionally and psychologically exhausting.

Everyone is different, but it’s important for you and your family to have access to emotional support and to have plenty of time to talk and ask questions. This can be with members of your child’s medical team, your local GP, health visitor, social worker, psychologist or a counsellor, as well as family and friends, a spiritual leader, support groups, or online communities.

You may also find it helpful to use local short break services. These may be possible at your home or at a children’s hospice. Ask your GP, community nurse, health visitor or social worker for more information.
Support and Resources

The International Standards of Care for Spinal Muscular Atrophy (2017) can be read / downloaded from here: www.smasupportuk.org.uk/international-standards-of-care-for-sma

SMA Support UK

Phone: 01789 267 520
Email: supportservices@smasupportuk.org.uk
Website: www.smasupportuk.org.uk

We provide free information and support to families in the UK affected by SMA. Our outreach workers are able to visit you at home. They offer personalised support and information and are available to answer questions. They can discuss with you the support you and your family can access. Please note, we do not give medical advice. Multisensory toy packs are also available free of charge for babies in the UK diagnosed with SMA Type 1.

You can upload a copy of your child’s latest emergency health plan using our EHP app which follows the NHS guidelines for data privacy. It’s free to download on Android and iOS. You can find out more at: https://ehpapp.com

Our Route Maps for SMA have other information about day-to-day life and signpost to possible sources of support and advice. At the moment they are organised according to Type of SMA. The route map that is likely to be most helpful is for SMA Type 1. You can find this at: www.routemapforsma.org.uk

We are currently re-organising this information so that it is more accessible. It will be located on a new part of our website which we will call ‘Living with SMA’. As soon as it is ready we will let people know via our monthly e-news. You can sign up for this here: www.smasupportuk.org.uk/sign-up-for-mailings

You’ll find more information about nusinersen and what is happening in the UK here: www.smasupportuk.org.uk/nusinersen

This website section tells you about other research developments: www.smasupportuk.org.uk/drug-treatments-whats-happening-now

Contact for Families with Disabled Children

Phone: 0808 808 3555
Website: www.contact.org.uk

Provide information and support to families who have a child with a disability, 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. They also have condition specific ‘alert cards’ which can be used to provide medical professionals with information. A link to the alert card for SMA Type 1 can be found at: www.musculardystrophyuk.org/about-muscle-wasting-conditions/information-factsheets/conditions/alert-cards-and-care-plans/alert-cards/

Together for Short Lives

Phone: 0808 8088 100
Website: www.togetherforshortlives.org.uk

Provide information and support to families who have a child with a life-limiting condition, including details of hospice services.

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


We are grateful to the writers and reviewers who assist us in our information production. A list of who this includes may be viewed on our website: www.smasupportuk.org.uk/our-writers-and-reviewers-panel or requested from supportservices@smasupportuk.org.uk

Whilst every effort is made to ensure that the information in this document is complete, correct and up to date, this cannot be guaranteed and SMA Support UK shall not be liable whatsoever for any damages incurred as a result of its use. SMA Support UK does not necessarily endorse the services provided by the organisations listed in our information sheets.

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