## Is there a cure for SMA?

There is currently no cure for SMA but improved understanding of the condition has led to encouraging breakthroughs in developing treatments. Our website has the latest information about their progress and availability. Symptoms of SMA can also be managed and the highest standard of care given so that people with SMA can have the best possible quality of life.

## 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.

## How You Can Help Us

We do not receive government funding. Please help us keep busy working to support the research community in their efforts to address the causes, treatment and management of SMA.

**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 (9.00am –1.00pm)
- Closed on public holidays.

**Email:** office@smasupportuk.org.uk

**www.smasupportuk.org.uk**



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

September 2017


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

# What is Spinal Muscular Atrophy?

Key Information

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

## What is Spinal Muscular Atrophy?

Spinal Muscular Atrophy (SMA) is a rare, genetically inherited neuromuscular condition. It causes progressive muscular weakness and loss of movement due to muscle wasting (atrophy).

SMA is passed from parents to their children through the Survival Motor Neuron 1 or *SMN1* gene.

- Approximately one in 40 of us carry this gene which equates to around 1.6 million carriers in the UK.
- If two carriers of the gene have a baby there is a one in four chance their baby will have SMA.

Studies suggest that worldwide, approximately :

- one in every 10,000 babies born have a type of SMA.
- between 1 and 2 children, young people and adults in every 100,000 have a type of SMA.

## Types of SMA

SMA is often grouped into 'Types' based on the age at which symptoms first appear and what physical 'milestones' a baby or child is likely to achieve. There is a wide spectrum of severity both between the different types of SMA and between individuals within each type. The main childhood onset forms are Types 1, 2 and 3.

## Spinal Muscular Atrophy Type 1

SMA Type 1 is the most severe form of SMA. Symptoms begin between the ages of 0—6 months. Babies are unable to sit without support. Sadly, without intervention, most children with SMA Type 1 rarely survive beyond two years of age, usually due to breathing difficulties.

## Spinal Muscular Atrophy Type 2

Children with SMA Type 2 are unable to stand or walk without support. Though this is a serious condition that may shorten life expectancy, improvements in care standards mean that the majority of people can live long, fulfilling lives.

## Spinal Muscular Atrophy Type 3

Children with SMA Type 3 are able to stand and walk, although this will become difficult and they will need more support with this over time. Life expectancy is normal and most people can live long, fulfilling lives.

## Rarer forms of SMA

There are other rarer forms of SMA. These often have different genetic causes. They include Adult Onset SMA, Distal SMA, Kennedy's and SMA with Respiratory Distress (SMARD) .