



Rhythms and Routines

Rhythms & Routines: 10 Things I've Learned

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from kindnessmatters50.com/blog

Sharon is one of our FOP friends and lives in Tennessee, USA. She lives with FOP and has been a source of friendship and support for so many, the world over. She has a passion for all things creative and loves to card-make. Sharon was the editor of the 'What is FOP? A Guidebook for Families' which is an invaluable resource for every family.

Here, Sharon reflects on her life with FOP and the little things she has done to make things better.

First, there is no one-size-fits-all solution to life with FOP. Families live in different circumstances with different resources. These are 10 things I've learned through the years that help me and my family cope and make living with a difficult condition a bit easier.

1. Help: Many of the things I do require help from others. A few things can be done independently, such as using the TV or the computer. Over the years, I've figured out that sometimes I'm better off letting others help me more because it allows me more time to do the things that I enjoy. That's a place where we each have to figure out which approach works best for us. Another useful thought is remembering that, no matter how dependent I am on others, help can still be a two-way street. I try to make a special effort to help others in ways that I can: computer help, learning more about a topic and then teaching it, etc.

2. Schedule flexibility: I find that I work best when I have a schedule, but also schedule some built-in flexibility.

3. Space and "free time": I find that my family works best when we all get some space to enjoy different things. One thing that has really helped a lot has been taking the big step of getting a part-time caregiver. This has given my parents more free time but it's also been beneficial for me because it gives me someone outside of my family to whom I can relate. It's worked well for us all, in our ways.

4. Change is necessary, but not all changes are inevitable: When I was growing up, my family had no idea what to expect from FOP because we didn't know other families who lived with my condition. Looking back, there are things we could have planned for better if we had known what the future might have held. One-storey homes are awesome. Ways to avoid stairs are extra awesome. Roll-in showers are really nice. But you can't predict everything that will happen. Don't try!

5. Be okay with plans not working out and look for the good in some of the most difficult situations: If you are going through a really tough time, name 1-3 things each day that you are grateful for. I like to think of this as the "silver lining" rule. For example, all of my favourite people are people I wouldn't have met if I didn't have FOP. And I'm fairly certain that I'm a stronger and more empathetic person because of FOP.

6. Embrace the place where you are even when it turns out differently than you expected: When I was in my 20s, I pictured myself working full-time in a job I loved. Once my elbows became fused, it became more difficult to pursue my chosen career of teaching. Anyone who knows me will tell you that I always find plenty of things to do now—even though I spend most days at home. I have a better balance of different things in my life too.

7. This one is in honour of dads. Duct tape can solve everything! Well, not everything, but I use it every day when I brush my teeth and it was used for my original extension fork when I woke up and couldn't bend my arm. It's an example of how special tools don't have to be fancy or expensive.

8. It will likely take longer than you think: I'm notorious around here for underestimating how much time it will take to do something. Maybe that happens to you too—in lots of little and big ways, from how long it takes to do a seemingly simple thing to how long it takes a flare-up to resolve.

9. Sometimes you have to invent new guideposts and change things up when old ways aren't working.

10. Show love, kindness, gratitude, and grace whenever possible: It's hard being dependent on others, and it's hard on others for us to be so dependent on them.

