Diagnosis and Your Normal

Living with your physical disability is a lifelong journey, with highs and lows. Everybody feels the impacts of ageing as they get older.

While most people begin to feel the impacts of ageing in their 60s, people with a physical disability often begin to feel tired and sore earlier and may start to slow down much earlier in life, some as early as their 30s.

Many people living with a physical disability comment that they wish they had known what was going to happen and wanted more information to help them prepare.



Diagnosis

The first step in being prepared is knowing and understanding your diagnosis and what it means for you. Remember though, your diagnosis is not your identity. Everyone is different with some things that are similar.

Important questions to ask:

- What is the diagnosis? What do the words mean?
- What is expected for someone with your diagnosis?
- What is possible?
- What is not possible?
- Are there changes likely to happen over the lifespan?

Ask your therapy team, GP or specialist to explain your diagnosis and what it means for you.



Cerebral palsy is a

developmental disability. It results from damage to the brain. Impairments that are associated with cerebral palsy are non-progressive but permanent. Words like "non-progressive" can be a bit confusing. The definition is talking about the brain injury. It is not talking about how your body works. Your body does change and some things do progress. Some things improve, some things get worse and others change during your life.

Diagnosis and Your Normal cont.

Your Normal

Knowing your normal and making sure those who support you also know your normal will assist you to explain any changes in your abilities to health professionals and other people supporting you. Ask yourself these questions, everyone's answers will be different, they are "your normal".

- How do you walk or transfer or move yourself up the bed or roll in bed?
- How much can you do by yourself? If you get help, do you get help because you want to or need to?
- What parts of your body can you move? There may be parts of your body that you have had trouble moving and other areas that you have always been able to move.
- What parts of your body can you feel? There may be parts of your body that you have never been able to feel if they are moved or touched while other areas that you have always been able to feel if moved or touched. It may feel the same on both sides or feel different.

- Do you cough when you are eating or drinking? What foods and drinks are easy to swallow or more difficult?
- If you get regular chest infections, know your resting heart rate and oxygen saturation when you are well. Your physiotherapist, nurse or doctor can help you find out these.
- If you have any medical conditions, know what your baseline is and have these reviewed regularly by your doctor e.g. diabetes, asthma.

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