

Who We Are

We are an established charity that supports and empowers anyone affected by Spinal Muscular Atrophy. We are advocates for better services and access to new treatments, raise public awareness and fund research related initiatives.

Our services are free to those in the UK but we do not provide medical services/advice, which must come from your medical team.



How You Can Help Us

We do not receive government funding and rely on the generosity of our supporters to maintain our services. If you can help us please go to:

www.smasupportuk.org.uk/donate



How to contact us

Spinal Muscular Atrophy Support UK
40 Cygnet Court
Timothy's Bridge Road
Stratford-upon-Avon, CV37 9NW

Phone: 01789 267520

Lines open:

- Mon – Thurs (9.00 am—3.30 pm)
- Friday (9.00 am—1.00 pm)
- Closed on public holidays.
- Ask for Support Services – we can call you back.

Email:

supportservices@smasupportuk.org.uk

www.smasupportuk.org.uk

Registered Charity No 1106815
Company Limited by Guarantee No 5137534
Registered in England and Wales

June 2017

How We Can Help You

Our Services



Help for today - Hope for tomorrow

Information

Our website includes a wide range of information about Spinal Muscular Atrophy (SMA) and related topics. We also have online 'Route Maps' which summarise services and resources available in the UK. We are accredited to the Information Standard as providers of safe, reliable, high quality health and social care information.



Outreach

Our Support Services team can talk to you through information and also offer emotional support, practical advice and guidance. This may be by phone or email for adults, young people, parents, relatives and friends affected by SMA and for health, education and social care professionals. Our Outreach Workers can also visit people at home.



Toy Packs

Our free multi-sensory toy packs for babies newly diagnosed with SMA Type 1 or SMARD can be sent out on request.



Sharing Experiences

We are in touch with a wide range of people who all have personal experience of SMA and are willing to answer questions about how they have managed the condition.



You may want to meet up with other people at one of our information, support or social events, or read about people's personal experiences in the 'SMA Voices' section of our website.

Research and Treatment Updates

Our Research Correspondents post updates about the causes, treatment and management of SMA on our website. This includes accurate information about drug treatments proven to be effective for SMA as well as those currently being tested in clinical trials. It also includes summaries and reviews of clinical care and practice.



Campaigns and Consultations

We enable opportunities for people's voices to be heard via surveys and consultations that cover a wide range of topics—such as transport and employment. We also work with the SMA community to campaign for access to new treatments in the UK, with a current focus on nusinersen. Our website, monthly E-newsletter and social media keep people up-to-date with what is going on.

Our Monthly E-Newsletter

You can sign up to keep in touch with what is happening in the SMA community:

www.smasupportuk.org.uk/sign-up-for-mailings