

## On the occasion of the first International Sepsis-symposium in the Netherlands, on the 12<sup>th</sup> of September 2014

*From the patients' perspective*

Sepsis nearly killed me, but thank God I survived, thanks to the doctors, nurses, and the loving care and prayer of my family. I got ill on April the 5th in 2007, and spent 5 days in ICU. A woman lying next to me, on the other side of the curtain, *didn't make it* and after I had woken up she took her last breath. The border between life and death is incredibly thin and complex, especially when it comes to sepsis. I was somewhere between life and death during the time that my situation was critical: it was peaceful 'up there'. Until today I treasure that feeling but it illustrates even more the contrast with the struggle my body and mind went through, dealing with sepsis in *this* reality. To start with: sepsis is so sneaky; it strikes you like lightning, as it does your beloved ones. Often so little warning and viciously resembling a flue... In a few hours I went in to shock and developed ARDS and DIS or DIC, the meaning of which comes close to **Death Is Coming**. Earlier that morning, before being admitted to the ICU, I had already been put on antibiotics. I tried to make sense of it all; and so my doctor did; *how come* my condition was worsening all of a sudden? Eventually I was sent to ICU. But so many victims are being misdiagnosed. Education about the early signs and the 'Golden hour' has to be top-priority. Sepsis *is* an emergency. I was terrified at the time; it was like *some force* was pushing my body over the edge....

Maybe you've heard of prof. dr. Kevin Tracey. He had this patient, an 11 year old girl and she developed a sepsis and, despite of finding the cause and treating it with antibiotics, he still had to tell her mom and dad that she wasn't going to make it. That's why sepsis sucks! Dr. Tracey wrote a book about it: 'Fatal sequence, the killer within'. *I did too*: it's called: 'Septische shock', it offers a lot of information and guidance. And I started coaching *survivors* and their family-members, helping them to recover. You know why? Because the recovery of sepsis feels like a 'No man's-Land' to 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 Centered Intensive Care, because the survivors of septic shock and their relatives are the survivors of ICU as well, and they really need extra attention. Furthermore I started 'Sepsis en daarna', and together with Rob Bruntink: the website [opeenicliggen.nl](http://opeenicliggen.nl).

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. And I thank you for all the research and efforts (including the Surviving Sepsis Campaign) to address the problem of sepsis! Ending my story, I'd like to ask you 3 things:

- 1) Please communicate (the word) 'Sepsis' to patients and relatives and
- 2) *Do* carry on preventing it ..and
- 3) Provide aftercare, for a start: make patients aware of the information and support available, as I mentioned earlier. We're in this together, as experience experts and professionals, let's join forces!

Idelette Nutma