Hearing Your Child's Diagnosis of Spinal Muscular Atrophy (SMA)

You can also read this guide on our website at smauk.org.uk/h97r where you can follow all the links we give to further information.

This information is for parents or carers whose child has:

- started to show symptoms of Spinal Muscular Atrophy (SMA) and
- recently been diagnosed with the condition.

It talks through:

- some of the emotions, thoughts and feelings you may be experiencing
- who you can talk to for support
- some practical suggestions for what can help.

1. First Reactions

You may have been concerned about the symptoms your child has had and been trying to get an answer to what the cause is for some time. Depending on their age your child may have been frustrated or worrying about them as well.

Getting a diagnosis of SMA can lead to many conflicting emotions. You may have experienced some or all of the following:

- Distress and disbelief
- Relief at knowing what the cause is
- Fear and anxiety
- Sadness and upset
- Anger and frustration

There is no 'right or wrong' way to feel. People can experience different combinations of these emotions at different times. They may have other reactions. For example, different levels of acceptance, hope, and expectations for the future. Whatever you are feeling, it is important to know that as well as your family and friends, there are other people you can turn to for support.

Your child's specialist clinician will meet with you to discuss what care your child will need, and possible treatment options. It is important that they acknowledge and address:

- the emotional impact this diagnosis has on you and your child
- your understandable protectiveness towards your child.

Taking in and understanding what this diagnosis means will seem overwhelming. There is a lot to take in at a time when concentrating and remembering what you have heard can be very challenging.

If possible, it may be helpful to have both parents or carers, or a family member or close friend with you to hear what is said. You will have many questions to ask as many times as you need. It can help to have someone else there to talk things through with afterwards.

Before any meeting it may be useful to write down any questions you would like to ask. One of you could write notes for you to look over and talk through later.

During your discussions you will be made aware of the importance of starting any **disease-modifying treatment ›** as quickly as possible. This is because the effect of any of the treatments is expected to be greater the earlier it is started. Having to make a decision about treatment options can feel very pressured.

Some people want to do their own research during this time. This may include through internet searches and on social media. While there is lots out there that can be helpful, it is worth remembering that:

- no two families have the same personal circumstances
- no two children are the same in terms of the impact of their SMA
- no two children respond in the same way to any treatment.

There is also lots of outdated and misinformation out there. It is better to try and find information from reputable sources. These are ones that have quality healthcare marks on them. The SMA UK website has a trusted information creator status shown by **the Patient Information Forum TICK ›** We are signposted by the **NHS website ›**.

2. Your Child's Clinical Team

Your child's reaction to their diagnosis and the questions they have will depend on their age and understanding. It will also depend on the impact their SMA symptoms is having on their day-to-day life and what care and / or treatment plans are agreed with their clinical team.

The clinician who has made your child's diagnosis should answer any immediate questions you and your child have. They will discuss the impact SMA is having on your child's day-to-day life and what care and / or **treatment plans ›** are possible. They will be used to talking to children and should help with answering your child's questions.

Your clinician should also offer you support from the wider clinical team. Over time, this could include:

- Your child's Neuromuscular Care Advisor (NMA)
- Your child's nurse / physiotherapist
- A counsellor / psychologist

You can read more about the different sorts of health and social care professionals who may be involved in your child's care in our information sheet, **Who's Who of Professionals ›**.

3. SMA UK's Support Team

We have an experienced Support Team who work UK-wide to support anyone affected by SMA. The team offers emotional support, practical advice and guidance, and is here to listen – whether at diagnosis or beyond. This free, confidential service is for any family member or carer affected by SMA.

The team can be in contact by email, phone, text or virtual meetings (such as on Zoom or Microsoft Teams). They are also able to visit you at home, if that is something you would find helpful.

Find out more and get in touch with our **Community Support Team ›.**

4. Family and Friends

You may worry about how this diagnosis and the care your child may need will affect your immediate and extended family. It may be hard to know how to talk to them about what the diagnosis means. They may, in turn, have concerns or questions about how SMA might affect them and their children. Your child's clinical team should be able to help with this.

You may find the information pages about 5q SMA in our section **About SMA ›** useful. These include:

- **The Genetics of 5q Spinal Muscular Atrophy ›** We also have information about **other rarer forms of SMA ›**

You should be offered genetic counselling. Family members may also ask for this via their GP.

Your family and friends will want to know how best they can support you. Sometimes it can be difficult for them to know what to do or say. If you are comfortable doing so, talking with them about your child's diagnosis might help. There may also be practical things they might be able to do (see more below).

Our **information for family members and friends ›** may be helpful.

5. Religious or Spiritual Support

You may have your own religious leader or community that you can turn to for support.

A spiritual care team or chaplaincy service should also be available at most hospitals. These professionals are trained to talk about emotional and personal wellbeing. They will talk to anyone, no matter their beliefs, religion, or cultural identity. They will also be able to tell you about services which are local to you.

6. The SMA Community

You may wish to speak to other parents or carers whose children have SMA and have been through the diagnosis journey. Our **Support Team ›** may be able to connect you with another family.

Or

When the time is right, you (and others in your family) may be interested in joining one or more of our **Community WhatsApp Networks ›**. These are for those affected by SMA to connect with others. They can be useful places to share experiences and ask questions.

7. Emotional and Psychological Support for You and Your Child

Over time your child may find adapting to living with SMA emotionally challenging. Our website pages have suggestions to help support their emotional and psychological well-being:

- **For Children ›**
- **For Teenagers ›**

Talking Therapies and Counselling for you

Some people find it helpful to talk about their feelings and how they are managing day-to-day, with an independent, trained professional. It can be an opportunity to express feelings you may not have wanted to say out loud to your partner, or anyone in your family or friendship group:

Free Talking Therapy Services:

England:

For those aged 18+ you can access free NHS Talking Therapies (formally known as IAPT – Improving Access to Psychological Therapies) for anxiety and depression. You can either refer yourself directly without a referral from a GP, or a GP can refer you. Either way, you need to be registered with a GP to get talking therapies on the NHS.

- **Find out more ›**

Scotland:

NHS Scotland offers 'Living Life' – free phone support sessions (for those aged 16+). They use Cognitive Behavioural Therapy (CBT) based techniques. You can refer yourself for an assessment by phoning 0800 328 9655.

- **Find out more ›**

Wales:

People aged 16 and over can sign up for a free 12-week course of online therapy called 'SilverCloud'. They use methods like Cognitive Behavioural Therapy (CBT) to help people manage any challenges they are facing.

- **Find out more ›**

Northern Ireland:

Referrals for any talking therapies must go through your GP.

- **Find out more ›**

Waiting times for an appointment with these services will vary and may be quite long. If you are employed, you may be able to access counselling through your employer which can sometimes be quicker than NHS.

Private counselling

If you think counselling would be helpful for you and it is an affordable option, you could consider seeing a local private counsellor. These organisations can help you find one:

British Association for Counselling and Psychotherapy (BACP) › guidance on counselling and how to find a suitable counsellor. Phone: 01455 883 300.

Counselling Directory › online information about different types of counselling and a directory to search for qualified counsellors.

If you are not sure who to speak to or which is the right route for you, our Support Team › is here to talk through your options.

8. Caring For Your Child

As well as the support from your child's medical team, you may find our 'Looking After' guides helpful. These talk about the practical side of caring for a child who has 5q

SMA who has been recently diagnosed. They have been written with both parents and carers of children who have SMA and expert healthcare professionals.

There is great variation in how children are individually impacted by SMA. Similarly, there are great variations in how they are responding and developing if they are receiving drug treatment. you may find that only some of the information is relevant for your child. Your clinician can help guide you:

- **SMA Type 2 – Looking after your child who has had a recent diagnosis ›**
- **SMA Type 3 – Looking after your child who has had a recent diagnosis ›**

We have **information about other rarer forms of SMA on our website ›.** We regret that as these conditions are very rare, we do not have specific 'Looking After' guides for them. If your child has recently been diagnosed with a rarer form of SMA, then our **Support Team ›** is here if you have any questions or would like to talk things through.

We also have a wide range of information about all aspects of life that may be useful:

- **Living with SMA – Children ›**
- **Living with SMA – Teenagers ›**

9. Caring For Yourself

It is really important that you look after yourself – both mentally and physically. This will enable you to look after your child in the best possible way. This might include:

- getting rest
- eating well
- getting out and about to see people
- spending time outside in green spaces such as a local park

To help with this, you could let family members and friends help with practical things like shopping, cleaning or other household needs.

You may find some things help you manage your thoughts and feelings, such as exercising or listening to music. Some of the **guides tools and activities signposted on the NHS website ›** may be helpful.

You may also find you need private space from time to time. It may be a place where you can express your anger or sadness in a healthy way by shouting, screaming, or crying.

10. Other Charities and Organisations

You may find it helpful to have contact with:

Contact › Phone: 0808 808 3555 – information and support for families who have a disabled child. Contact also offer a one hour 1- to – 1 **Listening Ear ›** phone service for parents looking for emotional support.

Scope › offer advice for managing the emotional impact of your child's diagnosis.

Home Start › Phone: 0116 464 5490 – depending on services in your area, volunteers may be able to offer friendship and practical help to families going through difficult times and those affected by disability. Parents can refer themselves for services or a referral can be made through a midwife, GP, social worker or health visitor.

11. Useful SMA UK Resources

- ### For your child:

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 ›**

- **For family and friends:**

About SMA › This section of our website has a wide range of information.

- **For nursery and primary schools:**

5qSMA – Information for schools › provides a useful summary.

- **For parents and professionals:**

Support for you › links to our other resources.

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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