

From stroke survivor to advocate: Lived experience on advocating for long-term rehabilitation

By Johanna Persson | www.vasaconceptgoteborg.se

My stroke and life before



I had a stroke in 2018, when I was 48 years old. My right side was affected, and overnight I lost the career I loved as a classical musician. My body no longer responded the way it used to and I had to relearn even the simplest movements. I received two years of rehabilitation through the Swedish healthcare system. I worked hard and made progress, but when the support ended, I felt unprepared and discouraged. I still believed there was more potential in my body, but I didn't know where to turn.

More than two years after my stroke, I came across another rehabilitation approach called the Vasa Concept. It offered me a different way of working with my body and understanding movement after brain injury.

For me, it marked the beginning of a new phase of recovery, even though I was already in the chronic stage.



Using my experience to drive change

Because there were no trained therapists near me, I began training remotely with Dr Rajul Vasa in India. Every week, I record videos of my exercises and receive feedback.

Through this journey, I realised how limited the options can feel once formal rehabilitation ends. Many of us are told, directly or indirectly, that we have reached our maximum recovery. My own experience has made me question that idea.

This led me to found Vasa Concept Göteborg, the first non-profit Vasa Concept association in Sweden, and applying for funding from Allmänna Arvsfonden. Our aim is to organise

workshops where stroke survivors and therapists can learn Vasa Concept side by side. Another motivation for me is to build the kind of community and support network that I have found so meaningful. I want stroke survivors in Sweden to feel less alone and more supported in the long-term phase of recovery.

I also take part in research projects whenever I can. For me, this is a way to give something back and to show that changes can still happen years after a stroke. I hope that by sharing my experience with Vasa Concept, I can help spark more interest in long-term recovery, generate more research and in listening more closely to the survivor perspectives.



What I have learned

Here are some things my experience has taught me:

- Recovery doesn't have a strict time limit. Even years after my stroke, I have continued to notice changes.
- One size does not fit all. Discovering Vasa Concept has really changed my life!
- Stay curious about your body. Small improvements can build over time.
- Community and network is EVERYTHING. Having the support of people and professionals who understand and encourage you on your journey can inspire you to carry on.

- Your experience matters. Sharing your story can help professionals and researchers understand life after stroke more deeply.
- You are more than your stroke. Losing my career could have been devastating, but thanks to my supporting family and friends, I only enjoy searching for new solutions and finding new goals.

My life changed in ways I never expected after my stroke and I enjoy my new life. And by continuing to explore, learn and speak up, I am creating new ways to help others feel less alone on their own recovery journey.

What is Vasa Concept? In standard stroke rehabilitation, I focused on getting the muscles on my affected side to move again. Through Vasa Concept, I was introduced to a different perspective that encouraged me to think more about how the brain and body communicate after injury. The exercises place emphasis on working with gravity and body positioning, which for me offered a new way of approaching movement and recovery.