

Survivors Against All Odds –

An insight to the lives of CF-patients 40 years of age or above in Sweden.



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BACKGROUND / AIM

Sweden has a centralized care for Cystic Fibrosis since the 1970's and a high part of the CF population are older adults, 20% (146/720) of CF patients in Sweden are over 40 years of age. The Swedish CF Association has started the project "Survivors Against All Odds" and the aim is to find out how people with CF, having survived past 40 years of age, have coped as the disease changes with age as new diagnoses and complications emerge. The struggle against the disease needs attention and there is a need to secure quality of life for the future.

My name is Kristina Radwan, I work at the Swedish CF Association as a project manager for "Survivors Against All Odds". I was diagnosed with Cystic Fibrosis when I was 2 months old and today I'm 59 years old and I live in Stockholm with my daughter Emma Tess, 23 years old. I

had a lung transplant in 2008. I want to find out how CF patients cope as they grow older with the disease.

METHODS

We asked people with CF over 40 years of age to write their personal story to get an idea of what their life is like in general. The purpose is to use real life stories to create a care plan for patients over 40 and to use the stories for future research using qualitative methods.

RESULTS

We received 10 real life stories of 3 to 10 pages from patients all over Sweden as part of this project. The stories bear witness of strength and gratitude to life but also concerns for the future, how the symptoms of CF will develop, personal economy, sequelae like diabetes and cancer as well as growing old with CF in general.

- Older CF patients are used to feeling ill. For many, it is a miracle that they're still alive, leading a seemingly normal day to day life while suffering from many different diagnoses and side effects from years of heavy medication.
- As a part of this project, we started a collaboration with the CF team at Karolinska University Hospital Huddinge to implement routines for patients aging with CF.
- The writers of the stories are in general happy with the centralised CF care, but they emphasise the need of doctor continuity, the importance of seeing all aspects of their health and that side effects, sequelae and daily struggles are taken seriously. CF care needs to be individualised and address the psychological burden that a multi chronic disease give.
- Everyone growing old with CF have unique and sometimes very heart-breaking life stories. CF treatment is extensive, and many suffer from feelings of guilt when not managing and being under constant pressure.
- Personal stories from patients are essential to the development of CF care for adults. Patients growing old with CF have more concerns and fears in regard to their care and future than previously understood.
- An adult with CF often have many other serious diagnoses as well, which is easily overlooked.
- As patients survive to older ages, a care plan must be developed to ensure their care is optimised.



EVA & TOFFE WESTMAN

Eva Westman, 57 years

"Sometimes I think that what I have endured so far in life should be enough, but I have realised that this is my share in life."
"It is my work and my desire to do what's right that kept me active and not focused on my illness"
"The hardest part is losing friends with CF"

Jeanette Evenstedt, 51 years

"Me and my partner have a 25 year old daughter. Unbelievable when you think back"
"Every day is a fight with both my weight and my lungs, but it has become a way of life"
"I need good care because I intend to live for many more years"



Linda Berglund 40 years

"I learned how to read and write early and my first works were illustrated poems about death"
"I have always been curious and adventurous, perhaps because I felt like my time was limited"
"All my life I've been at the mercy of healthcare, which led to a feeling of not owning my own body"



Petra Holmberg, 42 years

"To be responsible for your own care at an early age is important"
"I always try to find something positive in every situation, which made me a survivor"



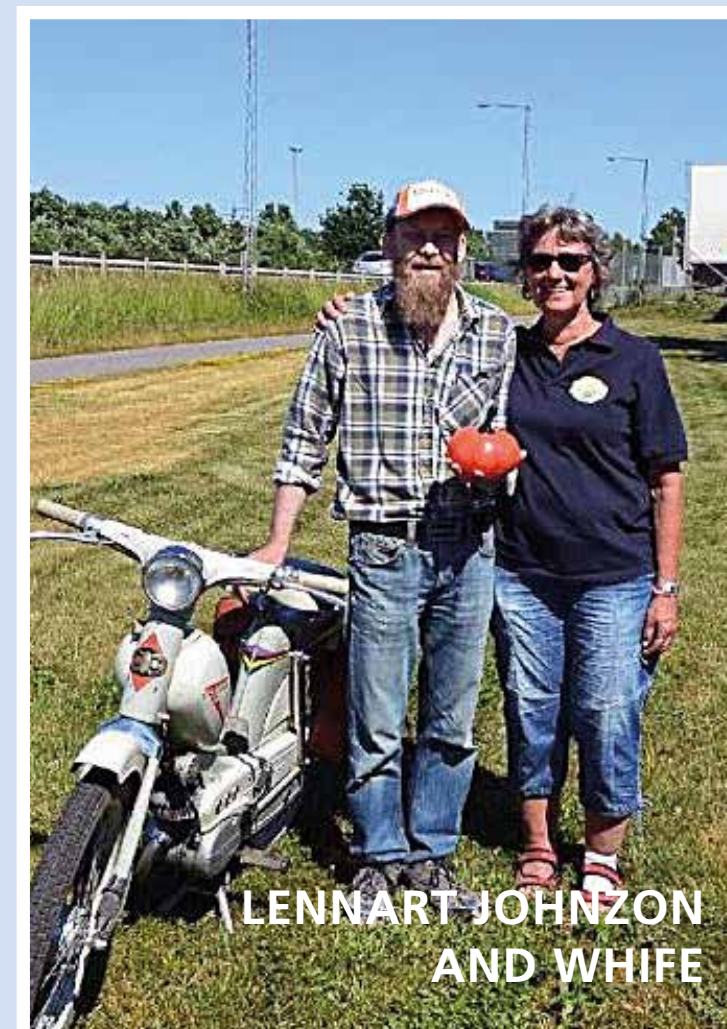
Ingela Ahlm, 52 years

"When I was 11 years old I became more aware of my illness and that it could kill me. I got a lot of anxiety, but I was too scared to talk about it"
"I often sat alone on the windowsill during the breaks at school and thought about what it would be like to be buried. It was hard to keep from crying. I was sure I wouldn't live for much longer. I thought I had to prepare"



BENGT & INGELA AHLM

"My intestinal issues give me diarrhea daily, which makes me feel bad and prevents me from functioning as I would like, especially socially."
"I'm so grateful for my new lungs and I thank my donor every day"



Lennart Johnson, 60 years

"In my free time I work on my three veteran mopeds, travel with like minded friends and listen to music, I love my old vinyl's."
"Two of my three brothers died from CF at very early ages"
"I think my old age is fantastic, when I look back on my life before my lung transplant I realise just how sick I was"



MARGARETA GUSTAFSSON

Margareta Gustafsson, 69 years

"I feel very unsafe growing old"
"It would be wonderful to not have to worry about aging and use my energy to enjoy life to the fullest"



Maria Vallin, 61 years

"While I look forward to retirement, I worry about my health and my economy"
"I feel very unsafe growing old"
"To not have to worry about aging and use my energy to enjoy life would be wonderful"

Patients growing old with CF often have many other serious diagnoses, in addition to CF, which is easily overlooked. This is a list of diagnoses from one CF-patient, 59 years old:



"I'm so used to being ill and just following protocol, enduring whatever happens to my body that everything seems to blend together, but each thing requires attention and care from me as well as my medical team."
Kristina Radwan

- I still have CF in the rest of my body, while my new lungs are healthy.
- I take heavy medication several times a day to prevent my body from rejecting my new lungs.
- I have a CF induced diabetes that requires two different kinds of insulin and regular bloodsugar measurements (with Freestyle, a button on my arm)
- I had breastcancer, which I had surgery for two years prior to my transplant and it risked my ability to have the transplant in the first place. I've also had an indication diagnosis for the cancerform myeloma, which requires yearly checkups and is very difficult for me to deal with emotionally since my mother died from myeloma.
- I have serious digestive issues, more so than before the surgery. It requires daily medication and a constant awareness of what I eat and where the nearest restroom is. I also wake up every morning with stomach pains.
- My hearing is deteriorating, which is a side effect of all the different

types of antibiotics I've taken in my life. I will probably need hearing aid in the not so distant future.

- I suffer from tinnitus as a result of my reduced hearing.
- I have no sense of smell at all, which means I can only taste with my tongue and smell nothing.
- I have very severe lymphoedema, which I was diagnosed with following my transplant. I constantly have to wear compression socks all the way up to my thighs (even on the hottest days of the year), have to have specialised massages every two weeks and sometimes my whole body swells to grotesque proportions, making me almost unrecognisable. My lymphoedema has caused me a lot of pain and suffering, and I feel like its severity has been neglected by my CF team.
- I have gout in both my feet, which is extremely painful. This is caused by all the diuretic medication I take due to my oedema. This also needs to be medicated.
- The strong medications I take to prevent rejection is very damaging to my kidneys and they require frequent checkups.

- I have high blood pressure, which is being medicated.
- My upper airways are partly blocked, which makes breathing through my nose challenging, this is mostly a pain when exercising, and its treated with nasal spray and expectorant medication.
- I have very dry and fragile skin which require prescribed specialist skin cream daily.
- All my medications are harsh on my teeth, so I need to get them checked often and take very good care of my oral hygiene.
- My joints are very painful, particularly in my hands and feet, and it gets worse in the winter.
- After the transplant my short term memory has deteriorated.
- My whole life my tongue has been very sore, often my mouth feels like one big wound and it really limits what I can eat.
- My most recent diagnosis is sleep apnea. It made me very sad, I wondered if there would ever come an end to my issues. I now have to sleep with a mask to help me breathe through the night.