Looking after your child who has SMA Type 3

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

Includes

Healthcare teams who support you

Exercise and mobility

Breathing and healthy eating

Support and resources

BMA
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spinal muscular atrophy uk
Help for today, hope for tomorrow

Health & care information you can trust
The Information Standard Certified Member

What's in this guide?

This guide is for parents and carers whose infant has had a recent diagnosis of Spinal Muscular Atrophy Type 3 (SMA Type 3). It explores options that aim to manage symptoms, reduce complications of muscle weakness and maintain the best quality of life. The guide is designed to be used alongside medical advice which should always come from your child's medical team.

The impact of SMA Type 3 varies greatly between individuals and may change over time.

One of the first questions you might be asking your child's medical team is what treatment might be possible. Research is ongoing and drugs to treat SMA are at different stages of development. Currently in the UK, the only approved drug treatment for SMA is nusinersen. If you are considering the possibility of treatment for your child, you may find it helpful to read our information sheet: **Nusinersen (also known as Spinraza™) treatment for those diagnosed with SMA Type 2 or 3.**

You can find out more about nusinersen and other potential drug treatments at:

www.smauk.org.uk/drug-treatments-screening-whats-happening-now

Whether or not your child is receiving drug treatment, their medical care should be guided by the 2017 International Standards of Care for SMA (SoC)[1,2]. This outlines best practice and management for the three more common childhood onset forms of SMA – Types 1, 2 and 3.

More information about the Standards of Care is at:

www.smauk.org.uk/international-standards-of-care-for-sma

The information in this guide refers to the sections in the SoC headed '**walkers'**. Your child's medical team can talk through with you which information is most useful for you to refer to at which time.

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 3. 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.smauk.org.uk/about-sma**

Who will be in my child's medical team to support us?

Your child should receive care from members of a multidisciplinary healthcare team, who all have an important role to play. Over time, you may have contact with specialists in:

- neuromuscular conditions
- hospital or community paediatrics
- physiotherapy
- occupational therapy
- orthopaedics
- dietetics

One of the team should act as your keyworker. Their role is to help co-ordinate services for your family.

The aim of the healthcare team is for your child to stay healthy and enjoy 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 can find out more about how these people can help in our information sheet **'Who's Who of Professionals'.**

You should be given time to ask questions at every appointment with a member of your child's team so that you can jointly decide what support is best for your child.

What vaccinations should my child have?

The SoC recommends that anyone with SMA should have the same vaccinations as given to any child in the UK. The only extra vaccinations are the pneumococcal vaccine (over the age of two this should be the vaccine with wider coverage known as '23 valent') and annual flu vaccination.

What about exercise and my child's future mobility?

Your child's physio is likely to suggest an individualised exercise programme so that your child can work on their strength, endurance, flexibility and balance. It'll include exercises to preserve the flexibility of their joints – especially ankles and knees. Your child may be given supportive splints to help with this. The programme will take into account any difficulties they are having and what activities they would like to be able to do.

If your child is having difficulty with walking and keeping up or is 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).

Children with SMA Type 3 have at some point been able to walk unaided.

SMA Type 3 can be further broken up into:

- **Type 3a** where symptoms begin at less than 3 years of age.
- **Type 3b** where symptoms begin over 3 years of age. Children diagnosed later usually have difficulties with standing and walking later.

Will my child have any breathing difficulties?

The vast majority of individuals with SMA type 3 have no breathing problems; though a small proportion have been seen to have a small reduction in breathing ability.

If your child does have chest infections your team will want to check the strength of their cough and whether they have any symptoms that suggest difficulties with breathing at night. Symptoms for this are things like: poor sleep quality, headaches, and daytime sleepiness. If they're showing these signs they may need regular breathing tests. Unless you or your child are concerned they won't 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'.**

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 Smokefree website:

www.nhs.uk/smokefree

What advice is there on eating, drinking and diet?

If your child is having difficulties with weight or eating, the SoC recommend you seek dietary advice from a professional, usually a dietician or nutritionist. They would work out the best diet for your child which would include correct calories, fibre for possible constipation, and nutrients, including adequate calcium and Vitamin D for bone health if needed. Dieticians will also help prevent or treat any weight problems.

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

I'm worried about how we're going to cope with this, what other help can I get?

It's important that you and your child have emotional support and 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.

Over time, so that your child can participate fully in activities, you may need further information and support on mobility, education, equipment and sources of funding. You can find out more by talking to your child's healthcare team, SMA UK's Support Services Team, and the other people and organisations listed at the end of this leaflet.

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

What about any Financial Support?

Families living in the UK may be eligible for financial benefits to help towards the cost of providing any 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 UK for more information or see the Living With SMA area of our website. (more details at the end of the booklet).

Your health visitor, community nurse, neuromuscular care advisor, social worker or outreach worker may be able to help you with applications for financial benefits.

Support and Resources

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

SMA UK

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

We provide a free **Support & Outreach Service** for families by email, phone, text and outreach home-visiting. Our experienced team offer personalised support and information and are available to answer questions and talk things through. Though we don't give medical advice, we can discuss with you the support you and your family can access.

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

If you're wondering about an aspect of life with SMA, we hope the **Living With SMA** area of our website will be a helpful starting point, giving you useful information and ideas. It builds on knowledge and advice from the SMA Community and SMA UK's Support Services Team, and covers a whole host of topics, including: health & wellbeing, equipment, homes, education, work, transport, leisure, holidays, financial, and emotional & social support: www.livingwithsma.org.uk

Any family affected by SMA, living in the UK, can request a free copy of the following books:

- **Smasheroo** - written by the mother of a child who has SMA, with illustrations by Mary Hall, this uplifting story highlights that everyone is different and everyone is special in their own way.

- **SMA Type 3 and Me** - an illustrated book published in 2016 for children aged 8 – 12 years, but it could also be read to a younger child. As of October 2019, it remains factually correct and may still be useful. We will not be updating this book and instead are building new resources in the Living With SMA area of our website: www.livingwithsma.org.uk/children/resources-for-parents-health-wellbeing

You'll find more information **about nusinersen** and what is happening in the UK here: www.smauk.org.uk/nusinersen Our information sheet **'Nusinersen (also known as Spinraza™) treatment for those diagnosed with SMA Type 2 or 3'** can be read / downloaded from here: www.smauk.org.uk/treatment-information-leaflets

This website section tells you **about other research developments**: www.smauk.org.uk/drug-treatments-screening-whats-happening-now You may also find our information sheet '**How Clinical Trials Work**' useful: www.smauk.org.uk/clinical-trials

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 their alert card for SMA Type 3 can be found at: www.musculardystrophyuk.org/about-muscle-wasting-conditions/information-factsheets/conditions/alert-cards-and-care-plans/alert-cards/

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.

Online communities
These have been set up by people in the SMA Community. If you're interested in any of the support groups offered, please contact the group directly. You can find details of some of them here: www.smauk.org.uk/online-sma-communities

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Highly commended

This information booklet is one of our 'Looking After…' series, which was highly commended in the 2019 British Medical Association Patient Information Awards.

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If you have any feedback about this information, please do let us know at
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