



Coltrane



Juho my nephew



At home



## Coltrane Partanen Finland

My name is Coltrane, I am from Finland.

My mother is Finnish, but my father is from America. I am 39 years old and live, together with my husband, in the lovely countryside of Finland near Helsinki, in a small place called Sundsberg. Before being diagnosed with Ehlers Danlos -Syndrome I worked as a marketing specialist. But due to the disease I had to quit my job and now have a disability pension. Today I work from home every day and do the usual house-work, but I've also started to write down my experiences in a book to share not only my feelings and information about my disease and the everyday problems, but also the little victories. I am also a student of social psychology at the Open University of Helsinki.

# How I manage my work whilst living with rheumatoid arthritis

**I wake up slowly. The light tries to penetrate through my eyelids, gently tempting me towards a new day.**

However, my eyelids seem to weigh a ton, and it feels like such a great effort to open them. I curl up more tightly under the blanket. I feel my body, waiting for messages to arrive in my brain before I dare to move myself.

During the night I kept waking up in pain, but by moving my joints carefully, they seem to join my awakening process. By force of habit, I slide myself very carefully to the edge of the bed and stay still for a moment. I turn off my alarm clock. It would soon go off to remind me to hold on to my daily routine.

In the kitchen, I plan my day of work. I wonder how much energy I will need to empty the dishwasher and clean up the kitchen. My eyes automatically fall on the oven dishes, which are heavy, and which need to be placed on the bottom shelves of the cupboard.

There are sheets and other regular items of washing in the laundry basket. I feel I should

take the big sheets out of the basket as they take up a lot of space, but again I must resign myself to reality; hanging them up without help would be mission impossible. In addition to getting sore, the job would be left unfinished, so I end up washing the clothes, but leave out the heavy jeans as well. I contentedly watch the happy whirling of the laundry through the glass of the washing machine and smile with content: the first achievement of the day.

My calendar tells me what's going on outside of the home and often lists a number of other appointments to remember. My physiotherapy session is at 13:00. The beautiful clock on the kitchen wall shows me it's nine o'clock. The clock was bought from the Clock and Mirror Store of Old Rauma, and looking at it always makes me happy. Even now I find myself smiling at the clock. The clock tells me everything I need to know; whether there is time to potter about or not before I leave. That is all the information I need from it.

I enjoy a relaxing breakfast. My mobile phone has been on silent throughout the night, and I am in no hurry to be reached. My husband has left for work,

and I enjoy the tranquillity of my home. Pleasant music, appropriate for my state of mind, gets me started at a leisurely pace, and little by little my body becomes supple, waking up to a new day. It takes a while before the medicines kick in, but I know that the stiffness and the state of pain following the night will get better. I eat just the delicacies I feel like eating for breakfast. I have given up munching on a quick sandwich and downing it with a coffee, instead, I see what I fancy each morning.

I continue reading the paper in bed. I manage to adjust my electric bed into a position that feels comfortable. The daily news is spread out before me, and by waking up my consciousness, my brain slowly begins to function as well.

The pain eases up, and I slowly stretch myself out. My body is longing for movement, and I clean up the kitchen. I love the smell and look of a clean kitchen: what a wonderful feeling, when everything is sparkling! The next time I go there, I know how much it will please me. I am lost in my thoughts for a moment. By now, I would have been in the office on a coffee break or looking at



Shopping together with Age-Elina, my personal assistant



Coming home



Yoga

Photos:  
Marja Haapio

the clock, meetings and my own work would be there waiting for the short break to end. Time would stand for performance, and each minute would feel like a waste of time. I sneer. It has not been easy giving up on the compulsion to perform. For a long time, I suffered from a guilty conscience with each moment of rest, until I learned that they are a part of my working day. My current working day.

I station myself in front of the computer. I read my e-mails and quickly reply to my friends and relatives. There are many messages; the computer has turned into a social medium and replaced the contacts which I used to have every day. I read my e-mails and, when my physical and mental wellbeing are up to it, I can find times when I can be sociable. Of course, I long to talk and for intimacy, eye contact and conversations, but I have become used to new habits and rhythms in my social sphere. My friends are at work during the day, and I do not want to disturb their working day. I can get hold of a few of my friends during the day, if the necessity for conversation – listening and talking – is especially great at any one moment.

After the e-mails I set to work on writing my book. Today is one of those days, when ideas are pouring out of my head, and it is hard to get them written down in an organised form. I get more written on some issues and make a jot down the most important words on other areas I will continue with next time. Some days it feels as if there is a fog in my brain, which makes writing completely impossible. I am very happy with my accomplishment. Five pages is a lot.

After a moment of rest, I get up and listen to my body. My energy reserves seem to be charged enough for me to go to the physiotherapist by car instead of taking a taxi. I enjoy the luxury of driving and playing my favourite music loudly, I choose a beautiful route and admire the landscape. Even though I take the same route, I discover something new every time, something I have not noticed before. This time my attention is caught by a branch poking up from a snowdrift and bent into the shape of a ball. There is an unusual amount of snow on top of the branch, the white snow against the clear blue sky makes an incredibly beautiful sight. I decide to stop on my way back to admire the landscape.

**“My energy reserves seem to be charged enough for me to go to the physiotherapist by car instead of taking a taxi.”**

On arriving home, my energy levels are running out. Luckily, I have anticipated this happening, and I take a pre-prepared lunch from the fridge. An afternoon nap is what is needed, and afterwards, when I wake up, I feel like a new person. I immerse myself in my texts for a while, hang up the laundry and start preparing for dinner. Luckily, today is one of those days where I am able to hang out the laundry. As I look at the laundry on the clothes horse, I feel a special kind of pride. The scent of the clean laundry pleases me and reminds me of my accomplishment.

My working day has been rewarding and full of accomplishments. In my eyes my home looks beautiful. Soon the smell of food will welcome my spouse whose working day in the office has been very different from mine. I have learned to appreciate my own achievements and each day I am a little closer to my goal of working without the pressure to perform, but only listening to myself. Each step towards this is already a great achievement in itself. I have learned to notice the little things, and to give time to them. I take joy in things, which I hardly even noticed before. This is the work that I can do. My working days are different, and by listening to myself, I find my own rhythm for each of my working days. I have already learned the most important thing; to see my own achievements and to appreciate them.

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