



Peter

Peters is 9 years old and he has a spinal cord injury. He has a tracheostomy and he has been on home ventilation for the last year. He is fed through a gastrostomy tube. He is confined to a wheelchair and he lives with his parents, who are his primary carers, and his 2 older sisters.

They say that they rarely refer to medication leaflets as they do not find them useful. This is because Peter’s medication management can change as he grows and with any fluctuations with his clinical condition.

Medication & Therapies

Prescribed by doctor - 14 active prescriptions including medications to support respiratory, cardiac, gastric and neurological functioning, and pain medications.

Care Professional Concerns

As Peter’s parents are his primary carers it is essential that they have constant access to relevant up-to-date information. They require access to information on side effects and potential drug interactions. Peter’s parents live over 200kms from their nearest tertiary care centre and there is very little access to respite care in their area.

How they prefer to interact with Healthcare providers

Their main point of contact in the community is the complex care service manager who leads a team of nurses who come in to care for Peter for 20 hours every week. She is concerned about the level of care that Peter’s parents have to manage. They usually speak to her when they have any questions on any aspect of Peter’s care on a day-to-day basis, in between visits to specialists. They also connect regularly with their local pharmacist who assists them with accessing Peter’s medications. They have 6 monthly visits to the tertiary care centre where Peter has a full review by the neurology, respiratory and orthopaedic teams. During COVID-19 Peter’s parents stopped all usual home care to avoid infection and are very fearful of the risk of infection to him.

Sharing Peter’s health information

VERY WILLING | VERY UNWILLING



Medication list

There is a list of Peter’s medications in the kitchen and in his bedroom and in the car. Peter’s parents keep a list of any queries or concerns and will ring the complex care service manager with any questions. Peter usually has 8 medicines in the morning, 6 at lunchtime, 6 in the evening and 5 at nighttime. Peter’s medication routine will often depend on his respiratory status and other clinical parameters (depending on Peter’s respiratory status).

Frequent care:

- home nursing team
- physiotherapy
- occupational therapy
- neurology team
- orthopaedic team
- pain team
- respiratory team
- physical therapy,
- psychology and social care.

No of HCP that Peter’s parents interact with: 18

Pain Points/Problems

- Medical care and changes as Peter grows
- Polypharmacy
- Transport
- Access to therapies
- Supporting siblings
- Access to respite care

Dependency

Peter’s parents are very dependent on support from the home nursing team and all allied health professionals

VERY INDEPENDENT | VERY DEPENDENT



Health Literacy

VERY HEALTH LITERATE | VERY HEALTH ILLITERATE



Digital Literacy

Peter’s parents have good digital literacy and frequently use social media.

Support Network

Peter’s parents rely on the home care team and HCPS. They have no family living close to them, though they have very supportive friends nearby. They have a list of emergency contacts which includes some of the home care nurses and the complex care service manager and local GP.