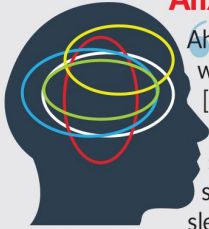


# How SMA affects us mentally

The mental health of persons with spinal muscular atrophy (SMA) and their caregivers can be significantly impacted by the presence of the condition.

## DIRECT IMPACT

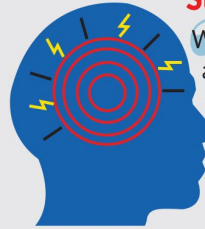
### Anxiety



Ah, at night, I never slept soundly. Every once in a while, I would get up to pray. I would recite [prayers] with my husband. I sleep, I recite, we look at her – we look at her every night. I can't sleep because I am scared [that] when I wake up, she won't be here because ... Every night I can't sleep (voice chokes with emotion).

– A mother of two deceased children with SMA type 1

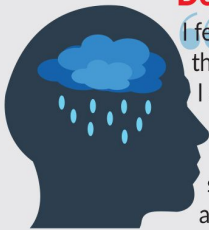
### Stress



Women, when we return home after work, we will be stressed – stressed from work and bring it home. [Then] at home, I will have to handle [the chores]. Sometimes, I feel burnt out.

– A mother of two children with SMA

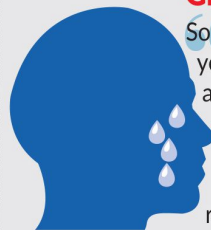
### Depression



I feel [frustration and hopelessness] most of the time, I don't know why. Maybe because I am alone, so I get overwhelmed with everything. Maybe it is too much to bear sometimes ... I also have my limits, sometimes I keep pushing myself and I am like: AAHHH! And just, you know, spiraling into despair.

– A woman in her 20s with SMA type 3

### Grief (for caregivers)



Some people commented, 'Don't worry, you're still young, you can get pregnant again.' It's very hurtful, you know?! No one can replace anyone. Even if he is no longer here, even if I have 10 babies, 10 more kids, we cannot replace this baby. Even now, with our second child, we talk, we tell him, you had a big brother before.

– A mother of a deceased child with SMA type 1

There is need for a support system at each stage of SMA as many parents have painfully shared the mental torment, anger, stress, depression and anxiety they go through at each stage of the disease. This includes dealing with the shock and grief that comes with the diagnosis and prognosis, the mental burdens of caring for their child and the grief when the child passes away.

– Living With Spinal Muscular Atrophy in Malaysia: A Study

## INDIRECT IMPACT

### On the parents' relationship

The differences between male and female ways of handling and expressing emotions such as non-acceptance, anger, guilt and fear, can also potentially lead to a rift in the marriage. ...

The hereditary factor of genetic diseases like SMA can pose unique issues for patients and families. This includes parental guilt regarding transmission, the potential for prenatal diagnosis, ethical and moral dilemmas with regards to the ability to terminate an affected pregnancy, and foreknowledge of the disease and its prognosis.

– Living With Spinal Muscular Atrophy in Malaysia: A Study



### On siblings

The care of a child with SMA means that other children (their siblings) are given less attention, and therefore, often felt neglected. Mrs SS [a mother of a boy with SMA type 1] shared the experience of how her older child started hurting himself when he was four-years-old, in order to get her and her husband's attention.

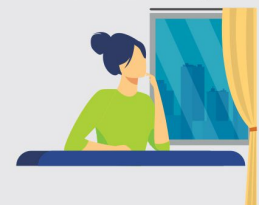
Living With Spinal Muscular Atrophy in Malaysia: A Study



### On social and family relationships

For family occasions, kenduri, weddings, I would reject invitations from all my relatives; I never went for any.

– A mother of a deceased child with SMA type 2



#thinkSMALLactBIG

