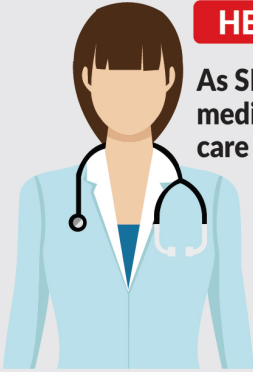


How much SMA costs

Below are the various expenses related to the management of spinal muscular atrophy (SMA), which can greatly strain a family's finances.



HEALTHCARE

As SMA involves progressive weakness of the body's muscles, many medical specialists and allied health professionals can be involved in the care of a person with SMA (PWSMA). These include:

- Paediatrician
- Geneticist
- Neurologist
- Respiratory physician
- Orthopaedic surgeon
- Gastroenterologist
- Physiotherapist
- Occupational therapist
- Nutritionist/Dietitian
- Speech therapist

There are currently three drugs that can treat SMA: nusinersen (Spinraza), onasemnogene abeparovovec-xioi (Zolgensma) and risdiplam (Evrysdi).*

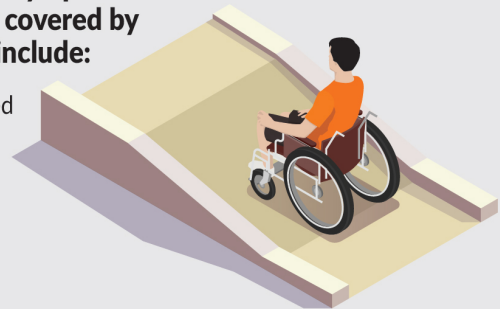


While healthcare services and medications can be obtained at a minimal cost at government hospitals, the long waiting periods and short time availability of healthcare professionals may drive PWSMA and their caregivers to seek private services.

EQUIPMENT

PWSMA often require crucial equipment to help manage their symptoms that are neither provided for by the government hospitals nor covered by medical insurance, and must be paid for out of pocket. These include:

- Cough assist devices
- Non-invasive ventilation, e.g. CPAP and BiPAP
- Suction devices
- Orthotics
- Mobility devices, e.g. powered wheelchair
- Nutritional supplements
- Home renovation, e.g. to fit wheelchairs



OTHER EXPENSES

- Obtaining and paying for a **domestic helper** (usually foreign workers), especially for independent adult PWSMAs.
- **Travel and accommodation** while obtaining healthcare services only available far from the PWSMA's home. (Note: This might also entail **loss of income** for PWSMAs or caregivers paid by job or time.)

Couples who are both carriers of the mutated SMN1 gene that can result in SMA may also wish to undergo:

- Prenatal diagnosis (to determine if their fetus has SMA)
- Pre-implantation genetic diagnosis (to determine if their embryo - formed through assisted reproductive technology - has SMA)

Each of these procedures has to be paid out of pocket by the couple.

POLICY RECOMMENDATIONS

- Subsidise the drugs that can treat SMA if and when they are approved in Malaysia.
- Implement a systemic approach to preventing and diagnosing SMA at a population level, i.e. prenatal diagnosis, newborn screening and pre-implantation genetic diagnosis.
- Remove taxes on imported medical equipment essential for the management of SMA.
- Prohibit genetic discrimination by insurance companies.
- Create a **respite care programme** for caregivers of PWSMA.

REIMBURSED

*None of them are currently available on the market in Malaysia.

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