

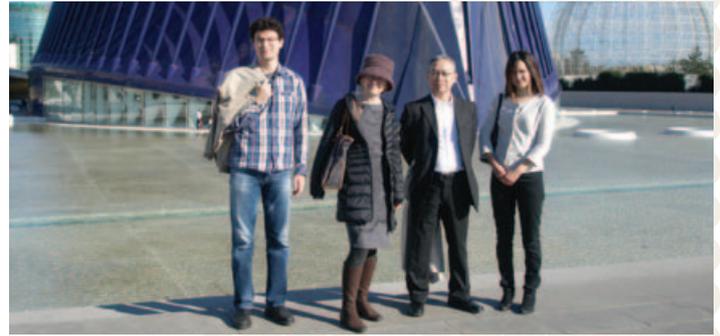


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Mette



Kamishibai storytelling



New Year's vacation in Valencia with my family

Mette Toft – 2013 Stene Prize winner from Denmark

56-year-old Mette lives in Elsinore, north of Copenhagen, with her Japanese husband, who is a professor of Japanese at Copenhagen University. They have a 31-year-old son and a 28-year-old daughter, both of them classical musicians.

Mette has an MA in Japanese and Danish. Before being diagnosed in 2005 with systemic lupus erythematosus, other rheumatic diseases, multiple contact allergies and multiple chemical sensitivity (MCS), she had been teaching Japanese at universities for six years and then Danish as a second language at language schools for grownups for another six years. Mette also has had a picture book, ABC, and two books on Danish pronunciation published.

In 1995 she introduced the Japanese kamishibai, 'paper theatre', to Denmark. She visited schools all over Denmark in 2005 to put on shows and teach pupils how to write, illustrate and perform their own kamishibai plays. She was well on her way to making her number one hobby her future full-time job... But then lupus put a sudden stop to all of that.

Mette is a member of Gigtforeningen, the Danish Rheumatism Association, and learned about the Stene Prize from their website. The topic of this year resonated with her and so she decided to submit her essay and "give it a try".

How did you react when you heard your contribution had won the 2013 competition?

Mette: I was absolutely thrilled – as well as honoured! I was also really excited about the opportunity to participate in the EULAR Congress in Madrid.

These huge annual gatherings are magnificent and unique I think – where experts on various rheumatic diseases from all over the world and patients are welcomed on an equal footing.

The Stene Prize is a very special prize, reflecting the importance assigned by EULAR to the patients' perspective. So I am really happy and proud to have won the prize this year.

You have a very positive attitude and enormous strength to deal with difficulties. Where does this strength come from?

Mette: That is a very hard question. The easy answer would be that it is probably due to some specific combination of genetic and environmental factors. Well, if there is a gene for positive attitude and mental strength, I probably have it. The workings of environmental factors, however, are much more difficult to sort out, if you ask me.

I think of myself as having had a happy childhood. And I really did, in many respects. But I could also tell an equally true story filled with childhood memories that most people would call sad or shocking. As a child – and well into adulthood – I made a point of not telling anyone about the "traumatic" stuff, because I didn't want people to think of me as being different or damaged because of that. Today I don't mind telling people about these things, but why bother. Bad stuff happens,

but it doesn't define who you are.

Diseases or diagnoses do not define who you are, either. You are still you. And, as the song goes: "What doesn't kill you makes you stronger". Right?

As many fellow patients will attest, if you can steer clear of self-pity, having a serious disease can make you a more focused, a more appreciative and a more positive human being.

What would you recommend for people with RMDs who are having a difficult day, when pain and frustration can easily take over?

Mette: If it is just one difficult day, don't fret; just take it slow. Listen to what your body tells you. Maybe it tells you to call in sick or to rest more than usual. Or maybe it tells you to go for a walk or to do your fitness routine.

Distract yourself from the pain with your favourite entertainment or some creative activity. Allow yourself to feel frustrated, if you absolutely must, but not for more than two minutes. Frustration will get you nowhere. Open the window and let it out. The answer to frustration is acceptance and action.

If you feel worse than usual and for more days in a row, you should definitely call your doctor and get an appointment.

What can patient organisations, like Gigtforeningen, provide to support people with RMDs in different phases of their life?

Mette: Patient organisations can provide information, general advice and personal telephone counselling on all the different aspects of living with RMDs. They can support networks where patients can meet other patients with the same

diagnosis, with special networks for younger patients, and so on. Gigtforeningen does all that.

A recent initiative is a patient education programme, "Know Your Lupus", which has been a great success.

Healthy Ageing is also a hot topic for policy makers – what would be your call to action for policy makers so that people with RMDs can grow up or grow older as healthily as possible?

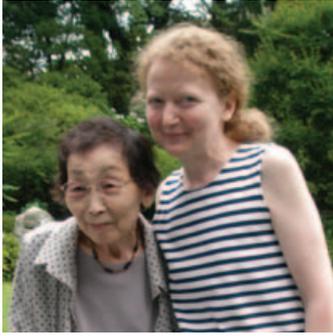
Mette: Basically, whether a person has a disease or not, choosing a healthy lifestyle is the responsibility of the individual, I think. My essay is about that.

Policy makers should make sure that people with RMDs get an early diagnosis and the right treatment without having to fight for it. That is really important for a good outcome.

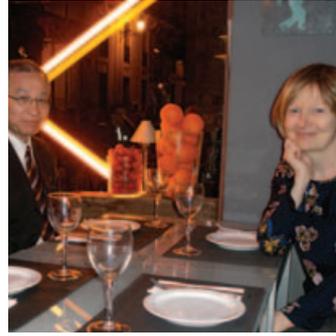
In order to reduce the number of people getting sick in the first place, policy makers should also take action to improve the environment. Undoubtedly our modern lifestyle, with loads of unnecessary chemicals everywhere, plays a part in many diseases, including the autoimmune ones.

What are your dreams and plans for the future as you grow older?

Mette: That's easy! My plan is this: When my husband retires in a couple of years, we'll get ourselves a car, he'll be my chauffeur, and we'll drive around to different parts of Denmark to do story-telling shows with the Japanese paper theatre, kamishibai. My husband has agreed to this plan – except he won't let me put him in a costume and make him part of the show!



My role model, my mother-in-law



Good food



Surrounded by my Japanese family



What I miss the most

Growing up or growing older – my secret for staying healthy with rheumatism

When the World Health Organization (WHO) was established in 1948 under the auspices of the United Nations, it was, of course, necessary to define what health actually meant in its constitution. They came up with the following grand statement: *“Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”*.

This definition has since been criticised, not least for being unrealistic, and for defining happiness rather than health. But I find that, for those of us who have been diagnosed with an illness, it is particularly problematic and annoying that, according to the WHO, we cannot – by definition – be healthy because we are sick.

The topic for this year’s Edgar Stene competition clearly takes a different definition of health as its starting point – one where health and illness are not opposites, but where health is something we can strive for whether we are sick or well. Hurrah! I quite agree. Of course it is possible to be healthy even if you are ill, just as someone can be unhealthy even if, on paper, they are well. So here are a few of my tips for how to make the journey from cradle to grave in reasonably fine fettle in spite of chronic rheumatic disease.

“Health and illness are not opposites”

Health secret number 1: Don’t worry – be happy!

“Tell me, how can you sit there smiling when you have all those illnesses to contend with?” a neighbour asked me recently when we were having coffee together. She meant no offence; she was genuinely mystified. I was totally stumped. How could I answer her? “Sorry, it was wrong of me. I won’t do it again!” or “Well, you know, it’s just a brave face I put on when I’m in good company!” No. After a brief pause for thought I could only tell her the truth: “But that’s just the way I am!”

“That’s just the way I am”

Once again, I was reminded how lucky I am, because I am, at heart, a happy soul. However, I also think that a positive outlook on life is something you can consciously choose and try to hold on to – and that it pays to do so because it makes life so much easier, whether we are sick or well.

That cheerful disposition stood me in very good stead when, in the autumn of 2005, I came down with what I thought was a bout of flu. From then on the diagnoses began to rain down on me. I was 48 when, all of a sudden, I went from being fit and healthy to sick and wretched.

Systemic lupus erythematosus was the first interesting diagnosis I had to get acquainted with, and a handful of additional diagnoses followed in swift succession:

Sjögren’s syndrome, Hughes syndrome, steroid-induced osteoporosis and discoid lupus, among others.

At that time, when I was at my most ill and exhausted, and unable to do much else, I hit upon the idea of putting myself through a kind of laughter therapy. It didn’t come naturally to me to laugh out loud at any old thing the way some people can. Instead, I sought out funny books, films and TV series, absolutely determined to laugh long and loud if anything was even the remotest bit amusing. I laughed like a madwoman – and had to reassure my husband, who was initially alarmed, that it was deliberate.

Does it work? Yes. Try it yourself and see! It is very hard to brood on things and remain tense when you are laughing out loud, isn’t it? But it doesn’t even take as much as that. Try just a big smile. Don’t you feel much better already?

Health secret number 2: Health recommendations only help if you follow them

I wonder if I am the only person who is tired of listening to all the talk about health and slimming. Tired of TV programmes about people who need to lose weight, instead of proper entertainment that makes us laugh. Tired of the glossy pictures in women’s magazines of beautiful, well-turned-out people eating correctly and exercising properly in smart outfits, showing us how it should be done.

Honestly, this is just too feeble

and excessive. Grown adults who need a personal coach in order to eat sensibly, and other grown adults who devote a large number of their waking hours to keeping fit and looking good? Don’t we have more important things to achieve here on earth in the short time we are here? Enough of this!

We have heard all the recommendations, ad nauseam. Whether we take them on board is up to us. Whether you are sick or well, you are sure to be able to find plenty of excuses for your hard luck. But one thing is certain: health recommendations only help if you follow them, and no one can do that for you. Not your mother, not your doctor, not your Aunt Nellie.

If you want to stop smoking, just make up your mind and do it.

If you want to eat a healthier diet, only buy and eat healthy food.

If you want to lose weight, just eat less and check your weight morning and evening.

If you want to put on weight, just eat more and check your weight morning and evening.

If you want to exercise more, just get up off the sofa, turn off the television, log off from Facebook, and get going!

Enjoy your healthier lifestyle instead of feeling sorry for yourself – and then use the new energy this gives you to do some of the things you want to do.

And above all: do something that makes you happy!