

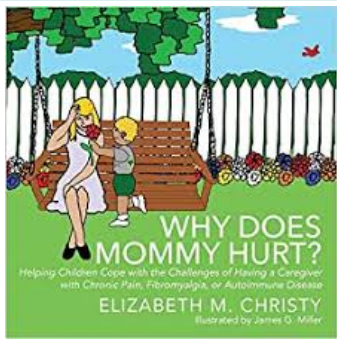
Parenting and Pacing

With Complex Chronic Diseases

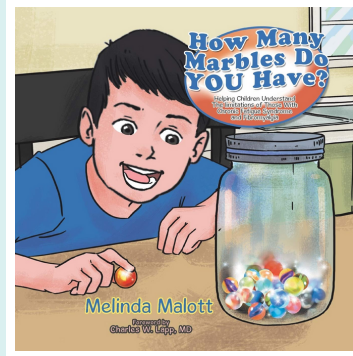
Let your child know what is going on

It can be difficult to explain why you might have to rest or cannot play tag. Explaining your condition as is age appropriate can help your child understand why you have to do what you have to do. Here are some ideas:

- Use visuals (e.g. colour codes like red, yellow, green or a bowl of marbles)
- Create your own analogy with your child so they can relate to it
- Use books to help explain. See the books pictured below.



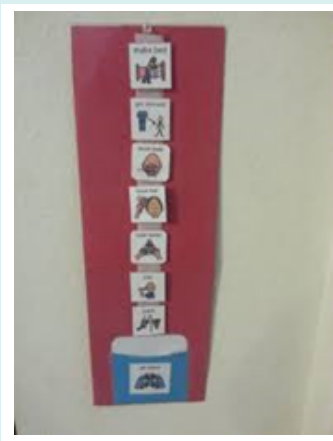
Why Does Mommy Hurt? Helping Children Cope with the Challenges of Having a Caregiver with Chronic Pain, Fibromyalgia, or Autoimmune Disease.
Elizabeth M. Christy



How Many Marbles do YOU Have? Helping Children Understand the Limitations of those with Chronic Fatigue Syndrome and Fibromyalgia
Melinda Malott

Children like structure:

If you are finding yourself homeschooling all of a sudden, think about what structure your children usually have at school. Creating a visual schedule can be reassuring to kids.



Time	Activity
7:00 am	
7:15 am	
7:30 am	
7:45 am	
8:00 am	



Education at home

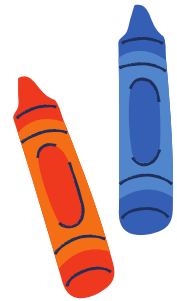
Try to stick to a routine for education, as this provides consistency and predictability. Depending on the age of your children, building in fun physical breaks between tasks can help with attention and focus (e.g. 20 seconds dance break between math questions), as well as allows your kids to release energy.

Chores

Children often can help out with age appropriate chores. Coming up with a system that works for your family can be helpful like, a chore chart that can be checked off, or completing chores to earn screen time, or using a whiteboard and dry erase marker. You can find lists of age appropriate chores online.

Activities for a bad day

Keep a "quiet box" or flash cards with ideas for low energy activities. For example, quiet games, books, craft materials, colouring books or movies. To support younger kids to understand, you can use colours to identify how you feel (e.g. red = low energy, green = feeling well).



Understanding the concept of time

Time can be a tricky thing for kids to understand. Understanding how long a 10 minute rest break is for you can be hard. Using a visual timer can help.



Relaxation

Starting to practice a relaxation exercise as part of your treatment plan can be tricky, especially when parenting. It can be a skill you also want your kids to learn. Making relaxation into a shared activity means you get to practice and your kids learn a new skill too. There are many different relaxation exercises that were carried for children. Here are some examples:

- Smiling Mind: <https://www.smilingmind.com.au/>
- My Life - Stop Breathe Think on You Tube: <https://www.youtube.com/c/MyLifeSBT/featured>
- Insight Timer app: <https://insighttimer.com/meditation-topics/kids-meditation>
- Super stretch Yoga app: <https://apps.apple.com/us/app/super-stretch-yoga/id456113661>

