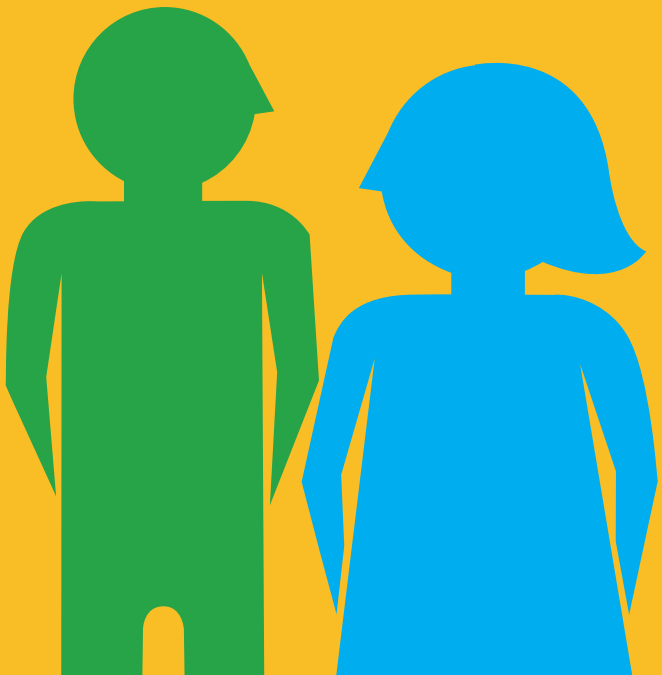
TALKING ABOUT FABRY DISEASE

A guide for students

Part of living with Fabry disease is talking about it with friends and classmates. They may ask questions. People may want to know about this condition. A few might not understand why a student with Fabry disease needs special timetables and extended deadlines at school.

Here are some ways to talk to people about Fabry disease and answer their questions.



Amicus Therapeutics has developed this educational resource in collaboration with the rare disease community and thought leaders.

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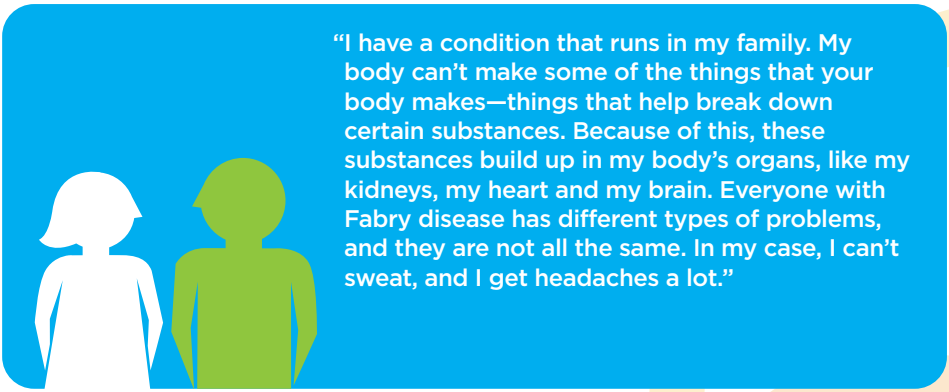
Fabry disease: Keep it clear and short

When friends or classmates ask about Fabry disease, it helps to be ready with a simple answer, like this one:



"I have a condition that runs in my family. My body can't make some of the things that your body makes—things that help break down certain substances. Because of this, these substances build up in my body's organs, like my kidneys, my heart and my brain. Everyone with Fabry disease has different types of problems, and they are not all the same. In my case, I can't sweat, and I get headaches a lot."

Answering questions

At school, people living with Fabry disease may require different timetables and deadlines.[1] Friends and classmates might notice, and ask questions like these:

- **"Why do you miss physical education so much?"**
- **"Why do you have to miss so much school?"**
- **"Why can't you come to my birthday party?"**
- **"Why are you allowed to go to the toilet without asking?"**
- **"Why does the teacher give you extended deadlines on coursework?"**

Any or all of these questions could be answered with a simple statement like:

"It's part of the care I need for a condition I have."

What Is Fabry disease?

Fabry disease is a rare condition passed down from a person's mother or father.[2-4] Though almost always inherited, Fabry disease can occur spontaneously from *de novo* mutations in people with no family history of the gene.[5] When people have Fabry disease, their bodies do not break down a substance called "GL-3."[3-7] The GL-3 builds up in the body. This can cause problems in many parts of the body, including the kidneys, heart, nerves, stomach, eyes and skin.[7-9]

Dealing with people who don't understand

Sometimes a few classmates may not understand Fabry disease.[1] They may say that Fabry disease gives an advantage because of special timetables and extended deadlines for coursework.[1] They may not respect boundaries for information or they may make rude comments like "I wish that I didn't sweat."

People living with Fabry disease must learn to deal with people who don't understand:

- Set clear rules for how to be treated: 'Those questions are too personal, so I won't answer them'
- Ask that boundaries be respected; if people continue to ask questions that are uncomfortable to answer, walk away or say, 'Please stop asking that. Otherwise, we won't be talking about this anymore.' Make sure to let a responsible adult know about the episode, so they can help prevent it from happening again
- It is always a choice, calmly but firmly, to ask classmates to speak with the teacher, nurse or head teacher if they have concerns

Talking about Fabry disease is a personal choice

Some people with Fabry disease choose to tell a lot. Some choose to share very little about the condition. Every person living with Fabry disease is unique and will have his or her own way of talking about the condition.[1] What to tell, who to tell and how to tell are all personal choices. No one should be rushed or pressured into talking about the condition. The important thing is to be ready to respond when friends or classmates want to know about Fabry disease.

Getting extra help

Talking about Fabry disease can take practice. Reach out to teachers, nurses, counsellors and other people living with Fabry disease. They can suggest ways to talk about the condition. They can also role-play questions and answers.

References:
1. Paz-Lourido B, et al. *Health Qual Life Outcomes*. 2020;18(1):109. doi: 10.1186/s12955-020-01351-x. **2.** Bugescu N, et al. *J Pediatr Genet*. 2016;5(3):141-149. doi: 10.1055/s-0036-1584357. **3.** Schäfer E, et al. *Hum Mutat*. 2005;25(4):412. doi: 10.1002/humu.9327. **4.** Germain DP. *Orphanet J Rare Dis*. 2010;5:30. doi: 10.1186/1750-1172-5-30. **5.** Iemolo F, et al. *BMC Res Notes*. 2014;7:11. doi: 10.1186/1756-0500-7-11. **6.** Cairns T, et al. *Postgrad Med J* 2018;94(1118): 709-713. doi: 10.1136/postgradmedj-2018-136056. **7.** Ortiz A, et al. *Mol Genet Metab*. 2018;123(4):416–427. doi: 10.1016/j.ymgme.2018.02.014. **8.** Laney DA, et al. *J Genet Couns*. 2013;22(5):555–564. doi: 10.1007/s10897-013-9613-3. **9.** Mehta A, Hughes DA. In: Adam MP, et al, eds. *GeneReviews*® [Internet]. Seattle, WA: University of Washington; 1993-2021.

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