

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.

Who this is for

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.

In this guide

This guide tells you more about:

- Treatment & Care
- Your child's healthcare team
- Vaccinations
- Exercise and mobility
- Breathing and diet
- Emotional and financial support

These pages tell you more about 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.

1. Treatment and Care

Since late 2016, the gradual worldwide introduction of drug treatments for children, young people and adults who have SMA Type 3 has seen positive outcomes for many.

In the UK, the NHS currently funds two possible treatments for children, young people and adults who have SMA Type 3. Your child's medical team will talk you through what is known about each one and 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 ‘walker’ – able to walk though may lose this ability over time. The guide recognises that, with drug treatment, this may change.

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

Whether or not your child receives a drug treatment, your child should receive care and support from members of a multidisciplinary healthcare team, who all have an important role to play. Over time, you may have contact with specialists in the hospital and community 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. Roles within a team may overlap. For example, a task or assessment may be performed by either a nurse, physio or doctor. Roles may also vary between centres; for example, a nurse in one centre may carry out different tasks to a nurse in another centre.

The aim of everyone involved in your child's care is for your child to stay healthy and enjoy a good quality of life.

Different members of the team will meet you regularly both to measure any change in your child's health 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.

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

3. Vaccinations

Children who have SMA should have all recommended vaccinations. They should also get regular flu and pneumonia vaccines. Covid vaccine should also be added.

4. Exercise and Mobility

Your child's physiotherapist should suggest an individualised exercise programme so that your child can work on their strength, endurance, flexibility and balance. It will

include exercises to help maintain a good range of motion of their joints – especially ankles and knees. Your child may be given supportive splints to be used during the day or night to help with this. These may also be prescribed to help with walking. The programme will be built around any physical challenges they are having and what activities they would like to be able to do.

Children diagnosed with Type 3b usually have difficulties with standing and walking later than children diagnosed 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 is 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 and improve independence. You can discuss what options there might be with your physiotherapist (physio) or occupational therapist (OT).

5. Breathing

The vast 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 are showing these signs, they may need an overnight Sleep Study. 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.

Unless you or your child are concerned, they will not need any proactive management for breathing problems. In the unlikely event of your child having breathing difficulties, information, advice and options for management are outlined in [Looking after your child with SMA who has had a recent diagnosis of SMA Type 2](#) >.

6. 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 serious respiratory infections.

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 are not available yet, so their advice may be based on standard growth charts for children. These growth charts do not 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 are 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.

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 >](#)** talks about this and what support is available.
- **[Family and Friends / Challenges and Support >](#)** may also be helpful.

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 [Financial Support & Benefits >](#).

Your health visitor, community nurse, neuromuscular care advisor, 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 >](#).

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 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 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 Support Services Team. It covers a whole host of topics, including: equipment, homes, nursery and school, transport, leisure, holidays, financial, and emotional and social support.

We offer a number of ways for you to [Connect with the SMA Community >](#).

We have a number of [Grant Schemes >](#) that may be useful.

Any family affected by SMA and living in the UK, can request a free copy of **Our SMArt World**. Written for children age 7 – 11, it is all about SMA and living with the condition. **Smasheroo** is another free book written for younger children. You can order these and other items through [our shop >](#).

Other resources that may be useful are listed in our [Resource Hub >](#).

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

Muscular Dystrophy UK >

Phone: 0800 652 6352

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

Contact >

Phone: 0808 808 3555

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



Version 10

Author: SMA UK Information Production Team

Last updated: October 2024

Next full review due: November 2026

Links last checked: November 2024.

This publication, and its links, provides information. This is meant to support, not replace, clinical and professional care. Find out more about [how we produce our information >](#).

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

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