Our worries and wants

These are the worries and concerns, as well as the hopes and wants, of persons with spinal muscular atrophy (PWSMA) and their caregivers.

WORRIES AND CONCERNS

1. Losing their independence or never being able to be independent
2. Losing their functional abilities
3. Not being able to lead a normal life
4. Unable to join in social activities due to lack of accessibility
5. Lack of employment opportunities
6. The high cost of raising a child(ren) with SMA
7. Decreased mental and emotional health due to:
   - ➢ Loss of sleep and stress
   - ➢ Feelings of frustration and hopelessness
   - ➢ Feelings of uncertainty and anxiety
   - ➢ Depression and loneliness
   - ➢ Feelings of grief and sadness
8. Facing premature death, which includes:
   - ➢ The fear of dying or your child dying
   - ➢ Preparing to die
   - ➢ Living a meaningful life
9. Facing difficult treatment choices

HOPES AND WANTS

1. Access to disease-modifying treatments and clinical trials
2. Access to holistic post-diagnosis care, including:
   - ➢ Palliative care support
   - ➢ Professional mental health counselling
   - ➢ Respite care
   - ➢ A patient support group
   - ➢ Personal assistants for adult PWSMA
3. Help from the Government to:
   - ➢ Increase awareness about SMA
   - ➢ Improve accessibility for ease of movement for PWSMA, to education and employment, as well as to promote societal inclusivity for PWSMA
   - ➢ Improve medical care services for SMA, e.g. subsidise or reimburse treatment costs

People are not disabled by their medical condition, but rather the attitudes and structures of society, says the social model of disability. When these barriers are removed, disabled people can be independent and equal in society, with choice and control over their own lives.

#thinkSMALLactBIG

We Care Journey

Biogen