

European
**Life After
Stroke**
Forum

**What kind of evidence
is really important?**
- A personal perspective –

Grethe Lunde, 11 March 2024
Member of ELASF scientific committee

Conflict of interest / Disclaimer

- There are no conflict of interest to declare.
- I will share my own experience as a stroke survivor in this presentation.
- In the theme regarding physiotherapy, I had some help from my PT in Norway, Joakim Saerheim.
- ***“Please talk to your GP before starting on heavy weightlifting, hard exercise or if you have any other medical questions in this regard.”***

1 of 9 million

- I am one of more than nine million stroke survivors in Europe.
- Every stroke is different – and how can my stroke story be beneficiary for other stroke survivors?
- The power of listening to us about what works and what is needed to help support stroke survivors (us), can't be underestimated.
- As the “A life saved is a life worth living”-report mentions it should always be about making sure that stroke survivors gets to live their lives with as good quality as possible.

Evidence is not just reviewed studies

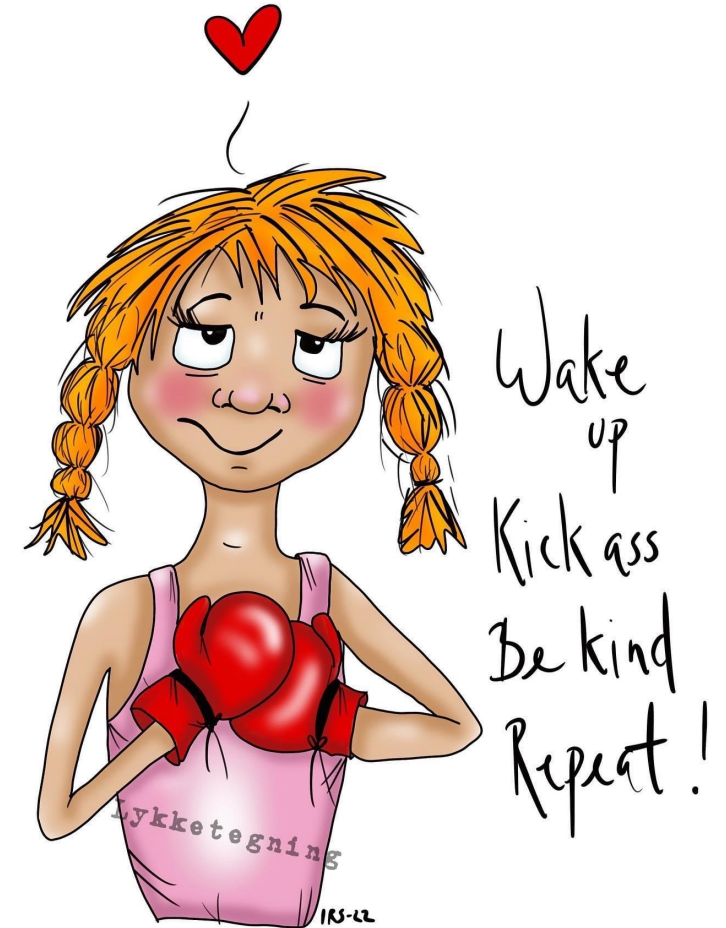
- Evidence is not just reviewed studies; it is also about how stroke survivors can experience change over time. Sometimes over a long time and where the most powerful tool is patience and rehabilitation on repeat.
- My hope is that my experience and stroke story can motivate and trigger inspiration in other stroke survivors and ultimately make their lives better.

Short introduction

- I experienced a lifechanging Cerebral Sinus Venous Thrombosis (CSVT) in 1994 – 30 years ago.
- I was 22. That was my superpower.
- I was in an induced coma for 10-12 days and woke up totally paralysed.
- I could only blink with my eyes.
- And yet, my goal was to go back to work – full time.
- I made that goal after 10 months of exhausting rehabilitation.
- I used all my energy to reach it. Against all odds and doctoral advice.
- Again, I was 22.

How I keep motivated

- Exercise for me personally is an endorphin boost that results in
 - *Better mood (serotonin)*
 - *Pain relief (endorphin)*
 - *The feeling of being rewarded (dopamine)*
 - *Enough energy to last for days*
 - *Increased quality of life*
- At least one hour of heavy weightlifting and an increased heart rate every week keeps me on a steady level.



How I keep motivated

- Well, that is if it's a "good energy"-week. When I experience fatigue and severe pain, a 5-10-minute hand cycle session is more than enough.
- I normally respond well to exercise and heavy weightlifting and over time I can seriously experience the positive change (evidence).
- Patience, perseverance, and persistence is now my 3 best motivators.



My journey back to a life worth living

- I have used physiotherapy from my time in a coma until now, 30 years later.
- My special designed “walk” all these years has left me with a severe pain situation, and I was only able to go work for about 10 years before I got to know the **TIGER** (severe pain) and had to stop working due to an overload of pain (now long-term).



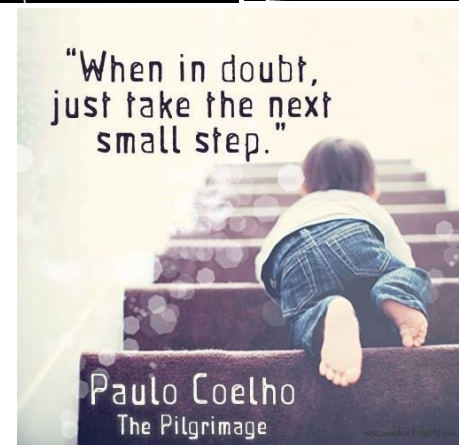
The journey back to a life worth living

- My new “friend with benefit” - **my wheelchair**, is now a great friendship.
- When I stopped using all my energy at work and on walking my energy level raised back to an acceptable level again. I can even walk without too much pain (I am only allowed to “freestyle” using my walker).
- FYI: Freestyling is walking with my legs without the use of any aids. Like you all do to get from A to B.



The journey back to a life worth living

- As a result of overuse of my unaffected side I've had four incidences of broken bones and after that quite a long rehabilitation after each one.
- Each time I chose to start from “ground zero” to try to reach my set goals. 4 TIMES.
- The first 3-4 months to heal the broken bones (i.e.: no use at all), then to learn how to walk again.
- I now choose to live my life as a “walking” wheelchair user. I can walk – but I also need to save my energy and consider the pain level. Hence the wheels.



Evidence – my personal thoughts

- Why is evidence important for stroke (survivors) care?
 - If you (as a stroke survivor) can see results that other survivors can accomplish, this can motivate you to do the same. The evidence is then obviously “if you can do it – I can do it too”.
 - Use stroke survivors as good examples and motivators. Let us tell our story. It has an impact.
 - And if you share your story, other stroke survivors will most likely be motivated to do whatever is necessary to reach their own potential. And, by that give others an increased believe in themselves.



Evidence – my personal thoughts

- During my 30-yearlong stroke journey I have been working with physiotherapists from the beginning and all of them can tell you that if you exercise regularly, you will improve. Gradually. That is guaranteed. Again – patience is key.
- Even if you don't respond to exercise due to fatigue, you can always exercise 5-10 minutes (or whatever you can that day).
- Think of it as a small contribution to reach your long-haul goal.

Evidence – my personal thoughts

- Evidence is for me the result of hard work over time. Yet, stroke is a slow “learner” and needs more time and patience than we often expect.
- My consistent experience throughout the years has shown me that repetitive practice can activate neuroplasticity and help the brain heal itself after a stroke. If you can do it one, two and three times – that also means you can do the at least 20 000 repeats needed for your leg to move if that’s your goal.
- It just takes time. Years even.

Thanks for listening!

- My takeaway-message for you:

A saved life should absolutely be a life worth living – and if nothing else seems to be working – SMILE.

- Make stroke a priority in ALL aspects of life. Just do it.

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



But my smile is!!

