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 a charity that has been supporting individuals, families and research for over 30 years. We provide information about the condition, are advocates for better services and access to new treatments, fund research related initiatives and raise awareness.

How You Can Help Us

We don't receive government funding. Please keep us busy supporting people affected by SMA and researchers addressing 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

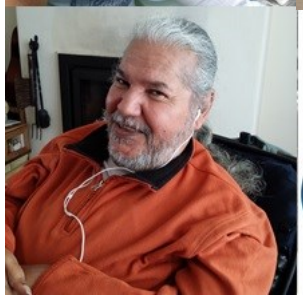
Registered Charity No 1106815
Company Limited by Guarantee No 5137534
Registered in England and Wales

June 2018

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 muscle 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 faulty gene - that's 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 broadly on the age symptoms first appear and what physical 'milestones' a baby or child is likely to achieve. The main childhood onset forms are Types 1, 2 and 3. The impact of the SMA varies greatly within and between each type. and is very individual and

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. It's not possible to predict life expectancy accurately but, due to breathing difficulties, without intervention this has usually been less than two years of age.

Spinal Muscular Atrophy Type 2

Children with SMA Type 2 are unable to stand or walk without support. and are vulnerable to chest infections. Though it's a serious condition that may shorten life expectancy, improvements in care standards mean that the majority 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. Their life expectancy is normal and most can live long, fulfilling lives.

Rarer forms of SMA

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