TreatSMA
Treat Spinal Muscular Atrophy

Hospitalisation Care Information

Important Information

My name is:

My date of birth & address is:

My next of kin & phone number is:

My NHS number is:

My diagnosis is:

My weight is:

My height is:

Important Information Cont.

My medications are:

My allergies are:

My specialist's contact details are:

Important Information Cont.

My medical history is:

- ☐ Spinal growing rods, date:
- ☐ Spinal fusion surgery, date:
- ☐ Hip surgery, date:
- ☐ Supra pubic catheter
- ☐ Mitrofanoff catheter
- ☐ Tracheostomy
- ☐ PEG
- ☐ Recurring chest infections, last infection date:
- ☐ Other:

Additional medical history details:

Important Information Cont.

My equipment needs are:

- ☐ Hoist
- ☐ Slide sheet
- ☐ Pressure relieving mattress
- ☐ Sling – size:
- ☐ Transfer board
- ☐ Walking frame
- ☐ Wheelchair
- ☐ Other:

My respiratory needs are:

*Please refer to Standards of Care for safe oxygen use and information on chest physio provision

- ☐ BiPAP
  - Settings when well:
  - Settings when unwell:
- ☐ Cough assist
  - Settings when well:
  - Settings when unwell:
- ☐ Nebuliser

My personal care needs are:

- ☐ Own carer able to stay 24/7
- ☐ Soft diet
- ☐ Tube fed
- ☐ Drink thickener
- ☐ Assistance cutting food
- ☐ Straw to drink
- ☐ Aspiration risk
- ☐ Continence care e.g. catheter
- ☐ Unable to press buzzer
- ☐ Non-verbal
- ☐ Unable to weight bear
- ☐ Unable to sit unsupported
- ☐ Unable to self transfer
- ☐ Skin integrity risk
- ☐ Liquid medication only

Important Information Cont.

My personal care further information:

About Spinal Muscular Atrophy

Spinal muscular atrophy (SMA) is a rare, inherited neuromuscular condition caused by a fault in a gene called SMN1 (Survival Motor Neuron 1). This gene is responsible for producing a protein called SMN, which motor neurons in the spinal cord need to survive. Without enough SMN protein, these motor neurons progressively deteriorate and die.

As motor neurons are lost, the muscles they control become progressively weaker. This is why SMA primarily affects movement — the ability to walk, sit, hold the head upright, swallow and breathe can all be impacted, depending on severity. SMA does not affect intelligence or cognitive ability.

Significant treatment advances since 2017 have dramatically changed the outlook. Today, with early treatment, many children with SMA are reaching developmental milestones that would have been impossible a decade ago.

> **Important**
> SMA does not affect intelligence. People with SMA have the same intellectual capacity as anyone else — the condition affects motor neurons only, not thinking, memory or emotion.

Types of Spinal Muscular Atrophy

Please note: Types are guides, not fixed destinies

These categories reflect the typical natural history without treatment. Pre-symptomatic treatment can fundamentally alter the course of the disease — a child identified via newborn screening and treated before symptoms appear may far exceed the milestones historically associated with their SMA type.

Type	Also called	Onset	Milestones (untreated)	SMN2 copies
Type 0	Prenatal	Before birth	Rarely survives beyond a few weeks	1
Type 1	Werdnig-Hoffmann	0–6 months	Cannot sit independently; without treatment survival typically <2 years	1–2
Type 2	Dubowitz	6–18 months	Can sit; cannot stand or walk independently	3
Type 3	Kugelberg-Welander	18 months onwards	Can walk; many lose ability to walk later	3–4
Type 4	Adult-onset	Adult life	Ambulatory; slow progression; near-normal life expectancy	4+

International SMA Standards of Care

The International Standards of Care for Spinal Muscular Atrophy were released in two parts in 2017:

- Part 1: Diagnosis and Management of SMA: Part 1 — Recommendations for diagnosis, rehabilitation, orthopaedic and nutritional care
- Part 2: Diagnosis and Management of SMA: Part 2 — Pulmonary and acute care; medications, supplements and immunizations; other organ systems; and ethics

If this document is being accessed virtually, you can follow the links at www.treatsma.uk. If it is printed, please refer to that website for current links.

There is also a family friendly version and translated versions available at:

- The Family Friendly UK Guide to the 2017 SoC (pdf)
- Translations of the Family Guide to the 2017 SoC