



Spinal Muscular Atrophy (SMA) is an inherited genetic (it is NOT contagious) muscle wasting disease. This weakness not only affects arms, legs we see, but also all internal muscles; including breathing, coughing and swallowing. As time progresses coughing becomes difficult and breathing becomes laboured.

***There is no known cure for Spinal Muscular Atrophy.***

## SMA FACTS

- 1 in 35 people carry this gene. Being a carrier does not mean you are affected by the disease.
- A SMA baby is born when BOTH parents are carriers of this gene, neither parent is to blame. There is a 1 in 4 chance of having a baby with SMA.
- A baby is born with SMA every 7 hours (worldwide).
- Around 630 people die from Motor Neurone disease every year in Australia. Spinal Muscular Atrophy is the childhood version of motor neurone disease. (ABS).
- Genetic testing for SMA prior to / at early pregnancy is not widely publicised and the test does not attract a Medicare rebate (i.e. the current cost is approx \$400 to the individual).
- Children with SMA catch germs very easily so washing hands before having contact is very important. Avoid visits by anyone suffering a cough / cold or anything contagious.
- Infants / Children / Adults diagnosed with Type 2 and Type 3, have a good survival rate, but mobility and dexterity are compromised. Most sufferers are wheelchair bound by early childhood. With some requiring steel rods in their back to allow them to sit upright and prevent scoliosis. All sufferers require assistance with activities of daily living such as grooming and feeding etc.
- Babies born with SMA appear perfectly normal in every way except they are extremely weak. They are bright, alert, interested in people and what's going on around them. They enjoy music and being played with – just like other babies.
- There is no known cure for Spinal Muscular Atrophy and babies born with the most severe form of SMA - Type 1 - rarely live past 2 years of age.
- SMA is a physical disease only. Children with SMA have reduced movement.
- SMA Children's intelligence is unaffected. Many children with SMA have above average intelligence.
- Include the child in ALL aspects of play and do not isolate them from conversation or play, just because they are in a chair.

*This Fact Sheet was prepared by the Spinal Muscular Atrophy Association of Australia Inc.*

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