

# DISCUSSING PAIN & TIREDNESS WITH HEALTH PROFESSIONALS

You, your child or someone you know has a hepatic GSD. You may have googled or asked about it and found out about missing enzymes, large livers, special diets, weakened muscles and even metabolic pathways. But did anyone ever tell you about two symptoms that loom large yet are rarely discussed - pain and tiredness?

*Aurel Tankeu* and *Cristel Tran*, researchers at the medical genetic centre in Lausanne, France have noted that chronic fatigue is common and is often exacerbated by physical exertion, infection, fasting or cold. The tiredness is real. Health professionals see tired and hurt people every working day and these kindly and concerned practitioners will offer pain killers, sympathy, and walking aids.

They no doubt will worry about how best to help. You have an appointment and are told that your blood results are good/not good and what the scan showed. But as you walk away with a smile maybe you are thinking, 'do they really know how I feel?' There are so many questions that could be asked.

- What do you not do because of the pain and tiredness?
- How do you sleep?

- How did you find the journey here?
- You were OK yesterday, but are you OK today?
- Did one day's activities affect you for the rest of the week?
- Are there days when you can't think too clearly?
- Are pain and tiredness affecting your school or work?
- Are you missing out on what could be considered a normal life because it easier to stay at home and rest?
- How is your mood and how do you cope when you are feeling low?

An endless list of questions and everyone will have their own, unique thoughts.

What can be done? There are many answers such as eating and sleeping well, being kind to yourself, but one path is sometimes overlooked; communication. But just how can communication be done effectively? Think how your life is affected. Talk about how you manage on an everyday basis. If you want, write down your thoughts before you meet your health professional for your regular appointment and remember it is always possible to phone or write after the appointment if you feel an important

*"Pain, tiredness and good communication are issues I grapple with every day. I am aware how difficult it is to reach a good level of understanding, but I do know that it is something that must consistently be worked at by everyone."*

topic has not been covered. Plan with your health practitioner. You have a partnership, and they want to help you. The pain and tiredness you are feeling is not small. Be strong while you represent yourself. Don't dismiss pain and fatigue as symptoms that 'have to be put up with'. The benefits could be immense with possible improvements to every single area of your life.

*"Living with this level of tiredness isn't just about feeling sleepy. It's a deep, heavy exhaustion that affects everything—physically and mentally."*

*"Fatigue with this condition is like trying to move through thick mud. No amount of rest feels like enough, and sometimes even the smallest tasks can feel overwhelming."*

*"I've found it helpful to ask professionals to repeat back what I've shared with them, in their own words. It makes me feel heard and understood, and it shows we're on the same page about my needs."*

*"It really helps when professionals take the time to ask about the hardest parts of my day-to-day life. Even just asking questions like, 'What's the worst part for you?' shows they're listening and trying to understand, and that makes such a difference."*

*"If the time comes that you need to use a wheelchair, try not to feel embarrassed; mobility aids are there to help you, not make you feel worse".*

**TOP TIP:** Keep a running notebook of all your medical appointments so you can remember who said what and when.



**TOP TIP:** Keep fighting for the best care, the best doctor, the best consultant. Not everyone is a GSD expert!

This information sheet was written by a health practitioner and a mother of child with a hepatic GSD.