Understanding Episodic and Fluctuating Rare Disease Disability in the Education Setting

Supporting Students: Practical Strategies for Inclusion, Participation and Learning

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.

Every student deserves the opportunity to participate

For students living with episodic and fluctuating rare disease disability, school can provide learning, connection, friendship and a sense of belonging. Every student deserves the opportunity to participate and contribute, even when participation may not look the same every day. There are always possibilities for engagement, learning and participation. A support person's role is to recognise what is possible today and to adapt support to make it happen. Small adjustments can make a big difference.

What schools often see

A student may:

- Have changing energy or health
- Need more rest breaks or support
- Miss school due to illness, appointments or treatment
- Participate differently from day to day

Build flexibility into learning

Allow adjustments to:

- Attendance expectations
- Assessment tasks
- Deadlines and due dates
- Physical activities
- Learning methods
- Plan for good days and difficult days

These changes are not a lack of effort or motivation. They are just part of living with rare disease disability.

Consider

- Interest based learning
- Alternate ways to participate
- Quiet spaces
- Shorter or broken-down tasks
- Extra time and rest opportunities
- Different ways to demonstrate learning
- Individualised learning plans

What helps?

Focus on participation by adapting activities for their ability on the day. Success is what can be achieved despite the difficulties, even if it looks different to others. Be guided by the student, the family and therapy team.

Maintain regular communication

Agree on a way to communicate:

- Fatigue levels
- Medical issues
- Strategies that work at home and school
- Emerging changes and triggers

A parent's perspective

"Inclusion means being part of the school community no matter how she presents, sharing experiences, forming friendships and being included in the everyday moments that make school so special."

Helpful questions for schools

When planning support consider:

- What adjustments may help
- How to balance consistency with flexibility
- How needs change and are communicated
- How to maintain inclusion and belonging
- Where to access information and support
- How quickly needs can change

For more information

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

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This resource was developed for the Peer Support and Capacity Building grant for the NDIS.