

Communicating to children about your chronic illness

Communicating with children about chronic illness, requires honesty, age-appropriateness, and reassurance. It's crucial to address their concerns, answer questions truthfully, and create a supportive environment where they feel safe expressing their emotions. Regular, open communication is key, as is involving them in age-appropriate ways in decision-making about the care of the person with the chronic illness, whether that is themselves or a close member of their family.

Things to consider include:

- **Find out what they know:**

Start by asking what they already understand about the illness. This helps you gauge their current understanding and address any misconceptions.

- **Explain in simple terms:**

Use language they can understand, avoiding medical jargon. Explain what the illness is, how it affects the body, and how this may affect their life. Use analogies such as the spoon theory or the broken battery when explaining someone's debilitating fatigue.

- **Address their fears:**

Children often fear the unknown. Explain what to expect from having someone with a chronic illness in the house and offer reassurance.

- **Create a safe space:**

Encourage them to ask questions and express their feelings without judgment. Let them know it's okay to be scared, angry, or sad.

- **Be honest and consistent:**

Provide accurate information and updates. Avoid withholding information or sugarcoating the situation, as this can erode trust.

- **Check in regularly:**

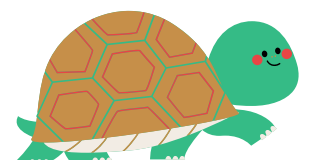
Make time for ongoing conversations about how they're feeling and coping. This could be through daily check-ins, or by creating a "communication book" for younger children to share updates with school and home.

- **Normalise reactions:**

Be prepared for a range of reactions, including anger, sadness, or withdrawal. Reassure them that their feelings are valid and that you're there to support them.

- **Age-appropriate participation:**

As children get older, involve them in age-appropriate decision-making about their care or the care of their loved one. This may include discussing treatment options or lifestyle adjustments.



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- **Promote self-management:**

Encourage them to take on increasing responsibility to help themselves or their loved one by undertaking age appropriate tasks such as doing their own laundry, helping make meals or arranging grocery deliveries.

- **Don't hesitate to ask for support:**

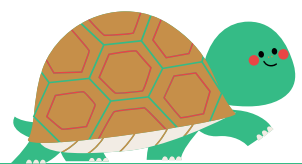
If you're struggling to communicate with your child or if they're having a difficult time coping, reach out to your paediatrician, a social worker, or a mental health professional.

Emerge ACT offers a publication for other family members and close ones called **“Information for family and friends of people with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Fibromyalgia, Long COVID, and other conditions with debilitating fatigue”**. A copy is available on our website.

This information sheet was created from Google's AI overview, which used a range of open-use sources including Child Mind Institute, Harvard Health and American Psychological Association (APA):

<https://childmind.org/article/mental-health-in-children-with-chronic-illness/#:~:text=There%20is%20a%20lot%20that,it%20a%20little%20less%20frightening,https://www.health.harvard.edu/blog/how-to-talk-to-children-about-the-serious-illness-of-a-loved-one-2019120218468#:~:text=Talk%20about%20the%20helpers,Talk%20to%20your%20pediatrician,https://www.apa.org/topics/chronic-illness/child#:~:text=Relating%20to%20your%20child&text=But%20children%20crave%20structure%2C%20and,than%20uncertainty%20about%20their%20survival.&text=Sick%20kids%20can%20also%20feel,for%20their%20brother%20or%20sister.>

This factsheet is part of our Club Tortoise program for pacing with energy-limiting conditions.



For more information or help managing your condition:

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