Understanding Episodic and Fluctuating Rare Disease Disability in the Education Setting

Overview of Episodic and Fluctuating Rare Disease Disability

How to use this resource

Parents, students and educators can use this fact sheet as a guide to support conversations or to prepare for a meeting. It contains general information that must be adapted to each individual student.

What does episodic and fluctuating disability mean?

Episodic and fluctuating disability describes a condition where a person's abilities, symptoms or support needs change continuously or over time.

Students living with rare disease disability can experience changes in their health, energy, mobility, communication, learning, behaviour or independence from day to day, and sometimes from hour to hour. A student who is actively participating in class one day may need significant support the next. Perhaps they may be able to do something but not sustain the effort. Changes are often invisible to others but are a very real part of daily life for many students.

Changes may be caused by:

- Fatigue or poor sleep
- Seizures
- Illness or infection
- Medication changes
- Stress or sensory overload
- Disease progression
- Pain

The result is that a student may have:

- Good days
- Difficult days
- Unexpected changes
- Different support needs at different times
- Challenges that are not always visible or predictable

What schools should know

The child is not being difficult. Their condition may genuinely affect what they are able to do on any given day. What worked yesterday may not work today. Flexibility, understanding and open communication are key to achieving the best outcomes for students and families.

A family's perspective

"One day our child can participate in class, play with friends and complete schoolwork independently. The next day they may be exhausted, struggling to communicate or unable to take part in the same activities. Both days are real."

What helps?



Be flexible

Adjust expectations when needed



Focus on participation

Support students to engage in ways that work for them on that day



Listen to students and families

Parents and carers often recognise changes before anyone else



Plan for change

Expect that support needs may vary over time

It's important to keep communication open

Don't assume... ask. Regular conversations help everyone respond early and effectively.

Remember

Support should be based on what a student can do in this moment.

For more information

Scan the QR code or use the web page link below. It has useful resources and information to help support students.

bdsraaustralia.org/livingwell

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