



Litsa



Florence 2010 with colleagues



Celebrating my name day with friends



**Litsa Kyriakides
Cyprus**

My name is Litsa Kyriakides, I am 51 and I am from Cyprus, living in the town of Nicosia. I learned about the Stene Prize from The Cyprus League Against Rheumatism and also from the information on the EULAR website. I chose to participate in the essay contest mainly because I wanted to encourage people never to give up on 'staying alive'.

With this essay, I actually wanted to motivate and inspire people to participate in every part of life and to share the joys of life with other people. By 'overcoming the challenges of getting around with a rheumatic or musculoskeletal disease' you become a champion. In my case, although I have suffered from severe rheumatoid arthritis for more than forty years, I have had a full time job for 26 years, I am a volunteer with two N.G.O.s and I have traveled all over the world (Africa, America, Australia, Europe, Middle-East, Hong Kong, China, Bangkok), sometimes in a wheelchair. I have a great family with two excellent parents, and many wonderful friends and colleagues.

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



Christmas 2010 in the hospital with colleagues & friends



Barcelona August 2011

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 give that daring decision some serious thought. But I won. I enjoyed the trip, even if I had to do it in a wheelchair. I feel that

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 unflinching love so generously offered to me by this invisible energy known as God, which gives me the strength to go on with my battle.

"Asking for help is not something one should be ashamed of."

I entered the place where I have worked for the past 26 years. I parked my car in the space my employers gave me five years ago, when I started having difficulties walking, to make it easier for me to move around. It is very close to the entrance of the building and not very far from my office. Since I came back to work after my accident, my colleagues are always happy to help me out of the car and escort me to my office, as I'm not yet strong enough. Asking for help is not something one should be ashamed of, especially when it is from people who love you. You may find it surprising, but I always manage to find someone to help me up stairs, cross the road, or just hold my hand going through life.

"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 benches everywhere for me to rest, as well as cafes and cinemas. This means 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 and on...

"But I never stop. I just keep on going, on, and on and on..."