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

You can also read this guide on our website at smauk.org.uk/lb0o where you can follow all the links we give to further information.

This information sheet is for parents or carers whose babies:

- are aged 0-12 months **and**
- have been diagnosed with SMA because of their symptoms.

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.

If your baby has been diagnosed via the Generation Study › please talk to your clinician about what information may be useful.

1. First Reactions

A baby's diagnosis of SMA often comes as a big shock. Some of the most common reactions include:

- Distress and disbelief
- 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 the 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 understandable protectiveness towards your child.

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

If possible, it may help 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 a lot out there that can be helpful, it is worth remembering that:

- no two families have the same personal circumstances
- no two children are impacted by their SMA in the same way
- 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 Baby's Clinical Team

The clinician who has made your baby's diagnosis should answer any immediate questions you have. They will be very aware how pressured making decisions about treatment can feel. They will support you to think about options. They will listen to and answer any concerns you have.

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

- Your baby's Neuromuscular Care Advisor (NMA)
- Your baby's nurse or physiotherapist
- A counsellor or psychologist

You should be able to discuss any fears and anxieties you have openly with your baby's team.

In some areas you may be offered support from the **Palliative Care Team**. This is often associated with end-of-life care. Though this is one aspect, **unless needed, it is not a focus for these services.** Palliative Care includes providing:

- information and practical support
- advice about the management of symptoms
- short breaks from caring.

The overall aim is to achieve the best quality of life for your child, whichever medical options you may choose.

You can read more about the different sorts of health and social care professionals who may be involved in your baby'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.

You can 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 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 babies 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 connect those affected by SMA with others. They can be useful places to share experiences and ask questions.

7. Talking Therapies and Counselling

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'. This uses 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 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 baby'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. They have been written with both parents / 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 baby. Your clinician can help guide you:

- **SMA Type 1 – Looking after your child who has had a recent diagnosis ›**
- **SMA Type 2 – Looking after your child who has had a recent diagnosis ›**

We have information about **other rarer forms of SMA on our website ›** but 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, 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 in the Children's section of Living With SMA ›.

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
- taking breaks
- 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 useful.

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.

WellChild Nurses › care for children and young people with a variety of long term or complex health conditions. This is a specialist network that provides a co-ordinated and high-quality model of care both in hospital and the community. They are employed by NHS Trusts in some areas. You may be introduced to one by your clinical team.

Home Start › Phone: 0116 464 5490 – 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. Services vary between areas.

Some babies and children diagnosed with SMA may be very unwell. In these circumstances, families may find these support organisations helpful:

Together for Short Lives › Phone: 0800 808 8100 – information and support to families who have a child with a life-limiting condition. They will be able to tell you about hospice and other services in your area.

Rainbow Trust Children's Charity › Phone: 01372 363 438 – emotional and practical support to families who have a seriously ill child. You will need to see if services are available in your area.

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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