

## On the occasion of the third International Sepsis-symposium in the Netherlands, on the 15<sup>th</sup> of September 2016

First of all I'd like to thank the organizers of this sepsis-symposium for giving me this opportunity and for drawing attention to sepsis. I'm very grateful for the efforts you all put into sepsis research, improving sepsis-outcomes and pointing out that sepsis is an emergency! But we all know we have a long road ahead of us when it comes to getting sepsis high on the list of priorities in our country and getting the message through to the public and the politicians as well. Making clear and recognizing that sepsis leaves survivors and their relatives with long lasting sequelae, definitely is a key factor in this process. And another key-factor is 'communicating sepsis'. That's why I wrote 'Sepsis and afterwards'.

I'll read to you a small excerpt from my book Sepsis and afterwards, that was published a week ago: "In 2007 I got ill due to a septic shock, and spent 5 days in ICU, related to a Hantavirus infection. My condition was critical and my family was informed that 'it could go either way', leaving them between hope and fear. Fortunately, thank God, I turned the corner, after having been ventilated for a few days. It was not until my discharge that I came to understand the extensive process of recovery after critical illness. Moreover, I came to realise that the need for explanation, support and advice, as well as the importance of providing the patient with a good start of the recovery process, was seriously underestimated. Having been a former nurse, I considered this an important eye opener."

In coping with your sequelae information and tips are so important! During my recovery I felt like I was in 'No man's-Land', and that's what it feels like for most people. No one ever mentioned the word sepsis to them, neither to me. And when I eventually found out, I wanted to know all about it and share it. For that reason I also joined the network called Family and patient Centered Intensive Care, because the survivors of sepsis and their relatives are often the survivors of ICU as well, and they really need extra attention.

Furthermore I started 'Sepsis en daarna', I offer guidance to patients as well as relatives who have suffered from sepsis. Last week I received a phone call from

a woman whose sister had just passed away in the ICU, due to sepsis. She told me that in a few days' time her sisters' legs had turned purple and black; she literally watched her sisters' body-cells die off and witnessed her sister leave this life bit by bit.....Horrible, it's one of the terrifying faces of sepsis. Of course I am very grateful that the sepsis didn't kill me or leave me with necrosis, heart- or kidney-failure. But do you know the hidden world behind sepsis? Do you know what it does to your immune-system, your neurocognitive functioning? And that it leaves you with a crippling tiredness, not to speak of all those patients being treated in ICU, saddling them *and* their relatives with Post-Intensive-Care-syndrome, while their sepsis is worsening their Critical Illness Polyneuropathy, their delirium, their neurocognitive sequela and Post Traumatic Stress? I was re-admitted to hospital 3 times, and still my body feels different. I had to quit my initial job and my husband and 3 daughters have suffered a lot, also during my recovery. I thank them for their patience. Moreover: they inspired me to make my experience useful to others, to fellow-survivors and to professionals as well. Therefore, the book Sepsis and afterwards contains practical advice for professionals and offers patients the latest insights and explanation on sepsis as well. In that way I want to address both professionals and patients and their relatives and build a bridge. Because it's so important that we exchange and share more knowledge so we can stand stronger together, being allies in raising the alarm on sepsis. Stop sepsis, save lives! Thank you very much for your attention!



15-9-2016, Idelette Nutma