

European
**Life After
Stroke**
Forum

**Navigating invisible
disabilities in the
workplace**

- **A stroke survivors' perspective**

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Conflict of interest / Disclaimer



- There are no conflict of interest to declare.
- This is my own experience as a stroke survivor.
- I have some speech- and language issues, so please forgive me if I suddenly find my inner stammer or I can't seem to speak out loud certain letters.
- It is easier for me to read, hence the “packed” presentation.
- It is still the road back to my great job(s).

Short introduction

- I experienced a lifechanging Cerebral Sinus Venous Thrombosis (CSVT) in 1994 – 31 years ago.
- I was 22. My superpower.
- I started my journey in an induced coma for 10-12 days and woke up totally paralysed.
- I could only blink with my eyes in the beginning.
- Long story short; I could take a couple of steps after 6 months of hard work – a monster achievement in my eyes.

You will learn this from me today:

1. My experience on returning to work
2. The challenges I faced on my return
3. How I cope (d) with the situation and
4. My take-home message for stroke survivors planning to return to work

My main goal – MY JOB – and how I DID it

- I had to learn how to read, write and type on a keyboard again in combination with the intense rehab on how to stand, walk and climb stairs to make me able to come to my desk one floor up at my workplace.
- Before I returned to work full time, my co-workers picked me up at home to help me get used to my computer, the programmes I used (a rather complicated database I had built before the incidence) and to increase my stamina in front of a screen in general.
- I had to ease into my role as a project coordinator.
- I am extremely grateful that they took the time out of their day to do this – as it helped me believe in my abilities.

When my job gave me energy

- The first years of working post stroke GAVE me lots of energy, despite having to hide some of my pain and concentration issues. I could deal with those after hours. Not wise – at all.
- But still - I managed to get my Trade Certificate in office administration before I applied for a position as a secretary in Statoil, the Norwegian Oil Company.
- I also took advanced English-classes there (English were our corporate language) and included IT-coordinator to my responsibility.
- But it took me years to realise that I didn't just have physical effects following the stroke. I had loads of hidden disabilities as well.

What you can't see you have to explain

- Atle, my blind husband discovered my invisible and cognitive issues. I had told everyone that I just had physical ones, and they believed me. But he did not.
- Amongst my issues you can find a rather fine collection of:
 - Severe pain (neuropathic- and muscle pain), concentration-issues, light aphasia, time-management issues and a draining fatigue.
 - I am also sensitive to noise and struggle to multitask over time.
 - When pain is on the horizon, I tend to get irritated – something I must explain to him. But now he can notice it before me most of the time.
- I tend to still hide some of my hidden disabilities, but if I have time – I will gladly explain. I don't want to hide them, but my wheels speak LOUDER.

Do you plan to go back to your work?

- Then do just that – planning is everything. Ease into work, rather than fall out. Ask your employer for easier tasks, but meaningful ones to you. It is possible if both parties adapt.
- Talk to your employer about your issues and suggest solutions.
- Listen to your doctor, starting full time might not be the best option. Learn from my experience. I went for it and crashed.

It is possible to work part time

- I am now working from home as my husband's secretary and eyes (paid from government), and I can do so when I have better days and an acceptable energy level.
- He is working from home as an advocate for better health services in our region and are involved in a lot of projects in our health region.
- I also engage in SAFE-projects – it's really needed that stroke survivors share their stories, and my go-to answer is always YES. Our experience is on demand.

How I manage my invisible disabilities

- To preserve energy, I try to plan my week to not have too many appointments. When I have crowded weeks, I tend to be more of a loose cannon and that is not good for anyone. Barking is only fun for dogs...
- I meditate regularly to keep my sanity and energy in balance
- I use knitting as my safety net when I experience pain overload – which is perfect for those I knit for...
- I use mindfulness as a coping mechanism to be present in what I do, I do certain breathing techniques to relieve the feeling of stress in my body.

Takeaway Message:

- If you really want to do something, start small.
- If you can manage to work even just a couple of hours every week, be proud.
- If you can't – that's also fine. Be a volunteer instead, helping others are fantastic.
- Setting approachable goals are the key to success - even better, breaking them up in smaller pieces will help you to reach them.

Thank you for listening!

don't worry.
my disability
isn't contagious...



But my smile is!!

