



CONVERSATION GUIDE FOR PAEDIATRICIANS AND GPs

This conversation guide offers prompts and important things to remember when discussing a baby's motor skills development with a concerned parent.

As a physician, you are uniquely placed to spot whether an infant is developing as they should, whether this is at a routine check-up, or if parents or caregivers raise any concerns.

The first signs of spinal muscular atrophy (SMA) can be seen up to 3 months of age. Although babies develop at different rates, parents and caregivers who spend a lot of time with their baby are often the first to notice abnormalities in their development. These concerns should not be overlooked.

SMA is typically classified into **4 phenotypes (Types 1 to 4)** that range in severity.¹ In SMA Type 1, the most severe and common form, most **lower motor neuron degeneration** occurs in the first few months of life.

Fast diagnosis is vital because any lower motor neuron damage occurring before treatment is irreversible.^{1,2}

Refer babies up to 3 months of age to a paediatric neurologist for urgent review if you see any of the following 3 signs:

1 Head lag^{3,4}



2 Hypotonia (floppiness)⁵⁻⁷



3 Inability to reach^{4,8}



QUESTIONS TO CONSIDER WHEN SPEAKING TO A CONCERNED PARENT OR CAREGIVER:

1. What is concerning you about your baby's movements?

Is your baby moving less than you would expect?
Have movements decreased recently?

2. When did you first notice something that concerned you about your baby's movements?

The early signs of SMA Type 1 are typically first noticeable within the first 3 months of age and untreated babies with SMA Type 1 usually do not acquire any gross motor skills such as head control or sitting unsupported.

3. Does your baby have control of their head and neck?

When your baby is picked up can they support their own head, or are they beginning to acquire this skill?
How long can they support their head for?

4. How does your baby move when on their stomach?

Laying a baby on their stomach shows how much muscle strength they have in their neck and shoulders. Can your baby lift their head at all when on their tummy?

5. How is your baby feeding?

In severe cases of SMA, babies can struggle with feeding, specifically latching and suckling, and can sometimes cough or choke when swallowing.

Notes:

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References: 1. Farrar MA, et al. *Ann Neurol*. 2017;81:355–68. 2. Glascock J et al. *J Neuromusc Dis*. 2018;5:145–58. 3. Markowitz JA et al. *JOGNN*. 2004;33:12–20. 4. Wang CH et al. *J Child Neurol*. 2007;22:1027–49. 5. Leyenaar J et al. *Paediatr Child Health*. 2015;10(7): 2005. 6. Hammersmith Infant Neurological Examination (v07.07.17). 7. Mercuri E et al. *Neuromusc Disord*. 2018;103–115. 8. De Sanctis R et al. *Neuromuscul Disord*. 2016;26(11):754–59.