

How SMA affects me physically

Here are five physical limitations that affect persons with spinal muscular atrophy (SMA) the most on a daily basis.



“I am not worried about death. I am worried about being an invalid.”

- A woman in her 30s with SMA type 2

In this study, the foremost issue was the lack of independence and mobility. In particular, this was a critical milestone for patients with SMA type 3 as they transitioned from being independently mobile to becoming wheelchair-bound. On the other hand, wheelchairs are a part of life for those with SMA type 2, who are usually adept at utilising powered or electric wheelchairs. However, all face difficulty travelling independently or navigating their environment due to sub-optimal infrastructure and public amenities that are inaccessible to wheelchairs.”

- Living With Spinal Muscular Atrophy in Malaysia: A Study

1. Being unable to move about independently



2. Being unable to transfer one's self from one piece of equipment to another (e.g. from wheelchair to bed)



3. Being unable to conduct normal physical activities



4. Being unable to go to the toilet by themselves



5. Unable to be truly independent



“My most worrisome situation is when I suddenly have phlegm in my lungs [and] I cannot cough it out and the helper is not able to push or rub my body correctly to expel it. Another major concern I can think of maybe is deterioration in respiratory function. I may not be able to take it as I am scared and also worry too much over this declining respiratory function. I am concerned that when the time comes, I may need to rely upon and be dependent on a respirator when my respiratory system deteriorates.”

- A woman in her 40s with SMA type 2

The main symptoms of SMA that affect a patient's quality of life are:

Muscle weakness



Joint contractures



Lung infection



Fatigue



Inability to cough effectively



“Because with SMA, you get weaker with time – progressive weakness – I worry about losing the ability to do things I like and the things that matter, for example, just being able to hold the fork and spoon. ... It is something basic, but I am losing my ability to do it, so I worry about all this.”

- A man in his 20s with SMA type 2

“My son was not achieving his milestones, like crawling or sitting up by himself, by the time he reached six months, unlike his older brother. He had a very soft cry and soft limbs. He couldn't lift up his head well. The doctor called it hypotonia. We did physiotherapy for six months but it didn't help.”

- A mother of a boy with SMA type 1

#thinkSMALLactBIG

