

2021 STENE PRIZE WINNER

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Denmark



I live in Aarhus with my husband and our three-year-old son. I was born in April 1985 and graduated from the Danish School of Journalism in 2012. My arthritis made it difficult for me to work so, ultimately, I was forced into early retirement. I have a highly creative mind and, these days, I like to express myself through drawing, painting and writing. I am currently working on a children's book.

I became aware of EULAR and the Edgar Stene Prize competition through the Danish Rheumatism Association's member magazine. I intuitively knew that I would want to participate at some point – but the topic had to be right for me.

I am a mother, wife, daughter, sister and friend. I am also a person with a disease that limits me in my social life. The feeling of being excluded from social events has been difficult for me. Throughout the pandemic, for the first time in many years, I have felt like I am a part of the community thanks to the digital solutions which have been introduced to almost every aspect of our lives.

So, I really had something on my mind, and just knew that this was the year for me to participate in the competition.

2021 STENE PRIZE - WINNING ESSAY

On an equal footing

A shaft from a spotlight splits the darkness that envelops the stage. Only the lead singer behind the microphone stand is lit up now.

“Are you all with me out there?” he shouts.

Before I have time to even open my mouth, he strikes the first chord on his guitar. At that very moment, the rest of the band lights up. The bass and drums join in and are immersed in a mesmerising red light that flashes in time with the beat.

My view of the stage is perfect, and the music soaks into my skin and fills my body with a lightness that I haven't felt for a long time. The notes are lightening the load that always weighs me down. Right now, I just am.

Out of the corner of my eye, I see my husband. He is sitting at our dinner table folding laundry. I look down: I'm wearing pyjamas and socks. I feel the corners of my mouth moving up as my eyes meet my husband's. He smiles back. I reach for my ears and adjust my headphones. I'm tearing up – I can't believe I'm having a real concert experience for the first time in three years. At home in my own living room.

I'm old enough to remember the time before the internet. But I'm also young enough that I'm often told: “Come on... you're too young to have arthritis”. Many believe, wrongly, that all I have to do is to take some painkillers and be on my merry way. Unfortunately, that's not how it works. Not at all. The differences between what I was able to do before and what I can do now are so clear-cut that it almost boggles the mind.

When the global Covid-19 pandemic placed Denmark on lockdown, we were all cut off from normal life as we knew it. We were unable to go shopping, go to cafés or meet people as we normally would. The museums were closed, and football matches and concerts were cancelled.

The thing is, those restrictions and deprivations that everyone suddenly experienced are actually remarkably similar to what my normal life has been like since arthritis went to work on me. I've felt excluded from – and existed outside of – social situations for a long time.

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2021 STENE PRIZE - WINNING ESSAY

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The government told the entire population that, because of Covid-19, we were not allowed to. My body is telling me that I'm unable to.

Locking a whole society down forces people to turn up their creativity dial and find new solutions – especially digital solutions. Patients are now seeing their doctors on their iPads; and people are attending parent-teacher conferences on their computers and shopping for groceries online.

And, because people can no longer gather at small music venues and fill concert halls, streaming technology has allowed live music to move into people's living rooms. That has meant, among other things, that I'm now able to see my favourite band live. Wearing day-old nightclothes and woolly socks. I no longer have to worry about how to get there; whether I would have the stamina to remain on my feet; or the aches I would have to deal with the following day.

Although I am standing here by myself wearing headphones, I am not alone. There are other concertgoers watching with me. Alongside me. And that's the essential part: I no longer feel alone. For the first time in a very long time, I feel included and part of a community. Digital solutions are making a difference for me – especially in terms of experiences.

It's one thing to shop for groceries, train with your physiotherapist or see your doctor online. These are practical chores for which digitalization has made our lives easier and freed up energy to do other things. Energy that, in my case, I can now expend on my three-year-old son. It's something else entirely to be able to take part in social events, listen to live concerts and lectures or attend theatre performances in my living room. These are all experiences that expand my horizon, give me new perspectives and enrich my life in a way that I have not been able to experience in a long time.

What many have perceived as limitations, I have felt to be progress – with more and better opportunities to be part of something. The ability to get together virtually means that my family and I, for a moment, can forget about my condition and limitations. I can participate on an equal footing with everyone else.

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2021 STENE PRIZE - WINNING ESSAY

(continuation from page 2. Essay "On an equal footing" by Stine Bjørk Brøndum Jepsen)

When my husband's company held its Christmas party this year, it took place on the conference app Zoom. We were sent a big bag of Christmas treats, various materials for making decorations and a present for our boy. All employees were sent a goodie bag. For the first time in three years, I was able to participate because it took place at home. I could relax on our sofa during the festivities, and we celebrated together as a family. We shared an experience which is rare, because my body so often forces me to cancel at the last moment.

Our friends don't face the same challenges as us. But they also slog through life with jobs, laundry and small children. In other words, it is often difficult to find the time and energy to see each other. But this year, the obvious solution is to just meet virtually once the kids have been tucked in and you've poured yourself a glass of wine. In fact, we're "seeing" each other more now than we used to.

At Aarhus University, Professor Dorthe Døjbak Håkonsson has conducted research into why in-person meetings are important to us humans. In line with other researchers, she agrees that a great deal of communication is lost when it takes place on a screen instead of face-to-face. Sure, something is lost between people when we meet virtually. But, regardless of whether it is a Christmas get together with my family, an after work drink with friends or a live concert, not doing so digitally means not engaging at all for me.

Once we reach the other side of this pandemic, I'd like to implore everyone: Can we please continue this wonderful trend of using digital solutions? That way, people like me – who might otherwise not fare well in the analogue world – can still participate and feel part of the community. On an equal footing.