

Understanding _____'s PH1

(name)

This confidential handout is to let you know that this person has a rare, inherited disease called primary hyperoxaluria type 1, also known as PH1. While the disease stays mostly invisible, here's some information to help you understand how to best support them in managing their condition.

What to know

There are a few important things to know about people with PH1:



THEY NEED TO DRINK LOTS OF WATER

People with PH1 need to drink more water than usual, this may mean they need to take frequent trips to the bathroom.



THEY MAY NOT FEEL WELL

People with PH1 may experience great pain or discomfort, feel ill or tired, or experience feelings of anxiety and isolation.



THEIR ATTENDANCE MAY BE AFFECTED

People with PH1 may have frequent appointments with their care team, and may have to miss events from time to time.*

*Some people with PH1 have to undergo dialysis, or may need a liver and/or kidney transplant. In these cases, attendance is likely to be more severely affected.



If you have any concerns or questions, please contact _____ at (_____) _____. In case of emergency, always call 999.

If you would like to know more about PH1, visit LivingwithPH1.eu

Use this space to write down any notes or questions you might have about PH1, and then speak to the person living with PH1 to find out how you can best support them.

