Looking after your child who has had a recent diagnosis of SMA Type 3.

You can also read this guide on our website at smauk.org.uk/zk1f 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 3 ***and***
- has been able to walk unaided and has shown symptoms of losing this ability.

Your child may have been diagnosed with either:

- **Type 3a** if their symptoms have begun at less than 3 years of age, ***or***
- **Type 3b** if their symptoms have begun at over 3 years of age.

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**	2
2	**Your Child's Healthcare Team**	5
3	**Vaccinations**	5
4	**Exercise and Mobility**	6
5	**Hips and Spinal Care**	7
6	**Breathing**	9
7	**Eating, Drinking, Diet**	11
8	**Emotional Support**	12
9	**Financial Support**	13
10	**Support & Resources**	14

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.

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 3.

Children are diagnosed with SMA Type 3 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 3. Not every treatment is possible or suitable for every child. Your child's medical team will talk you through what is known about each one and the benefits and any risks. They will help you decide according to what's possible 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 members of a multidisciplinary healthcare team. 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
- orthotics
- orthopaedics
- dietetics
- general practice and community healthcare

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. These include protection against flu and covid where eligible.

4. Exercise and Mobility

Your child's physiotherapist should suggest an individualised exercise programme. It will focus on your child's strength, endurance, flexibility and balance. It will include exercises to help maintain a good range of motion of their joints.

Your child may be given supportive splints to be used during the day or night to help with this. Individually made and fitted orthoses may be prescribed to help with walking. These may be:

- An **Ankle-Foot Orthosis (AFOs).** This is an L-shaped brace support worn on the lower leg and foot. It keeps the foot from dragging, stabilizes the ankle
- A **Knee-Ankle-Foot-Orthosis (KAFOs).** This sort of brace covers the leg from the thigh down to the foot. It stabilizes the knee and ankle joints.

The exercise programme will be built around any physical challenges they are having and what activities they would like to be able to do. As for anyone, it should include active work to make the heart and breathing muscles work a bit harder. This may be achieved with modified PE.

Children diagnosed with Type 3b usually have difficulties with standing and walking later than children with SMA Type 3a. But all children are individual. SMA affects all children differently.

Even with treatment, as they grow and muscles have to do more work, some children can lose their ability to walk. It's essential that your child is monitored by their specialist team. They will advise on how best to manage changes including any aids or orthoses.

If your child is having difficulty with walking and keeping up, or is too old or too big for a buggy, a lightweight wheelchair may be helpful. It will also improve independence. You can discuss what options there might be with your physiotherapist (physio) or occupational therapist (OT).

5. Hips and Spinal Care

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

Your specialist team will decide if and when x-rays are needed to monitor your child's hips. It's important to report any pain to the specialist team. This can happen for children who are walking or no longer walking.

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 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 If:

- a scoliosis is developing or
- maintaining a good upright posture is difficult or
- sitting up straight is difficult

Your physio will make a referral to the orthotics department where this will be custom-made. Your physio will explain when, and how often, your child should wear their brace.

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

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.

6. Breathing

The majority of people who have SMA Type 3 have no breathing problems. A small number have been seen to have a slight reduction in breathing ability.

If your child does have chest infections, your team will want to check the strength of their cough. They will also want to find out if they have any symptoms that suggest any difficulties with breathing at night. Symptoms for this are things like:

- poor sleep quality
- fatigue
- reduced appetite
- headaches
- daytime sleepiness.

If they're showing these signs, they may need an overnight Sleep Study. This 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.

Unless you or your child are concerned, they won't need any proactive management for breathing problems.

It's unlikely your child will have breathing difficulties. If they do, information, advice and options for management can be found in:

- **Looking after your child with SMA who has had a recent diagnosis of SMA Type 2 ›**

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 ›.

7. Eating, Drinking and Diet

Eating and swallowing difficulties are rare for children, young people and adults who have SMA Type 3.

Good nutrition is vital for the well-being of any child who has SMA. If your child is having difficulties with eating or either gaining too much weight or being underweight, discuss this with your child's team. They may support you to access dietary advice from a professional. This is usually a dietitian or nutritionist.

A dietitian would work out what diet your child needs. SMA-specific growth charts aren't available yet, so their advice may be based on standard growth charts for children. These growth charts don't take account of children who have SMA having reduced muscle mass. Your dietitian will take account of other individual measurements for your child.

Your child's diet may be adjusted so that they're getting the right calories, protein, fat and carbohydrates. It would also include the need for the right amount of fibre and fluids. This is to help with any possible constipation caused by reduced physical activity. Similarly, the amount of nutrients is important – especially calcium and Vitamin D which are needed for bone health.

Oral hygiene

This is important for all children, 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.

8. Emotional Support

A diagnosis of SMA Type 3 and the future uncertainty it brings can have a very big impact on families.

- **Hearing your child's diagnosis of Spinal Muscular Atrophy > is about 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.**

Depending on your child's age, these pages may be useful:

- **Children's emotional and psychological mental health and well-being >**
- **Teenager's emotional and psychological mental health and well-being >**

9. Financial Support

Families living in the UK may be eligible for a number of financial benefits to help towards the cost of providing any extra care their child may need. This depends on your individual circumstances. For further information, see:

- **Living with SMA: Financial Support & Benefits >**.

This page also has a section on **Cost of Living Support**.

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

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

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

10. 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're flexible in how we can support you and can be in contact by email, phone, text or virtual meetings (such as on Google Meet or Microsoft Teams). We're also able to home visit if you would 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 a pack suitable for children living in the UK who are 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 ›.**

Muscular Dystrophy UK

Phone: 0800 652 6352

Website: www.musculardystrophyuk.org

They provide information, support and grants towards specialist equipment.

Contact for Families with Disabled Children

Phone: 0808 808 3555

Website: www.contact.org.uk

They provide information and support, including information on benefits and grants.

Treat SMA

Website: www.treatsma.uk

They offer independent information, real stories and practical support.



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*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 ›.***