

Cees Smith Testimonial¹



The quintessence of my personal story is that in over sixty years of life, I became a person with multiple chronic diseases (hemophilia and therefore serious orthopedic problems; HIV; hepatitis C which is now cured; diabetes and renal failure). I have a wide range of healthcare contacts as you can see in the illustration below and I believe many other people with chronic diseases have a comparable experience.

While I'm getting older, my care-givers are getting younger. By now, I have to deal with the 6th generation of caregivers and most of them have no clue about my medical and social history. When decision-makers are talking about concepts like 'healthy ageing' and 'self-management', my personal experience is increasing health problems and a decreasing ability to manage my own care in the future. Incorporating the challenge of comorbidities with healthy ageing is a key issue.

Three problems worry me with comorbidity:

- the **lack of coordination** between medical specialists
- the use of multiple medications
- The 'fear factor'

¹ This testimony arises from the Joint Action addressing Chronic Diseases and Healthy Ageing across the Life Cycle (JA-CHRODIS) which has received funding from the European Union, under the framework of the Health Programme (2008-2013). Sole responsibility lies with the author and the Consumers, Health, Agriculture and Food Executive Agency is not responsible for any use that may be made of the information contained therein.

Like other patients with severe haemophilia, I have particular fears: lack of control when you are hospitalised, when you need medical treatment from physicians who have no experience with haemophilia or when you are involved in a serious traffic accident. In all of these cases, you, as a well-educated manager of your disease, may not be able to influence your treatment. The ambulance may take you to a hospital that has beds available but no experience with haemophilia, and valuable time may be lost. Older people with haemophilia are often not in good physical shape due to orthopaedic or viral complications. So when, surgery is proposed we fear the operation, and also the consequences of this operation for total body functioning. Our state of health is a delicate balance.

In rehabilitation, paediatric and geriatric care, a holistic approach has been developed in which the patient is seen as a person in relation to his environment. Care encompasses not just the child/ old person but also the family. This compares with the way I grew up in the hospital setting – at a time when there was no treatment for haemophilia – where the matron regarded her patients as more than their illness. Although for haemophilia this concept already exists since the introduction of specialised comprehensive care centers, I wonder whether it is also possible to introduce a comparable hospital setting for patients with other multiple chronic diseases. This will be in sharp contrast with the way most hospitals are now organised, but it's worth the effort to start piloting this approach.

