

# Needs and recommendations for doctors

Doctors play a crucial role in these areas for persons with spinal muscular atrophy (PWSMA) and their caregivers.

While SMA may be considered a rarity by most clinicians, new advances in SMA management, such as the emergence of novel therapies, has escalated the need for SMA education and awareness among all levels of healthcare providers, especially paediatricians and general practitioners.

- Living With Spinal Muscular Atrophy in Malaysia: A Study

## DURING DIAGNOSIS

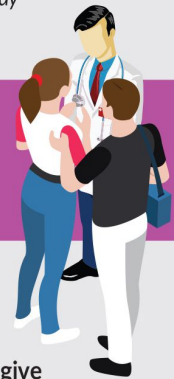
> Developmental delays need to be recognized early.



There is a lack of knowledge and very little attention or urgency given to developmental delay in infants among healthcare professionals, as evident from expressions such as 'It's nothing' and 'Biasalah (It's normal)'.

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> Sensitivity and compassion are crucial when giving the diagnosis.



Doctors lack empathy and did not offer much help. The doctor said, 'Eh, you know or not, your child ah, can't live long. I can only give you a period of a maximum of two years.'

- A father of two children with SMA Type 1

## AFTER DIAGNOSIS

> Multidisciplinary care and collaboration are essential.

Among the main areas of concern for persons with SMA and their caregivers are:

Respiratory care



Physiotherapy



Occupational therapy



Nutrition



Orthopaedics



Mental health



Palliative care



> Help with referrals for financial aid and resources like SMA support groups.



> Listen to and work with PWSMA and their caregivers.



Yes, we understand that the doctors cannot know everything, but try to work with the parents. Trust the parents or listen to what the parents want first. Don't see our child as a disorder, see our child as a human first.

- A mother of a boy with SMA Type 1

Support groups can provide mutual aid and information-sharing, which enables parents to feel less helpless and more adequate in caring for their children.

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#thinkSMALLactBIG

