

My name is Dorthe Lykke. I was born in 1942, and I got the diagnosis HSP (Hereditary Spastic Paraplegia) in 2004.



After 34 years as a teacher in Greenland I came back to Denmark – Copenhagen – in 2001.

How the disease started

My health has always been perfect and I have only lost a few days through sickness. But in 2002, after my 60th birthday my left foot suddenly started dragging. At that time I went in for aerobics 3 times a week and I also did laps in the swimming baths once a week so my condition was tip-top. But this disease came insidiously. I couldn't keep stroke on the (stepboard?) I lost my balance, I couldn't run, I couldn't lift my leg when getting on my bike and so on. My GP referred me to Bispebjerg Hospital, and for 1 ½ years I went to countless medical examinations there and also at Rigshospitalet (the National Hospital of Denmark). Finally I was referred to neurologist Jørgen Nielsen at the neurological clinic at Rigshospitalet and on July 1 2004 I got the sentence: HSP – slowly progressive and incurable. The disease is hereditary but no one in my family on any side has suffered from it. It has been easy to find out because we have a profound family history.

There's no treatment but the doctors recommend physiotherapy and exercises. My GP referred me immediately to Vesterbro Physiotherapy where they also have a fitness center. Here I can come as much as I like – for free – for the rest of my life. 3 times a week there are gym classes for neurological patients where we do workout and balance exercises in small groups.

The development of the disease

I worked at a language centre from 2001 and I went about my job until December 2007. I went on sick leave until I retired in June 2008.

My smart sports bike was exchanged with a bike with a low entering and in 2005 this bike was again exchanged with a 3-wheeler bike. My legs became more and more stiff and I have fallen a number of times. It has been hard on my wrists, my elbows, my shoulders and my nose and in April 2005 I broke my right ankle when my leg was caught between the leg of a chair and the leg of a table. I turned to throw something into the wastebasket but my legs didn't move. My knees don't bend and I have to talk to my legs to make them move. I cannot walk and make a turn at the same time – one thing at a time. Often I lean against the wall or the furniture at home. Climbing the stairs take quite a long time but I consider the stairs as disguised training. My balance has gone and I avoid stairs which have more than one step if there's no banister. Because of my many falls I've become nervous to walk outside the house by myself – even with my cane (?) I've now got a street walker which I keep in my car. It stayed

there for a year until I finally realized that it was absolute necessary for me and today I use it when I have to walk more than 100m. I walk so badly that I cannot carry a cup of coffee without the coffee splashing over. It's really depressing so much worse I have become these last years.

Aid

I have got a handicap sign for my car and a handicap parking space in front of my house which is nice. In 2009 I received financial support to a handicap car. It has automatic gearshift (not common in Denmark) and a pre-heater which is good because coldness influences the muscles. The Center for Handicap Aid has arranged that my doorsteps have been removed and that I have got extra handles in my bathroom and at the front door. Since I turned 65 I have belonged under The Social Security Office for Pensioners which has granted house cleaning, laundry service and shopping via internet. (They pay for transport)

My situation today

I live by myself and I'm doing fine. I exercise persistently to keep the functions I do have as long as possible. Mondays, Wednesdays and Fridays I go the fitness centre and to gym class, On Tuesdays I do water aerobics and on Saturdays I go the swimming baths. Besides that I have individual physiotherapy once a week and I have massage every two weeks.

I'm very fond of water aerobics and water jogging raises my spirits – it's a wonderful feeling to be able to run in water when you can hardly walk on the ground. In the swimming baths I go with a friend – or else I wouldn't be able to walk around the pool on the slippery tiles.

Unfortunately I have got "dysarthria spastica" – spastic paresis of part of my tongue. Therefore it has become fatiguing to speak. I speak slowly and in a deeper voice and less melodious than before but still understandable. I was referred to a speech therapist last year and I have seen her once a week. Right now I take a break.

I still feel it depressing suddenly to get a chronic disease which wants to direct my life but I try to do everything possible not to make it limit my opportunities more than absolutely necessary. Along the way I have learned to accept a helping hand. For one thing it's necessary when I go the swimming baths or to the cinema – and everywhere where I go by bus. I have stopped believing that one morning I'll wake up and be able to do everything as before – that it was just a bad dream. More and more seldom I get hysterical when I fall and need help to get up.

It has taken some years to get to this point and I still find it difficult to accept that I cannot do the same things as before. Every time I lose a function I get depressed – for instance when I lost the ability to run – then dance – and sing.

Network

I'm very happy for the e-mail network which I have got with other HSP-sufferers. It has been a great help to me to learn how others have come to accept their disease and how they cope with the depressions which do come. I hope that more HSP-sufferers will contact me.

Dorthe Lykke (Sept. 2010)

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