EDGAR STENE PRIZE 2010
WORKING WITH A RHEUMATIC DISEASE
— MY DAILY REALITY

eular Standing Committee of People with Arthritis/Rheumatism in Europe (PARE)
The European League Against Rheumatism (EULAR) is the organisation which represents the patient, health professional and scientific societies of rheumatology of all the European nations. EULAR endeavours to stimulate, promote, and support the research, prevention, treatment and rehabilitation of rheumatic diseases. Within EULAR, the national organisations of people with arthritis/rheumatism across Europe work together and develop activities through the Standing Committee of PARE. For more information please visit www.eular.org
I am delighted to have been given the opportunity to write a few words on the theme of this year’s Stene Prize “Working with a rheumatic disease – my daily reality”. It was with great pleasure that I learned that this year’s competition has received such a high level of interest from our member organisations and, with 18 entries, has been the most popular Stene competition ever. On the other hand, this great response did not surprise me as work is an essential part of all our lives. It is proven that working has a positive effect on self-esteem, provides social inclusion and allows economic independence. It was very moving and insightful to read about the determination, courage and strength which people have adopted to fight against the daily challenges of working and living with their disease.

A major responsibility of my role as a rheumatologist is to do my best to keep my patients in work. Early diagnosis, effective treatment and good management are essential in order to help prevent disease progression and disability. Disability tends to be irreversible once it has occurred, and this increases the likelihood of people losing their ability to work. I would like to see the ability to work used as a marker of disease control. Having a rheumatic disease not only has a dramatic impact on the quality of life of the patient, as we can read in this year’s essays, but loss of work and early retirement due to disability caused by rheumatic diseases can also have a direct economic impact on society.

Over the past two years, EULAR has made the topic of work its main focus for many important activities. The EULAR Charter for Work for people with rheumatic diseases aims to raise awareness of the economic and societal benefits of keeping people with rheumatic diseases in work and calls for policy makers, employers and health professionals to create an inclusive and supportive environment. In 2009 the Charter was presented at the European Parliament and it has already been launched in a number of European countries. With the EULAR Working Wonders exhibition, which is now being successfully displayed in countries across Europe, we can see some impressive testimonials demonstrating that people with rheumatic diseases can work if they are adequately supported.

I very much hope that the powerful essays written for this year’s Stene Prize will help all of us – politicians, healthcare teams, employers, co-workers and people with rheumatic diseases – to work together to make a difference and implement the changes that will benefit our society as whole.

Paul Emery
EULAR President
Rheumatic diseases cover more than 200 musculoskeletal conditions and affect over 100 million people of all ages across Europe. Rheumatic diseases have a significant impact on people's ability to work. By work we include paid employment, work undertaken in the home to support a family and voluntary work.

The right to work is essential for people with rheumatic diseases to fully participate in society. According to the Universal Declaration of Human Rights everyone has the right to work. The European Employment Directive provides a legal framework and should prevent people from being discriminated against on grounds of religion or belief, disability, age or sexual orientation. This right has been reinforced by the Convention on the Rights of Persons with Disabilities. It is important that existing law protecting the rights of more than 100 million European citizens is fully implemented at a national level. Work is important to people with rheumatic diseases and their families both financially and for their quality of life and well being. The direct and indirect costs of providing health and social care for just individuals with rheumatoid arthritis in 2007 was 45 billion Euros. Evidence suggests that enabling people with rheumatic diseases to work and including them in the workforce is of significant financial benefit to society. This charter recognises the role that policy makers, employers, healthcare providers and other stakeholders can play in creating a legal framework for a working environment that is inclusive of people with rheumatic diseases. The collective voice of people with rheumatic diseases should be sought through their representative patient organisations and be included in all decisions that affect them.

This Charter calls for: Awareness and recognition

This charter calls for greater public awareness and understanding of rheumatic diseases. It demands the recognition of the knowledge, skills and experience which people with these conditions bring to the workforce and to wider society. Opportunities and choices at work need to be increased for people with rheumatic diseases. Flexible working and creative job design can play a positive role in opening up access to paid employment and voluntary work.

Policy makers to legislate for access to work

This charter calls for policy makers to create and enforce legislation requiring employers and planners to create an accessible environment so people with rheumatic diseases can get to and from work and access the workplace. Appropriate technology, education, training and support allowing people to work must also be provided. Good employment conditions could include tax incentives for employers and employees, part time work, job share and the promotion of flexible working conditions. Such practice benefits all members of society.

Employers to create an inclusive and flexible work environment

This charter calls for employers to be active in creating an inclusive work environment where people with rheumatic diseases are not discriminated against and feel free to discuss their situation with employers and co-workers without prejudice. Employers must also be active in creating more flexible work conditions with an accessible and adaptive environment and appropriate technologies to ensure people with rheumatic diseases are able to contribute fully to the productivity and profitability of their employer.

Support from healthcare providers

This charter calls for healthcare providers to focus on the abilities of people with rheumatic diseases rather than on what they cannot do and give them the support they need to find work or to remain in their current employment. Success in this area should be regarded as a legitimate clinical outcome. Early diagnosis, access to the most appropriate treatments and therapies, rehabilitation and ongoing care will enable people to rejoin or be retained in the workforce.

1. Universal Declaration of Human Rights by UN 1948, Article 23
First awarded in June 1975 at the EULAR Congress in Helsinki, Finland, the Edgar Stene Prize was created by EULAR to honour the memory of Edgar W. Stene. Stene was the founder and Secretary-General of the Norwegian Rheumatism Association and himself a person with ankylosing spondylitis (Morbus Bechterew). Preparations to create the prize followed the establishment of a new EULAR Constitution at the organisation’s General Assembly in Paris, 26 May 1973, which brought into EULAR the “National Community Agencies active in the struggle against rheumatic diseases”. The creation of a Standing Committee for Community Agencies, today called Standing Committee of People with Arthritis/Rheumatism, was put into practice at the same time as the Constitution.

Professor J. J. de Blécourt (The Netherlands), the first elected EULAR Vice President representing the organisations of people with arthritis, said about the occasion: “We may speak of a historic moment in the history of EULAR. The basic philosophy behind this development is: the fight against rheumatism can only be effective, efficient and extended when not only the doctors (rheumatologists) but also the ‘rest of the community’ (...) take part in the work of EULAR (the management of the fight against rheumatism). This is a modern way of organising health care, research, fundraising, patient care, education, public relations, etc.”

Edgar Stene was born in 1919 and was a police sergeant, a sailor and a mechanic. During World War II he served in the allied forces’ navy and it was then that the onset of his disease began. The symptoms of the disease worsened and his doctor recommended hospitalisation, but he remained at his job due to the relevance of his position as a ship’s mechanic. After the war Stene was involved in welfare work. He played an important role in Scandinavian and international organisations and received recognition from the Norwegian King and the Swedish Federation Against Rheumatism, among others. Edgar Stene was “…a great promoter of cooperation between doctors, patients and community workers.” He advocated the union of people with rheumatic diseases in a specific organisation to provide a platform for effectively addressing the issues that concerned them. He also emphasised the importance of people with rheumatic diseases having an active and positive attitude towards their condition and preparing themselves psychologically and physically to face their challenges.

Rules of the 2010 Edgar Stene Prize

From 2010 onwards the Stene Prize will be awarded annually, rather than every two years, to the person with a rheumatic disease submitting the best essay describing his or her individual experience of living with their condition. Competition details are distributed to EULAR member organisations to run the competition nationally. Member organisations select the best entry from their country to submit to the EULAR Secretariat for judging by the jury.

For 2010 entry was open to people with a rheumatic disease who are 16 years of age and over. From this year, entries can not only be submitted in English, French and German, but also in the native language of the author.

The winner of the Edgar Stene Prize is announced by the EULAR Standing Committee of PARE on the EULAR website and in their newsletter. The Prize is awarded at the annual European Congress of Rheumatology. The value of the prize is EURO 2,000 and EULAR also covers the cost of the winner attending the congress to receive their prize.
The 2010 Stene Prize jury was appointed in autumn 2009 and includes some new faces, as well as previous jury members.

**Neil Betteridge**, EULAR Vice President PARE and **Marios Kouloumas**, Chair of the EULAR Standing Committee of PARE took the lead for the first time in this popular and important EULAR activity. Both are ex officio members of the jury, guiding the overall process, but not involved in the actual judging.

Marios says of the Edgar Stene Prize, “This competition gives people with rheumatic diseases from across Europe the opportunity to tell their story and to illustrate to others what it is like to live with their conditions - how they cope with the daily obstacles related to the disease itself and with the many barriers caused by the infrastructures and attitudes of society.”

Neil adds, “Writing about the personal and very precious experiences of living with a rheumatic disease has a therapeutic value for all concerned.”

The jury members agreed that this year’s theme around work is a very important topic. Work is a valuable part of everybody’s life, including people with rheumatic diseases who want to be able to participate fully in all aspects of life and to make an equal contribution to society. The 2010 Stene Prize competition attracted entries from 18 countries - the highest number ever, confirming the relevance of the 2010 theme.

Entries were submitted to the EULAR secretariat by EULAR member organisations from Cyprus, Czech Republic, Denmark, Estonia, Finland, Germany, Greece, Hungary, Iceland, the Republic of Macedonia (FYROM), Malta, the Netherlands, Norway, Poland, Portugal, Sweden, Switzerland and the United Kingdom. Once again it was very difficult for the jury members to choose the winner, as all the entries were of such a high standard. In order to compare the essays the jury was asked to give ratings for creativity, writing skills and the inspirational aspect of the stories.

Neil and Marios were supported by five voting jury members. The Standing Committee of PARE invited **Professor Iain McInnes (United Kingdom)**, rheumatologist and Chair of the EULAR Standing Committee on Clinical Affairs to join the jury. “In treating people with arthritis we seek to bring normality and stability to lives often significantly damaged by disease. We seek to support those individuals with arthritis in their aspirations within the family and beyond in wider society. For many, having an occupation or making voluntary contributions to the community constitute an important part of those aspirations. It is an honour to serve on the Stene Prize jury and to gain insights into how people manage their lives and work,” said Iain.

Another new jury member was **Maria Matheou (Cyprus)**, a psychologist and active member of the Cyprus League Against Rheumatism, representing the EULAR Health Professionals in Rheumatology. Maria said, “From a psychological perspective, work is a way for people with rheumatic diseases to stay active, productive and positive, which is important. It shows that the appropriate support from all the different health professionals can have positive outcomes on the lives of people with rheumatic diseases.”
McInnes adds, “Upon reflection, I cannot recall a more emotive series of papers for review than those which I read in my participation in the jury for the Stene Prize. Each essay told a life in a story with insight and passion. I was moved and educated in equal measure. I commend these essays to all.”

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diseases. I really enjoyed being part of the jury and reading all those inspiring essays. Even though I had no idea who the person was who had written each of the essays, I was still able to understand a bit of the psychological state of each person, a bit of his or her feelings and experiences, and to be part of their daily life. I was very impressed by the different ways each person dealt with his or her rheumatic disease and his or her daily life with all the obstacles they have to face. At the same time I was very moved that so many continue to see the bright side of life.”

For **Jack Skrolsvik** from **Norway**, **David Magnusson** from **Sweden** and **Ovidiu Constantinescu** from **Romania** this was their second year of serving on the Stene Prize jury. For Ovidiu the theme of work is a topic that is very relevant at a time when all European countries are being severely affected by the economic crisis. “Is my rheumatic condition a disability or a handicap? Should I tell my employer about my condition or not? Should my colleagues know about my condition or should I suffer in silence? What is more stressful – my task or my pain? These are day-to-day dilemmas that ought to be shared with others,” feels Ovidiu, who adds, “Being a member of the Stene Prize jury has been a tremendous experience as, through all the essays I have read over these two years, I have had the chance to reflect on my own condition as a person with rheumatoid arthritis. If a child is able to turn a grimace into a smile that defeats the pain and suffering, then there is hope… if one has the determination to fight on despite countless set-backs and limitations then there is hope… if one can produce a powerful piece of writing that sprung out of hatred and revolt against a crippling condition and against the fact that being ill is a full-time job, then there is hope… if one can write an essay about how somebody manages to get for herself a tranquil, rewardedly uneventful day amid pain and suffering, then there is hope… Essentially, each and every one of the Stene Prize essays has the same message, that living every day in severe pain and being able to write about it makes it easy to understand someone else’s suffering; that writing an essay is an act of courage; the will to succeed despite all odds.”

David continues, “The Stene Prize is a very special way of telling your own story in the form of a novel. In 2010 we hoped to see many examples of how people address problems that are related to working with a chronic disease and how these are solved by different people in different countries. I think this is very useful in many ways; it can inspire people when reading the stories, as well as providing concrete ideas on how people can improve their own situation by learning from others’ experiences.”

For Jack this was his last year on the Stene Prize jury, as each jury member can only serve for two consecutive years. He said, “Having been on the jury was a great and rewarding experience for me and I would like to thank all involved for making this a really special project – in particular my fellow jurors and all the people who have shared their personal experiences with us in the past two years. The Stene Prize represents a relevant opportunity for people with rheumatic diseases to express their personal thoughts and experiences about their everyday life and challenges in a written form. This is also extremely valuable for all healthcare professionals in order to help them to do an even better job.”

After the great success of the first Stene Prize booklet in 2009 and the high quality of the 2010 contributions, it was decided to publish a selection of entries in order to share the powerful testimonies with a wider audience. The Standing Committee of PARE would like to thank all those who contributed and supported the 2010 Stene Prize competition and who have made this booklet possible. “We hope that these stories will help politicians, healthcare professionals and the public to understand that people with rheumatic diseases want to work and that the majority can continue working if adequately supported,” says Marios Kouloumas. Professor Ian
An interview with Karin Nørgaard, 2010 Stene Prize winner

“The driving force behind writing about my personal experience with RA was wanting to thank my colleagues and my employer in the clinic where I work for all the thoughtfulness they have shown me when I am feeling tired and the support they have given me in providing me with the equipment I need to carry on with my work.”

Karin, who is 44 years old and from Copenhagen, Denmark, lives with her husband and their two children, aged 10 and 13 years, in a small house in the northern part of the city. She studied psychology at the University of Copenhagen and since has worked and specialized in neuro-psychology in posts at different somatic and psychiatric hospitals in the Copenhagen area. Currently Karin is in full time employment at an epilepsy clinic at the Hospital of Glostrup.

Karin read about the Edgar Stene Prize on the homepage of The Danish Rheumatism Association website – www.gigtforeningen.dk – and thought it sounded like an amusing challenge and opportunity to see herself and her disease from the outside – or even from below!

What did you think when you heard that your contribution had been chosen to win the 2010 competition?

Karin: A patient had just left my office and I had a little break before the next patient. The door was still open when Connie from Gigtforeningen (The Danish Rheumatism Association) called me and asked if I had seen “the e-mail”? “No,” I said with bated breath, but in a split second I thought to myself, “what if I have won?” I pushed the thought away immediately and was fully prepared that she would ask me a question like: “could you please send us a picture of you and your husband – or your food?” But she didn’t. She told me, that I had won the Edgar Stene Prize, and my immediate reaction was, “You are absolutely kidding!” A feeling of happiness was spreading inside, I smiled all over and suddenly the information hit my brain and I shouted into the phone: “it’s fantastic!” Afterwards I rushed out and told my colleagues that I had to redeem my promise: “We are all going out for sushi,” which is the clinic’s favourite.

What does being able to work mean for your daily life?

Karin: It means a lot to me. My diagnosis is relatively new, so I can still work full time and don’t spend much time worrying about the future. But I know I’m going to have to think about it later on.

What do you like to do when you are not working? What are your hobbies and the activities you enjoy outside of work?

Karin: We live in an old house and, now that the children are older, we have started to do a bit of renovation on the house. So in my spare time I’m a “handywoman”. I can sand down, fill, paint and put up wallpaper etc. In the springtime I find it relaxing to do my kitchen garden. My daughter often helps me and we have a wonderful feeling of success and the smallest steps give me a feeling of success and managing my condition.

How did your colleagues and the hospital that employs you react when they found out about your RA? What helped you the most?

Karin: I think my case is a bit unusual, because it was my colleagues - a nurse and a doctor - who saw that something was wrong and took action – while I was trying to deny most of my symptoms! So from the beginning they have been following my journey from symptoms to diagnosis and treatment. And they still keep an eye on me. But amongst all my colleagues and employer I don’t feel any change in their expectations of me. I have an agreement with my manager, that if I need any changes in my work I will let her know. I feel that I have all the support I need.

Has being diagnosed with RA affected the way you work with your epilepsy patients, for example by giving you more understanding and insight into some of the problems they face in dealing with a chronic condition?

Karin: Yes, in many respects. First of all I can recognize the desperation of being diagnosed with a chronic disease. Suddenly everything becomes unpredictable. Many patients with epilepsy struggle with anxiety and depression because of their fear of seizures. With my own diagnosis in mind, I have become more focused on regaining control, rather than leaving it to the disease. Even the smallest steps give me a feeling of success and managing my condition.

Do you have any advice for people finding themselves in a similar situation?

Karin: For me it is helpful to inject as much humour into my life as possible. It often helps me overcome my troubles because it changes my mood in a positive direction. At the same time I hope everything around me will remain focused on me as a person and not as a disease.
Working with a Rheumatic Disease – My Daily Reality

Please allow me to introduce myself. My name is Rheumatoid Arthritis, and I live in a two-room apartment in the right forefront of my host, close to the 2nd and 3rd toe. It's a lovely and large apartment which I have renovated and modernized over a period of time. This has rubbed off on my neighbours, so now they are also renovating their kitchen and bathroom. I can hear my host complaining in the distance - and sometimes she resorts to painkillers to reduce the hassle of the renovation.

In spite of my small size, I manage to keep her under control. Our daily battle concerns her choice of footwear for work. Here, during the winter, she prefers to wear fancy boots, but I only want her to wear the black running shoes. I win - every morning.

My host's name is Karin; she is forty four years old, married with two children aged ten and thirteen.

She works full time as a neuro-psychologist in an epilepsy clinic at Glostrup Hospital, where she was hired on the first of November 2008. Here she talks to patients afraid of epileptic attacks, tests those with concentration and memory challenges related to their epilepsy, and talks to people with attacks that resemble epilepsy, but are not epilepsy, but rather emotional problems manifesting themselves as epilepsy-similar attacks. She is also responsible for a youth group for young people who need to learn to self-manage their epilepsy. Evidently, she has many different tasks, and I often hear her talk very enthusiastically about her work. She does not need to walk much, as her office is situated centrally in the clinic. However, lately she has decided to stay away from morning conferences in another building, due to morning stiffness and soreness in different parts of her body.

She has only known about my family’s existence since 19 March 2009, but we have been living in her body for longer than that. Actually, it was my cousin in her neck who crawled from her left shoulder joint to her right one and back again, that started her Odyssey to try and locate and track her tormentors. She ran from doctor to physiotherapist to chiropractor, and back again. And while she was lying down on a bed receiving treatment for her neck, one of us would take hold of her right knee or her left index finger. She did not mention this to anyone, as she thought it was just a coincidence - even though it happened a lot. We had a grand time, peace and quiet to multiply ourselves.

"We had a grand time, peace and quiet to multiply ourselves."

She has now been working in the clinic just over a year. In the beginning, she did not mention her sporadic pains. She tried to cover them up, but after a while, an alert nurse commented that she had noticed that my host was walking with a limp, and that she had to use both her hands to lift a half-empty coffee cup. My host tried to play it down and said it would probably soon pass. We all nodded eagerly in agreement. Five minutes later, she was holding a blood test note in her hand with a lot of checkmarks on it. She felt as if her blood had been drained away.

That was the beginning of a somewhat more difficult life for me and my family. She began taking MTX and felt better. We were dislodged for a while, but slowly we are regaining ground.

You cannot tell anything is wrong by her appearance, except for her limp, which is caused by me. She can take care of her work without any problems and she does not feel ill. She hates to admit that her energy levels are not as high as they were. She has caring and supportive colleagues. Before she had even thought about it herself, the secretary had ordered a vertically adjustable desk. Now I can no longer see her face, but I think she still looks a little tired at times. Her colleagues have tried a few times to make her lie down on one of the couches in one of the examination rooms, but so far they have not been successful. Her manager has told her that, if needed, she can also work from home some days. Evidently, there is no lack of support.

I will not disclose what her future will be. She lives in the present, and does not expect her condition to change considerably. She disregards the fact that I and my family have grown in size and strength. She does not spend time studying what kind of creatures we are, or which prospects she has before her. That is her choice. She will gradually become wiser. At least, we intend to remain in her body.
Irene Pitsillidou
Cyprus

My name is Irene, I am 56 years old.

I am married with three children and live in the capital of Cyprus, Nicosia. I work as a private secretary and learned about the Stene Prize from the organisation I am actively involved with, the Cyprus League Against Rheumatism. For me it is important that people understand how a person with a rheumatic disease lives, works and survives with all the difficulties linked to this disease. I hope that my experience will also help others, many of whom may face similar problems, and offer them some solutions.

My telephone rang ten minutes ago, but when I ended the call, I took the opportunity to have another little nap. Now it’s ten past six. Time to get up, Roulla, if you want to get everything done. But a slight feeling of numbness in the fingers and shoulders reminds me that I need to gradually get my circulation going and take my medication.

I get up, stretching my limbs, and begin to prepare breakfast for my children and my husband. I get dressed, get myself ready, pick up my folders, invoices, receipts, and finally check my diary to see what I have to do and whether I need to take them with me. I remember that today is the day for my hydrotherapy and exercise. My bag has been ready since last night, with towels, soap and everything. I take my medication, because without it, the numbness and pricking in my hands gets very annoying, especially when I am driving or typing in the office.

For no particular reason, I start thinking about 1994. The year the clock stopped forever, as far as my health was concerned. Rheumatic disease in my hands damaged the muscles and nerves, leaving me disabled. I remember the endless pain, numbness, the hot sensation, the pricking, the inability to lift a weight, to cook, to type on the computer, to do the cleaning or even open a bottle just to mention a few things. It spread to my left leg, making walking and driving difficult for a long time. I remember the endless nights when I didn’t sleep a wink because of the pain, until finally I couldn’t stand it any more and took the initiative of asking my doctor for medication to help me sleep. After some months of treatment and medication, I began to be in a more bearable state and went to work (working for a public service organisation), stubbornly determined to fight my problems and come out victorious. But at work I was faced with endless trials and tribulations, it was a living hell. I went to the trouble of getting doctor’s certificates, only to find that my work still doubted me and refused to change my duties, even though I could not work on the computer. I went through so much, a daily martyrdom, physical and mental stress, with many tears, threats and dismissal letters, rejection by old “friends” and colleagues. I dug in my heels and fought against my illness on the one hand and my work environment on the other. Three children and life as a displaced person did not leave me much scope for giving up without a fight. I achieved some better days at work and in my everyday life thanks to a lot of physiotherapy, some medication, and by gathering what hope and strength I could find within me to survive and live while ‘self-managing’ my illness.

“Mum, what’s happening today; aren’t you going to work? Dad’s waiting for you to go to the laboratory.”

I jump, startled. So many years have passed. Sixteen whole years, and many times – like a nightmare which you drive away only to see it return and come to life again – my mind has been haunted by the pain of rheumatic disease in all its misery, until I come to my senses, frightened, and say to myself, Roulla, you must be strong, rheumatic disease will follow you wherever you go, so accept it and keep going.
In the laboratory, I discuss work with my husband, and begin by catching up with outstanding office tasks before turning to external work. I don’t type anything on the computer because that is impossible for me; the only thing I can do is update myself on business matters. Today I have to go to two banks on business and, on the way, pick up some small parts and collect payments from various customers. I finish all my work and my fingers are complaining about the driving, in addition to the numbness which I usually have on other days. In spite of this, I enjoy every day and consider myself blessed to be able to do all the things I do. I work, deliver, and I’m paid. At 12.30 I have an appointment for hydrotherapy and exercise. I have to go at least three times a week, so that my condition, as far as possible, is tolerably good, with less pain and less medication.

“In spite of this, I enjoy every day and consider myself blessed to be able to do all the things I do. I work, deliver, and I’m paid.”

At my physiotherapy sessions I convince myself that it doesn’t matter that for many hours of my life, whether I like it or not, whether it’s hot or cold, I have to go. I’m convinced that rheumatic disease and physiotherapy go together, rheumatic disease and doctors go together. At physiotherapy I say hello to people, talk and have a great time with my friends and the physiotherapists; I talk about my pain and my problems and I hear about theirs. It’s my second home, my second family. Instead of being indignant and getting irritated about my rheumatic disease, I tell myself that I am lucky to enjoy doing exercises and getting to know other people with the same problem. Time goes by very quickly until lunchtime. At 2 o’clock the children come back and my husband and I are already at home and I am cooking. Today I am cooking beans, but it’s difficult for me to shell them – so, the night before I have to plan things like a good housewife, I set my daughters the task of shelling the beans for me, so with the help of the family I can enjoy the food.

My husband goes out and the children and I put the plates in the dishwasher, make the beds and do a little tidying. Now it’s time to hang up the clothes. The girls take on this job, because it’s a very laborious task for me. I just hope my children will stay healthy, because they have always helped me since they were little. I remember the little one who knelt on the chair to help me make pizza. Rheumatic disease can’t be beaten without the help of my family working as a team. Even my son, I remember, helped me many times with the dishes and washing the clothes, and my husband cooked or helped with scrubbing the pans.

But now it’s evening and we have to do the ironing. Once again, I can’t help. It’s the worst job for me, it literally wears me out. The girls share the ironing while I prepare a meal or do the business accounts and organise the folders and receipts for the next day. Feeling very tired in my body, with a lot of aches and pains and numbness in my hands, I sit down to rest for a while. I put on some soothing cream or take a painkiller and sit with my family to talk and relax.

“But now it’s evening and we have to do the ironing. Once again, I can’t help. It’s the worst job for me, it literally wears me out.”

For me, another day has passed. I am happy and pleased that I have been able to work, complete my physiotherapy and, for one more day, I have done the best I can for my family. But my rheumatic disease, my problem, is still there. Rheumatic disease and I, like two friends who cannot part, have got through another day.

Translated by Verbalis GmbH
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
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.

Translated by Verbalis GmbH
Maria Batziou
Greece

My name is Maria and I am 36 years old.

My hometown is the capital city of Greece, Athens, where I work as a high school teacher. I am single, but happily in a relationship. I read about the Stene Prize on the EULAR website and I liked the idea of a contest where people can express themselves through writing.

Work is a big topic for almost everybody because it covers the largest part of their lives. It's exactly the same for me. Work for me is as necessary as breathing and I couldn’t imagine myself stopping work, even if I couldn’t move my hands or legs. I strongly believe that when there is a strong will, the obstacles will disappear.

Working with a rheumatic disorder – my day-to-day reality

Every day when I wake up, my first thought is about the things I have to do during the day. I don’t think I could imagine a life without working and making a contribution. For me, it is the oxygen I breathe and the driving force of my daily life.

As a teenager, about 20 years ago, when I was at the gymnasio (lower secondary school), I was diagnosed with lupus, a disease which not even doctors knew much about at the time. I gradually discovered for myself, often in a painful way, what the symptoms of this unknown disease were, and began to adapt myself to a new way of life. I accepted it, but I never shared this experience with anyone, not even my doctor, who confined himself to prescribing medication and observing the course of the disease. By writing this, I am perhaps sharing my experience for the first time.

In spite of this, I do not remember my health problems ever being an obstacle in my life, my studies or my work. It seemed to be a tacit agreement I had made with myself, or a stubborn refusal to accept that there were any physical obstacles for me. And the truth is that I managed to overcome the pain and other demanding situations, because I ignored them and only focused on my goal. Inefficient systems, and also people, have at times been the real obstacles for me.

I am a teacher and I love children. At the moment I do not have a steady job; I, too, am a victim of the new scourge of our times, steadily growing unemployment, which has already been a cause of disillusion and despair for millions of people. To earn a living, I now give private lessons to children aged 9-15. As well as the feeling of uncertainty and insecurity that goes with being self-employed, it is an occupation that is beginning to tire me out, because of the unpredictable timetable and the constant changes in location. In order to satisfy your clients, you have to accept the hours that suit them, regardless of your own need for rest.

“[I find that a positive mental attitude is what gives me the energy I need.”

With lupus, getting tired easily is one of the things you have to deal with. In spite of this I try to satisfy all my clients, weighing up the tiredness which a difficult timetable entails against the satisfaction I get from this work and from contact with the children I adore. I find that a positive mental attitude is what gives me the energy I need. I have discovered that with a positive mental attitude you can face very difficult situations and physical disadvantages such as, in my case, being easily fatigued. And this is how I cope.

But whatever the case, it is very difficult to make your clients or your employer understand how you feel, what you need, and to describe your situation to them. My experience so far has shown that most of them don’t understand and will judge you negatively, even if you tell them about your condition and explain it to them, because it is difficult for them to understand.
something that they have not experienced themselves. The most likely outcome is that they will accuse you of making excuses and will misunderstand you.

Of course there are those who are willing to support you, I don’t deny it, but I need to work and the only source of income I have is from my private lessons. I am not going to take the risk of testing the person who is paying me to find out how understanding he or she is, even if this means working under greater pressure. I prefer to take the pressure on myself rather than risk an unfair dismissal.

So I continue on my silent course, praying that as far as possible I will be able to control my illness, rather than be controlled by it, and that I will manage to overcome whatever problems arise, without losses. In any case, life is full of risks and full of choices, and I have made mine. I am optimistic and believe that I will continue to cope as I have done up until now. I have promised myself that from now on I will take a little more care of myself than I have done so far, so I can continue to put up the same fight in the future. Because for me, paid work, apart from being a means of survival is a basic psychological need which I must meet in order to be socially and psychologically healthy.

Another aspect of my life is voluntary work, which for me means selflessly giving to those in need, be they adults or children. This fulfills my inner need to make a contribution. As I have personal experience of a chronic disease, my voluntary contribution is mainly aimed at those with a difficult health or social situation, in order to help them cope with it as well as possible. I work as a volunteer for two associations with these aims, and for an association providing help to children. When I am making a contribution to the lives of others, and when I see the suffering of my fellow human beings, I forget my own cares, which usually fade into insignificance. The satisfaction of making a contribution becomes my treatment. I remember when I was doing my nursing practical in the emergency department of a National Health hospital as a Red Cross volunteer, despite the long hours on my feet and a workload that was so heavy that I often missed my break, at the end of the shift I still had energy and was on a high, with that sweet feeling of satisfaction that I, too, had in some way helped some people who were greatly in need. When you experience something like that, you cannot complain about tiredness, because you would sound like an out-of-tune instrument in a symphony orchestra.

Who said that work is a harsh reality when you have a chronic disease? For me it is an interesting reality which, despite its problems, makes me feel active and lively. Because life for me means action, making a contribution and being creative, without discrimination or limitations; everyone contributing in whatever way they can. It is like an endless journey…
My name is Zita and I am from Hungary.

I am 53 years old and live in a small town – Cegléd – near Budapest. I have one daughter who is an economist. By profession I am a Hungarian language and literature teacher. During a visit to my rheumatologist, Dr Zsuzsa Bihari, she showed me the quarterly magazine of the Hungarian League of Patients with Rheumatic Diseases - Reuma Híradó – which contained an announcement about the Edgar Stene Prize contest. I decided to participate in this contest, because I know that pain is the strictest teacher. We must be good pupils and go beyond the pain.

If what is straight starts to curve, you get a smile. Fate has given me plenty to deal with, it has pitilessly created three curves on my spine, one below the other. So for twenty-four hours a day, without a break since I was a child, the cervical, dorsal and lumbar vertebrae have been pulling and dragging each other into a distinct arc.

The exception proves the rule; the three bulging S-shaped curves, traced from the straight line, are not a series of smiles, but rather the grimaces or scowls of a twisted spine.

The whole business started when I was twelve years old, when the middle part of my back started to burn, ache and have shooting pains. The disease, like a burning coal, had burrowed itself between two of my vertebrae. I could hardly move or breathe from the pain. It was during the summer holidays. “Lie down on your stomach in the sun, that will cure it,” said my mother. So from morning till night I basked in the sun in the yard, and sometimes I would feel better when a little shower of icy rain started to fall. Nature’s cold compress soothes the inflammation.

School started. I was summoned for a chest X-ray. I knew, I absolutely knew they were going to call me back because they had found a problem. They did find one. They sent me to a sanatorium.

“What’s wrong with my daughter?” asked my mother. “Scoliosis,” replied the professor. Many questions followed many answers. “How will this affect my daughter’s life?” My ears pricked up in the little room where I was getting dressed after the examination.

“Since their misshapen chest puts a great burden on the hearts of people suffering from this illness, on average they can only expect to live to the age of forty.”

That’s great, I thought excitedly, then I’ve still got lots of time left! However, my sky was darkened by a cloud of despair. “How can I realise my dream of becoming an actress? Shaped like this that’s never going to happen.”

“No one would notice the scoliosis when you’re dressed, or only if they stared very hard at your back,” my mother reassured me.

In the sanatorium all the children and adults were struggling with their deteriorating, unmanageable bones. When I was admitted I became part of an army of hunchbacks. Out of joint, tangled up, misshapen people greeted me. But, funnily enough, they formed a happy family. In the land of the blind, the one-eyed man is king, as the saying goes. I was a queen, I maintained my straight bearing with rare fortune, but I forgot to smile. Rather I buried myself into books and newspapers. I came across the “Women’s Weekly”, and in it found an extraordinary article. It was about Felicitas, an Italian duchess, who was the patron and muse of countless artists. She suffered from scoliosis, but dressed so skilfully, and was at the same time so clever and beautiful, that she was surrounded by an army of admirers her whole life long. Incredibly, my name Zita, comes from the Italian name Felicitas. There is no such thing as a coincidence! This story was a message, a sign that I shouldn’t give up. A smile fitted across my soul. Now I’m not a duchess, nor am I rich, but the rest
corresponds. I have dark hair and blue eyes, just like an aristocratic woman, I design my clothes, my credentials up until now have been excellent, and no one can deny my beauty, because the professor said that a little girl with such a beautiful, angelic face shouldn’t be bitter.

There were people in the sanatorium who suffered from tuberculosis of the bone. That is to say, due to the TB, their bones weaken and then bend or snap. To begin with they also treated me for this with medicine, but the X-rays revealed that I had enough calcium in my vertebrae, and the cause of my illness was unknown.

Some people had operations where their bent spines were attached by wire to some kind of straightening contraption, a calf-splint, and then, when their spine became straighter, the bolt and the wire were pulled tighter and the support alternated from the one to the other. Some had a plaster breastplate wrapped round the whole of their upper body – they could have gone into battle if they had wanted! Others were suspended from the neck down several times a day, attached to a leather strap which was fastened to a board on the bed. The rest did gymnastics and swam, as I did too. Fortunately, they couldn’t operate on me because after they had rectified the three curves, I would have become stiffer and more rigid. When they let me go home weeks later, we had to have an iron corset made. I wore it home. I would have been received with great honour in a medieval order of chivalry. Since there were no orders of chivalry in 1968, I took it off as soon as I got home, and burst into tears; if ever I had to fasten it onto myself again I would throw myself off the roof.

The day came when my mother and I travelled to Slovakia to see the osteopath. There was a long winding queue in front of old Uncle István, who lived in a dirty peasant’s house which smelt of dung. He put back my dislocated hip, and realigned my spinal column, disk by disk, which within a week had completely regained its old, curved position. I slowly learned to live with the pain. I took no notice of it, I considered it to be my normal condition. I realised that I had to find work in which I could change my bodily position frequently, because I couldn’t sit or stand for a long time without a break. I became a teacher, and so an actor at the same time. When I recited works of literature or poems to my pupils I always looked on these occasions as performances. So did they and I received applause and love from them. I could easily relate to pupils with physical defects or emotional problems. I was able to help them to accept themselves, and forgive their weaknesses. They were not alone.

Pain makes those who know it wiser and richer, in comparison to those who haven’t had the pleasure of being acquainted with it. I too had plenty of admirers, like the duchess Felicitas. I got married at a young age. I became pregnant, in hospital I didn’t let on that I had a pelvic distortion, because I wanted to give birth to my child in the natural way. This caused a lot of panic. “Why didn’t you tell us before?” chided the midwife, “we would have given you a caesarean section.” “That’s why I didn’t say anything,” I thought.

We were both lucky, my daughter and I, if you don’t count the three months of limping which followed on Afterwards. Well, I had never experienced anything like that up until then. It was interesting and it was gratifying when it passed. Like in the tale, the benevolent time has broken the spell for me.

I passed my fortieth birthday thirteen years ago now, and, look, I’m still here. It’s true I have exchanged the teacher’s desk for a writing bureau. I’ve become a writer. During that time there hasn’t been a month that’s gone by when a nerve hasn’t got trapped in my spine while I’ve been combing my hair or doing some other simple activity. The joints on both of my hips and in my knees and ankles have become askew. I limp sometimes when I walk; my bones beat a marching song to my praise. Because of the curve in my cervical spine I also suffer from balance problems. All my limbs are numb, but fortunately they alternate between each other so it’s not so monotonous. Compared to other people, it’s been a pleasant occupation, in that I have been able to get to know all the country’s health spas, even the National Institute of Rheumatology and Physiotherapy, into which I have already been slapped three times.

“I passed my fortieth birthday thirteen years ago now, and, look, I’m still here.”

Groaning and moaning – but simply because it feels better that way – I do my housework too. Then I rest between cleaning two rooms for one hour, or, if necessary, for a whole week. And most importantly of all, if required by a special occasion or celebration, I put on stiletto-heeled shoes and a low-cut dress. Then I forget that I am not perfect. And so do other people.

In the beginning God drew a straight spine in my body, illness deformed it, but God, by way of balance, has put it right as much as possible. Thank you!

Translated by Verbalis GmbH
**Working with a rheumatic disorder – my day-to-day reality**

It’s 1986, I am 19 years old and I find out I have rheumatoid arthritis.

Well, so what, I think, still fairly unconcerned, that’s something for old people to worry about. As for me, I’m just going to get on with my life. At that moment I still have absolutely no idea that I will find myself coming up against limitations time and time again. The fact I notice little, if anything of the rheumatism and I think it’s all over and done with. Until I experience my first rheumatic attack in 1989 that is. The first drugs now make their entrance. It is then that I realise I’ll need to do things differently.

I’m working at that time behind a bar in a club in the evenings and in a dress shop during the day. I love the work! I’m always meeting lots of new people and I’m enjoying life to the full. I want to have my own bar or my own dress shop. Which of the two it will turn out to be I don’t know yet, because, after all, there are many years ahead of me for me to decide that. I’m doing both at the moment because it’s such fun.

Standing behind the bar became too much though and despite the fact that it was very quiet in the dress shop, that soon became too much as well. I realised that I would need to organise my life differently. But I continued to work in several dress shops and during the summer I took a job with a travel agency that ran summer camps for children. It was a marvelous change, having energetic people all around me again and a life full of activity! I thoroughly enjoyed it. There I was, literally and figuratively right in the middle of life at its most beautiful. When I got a job in a department store during the winter months though, I noticed that standing just wasn’t really possible any more. Constantly standing and walking around didn’t work for me any longer, but even so I simply carried on. It is such fun to work in a shop in the ‘parcel months’, as we say here in the Netherlands.

I kept up that pace until the end of December, but by then I was forced to conclude that a standing job at that particular time wasn’t a possibility. Perhaps it would never be possible again. So then, it was time to re-train, time to move on to a sitting down job!

I could no longer get around the limitations that rheumatism brought with it. I let myself be talked into a training course to become a secretary. I went to work for the Provincial Government for 24 hours a week with a training course tacked on to it. After a couple of months though, everything went completely wrong and I was admitted to hospital for four weeks. New drugs and convalescence. I could no longer get around the issue. I was a rheumatic. Limitation had become a harsh reality. After that, I returned to my job with the Provincial Government for a while, but the contract was not extended because they were now looking for somebody to work 38 hours a week and that was more than I could do.

Everything caved in for me at that moment, I hadn’t wanted an office job, but there had been no other option. And now they didn’t even want me any more. I could see absolutely no options open to me at the time and it was as if life had come to an end. After weeks of doing one thousand piece jigsaws, a light turned itself on in my brain again and with it the sense that I needed to tackle things very differently. You have to accept limitations and try to sail around them. Easily said of course, but how do you really do that? And yes, I know you will hardly believe it, but right at that moment, one of my uncles...
offered me a terrific job working alongside him in his business. A few hours a week, updating administrative records, answering the phone, serving coffee, bookkeeping and so on. It was not what I had in mind ideally as far as work was concerned, but the firm turned out to be a tremendous place to work and I have come back to life and started to feel valued again. I learn all kinds of new things and meet lots of new people again. If things become impossible, I just go in later the same day or go in on the next day. Everything is possible, but nothing is compulsory. The best possible job and with the best possible boss!

A period of four years passed and everything was fine and in order. Then the company downsized and there was little left for me to do, so I decide to look for work elsewhere. As a result of my last job, I can see possibilities again and new opportunities. I have been able to discover what I can do and also, that despite what you might think, there really are some very nice ‘sitting down’ jobs. Full of enthusiasm, I start on a 32 hour working week as head of the telephone department of a taxi firm. Unfortunately though, this project falls flat on its face! After just three months I revert back to working only 24 hours a week and then, after a couple of months, even that becomes too much. My limitations are nearer to me than I thought. My former courage sinks back into my shoes again. But still I want more! I want to go on further. Back to what I like doing.

When I start making necklaces as a hobby, my friend suggests I should start up my own business and sell them. At first all I can see is all kinds of ‘rheumatic’ hurdles in the way, but soon I start to think what the heck, what have I to lose? And before I know it, all kinds of exciting plans are forming themselves in my head.

Within the short space of three months I have passed the milestone of starting my own business and I open my shop on two and a half days every week. Everything is going fine, there is no profit as yet, but I’m almost breaking even and I’m enjoying life again! Making the most beautiful things you could imagine and running my own business into the bargain. And despite the restrictions imposed on me by the rheumatism, I feel happy. But after the first three years, it dawned on me that there was no profit to be made if I only opened up two and a half days a week. I needed to open for longer. The limitations rear their ugly head again. Longer opening hours quickly prove to be too much for me. I am constantly tired and the amount of medication I take has to be increased. Medicines by infusion make their appearance and the rheumatism remains restless.

I make a difficult decision and close the shop. And then I become tired, constantly tired, endlessly tired, and I all I want to do is rest. Deciding to close the shop was a good decision, with very mixed emotions I confess, but after a little while the itch is there again.

By this time, I have reached the age of 40 and I discover that I only want to do the things I like. That idea has now become my motto. The idea that, ‘I can’t expect anything better because of my limitations’, makes me angry. It is just a negative way of looking at rheumatism. You need to simply decide to do what makes you happy and concentrate on the things that you really can do.

When I was about 20 years old, I once made a list of all the things I wanted to do before I die. I kept that list in a safe place and I added to it from time to time. The final entry will most likely be that I want to swim with a polar bear, because that’s something I wouldn’t survive. But one of the things on the list was that I wanted to work in a museum. The very next day (there’s no such thing as coincidence) there was an advert in the paper asking for volunteers to work in the cafe at a museum. I called them straightaway and was offered a volunteer position almost immediately for one half day a week. Fantastical! Back in a situation where you meet a lot of different people in a pleasant and stimulating environment and with a cafe ambience added into the mix. Within the next six months, they had asked me to come and work as part of the museum-counter reception staff. There I was, all of a sudden, working as a paid member of staff on the actual reception counter of the museum itself. Nothing in the world could have been more ‘me’ – welcoming visitors to the museum! And I’ve continued to do that right up to the present day with great pleasure and I’ve discovered that I’m totally in my element in this job.

In the meantime, I also run “do it yourself” afternoons at an animal rescue farm as a volunteer. This work has opened up a whole new world for me. Two things that really appeal to me are combined here, wonderful people and creative activities. Am I beginning to find my niche as far as work and my rheumatism are concerned? Can I still find pleasure in what I do despite my limitations due to my rheumatism?

Meanwhile, things are going so-so with the rheumatoid arthritis. I’m experiencing more and more inconvenience with my joints and tiredness, and the side-effects from the drugs are becoming more pronounced. I encounter more and more things that don’t work for me. I realise that I have difficulty with the fact there are things I can’t do any longer and that I’m becoming more dependent on other people and that I need to ask for help. Even though you can hardly see any of that when you look at me. A young woman of well cared for appearance who laughs often is how my therapist once described me. She’s completely right of course; that’s exactly what I am! I stand here positively and assertively right in the midst of life and I still enjoy everything I do.

But there are also days when I want a career with an income instead of being a volunteer on a frugal welfare benefit and when I’m furious with my body because it won’t do what I want it to. Often, I have the feeling that people don’t believe I really have anything to offer; after all, there’s nothing you can see is there? Is that my lack of confidence? People are of course too quick to judge me. I have always been envious of people who knew what they wanted to be from when they were very young. People with a passion for their niche in life. Growing up into something that seemed to be absolutely right for them, without any limitations. That appeared to be really marvelous to me!

Out of the blue now while I’m writing, I suddenly realized that I still really don’t know what I want to be ‘when I grow up’. Is that because of the fact that I can’t do everything I want to, or would I still not have known, even if there had been no rheumatism?

“I stand here positively and assertively right in the midst of life and I still enjoy everything I do.”

Translated by Verbalis GmbH
I’ve never had a day off. I’ve never left work early. I’ve never had a lunch break. I’ve never been on sick leave. I’ve never been given recognition for my hard work. Who would have given it to me?

I don’t have a boss. No colleagues. Nobody works with me. Nobody gives me support during my working day – a workday that never ends. Or starts.

Well, it does start. My working day starts every day, all week long, every week, all year long, every year, at about 9.30 am. It starts when I’m in bed, where I lie thinking about the fact that my working day has already started and that there’s nothing I can do about it. Half an hour later, I am half an hour into my working day. My teeth have now been brushed and my medicines have been swallowed down with half a glass of water. Maybe I’ve managed to brew my morning coffee. Maybe I’ve managed to lie down on the couch. Not so that I can watch TV, but so that I can work.

The couch is where I lie, flat out working. I think if anybody saw me, while I’m lying down working, they would think that I’m just being lazy. There’s something very annoying about men lying flat out on a couch. Women can go crazy just looking at men in that position. In extreme situations women can do extreme things. You never know. So I usually pretend to be reading the paper. But I’m not just lying down being lazy, I’m working.

Just a few more minutes and I’ll be able to walk to the kitchen in order to turn on the coffee-maker. During the winter the beginning of my working day can be really challenging. I’m very fragile and very afraid of slipping and falling on the icy roads. It’s even worse if I have to shuffle along in the snow. It’s quite a challenge. While shuffling in the snow, I think if anybody was watching me while I move around, as if I’m auditioning for ‘Brokeback Mountain’, they would have a good laugh. I think it would actually be good if someone did just that. A workday is much easier to handle with a good portion of humour and laughter.

Four hours into my working day, it’s four hours into my workday.

My wife calls. She wants to know what’s for dinner. As usual, I don’t have any good suggestions. I think that I don’t really have time to figure out stuff like that. I’m busy working you know. My wife as usual suggests fish. She tells me fish is healthy. I listen to my wife. She generally knows what she’s talking about.

I drive to the store. My favourite store has a very appealing ready-made food section with lots of lovely dishes. I think I’m lucky that I get to visit such interesting places while at work. I also have to mention that the parking outside my favourite store is exceptional. The car park is very flat and has lots of room to get in and out of the vehicle. I think that lots of stores could learn something from this one. I’ve got a trained eye when it comes to car parks. It’s a part of my job you might say.
“When you think about it, we are all in the same situation, those of us whose work is rheumatism. We never have time off.”

However, I don’t have time to absorb the inspiring atmosphere for too long, because I’m at work and I don’t have time to mess around.

Later that day my wife makes me clean the dishes. I think that an ordinary workday contains lots of different challenges, and doing the dishes is definitely one of the most difficult ones. Not because the water is too hot, or the dishes too dirty, but because my kitchen bench is too low. I’m forced to take on a bent position. It strains me, but no work is done without sacrifice.

The hot water makes my hands less sore. It feels quite good. I think that if my job had been arthritis, I would have loved doing the dishes. Those whose job is osteoarthritis, always say how good the heat is. Their joints feel better. I envy them a bit, those who work with arthritis, but I also think that their workday is probably just as tough as mine. They don’t have a boss either, or colleagues or days off. No, they don’t even get to take a single break. When you think about it, we are all in the same situation, those of us whose work is rheumatism. We never have time off.

Eight hours into my working day, it’s eight hours into my workday.

I think about that day when I got a few minutes off from my Rheumatoid Arthritis (RA). It was a beautiful autumn day a few years back. I woke up with a cut on my forehead. I had passed out and hit one of my mother’s flower pots on the way down. I remember a feeling of joy. The blood that came streaming out of my forehead quickly mixed with the spilled dirt from the flower pot, and I remember thinking that this was the closest to nature that I’d ever come. It feels good to daydream about that small break from my working day.

As I take off my socks and get ready to brush my teeth, I think that it is a lot easier to tear something down, than to build something up. My evening routine is a major part of my job and it can be really challenging sometimes. Teeth must be brushed, medicines must be swallowed, and I think that at times like these, what with the financial crisis and all, we all do what we can to be as efficient as possible. So I swallow my 14 tablets all in one go, and I think that I do what I can to ensure a stable workforce in this country.

Ten hours into my working day, it’s ten hours into my workday.

My head is on the pillow. This is one of the most critical moments of my workday. Important decisions are to be made. What book to read today? What direction should my head point? This last issue is a major one, because there is no way back once the decision has been made. A neck stiffens so quickly. Although I have heard about professional rheumatics who are able to turn over in bed twice, but I think that they are at a totally different stage to me. I’ll never get there. Or, who knows? I’m still at the beginning of my career. Maybe I will be able to turn over in bed one day in the future?

I dream about that day as I close my eyes. Not because my working day is over, but because I have to get some rest. Because tomorrow is another day and it brings along another working day that will never end.

Photos: Audun Andreassen
My name is Janina and I am 56 years old.

I have two daughters who are already grown up and one grandson who is four years old. For 30 years I have worked as a teacher – specialising in Polish philology. I was teaching in the biggest school in Stalowa Wola, an industrial city with about 70,000 inhabitants in southern Poland. Today I am retired, but I work in the socio therapeutic day room helping children to prepare their homework and supporting them with difficult situations in their lives. When my disease progressed I wanted to find out more about it and got in touch with the Association of Rheumatic People and their Friends – a Polish patient organisation. I read about the Stene Prize on their website and decided to share my life story and battle with the disease during my active working life with other people.

Janka

Like a wild beast
Misfortune befell the man
And fixed its terrible eyes on him...
– It waits –
Will the man turn away?
C. K. Norwid

She had taken the same route, every day, for years: two kilometres on foot. She would enter the school building a quarter of an hour before the first bell and immediately disappear in a crowd of children, who were often still sleepy because 7 a.m. is an ungodly hour to begin lessons. She was a school counsellor. Back then, in the 1970s, this meant that she would be landed with the most difficult problems and the children that nobody else could cope with. She would assist, support and advise others – on how to deal with unruly Jaś, or how to comfort tearful Marysia.

The same routine, day after day, year after year...

And then, after ten years of employment, just before the holidays, a surprise: promotion to the post of deputy head! This was a great distinction, a source of pride; it was the biggest school in town.

Janka was capable and diligent; she would surely manage.

However, after the first year in her new job she was completely worn out. But at least the summer holidays had arrived, so she decided to spend more time with her children and accompany them on a summer camp, where the kids could rest and Janka could work. Despite her many responsibilities, she would try to find a little time for herself. Her holiday was coming to an end and yet she felt extremely tired. To cap it all, she had an awful pain in her hands and feet and had no idea why. She lost her appetite and returned from the summer camp pale and thin. She decided to see a doctor, but wasn’t even registered with one – she had no time to be ill. The doctor prescribed painkillers, which helped a bit, though not for long. Several more visits to the doctor did not improve the situation, and the pain became increasingly unbearable.

September arrived, and the new school year presented a major challenge. After all, she couldn’t admit she was ill, because they would put her on sick leave.

Her job meant everything to her and was wonderfully fulfilling. Under no circumstances could she resign, for she had proved herself and so many people were counting on her. There was so much going on at school, and nothing could stand in the way of Janka achieving her goals. But misfortune befell her, the illness – rheumatoid arthritis.

The pain became impossible to bear. Her knees, elbows and wrists became swollen. She covered them with long sleeves and a long skirt, but pain cannot be masked. She couldn’t show anyone how bad things were, but it was obvious. She was emaciated and aching all over. Every day she would rise at dawn – two hours before the alarm would wake the rest of the household – in order to exercise her joints a little, slowly dress, and prepare breakfast for her husband and children. They, too, did not know what was really going on. Janka told them little and she never complained. All the time she hoped that a miracle would change things for the better.

“She would do her make-up with difficulty, her daughter would help her put on her jewellery and she would choose her clothing carefully in order to look presentable.”
Supporting pupils and their studies

Succeccive visits to other doctors in the town did not help much either. She took more and more tablets, but the results were lamentable. She would do her make-up with difficulty, her daughter would help her put on her jewellery and she would choose her clothing carefully in order to look presentable. Each morning she would greet everyone at school with a smile, ask them how they were and wish them a good day. She had to walk up three flights of stairs, check if all the teachers had come to work, organise replacements for those who hadn’t, then supervise lessons in person, take phone calls, attend meetings, give extra lessons to children with learning difficulties, and many other tasks. Someone remarked: ‘it’s a real madhouse’. But it was a madhouse in which you did not have time to think about pain or illness – this meant she was less terrified, sometimes even happy and fulfilled. Another three years passed. The pain became more frequently unbearable, the tablets stopped working, and despite many visits to the doctor in her home town, no one seemed able to help her. Not once was she referred for specialist tests, even though her disability was becoming increasingly evident – she limped on account of her rigid knees, and could only hold a pen or piece of chalk with great difficulty. Yet she always came to school. In winter, when there were huge numbers of absentees, Janka would appear at her post every day, without fail, at the same time. Where did she get the strength? Only she knew.

During the next holidays, with the help of sympathetic friends, she visited a clinic in a larger city. She described her suffering to the professor, who nodded his head with understanding, took a few deep breaths and said, calmly, “I will look after you”. From that moment she felt a huge relief, although the pain did not lessen at all. She did the tests the professor had recommended. It turned out that the illness was at a very advanced stage, and that the only way to reverse it would be to drain the joints and treat them with gold. She took comfort in the fact that it was the holidays – perhaps by September she would be better and would not have to justify her frequent trips to anyone. She would return to work as if nothing had happened. The worst thing was that she had to ask her local doctor to carry out the gold injections. How did he react? The conversation was not altogether pleasant, but he did the injections nonetheless. Improvements took place very slowly, and at school, after the holidays, she would pick up gossip here and there, that she was being replaced with a “better model”, or at least a healthier model. They would say: “something strange is happening to that woman, she seems to be hiding something”. But a few people, who were friendly with Janka, knew the real story. When something finally changed, and the pain became momentarily less intense, her hope was that she would not have to resign from her job after all. Now and then, some “sympathetic” soul would inform her that the appointment of a new deputy was being planned and that at some stage she would be dismissed. But it didn’t happen, because Janka began to feel much better and was no longer the ‘lame headmistress’, as she was called by the spiteful pupils – and, unfortunately, not only by them.

A time came when she began to feel better and she signed up for postgraduate studies in Polish literature and a course for teachers taking integrated classes, such as the classes that were being established in the school. She felt the need to test herself through work with special needs children; she understood them better, and taught them up until her retirement.

After several years of gold injections she had to discontinue the treatment, but fortunately new methods of treating rheumatoid arthritis emerged, and these proved to be equally effective. It was amazing that she had managed to fulfil all the responsibilities that she had consciously placed upon her own shoulders. She had done so in order to face up to the illness. It is hard to imagine, but for the twenty years that she was ill, she did not take a single day of sick leave. Each annual check-up confirmed her ability to work – such was the nature of the check-ups. And yet, perhaps it was good that it was so.

Janka found the strength to fight the illness thanks to hard work. Not for one moment did she think of giving up. She fought every night, every day, and after thirty years of employment, including twenty with the illness, she took retirement. But she isn’t resting. She works at a social therapeutic centre, helping children with their studies; she talks, assists, comforts those who need it. How would her illness have proceeded had she not worked or if – God forbid – she had taken a disability pension? It’s hard to say.

She found within herself an enormous strength to fight the illness, and it was this that enabled her to follow her career path. She tapped into a formidable willingness to struggle in the face of adversity. She was, and continues to be, full of hope and humility. And now she thanks God for each passing day.

Translated by Verbalis GmbH
Working with a Rheumatic Disease: My daily reality

I am a branch manager responsible for a retail outlet that turns over twenty million pounds a year and employs one hundred and forty people.

I am thirty years old and have scleroderma of the lung. I hope to give you an insight into my working life and how my scleroderma affects me on a daily basis.

I start the day by convincing my joints that getting out of bed and heading to work really is a better idea than staying in bed a little longer. I enjoy what I do and look forward to my journey to work, except when my car needs de-icing. I don’t know anyone who enjoys this job, but trying to de-ice your car when the circulation and feeling has gone from your fingers is quite a challenge.

My day at work begins with a walk across the shop floor. I say hello to all of my staff and check in with my managers that we will be ready to open. I then read emails, check sales figures and open the doors for another day’s trading to begin. I enjoy this time of day as there is often so much information to take in, the whole shop floor to check over and a morning meeting to hold – I like it because by the time I take a break my joints agree with me that coming to work and walking around was absolutely the right thing to do.

I often welcome visitors to my branch, from other shops and from the local community. If you were to visit me at my branch, I would meet you at the customer service desk and you might notice that I’m wearing gloves that match my suit; you might also notice how cold my hands are when I take off my gloves to shake your hand. Our visit might start with a brief tour of the shop floor. I would be careful to set the pace of walking to a slow speed, which means I can conceal my breathlessness. I hate people to see me breathless, I worry that it makes me look like someone who isn’t well, or worse, someone who can’t cope. I might take a quick break and go to the bathroom, I would check my reflection in the mirror, I’m not checking to see if my mascara has run or lipstick smudged, I’m checking that my red rash is concealed. I’m looking to see if I look like a girl with scleroderma or a leader of a business; I always hope it’s the latter.

Possibly the greatest challenge in my day to day life is managing people. I make time every day to walk the shop floor and ask my employees how they are, how their families are and how life outside work is. I believe that having scleroderma makes me a better manager, although it has taken me some time to arrive at this view. My initial feelings towards my scleroderma were to see how it limited me, how it interfered in my day to day life, how it always seemed to misbehave when I really needed to have a good day. I now believe that my scleroderma gives me empathy. A supermarket is like a microcosm, all of human life is here. Over the years I have encountered employees who are dealing with marital...
break-ups, ill children, domestic violence and serious health diagnoses. I think that my own experiences with my health help me to empathise with those facing difficult times. Let me be clear: I don’t openly talk about my medical condition at work, I prefer people to regard me as the boss, as a capable manager rather than someone who has a rare medical complaint. That said, there are times when in order to allow someone to talk it helps to give something of yourself. I relate to them how I felt when I was first diagnosed, how I cope and how I maintain that a positive attitude is the only option when facing life’s inevitable challenges.

After spending time in the warm sanctuary of my ground floor office, I head out to the shop floor for a final check around. Scleroderma has taught me the power of delegation. I am a perfectionist and prior to my diagnosis I would try and do everything myself. I’ve learnt that this is often to the detriment of my team; my managers will not learn if I do not allow them to make their own mistakes. I’ve learnt that I have to trust the people around me. I hand over to my duty manager, pick up some shopping and leave the branch. I’ve learnt that if I work excessive hours one day I won’t be able to do my best the next day.

“Can I inspire and lead a team of people when I’m too breathless to speak?”

As I climb into my car a wave of fatigue creeps over me. As I drive home I reflect on the day I’ve had and I realise how lucky I am. I work for a business that has always supported me, that has promoted me in spite of my medical background, that has given me my own branch that has no stairs. My employer has a holistic approach to business, where the happiness and welfare of the people who work for the business are as important as commercial success. I recognise that not everyone is so fortunate. And yet it is not the physical manifestations of scleroderma that pose the greatest challenges to me in the workplace. It is how scleroderma can make me feel. It causes me to ask questions, Can I do this job? Can I physically run around a shop and do a job I love with less than fifty percent lung capacity? Can I inspire and lead a team of people when I’m too breathless to speak?

“It causes me to ask questions, Can I do this job?”

I am a proud person. I take pride in what I do; my job is a central part of my identity. It gives me purpose and satisfaction and it is one of the reasons that I will continue to tenaciously manage my scleroderma in the same way I want to continue to manage my branch, irrespective of the hurdles and challenges that I anticipate my scleroderma will place in front of me.

For now though, as is often the case, my joints have the last word, and on this occasion they are absolutely right, a hot bath and an early night are exactly what I need.