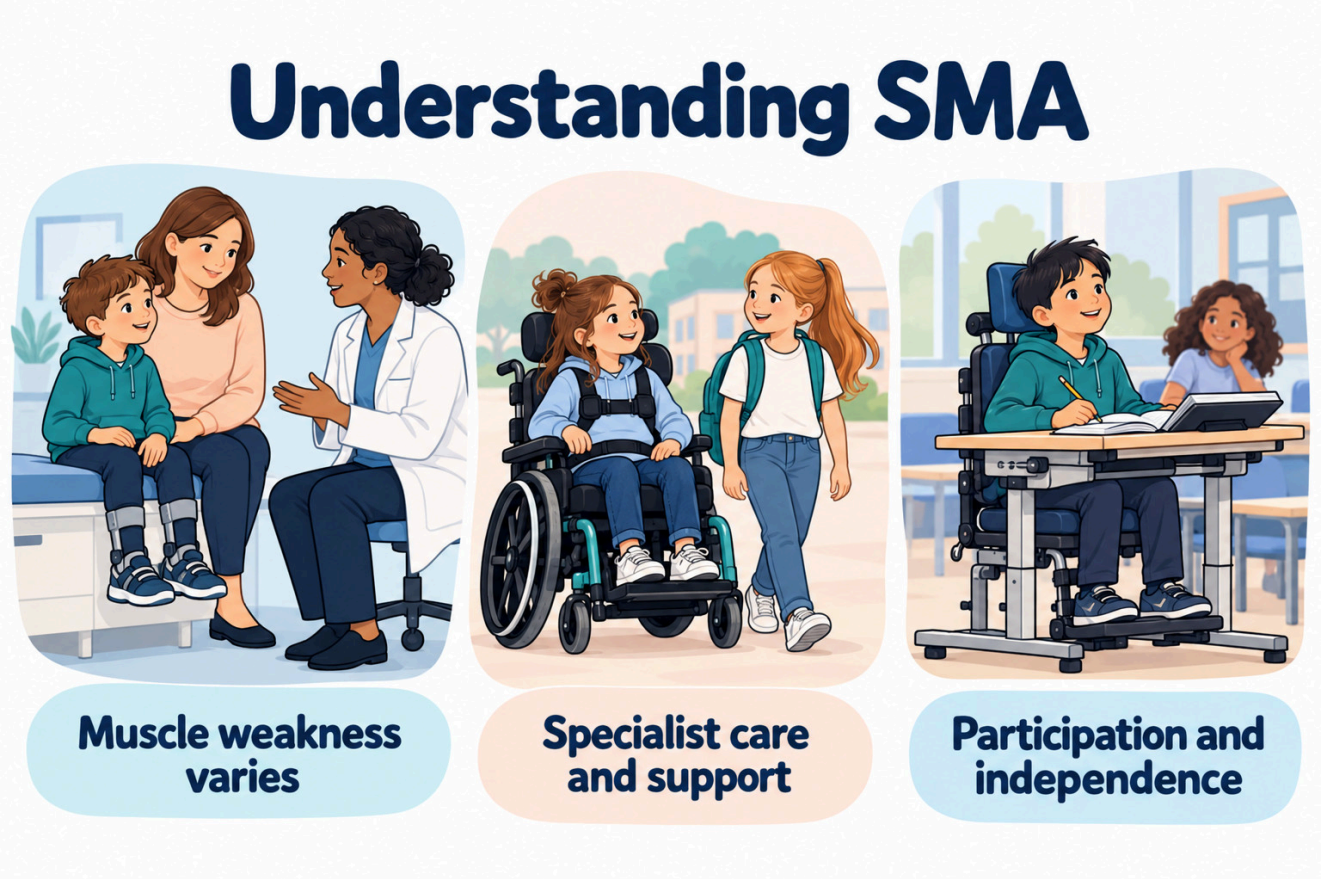
Spinal Muscular Atrophy

Information for children, parents and carers

Spinal Muscular Atrophy

A guide to symptoms, treatment and recovery



Understanding the condition

Spinal muscular atrophy (SMA) is a genetic neuromuscular condition affecting motor nerves that control movement. It causes muscle weakness and can affect sitting, walking, breathing and sometimes swallowing.

Supporting your child

Every child's needs differ. Early diagnosis, specialist treatments and coordinated support can improve outcomes. Physiotherapy and adapted activities should follow the neuromuscular team's individual plan.

Symptoms and assessment

Understanding the cause and when to seek help

Why does SMA happen?

SMA usually involves changes in the SMN1 gene, reducing a protein needed by motor nerve cells. It is commonly inherited in an autosomal recessive pattern. Genetic counselling helps families understand inheritance.

Types and individual differences

Traditional types describe onset and motor abilities: type 1 begins in infancy, type 2 often between 6-18 months and type 3 later in childhood. Type 4 begins in adulthood. Severity and support needs vary within each type.

Possible signs

Weakness in arms, legs or trunk, reduced muscle bulk, delayed motor skills, fatigue, difficulty sitting or moving, and sometimes scoliosis. Breathing, feeding or swallowing problems may also occur.

Diagnosis

Genetic testing can confirm the diagnosis. Examination and muscle strength assessment help plan care; nerve or muscle electrical tests are sometimes used. Early assessment supports timely treatment and help.

When to contact the team

Report increasing weakness, sudden loss of function, frequent chest infections, feeding or swallowing problems, or worsening breathing. Seek urgent help if breathing becomes difficult.

Key message

Every child’s needs differ. Early diagnosis, specialist treatments and coordinated support can improve outcomes. Physiotherapy and adapted activities should follow the neuromuscular team’s individual plan.

Treatment and daily care

Activity guided by your child's healthcare team

Before starting activity

The neuromuscular team should choose movements, positioning, equipment and breathing support for your child. Avoid a fixed exercise routine that ignores their abilities or fatigue.



Activity guidance

Movement: use gentle strength or flexibility work as prescribed.
Posture: use advised seating, positioning and mobility support.
Pacing: allow rest breaks and watch for fatigue.
Breathing: follow the specialist respiratory care plan.

Important precautions

Seek urgent help for breathing difficulty. Contact the team for sudden loss of function, worsening weakness, feeding or swallowing problems or repeated chest infections. Do not push through exhaustion.

Treatment and next steps

Caring for your child and finding support

Specialist medical treatment

The neuromuscular team advises which treatment fits your child. Options include nusinersen, risdiplam and gene therapy for eligible children. Suitability and monitoring require specialist assessment.

Therapy and everyday care

Physiotherapy may include gentle movement, positioning, water-based therapy and prescribed aids. Respiratory and feeding specialists provide support when needed. Encourage play within ability, safe seating and regular rests.

School and social participation

Wheelchair access, extra time, support staff, seating aids and an individual health plan may help. Coordinate with school and the healthcare team so your child can participate with appropriate support.

Questions or urgent concerns?

Seek urgent help if breathing is difficult. Report increasing weakness, sudden loss of function, feeding or swallowing problems or frequent chest infections. SMA UK, genetic counselling and children's therapy services offer support.

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