

## Who are SMA Support UK?

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](http://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

- 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](mailto:supportservices@smasupportuk.org.uk)

[www.smasupportuk.org.uk](http://www.smasupportuk.org.uk)

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# Sharing Experiences

## Our SMA Community



 **Spinal Muscular Atrophy Support UK**  
Help for today • Hope for tomorrow

## Sharing Experiences

Although no two people with SMA are the same, it can be helpful to have contact with others with direct experience of the emotional and physical impact of a diagnosis of SMA, and the on-going challenges.



We offer a variety of ways for people affected by SMA to share experiences...

## The Sharing Experiences Network



You can use our Sharing Experiences Network to gather tips and ideas from others with SMA. Ask a question, or sign up to share your own experiences. Email is used and everyone's privacy is maintained.

## Direct Confidential Contact



If you're over 18, you may request direct confidential contact with one of our Peer Support Volunteers who have SMA themselves or who are parents or grandparents.

Our volunteers are at least two years on from diagnosis or bereavement and are able to listen, share and provide on-going support for you, by email or phone.

## SMA Voices



You can find these stories on our website. Parents talk about their experiences of diagnosis and caring for their babies and young people. Families and adults describe how they manage their condition, overcome social and institutional barriers and achieve their ambitions.

## Meeting Up

You may want to meet up with others at one of our summer or winter social events.

We also organise occasional information and support days and let you know about other events and opportunities that may be of interest.



## Online SMA Communities

Some people find online forums and social media groups helpful. We can signpost you to groups which others have recommended.

