



## 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.<sup>1</sup> 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.<sup>1,2</sup>

### 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<sup>3,4</sup>



**2** Hypotonia (floppiness)<sup>5-7</sup>



**3** Inability to reach<sup>4,8</sup>



### 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.