



Initiative for Awareness by the
Dutch patient organisation

HS AWARENESSWEEK



“ *A person is much more
than a few scars* ”

Dimphie (63) is married. She has two grown daughters and four grandchildren. Because of her hidradenitis (HS) she had to stop as a driving instructor, but she still does voluntary work as a hostess in a cultural center. Despite her scars, she dared to take the step to the sauna with a friend.

"I'm always fighting the fatigue," says Dimphie. "For the past fifteen years, the scars from the skin grafts have mainly bothered me. In my armpits, under my elbows, in my groin... They're like big burns and they pull terribly. I am still being treated by a good plastic surgeon at Erasmus MC. And I go twice a week to a scar therapist who massages everything loose. All in all, I have had more than fifty operations."

Close the shutters in time

The inflammations themselves are almost inactive with Dimphie. "I think this is just because of my age, after the transition the disease has become less severe. Sixteen years ago I also stopped smoking, which helps with good blood circulation and wound healing. Every now and then I still feel those pinpricks in my body. Then the disease comes back and I take it easy. I meditate twice a day and I have learned to close my shutters in time at night. No telephone or other screens, just sit back with a book or music and a cup of tea."

She still suffers most from her armpits. "The scars feel as stiff as a cowhide to me. As a result, my freedom of movement is limited and I cannot lift heavy things and open jars. And as I said: it is also the fatigue that sometimes breaks me down. I have to plan everything well. Sometimes you have to cross a boundary before you know where your boundaries are. I have learned to say: not now. Without me explaining it again and again."

Psychological assistance

Fortunately, Dimphie herself has a positive outlook on life. "I always look at the half-full glass. And I had good psychological help in the beginning. For example, he had me draw where all my scars are and then erased them. "Are you still there when you look at the drawing?" Asked the psychologist. "No," was my answer. As a result, he showed me and felt that those places have become a part of me. My second husband has also accepted me as I am from the start. A person is much more than a few scars. If I don't feel well, I just cycle to the city to buy myself a nice blouse or dress."

Nobody is perfect

Ten years ago a good friend asked Dimphie if she would like to go to the sauna. "Then I'll keep my bathrobe on," I said immediately. But of course she immediately replied that that was not possible. After some hesitation, I went along and it was a very good decision. Nobody is perfect, the most beautiful women have something about their bodies that they are not satisfied with. For example, in the sauna I had a nice conversation with a woman who had had a mastectomy. Since that first time I really like going to the sauna."

Stronger than you think!

With this interview, Dimphie hopes to encourage other patients in particular. "I would like to say: you are not alone. And you are stronger than you think. People with HS are really not wimps, otherwise you won't last. Stand up for yourself! So if you are not happy with a doctor, go to another. It is important to find a doctor you trust and who knows what he is doing. It's about your body. Keep taking good care of yourself. It's the dark moments when you find out how strong you are. We are not perfect, but we are unique."