Understanding Episodic and Fluctuating Rare Disease Disability in the Education Setting

Working Together: Communicating Needs and Navigating Support

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.

Students living with rare disease disability are often supported by a team that includes families, educators, health professionals, disability providers and community services. When everyone is working from the same understanding, students are more likely to receive timely, coordinated and effective support.

Why communication matters

Rare diseases can be complex, unpredictable and unfamiliar to many people. Teams need to be able to share information and insights about:

- The student's condition
- Changing symptoms
- What support is needed
- Why yesterday's plan may not work today

Good communication reduces confusion, builds confidence and helps everyone respond more effectively. Involve students in discussions where possible.

Building a shared understanding

A shared understanding does not require everyone to become an expert in a student's condition. It means everyone understands:

- What is important to the student and family
- How the condition may affect learning and participation
- What changes might occur
- What support strategies are helpful
- Who to contact when concerns arise
- How to respect privacy

What helps?

Use resources such as communication books, health management plans and emergency contacts to ensure that information is accessible. Families, schools and support providers need to communicate proactively and plan ahead for excursions, emergencies and changes in support needs.

A parent's perspective

"The best teachers weren't necessarily the experts in our child's condition. They were the ones who listened, adapted and worked with us when things changed."

Support may be available through:

- Education departments
- Disability services
- Allied health professionals
- School inclusion teams
- NDIS-funded supports
- Specialist clinics
- Disability advocates

Individual patient advocacy groups can be found on the Rare Disease Directory on the RARE Portal website: www.rareportal.org.au

Questions to guide conversations

For families

What would you like the support team to understand?

For schools

How can we adapt when needs change?

For support providers

How can we improve coordination and communication?

For students

What will help me to participate, learn and belong?

Discussions should be based on what is relevant to the individual student and realistic to the changing needs of any day. Document decisions, action items and make sure there is a follow up. Understanding the full range of a student's needs and abilities helps everyone be prepared for each and every day.

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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