



Raija



Travelling with my husband, Jussi



Our house in winter

## An interview with Raija Heimonen, 2012 Stene Prize winner

Raija is a 54 year old woman who was diagnosed with rheumatoid arthritis and Sjögren's Syndrome in 2003.

She loves writing and was very excited to learn about the Stene Prize on the internet. She believes that real life stories can not only support other people in similar circumstances, but also help health professionals to gain a better understanding of their patients.

Raija graduated from Helsinki University after studying mathematics and natural sciences and today works full time as a leading planner in the business department of the pension insurance company, Tapiola.

She is married with three children and, because of her husband's profession working in the forestry industry, has spent many years living abroad in Sweden, Belgium and Estonia. She speaks Finnish, Swedish, English and Estonian fluently and is able to understand German and French.

Twelve years ago the family returned to their home in Finland and now lives in the city of Espoo, which is very close to Helsinki. Raija and her husband have two sons, 20 year old Hermanni and 16 years old Oskari and an adopted daughter, 18 year old Heta Kairit, from Estonia.

Raija is member of the local branch of the Finnish

Rheumatism Association.

### What did you think when you heard that your contribution had won the 2012 competition?

**Raija:** I was surprised and, of course, very happy to hear that my essay had been selected as the winner of the Stene Prize. I am very fond of stories and was so pleased that my story succeeded in conveying something important about everyday living with rheumatic diseases.

### You have a wonderful sense of humour and a very inspiring attitude to dealing with challenges - what is your recipe for staying positive on a difficult day?

**Raija:** I think that everyone is given his or her own set of cards to play with in this life, so it is up to me to live my life with the cards I have been dealt. I had breast cancer 11 years ago. When I received that diagnosis I was also faced with the thought of death and it made me very conscious of the fact that I only have one life, and it's here and now.

My two opponents can really make my day miserable. Those days my recipe to stay positive is 'to count my blessings'. I beat my breast cancer, I have a wonderful family, I can work and I enjoy my work, summer is coming and so on. 'Counting my blessings' puts my diseases into perspective.

### With a large family and a full time job, how do you manage to cope with all your daily demands - in particular when your children were younger?

**Raija:** Good question! Having a large family was not easy and automatic for me and my husband. We were married for 10 years before we had our first son. Two years later we adopted a

daughter. And two years after that we were happy and surprised to have another son. So one day I found myself the mother of three children, all under school age!

Maybe the time spent hoping and waiting to have children gave me the right attitude and preparation for an active, lively, noisy, busy, colourful family life. I have learned to organise things. I don't demand too high level of housework.

I prioritise my work, housework, children's needs and hobbies, and my own time. Many of the household tasks and children's activities are shared with my husband and sometimes grandparents also give us a helping hand with our everyday life.

I enjoy working in interesting IT-projects with my professional colleges. Even though my work is demanding, it also gives me the opportunity to just concentrate on my own things and thoughts. When I am dead tired and fall into my bed my last thoughts are always: this is a full life! Our oldest son has already moved out to study and that reminds me of the shortness of childhood.

### You had the opportunity to live abroad in many different countries which gave you insights into their different health and social systems. From your current perspective what is it that you most value about being back in Finland? Is there anything you miss, or where you feel the system could do better?

**Raija:** Living abroad has given me a perspective on my own country. I see that nowadays the standard of healthcare is high in most countries in Europe. Also, patients are much more informed about their diseases and medical treatments because of all the

easily accessible sources of information. But I think that one of the most important things for a person who is diagnosed with a difficult disease is being able to communicate in your mother tongue. I can understand medical facts and ask questions in a foreign language, but I can only express my feelings perfectly in my native language. And faced with serious, chronic diseases patients are full of feelings: fear, disbelief, despair, hate, anger.

I value very highly the Finnish health and social care systems: I have received healthcare very quickly and at a reasonable cost. I am also happy that I am able to discuss all the sensitive issues concerning my diseases in my native language. But I hope that in Finland, doctors and nurses will become even better trained to deal with the feelings and psychological stresses faced by their patients.

### What do you love to do most on a good day when 'Mr Rheumatism and Mr Sjögren's' lie defeated on the floor?

**Raija:** Those are the days when I am full of energy. I simply love to do extra things around the house and garden. I change the curtains, move the furniture around, plant flowers and find new ways to use old items. I also love to create with my own hands some of the ideas I have had in my head: to make a coat rack out of old forks, or to cover a stool with Chinese newspaper etc.

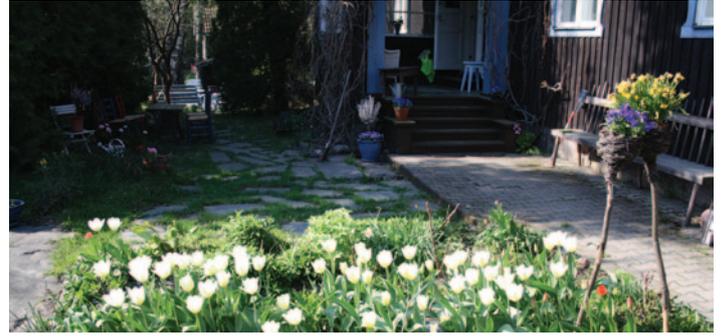
If the weather is nice, bicycling along by the seaside is very enjoyable, or I can ride my bicycle to a museum, fair or the cinema – all kinds of culture fill me with enthusiasm.



Raija



With my children



My garden

# How I overcame the challenges of my illness

Competitive wrestling started in Finland in 1897. The original rules dictated that a wrestling match was conducted in 15 minute sessions or 'bouts', with a one minute interval between each bout. As many bouts were fought, as it took to achieve a pin or submission. There was only one category, regardless of the differences in the sizes of the contestants. However, it did not take long for the rules to be changed so contestants were grouped according to their weight, and time limits were introduced. Does this mean that fit and healthy young men do not have the stamina to continue wrestling until their opponent is pinned down or submits?

I myself wrestle daily, according to the original rules. I have two international opponents in the ring with me simultaneously: Mr Rheumatism and Mr Sjögren's. My opponents are very experienced wrestlers.

Of the two, Mr Rheumatism is the stronger and more unpredictable. He is particularly active first thing in the morning and generally does not like to surrender, always going for victory. Mr Sjögren's [from Sweden] is an opponent of a slightly lighter weight class. For several weeks running, matches with my Swedish opponent can result in his surrender.

On most days, my opponents are forced to admit defeat. However, this would not be possible without attitude, humour and excellent equipment.

On normal workdays the wrestling match begins when the gong sounds. Even before opening my eyes, I appraise my opponents. I circle my ankle, flex my knee and raise my shoulders. Being an early bird, Mr Rheumatism is always ready for battle. The ankle hurts, my big toe aches and the knees

and shoulders feel stiff. I ease my eyelids open and note that my Swedish opponent, Mr Sjögren's, is also ready and waiting. My eyes feel like sandpaper.

I heave myself into a sitting position on the edge of the bed and start with the easiest task. I administer eyedrops in both eyes and, for a moment at least, Mr Sjögren's falls to his knees on the mat. I freely admit that I resort to doping. After all, this match is fought according to rules in force at the end of the 1800s, when doping was not an issue. Next I force myself into an upright position and my knees groan with pain. I keep hold of the bed; the balls of my feet feel tender and pretty painful. Dozens of needles stab my toes as I take the first steps of the morning. I stagger onwards on my shaky legs, rotating my shoulders as I go. I totter into the kitchen, fill a glass with water and drench my parched throat. Mr Sjögren's, who is still on his knees on the mat, gets a cold dunking. I then launch a chemical attack on my opponents: oxychlorine, Reumacon, cortisone, calcium.

My employer supports me in my daily matches. I have two work computers: one at home and another at work. On days when my opponents have me in a stranglehold, I am able to sit at my computer in my pyjamas, exercising my ankles and toes while I read the first e-mails of the day. I flex my fingers as I walk the short distance to the kitchen and make myself a strong cup of coffee to prime myself for the day's battle. Once the knees flex and the ankles are mobile, I get dressed.

I walk to work in my wide-fitting, soft-soled shoes. The distance is just under a kilometre. If I was a wrestler competing at national level, I am sure I would have a sponsor who would provide me

with the appropriate wrestling footwear. As it is, I have to dig deep to buy shoes which let me compete at all. Fortunately, I have managed to locate a couple of manufacturers who make suitable shoes. As in many sports, the outfits and accessories are not particularly elegant. I have had to give up shoulder bags, and instead have resorted to the type of bag which can be carried in your hand or in the crook of your arm. As long as you remember to switch the bag at regular intervals, adopting a certain rhythm – right hand, right forearm, left hand, left forearm, and so on – fingers and elbows have no time to tense up.

In my sport, as in so many others, the right gear makes all the difference. There is no point in gripping an umbrella; it only results in an achy elbow and fingers and, if I am unlucky, a sore shoulder too. A light rain mac is the best solution. On the other hand, sometimes as I am aiming for a quick victory over my opponent, with aching legs, screaming shoulder, and fingers in a vice-like grip round shopping bags, rain lashing into my gritty eyes, I nearly get caught up in my coat tails. In such circumstances, the best solution would be the umbrella hat worn by Chinese street sweepers. Unfortunately, my sense of humour has not quite stretched that far yet! Humour is also a useful tool on those mornings when the breakfast meeting starts at 08.00 am, and fit young men sit round the table with their bottles of water and bloodshot

eyes, after a night on the town. All this older lady can do is arm herself with down-to-earth humour and join them at the table, with equally red and smarting eyes and with her tongue sticking to the roof of her parched mouth. We open the meeting by taking a collective swig out of our respective water bottles.

Holidays demand attitude. Instead of relaxed leisure activities, wrestling matches are part of the daily programme. It is a shame, but there is no such thing as a holiday from illness. It is, however, novel and refreshing to take on your opponent under a hot sun and on various different terrains: beach, rainforest, metropolis.

There might be a day when I find myself in a darkened hotel room, lying utterly beaten under a cooling ceiling fan, while my travel companion freshens up in the oldest spa in the city. Another day, I find that I have got no further than a pedestrian underpass, just when the city's famous 'Noon Cannon' booms out, with my able-bodied travel companion already standing next to it. At least I managed to see the smoking cannon.

Whether on holiday or at home, the day always ends with the sound of the gong. Some evenings, having beaten my opponent, my whole body feels tender and achy. Sleep brings relief. Other evenings, I realise that I have managed to beat my opponents while suffering only minor injuries. The matches are never gentlemanly: I do not shake hands with my opponents, neither at the start, nor at the finish.

## Editors notes on English terminology:

**A gong or bell** marks the start and finish of a bout of wrestling

**Doping** is taking drugs to enhance performance

**'Dig deep'** is an English expression meaning dig deep into your pockets to find more money. It can also mean to 'look hard' to find something

**'Caught up in my coat tails'**, refers to the ends of the coat wrapping around the legs and making it difficult to walk

**A tatami** is a Japanese mat, used in martial arts as well as the home