

2021 STENE PRIZE *THIRD PLACE*

PENKA VELKOVA

Bulgaria



I am 45 years old, married and live in Plovdiv in Bulgaria. I am the manager of a personalised gifts studio. I have lupus but I enjoy life, love to dance, travel, and make handmade gifts

I received information about the competition from the Facebook group run by the Organisation of Patients with Rheumatic Diseases in Bulgaria.

This is the second time I have shared my thoughts and impressions on a given topic in EULAR's Edgar Stene Prize competition. I like to express myself and, in the same way, I want to read and learn about the aspirations of other people around the world. This way we can mutually benefit each other with ideas, advice and views on life.

2021 STENE PRIZE - THIRD PLACE ESSAY

Living in the digital world

The sun was caressing me through the window. The curtain was fluttering gently in the wind. It was September 2009: the first time I had regained consciousness of myself after a four-month battle for my life and receiving a lifelong diagnosis of lupus. I was beginning to observe the world again. It seemed the TV was the first object to catch my eye. Then it was the computer. I knew what I wanted. I could feel what I was doing. Facebook was the first thing which would distract my mind from the hospital, the doctors, the tubes. It was a Facebook game that helped me to detach myself from the shocking reality. That was my way to shed my fear.

In those first months of living with lupus, I had no desire to speak whatsoever. I felt like keeping silent; emotions were constantly overflowing. That is why I kept in contact with my few remaining friends using a chat programme. Again and again, I read and reread their comforting words, telling me they would be by my side, that everything would be fine. The funny pictures they sent seemed to add a little colour to my days. I still use Viber. In fact, in the months since the outbreak of the COVID-19 pandemic, this app has been my connection with friends and family, which we use not only to talk but also to see each other. In our live video chats, we enjoy our smiles, we boast in our flower gardens, we make toasts and life just goes on.

It's been 11 years since the beginning of my journey with lupus. I have changed, grown and learnt a lot. Many apps have helped me along the way. I find it is a great advantage to live in the digital world. Digital technology simply complements my lifestyle by making it easier – especially when consulting my doctors remotely. I often use Messenger, email, internet forums and an online booking platform for medical appointments. That is why I think that the idea of using telemedicine platforms, such as Healee, should be more widely implemented by health professionals. This type of contactless doctor-patient consultation saves time, limits physical contact, especially in the current pandemic situation, and allows for the creation of an electronic medical record, which is a great benefit for both parties. I hope that more and more health professionals will start to rely on such digital connections with their patients.

Our country is still lacking a unified eHealth system. In March 2019, we witnessed the relaunch of another scheme, but there are still no results. Yet the digitisation of health information is not just a matter of convenience – its introduction will increase the quality of diagnoses and result in better medical statistics.

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With my health being my priority, I started installing mobile apps on my smartphone to make it easier for me to take care of myself. The pedometer app encourages me to walk more. Sometimes I monitor my heart rate and blood pressure digitally. And the Drink Water smart app reminds me of my daily water intake requirements. I find these apps helpful to develop useful habits through personalised reminders.

I often use workout apps to help me keep fit at home because standard fitness workout plans are a taboo for me due to my health restrictions and joint replacement. My special immune system requires a lot of care and attention, and I have to restrict my contacts with people. That is the reason why I have to do my personal workout at home. Sometimes I feel like shouting out that I want to live a complete life, to grab life with both hands. My disease, however, limits me. Yet, I still keep looking for my own ways to overcome these limitations and enjoy life.

My diagnosis has also forced me to focus on working from home, relying heavily on design and graphic editing applications, such as Canva. I use my imagination to create cards, collages, posters, business cards and banners. This way, I have carved out a career for myself that has allowed me to move forward, feel accomplished and fully engaged.

Since I am constantly trying to rely more on positive emotions, I am extremely happy with the virtual tour apps. When I use them, it takes me only a minute to get to the other side of the world and enjoy hundreds of sights. Such digital tours are a source of relaxation, especially in a pandemic. That is why these pleasing activities have turned into a medicine for my soul, which I take with pleasure every day. I also find it convenient to use a digital shopping assistant. It helps me keep track of the current deals and products on sale, I can make a shopping list and, sometimes, I come across interesting recipes. I know exactly what I'm looking for and save both time and money. Another great option is that products can be added to the digital shopping cart and delivered to my home.

It is a fact that my disease has changed many aspects of my life, which is made much easier by using a range of different digital apps. Now the world is only a click away. I want to be a fully-fledged person – to develop, to learn, to help myself improve my health and look for little moments of happiness. These applications help me to be involved in life in an easier way. With them, I have my tiny window to the world.

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There is still hope that our lives can get easier and more meaningful with the further development of digital applications – because dreaming of a better future and quality life is an aspiration for each and every one of us.