

eular

fighting rheumatic & musculoskeletal
diseases together

edgar
stene
prize¹⁸

Runner-Up: Per Clausen, Denmark

“My name is Per Clausen and I am 56 years old. I am a disability pensioner, but previously I worked as a mechanic. I have been married for 28 years, and I have two grown-up kids aged 19 and 21.

I live in Bramming in Denmark where I enjoy working around the house and in the garden, as well as making small trips with the dogs “into the blue”.

I saw the information about the Edgar Stene Prize competition on Gigtforeningen’s website. I

really felt like telling the story about how I overcame the toughest time of my life. Writing the essay showed to be good therapy. I cried but, in the end, a lot of things fell into place”.



My personal champion – supporting my everyday life with a rheumatic and musculoskeletal disease

I was in the middle of my life when it happened.

It came sweeping in from a siding and hit me like a speeding goods train. It was as though an enormous, fearsome monster had mowed me down with a power that I didn’t think it possible for a human to survive.

In fact, when I thought about it afterwards, there had been signals in my life of a future change of track, but I had ignored them. I had closed my eyes to the fact I needed help to manage more and more parts of my job as a mechanic. I had closed my eyes to the fact that I was becoming tired more quickly and found it more difficult to keep a handle on things at home.

I was in the middle of life and I wasn’t ready to allow this to force a change of track.

To change direction – not now!

After many months in bed and in constant pain, after numerous visits to the hospital, and more medicines than I knew existed and could hardly understand, the judgement fell. A doctor, who believed that he was God himself, sentenced me without a thought to a life that I had no wish for! My severe pain would remain the same and I would continue to sleep my days away.

My life stopped in an instant. I stopped there in the middle of the track. Completely still.

Then the tears started to fall. I felt hopeless.

The walking frame, the wheelchair and other aids made their appearance shortly after. Cupboards and drawers were turned upside-down and reorganised to place things so I could reach them more easily. The furniture was put up on blocks.

The daily struggle. My new me.

The role of father, spouse and employee all seemed completely impossible.

A work assessment forced me further onto my knees. When I was granted early retirement on the anniversary of my sick note, I felt nothing but distress!

From day one I had my personal hero completely by my side, even though I wasn't aware of this at the start. From one day to the next she acted as my personal nurse, my case handler and my advocate.

In the evening, when the pain allowed it, we would lie in the dark. Even holding hands caused too much pain. So over time we learned to love each other without any contact.

My personal hero helped me to create a new identity. It was an identity without connection to the world of work. As the medicines started to have an effect, she challenged me to set goals, dreams.

We got a dog – a dog who could keep me company when she was at work. A dog that had to be looked after and taken outside. Slowly, very slowly, I developed more and more staying power and, one day, I could walk the dog myself. Making use of the benches along the path where I could rest, I managed to walk almost an entire kilometre.

My personal hero ensured that I never stayed still on the track for too long at a time.

At Sano (the Danish Rheumatism Association's treatment centre), I retrained my leg muscles before receiving my first new knee. This was followed by a second knee and three knuckles.

My personal hero was a step ahead of me the entire time. She read about arthritis, read about exercise and about the latest research in the area. She reached out. Every idea just had to be tried! And most of all, she kept up hope!

Free physiotherapy and orthopaedic footwear helped me with my walking distance and speed.

An electric tricycle helped me get out into nature again and gave me a feeling of freedom. I could reach further than my legs could ever take me. This was her idea as well, and it was also the fruits of her work when the bike, after a very long fight, was finally granted to me.

My personal hero registered me with GOK (the Danish Rheumatism Association's Information Circuit) and got me swimming in the local swimming pool. Over time, I started to function so well that I could also participate in the physiotherapeutic GLA:D (Good Life with osteoarthritis in Denmark) training!

We struggle daily in a fight to maintain my abilities. I exercise. She thinks up new ideas and finds solutions to the problems that arise.

I am now much better!

I can now do a great many things again, and my personal hero allows me to do these, even if I do them slowly. She also has to hide her concern that I'm overexerting myself.

This is just a little insight into how my personal hero has helped and continues to help me. Do I need to explain that my personal hero is my wife of 28 years?

Let me end by presenting myself. My name is Per and I am 56-years old. I am a father, I am a husband and I perform good work in the home every day. I am much more than my disease, which is severe psoriatic arthritis.

I stood still in the middle of the track six years ago. Completely still. But only until the shunter train connected!