EDGAR STENE PRIZE 2012

OVERCOMING THE CHALLENGES OF GETTING AROUND WITH A RHEUMATIC OR MUSCULOSKELETAL DISEASE

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 in Europe (PARE) work together and develop activities through the Standing Committee of PARE. For more information please visit www.eular.org

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The Standing Committee of PARE would like to thank all those who have contributed to this publication.
I am delighted to have been given this opportunity to write a few words on the theme of this year’s Stene Prize, ‘Overcoming the challenges of getting around with a rheumatic or musculoskeletal disease’. 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 19 entries, has been the most popular Stene competition ever. On the other hand, this great response did not surprise me as we all need to get around each day to go to work or school, to go shopping, to the doctor and to see friends and colleagues. We also like to go out just for fun or to walk in nature or to travel abroad. Being able to get around is an essential part of life which most people take for granted. However, it can be a different story for people with RMDs, who comprise a large sector of society but whose independence can be severely restricted by disabling factors, including environmental barriers and discriminatory attitudes, which unfairly limit their full participation in that society. It was very moving and insightful to read about the determination, courage, strength and imagination which people have applied to fight against the daily challenges of living with their disease.

Our responsibility as rheumatologists is to do our best to ensure that our patients have access to the latest and most appropriate treatments and care. Early diagnosis, effective treatment and good management with a multidisciplinary team are essential in helping prevent disease progression and disability. Disability tends to be irreversible once it has occurred and has a dramatic impact on the quality of life of those affected. Within the health care team, and in particular in close collaboration with the health professionals in rheumatology, we have to discuss the individual needs of each patient in order to maximise the positive benefits of their treatment. It is important that the patient is at the centre of this discussion and equally involved in all decisions about their health. Of course, it is our mutual goal to ensure that people with RMDs can live independently and participate in life without restrictions. Unfortunately, outside factors such as the built environment and lack of accessible transport for people with RMDs, especially in rural parts of Europe, can make it difficult for us to succeed. Here I would like to emphasise the important role that EULAR member organisations of people with RMDs are playing at a national level in addressing these discriminatory challenges for people with RMDs with politicians and other stakeholders in order to bring about improvements.

The Stene Prize essays offer a great deal of practical advice which will be inspirational not only for people with RMDs, but also their healthcare teams and wider stakeholders. The advice and easy to implement solutions provided by people with shared challenges are invaluable. I am convinced that the powerful essays written for this year’s Stene Prize will help all of us – healthcare teams, people with RMDs, architects, planners, designers and policy makers – to consider the needs of people with RMDs more carefully in all elements of planning for the future.

Maxime Dougados
EULAR President
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 the Standing Committee of People with Arthritis/Rheumatism in Europe (PARE), 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 PARE, said about the occasion: “We may speak of an 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 in his job because of the importance 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 and musculoskeletal diseases (RMDs) in a specific organisation to provide a platform for effectively addressing the issues that concerned them. He also emphasised the importance of people with RMDs having an active and positive attitude towards their condition and preparing themselves psychologically and physically to face their challenges.

**Rules of the 2012 Edgar Stene Prize**

Every year the Stene Prize is awarded to the person with a rheumatic or musculoskeletal disease submitting the best essay describing his or her individual experience of living with their condition. Competition details are distributed to EULAR member organisations so they can run the competition nationally. Member organisations select the best entry from their country to submit to the EULAR Secretariat for judging by the Stene Prize Jury.

For 2012, entry was open to people with a rheumatic disease who are 16 years of age and over. Entries can be submitted in the native language of the author and EULAR has these translated into English.

The winner of the Edgar Stene Prize is announced by the EULAR Standing Committee of PARE on the EULAR website and in its 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.
Each year a jury is appointed to judge entries to the Stene Prize competition. Under the rules, jury members can participate in the judging for two years running. For 2012 all eligible jury members were delighted to continue in their role for another year and when the jury convened in the autumn of 2011 it was joined by two new faces from Serbia and Greece.

Maria Batziou from Greece, the new Chair of the EULAR Standing Committee of People with Arthritis/Rheumatism in Europe (PARE), was delighted to be involved in the Stene Prize for the first time this year. Together with Neil Betteridge, EULAR Vice President, representing PARE, they serve as ex-officio members of the jury and do not participate in the judging, but use their experience to help guide the overall process.

Maria says of the Edgar Stene Prize 2012, “The Stene Prize competition is a wonderful chance for people with rheumatic or musculoskeletal diseases (RMDs) to express their thoughts, feelings, sorrows, hopes and dreams to the public. After love, writing is one of the most effective ways of communicating and the process can be healing and restorative for the writer. When I was invited to say a few words about the 2012 Stene Prize theme’, ‘Overcoming the challenges of getting around with an RMD’, my first thought was that there is nothing to equal the real experiences of people with RMDs as expressed through these essays. It was such a wonderful experience for me to travel through the lines, words and feelings found in this year’s essays and to try to understand the many beautiful messages they contain.”

Neil adds, “It is said that even the longest journey begins with a single step. For people living with RMDs, however, journeys are not always measured by their length, but by the pain involved, or by the number of barriers which society and our environment places in our way. It can be as big a challenge sometimes to move from the bedroom to the bathroom, as to fly half way round the world. It all depends on two things: how we feel at that particular moment in time; and how well our environment allows us to function. Sadly, the general population does not typically understand this. So by selecting this topic for the Stene Prize, we hoped to promote greater awareness of these issues, as well as giving people with RMDs the opportunity to tell their personal stories of getting around. I hope you enjoy these accounts, which are rich in humour, anger and frustration – but above all, with absolute determination to take that first step, which is often our very own Marathon!”

“I hope you enjoy these accounts, which are rich in humour, anger and frustration – but above all, with absolute determination to take that first step, which is often our very own Marathon!”

The 2012 topic still relates to EULAR’s overall focus on RMDs and physical activity under the World Arthritis Day theme of ‘Move to Improve’. The jury members were excited to invite people with RMDs to write about how they manage to get out and about and address barriers like the built environment, as well as the pain and fatigue they face in their daily lives. The response from 19 organisations submitting essays to the 2012 competition was the highest number ever received, clearly demonstrating that there is a great deal of interest in this topic and a lot to share!

Entries were sent to the EULAR secretariat by EULAR member organisations from Belgium Flanders, Belgium Wallonia, Bulgaria, Cyprus, Czech Republic, Denmark, Finland, ...
Greece, Hungary, Iceland, Italy, Israel, Latvia, Poland, Portugal, Romania, Slovakia, Sweden and the United Kingdom. Several organisations participated in the competition for the first time, which is a wonderful development. Once again it was very difficult for the jury to choose the winner, as all the entries were of such a high standard. In order to compare the essays the jury members were asked to give ratings for creativity, writing skills and the inspirational aspect of the stories.

Codruta Zabalan from Romania, an active member of the Romanian League Against Rheumatism, chaired this year’s Stene Prize Jury. “It has again been a great privilege for me to be involved in this project. Being able to move around and to reach places means a lot for a person affected by a rheumatic or musculoskeletal disease. I live in a flat with only a few steps to separate me from the world, so you might think it would be easy for me to get out. But this is not the case because going down or climbing up those stairs is only the start. Once you are in the street you don’t find a well organised network of public roads adapted to your special needs, you find a jungle with traps and obstacles. So, let us share ways to tame that jungle and to master it!”

Codruta was supported by four other voting members of the jury. The Standing Committee of PARE invited Professor Nemanja Damjanov, rheumatologist and General Secretary of EULAR to join the jury for the first time. “We are all well aware that drugs alone cannot help our patients improve their quality of life. Despite the reduction of disease activity, many patients continue to suffer from pain, fatigue, functional disability and psychological stress. Stress-evoked physiological changes, on the other hand, might have detrimental effects on disease activity. The role of rheumatologists is not only to provide medical care and treatment for their patients, but to help them cope with the physiological challenges of their condition. Stress management is important for improvements in psychological and physical functioning in patients with RMDs. The inspiring stories written by the patients themselves can motivate others to get to grips with the challenges of their condition. These stories reveal patients’ remarkable resilience to endure and to improve their quality of life. As a General Secretary of EULAR I strongly believe that our goal is not only to stimulate, promote and support scientific research, but also to closely cooperate with our patients and thus contribute towards disease prevention and rehabilitation”, said Nemanja.

Alison Kent from the United Kingdom was also enthusiastic about this year’s Stene Prize theme: “This is my second year of serving on the Stene Prize Jury and it has been a real honour to again be involved in this very special competition. This year’s title will raise awareness of the obstacles many face on a daily basis with ‘getting around with a rheumatic disease’; barriers often imposed by society’s attitude to long term conditions. From being able to get around in ones own community to traveling the world such challenges need to be highlighted and the ways in which they can be overcome, shared. This year’s topic, provides insights and some answers for us all and, as Confucius said, it doesn’t matter how slowly you go, so long as you do not stop.”

The EULAR Health Professionals in Rheumatology were represented on the jury, by Jenny de la Torre from Spain, who commented, “One of the main characteristics of many rheumatic diseases is their chronic state. This fact, as well as the unpredictable course of the disease, produces a high level of anxiety, fear and a sense of helplessness in many people with RMDs. As a nurse, I would say that a great deal of our efforts go into empowering patients and providing them with the tools to become more independent, by increasing their self-management skills and aptitude to be self-sufficient. In these 2012 Stene Prize essays we have the opportunity to read many wonderful stories. This is one of the reasons why I have so enjoyed being part of the jury.”

Also being part of the Stene Prize Jury for the second time was Fatima Lavoll from Norway, representing the Norsk Revmatikerforbund. “Many of us with a rheumatic disease have challenges in getting around in daily life. But most of us are good at finding coping strategies. Some of the strategies are good, but sometimes we just push ourselves too far. The topic is very relevant. It was really interesting and inspiring to read this year’s essays about how people overcome their challenges and are managing their daily lives.”

After the great success of the first three Stene Prize booklets and the high quality of the 2012 contributions, it was decided to once again publish a selection of entries to share these powerful testimonies with a wider audience. “The Standing Committee of PARE would like to thank all those who contributed to, and supported the 2012 Stene Prize competition and who have made this booklet possible,” says Maria Batziou. Professor Nemanja Damjanov adds, “Reading the essays was an inspiring, moving, sometimes even dramatic experience! I learned a lot. I believe it helped me to be a better rheumatologist. It is a pleasure being the part of this unique project!”

“Reading the essays was an inspiring, moving, sometimes even dramatic experience! I learned a lot. I believe it helped me to be a better rheumatologist.”
An interview with Raija Heimonen, 2012 Stene Prize winner

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

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

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

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

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

Raija is member of the local branch of the Finnish Rheumatism Association.

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

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

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

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

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

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

Raija: Good question! Having a large family was not easy and automatic for me and my husband. We were married for 10 years before we had our first son. Two years later we adopted a daughter. And two years after that we were happy and surprised to have another son. So one day I found myself the mother of three children, all under school age!

Maybe the time spent hoping and waiting to have children gave me the right attitude and preparation for an active, lively, noisy, busy, colourful family life. I have learned to organise things. I don’t demand too high level of housework. I prioritise my work, housework, children’s needs and hobbies, and my own time. Many of the household tasks and children’s activities are shared with my husband and sometimes grandparents also give us a helping hand with our everyday life.

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

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

Raija: Living abroad has given me a perspective on my own country. I see that nowadays the standard of healthcare is high in most countries in Europe. Also, patients are much more informed about their diseases and medical treatments because of all the easily accessible sources of information. But I think that one of the most important things for a person who is diagnosed with a difficult disease is being able to communicate in your mother tongue. I can understand medical facts and ask questions in a foreign language, but I can only express my feelings perfectly in my native language. And faced with serious, chronic diseases, patients are full of feelings: fear, disbelief, despair, hate, anger.

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

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

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

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

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

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

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

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

On normal workdays the wrestling match begins when the gong sounds. Even before opening my eyes, I appraise my opponents. I circle my ankle, flex my knee and raise my shoulders. Being an early bird, Mr Rheumatism is always ready for battle. The ankle hurts, my big toe aches and the knees and shoulders feel stiff. I ease my eyelids open and note that my Swedish opponent, Mr Sjögren’s, is also ready and waiting. My eyes feel like sandpaper.

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

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

I walk to work in my wide-fitting, soft-soled shoes. The distance is just under a kilometre. If I was a wrestler competing at national level, I am sure I would have a sponsor who would provide me with the appropriate wrestling footwear. As it is, I have to dig deep to buy shoes which let me compete at all. Fortunately, I have managed to locate a couple of manufacturers who make suitable shoes. As in many sports, the outfits and accessories are not particularly elegant. I have had to give up shoulder bags, and instead have resorted to the type of bag which can be carried in your hand or in the crock of your arm. As long as you remember to switch the bag at regular intervals, adopting a certain rhythm – right hand, right forearm, left hand, left forearm, and so on – fingers and elbows have no time to tense up. In my sport, as in so many others, the right gear makes all the difference. There is no point in gripping an umbrella; it only results in an achy elbow and fingers and, if I am unlucky, a sore shoulder too. A light rain mac is the best solution. On the other hand, sometimes as I am aiming for a quick victory over my opponent, with aching legs, screaming shoulder, and fingers in a vice-like grip round shopping bags, rain lashing into my gritty eyes, I nearly get caught up in my coat tails. In such circumstances, the best solution would be the umbrella hat worn by Chinese street sweepers. Unfortunately, my sense of humour has not quite stretched that far yet! Humour is also a useful tool on those mornings when the breakfast meeting starts at 08.00 am, and fit young men sit round the table with their bottles of water and bloodshot eyes, after a night on the town. All this older lady can do is arm herself with down-to-earth humour and join them at the table, with equally red and smarting eyes and with her tongue sticking to the roof of her parched mouth. We open the meeting by taking a collective swig out of our respective water bottles.

Holidays demand attitude. Instead of relaxed leisure activities, wrestling matches are part of the daily programme. It is a shame, but there is no such thing as a holiday from illness. It is, however, novel and refreshing to take on your opponent under a hot sun and on various different tatamis: beach, rainforest, metropolis. There might be a day when I find myself in a darkened hotel room, lying utterly beaten under a cooling ceiling fan, while my travel companion freshens up in the oldest spa in the city. Another day, I find that I have got no further than a pedestrian underpass, just when the city’s famous ‘Noon Cannon’ booms out, with my ably-bodied travel companion already standing next to it. At least I managed to see the smoking cannon.

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

Editors notes on English terminology:
A gong or bell marks the start and finish of a bout of wrestling
Doping is taking drugs to enhance performance
‘Dig deep’ is an English expression meaning dig deep into your pockets to find more money. It can also mean to ‘look hard’ to find something
‘Caught up in my coat tails’ refers to the ends of the coat wrapping around the legs and making it difficult to walk
A tatami is a Japanese mat, used in martial arts as well as the home
How to overcome the challenges of living with a rheumatic disease?

My name is Marlies, I am 18 years old and from Belgium. I am a student and, together with my family, I live in the little town of Oud-Turnhout.

I read about the Stene Prize in the ReumaNet e-newsletter. With my contribution I hope to inspire others with practical solutions to living and dealing with rheumatic and musculoskeletal diseases. Maybe I can give some support to others so they will look into the future with more optimism. I also think there needs to be more awareness that rheumatic diseases also affect young people. I hope my story can help to end the myth that rheumatic diseases are only a problem when you are old and to draw attention to juvenile spondylarthropathy.

I am also working on a book explaining how my disease affects my daily life. This is my way of coping with it and letting others (especially young people) know that you can still enjoy life, despite the pain.

“My aim? To find ways of coping with my juvenile rheumatism - and I’ve done it!”

Getting up is the first challenge of the day. Whenever the alarm sounds, I feel I could go on sleeping for hours. Also, in the mornings the stiffness in my body has the upper hand and I feel like an old woman of 80.

A year ago, I got over it and managed to crawl on to a bike. Now I go to school every day and I can honestly say that no one has made any comments about it. By buying an electric bike, I finally got my freedom...
back and I’m still on the move. For a year, everyone could overtake me, even elderly people, but now I am catching up. You cannot imagine what a marvellous feeling that is!

Being in school was still something of a challenge. It is anything but pleasant to sit for hours on a wooden chair when your lower back is inflamed. One solution is to walk round the playground to loosen up your back again every time there is a break. To counteract fatigue in the classroom you can go and lie down flat with your head on a bench. It is not exactly the most ergonomic position, but it is ideal for a little nap, with the additional advantage that you are not asked to read out any text or to answer a question.

Exams are certainly a challenge for an adolescent with juvenile rheumatism! But you can tackle this problem and still learn all the necessary information by studying lying in bed with your back and neck relaxed. Perhaps this should even be considered as a new way of learning, because I always get good marks!

Of course, going to school is not the only thing you do as an adolescent. Shopping is something that every girl likes, and I am no exception. Yet shopping is quite a challenge when you have rheumatism! Walking down a long shopping street, looking at clothes and then not finding anything that fits me takes tremendous energy. One solution is to send your mother off to see if there are any nice clothes in the shops, but she must, of course, have great taste in clothes! This way, you don’t have to walk along the whole shopping street, because you already know which shops to go to. It’s also convenient if you can park near to the shops. This also saves you a lot of pain in the knees and Achilles tendons. When you are trying clothes on, it is important that the shop has something to sit on in the fitting room. This way you can try on the clothes while sitting down and that is much easier for me!

“Shopping is something that every girl likes, and I am no exception. Yet shopping is quite a challenge when you have rheumatism!”

Going out is always a challenge. It actually took me two years before I dared to go out.

My friends suggested I should drink alcohol to feel less pain, but they obviously had not considered the amount of medication I have to take and that it is not advisable to drink alcohol with it. So that was no solution. What really works well is to try not to dance too much and to rest for the remainder of the weekend. If I keep to this, I can occasionally manage to go out with friends, which makes me very happy!

“What really works well is to try not to dance too much and to rest for the remainder of the weekend.”

Another challenge is to keep my back supple and mobile. This is certainly not easy when you are always in pain. After two years I dared to play table tennis again. You see, before my diagnosis I was a keen table tennis player, but now I am no longer able to move round the table very well, so instead I use my reflexes. Because of my quick reflexes, I can return one ball after another without having to make much effort. In fact, I make my opponent run from pillar to post and I hardly need to move at all!

Living with a juvenile rheumatic disease is certainly not easy and I still have many challenges to face. Yet I have learned not to be resigned to my illness, but to fight it. You should try to find a balance between your activities and the rest that your body needs. And the most important thing of all - you MUST enjoy every day of your life, because even with rheumatism your life looks great!

“Yet I have learned not to be resigned to my illness, but to fight it.”

Editors notes on English terminology:
The upper hand – has the advantage
A piece of cake – really easy
Overcoming the challenges of getting around with a rheumatic disease

Julie van Wambeke
Belgium Wallonia

My name is Julie, I am 30 years old and, together with my longtime and wonderful partner, I live in the town of Tournai in Belgium. I teach maths and French and am a professional secretary.

Currently we are very busy as we are building our house and will hopefully move in later on this year. In one or two years we would also love to start a family and have children to fill the house with life.

I learnt about the Stene Prize through “Le lien”, the Belgian Lupus Association's newsletter. I wanted to take part because I like writing and the subject “made me smile”. I was diagnosed with lupus erythematoses in 2003, but I am happy to say that I have now taken my life back into my own hands.

‘Overcoming the challenges of getting around with a rheumatic disease.’ I wouldn’t have described it like that. I would have opted for, ‘How to choose your method of getting around?’ or, for perfectionists, ‘Which way of getting around best suits your needs?’ or, for the undecided, ‘How to try out different ways of getting around during the course of your life?’ Ultimately, something like that…

From a purely practical perspective, I very often manage to get around. My grandmother always used to say, “If you have a tongue in your head, you can go anywhere.” She probably meant that if you can ask your way around, you can go wherever you want. She was in no doubt that this would work just as well if she was merely asking for help to clamber aboard a train, a plane or car! Even to climb up onto a motorbike, and why not?

The real challenge is to dare. Daring to ask, daring to have confidence, daring to accept, daring to want to be surprised. Daring to surpass yourself. Daring to feel capable.

“If you dare, you’ve already succeeded.”

Reading is a means of transport which is modern and ecological – on recycled paper, naturally! By its nature, it provides a good alternative to resting, which is sometimes enforced, sometimes wished for. It is passive and low energy!

For a start, off the top of my head, I could mention walking beside Jean-Baptiste Grenouille, the celebrated Parisian Nose, or with Arthur Rimbaud. Or taking the train and boat to complete a trip around the world in 80 days, as well as travelling with the same author to dive to 20,000 leagues under the sea in a superb submarine. Not forgetting a little trip in a rocket in good company – someone with a bright future, thanks to Spielberg!
I’ve been all over the world on horseback, on a sledge, on the back of a camel, by tricycle, by steamship, on a flying carpet, even by teleportation, thanks to a wizard friend. I also remember having time travelled with ‘Sophie’s World’. However, I still haven’t found my preferred means of transport.

“Ultimately, all you need to do is let yourself go, on the whim of the wind, or as your wishes or mood take you!”

To be honest, the question now is to choose which book or which author in my library is going to take me for an outing! Ultimately, all you need to do is let yourself go, on the whim of the wind, or as your wishes or mood take you!

While I was engaging in these travels, the first line of a poem came to my mind, ‘Freedom, I write your name.’ It’s while catching my breath in mid-sigh that these ideas come to me, ‘Escape, I live through your words.’

Then in the evening, weary of turning the pages and pretending to be tired, I let myself be lifted up into the protective arms of my Prince Charming, as it were, who carries me off to the land of dreams with an unsteady step (even though I only weigh a few kilos and am as light as a feather!). Of course, he is my preferred form of transport!

“I’ve overcome the challenge – all these sensations spin around in my head!”

“While I was engaging in these travels, the first line of a poem came to my mind, ‘Freedom, I write your name’. It’s while catching my breath in mid-sigh that these ideas come to me, ‘Escape, I live through your words’.”
I have lived in the Dragalevski Monastery since 1997. The monastery is located at the foot of the Vitosha Mountain in Sofia. I graduated in theology at the University of Sofia and after my graduation I lectured on religion in several high schools. My parents were actors and I am very sad to say that they are unfortunately no longer with us today.

I have various daily responsibilities in the monastery as it is one of the most visited places in Sofia and in Bulgaria overall. To do my job well I need to be physically active. I am happy that I found wonderful friends in the Bulgarian Ankylosing Spondylitis Patient Society and the Organisation for Patients with Rheumatic Diseases. Together we work to improve the quality of life of people with our problems.

I was 23 when I started to feel searing pains in my spine and legs. I never suspected that one day I could become stiff and crooked like a Japanese bonsai, or that something so natural – movement – would turn into such a trial. The pain that developed and took me over seemed unnatural, impossible, unreal!

Ever since I was a little girl, I was always full of beans and soon developed an enthusiasm for different sports, including swimming, volleyball, table tennis, badminton and ice skating. I was quick to master the mechanics of movement, and was always trying out new ways to keep my balance and get faster. The onset of my disease coincided with my life decision to take my vows at a monastery on Vitosha Mountain, not far from Sofia. There is no public transport to the monastery, and the rare buses in that direction stop far away. I often had to walk down from the village and back because my elderly father remained living alone in the city. I liked to bring him pure spring water from the monastery, but the pain in my spine worsened. Although I had to stop taking my heavy backpack with me, I still went down the mountain. The pain made me start to faint – whenever I tried to hurry, I would suddenly collapse to the ground and cry helplessly. The doctors prescribed physiotherapy, radiotherapy and medication. I chose a sanatorium near the monastery and asked to be an out-patient so that I could carry on with my work, but I had overestimated my strength. Although the monastery was an hour’s walk from the sanatorium, it would take me much longer. Alone on the mountain, gasping from pain, I would carry on agonisingly and slowly. The treatment made me feel better and when it was over, something clicked and I regained control over my legs. Walking was still painful, but I was no longer falling over!

I don’t know much about plants, but I admire beautiful gardens where different flowers bloom and change with the seasons. I never imagined I could tend to them myself, but now nurturing flowers is part of my life – raking pebbles out of the soil, fertilising, watering and weeding. Having to tend to plants has helped me achieve the impossible – to ‘treat’ myself by forgetting about me. They have taught me a new inner experience and beauty.

The treatment made me feel better and when it was over, something clicked and I regained control over my legs.”
terraces. We would remove stones in buckets, and use a wheelbarrow to bring new, rich soil from the forest and sand to make the soil viable. I wore a corset to support my lower back. It was painful, but I wasn’t giving up! At the time I somehow sensed that this was my only therapy. In my thoughts I associated the rotting compost and manure we carried with my pain; it may be nasty, horrible stuff to handle, but it helps the flowers grow and give off their fragrance. The pain fed my willpower and taught me perseverance and patience, but it also often made me irritable and rude to people. After such episodes, I realised the strength of the inner hurt I was causing others and that I had no right to take my pain out on them. From dealing with the ‘rotten manure of pain’ I had accumulated over the years, I learned that suffering, grief and fear confuse you, and make you rude and irritable. But I could and had to change this and learn to persist and even to smile! I gradually realised that overcoming the hardest and most problematic moments in my life had come from the ‘rotten manure’, which had nourished my character and willpower and taught me to appreciate the little things in life; it opened my senses to see and empathise with the pain of others.

“The pain fed my willpower and taught me perseverance and patience, but it also often made me irritable and rude to people.”

Years later, because of recurring eye infections – iridocyclitis – I found out my real diagnosis – ankylosing spondylitis. Some doctors convincingly rejected my diagnosis. This confused me, but by now we had the Internet at the monastery and I logged onto medical websites with forums and discussions for patients with rheumatic conditions. I read a great deal and was convinced that what I had experienced over the years corresponded precisely with the symptoms of ankylosing spondylitis. Unexpectedly, in the midst of the pain, the gloomy prognosis of the disease and the ‘rotten manure’, I also found beauty: instead of flowers I found people who, like me, were suffering from the disease, but wanted to share their time and compassion to support others, and to improve their ability to access treatments. Out of the pain and the ‘nourishing manure’ in my soul arose gratitude and the belief that my suffering has not been in vain. I saw another side to life and realised that there are others who, like me, do not give up but carry on struggling on a daily basis, giving their all to help others and to nurture their spiritual beauty and fragrance, just like flowers.

“Out of the pain and the ‘nourishing manure’ in my soul arose gratitude and the belief that my suffering has not been in vain.”

Editors notes on English terminology:
Full of beans – lively, always running and jumping about
Compost – organic matter left to rot and then used to fertilise soil
Manure – animal dung used to fertilise and enrich soil
Living with a rheumatic disease and facing the challenges of mobility

“I’m going to Barcelona.” This announcement really took my loved ones by surprise. Their faces — pictures of intense emotional distress — reminded me of Edvard Munch’s painting of ‘The Scream’. Seeing their tragic-comical reaction, I didn’t know whether to laugh or cry. I decided to wait for them to find their voices again and was then inundated by their questions and concerns.

“When? How? Have you thought this through? You are still recovering from a serious fracture to your femur bone and a major operation. After seven months of inactivity you have only just managed to get back on your feet and you know perfectly well that this severe, debilitating rheumatoid arthritis (RA) you have developed makes everything even harder. Your muscles are very weak and you don’t have good balance. You have already undergone 18 to 20 operations. We have literally lost count and we don’t want you putting yourself at risk again so soon by taking a trip like this. We know you love travelling, but you’re just not facing the facts. You should postpone your trip until next year. That will give you time to recover your strength.”

I looked at them all, one after the other, and responded calmly to their avalanche of questions.

“Of course, some of my plans have changed, but I want to live in the present, as much as I can.”

“I am leaving with Angelika in two weeks time. We have been planning this trip since last year when we went to Italy. An accident won’t stop me from travelling. Of course, some of my plans have changed, but I want to live in the present, as much as I can. Each year my arthritis makes it harder for me to move around. I can adapt my trip depending on how I’m feeling at the time. This is what my RA has taught me to do for the past 40 years. I adjust my plans, I don’t change my targets. I can do the whole trip in a wheelchair. After all, Angelika is my physiotherapist and she knows just how to deal with my situation.”

“I adjust my plans, I don’t change my targets.”

I went online and looked for an accessible hotel with facilities for people with disabilities, and checked the location to see if it would be easy for me to move around. Next to the hotel there is a large shopping mall with many shops and restaurants – I could even walk there. I found a “hop on-hop off” bus tour with buses that are accessible to people in wheelchairs. There’s a stop outside the hotel and the buses
stop right outside the different sites of interest, so it won't cause us any hassle. The numerous problems caused by my RA have made me realise I can no longer follow an organised tour group on these trips, but I find these buses very convenient. They are ideal for people with rheumatic diseases, as well as other disorders or disabilities. You can choose the sights that interest you the most, so you don't end up wasting your energy on seeing places that do not interest you. You can take your time to enjoy them and if you feel tired you can stay on the bus and just sight-see or go to a café to enjoy a cup of coffee or a nice meal, get some rest and then continue on afterwards.

“Think about it this way. My emotional state will improve, it will boost my morale. Having spent seven months indoors and in a bed, I think I deserve a change.”

Then their faces calmed down and they decided to keep any doubts they might still have to themselves.

And here I am now, three months after my wonderful trip, driving my own car and going to work. I am glad that I’ve made it through another year, and I have done it with a positive attitude towards everything. My body may hurt, the steering wheel may feel heavy, but holding it I feel I have my independence in my own hands again. I won't deny that I had to find someone to help me up stairs, cross the road, or just hold my hand going through life.

this year I have again managed to deal with the enormous challenge of my mobility.

I looked to my right and saw the small church in front of my workplace. Thank you, I whispered, I suddenly felt an overwhelming desire bubbling up inside me to give thanks for the unfailing love so generously offered to me by this invisible energy known as God, which gives me the strength to go on with my battle.

“I feel that this year I have again managed to deal with the enormous challenge of my mobility.”

In the afternoon, I rest and then arrange to go to a shopping mall with some of my friends. Here I can park my car in a space designated for people with disabilities, near the underground entrance and very close to my favourite stores. This means that I don’t have to walk very far and won't be exposed to the weather outside, which could make it harder for me to move around. As the years go by and my condition deteriorates, I usually choose places that provide me with both services and entertainment. In shopping malls there are many shops I like and favourite stores. This means that I can enjoy a variety of services without having to go very far. I usually opt for days when it's not very busy, so I won’t have to deal with queuing and, possibly, being jostled by the crowd. At nights, when I go out with friends, we usually go to restaurants or theatres and cinemas with easy access for me. And when my arthritis makes me feel exhausted, I do my shopping online or choose what I want from catalogues without the bother of going to shops. I watch a bit of television, read books, listen to music, or invite friends over to keep me company in my small, one-level flat. My flat has been ergonomically designed and comes with a ‘walk-in shower’ for easy access and an ‘electronic bidet’ for personal hygiene and cleanliness. The place is flooded with light and has many windows with views of the sky!!!

Over the years, I have learnt to move around using every kind of transport: cars, buses, taxis, crutches, or a wheelchair. There’s always a hand for me to hold on to, or someone to give me a loving hug, and this helps me go on. But I never stop. I just keep on going, on, and on on...

“But I never stop. I just keep on going, on, and on and on...”
My name is Maya and I am 32 years old. Together with my lovely two year old daughter, Freya, I live in Aarhus, which, after 12 years of living here, I now consider to be my second home, having originally come from Kolding. I am a clinical dietician, but I am not working at the moment. I read about the Stene Prize, in the magazine ‘LedSager’ which is edited by ‘Gigtforeningen’, the Danish Rheumatism Association. I chose to participate in the contest because my mother told me I had better write an essay about my situation, since it has recently become extremely difficult and challenging for me to get out and about. I wrote it thinking that in any case it would be good for me to think and write about the subject, if not to win the contest, then just to work it through and clarify it in my own mind.

I’m sitting here with an old Lonely Planet guide, which I took with me when I went off travelling. I was 19 years old then and ready for the world, because I could handle anything.

I never opened the book while I was away. When I came home again, I discovered that each chapter in the book had a section entitled: ‘Getting there and getting around’. It seems funny now, many years later, to think it was only when I came home as a 20-year-old – returning with arthritis as part of my baggage - that it was just this section that I really needed. For it suddenly became very difficult to get around in life. Unfortunately, the section only covers things you can easily find out by asking people on the street, such as which bus to catch, while it leaves out what is most important for me, such as how do I get to the bus? And on it? And off it?

Tomorrow, New Year’s Eve, is my birthday, when we wave goodbye to the old year. It’s time to take stock! My arthritis and I have now been together for 12 years; in other words, I have had plenty of time to find out for myself what should be included in my section on “Getting there and getting around”. In my section, bikes play a key role!

Back then I was very badly affected and had swollen knees, from which one could easily extract 25 ml of fluid. I was also cycling at that time. I sat on the luggage carrier of my recumbent bike and pedalled away defiantly, because movement had become extremely important to me, but could never be taken for granted.

“It was great that it was an entirely ordinary bike, so I looked like an entirely ordinary person and not someone who had a chronic disease.”

The bike has taken me far and wide - to school, to dancing, to the rheumatology outpatients’ clinics. To parties, into the forest, to see my case worker, and on cycling holidays in many other parts of Denmark. At the same time, it has ensured that I have kept in shape and got out into the fresh air. It is my daily exercise equipment, but I don’t ever think that I’m using it for training, because it is also my number one means of transport.

I am the single mother of a wonderfully healthy and spirited two-year-old girl, but it has been a huge challenge to get around with her, because suddenly there were twice as many feet that couldn’t walk very well and, indeed, twice as many wills dictating where we should go! It was hopeless to start with, when she was six months old and going to and from day-care. I couldn’t really take the bus with her, because I couldn’t carry her all the way to the bus, she couldn’t walk by herself, and I couldn’t get the pram on or off the bus, so I had to ask others to carry it – and her.
Neither could I travel the four kilometres to the day-care with her and four kilometres home again with the pram, sometimes in the snow, and then to have to cover the same distance again later in the day when she had to be collected. I didn’t have a car, because I couldn’t afford it. Driving also makes my knees swell up because of the constant tension around the joint from putting pressure on the accelerator, brake or clutch.

I still had my good old bike, but on a bad day with arthritis in my knees, feet and hands – and I had a lot of those days – I couldn’t balance safely when setting off at the kerb or the road with my daughter in the child seat on the back, or balance the bike while I fastened her in. But good advice was expensive – literally, as it would turn out.

My lovely doctor came up with the suggestion that I should apply for a grant from the local authority for a delivery bike. A three-wheeled bike with a box on the front that is stable, doesn’t overturn easily, and has room for both children and relatively large purchases in the box. Such a bike is hugely expensive, but I managed to buy it when I clubbed together with the local authority.

As I sit on the saddle and control the pedals and the throttle, my daughter sits on a bench at the front with a safety harness and her smart red cycle helmet, holding her cuddly toys whilst ensuring the little windmill on the box is still spinning. Since my beautiful Christiania bike has an electric motor, which can be turned on and off, while you pedal yourself or rest, it provides us with wonderful freedom!

“We can go to the beach in summer or take a packed lunch to the woods.”

Most importantly, I can now transport my daughter to and from the day nursery easily without overdrawing on my pain account. We can cycle out to visit friends and easily take along everything we need for an overnight stay. Or we can cycle into town and throw the stroller into the cargo box. The stroller is incredibly easy to fold up - I can do it by myself with one hand. We can go to the beach in summer or take a packed lunch to the woods. In winter it has worked as a snow clearer on the cycle paths, with the truck body doing the rough work in places where the snow is deep. We have been on cycling tours with our neighbour’s boy and my daughter. When she turned two my bike was decked out with flags like a state coach, and it has transported us to everything from christenings to samba practice.

I plan to get a mattress specially made for the bottom of the box, so my daughter can take her nap in it in the summer when we are on a cycling holiday together. For we will be able to do this now I have found the right information for my section on ‘Getting there and getting around’.

“Most importantly, I can now transport my daughter to and from the day nursery easily without overdrawing on my pain account.”
Overcoming the challenges of getting around with a musculoskeletal disease

When I was 24 years old, I sustained an injury whilst practising handball, my favourite sport, and this meant that over the course of the next four years my right knee had to be operated on not once, or twice but three times.

The main reason was a lesion on the joint cartilage, which did not heal well. As if that wasn’t enough, the medial meniscus also needed to be removed. High-level competition came to an abrupt end and with it my dreams crumbled and I was faced with a seemingly unimaginable challenge. There were months and then years of physical and psychological adaptation. As someone who was seen as a tomboy with a degree in physical education, my days of being able to run, jump and pursue risky activities were over.

Without realising it, in addition to the unconditional support of friends and family, it was my father’s experience that proved fundamental to my recovery. Without doubt he has left an unmistakable mark on the way I deal with life. A transfemoral amputee from a young age, and later stricken by hemiplegia, he made a miraculous recovery thanks to his extraordinary willpower and the constant physical exercise he undertook – and always with a smile on his face.

Premature osteoarthritis (OA) of the knee seemed to be my enemy, but they say you should love your enemies. It seemed impossible for OA to become my friend, but it was the right approach to take. Instead of focusing on what I was no longer able to do, I started appreciating almost everything that my knee still allowed me to do. During my daily routine I would enjoy a long hot shower to relax my muscles and reduce the stiffness, and perform joint mobility exercises. Another priority was the stretching to maintain the articular range of motion, and static contractions of the quadriceps muscles – which are responsible for stabilising and cushioning the knee – in order to combat the atrophy triggered by the pain.

Right now I only have a few limitations at home. Apart from climbing up to reach the highest cupboards, I have got used to being less self-sufficient and more accepting about asking my daughter for help, or simply not being able to perform a task. This does not imply weakness, but rather an awareness that my body’s limits have changed. It wasn’t always this way! To start with I felt hurt when people didn’t realise I needed help.

I know I should spare my knee and that trips to the supermarket with a full shopping trolley are not a good idea. I avoid carrying heavy weights, as the pain soon makes itself felt. The best remedy is to alternate effort with rest, and so when I get home I find the sofa, stretch out my legs and pick up a newspaper or magazine, and take a ‘siesta’ when the fatigue gets too much. But I am finding ways to deal with this situation, which have already made a difference; my husband either takes my place, or orders the supermarket shopping online each month, thereby saving me having to carry it.

I consider myself to be a quiet person, and my husband is also more of a homebody. When we
go out to a restaurant with friends, if necessary, I am dropped off by the door on arrival. On the way back, if the car is nearby I can manage a short walk, but otherwise I am picked up once again. When we go on beach holidays my limitations vanish and I feel like a fish in the water, but this year I wasn’t able to accompany my husband on strolls along the shore. The disease had intensified to the point that the pain wouldn’t leave me.

“When we go on beach holidays my limitations vanish and I feel like a fish in the water...”

I am a teacher at the Faculty of Human Movement Studies, and about two years ago my office was on the ground floor, but then I was forced to move. There were two options for my new office: on the first floor, but with too steep a staircase, or on the third floor in the tower of the old office. I decided to be closer to the sky, but that option meant that I had to reorganise my everyday life, planning the number of ascents and descents I could make each day. I try to take advantage of each descent to carry out several tasks, before going back up again. So when I have to run errands, meet friends or go to a bar, I combine it with lessons that I will have before or after; it’s not two in one, but a ratio of three/four in one. However, my days are not always the same and today my planning failed completely. The place I had to go to closes at midday and it was still too early for lunch. I had to hand in some documents and go up again only to come back down an hour later, and in the afternoon the situation repeated itself. As a result, in addition to pain in the affected knee, I overburdened the other knee, so I haven’t left the sofa since dinner. If it gets really bad, 10 minutes of ice relieves the pain in the swollen knee; other times, if the cold is intense, I heat a bag belonging to Glória, who is also a patient at LPCDR [Portuguese League Against Rheumatic Diseases], which does wonders for joint stiffness. I have also devised strategies for protecting my knee when going up and down stairs, by using it as an opportunity to do functional training, exercising the extensor muscles of the leg. On the way up I ease the burden by holding the bannister with the opposite hand, whereas on the way down my strategy is different: I prolong the weight-bearing on the good limb and only put weight on my bad knee for a second, thus shortening the duration of weight-bearing and avoiding excessive overburdening. This way the pain is silent, or at least hushed.

Knowing that low-impact exercise, muscular strengthening and stretching are essential for treating OA in the knee, I decided to join a gym. I made a deal with myself to prioritise the trips to the gym or the pool two or three times a week. Since the impact of running is unbearable, I do my warm-up on a stationary bicycle without resistance and use machines that target the lower limbs. The secret is to increase the burden of each exercise with the number of repetitions and minimal weight increments (1 to 2.5 kg). Sometimes people wonder why I use such a low weight, but now I’ve got used to that. Another method I’ve adopted is not to leave out a single leg muscle. By strengthening all of them, the stronger ones can take over from the weaker ones around the knee. And the results are apparent!

“Another method I’ve adopted is not to leave out a single leg muscle. By strengthening all of them, the stronger ones can take over from the weaker ones around the knee. And the results are apparent!”

How many times have I asked myself, “why me?”, blaming the Creator for what happened. But after giving it a lot of thought, I had to ask for forgiveness. After all, it was me who chose to play another year, despite the pain I felt and my mother’s warnings. Later, I understood that everything in life has a purpose and that God is good and doesn’t make mistakes. The pain that follows me has gone from suffering to a gift. Looking back I understand that this tribulation has changed the way I am: I have become patient, gained experience and with it I hope to be able to help others in a similar situation. My dream is to leave a legacy to those I work with in exercise and health, to develop educational programmes and to try and encourage people to view and treat those with musculoskeletal diseases with respect and compassion, helping them to face their condition.

“The pain that follows me has gone from suffering to a gift.”
On a beautiful autumn day, my entire existence changed. The dreamy teenager who believed that everything is possible in life if you really want it, found out that there are illnesses that create barriers which are sometimes very difficult to overcome. I, too, was diagnosed with one of these illnesses: rheumatoid arthritis. And then nothing was ever the same again…

Today, twenty years have passed and this illness is part of my life, and I am still fighting the limitations enforced by my condition and society.

Inside my home, I can move about fairly easily, because over time, it has been adapted to my needs. The doors and windows have been changed so they are easier for me to open and close, the bed has been raised so I can sit or stand up easily, and the sockets and switches have been moved to a height where I don’t have to bend over or stretch up high to reach them. I place all the objects I need on the middle shelves of my cupboards, again so I don’t have to bend over or stretch up high to reach them, which would be too difficult for me. To increase my independence, I also use a range of tools that are useful when you have reduced mobility, such as a sock aid, or a ‘grabber’ to help me pick up objects from the floor. The only problem I still have is the steps at the entrance. I try to go up and down these steps in places where I can support myself on something, or I use crutches. Apart from this, I would say I am independent in my home.

However, things become more complicated if I want to leave home and go anywhere. Why? Because I live in the countryside and the roads here are covered with gravel, not asphalt. This means, I can’t leave the yard alone because of the condition of the roads. I just don’t have the confidence to go out on my own on roads like this. I can’t go to the nearest shop to buy anything by myself, and I can’t visit anyone on my own. Making my way to the doctor’s surgery is out of the question. It is two kilometres away from my house, which is much too far for my physical ability.

 sounded made, and the sockets and switches have been moved to a height where I don’t have to bend over or stretch up high to reach them. I place all the objects I need on the middle shelves of my cupboards, again so I don’t have to bend over or stretch up high to reach them.
My computer, connecting me with the outside world

“The nearest bus stop is one kilometre away from my home — one kilometre down an un-made road that I find very difficult to walk on.”

Another major inconvenience is that I can’t use public transport to get to the nearest town, which is 10 km away from my village. The nearest bus stop is one kilometre away from my home — one kilometre down an un-made road that I find very difficult to walk on. And if I manage to walk this kilometre and reach the minibus, I can’t get on because these vehicles are not adapted to the needs of people with reduced mobility; in fact, these minibuses are so high off the ground that even a healthy person finds it difficult to get on and off them. So it is goodbye to any trips on public transport when I want to go shopping, or for a specialist medical consultation, medical examination etc. Therefore, I have to pay someone to take me in a car whenever I want to go into town. Once in town, I cannot walk about by myself because I can’t climb up and down the high kerbs of the pavements, or the steps to various shops and public institutions etc.

A few times a year I do, however, have to use public transport when I have to travel the 200 kilometres to visit the hospital in Bucharest where my condition is assessed and treated. Travelling this distance is a real adventure. I have someone take me by car from home to the nearest bus station, which is 13 kilometres away. Here, I have to be helped up into the minibus that will take me to Bucharest. When I reach the bus station in Bucharest, someone has to help me off the bus, and then I take a taxi to get to the hospital.

I haven’t been able to travel by train for a very long time, for the same reason – they are too high and it is really difficult to get on and off them.

When you suffer from stage four rheumatoid arthritis, life is not exactly easy. Apart from the illness itself, it is very difficult to have a social life. You can’t have a job you go to every day, and you can’t go out to socialise or solve other problems by yourself. Going out with friends has been replaced by internet chats and telephone conversations. These are the main ways in which I keep in touch with friends. We rarely see each other face to face, because they live in different parts of the country.

But then, what is life but a challenge we have to take one step at a time?

“But then, what is life but a challenge we have to take one step at a time?”
How to overcome the challenges of living with a rheumatic disease?

Everyone has to face up to some sort of challenge every now and then – whether it’s getting to school on time, changing a tyre or, as in my case and like so many others who have some kind of disability, trying to live life to the full and on the same terms as the people around you. This is the greatest challenge I have ever taken on and the main reason for all the other trials and tribulations I have faced, which have led me to where I am today.

How do you deal with a challenge like this? Live a full life where you make all your own decisions? Since I have hugely restricted and stiff joints, many of my challenges are and have been of the physical kind: being able to go slalom skiing, compete at athletics, being able to carry my brother when he was a baby, or quite simply being able to go food shopping by myself. I have long since realised that I will always be dependent on help when it comes to certain physical tasks, and I have also accepted this fact. However, it should be up to me to decide when I want help, how I want to be helped, with what, and who I want to help me. Although many of my challenges today are of a physical nature, the psychological aspect is a large part of this. It is in my head that the journey towards independence starts. I must make the decision to work on overcoming my disabilities. I am the only one who knows what my dreams are and what I want.

“I’m often told that I have incredible mental strength or, as my family proudly expresses it, ‘You are so stubborn!’.”

I’m often told that I have incredible mental strength or, as my family proudly expresses it, “You are so stubborn!”. I have never been that. I have experienced many dark hours, such as when I was eight years old and went through a period in my illness when I stopped walking and had to start using my wheelchair all the time. Not forgetting the usual insecurities you experience when you’re growing up, regardless of whether you have a disability or not. I got through those days, sometimes months, with the help of people around me: friends and family, who always see me as the person I am, not just a disabled person with a diagnosis.

Many people say that I am an impulsive person and I agree with them, but it’s not always easy to be impulsive when you’re wheelchair-bound and also suffer from rheumatism, with good and bad days. If I’m honest, there are some days when you just want to lie on the sofa and watch TV, because then you get to feel...
‘normal’, like a completely healthy person, to have an hour when you aren’t thinking about an aching knee or a back that has seized up again. That is when it is good to have an outgoing personality that makes it easy to acquire friends that are just as impulsive and ingenious as you are, and to have a fantastic family that provides support and has taught you that nothing is impossible. Naturally all these people around you notice when you are having a bad day, but that is when their imagination, inventiveness and humour are most valuable. Friends who help you to forget that aching knee or rigid back just by being there and being themselves, friends that let you trail along with them on an adventure halfway across the globe, friends that lug and carry you when there are stairs in the way, the lift doesn’t work or we simply want to sit in the middle of the cinema instead of where the wheelchairs go.

My family – especially my Dad – has always supported me and come up with new and sometimes slightly different solutions. Like the time when I wanted to play hockey with my younger brother and my Dad put on his skates, then mine, got hold of me under the arms, let me stand up as much as I could and then took us out onto the ice. Or the time I wanted to start slalom skiing but had stopped walking altogether and just couldn’t stand up. A little while after we were at a camp where I discovered one of my great passions and a real drug for a speed addict like me, skiing. Or when we had sports days at school and my Dad took the day off work to take me out into the woods with my assistant and friends so that I could be involved too. My family is the reason why I now have so many ideas about how to solve physical problems, so it is always possible to participate.

I like to say that I can achieve the same goals as my friends and do everything that they can do.

I could write about the practicalities that help me manage my everyday life with the help of wheelchairs, ‘grabbers’, power wheelchairs and other inventions that provide physical assistance, but what use are all these things if I don’t have the imagination and mental force to use them in new, innovative ways to improve my life? It is my imagination, my ideas and my mental strength that have driven me to break down all the ‘impossible’ barriers so far.

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This is my story. This is me, Frida, 22 years old, with juvenile dermatomyositis and weighing 30 kilos. I live in my own apartment, I have a job, I have swum 500 metres, even though I can’t float, I have played football and hockey, even though I can’t walk, I have travelled to Greece by myself, I ride my own snow scooter in winter, I have competed in athletics in the Stockholm Stadium and won a gold medal, I have stood on stage as a singer, I have somersaulted in my wheelchair, I’ve cut wood with an axe, I’ve jumped on snowboard slopes in my ski cart, I fought with my brother when we were younger, I’ve been on TV, I did better than many of my able-bodied friends in school sports, I have bet myself that I should be able to do everything that my friends can do. I have decided to live my life to the full and I am doing it. I have never given up and never will give up, and it is with this attitude that I overcome my disabilities and challenges. I’m living my life to the full – are you?

“I’m living my life to the full – are you?”

“I like to say that I can achieve the same goals as my friends and do everything that they can do.”

“I’m living my life to the full – are you?”

“It is my imagination, my ideas and my mental strength that have driven me to break down all the ‘impossible’ barriers so far.”
Overcoming the challenges of getting around with a rheumatic or musculoskeletal disease

David Lewis
United Kingdom
I was born in Birmingham 29 years ago and still live there today together with my parents and my two younger sisters.

Having obtained a degree in Media and Communication, my full time working positions have included working for the Birmingham City Council and as a researcher for BBC WM (a local radio station). I do still work there on a casual / freelance basis, but not full time due to my health.

I do a lot of campaign work with various arthritis charities to raise awareness of the condition, especially in young people, and I would like to begin a young person’s arthritis support group in the West Midlands.

In my spare time I am a sports fanatic, but my sporting interests do not stop at watching, as for the last four years I have played Powerchair football for Sporting Club Albion. I am now the captain of the ‘B’ team and we are in the top division of the WFA (Wheelchair Football Association) National League structure along with the club’s ‘A’ team. An ambition of mine is to be selected for the WFA England Squad, which reached the final of the World Cup last year.

I have lost count of the times someone has said to me, “I could do with one of those electric wheelchairs”, as they walk seemingly without difficulty. My response, depending on my mood at the time, is usually along the lines of, “you can have my wheelchair, if I can have your legs”.

Sure they are trying to have a laugh when they say these things and I like a joke more than anybody else as people will testify, but that doesn’t stop it being annoying. Little do they realise the circumstances that have led me to my four wheeled friend. I am in a wheelchair out of necessity and not out of choice. I don’t enjoy being stared at and overhearing loud whispers of “look at that little man”. Nowadays I have learnt to deal with it in a different and more comfortable way and get on with my own life.

Since being diagnosed with systemic onset juvenile idiopathic arthritis in 1985, aged two, I have continuously battled with the condition which has led me to overcoming and adapting to new ways of getting around. At just four foot five inches tall and with over 30 operations to my name with every scar telling a different story, the condition has been extremely aggressive and the damage caused throughout my body has been relentless.

 Having a full time disability is tiring as my body is constantly attacking itself, I will never forget when my surgeon said to me, “you are unbelievably good at dissolving your own bone”. This has led to the total replacement of both knees and hips as a teenager because of eroded and exceptionally painful joints. In 2011 alone I have had a hip revision due to dislocation and my ankle fused and re-aligned due to severe damage and deformity of the joint. Other major surgery includes spinal fusion and removal of an infected large bowel.

With a whole cocktail of medications and treatments to speak of, plus endless visits to the hospital for hydrotherapy and outpatient appointments, the hardest question to answer is how do you cope, or overcome living with your condition?

“It’s only pain and I find it will only get worse the less you do and more you think about it, although admittedly this is easier said than done!”

A strong positive attitude, a sense of humour with the ability to laugh in a self-accepting way is a necessity for me. Getting out of bed in the morning with terrible pain is the hardest thing to do, but it’s important to have the self-motivation and the dynamism for life to make that seemingly giant leap. It’s only pain and I find it will only get worse the less you do and more you think about it, although admittedly this is easier said than done!

Whilst I have never been the most active and athletic person in the
world, I have always striven to maintain the best mobility I can which consisted of varied short distance walking styles around my home, using my stair lift to go to my room upstairs and using my electric wheelchair for outdoor adventures.

However in May 2009 I had a fall and broke my right femur and subsequently spent a bed ridden nine months in traction and a total of 355 days in hospital. This provided me with little benefit, the bones have never healed and I now live with a broken leg which causes me immense pain and discomfort.

“One of my best achievements was learning to drive over seven years ago.”

Every waking minute is now spent on four wheels in my electric wheelchair and many alterations have been made to accommodate my decline in mobility although the house I live in with my parents has always been modified to my changing needs. I have said an emotional farewell to the stair lift and I now live on the ground floor after an extension was built with a fully accessible downstairs bathroom enabling me to manage independently.

One of my best achievements was learning to drive over seven years ago. I am the proud owner of a fully adapted car which gives me my freedom and independence to go anywhere and do anything. Together with my wheelchair these modes of transport take me to work, to see friends, to hospital appointments and to my hobbies which mainly involve sport.

Voluntary work is a big interest in terms of raising awareness for young people with health conditions and using my experiences to give something back to improve services. I also undertake campaign work for various arthritis charities and I am part of numerous patient groups within hospitals, where I attend regular meetings.

Despite missing a lot of time from my education, I managed to achieve my grades and I obtained my degree at university. Since leaving university I have had some excellent full time jobs but unfortunately I can now only work part time due to pain and tiredness that sets in, although even my part time work has been interrupted this year because of various health issues and two-weekly trips to the hospital.

As a sports fanatic I regularly go and watch sport including football and cricket but my biggest enjoyment is playing Powerchair football. Playing competitive sport has always been a dream rather than a reality due to my upper and lower body being so badly damaged, but Powerchair football enables me to do this at a level that is comfortable for me. Holidays aren’t a frequent occurrence for me due to complex travel and accommodation needs, but my car enables me to go a certain distance. Friends over the years have been invaluable and a night out or night in with them is a common event, the same as anybody else.

“Friends over the years have been invaluable and a night out or night in with them is a common event, the same as anybody else.”

The impact and the changes since my fall a few years ago have been dramatic with my mobility at present being no more than a few supported steps. Remembering what I used to be able to do in terms of walking short distances, makes not walking at all even more frustrating. Although I found it very difficult at first to adjust to a huge difference in lifestyle, I have learnt to accept my new way of life.

Although it’s taken a while, I now do most things I did before my fall. The difference is I do them in a different way with even the simplest of tasks taking a lot longer. Although there have been many changes over the years, one feature does remain as consistent as ever and that’s the magnificent support I get from my parents and sisters, I wouldn’t be half the person I am today without their endless support.

Even though my condition is currently controlled, I have a lot of long term damage which will remain even if the arthritis went tomorrow. It is highly likely that I will live the rest of my life in a wheelchair and I have no fears in saying that. I am of the mindset that life must be lived, no matter how, by embracing and adapting to changes and moving forward.

The truth is I probably wouldn’t swap my wheelchair for the average person’s legs as I am who I am and that is largely born out of my experiences with my arthritis. I have come to realise over the years that although I am in a wheelchair it enables me to be an independent person, my wheels are my legs.

“...one feature does remain as consistent as ever and that’s the magnificent support I get from my parents and sisters, I wouldn’t be half the person I am today without their endless support.”