

I Wish My Family and Friends Knew That...



- I get tired sometimes. I am not being lazy; I just need to rest.
- Sometimes I struggle to remember to take my medication and I appreciate their help to keep me on track.
- While I value my independence, there may be some things I can't do and I may need their help.
- Even though cystinosis can be well managed, I may still have health issues and we need to focus on knowing my limits and finding balance.
- Some days are better than others and we may have to be flexible with our plans based on how I am feeling that day.
- Sometimes I know more about cystinosis than my doctors do and it is frustrating that we may have to educate my doctors.
- It is important to me that they take good care of themselves, too.
- Balancing my adult responsibilities with managing my disease can be a lot for me to handle.
- I need them to let me do things for myself when I am feeling well.
- I appreciate all of their help and they can ask me any questions about my disease.

