

When weekdays feel like Sundays...



When weekdays feel like weird Sundays sometimes ...

Some weeks ago, everything was ok. I lived a normal life. With MS. I travelled, worked, was in touch with other people, was active and sometimes a little bit stressed. But life was good. Then corona arrived and with it the restrictions and new rules for us all. Not easy for some people and lots of questions came up. Panic was there and people started to hoard food and other things. It seemed that the most important thing at first was to have enough toilet paper, then anxiety and worries found their way. Patients were especially worried about their treatments, care and doctor visits. The whole situation is overwhelming for all of us and for some really dramatic. We can see that in the news.

My life with MS now ...

I was also asked these days how it was to be socially isolated. Honestly not that bad, it hasn't changed so much. As I work in a very digital environment, I sit most of the time in front of my notebook, typing articles, reports, doing social media strategies and analyses etc. in my home office. And my day is very well organised. There are coffee breaks, also time for lunch and resting time in the afternoon. This is daily business for me. I go out for a walk to have some fresh air or to my grocery store to buy some food for my family. I also have a household to manage and of course some hobbies. I have a very small garden, but it is enough to sit in the sun to have a coffee when it's warmer outside. As my friends live across the world, I very often have talks with them via skype or facetime. We are in touch. Before corona and now.

But there is a difference ... the weird Sundays ...

There is one difference now: I have more time. Life is not as stressful as usual. I am not allowed to travel and have to stay at home. The world is much slower now. Silent. And this is new. Weekdays sometimes feel like weird Sundays. I can relax and rest more and this has a positive impact on my MS. Some weeks ago, I was struggling with a MS hug for some days, again and again. It was very painful and hard to deal with, because my business continued - I can't stop the job whenever I want to. Now I have time to recover from it completely and at

my own speed. I have better sleep and I feel calmer. It really feels like a Sunday to me, because of the time I have and the possibility of sitting down, reading a book or knitting, which is one of my favourite things to do in my free time. This is something I enjoy, and it also has a positive impact on my mood and mental health and on my MS. Because it calms me down, trains my brain and knitting a pattern can also reduce the pain. So, it helps.

Yes, it is serious! Life as a person with a higher risk!

Of course, there is corona and being a patient with MS also means being a member of the group of persons with higher risks. But I am careful. Have my wipes always with me, keep the distance, do my handwash every hour and eat healthily. I avoid going to my doctor's and my physiotherapist has closed his office for the next weeks. My MS isn't bad at the moment so I don't see the need to go to a doctor's, because I would have to go to his office - we have no telemedicine available in Germany. So, I try to keep the risk as low as possible. MS is under control and I can call the doctor, if I have an issue.

Infotainment? How to handle the flood of information!

On the other hand, there is the huge amount of information about the virus. As a journalist, I have learned to sort out information as good or bad. But during the last days it was also too much for me. So, I have started to read verified and trustworthy sources just 3 times per day. And believe me, this is absolutely enough to stay up to date. I don't think that it helps to go with the corona flow and read or watch every single piece which is out to inform people. Also, there is a huge amount of wrong information out.

Patient Advocacy? Of course! Don't stop helping people!

As a blogger I also help other people living with the disease. They write me messages, comment on my different profiles on social media and ask for help sometimes. And of course, I am there. It is my challenge to help or to encourage people to stay active and not believe everything. I also connect them with others and help them find solutions or answers by providing them with trustworthy sources like the ESR website and linking them to my ESR Patient Advisory Group colleagues, or to sources I know very well.

So, what can we do in anxious moments?

Yes, times are scary and of course I also have these moments too. Anxious, sad and feeling alone. But it helps to reduce the flood of information and to do something for yourself, something to cheer you up. Also, living every day as it comes helps to move forward. Set yourself some goals like finishing a book, doing a training at home or asking a person how their life is going and having a short daily chat via social media. By the way, my next goal is to clean my windows, because it is needed and to be productive with a visible result is also positive.

Do the #done challenge!

I found this on social media, a contact of mine has started it. People sitting in their home offices post things they have finished on social media with the German hashtag #erledigt,

which means finished. Start something like this too. Let people know that you are active and motivate them to do things in the same way. This way you can see people doing things in a virtual way!

So, what have you #done today already? Let us know!

Stay safe!



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