RAISING AWARENESS:THE TEDDY KIDS' WAY

Why Patients' Rights Matter to Young People

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Why Patient Rights Matter to Young People

- Children and young people living with rare or chronic conditions often grow up navigating healthcare from a very young age

- Knowing their rights transforms them from passive recipients of care into active, respected partners in their own health journeys

The "Good Soldier" Problem……

Young patients are constantly told what to do (treatments, exams, behavior). These instructions come with good intentions, but can teach children that being a "good patient" simply means following orders. Some healthcare professionals even describe compliant children as **"good soldiers.“**

When you're a child,
you may learn to do
what you're told,
even when you don't
understand why.



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Why rights are important:

- Enables active participation

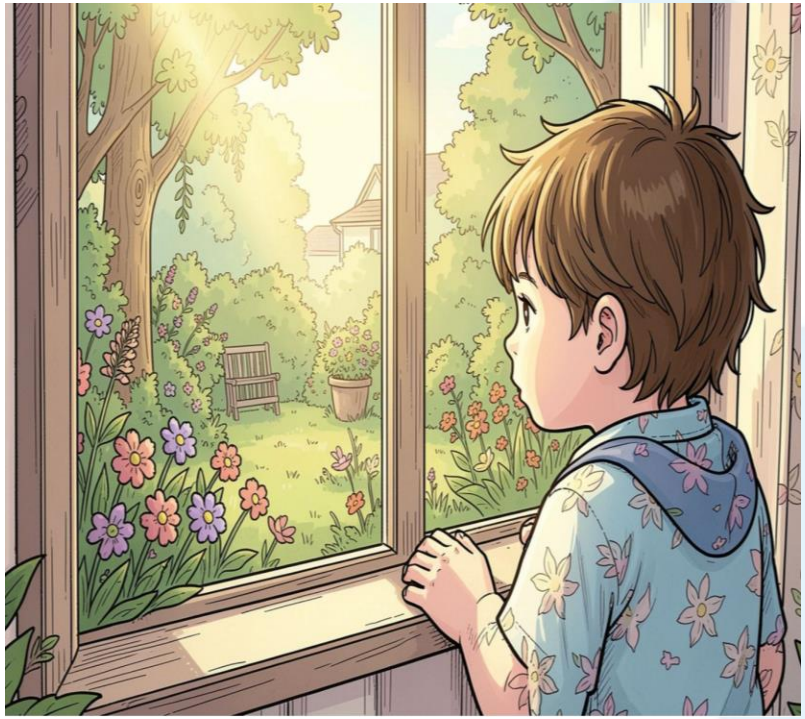
Rights help young people ask questions, express preferences and participate in decisions about their own health

- Builds trust

  Understanding rights builds trust in healthcare professionals, in systems and in themselves.

- Prepares for independence

  For teenagers and young adults, rights become especially important during the transition toward independent healthcare.



Rare Diseases: a unique challenge

Many rare diseases present in childhood. Young people may spend years navigating appointments, uncertainty and symptoms others their age don't experience. Sometimes even healthcare professionals don't have all the answers.

This is why it's so important for young people to understand: **they have a voice and they have the right to understand what is happening to them and why**

TEDDY - European Network of Excellence for Paediatric Clinical Research

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UNCRC Art 3: Best Interests of the Child...

The UN Convention on the Rights of the Child establishes that the **best interests of the child** should be a primary consideration in all decisions concerning them including healthcare

Healthcare professionals, parents and decision-makers must always consider what is best for the child's health, development and overall well-being

Acting in a child's best interests does not mean making decisions without listening to the child

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Article 12: The Right to Be Heard…

Children have the right to express their views freely in matters affecting them and for those views to be given **appropriate consideration according to their age and maturity.**

Being heard means creating real opportunity to participate by asking questions like:

What do you understand?

What worries you?

What would make this easier?

What do you think?

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The Right to Information…

A child cannot meaningfully participate in decisions about their health if they don't understand what is happening.

Information should be:

- **Accurate and understandable**
- **Age-appropriate and accessible**
- **Communicated in a way that allows questions**

Good information reduces fear and gives young people a greater sense of control.

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Consent & Assent

- **Consent;** a legally valid agreement to a healthcare intervention or research, given by a person with legal capacity to make that decision

- **Assent;** the child's affirmative agreement to participate when they cannot legally provide full consent. It recognizes their developing capacity, maturity and autonomy

Assent is not simply "consent, but for children."

It reflects that even when a child cannot make the final decision, their wishes, understanding and concerns still matter. *Both are governed by the Oviedo Convention (Articles 5, 6, 17, 20)*

Why Being Heard Matters in Rare Disease…

🧠 **Lived Experience Is Knowledge…** young people know which symptoms affect daily life most. They notice things that don't appear in a medical record.

🔬 **Improves Research…** when researchers understand how a disease affects lives, they can identify which outcomes actually matter to patients.

☆ **Empowers Young People…** when young people know their experiences matter, they become more confident speaking up and advocating for themselves.

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Participation prepares for adulthood…

Participation is a skill that needs to be practiced.

Healthcare decisions should not happen *around* children and adolescents; they should happen **with** them.

Healthcare professionals have medical expertise. Researchers have scientific expertise. Parents have their perspectives.

But the young person has something nobody else has: the experience of day-to-day living with their condition.

And that experience deserves a place at the table.

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