

# Ageing with SCI / ESCIF 2014

by Dick te Winkel

I decided to divide my paper into two parts: the first part as a sort of auto-biography and the second part with a review of the physical problems that I experienced plus the approximate age that I had when they turned up.

I was borne in 1937 in the city of Enschede near the German border. My first memories involved having to leave the town because the Germans were trying to find my father. My father, who was a lawyer, joined the board of directors of a Jewish textile factory, hoping that the Germans would not confiscate the factory with an Aryan on the board.

We moved to a city near Arnhem. We lived there until we had to leave as the Allied forces approached the other side of the River Rhine.

After the war we returned to Enschede, but the house we had left in 1942 had been destroyed by bombs.

After primary school I went to High School and afterwards I joined the army. After my military service I went to Delft to study mechanical engineering at the Technical University. In my second year I heard that one could work on board of a ship of the Holland America Line. A friend of mine and I signed on for a job on new SS Rotterdam on a roundtrip to New York. It was hard work. On the trip to New York I had to stand up for 10 and a half hours as dishwasher in the tourist class cleaning hundreds of coffee and tea cans after each meal. However, the meals, were excellent for us as a crew as well. And furthermore, it was wonderful to breath the fresh ocean air after work before going to bed.

In New York I went up on top of the Empire State Building. I sat on a bank on Times Square and visited Bird-land, the Jazz Corner to the World, where Dizzy Gillespie and Horace Silver were performing. Experiences that I will never forget.

My life changed in the summer of 1961. I volunteered as a counsellor at a boys camp of the Dutch Christian Student Society. I had spent my holidays several times in such a camp when I was a schoolboy. On the second day I dove into the lake and broke my neck. I floated face up and the boys who watched me saw that I could not move arms nor my legs. They put me on a tabletop and carried me to a pub where the nearest telephone was and called for a doctor. The doctor called for an ambulance. He also contacted the nearest hospital, but there they could not accept me as they were afraid of respiratory problems.

In the Academic Hospital of Groningen the surgeon of the neurology department made a splint and fixed it to the broken vertebra. I was laid down on a Stryker frame so the broken spine was immobilised. I stayed here for six months before I went to the military rehabilitation centre, because my parents had no idea what should be done. The rehabilitation doctor advised them, he knew the head doctor of this centre where they also accepted civilians to keep their knowhow up to date in peacetime.

In the rehabilitation centre I was aware that I had serious problems in my mobility and in my capacity to return to my former physical abilities. However, I was determined to participate as much as possible in activities that could develop my remaining possibilities. I shared the room with two young men both with a c4/5 SCI. During my rehabilitation I also flew to England to play table tennis in the Stoke Mandeville Games, the forerunner of the Paralympics. When I left the rehabilitation centre I heard that all three other men with SCI who were in the hospital when I was there had died.

There was no other place to go to than the house of my parents. I had a difficult time there as my family could not cope with my handicap, the house was not handicap friendly and I was dependent in many aspects.

Against all of these odds I reassumed my study in Delft after a year. I spent a year without doing much: my room was extremely cold and I had no transportation. During that year I met a young woman at a conference. She was deaf from birth and yet we understood each other well. We decided to get married and to live in Amsterdam in a nice and warm apartment as she had a job there. I had switched my studies from mechanical engineering to mathematics. The first computer had been introduced. Once a week I commuted to Delft for my studies. The other days I studied at home, having the good fortune to have a friend who attended the lectures: and allowed me to make use of his notes. At that time I was the only student in a wheelchair and the university building was hardly accessible. I had to rely on other students to help me up a flight of stairs before I could enter the main entrance.

I finished my study in the Operations Research Department of KLM Royal Dutch Airlines. When I attained the prestigious degree from Delft University I remained with KLM and enjoyed the feeling of equality with my peers. I was fully accepted as one of the team.

In the late ninety-sevenths four important things happened:

First: my wife and I decided to separate. In a suburb of Amsterdam I found a new wheelchair-friendly apartment.

Secondly: I heard that some people, who knew each other from the time they were in the rehabilitation centre, had founded a foundation for people with SCI. That was exactly the thing I missed in my life: meeting other people who were active with SCI. Since then I have been active in this foundation until the age of 70. The goal of the foundation was offering help to people with SCI during the time after their rehabilitation. The volunteers of the foundation were persons who had lived at least five years after their

rehabilitation and had acquired experience in living with SCI in their daily life. Gradually we noticed that new people with SCI had the need to be a member of an association of fellow sufferers from SCI and to read their magazine without being a volunteer. After some years the foundation was transformed in such an association.

Thirdly: I met Sabine, my wife, in Germany. After five years Sabine and I got married.

Fourthly: I made a trip to Ecuador and Peru with friends who lived in Curaçao.

In 1996 I retired because of shoulder problems and in 2008 Sabine and I moved to a new house in the Eastern part of Holland, far away from the aircraft noise. I spend a lot of my time reading, once a week I attend my oil painting course and I teach my refugees from Uzbekistan and Iran the Dutch language.

When I look back I on the 53 years with SCI I remember how useful it was to have easy access to a rehabilitation centre sometimes just to see a SCI specialist, sometimes to spend there some time when this is necessary. During such a stay I came in contact with quad rugby players. I have been a player with the Amsterdam Terminators for some years. I also followed a course in self defence. Because I have been in close contact with them I have a feeling of solidarity with persons who have a high SCI and persons who are deaf.

A summary of my physical problems.

#### Respiratory problems:

During the past couple of months I have respiratory problems: Some days are worse than others. For this I have an appointment in the rehabilitation centre next month.

#### My skin:

In general my skin is very strong, except in the period, ten years ago, when I had the MRSA. I found out that if your body struggles with MRSA, there is little left to resist other threats. In the last year my skin has become dry and I have to rub it with Vaseline cetomacrogol.

#### My muscles:

I had strong arm muscles till te age of 50. I noticed a rather sudden decline as I could not get into my car anymore without help. Probably this occurred after a period of frequent erysipelas. My right shoulder is worn out and I can't lift my right arm above my shoulder.

#### My bladder:

During my rehabilitation I learned to empty my bladder by forcefully knocking on it. The reflex contracted the bladder and opened the

exit. When I was about 65 years old I noticed that the bladder contracted, but the exit was blocked. Since then I have a permanent catheter, because I can't make the transfer from bed into my wheelchair anymore. I haven't had problems with the permanent catheter, but a few weeks ago in hospital a pyelitis was discovered and some calculus still has to be removed.

#### My bowels:

Until 15 years ago I helped myself three times a week on a shower toilet chair with the only finger I could stretch, my right thumb. After many years I had haemorrhoids like a bushel of coconuts. When I broke my leg and it was in plaster, a nurse helped me with this task while I lay in bed. What a relief! Since some years I do it twice a week. On the night before I drink a glass with Movicolon and in the morning a Microlax. It is the only procedure that is easier now than many years before.

#### My diabetes:

Since two years I have diabetes type 2: I take Metformine 850 mg three time a day.

I shall finish with my motto: The secret of a happy life is a selective memory. When for instance my wife says: do you remember the summer of 2002 that you almost completely spent in bed with pressure wounds? I automatically answer: No, I forgot.