MAKE BLOOD CANCER VISIBLE

#LETSTALKABOUTBLOODCANCER

Patient Perspectives

janssen Oncology

Foreword

Despite blood cancers making up seven percent of all cancers worldwide, their disparate nature leads to a lack of awareness. Blood cancer has little public profile and this must change.

Our aspiration should be to transform blood cancer into a preventable, chronic or even curable disease by delivering innovative treatment options to patients who need them most. Of course, patients require more than treatment and care — they also need information and support.

Together, we can elevate the unmet needs of blood cancer patients and their loved ones by raising awareness of these cancers, and increasing visibility of the associated health, social and economic burden.

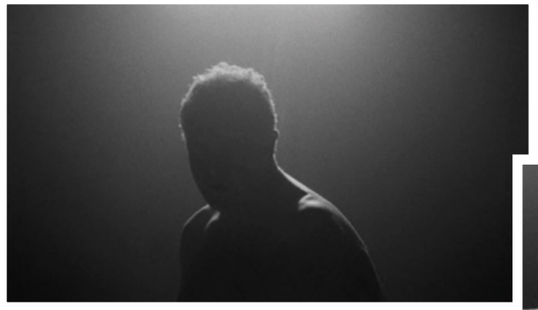
This book is a beautiful collection of personal stories from across Europe, shared by individuals affected by blood cancer. We hope that sharing these stories and experiences will build greater awareness of the true impact of these cancers and help patients, their family members, carers and friends. Indeed, to Make Blood Cancer Visible to the stakeholders who can drive necessary change.

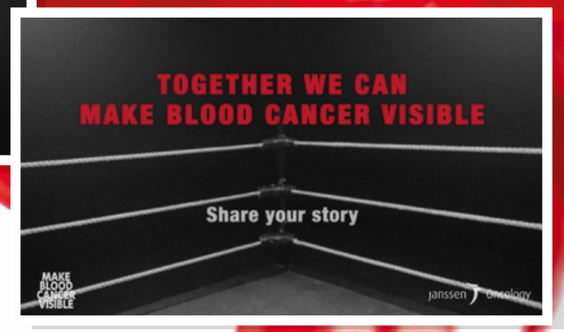
Jane Griffiths
Company Group Chairman,
Janssen EMEA

Make Blood Cancer Visible video

Inspired by the stories of patients with blood cancer, Janssen has developed a short video which directly invites you into the personal and emotive internal struggle patients may face. The video is intended to raise awareness and encourage others impacted by these severe cancers to connect through sharing their own experiences.

Watch the video at **janssen.com/emea/make-blood-cancer-visible** or via the QR code below, and share on social media to help Make Blood Cancer Visible.





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Full page images used in this book are stock photography and not actual patient images.

The facts[1-6]

Blood cancer is an umbrella term for cancers that affect the blood, bone marrow and lymphatic system.

There are 140 different types of blood cancer. These can be classified into three main groups.

Leukaemia

A cancer of white blood cells

1 in 3
cancers in children in industrialised countries is a leukaemia

12th
most common cancer in Europe

Lymphoma

A cancer that starts in the lymphatic system

Lymphoma is the most common blood cancer

11th
most common of all cancers diagnosed in Europe

Myeloma

A cancer of plasma cells in the bone marrow

39,000
people develop myeloma in Europe each year

Blood cells develop through a process called haematopoiesis. This involves bone marrow and part of the lymphatic system. To function properly, the body needs to produce exactly the right amount of each type of blood cell. Blood cancers develop when damage occurs to vital genes, disrupting the normal lifecycle of blood cells, and upsetting this balance.[7]

Risk factors include:[7]

- Infection
- Low immunity
- Chemotherapy
- Radiation
- Genetic disorders
- Chemical exposure
- Environmental factors
- Autoimmune disorders

Many symptoms of blood cancer are a result of fewer healthy, functioning blood cells, or overproduction of abnormal cells, causing a lack of space where blood cells are produced.[8]

Symptoms of blood cancer can vary, but commonly include:[8]

x Tiredness
x Breathlessness
Caused by a decrease in red blood cells

x Swollen/painful glands
x Bone pain
Cause by a build-up of abnormal blood cells in bone marrow and the lymphatic system

x Bruising
x Bleeding
Caused by a decrease in platelets

x Infections
x Fever
Cause by a decrease in white blood cells

Unexplained or unexpected weight loss

Patient Perspectives

Bulgaria

In search of peace

Anonymous

Chronic lymphocytic leukaemia

My story began two years before I was diagnosed. I am a single mother and at that time wanted to get pregnant again. In 2009 I tried to make a new family for myself and my child; I was in a relationship with a man who contributed a lot towards the onset of my disease. After dreadful jealousy, deprivation and fight for the new family, the doctors diagnosed me with chronic lymphocytic leukaemia. And instead of making plans for a new beginning, the big battle for my survival started. I still remember my doctor's words that this condition is untreatable but is affected by a patient's lifestyle; so I distanced myself from all surrounding irritants, learned how to suppress my extreme emotions and adopted a healthy diet.

In the spring of 2011 I left Bulgaria; I did not want my family watching me "mutate". Those were quiet and peaceful days in exile, far away from relatives and problems, but that was only a temporary solution. I came back in the winter of 2012, when my first serious relapse occurred, and it was then I first realised the seriousness of my condition. During the month I stayed in hospital, I met people with much more severe diseases than mine and realised how important it was to give courage to such people and how important it was to keep your morale high. I promised to myself that if I got better, I would travel abroad again, and so I did, twice.

One way for one to survive is to engage in work, a lot of work. Then one forgets. Until autumn of 2013 this was my guiding light. Unfortunately, since then I have been and still am in hospital, which prevents me from working and traveling, but I still manage to find ways to be active and still manage to find dreams to pursue.

Years go by for me, with constant disputes with doctors as to whether I should start a new treatment. I make short journeys around Bulgaria and Greece, and have plans to requalify as a social worker in healthcare facilities. I keep working for blood donor campaigns and focus my efforts on helping people with similar conditions. I keep dreaming, too! For me, CLL is not a disease; for me, CLL is a way of life!

"For me, CLL is not a disease; CLL is a way of life!"

Моята история започва две години преди да ме диагностицират. Аз съм самотна майка и имах желание да забременея с второ дете. През 2009г. се опитах да създам ново семейство за мен и моето дете, имах връзка с човек, който даде голямо отражение на това заболяването ми да се отключи. След безумна ревност, лишения и борба за новото семейство лекарите откриха заболяването - хронична лимфоцитна левкемия. И вместо да правя планове за ново начало започна голямата борба аз да оцелея. Още си спомням думите на лекаря, че това заболяване не се лекува, но се влияе от начина на живот. Дистанцирах се от всички дразнители около мен, научих се да потискам крайните емоции в мен и започнах да се храня здравословно.

През пролетта на 2011 год. заминах извън България. Не исках близките ми да гледат как „мутирам". Бяха тихи и спокойни дни на изгнание, далеч от родните и проблемите, но това бе моментно решение. Прибрах се зимата на 2012 год. при първия ми сериозен рецидив, когато за пръв път осъзнах сериозността на заболяването си. В продължение на месеца, през който лежах в болницата се сблъсках с хора с много по-сериозни диагнози от моята и осъзнах колко е важно да се дава кураж на тези хора и колко е важно да поддържаш духа си високо. Дадох си обещание, че ако се стабилизирам пак ще замина и така направих още два пъти.

Един от начините да оцелее човек е когато се ангажира с работа, много работа. Тогава забравя. До есента на 2013г. това беше моята пътеводна светлина. За съжаление от тогава до сега съм на стационар, което не ми позволява да работя и пътувам, но все още намирам начини да бъда активна доколкото състоянието ми го позволява и все си намирам мечта, която да следвам.

Годините отминават за мен, в постоянни спорове с лекарите дали трябва да почвам нова терапия, кратки пътешествия из България и Гърция, планове за професионална преквалификация като социален работник в здравни заведения. Не спирам да работя за кръводарителски кампании и се насочвам изцяло да помагам на хора, които се сблъскват с подобни на моето заболявания. Не спирам и да мечтая! За мен ХЛЛ не е заболяване, за мен ХЛЛ е начин на живот!

"За мен ХЛЛ не е заболяване, за мен ХЛЛ е начин на живот!"

Croatia

Staying optimistic

Dražen Vincek
Chronic myeloid leukaemia

My story began in 1998, when I received the diagnosis of diabetes mellitus type 2 after visiting my physician due to some changes in my body. My blood sugar was increased and I had to take some steps. I lost weight, became more physically active, followed my physician's advice, and took prescribed medications. Nevertheless, my diabetes took its toll and, over the years, caused damage to my blood vessels. In 2007 I suffered a myocardial infarction and was hospitalised. Soon after coronarography at a specialised hospital, I underwent a heart operation – a triple coronary bypass.

I took all my health problems seriously. I was disciplined and went for my blood tests regularly. In 2010, a CBC test showed some suspicious changes and I was told the alarming news. It took me by surprise. Having bad blood test results was something I had not expected at all. It came as a bolt from the blue since I had no related symptoms and felt healthy. Or so I thought. In reality, I did have symptoms, only they were similar to the symptoms of the other two diseases that I had, which is why I did not pay attention to increased fatigue and sweating and so on. Given my heart condition and diabetes, I thought that such problems were to be expected. After all, I did my best to be physically active. I climbed eight flights of stairs every day to get to my apartment at the fourth floor and just ignored the signals from my body.

The biochemical laboratory test results were unambiguous; the rest of the blood tests and bone marrow biopsy were done just for verification. I was worried and scared of further diagnostic workup, of pain... My first thoughts about leukaemia were negative and dark. All I knew was that it was a blood cancer and I remembered stories about people who got leukaemia and whose outcomes were unfortunate. It was the first shock. I did not know who to tell first... Information on the internet was not exactly morale-boosting, in fact quite the opposite. In short, I felt really depressed.

Uncertainty before the final diagnosis was unnerving while I waited for various test results. The fear of near death... I tried to find reassurance in people who were closest to me, but no one could provide the comfort I sought. It was happening to me, not to them. After a biopsy and an aspiration, the diagnosis was confirmed – chronic myeloid leukaemia (CML), i.e. Ph+CML. Then I began with the treatment and, luckily, my findings are still good and my disease is in remission.

The greatest encouragement I got came from the physicians who gave me clear information about possible treatments. I still remember what my physician told me: "You have leukaemia, but luckily, it is chronic myeloid leukaemia and you can have a good life with that disease." Still, I must add that the most important factor was my optimistic spirit - I was convinced that there must be a cure for my illness.

It is not always easy. I have bad days when I'm plagued with dark thoughts, because I'm aware of the problems related to treatment. I did my best to get detailed information about everything at the Patient Association. It is difficult for me to find support because I'm not the type of person who complains. I don't like talking about my problems to other people, not even the ones closest to me. Many do not understand the seriousness and severity of my everyday struggle. People say I look well and are often deceived by my smile. I think it is better like that. There's no use in crying. On the other hand, I am well aware of what it's like for other patients. I'm actively involved in the work of the Patient Association because it gives me the opportunity to help others in practical terms while they are going through everything I've gone through.

"People say I look well and are often deceived by my smile. I think it is better like that."

After the diagnosis, I'm even more aware of the importance of health. I look forward to helping others and appreciate every moment I feel well.

I'm actively involved in the work of the Croatian Leukaemia and Lymphoma Patient Association because I want to help others as well as myself, and because I believe that only adherence to the prescribed therapy and regular checkups can help us keep this disease under control and live with it. I'll use the words of a patient with the same disease who said: "I'm so glad that medicine and the pharmaceutical industry have responded so successfully to this disease. Unless I had to take the medication every day, I would not even know that I had cancer."

Moja priča započinje dijagnozom diabetes mellitus tip 2 1998. godine, čemu su prethodile neke promjene u mom organizmu, te odluka o odlasku liječniku. „Šećer“ je bio povišen, trebalo je reagirati, smršavio sam, više se kretao, i pridržavao se liječničkih uputa, te uzimao propisane lijekove.

Dolazi 2007. godina, diabetes je učinio svoje, stradale su žile, zakrčile se, došlo je do infarkta miokarda, bolničko liječenje, pa odlazak u specijaliziranu bolnicu na koronarografiju, a iste godine uslijedila je operacija na žilama, radilo se o trostrukom aortokoronarnom premoštenju (by-pass).

Iako sam svoje bolesti shvatio ozbiljno, došlo je i do razvoja više mikro poremećaja, no ja sam bio discipliniran i redovito odlazio na redovite krvne kontrole, a na jednoj od njih, kod nalaza kompletne krvne slike sredinom 2010. godine, utvrđene su neke promjene u krvi, a vrlo skoro dobio sam alarmantan nalaz.

Bio sam iznenađen. Nisam očekivao loš nalaz, bio je to grom iz vedra neba. Činilo mi se da nemam nikakve simptome, da sam zdrav. No, moji simptomi su se isprepleli sa simptomima te moje druge dvije kronične bolesti. Nisam obraćao posebnu pažnju na simptome poput povećanog umora, znojenja,.. Pa bilo je to normalno za očekivati obzirom na moju srčanu bolest i dijabetes. A uz obje bolesti, trudio sam se aktivno živjeti i kretati. Popeti se pješke na 4. kat moje zgrade bio je svakodnevni napor koga sam savladavao sve više ignorirajući signale tijela.

U biokemijskom laboratoriju vrlo brzo su utvrdili o čemu se radi, ostale pretrage krvi i koštane srži bile su samo nadgradnja. Briga i strah vezano uz dijagnostičke postupke, bol... Prve misli vezane uz leukemiju su bile negativne i mračne, sve što sam znao je da se radi o raku krvnih stanica i da se sjećam priča o poznatima i nepoznatima oboljelim od leukemije sa vrlo lošim ishodima. Bio je to prvi šok. Nisam znao kome prvome reći... Informacije na Internetu nisu mi baš digle moral, štoviše, uvelike su ga srozale.

Neizvjesnost kod uspostavljanja konačne dijagnoze je rasla, čekanje raznih nalaza, strah, smrt u bliskoj budućnosti... Koliko sam samo truda uložio tražeći pomoć od bliskih ljudi, no nitko od njih me nije mogao utješiti, pa sve se to ne događa njima, nego meni... Ovaj puta situacija je bila mnogo ozbiljnija, nakon biopsije i punkcije utvrđena mi je kronična mijeloična leukemija (KML), tj. Ph+CML. Od tada počinjemoje liječenje. Srećom, moji nalazi su i dalje dobri i moja je bolest u remisiji.

Potpora i nada koju su mi donijeli liječnici sa jasnim informacijama o mogućnostima liječenja su me ohrabrile za moju borbu. Riječi moje doktorice: “Imate leukemiju, no srećom, radi se o kroničnoj mijeloičnoj leukemiji, s time se da kvalitetno živjeti.“, još i danas pamtim. No, reći ću i ovo, najvažniji je ipak bio moj optimističan duh koji je pun sigurnosti prihvatio činjenicu da mora postojati lijek za moju bolest.

Nije uvijek lako. Ima teških dana kada mi dolaze crne misli, obzirom da sam svjestan o mogućim poteškoćama u liječenju, kroz Udrugu sam se nastojao dobro o svemu informirati..... Teško je naći potporu jer nisam osoba koja se voli i može žaliti drugima. Zato ni najbližima ne volim pričati o svojim problemima. Tako mnogi ne shvaćaju niti ozbiljnost niti težinu moje svakodnevne borbe. Čini im se da izgledam dobro i moj osmijeh ih često zavara. Meni se čini da je tako i bolje, od kukanja koristi nema. Ja, opet, dobro znam kako je drugim bolesnicima i zato sam vrlo aktivno uključen u rad udruge bolesnika jer na taj način konkretno pomažem svima koji prolaze moj put.

“ Čini im se da izgledam dobro i moj osmijeh ih često zavara. Meni se čini da je tako i bolje, od kukanja koristi nema.”

Nakon dijagnosticiranja bolesti još sam više svjestan vrijednosti zdravlja. Veseli me što sam u prilici da pomažem drugima, cijenim sve trenutke kada sam dobro...

Aktivan sam u Hrvatskoj udruzi leukemija i limfomi (HULL), na koji način želim pomoći drugima, a i sebi, jer smatram da se samo pravilnim pridržavanjem propisane terapije i redovitim kontroliranjem ova bolest može dobro kontrolirati, te da se da s njome živjeti. Kao što je rekao jedan od mojih supatnika, zadovoljan što je medicina i farmacija uspjela uspješno odgovoriti na ovu bolest, da on, da ne uzima lijek svakodnevno, ne bi ni znao da ima rak.

Denmark

The human touch

Tina Loevgreen

Acute myeloid leukaemia

Transcript of interview with Tina Loevgreen and Patrick Henriksen on overcoming acute myeloid leukaemia (AML)

If you mix a lot of love with the ability to communicate, although your life hangs by a thread, then you will also know how Tina and Patrick got through it when Tina had acute myeloid leukaemia.

Patrick Henriksen: *"We were good at communicating, and that fact saved our relationship. If we hadn't been able to communicate going through this, we probably would have split up as everything was so surreal."*

Tina and Patrick's world was torn apart on a summer's day in 2013.

Patrick Henriksen: *"On the day that we found out Tina was sick, our greatest problem was that Tina was taking two kids to the hair salon, 2.5 hours later, you're given a potential death sentence and it was incredibly surreal."*

For a long while, Tina had felt unusually tired. Her joints were also aching and she had night sweats.

Tina Loevgreen: *"I started to wonder why I was so tired and I conjured up a long list of excuses but as there were so many symptoms, I knew that something was wrong. However, I never imagined it was anything this serious."*

When the blood results were in, everything moved very quickly. Tina is suffering from acute myeloid leukaemia. She's immediately admitted to hospital and starts aggressive chemo treatments.

Tina Loevgreen: *"When I became ill, my first thought was: 'What about my children?' I already saw those magazine headlines you've seen over the years, growing up without mommy."*

Patrick Henriksen: *"Her first encounter with doctors at the hospital was very rough."*

Tina enquires about the planned treatment and she'd also liked to know when she can come home to her kids again.

The chief physician replies: "Lady you clearly do not get the seriousness of your diagnosis."

The chief physician's words completely pull the rug from under a vulnerable Tina and now she is afraid of the chief physician.

Tina Loevgreen: *"I was really scared, my life was in her hands! She is the one who is going to treat me and make me well again. Suddenly I'm now thinking is she not going to do her best, because we don't get on?"*

The chief physician did what she could and later apologises to Tina. Now the two of them hug when Tina has her check-ups.

Tina's treatment goes on for four months and one day, her daughter Melanie, wants some answers.

Patrick Henriksen: *She says "Mom, if you're going to die, would you please tell me so I can say goodbye? Those were incredibly tough questions."*

What was your reply?

Tina Loevgreen: I replied: *"I promise, honey. You'll have time to say goodbye. Then she turned around and went back to what she had been doing."*

Patrick Henriksen: *"We would have explained it more though and I had a lump in my throat."*

One day, Tina deteriorated. She has a fungal infection in her lungs and it can go either way really. Tina's dad has always taught her that things had to be in order so she called Patrick before being admitted to intensive care.

Patrick Henriksen: *"She called me and said: They're taking me to ICU now and we're getting married today. Okay I'm on my way, let me just drop one of the kids off at a party. I didn't go down on bended knee. My knee pressed against the hospital bed and I was sitting on a chair while Tina was in her bed. The priest had to stand between both us and all the machines. A bit untraditional..."*

Tina Loevgreen: *"At least I was wearing white!"*

Tina survived and was taken back to her ward. The ward has 12 rooms and two beds in each. Tina needs her sleep but is constantly woken by the other patients, machines and staff.

Tina Loevgreen: *"During my time in the ICU, my body had been under such pressure and my sleep had been disrupted all the time there too. For the 16 days, I slept no longer than two hours at a time, which really affects your body and I was already very poorly. So everything is augmented – sounds and smells. It was all very overwhelming. I just couldn't stand it, I'd had enough."*

See the original video version of this story at
www.facebook.com/letstalkaboutbloodcancer

Four months after being admitted, Tina could go home to her family. When Tina and Patrick look back, Tina did receive the best medical care available. However, something was missing.

Patrick Henriksen: *"My experience was most often... the people were nice enough and they were very professional but when you're in a tough situation and the pressure is immense. We had two young kids and we didn't know if they would lose their mother but we met several people without the expected empathy, so medically they really need to do something to include the human touch. Treatment is one thing, 80% of course is the treatment but when the last 20%, i.e. compassion, isn't there, it's inhuman and you need to do so much more to understand, that empathy is incredibly crucial when people are so seriously ill when they're lying in bed feeling weak, sick and poorly."*

Tina Loevgreen: *"The nurses had more empathy than the doctors. Doctors would perhaps benefit from things in the nursing programme."*

After Tina got the all clear, she in no way felt recovered. She began looking for help to rebuild her body again. She found help from a doctor whom Tina paid for privately and who is not afraid to use herbal medicine, supplements and vitamins.

Tina Loevgreen: *"My body needs vitamins and minerals after chemotherapy."*

Patrick Henriksen: *"We've a lot to learn in regards to anything remotely 'alternative'. It's horrible and dangerous but we read articles from abroad and we can see that it's working for Tina."*

There are so many songs for when a man loves a woman. You could write one about Patrick who has supported Tina 100%. But before we do, there is still one more thing he has to do.

You were married so quickly, is that something you'd like to do differently?

Patrick Henriksen: *"The pressure is on but I'd probably better do it right. One day, I have to propose, properly! And then I'll be in charge."*

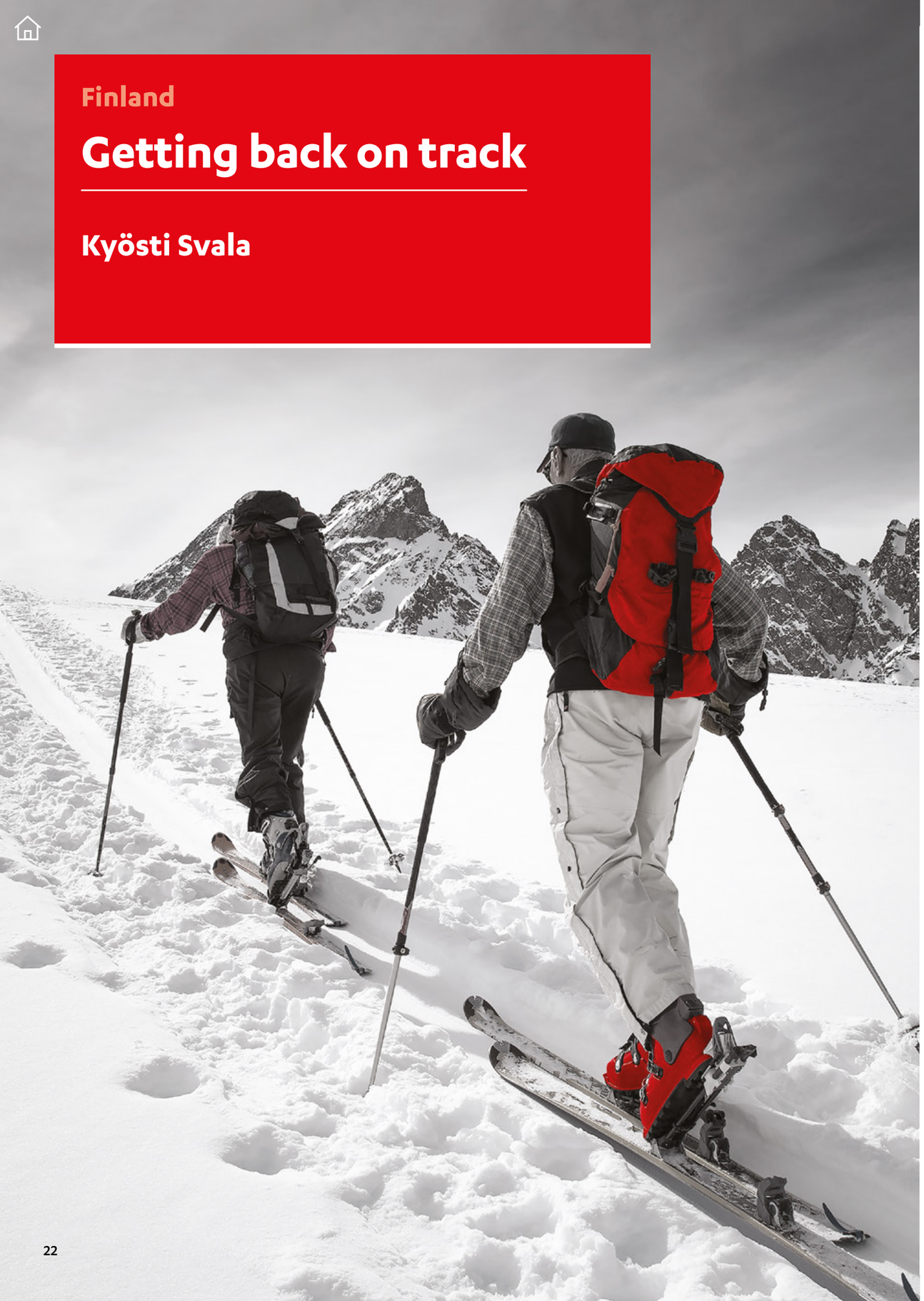
Tina Loevgreen: *"I'll look forward to that!"*

"That empathy is incredibly crucial when people are so seriously ill, when they're lying in bed feeling weak, sick and poorly."

Finland

Getting back on track

Kyösti Svala



13 years ago, entrepreneur Kyösti Svala, who lives in Kärsämäki, was diagnosed with blood cancer. Now, he says that he is living a well-rounded life.

"After getting the cancer diagnosis, I had to think about how to move forward. For seven years, the cancer did not affect my everyday life, but as the disease progressed, treatment started.

"Finally, an 'either/or' situation was reached. To survive, I needed a stem cell transplant, but the cancer cell amount in my bone marrow was too high. My doctor told me of a new drug. With it, the amount of cancer cells decreased, and the transplant could be performed.

"The recovery time is long, but now I am well again. I used to cross-country ski long distances, run marathons and row across the Gulf of Finland. Now, I have considered building a larger boat, and if my health allows for it, my goal would be to row from Vaasa to Umeå, in Sweden. I can now plan ahead in life again."

"My goal would be to row from Vaasa to Umeå, in Sweden. I can now plan ahead in life again."

Kärsämäellä asuvalla yrittäjällä Kyösti Svalalla todettiin 13 vuotta sitten verisyöpä. Nyt hän kertoo elävänsä täysipainoista elämää.

Syöpädiagnoosin kuultuani jouduin miettimään, miten tästä oikein jatketaan. Seitsemään vuoteen syöpä ei vaikuttanut normaaliin elämään, mutta taudin edetessä hoidot aloitettiin. Lopulta tuli joko- tai -tilanne. Selvitäkseni tarvitsin kantasolusiirron, mutta syöpäsolujen määrä luuytimessäni oli liian korkea. Lääkärini kertoi uudesta lääkkeestä. Sillä syöpäsolujen määrä saatiin laskemaan ja siirto voitiin tehdä. Toipumisaika on pitkä, mutta nyt voin hyvin. Olen aikaisemmin hiihtänyt pitkiä matkoja, juossut maratoneja ja soutanut Suomenlahden yli useamman kerran. Nyt olen miettinyt vähän isomman veneen rakentamista ja jos kunto sallii, tavoitteena olisi soutaa Vaasasta Ruotsin Uumajaan. Elämässä voi taas tehdä suunnitelmia eteenpäin.

“ Tavoitteena olisi soutaa Vaasasta Ruotsin Uumajaan. Elämässä voi taas tehdä suunnitelmia eteenpäin.”

France

The support of others

Christian Puppinck

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(Chronic Lymphocytic Leukaemia and Waldenström's Macroglobulinemia Patient Association)

When patients get their diagnosis they are alone. I'm alone with my disease. That's the first thing. This is very often followed by different reactions - isolation, revolt, even denial.

And it's only gradually that you recognise that in fact there are others... there are others. First there are spouses, family and friends who are there. And then, during the patient meetings we organise, there are others like you, other people on the same journey, the same trajectory. And that lets people share experiences and makes it easier to understand your own disease, and what you can expect.

The first thing about these diseases is that they are diseases that are not particularly common and even rare, for Waldenström's lymphoma. And then what may surprise people is that there's a diagnosis but not necessarily a treatment. That's already quite exceptional, and in my experience, something that's quite upsetting.

"It's only gradually that you recognise that in fact there are others."

Les patients, quand ils reçoivent leur diagnostic, sont seuls. Je suis seul avec ma maladie. Ca, c'est le premier constat. Il s'en suit très souvent des attitudes multiples de renfermement, de révolte, de déni même.

Et ce qui n'est qu'un peu à la fois que on se rend compte que pratiquement, eh bien il y en a d'autres. Il y en a d'autres. D'abord il y a le conjoint, il y a le proche, qui sont là. Et puis à l'occasion des réunions de patients que nous organisons, il y a d'autres moi-même, d'autres personnes qui ont connu le même parcours, la même trajectoire. Et ça, ça permet de rapprocher les expériences, ça permet de faciliter la compréhension qu'on a de sa propre maladie et de ce à quoi il faut s'attendre.

La caractéristique de ces maladies, c'est d'abord que ce sont des maladies qui sont peu fréquentes, et même rares, avec la maladie de Waldenström. Et puis, ce qu'il y a de surprenant, c'est qu'on a un diagnostic mais pas n nécessairement un traitement. Déjà ça c'est très particulier et d'expérience, à l'évidence, c'est très perturbant.

“ Et ce qui n'est qu'un peu à la fois que on se rend compte que pratiquement, eh bien il y en a d'autres.”

Germany

Giving up is not an option

Edelgard

Multiple myeloma

Edelgard was diagnosed with multiple myeloma in 2008. This malignant disease throws all aspects of her life – her professional career and her role as a mother and wife – into turmoil. She falls into a black hole of depression, but is able to draw courage from the support offered by her family, friends and doctors and the treatment she receives. The now 60-year-old is treated with a cancer drug that is both well-tolerated and effective for her. After a little while this leads to the first signs of success. Edelgard takes heart. She starts seeing life from a different perspective and can now take pleasure again in the small, everyday things of life.

Edelgard, what disease symptoms did you first notice?

From October 2007 onwards, I repeatedly suffered from infections. I felt lethargic. In addition, I experienced bone pain, especially around the area of my ribs. At first, I thought that I had broken something while exercising. However, an X-ray examination found nothing. The pain remained and I also often felt as if I were suffocating at night. In April 2008, my condition became so bad that I was sent to hospital. There the doctors performed a punch biopsy of one of the bones. During this procedure, they took a little bit of bone marrow and a small sliver of bone. The examination of these finally led to the diagnosis: multiple myeloma. I was immediately transferred to the University Hospital in Mainz, where a CT scan revealed how far my disease had already advanced.

How did you cope with the diagnosis?

My world fell apart completely. I felt extremely anxious and insecure. My self-esteem was shattered. I thought that I would never get through this. However, the support I received from my husband, my daughter and my friends restored my strength and courage. They were there for me. They motivated me not to give up and reminded me of the things that are worth living for. In addition, I received a lot of support from a psychologist who specialised in oncological disease.

Exactly how did the psychologist help you?

At that point, I was wracked with self-reproach. I thought that I had not taken enough care of myself and my body, and that I was the one to blame for my disease. I talked to my psychologist approximately twice a week. We instantly struck up a good rapport. She gave me the feeling of being at the centre of attention. She was also very patient with me and encouraged me. This meant that I was very quickly able to come to trust her.

So what is important to you concerning the doctor–patient relationship?

I find it very helpful when my doctor motivates and encourages me. For example, by talking me through which improvements I have already achieved as a result of my treatment. This gives me the sense that I will also be able to fight this disease in future. In addition, I value my doctor's expertise. I feel reassured when my doctor explains to me which treatment is most suitable for me. Getting a sense that I have been included in the decision-making process is also important to me. When all of this comes together, I feel that I am in safe hands. It also makes me think very quickly: Great, let's do it!

As a result of your treatment you were repeatedly able to enjoy periods of feeling better, but you also experienced setbacks. From where did you draw the strength not to give up?

My life followed a different path from the one I had hoped for. However, a new way of thinking has helped me to cope with this. I realised that I had often failed to notice the beautiful things in life before I became ill. I was always under stress and performing like a hamster in its wheel. Today, I am thankful to be able to enjoy the simple things of everyday life thanks to the support of my family and my doctors, and thanks to my treatment. Such things include, for example, being able to meet up with my friends or managing the grocery shop on my own. I have developed an eye for the small, beautiful moments of life, such as going for a dip in the lake or a walk in the countryside. I draw strength from these moments, and I have made it my habit to include many positive thoughts in my life.

"I thought that I had not taken enough care of myself and my body, and that I was the one to blame for my disease."

Is there also something in your life that has improved because of your illness?

My illness has changed many things. I used to be the main earner in the family. Now I am in early retirement and we have to cut our cloth to suit a smaller purse. But this is not to say that this is a bad thing. I no longer compare my life to that of other people and this has made me much happier. In addition, I have discovered new talents lying within me. For example, I have been painting for some time now.

Since your diagnosis, a lot has happened in the area of therapy. How do you view these developments?

I am a member of a self-help group and, at our meetings, doctors regularly update us on the latest treatment options. I attend these meetings together with my husband and I always find it very interesting to hear about all the new developments that are being investigated in clinical trials. It fills me with courage and hope to see that research is making progress and making new drugs available.

Do you have any advice that you would like to share with other patients?

It is important never to give up, even if things look very bleak. You have to try to confront your disease head on, because you cannot hide from it. A positive way of thinking and small encouragements from nature can help you to regain your courage. For example, when I see a dandelion fighting its way up between paving slabs, I think to myself that this is the way I want to approach things too. We should enjoy the small gifts of life and learn to be amazed again about all the beauty that surrounds us.

“I no longer compare my life to that of other people and this has made me much happier.”

Im Jahr 2008 erhält Edelgard die Diagnose Multiples Myelom. Die bösartige Erkrankung des Knochenmarks stellt das Leben der voll im Berufsleben stehenden Frau, Mutter und Ehefrau völlig auf den Kopf. Sie fällt in ein Loch. Doch durch die Unterstützung ihrer Familie, Freunde und Ärzte sowie durch die Therapie fasst sie wieder Mut. Die heute 60-Jährige nimmt an einer kleinen klinischen Studie teil, die ihr von ihrem Arzt empfohlen wird. Dabei erhält sie ein neues Krebsmedikament. Nach einer Weile zeigen sich erste Erfolge. Edelgard schöpft Hoffnung. Sie beginnt, das Leben aus einem anderen Blickwinkel zu sehen und erfreut sich regelmäßig an den kleinen und alltäglichen Dingen des Lebens.

Edelgard, wie hat sich die Erkrankung bei Dir bemerkbar gemacht?

Ab Oktober 2007 litt ich immer wieder an Infekten. Ich fühlte mich schlapp. Außerdem taten mir meine Knochen weh, vor allem im Rippenbereich. Zunächst dachte ich, ich hätte mir beim Sport etwas gebrochen. Doch der Röntgenbefund fiel negativ aus. Die Schmerzen blieben, hinzu kam, dass ich nachts oft keine Luft bekam. Im April 2008 ging es mir dann so schlecht, dass ich ins Krankenhaus überwiesen wurde. Dort führten die Ärzte eine Knochenstanze durch. Dabei wurden mir etwas Knochenmark und ein kleines Stück Knochen entnommen. Die Untersuchung brachte schließlich die Diagnose: Multiples Myelom. Ich wurde direkt in die Uniklinik nach Mainz gebracht, wo ein CT zeigen sollte, wie weit meine Erkrankung bereits fortgeschritten war.

Wie hast Du die Diagnose aufgenommen?

Ich wurde komplett aus meinem Leben gerissen. Ich war total verängstigt und verunsichert. Mein Selbstwertgefühl war zerstört. Ich dachte mir, das schaffe ich nicht. Doch mein Mann, meine Tochter und meine Freunde haben mir geholfen, wieder Kraft und Mut zu schöpfen. Sie waren für mich da, haben mich motiviert, nicht aufzugeben und mir gezeigt, wofür es sich zu leben lohnt. Außerdem habe ich sehr viel Unterstützung durch eine Psychologin erfahren, die sich auf onkologische Erkrankungen spezialisiert hatte.

Wie genau hat sie Dir geholfen?

Ich habe mir damals sehr viele Selbstvorwürfe gemacht. Ich dachte, dass ich nicht genug auf mich und meinen Körper geachtet habe und gab mir selbst die Schuld für meine Erkrankung. Mit meiner Psychologin sprach ich circa zweimal pro Woche. Wir waren uns von Anfang an sympathisch. Sie hat mir das Gefühl gegeben, dass es um mich geht. Außerdem hat sie sich sehr viel Zeit genommen und mir Mut zugesprochen. So habe ich schnell Vertrauen zu ihr aufgebaut.

Und was ist Dir in der Beziehung mit Deinen Ärzten wichtig?

Es hilft mir sehr, wenn mein Arzt mich motiviert und mir Mut macht. Zum Beispiel indem er mir aufzeigt, welche Fortschritte ich durch meine Behandlung bereits erreicht habe. Damit gibt er mir das Gefühl, dass ich auch künftig gegen die Krankheit ankommen kann. Außerdem ist mir seine Expertise wichtig. Es beruhigt mich, wenn er mir erklärt, welche Therapie für mich die beste ist. Und mir ist das Gefühl wichtig, in Entscheidungen mit einbezogen zu werden. Wenn all dies geschieht, fühle ich mich in guten Händen. Dann denke ich auch schnell: Gut, packen wir es an!

Durch Deine Behandlung gab es immer wieder Zeiten, in denen es Dir besser ging. Doch Du hast auch Rückschläge erlebt. Woher nimmst Du die Kraft, nicht aufzugeben?

Mein Leben ist anders verlaufen, als ich es mir erhofft habe. Doch neue Denkmuster haben mir geholfen, damit umzugehen. Mir ist klar geworden, dass ich vor der Erkrankung oft gar nicht auf das Schöne im Leben geschaut habe. Ich war immer im Stress und habe funktioniert wie ein Hamster im Hamsterrad. Heute bin ich dankbar, dass ich dank der Unterstützung meiner Familie, der Ärzte und der Behandlung die ganz normalen Dinge des Alltags erleben kann. Dazu gehört zum Beispiel, dass ich mich mit Freunden treffen oder

“Ich dachte, dass ich nicht genug auf mich und meinen Körper geachtet habe und gab mir selbst die Schuld für meine Erkrankung.”

auch einfach den Einkauf allein erledigen kann. Ich habe einen Blick für die kleinen, schönen Dinge des Lebens bekommen. So genieße ich zum Beispiel ein Bad im See oder Spaziergänge in der Natur. Daraus schöpfe ich Kraft. Ich habe mir angewöhnt, mit vielen positiven Gedanken zu leben.

Gibt es denn auch etwas, das sich in Deinem Leben durch die Erkrankung verbessert hat?

Durch meine Erkrankung hat sich vieles verändert. Früher war ich die Hauptverdienerin der Familie. Jetzt bin ich Frührentnerin und wir müssen kleinere Brötchen backen. Das heißt aber nicht, dass das schlecht ist. Ich vergleiche mein Leben nicht mehr mit dem von anderen Personen. Dadurch bin ich viel glücklicher geworden. Hinzu kommt, dass ich neue Talente an mir entdeckt habe. So male ich beispielsweise seit einiger Zeit.

Seit Deiner Diagnose hat sich in der Therapie vieles getan. Wie hast Du diese Entwicklung wahrgenommen?

Ich bin Mitglied einer Selbsthilfegruppe, bei deren Treffen auch Ärzte regelmäßig über neue Behandlungsmöglichkeiten informieren. Ich nehme an diesen Treffen zusammen mit meinem Mann teil und finde es immer sehr interessant zu hören, was alles neu entwickelt und in Studien untersucht wird. Es gibt mir Mut und Zuversicht, wenn ich sehe, dass die Forschung Fortschritte macht und neue Medikamente verfügbar sind.

Gibt es etwas, das Du anderen Patienten mit auf den Weg geben möchtest?

Es ist wichtig, nie aufzugeben, auch wenn es ganz schlimm aussieht. Man muss versuchen, sich der Krankheit zu stellen, denn man kann sich vor ihr nicht verstecken. Positive Gedanken helfen einem dabei, wieder Mut zu schöpfen, auch kleine Mutmacher aus der Natur. Wenn ich beispielsweise einen Löwenzahn sehe, der sich zwischen Steinplatten hervorkämpft, denke ich mir, so will ich es auch versuchen. Man sollte die kleinen Dinge genießen, die uns das Leben schenkt und wieder staunen lernen, über all das Schöne, was um uns herum ist.

“ Ich vergleiche mein Leben nicht mehr mit dem von anderen Personen. Dadurch bin ich viel glücklicher geworden.”

Hungary

A difficult journey

Szabó Judit

Chronic lymphocytic leukaemia

My CLL was detected by a routine screening test done at my workplace. I received my first treatment after 5 years. I got better, and I could work. In 2011 my disease became active again. I received several treatments. The chemotherapy was effective, my body responded, but the effect lasted only a short while. I permanently had episodes of feeling sick, nausea, vomiting, and various complications, including development of a skin condition.

I had the shingles, flu, upper respiratory tract infections, and I was fatigued. I was run-down.

She also had pneumonia.

Last year I had a nasty case of pneumonia which healed very slowly. I coughed a lot and I was tired all the time.

Can you recall what was your highest White Blood Cell count during that time of 1-2 years?

During that time my WBC was above 200,000. The highest count was 340,000. Leukapheresis was done several times to lower my WBC.

After such history the patient started taking a different treatment at the end of 2014.

I have been taking the drug since December 15, 2014. My lymph nodes retracted completely, and my blood count is recovering nicely. I don't feel tired any longer and I don't have the night sweats. I have not been hospitalized since the treatment.

I had my last transfusion in August last year. Several days go by without me thinking of the disease. This allows me to enjoy the smaller or bigger things in life.

I take the medicine in the morning, and then I can spend the entire day with my family. I can cook, do the gardening, do handicrafts, I can read, watch TV and play with my grandchild.

"Several days go by without me thinking of the disease. This allows me to enjoy the smaller or bigger things in life."

Egy rutin munkahelyi vérvizsgálat alapján derült ki hogy CLL-es vagyok. Öt év után kaptam az első kezelést. Utána jól voltam, dolgoztam. 2011-ben újra aktív lett a betegségem. Akkor több kezelést kaptam. Hatott a kemoterápiás kezelés, a szervezetem reagált, viszont nem volt tartós. Állandó rosszullét, hányás, hányinger és különböző szövődmények, bőrbetegségek.

Kétszer volt övsömöröm, náthás megbetegedések, felső légúti betegségek, fáradékonyság. Ez megviselt.

Tüdőgyulladása is volt.

Tavaly volt egy csúnya fertőzéses tüdőgyulladásom, ami nagyon lassan gyógyult meg. Sokáig köhögéssel és fáradékonysággal járt.

Vissza tud emlékezni, mennyi volt a legmagasabb fehérvérsejt száma ebben az egy-két éves periódusban?

A kettőszázezer fölött volt. Háromszáznegyvenezer volt a legmagasabb. Többször leukoferezis is volt, hogy csökkentsük a fehérvérsejt számot.

Ilyen előzmények után kezdett el egy másik kezelést a beteg 2014 végén.

2014. december 15-e óta kapom és szedem a gyógyszert, a nyirokcsomók teljesen visszahúzódtak, a vérképem szépen alakul. Megszűnt a fáradékonyság, az éjszakai izzadékonyság. A kezelés óta nem voltam kórházban.

Legutolsó transzfúzió tavaly augusztusban volt. Több nap eltelik és nem is gondolok a betegségre. Így tudok az élet apróbb - nagyobb örömeire gondolni.

Reggel beveszem a gyógyszert, és az egész napom a családommal tölthetem. Főzhetek, kertészkedhetek, kézimunkázom, olvasok, tévézek és unokázhatok.

“Több nap eltelik és nem is gondolok a betegségre. Így tudok az élet apróbb - nagyobb örömeire gondolni.”

Ireland

Ups and downs

Patrick Kilgallon

Chronic lymphocytic leukaemia

My name is Patrick Kilgallon. I'm from Mayo in the west of Ireland but I live in Dublin and I'm 73 years of age. I was first diagnosed with chronic lymphocytic leukaemia (CLL) back in 2002 when I went for a routine cholesterol check and the doctor called me to tell he had a bit of bad news. While my symptoms at the time of diagnosis were mild, I had found it difficult to fight colds and flu my whole life.

I wasn't a stranger to CLL as my sister also had it and passed away back in 2005. That said, I didn't know a lot about the disease but I did know that it was a blood cancer.

From what my family said about my grandmother's passing, I strongly believe she also had leukaemia but as it was the 1920s it wasn't diagnosed.

When I was diagnosed, I was referred to a haematologist who said that I might never need treatment and that I could lead a normal life but they would need to keep an eye on it with six monthly blood tests.

I kept working but moved to a less stressful job as a taxi driver. I didn't want to tell anyone that I had leukaemia as I didn't want everyone ringing me asking me questions about my condition. I know that might have been hard on my family but it was my way of not letting it impact my life too much.

The doctors told me that if I noticed any changes in my condition, like my lymph nodes swelling, I'd need to let them know. In 2004 I started showing these symptoms. I had a big lump under my arm, my lymph nodes were enlarged and changes also showed up on my routine blood test. As a result of these changes I had my first round of chemotherapy tablets.

Again in 2005, the lymph nodes and the blood tests changed so I was sent for another round of treatment with tablets. In 2006, my blood cancer became far more aggressive. My neck swelled up and my wife affectionately told me that I looked like Fred Flintstone as my neck was as wide as my face – there was no difference between the two! I was unable to work and others were noticing a deterioration in me. As a result, I was put on an intravenous chemotherapy treatment for about six months in three-week cycles in the hospital.

During this period of treatment, I was tired and I had diarrhoea. But the important thing is the treatment worked and I went into remission for five years. During those five years I was completely better and didn't even take one tablet.

Unfortunately, in 2012 I relapsed and my CLL returned despite me feeling fit and well. I went for my usual blood tests and my consultant noticed a change in the cells in my blood, I had too many lymphocytes. I had also developed a complication called the P53 deletion which meant I might not respond well to chemotherapy. My consultant told me about a new clinical trial and asked if I wanted to be part of it as he felt it was my best chance and I agreed to participate. However, I wasn't put on the new therapy in the trial and unfortunately didn't respond well to the standard therapy that was given.

My health deteriorated and led to me having a mild heart attack. I came under the care of a cardiologist who identified that I had several blockages in my heart and I had three stents fitted.

In 2013, my symptoms got much worse. I was losing weight and my lymph nodes were enlarged and I looked really pale, almost grey. This time around it was difficult for my consultant to treat. They tried several different chemotherapy treatments but I seemed to be getting worse.

At this point my health was quite poor. My diarrhoea was really bad, I had terrible night sweats, I couldn't sleep, eat or walk – as my wife said I was 'melting away' because I had lost so much weight.

In January 2014, my consultant told me my CLL was at an advanced stage and I was given 12 weeks to live. Thankfully due to the improvements seen by patients on the other therapy in the trial I was transferred over to that treatment.

After that my symptoms quickly subsided, I also started to gain weight for the first time in a year. I'm still on that therapy today and continuing to live a full and happy life with my wife. I did have to come off my therapy recently when I had to have a minor procedure and my CLL symptoms came back quickly so I know my disease is still there and I'll receive treatment for the rest of my life.

It's been a journey of ups and downs but what remained consistent was the support of my wife. I had to build a lot of mental resilience against my CLL and I did that by staying active and keeping to my normal routine as much as possible. I'm delighted to contribute to this book to mark blood cancer awareness month – making blood cancer more visible is really important for those who are living with it every day.

"It's been a journey of ups and downs but what remained consistent was the support of my wife."

Israel

Choosing life

Pini Lannman's story by Marsel Moseri

Chronic lymphocytic leukaemia

My wife and I built a nice home. It took us quite a few years. Well, we were a young couple with little money.

But when the children came along, they brought their blessings with them, and the home was filled with joy, plants and the aroma of cooking on Friday evenings, ahead of the Shabbat meal.

You know something? My wife is still beautiful, just like on the first day I met her. Sometimes, when she smiles at me, I can still see the young girl I fell in love with and look for something to keep me busy around the house so she won't see me blushing.

On the first floor of our house, I built a kindergarten for her. Yes, she wanted to take care of children, so I built her a kindergarten.

The walls are colourful, mobiles playing lullabies hang from the ceiling. There's a yard with swings, artificial turf, and a sandbox. And children, lots of children, come to the kindergarten and my wife's loving arms.

Every morning, I wake up to the sound of her singing and their laughter. I go downstairs and watch them from the side. They are so young, glowing. What do they know about pain and the illnesses of life?

I wish that they never find out, I think to myself as I go upstairs to prepare myself a cup of coffee and take a pill.

I take a pill in the morning, which keeps me alive. It's the thing that keeps my leukaemia in check, allowing me to watch my children grow up and hear the parrots that I raise chirp.

Sorry about the sudden shock. I depicted an idyllic scene, and now I am suddenly talking about pills and leukaemia, but it's a part of me. This terrible disease is deep within my body, and nothing but this pill can keep it away.

Well, in fact, except for faith. Yes, faith helps me.

Twenty years ago, my father was diagnosed with cancer, and he, who meant the world to me, asked me to support him throughout the process, to take him to the treatments, and hold his hand as his body slowly waned.

I did so. When he closed his eyes for the last time, I broke down and wept. But before the tears from his parting had dried - before I had grieved enough for him - my sister passed away from the same disease.

You do not know me, but I am tall and strong - I was once in the armed corps! I have large hands, real workman's hands and a deep voice. I am a farmer in soul, and nature is my great love.

But when the same killer, cancer, took them both, something began rotting inside me. It was as if, until then, I had the song and sun of farming in me, and then winter and storms had suddenly come upon me, and it never ends - that horrid winter never ends.

"I will not get cancer," I told my wife one morning. "You promise?" she asked.

"Have I ever broken a promise?" I replied as I stroked her face.

She did not respond.

In 2009, after a routine check-up at the family doctor, he calls and tells me to come over urgently.

My hands are shaking, so my wife is at the wheel. When we finally arrive, he throws the words "leukaemia" into the air.

My wife doesn't look at me. We both realise I had broken my promise.

"Lymphocytic leukaemia," he says. "Not the regular kind, but a rare one - a p17 type mutation."

At that moment, on the doctor's shoulders, I see the angel of death sitting and smoking a cigarette, looking at me and smiling. He said, "I got you, didn't I?" I look him in the eye, I want to answer him - to say that I am not like my father and sister, that I can fight him, I can beat him, but I can't.

The sound of my wife's weeping breaks me, and, suddenly, in a moment, I break down and cry too.

The future didn't seem rosy. My blood cell count doubled every moment, pain was in every part of my body, and the chemo exhausted me. Suddenly, I could do nothing at home, I didn't go to work and, except for lying on the couch watching everyone but me living their lives, I did nothing.

"So, as far as I am concerned, nothing is impossible."

During a periodic exam at the doctor's, I asked him, "Is there anything to do? Any drugs?"

"Only God can help you," he replied.

Another shock, but to the heart, as if it were not broken and shattered enough already.

I started thinking about Heaven, whether I would make the cut or not. You know, I wasn't so worried; even if I didn't make it to Heaven (although I had been a fairly good man, I must say), Hell would not be new to me. I had explored extensive parts of it here, on Earth.

God had not spared me from the evils of life.

I was told about an upcoming conference in Israel, to which some great leukaemia expert from a great hospital in Houston was coming.

The best doctors consulted him, told him about me, the disease and the mutation. He told them about a drug, the one that saved my life.

Its effect - within days of starting to take it - stunned my doctor.

It has kept me alive and has blocked the disease.

It took me time to get a hold of the drug, and money, lots of money.

It could save hundreds of leukaemia patients.

My father, may his memory be blessed, survived Bergen Belsen. A few days before his death, he told me, “Pini’le, nothing is impossible.”

So, as far as I am concerned, nothing is impossible. I was interviewed by all the media outlets, I held demonstrations, I paid a lot of money, and used my connections. Until one day, the drug arrived in the mail. Since then, I have not left it; it is the key to my life.

But what about all the rest of the patients? Won’t they get it? What about someone without a lot of money and his family at his side? Is he sentenced to death?

I, whom the doctor had given just six weeks to live, am alive and happy thanks to this treatment, and there is more to come!

How hard is it to add a life-saving drug, one that grants a long a good life, to the basket of healthcare services?

This drug saved my life, and it can save many others.

Some people can already receive it, and I wish that more patients will get this precious opportunity to live a long life.

I gave my wife a promise and, in the end, I kept my promise, thanks to the drug and faith.

There are no more tears. I smile more frequently. But don’t wipe it off.

I am fighting for other patients so they too can live. I beg you.

The day I learn about someone who cannot afford the drug, the day I learn that he is no longer alive, will be the day that I will remember my father, my sister and the emptiness of this world, and the pain.

The pain will break every wall and conquer every cell in my body. Which is already tired as it is.

בית יפה בנינו אני ואשתי, זה לקח לנו כמה שנים. טוב, היינו זוג צעיר בלי הרבה ממון.

אבל כשבאו הילדים, כמו הביאו ברכה איתם, והבית נמלא אושר, צמחים וריחות בישולים בשישי לקראת ערב.

אתם יודעים משהו, אשתי עדיין יפה, כמו ביום הראשון שהכרתי אותה, לפעמים, כשהיא מחייכת אליי, אני רואה את אותה הנערה הצעירה בה התאהבתי. ומחפש במה להתעסק בבית, כדי שלא תראה שאני מסמיק.

בקומה הראשונה בבית שלנו, בניתי לה גן ילדים. כן, היא ביקשה לטפל בילדים. אז בניתי לה גן.

הקירות צבעוניים, עליהם תלויים מוביילים המנגנים שירי ערש. יש חצר עם נדנדות, מדשאה מלאכותית וארגז חול. וילדים, המון ילדים באים אל בין כתלי הגן ובין ידיה האוהבות של אשתי.

כל בוקר אני קם למשמע שירתה וצחוקיהם, יורד מטה ומביט עליהם מהצד, קטנים כל כך, זוהרים, מה הם יודעים בכלל על כאב ועל תחלואי החיים?

הלוואי ואף פעם לא ידעו, אני חושב לעצמי ועולה למעלה, להכין לי קפה ולקחת כדור.

לא סתם כדור, את אותו הכדור ששם את החיים בחזרה בידי. אני לוקח אותו שלוש פעמים ביום והוא מחזיק אותי חי. הוא היחיד שמרסן לי את סרטן הדם, שנותן לי לראות את ילדי גדלים ואת התוכים שאני מגדל מצייצים.

אני מצטער על הבום הפתאומי, ציירתי לכם פסטורליה יפה ופתאום דיברתי על כדורים וסרטן הדם, אבל זה חלק ממני, המחלה הרעה הזו נמצאת עמוק בתוך הגוף שלי, וחוץ מאותו הכדור כלום לא יכול לה.

אה, בעצם, אמונה. כן, האמונה עוזרת לי.

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לפני 20 שנה גילו לאבי סרטן, והוא, שהיה עטרת ראשי, ביקש אותי ללוות אותו בתהליך, לקחת אותו לטיפולים ולהחזיק לו את היד כשהגוף החל לדעוך אט אט.

עשיתי כן, כשהוא עצם את עיניו התפרקתי ובכיתי וכשהוא הלך לעולמו, יבשו לי מהר הדמעות, לא הספקתי לבכות ולהתאבל מספיק עליו ואז גם אחותי הלכה אל עולמה מאותה המחלה.

אתם לא מכירים אותי, אבל אני גבוה, חסון, שריונר לשעבר! ידי גדולות, ידיי עבודה של ממש וקולי עבה, אני חקלאי בנשמתי והטבע הוא אהבתי הגדולה.

אבל מאז והלכו שניהם מאותו הרוצח, הסרטן, משהו בתוכי נרקב, כאילו ואם עד עכשיו הייתה בי רננה ושמש יפה של חקלאות, פתאום הגיע החורף והסופות, והוא לא נגמר, החורף המגעיל הזה לא נגמר.

”בי הסרטן לא יגע“ אמרתי לאשתי בבוקר אחד ”אתה מבטיח?“ שאלה

”פעם לא קיימתי?“ ליטפתי את פניה.

היא לא השיבה.

2009, אחרי בדיקות שגרתיות אצל רופא המשפחה, הוא מתקשר ואומר לי לבוא אליו דחוף.

ידיי רועדות אז אשתי נוהגת. כשאנחנו סוף סוף מגיעים והוא זורק לאוויר את צמד המילים ”סרטן הדם“

אשתי לא משירה אלי מבט. שנינו יודעים ומבינים, שאת הבטחתי לא קיימתי.

”לוקמיה לימפוציטית“ הוא זורק לחלל האוויר.

באותו הרגע, על כתפיו של הרופא, ראיתי את מלאך המוות יושב ומעשן סיגריה, מביט בי בחיוך ואומר ”שברתי לך את כל הכלים אה?“ ואני מביט לו בעיניים, רוצה להשיב לו, להגיד לו שאני לא כמו אחותי ואבי, שאני יכול לו, ואני עוד אנצח אותו, אבל אני לא יכול.

” אז מבחינתי, לא היה דבר שאי אפשר.“

קול בכייה של אשתי שובר אותי ופתאום, באחת, גם אני נשבר ומתחיל לבכות.

העתיד לא נראה ורוד, ספירת כדוריות הדם שלי הלכה והכפילה את עצמה בכל רגע, הכאבים לא דלגו על אף חלק בגופי והכימותרפיה התישה אותי. פתאום לא יכולתי לעשות כלום בבית, לא הלכתי לעבודה, וחוץ מלשכב על הספה ולראות איך כולם חיים את חייהם חוץ ממני, לא עשיתי כלום.

בבדיקה התקופתית אצל הרופא, שאלתי אותו ”יש משהו לעשות? יש תרופה?“

והוא ענה לי ”רק אלוהים יעזור לך“

עוד בום, אל תוך הלב, כאילו והוא לא סדוק

ושבור גם ככה.

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התחלתי לחשוב על גן עדן, אם אעבור סלקציה או לא. אתם יודעים, לא כל כך דאגתי, גם אם לא אכנס לגן העדן (אף על פי שהייתי אדם די טוב, אני חייב לציין) גיהינום לא יהיה חדש לי, בדקתי חלקים נרחבים ממנו עוד כאן, על פני האדמה.

אלוהים לא חסך ממני את הרע שבחיים.

סיפרו לי שיש כנס בקרוב, שצריך להגיע איזה מומחה גדול בסרטן הדם לארץ, אחד יודע כל.

טובי הרופאים התייעצו איתו, סיפרו לו עלי, על המחלה ועל המוטציה והוא סיפר להם על התרופה, זו שהצילה את חיי.

פתאום החיים נצבעו לי שוב בצבעים זוהרים, קמתי מהמיטה, הוצאתי את ערכת העבודה שלי, את המקדחה, המברג ומברשות הצבע והתחלתי לעבוד בבית.

ממש כמו ילד שגילה שוב את החיים, בבוקר לקחתי את התרופה, בצהריים היה עוד מתקן חדש בחצר

בצהריים לקחתי שוב את התרופה, בערב היה עוד קיר צבוע בבית.

החיים האלה, שנעצרו לי פתאום, מבלי שביקשתי בכלל, קיבלו סוללות בדמות כדור קטן.

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אבי, זכרונו לברכה, שרד את ברגן בלזן, כמה ימים לפני מותו אמר לי "פיניל'ה אין דבר שאי אפשר"

אז מבחינתי, לא היה דבר שאי אפשר, התראיינתי לכל אמצעי התקשורת, ערכתי הפגנות, שילמתי המון כסף והפעלתי קשרים. עד שיום אחד, הגיעה לי התרופה בדואר, ומאז אני לא עוזב אותה, היא המפתח לחיים שלי.

אבל מה עם השאר? הם לא יזכו? מה עם מי שאין ממון בכיסו ומשפחה לצידו? דינו למוות?

כמה שווים חיי אדם?

לו רק לא היה לי הכסף, לו רק חשבון הבנק שלי היה במצב גרוע יותר

האם הייתי עדיין פה? ביניכם? מספר לכם את הסיפור?

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הבטחתי לאשתי ובסופו של דבר קיימי את הבטחתי, בזכות התרופה ובזכות האמונה.

הדמעות כבר אינן

והחיוך בא אל פני לעיתים קרובות יותר.

אני מתנדב בעמותה המסייעת לאנשים כמוני, קורא ללחימה בכל עת, לתקווה גדולה ומכניס בחולים רוח חזקה שאינני זקוק לה עוד.

לפעמים, כשאני פוגשת איזה חולה שאומר לי שהוא רוצה להלחם, שהוא רוצה את התרופה, שהוא חייב להיות חזק- אני מחייך, חיוך גדול וטוב

אבל אל תמחקו לי אותו,

אני מתחנן,

ביום שאדע על מישהו שידו לא היתה משגת והתרופה לא באה אל גופו,

ביום שאדע שהוא כבר איננו בין החיים.

זה היום בו אזכר באבי, באחותי, ובהבלי העולם הזה

והכאב,

הכאב ישבור כל חומה ויכבוש כל תא

בגופי,

שגם ככה כבר עייף.

Poland

I was very fortunate in life

Janina Bramowicz

Chronic lymphocytic leukaemia

How did you learn about the disease?

I had frequent colds. My family doctor was becoming increasingly concerned and she decided to run blood tests that revealed very high white blood cell counts.

Your life has changed in that moment...

Indeed, a new chapter has begun. When I come to think about it now, I feel I've been very lucky in so many ways.

It is a strange thing to say for a patient suffering from chronic leukaemia for the past 10 years...

It's a blessing in disguise. I have always been very fortunate in life. Now, just as back then, I am taken care of; a guardian angel has been watching over me. Very importantly, I was lucky to meet top-notch doctors. An amazing doctor has been taking care of me from the very beginning of my disease. Also, I was qualified for a novel treatment and my therapy has been successful so far. Besides, my husband has been supportive the whole time. Still, I'd never believe it if you had told me a decade ago I would be saying this. When I first learned about my disease, I thought my life was over. For me it was a death sentence. I once even dreamt of my own funeral. I thought I would die soon. Not only was I terrified, I was ashamed of the diagnosis.

When you first learned you had leukaemia you thought it was a death sentence. Do you still believe it?

No, not at all. I have been living with leukaemia for so long. I'm not sure I use the right words, but my condition has become so normal for me. It has become a part of my everyday life and I sometimes don't even think about it. I'd never expect I would feel so good. Even the treatment hasn't been so hard to tolerate. I started my chemotherapy soon after I was diagnosed: five sessions, five days a month. I went to the hospital, had my intravenous infusion, and then went back home. I was tired during the first days. But I didn't experience hair loss or vomiting during my chemo.

What scared you most: treatment or the disease itself?

The disease. This was because I had no side effects during my therapy. But then again, I had my guardian angel right behind me as it turned out the disease relapsed just in time, so to say. An opportunity has arrived to introduce a novel therapy here in Ciechanów. I was the first patient to receive it, and my doctor calls still me this way. When I arrived at the hospital for my first intravenous infusion, I felt like a queen. All the doctors came to see me. The therapy was a bit more difficult to endure, but the results went back to normal after six sessions. I was ready to get on with my life. There wasn't anything to worry for several years. Two years ago my blood tests indicated the disease was getting worse again. But once again I was lucky.

Meaning?

This time I had genetic tests in addition to blood and bone marrow screening. My doctor told me I had a TP53 deletion that carried a poor prognosis. After all, this was good news. It turned out I had the chance to receive one more novel therapy. It was designed specifically for my type of leukaemia. Again, my doctor didn't waste any time. She learned of a new therapy introduced in Warsaw and sent my papers to the Haematology Institute. She hoped I might qualify. I was invited for a series of tests in Warsaw and I waited for the final verdict. After several weeks I received a positive decision. I was lucky again as I was told later I was the last or last but one patient to qualify to the program to receive the treatment.

How do you see your disease now?

This new treatment gave me hope. I realise I can live with this condition. I have been living with it for 10 years now and I hope I have 10 or more years to live. Now I consider it a chronic condition. Some people have diabetes, others have asthma, I have chronic leukaemia. And I want to tell these people that it's not the end of the world. You can live with a disease like mine.

"My condition has become so normal for me. It has become a part of my everyday life and I sometimes don't even think about it."

Jak się Pani dowiedziała o chorobie?

Często zaczęłam się przeziębiać. Moją lekarz rodzinną to zaniepokoiło i zleciła mi badania krwi, wyniki wykazały, że mam niesamowicie wysokie wskaźniki białych krwinek.

Diagnoza musiała zmienić całe Pani życie...

Rzeczywiście, wtedy zaczął się nowy roździał. Ale jak tak o tym teraz myślę, to uważam, że mam sporo szczęścia.

To brzmi trochę dziwnie, zważywszy na to, że od 10 lat choruje Pani na przewlekłą białaczkę...

Szczęścia w nieszczęściu. Zawsze mi się w życiu udawało. Jak widać nawet teraz, przy takiej chorobie, też ktoś otoczył mnie ochroną, jakiś anioł stróż nade mną czuwa. Np. mam szczęście do dobrych lekarzy. Od początku choroby prowadzi mnie świetna specjalistka; dwa razy załapałam się na najnowsze leczenie; a terapia przebiega bez zakłóceń. I przez cały czas mam ogromne wsparcie w mężu. Ale to prawda, gdyby mi Pani powiedziała 10 lat temu, że tak będę mówić to bym nie uwierzyła. Wtedy, kiedy pierwszy raz o tym się dowiedziałam, myślałam że to koniec. Wyrok śmierci. Śnił mi się nawet mój pogrzeb. Uważałam, że szybko umrę. Byłam nie tylko przestraszona, ale też wstydziłam się diagnozy, którą usłyszałam.

Kiedy pierwszy raz Pani usłyszała o chorobie, myślała Pani o tym jak o wyroku. Nadal tak Pani uważa?

Nie. Żyję z chorobą od tylu lat. Nie wiem, jak to określić, tak jakby choroba mi spowszedniała. Stała się częścią codzienności, czasem wręcz o niej zapominam. To, co mnie zaskoczyło, to to, że nieźle się czuję. Zresztą nawet leczenie znoszę i znosiłam całkiem dobrze. Bardzo szybko po diagnozie skierowano mnie na chemioterapię: pięć sesji po pięć dni w miesiącu. Chodziłam do szpitala, gdzie podawano mi leki dożylnie i wracałam do domu. Przez pierwsze dni byłam zmęczona. Ale na szczęście nie wypadły mi włosy, nie wymiotowałam.

Co panią bardziej przerażało: leczenie czy sama choroba?

Choroba. Bo podczas leczenia nie odczuwałam skutków ubocznych. Ale tu po raz kolejny czuwał nade mną mój anioł stróż, okazało się, że choroba wróciła w odpowiednim momencie, jeżeli w ogóle tak można mówić. Akurat pojawiła się możliwość, żeby tu u nas, w Ciechanowie przyjąć nową terapię. I byłam pierwsza - dlatego właśnie tak o mnie mówi moja pani doktor. Kiedy pojechałam do szpitala na pierwszy wlew (lekarstwo podaje się dożylnie) czułam się jak królowa. Przyszli wszyscy lekarze. Tę terapię zniosłam trochę gorzej, ale po sześciu sesjach wyniki wróciły do normy. Mogłam wrócić do zwykłego życia. I znów przez kilka lat nie musiałam się martwić. Dwa lata temu wyniki krwi po raz kolejny pogorszyły się. Ale znów miałam farta.

Czyli?

Tym razem zrobiono mi oprócz badań krwi i szpiku, również testy genetyczne. Pani doktor mi powiedziała, że mam „źle rokującą delecja genu TP53". Wbrew pozorom to okazało się dobrą wiadomością. Bo znaczyło, że mam szansę otrzymać jeszcze kolejną, najnowszą terapię. Celowaną na moją odmianę białaczki. I znów zadziałała moja doktor. Usłyszała, że w Warszawie ruszyło leczenie idealne dla mnie i wysłała do Instytutu Hematologii moje papiery. Liczyła, że może się zakwalifikuję. Zaprosili mnie na kolejne badania do stolicy, a potem czekałam na werdykt. Po kilku tygodniach okazało się, że udało się, dostałam się. I wie Pani co, tym razem – jak mi potem powiedz ieli – miałam szczęście, bo jako ostatnia lub przedostatnia dostałam miejsce w programie, w którym podają to leczenie.

Jak teraz postrzega Pani swoją chorobę?

Nowe leczenie dało mi nadzieję. Zrozumiałam, że z tą chorobą można żyć. Żyję już 10 lat i mam nadzieję, że uda się jeszcze 10 a może i dłużej. Teraz już traktuję ją, jako chorobę przewlekłą. Ktoś ma cukrzycę, inny astmę, jak mam przewlekłą białaczkę. I mam ochotę powiedzieć, tym, co zaczynają choroby, że nie jest tak źle. Że z tą chorobą można żyć.

“ Tak jakby choroba mi spowszedniała. Stała się częścią codzienności, czasem wręcz o niej zapominam. ”

Portugal

Believing in better

Luísa Torres

Multiple myeloma

My name is Luísa, I'm married, I have two children. I'm the youngest of six siblings. Like all the kids, I had dreams, ambitions. I always tried to walk in the direction of my achievements.

But life is like a sandcastle, it takes time to build but it can crumble in an instant. That was how I felt when I entered into the hospital in early March 2014 with pneumococcal pneumonia. In fact, no one imagined that this would be the beginning of a long and arduous path that I and my family would have to travel. Three months later came the verdict. "You have multiple myeloma," the doctor told me. I had never heard anything about this disease. It was not easy to manage the vortex of emotions that I felt and my family was also in shock!

Once I understood the disease, I explained it to my family. I tried to reassure them, although I was still afraid myself. The pain worsened day after day, I even lost mobility. I was dependent upon my family for the most basic needs.

In July 2014, I started a chemotherapy regimen that was followed by five months of treatment. In December 2014, with the approach of Christmas, the gift that I truly expected was to be called by the hospital to initiate the first part of the stem cell transplant. The gift came on December 29th. I was hospitalised, I did more chemotherapy, and on January 11th 2015, they collected the cells. Another step had been taken!

Back home to recover, I was confronted with the loss of my hair; this was truly a "painful" moment.

The last phase was imminent; on February 24th 2015, after more chemotherapy, I did the auto transplant. The following 15 days were honestly the worst of all the treatments to date.

The recovery at home was easier. The positive attitude that I kept was crucial towards a more efficient recovery. My hair was growing, I recovered my weight, and the analysis showed significant improvements.

After hesitations and questions in May 2015, I decided to participate in a clinical trial. New medicine can only be developed with the cooperation of the public, and that was the motivating factor that led me to accept.

Today the disease is controlled; I almost have a normal life.

This less positive period of my life resulted in a learning phase. I learned to prioritise and to relativise everyday situations. The support of my family and friends was crucial. I thank each one of them for the unconditional love that they gave to me, and still give.

I want to thank the healthcare professionals from both hospitals that carefully and lovingly treated me.

I leave a message of hope for all who fight against oncological diseases. I ask you to believe and to never give up this battle as lost.

Because I believe, I joined the team of volunteers of the Portuguese Leukaemia and Lymphoma Association, whose mission is to help and guide patients according to their needs and to share with other patient experiences with them.

Believe that the victory will be yours; part of the cure depends on the positive energy. Keep a positive attitude and soon this less good time will be overcome! Believe is the magic word!

"The support of my family and friends was crucial. I thank each one of them for the unconditional love that they gave to me, and still give."

O meu nome é Luísa, sou casada, tenho dois filhos. Sou a mais nova de seis irmãos. Como todas as crianças, tinha sonhos, ambições. Desde sempre procurei caminhar no sentido das minhas concretizações.

Mas, a vida é como um castelo de areia, leva tempo a construir mas pode desmoronar-se de um momento para o outro. Foi o que senti quando dei entrada no hospital, (início de março de 2014), com uma pneumonia pneumocócica. Na verdade, ninguém imaginava que aquele era apenas o início de um longo e difícil caminho que eu e a minha família teríamos de percorrer. Três meses depois chegou o veredito. "A senhora tem um Mieloma Múltiplo", disse-me a médica. Nunca ouvira falar desta doença. Não foi fácil gerir o turbilhão de emoções que senti e, por outro lado. a minha família estava em choque!

Depois de compreender a doença, comuniquei à minha família. Ainda que assustada tentei tranquilizá-los. As dores agravavam dia após dia, cheguei a perder a mobilidade. Dependia da família para as necessidades mais básicas.

Em julho de 2014, iniciei a quimioterapia, seguiram-se cinco meses de tratamento. Em dezembro de 2014, com a aproximação do Natal, o presente que eu mais esperava era ser chamada pelo hospital para fazer a primeira parte do transplante (a mobilização das células). O presente chegou a 29 de dezembro 2014, fui internada, fiz mais quimioterapia, a 11 de janeiro de 2015, recolhiam as células. Mais uma etapa ultrapassada!

De volta a casa para recuperar, fui confrontada com a queda do meu cabelo, este foi um momento verdadeiramente "doloroso".

" O apoio da minha família e amigos foi determinante, agradeço a cada um o carinho incondicional que me deram e dão. "

A última fase estava eminente, dia 24 de fevereiro de 2015, depois de mais quimioterapia, fiz o auto transplante. Os 15 dias subsequentes foram francamente os piores de todos os tratamentos anteriores.

A recuperação em casa é mais fácil. A atitude positiva que mantive fui fundamental rumo a uma recuperação mais eficiente. O cabelo foi crescendo, o peso recuperado, as análises indicavam melhorias significativas.

Depois de hesitações e questões em maio de 2015, decidi participar num ensaio clínico. A medicina só pode evoluir se houver cooperação da sociedade, foi este o fator motivacional que me levou a aceitar.

Hoje a doença está controlada, faço uma vida praticamente normal.

Este período menos positivo da vida acabou por se traduzir numa fase de aprendizagem. Aprendi a priorizar e a relativizar as situações quotidianas. O apoio da minha família e amigos foi determinante, agradeço a cada um o carinho incondicional que me deram e dão.

Deixo um agradecimento aos profissionais de saúde dos dois hospitais que cuidadosa e carinhosamente me trataram.

Deixo uma mensagem de esperança a todos os que lutam contra uma doença oncológica. Peço-lhes que acreditem e que nunca deem esta batalha como perdida.

Precisamente porque acredito. Integrei a equipa de voluntários da Associação Portuguesa de Leucemias e Linfomas (APLL), cuja missão é ajudar, orientar os doentes segundo as suas necessidades e partilhar com eles a experiência de ex-doentes.

Acredite o triunfo será seu, pois parte da cura depende das energias positivas que emanam de si. Mantenha uma atitude positiva e em breve este momento menos bom será superado! Acreditar é a palavra mágica!

Romania

Regaining life

Anonymous

Chronic lymphocytic leukaemia

I discovered in July 2012 a little lump on my neck, it did not appear to be a lymph node. I did my blood tests as recommended by the GP and I was told to also see a haematologist. After the physical exam and several tests, the diagnostics came quickly: CLL with small cell-B type.

It was quite a shock. I became agitated and angry, my wife also was shaken, we had little children. My life was upside down, all the plans for the future were suddenly cancelled. I had no idea if I could still work being ill, we had no money for going abroad to be treated. Everything was a mess. It seemed like we had no hope.

The haematologist was the only one able to calm me down, I was told that there are treatments available, and she explained to me how those treatments should be applied, so a little light was appearing at the end of the tunnel. We started with a classical scheme of chemotherapy, meanwhile the doctor was building the medical dossier for approval of a newer treatment. This dossier approval usually takes time, it is approved by a national commission that gathers on a monthly basis. Time is the only thing that I did not have.

I had 5 classic schemes until I received approval for the new chemotherapy, I had 4 courses of this until we had to stop it because my liver was severely affected by all the medicines that I took. During the treatment I managed to keep on working, I squeezed in the days that I had to be hospitalised between the working days. The fact that I was active kept me in a better mood and I think that helped me to better handle the adverse events that occurred and were pretty tough. The treatment was efficacious, the blood tests seemed normal, except the hepatic tests that were pretty ugly (TGO, TGP were higher than 1300). Because of that, in March 2013, the haematologist decided to stop the therapy. In 18 months the levels became normal, but I discovered that I was infected with the Hep C virus. Because of the virus, together with the haematologist we decided to wait for another option. In September 2015, I heard for the first time about a new therapy, from my doctor. It seemed to be the perfect solution for me, it was not chemotherapy. Then I researched more on the subject, it seemed too good to be true, but it was so new and in Romania was not reimbursed. So, again, bad perspectives. Still, I had had all the tests in order to see if I could benefit from this therapy.

In December 2015, my doctor called me and she told me that "we have therapy for you." I did not dare to ask any questions about how she managed this, I was so happy to start the treatment. In that specific moment the blood tests had high levels, the lymph nodes in the neck area grew and were bigger than 4 cm, and I started touching them every second.

After starting the treatment, in 3-4 days the lymph nodes shrank, I really could feel them shrinking, they reduced from the evening till morning. After a month they practically disappeared.

The blood parameters evolved exactly as described, they increased at the beginning, then, reducing, and after 7 months they are pretty normal, my liver is not affected and also my uric acid level is normal. The adverse events are minor, some dizziness or sensations of flu. The administration level is common, once a day.

I would say that there is also an effect on my mood. I became more active, more confident, I have a better performance at work. In short, I have regained my life.

" My life was upside down, all the plans for the future were suddenly cancelled."

In iulie 2012, am descoperit o mica umflatura moale in zona gatului care nu parea a fi un ganglion . Am facut analize de sange recomandate de medicul de familie , care aveau valori destul de mari incat am fost trimis la hematologie . Dupa un consult si mai multe teste diagnosticul a fost pus rapid : LLC cu celula mica tip B.

Am fost afectat zdravan, am devenit foarte agitat si nervos, sotia a fost de asemenea afectata, copiii erau mici, practic toata viata ne-a fost data peste cap, au disparut toate planurile de viitor, nu stiam cat timp voi mai putea lucra., nu aveam bani pentru tratamente scumpe in strainatate, totul devenise sumbru. Parea ca nu mai exista nicio speranta Medicul hematolog a reusit totusi sa calmeze lucrurile, am inceput sa inteleg ca totusi exista tratamente, cum vor fi aplicate, a inceput imediat o schema de tratament cu chimioterapie clasica, intrucat medicamentul considerat de baza - trebuia obtinut printr-o aprobare speciala a unei comisii la nivel national care se intrunea o data pe luna si putea sa dureze mult timp. Am facut 5 cure de tratament initial pana a fost aprobat dosarul . si apoi 4 cure cu un citostatic mai nou dupa care tratamentul a fost oprit intrucat aparuse o afectare grava a ficatului datorata toxicitatii medicamentelor folosite.Pe parcursul tratamentului cu citostatice am reusit totusi sa nu intrerup serviciul, natura profesiei imi permitea sa ma strecor printre termenele la care aveam lucrari si zilele in care faceam tratament. Faptul ca lucram cred ca m-a ajutat sa trec mai usor peste reactiile adverse ale tratamentului, care erau destul de dure in anumite momente. Tratamentul dadea totusi rezultate, analizele de sange tindeau sa se apropie de nivele normale, dar intrucat ficatul fusese afectat zdravan (TGO, TGP avea valori peste 1300) medicul hematolog a decis intreruperea tratamentului in martie 2013. Dupa aproximativ 18 luni fara tratament specific analizele la ficat au ajuns la valori normale, dar am descoperit ca intre timp aveam virusul hepatitei C.. Medicul hematolog a considerat riscant sa reia tratamentul clasic din cauza virusului C si a hotarat sa mai astept pana la gasirea altei solutii . Astfel prin septembrie 2015 medicul mi-a spus despre un medicament nou care nu era citostatic, parea foarte potrivit pentru cazul meu. Am aflat apoi mai multe despre medicament care parea déjà de domeniul science-fiction fata de tratamentele clasice, dar nu exista in sistemul medical romanesc, era nou, de abia fusese aprobat. Asa ca din nou perspectiva proasta. Si totusi am facut din nou toate analizele, pentru ca medicul sa fie sigur ca se poate administra in cazul meu.

In decembrie 2015 medicul hematolog m-a chemat, mi-a spus avem solutia , n-am indraznit sa intreb de unde , cum il gasise si asa am inceput tratamentul. In acel moment analizele de sange aveau valori mari , iar ganglionii din zona gatului se inmultisera si ajunsesera la dimensiuni mari, peste 4 cm, si din reflex ii pipaiam mereu. Dupa trei, patru zile de tratament ganglionii au inceput sa scada, ii simteam la pipait ca devin mai mici, scadeau de seara pana dimineata, dupa o luna au disparut aproape total , Analizele de sange au evoluat exact asa cum mi s-a spus , au crescut la valori mari la inceputul tratamentului dupa cre au inceput sa scada progresiv, dupa sapte luni se apropie de valorile normale, ficatul nu este afectat de tratament – TGO, TGP au valori normale, iar la rinichi acidul uric are valori normale. Reactiile adverse sunt minore , usoare ameteli sau senzatii de raceala Administrarea medicamentului este banala,o data pe zi. Cred ca exista si un efect legat de starea psihica , am devenit mult mai activ, mai increzator, am un randament mult mai bun la serviciu, pe scurt mi-a revenit pofta de viata.

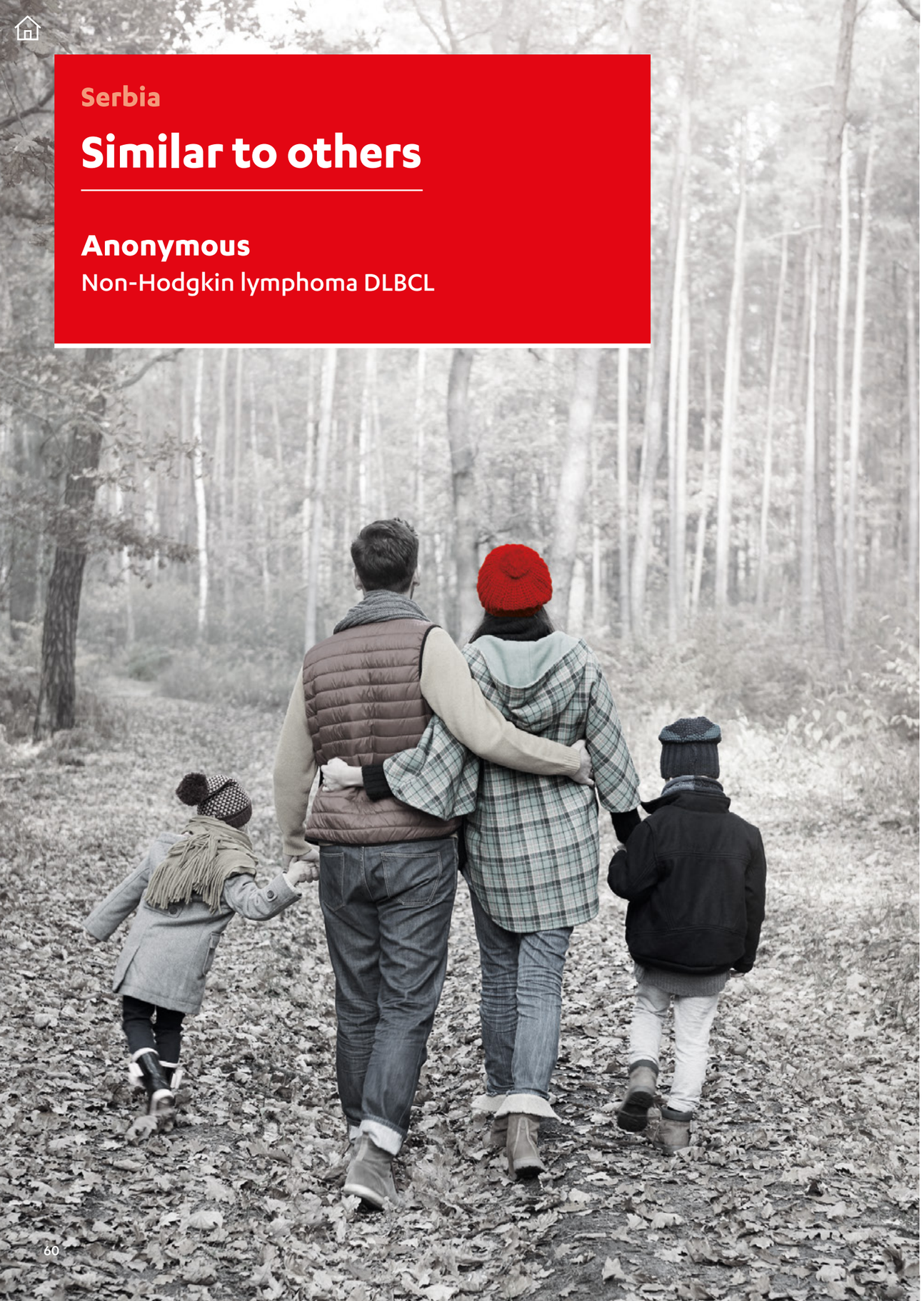
“ Practic toata viata ne-a fost data peste cap, au disparut toate planurile de viitor.”

Serbia

Similar to others

Anonymous

Non-Hodgkin lymphoma DLBCL



I feel that my story is overwhelmingly similar to the stories of all patients who fought and eventually won. The stories are so similar because we are so similar. The same fear, shock, disbelief and pain. That is why this is not just my story, but the story of others, and there are many of us, who travelled this road from defeat to victory, the road through lymphoma.

You know, I was just thinking that I accomplished a lot of things in life: mother, wife, successful at work. Everything somehow went smoothly, everything was as good as it gets, when suddenly, at the age of 32, I was diagnosed with lymphoma.

I have to be honest, at the beginning I was not scared, not a bit, since I did not understand what the doctor was talking about. I even thought: "Why is he so scared, when I am not?" Unfortunately, I very soon realised that his fears were reasonable. Lymphoma is a dangerous and serious disease. In my case, it started with mild fever, pain in my left leg and a growing lymph node but not on the neck, or in an armpit or groin, but on the head, where I frequently fastened a hairband for my ponytail.

That is how it started and then it got worse, with pleural effusion, high fever, unbearable pain and the diagnosis of IV C.S. non-Hodgkin lymphoma DLBCL. Very soon I was transferred from Niš to the MMA when the true battle began. I would not bother you with details like 'I received this treatment and then that treatment, then radiation, and so forth' although there were many of these, finishing with bone marrow transplantation and maintenance therapy to follow two years after the transplantation. I just want to say: I endured it all.

"Suddenly, at the age of 32, I was diagnosed with lymphoma."

It was difficult. Sometimes it appeared that there was no way out, but very frequently both I and the people around me remained positive even under these circumstances, in the mood for fun and a good laugh. I carried a positive attitude then and I still carry it now. I do not wish to forget everything and I do not want and cannot forget it. I am willing to help people who experience the same story now at least with a piece of advice. I discovered the beauty of life in small, tiny things such as a sledge in the snow, playing with my sweet girls, long walks, reading books... I used not to pursue these activities, seeing them as an unnecessary waste of time. And then, when you have abundance of time and a single thought, to heal, to return back to your family, you come to understand what you have missed. For years now I have been catching up with things that I missed before lymphoma, and I am doing quite well. I would be lying if I said no demons from the past ever frighten me. But, haven't we all got some of these?

You see, my story is nothing special or unique, since all of us are the same when it comes to fighting for one's own life.

Osećam da će moja priča u mnogo čemu neodoljivo da podseća na sve priče pacijenata koji su se borili I izborili. One jesu tako slične zato što smo svi mi tako slični. Isti strah, šok, neverica i bol. Ista patnja i ista radost kada sve krene na bolje. Zato ovo nije samo moja priča, već i svih onih, a na žalost ima ih dosta, koji su prošli put, put od poraza do pobede, put kroz limfom.

Znate, taman sam pomislila da sam dobar deo stvari u životu odradila, majka, supruga, uspešna u poslu, i da je sve proteklo, da bolje ne može biti,kad u mojoj 32.-godini dobih dijagnozu limfoma.

Moram priznati, u početku se nisam uplašila ni malo, jer nisam znala o čemu mi doktor priča. Čak sam i pomislila „Što se on toliko plaši, kad se ja ne plašim?" Na žalost, vrlo brzo sam shvatila da su njegovi strahovi bili opravdani. Limfom jeste opaka i teška bolest. Počela je kod mene, sa niskim temperaturama, bolom u levoj nozi i žlezdom koja je narasla, ali nije bila ni na vratu ni ispod pazuha ili u preponama, već na glavi, baš tamo gde sam često vezivala konjski rep.

Počelo je tako, a onda je krenulo na gore, izliv u plućima, visoke temperature, nesnosni bolovi i dijagnoza IV C.S. Non-Hodgkin limfoma DLBCL. Vrlo brzo sam posle Niša, prebačena na VMA, i tada počinje prava borba. Ne bih Vas sada opterećivala stvarima kao što su primala sam te I te terapije, zračenja, itd., bilo ih je stvarno mnogo, na kraju i transplantacija kostne srži i dve godine nakon transplantacije opet održavajuće terapije. Želim samo da Vam kažem jedno, izdržala sam sve.

Bilo je teško, nekad se činilo da nema izlaza, ali vrlo često smo ja I ljudi u mom okruženju i u takvim uslovima bili pozitivni, raspoloženi za šalu i smeh.

“ Kad u mojoj 32.-godini dobih dijagnozu limfoma. ”

Taj pozitni stav nosila sam tada, nosim i sada. Ne želim sve da zaboravim, jer ne mogu a i neću, rada sam da pomogem ljudima koji sada prolaze kroz istu priču, pa makar i savetom. Lepotu života našla sam u malim, malecnim stvarima kao sankanje i igranje sa mojim slatkim devojčicama, duge šetnje, čitanje knjiga...Ranije sam ih se odricala, bilo je to nepotrebno gubljenje vremena. Onda, kada vremena imate na pretek sa samo jednom jedinom misli u glavi, da ozdravim da se vratim porodici, shvatite šta ste sve propustili. Godinama nadoknađujem ono što sam propuštala pre limfoma i dobro mi ide. Slagala bih kada bih rekla da me demoni prošlosti ne posećuju, ali imamo ih svi zar ne?

Eto, vidite i sami, moja priča nije ni posebna ni jedinstvena, jer u borbi za sopstveni život svi smo isti.

Slovakia

Changing everything

Anonymous

Multiple myeloma

In April 2005 I was diagnosed with multiple myeloma – a cancer formed by malignant plasma cells found in the bone marrow. I accepted the illness with sadness but with humility. Immediately I surrounded myself with music and a large number of books in which I started to look for help.

I radically changed my diet. I started to eat according to the principles of macrobiotics, which is based on cereals and cooked vegetables. I rarely ate meat, milk products, fat and refined sugar. I have lost 12 kg and completely changed my image, which helped me a lot psychologically. This physical change was very quickly followed by a psychological change. Prayers, meditations, sleepless nights, tearful nights, conversations with God and with my late mother brought me everyday solutions and opened alternative views. I chucked away lots of old stuff and clothes which had previously been all over the apartment. Finally I discovered my roots in my mother's birthplace in Turiec. This, which for many people would be a hardship, became a blessing for me and, thank God, changed my entire life for the good. My family, friends and colleagues are at this time a big support for me.

In autumn 2005, I continued my chemotherapy treatment in the Faculty Hospital in Martin where I have been under the care of the excellent consultants during my illness. After each treatment in the hospital I was able to return to work. In October 2005, during a beautiful Indian summer my son, Michal, got married. Maybe as a result of all the physical and emotional exhaustion, I then fell ill with painful shingles, soon followed by a serious case of pneumonia which resulted in me being admitted to hospital. In February 2006 I underwent an autologous bone marrow transplant which proved to be successful.

After a two-week stay in hospital and a further week recovering at home, I was able to return to work again and participate fully in school life. I can honestly say that the bone marrow transplant was the most emotionally and physically difficult thing I have had to face in my life. It has not been easy to come to terms with the experience and the recurring memories and as a result of this I have since had treatment from a psychotherapist for depression. As well as this, I have also had some dental problems after a tooth extraction as the gum would not heal properly and this, in conjunction with sleeping problems, has meant it has been quite a challenging time. In April 2006 I was delighted to receive a special teacher's award from the Slovak Minister of Education for the high standard of results of my pupils. In terms of my diet, I have stopped following the macrobiotic diet I had been following, which I have come to regret as my weight has increased! I currently do not take any nutritional supplements but I do drink high quality red wine everyday – and eat sauerkraut. Despite being registered disabled, I am still working and have recently passed a computer course and feel that together with the support of my family, I will be able to live with multiple myeloma for a long time in peace. I want to thank you all.

"Together with the support of my family, I will be able to live with multiple myeloma for a long time in peace."

V apríli 2005 mi diagnostikovali mnohopočetný myelóm – nádorové ochorenie kostí. Chorobu som prijala so smútkom, ale s pokorou. Hneď som sa obklopila hudbou a množstvom kníh, kde som začala hľadať pomoc.

Radikálne som zmenila spôsob stravovania. Stravovala som sa podľa zásad makrobiotiky, ktorá pozostáva z obilnín, strukovín, varenej zeleniny. Nejedla som mäso a mliečne výrobky, tuky ani rafinované cukry.

Schudla som 12 kilogramov a úplne zmenila výzor, čo mi psychicky veľmi pomohlo. S fyzickou zmenou prišla rýchlo i zmena duševná. Modlitby, meditácie, prebdené a preplakané noci, rozhovory s Bohom, mojou mŕtvou mamou mi každodenne prinášali riešenia a otvárali nové cesty. Povyhadzovala som množstvo starých vecí a šiat, ktorými som dovtedy mala zaprataný celý byt. Konečne som objavila svoje korene v rodisku mojej mamy v Turci. Táto pre mnohých tvrdá rana sa pre mňa stala požehnaním a zmenila mi dokonale život – chvála Bohu k lepšiemu. Nasledovala autológna transplantácia kostnej drene. Bola som trochu boľavá a unavená. Toto obdobie nebolo najľahšie a trochu ma to psychicky vyviedlo z miery až tak, že som začala užívať antidepresíva. Veľkou vzpruhou je v tomto období pre mňa moja rodina, množstvo priateľov, kolegov a moji žiaci.

Na jeseň 2005 moje liečenie pokračovalo chemoterapiami vo Fakultnej nemocnici v Martine, kde som doteraz v starostlivosti výborných špecialistov. Po každom pobyte v nemocnici som nastúpila do zamestnania. V októbri 2005 za krásneho babieho leta sa ženil syn Michal a možno po mojom väčšom fyzickom a psychickom vypätí som dostala bolestivý pásový opar a ťažký zápal pľúc, ktorý si vyžiadal hospitalizáciu. Neskôr som úspešne absolvovala autológnu transplantáciu kmeňových buniek. Po dvoch týždňoch pobytu v nemocnici a týždennom domácom liečení som znova nastúpila do práce, kde som sa venovala akciám, ktorých som bola spoluorganizátorom. Samotná transplantácia však patrí k najťažším chvíľam v mojom živote po psychickej aj fyzickej stránke. Neustále vracanie sa v spomienkach k pocitom počas autotransplantácie, ma viedli k návšteve psychiatra a k následnému užívaniu antidepresív. Naviac sa pridružil problém s nehojacou sa ranou po vytrhnutom zube, a tiež problémy so spánkom. Čo sa týka životosprávy, prestala som dodržiavať makrobiotickú diétu, čo ma trochu mrzí, lebo som pribrala na váhe. Neužívam žiadne výživové doplnky, denne si vypijem kvalitné červené víno a jem kvasenú kapustu. Napriek tomu, že mám preukaz zdravotne ťažko postihnutej osoby, stále pracujem v škole na Konzervatóriu v Žiline. Urobila som si aj počítačový kurz a verím spolu s mojou rodinou, že s mnohopočetným myelómom budem žiť dlho v mieri. Za to ďakujem Vám všetkým!

“ Verím spolu s mojou rodinou, že s mnohopočetným myelómom budem žiť dlho v mieri. ”

Slovenia

One win at a time

Mojca Jambrešič

Hodgkin's lymphoma

I first came across cancer in my early childhood when my father was diagnosed with this disease. He left us at age 43 when I was only six years old. After that, I was not confronted with this disease until my own diagnosis.

The first symptoms appeared as shortness of breath at the slightest strain, even when walking on a flat and I was constantly experiencing a dry, irritating cough, chronic fatigue, and itchy skin. My cervical lymph nodes were significantly swollen; however, as a non-professional, I did not notice it. My difficulties intensified to such an extent that, due to breathing problems, I could sleep only in a half-sitting position.

After repeated visits to my personal doctor and ineffective treatments of "virus infections", I was finally scheduled for a lung scan. I received the results on a work day. The x-ray image showed a tumour in the mediastinum. A later puncture and an in-depth scan showed that the disease was malignant, widespread, and at a late stage. At that moment, my whole world collapsed. It felt that I would not be able to face the treatment that awaited me.

The next critical challenge was how to share the diagnosis with my family. I was about to face the biggest challenge of my life, which would also change the lives of all the people close to me. My family and friends stood by my side throughout every moment of the treatment, encouraging me, helping me, and celebrating even the smallest progress; from a better blood count, to better scan results, and a completed chemotherapy cycle. Each successful step was our common victory on the path to successful recovery.

Throughout the healing process, I experienced a wide variety of emotions. Fear, sadness, frustration, anger, and helplessness were especially prominent during the first days after the chemotherapy. At that time, I was at my physical worst, which was mentally draining as well. It was hard but there were fewer such days than I had expected. Any good news that the treatment was going in the right direction brought joy, relief, indescribable happiness, and ultimately an immense will to live.

Every two weeks, I had to come back to the Institute of Oncology. Each beginning of chemotherapy was full of uncertainty, fear, distress, and dilemmas but later I realised that I felt safe at the department, that the personnel were helping me to the best of their ability while being a great support to me too. I received all the professional information and the feeling that they genuinely care about their patients. I was in good hands. While at the hospital, I also met my soul mate, Marta Jurkovič, and together we created the Purple Stone Project, combining our common story in a demo film entitled *Our Purple Journey*.

My biggest motivation was my son Kristijan. I told myself: "Mojca, you can do it! Show that you are one heck of a woman! Show that it is possible to overcome even the most critical situations in life!" After the first chemotherapy, the tumour was reduced considerably, and I thought to myself: "Here's the first tick, things will only get better now. I will win this fight!" Further cycles of treatment followed, and it was not easy. The whole process was full of ups and downs. In order to make it easier to bear, I was constantly setting new goals. These thoughts and plans kept me going. The best news for me was that the tumour had responded to the first chemotherapy treatment. This was my first step on the path to victory, which gave me motivation for a great deal of positive thinking and the energy to heal.

The disease has changed my life. I learned not to worry anymore about inessentials. I am trying to seize every single moment, to live a full life, to co-create it and not just observe it as a bystander. In each situation, I have learnt to discern the best and help others in need. Today, I feel stronger. I am a fighter, and I am a winner! I know I could face the disease again. I have accepted the fact that it is all part of life, even a disease. We are all the first people to notice change in our own bodies. Therefore, I advise anyone thinking they might have a medical issue to seek and demand medical attention and not allow themselves to be easily dismissed when getting one!"

"I received all the professional information and the feeling that they genuinely care about their patients. I was in good hands."

Z rakom sem se prvič srečala v zgodnjem otroštvu, ko je zbolel moj oče. Poslovil se je pri 43 letih, ko sem jih sama štela komaj šest. Za tem se z boleznijo nisem soočila, do svoje diagnoze.

Prvi simptomi so se pojavili kot zasopihanost ob najmanjšem naporu, hoji po ravnem, prisoten je bil suh, dražeč kašelj, stalna utrujenost in srbeča koža. Vratne bezgavke so bile močno povečane, vendar jih kot laik nisem opazila. Težave so se stopnjevale do te mere, da sem zaradi težav z dihanjem lahko spala le v pol sedečem položaju.

Po večkratnih obiskih osebne zdravnice in neuspešnem zdravljenju »viroz«, sem se končno dogovorila za rentgensko slikanje pljuč. Za rezultate izvidov sem izvedela med delavnikom. Slika je pokazala tumor v mediastinumu. Kasnejša punkcija in globinsko slikanje pa, da je bolezen maligna, razširjena in v poznem stadiju. V tistem trenutku se mi je sesul svet. Zdelo se mi je, da zdravljenja, ki me čaka, ne bom zmogla.

Naslednji kritičen trenutek je bil, kako diagnozo deliti z domačimi. Čakala me je največja življenjska preizkušnja, katera je spremenila življenja tudi vsem najbližjim. Družina in prijatelji so mi vsak trenutek zdravljenja stali ob strani, me vzpodbujali, mi pomagali in z mano praznovali vsak najmanjši napredek; boljši krvni izvid, rentgensko sliko, zaključen cikel kemoterapije. Vsak uspešen korak, je bil naša skupna zmaga in pot k uspešni ozdravitvi.

Skozi proces zdravljenja so me obhajala najrazličnejša čustva. Strah, žalost, razočaranje, jeza in nemoč so se kazali v prvih dneh po kemoterapiji. Takrat je bilo fizično počutje najslabše, kar me je tudi psihično precej izčrpalo. Težko je bilo, vendar je bilo takšnih dni manj, kot sem jih pričakovala. Vsaka dobra novica, da gre zdravljenje v pravo smer, je prinesla veselje, olajšanje, nepopisno srečo in nenazadnje neizmerno voljo do življenja.

Na Onkološki inštitut sem se morala vračati vsaka dva tedna. Začetek kemoterapij je bil poln negotovosti, strahu, stisk in dilem, kasneje pa sem ugotovila, da se na oddelku počutim varno, da mi osebje pomaga po najboljših močeh in da so mi v veliko oporo. Dobila sem vse strokovne informacije in občutek, da jim je mar za bolnike. Bila sem v dobrih rokah. V bolnišnici sem spoznala tudi svojo sorodno dušo, Marto Jurkovič, s katero sva ustvarili projekt vijoličnih kamenčkov in skupni zgodbi združili v predstavitvenem filmčku »Najino vijolično popotovanje«.

Največja motivacija zame je bil moj sin Kristijan. Rekla sem si: »Mojca, ti boš to zmogla! Pokaži, da si babnica na mestu! Pokaži, da je mogoče premagati še tako krizne življenjske situacije!« Po prvi kemoterapiji se je tumor dodobra zmanjšal in mislila sem si: »Evo, prva kljukica, zdaj bo šlo le še na bolje. Ta boj bom dobila!« Sledili so novi ciklusi zdravljenja in ni bilo enostavno. To je bil proces poln vzponov in padcev. Da bi ga lažje prenašala, sem si nenehno izmišljala nove cilje. Take misli in načrti so me držali pokonci. Najboljša novica zame je bilo sporočilo, da se je tumor odzval na prvo zdravljenje s kemoterapijo. To je bil moj prvi korak na poti do zmage, ki mi je dal motiv za veliko mero pozitivnega razmišljanja in energije za ozdravitev.

Bolezen je spremenila moje življenje. Ne obremenjujem se več z nepomembnostmi. Poskušam izkoristiti vsak trenutek, življenje živeti polno, ga soustvarjati in ne le spremljati kot zunanji opazovalec. Iz vsake situacije se učim izluščiti najboljše in pomagati drugim v stiski. Danes se počutim močnejšo. Sem borka in sem zmagovalka! Vem, da bi se lahko znova spopadla z boleznijo. Sprejela sem namreč, da je vse del življenja. Tudi bolezen. Spremembe v telesu vsak najprej občuti sam. Zato vsakomur svetujem, da ko misli, da z zdravjem nekaj ni v redu, naj poišče in zahteva zdravniško pomoč in se od tam ne pusti zlahka odgnati!«

“ Dobila sem vse strokovne informacije in občutek, da jim je mar za bolnike. Bila sem v dobrih rokah. ”

Spain

My story

Teresa Regueiro

Multiple myeloma

The moment of diagnosis is brutal and shocking. When you don't know anything about cancer you're used to hearing things like "cancer has a cure now" and when you're told you have cancer you think "well, well, it has a cure, it has a cure" until you hear the word incurable. You don't know anything about myeloma, just something you've read on the internet, something disastrous, but you still think no, that a part of your skull has disappeared from other causes, not because of cancer.

My first thought was for my sons. I was very lonely that day and while I always thought that if I were to be diagnosed with a disease I would go crazy, I found a different reality. I was very calm, excited but so calm and I don't have an answer as to how I achieved it.

I needed to know what I was facing to find out if there was any hope. I wanted to know everything, everything they could tell me about myeloma, how they would treat me and what I had to do.

Myeloma broke into my life in a barbaric and cruel way. On a physical level it destroyed me: my immune system had gone , one part of my skull was also gone and all because of cancer.

The treatment was tough the same way it is for every person sick with myeloma; one treatment caused the most side effects. It not only affected me physically but also psychologically. It was a very tough time for me: repetitive thoughts and bad temper, I wanted to be alone all the time, I also thought that everyone looked at me with suspicion. It was a really bad period of time for me until I told the doctors about the situation and they immediately reduced my doses.

"As I began to get better physically I started doing more things. Cycling again was like a party for me."

The sick are often afraid to reduce doses because we fear that the effects will be smaller and all we want is to get better. I was willing to continue with this transitory madness, if it got me cured.

When the time for my transplant came I felt more hopeful. I was very lucky and in 2 weeks I left the hospital.

Because of "my myeloma" characteristics (17p (p53) among others things) and my age (45 years), it seemed advisable to maintain treatment for a year.

I made a slow recovery. I didn't want to rush things and 9 months after the transplant I began a completely strict remission. For many months I thought I would only get to the next checkup, fearing I would relapse soon so I didn't make any plans for the future.

As I began to get better physically I started doing more things. Cycling again was like a party for me, walking through Hyde Park in London 11 months after the transplant was like a prize for me which no one can understand. It's fantastic to walk on grass when you thought you would never do it again.

I can't complain and I mean it. I was going to die but I didn't so this is precious time I've been given, how could I complain? I never thought I'd get this far, so when a scared patient asks me what the transplant or the treatment is like I always try to answer the same thing: It's hard but it will end, and you will be better.

I can't finish without making a very important point. I was very lucky with my doctors. Doctor San Miguel was the person who turned a bad prognosis into long survival.

Surprisingly for many people. I also have to say that he was one of the few people who gave me hope and he never let me see in his eyes I would die.

Cancer takes charge of your life and impacts your environment in an unexpected way. It also changes the life of your family and friends.

Cancer does not change everything; it's just so hard that it brings reality to fictitious situations which don't survive the illness and it's in this reality where you find yourself really lonely.

This is my story.

El momento del diagnóstico es impactante y brutal. Cuando nada sabes del cáncer estás acostumbrado a oír "el cáncer ya se cura" y mientras te están diciendo que tienes cáncer vas pensando "bueno, bueno, bueno, se cura, se cura, se cura", hasta que oyes la palabra"incurable". No sabes nada del mieloma, has leído algo por encima en internet, algo nefasto, pero piensas que no, que eso no es, que parte de tu cráneo ha desaparecido por otras causas, no por ese cáncer.

Mis hijos, el primer pensamiento, ese primer día lo pasé en la soledad más absoluta y cuando siempre pensé que si tuviera una enfermedad me volvería loca, me encontré con una realidad diferente. Muy serena, emocionada pero serena, y no tengo una respuesta fácil para "cómo pude conseguirlo".

Necesitaba conocer a lo que me enfrentaba, para saber si tenía un resquicio de esperanza, quería saberlo todo, todo lo que pudieran contarme del mieloma y cómo me iban a tratar y que tenía que hacer yo.

El mieloma impactó en mi vida de forma brutal y cruel, a nivel físico me destrozó: mi sistema inmunológico prácticamente no existía, se lo llevó por delante, una parte de mi cráneo desapareció.

Tuve un tratamiento duro como todos los enfermos de mieloma. Uno de los tratamientos me produjo muchos efectos secundarios. Me afectó no solo físicamente, también lo hizo psicológicamente. Lo pasé muy mal, muy mal: desde pensamientos muy repetitivos, malhumor, quería estar sola todo el tiempo, pensaba que todo el mundo me miraba mal, no sé, fue una época muy difícil para mí hasta que lo comenté e inmediatamente me bajaron la dosis.

" Al ir mejorando físicamente, comencé a hacer más cosas, volver a andar en bicicleta fue una fiesta para mí."

Los enfermos tenemos miedo muchas veces a que nos bajen las dosis ya que tememos que no nos haga el mismo efecto y lo que queremos es ponernos bien, yo estaba dispuesta a continuar con esa "locura transitoria", si con ello me ponía bien.

Cuando llegué al trasplante me encontraba un poco más esperanzada.

Tuve mucha suerte, y en dos semanas pude abandonar el hospital.

Por las características de mi "mieloma" (17p (p53) entre otras) y por mi edad (45 años) era aconsejable un tratamiento de mantenimiento durante un año.

Me recuperé lentamente del trasplante, tampoco quería correr, y, a los nueve meses del trasplante, entré en remisión completa estricta.

Durante muchos meses pensé que solo iba a llegar hasta la próxima revisión, que llegaría la recaída pronto y no tenía ningún proyecto de futuro.

Al ir mejorando físicamente, comencé a hacer más cosas, volver a andar en bicicleta fue una fiesta para mí, pisar el césped en Hyde Park en Londres once meses después del trasplante fue un premio para mí que nadie puede entender, volver a pisar la hierba es algo fantástico cuando has estado un año pensando que no lo vas a hacer más.

Yo no me puedo quejar, y lo digo de corazón, me iba a morir y no me he muerto y esto es tiempo regalado, ¡cómo me voy a quejar!, nunca pensé llegar hasta aquí, cuando me pregunta algún paciente asustado cómo es el trasplante, o el tratamiento, intento contestar siempre lo que me hubiera gustado que me hubieran dicho a mí: es duro pero se pasa, se acaba, y vas a estar mejor

No puedo terminar obviando una parte muy importante para cualquier paciente. He tenido mucha suerte con mis médicos. El Dr.San Miguel fue la persona que consiguió que un mal pronóstico se convirtiera en una "larga supervivencia" de forma sorprendente para muchos. Tengo que decir también que fue una de las pocas personas que me infundió esperanza y, también, que en sus ojos nunca leí que me iba a morir.

El cáncer centra la vida del que lo padece y repercute en su entorno con un efecto dominó imprevisible e inesperado, no solo cambia tu vida, la de tu familia y amigos puede verse dañada.

El cáncer no es que lo cambie todo, es tan duro que pone realidad a situaciones ficticias que no sobreviven a la enfermedad y en esa realidad puedes encontrarte muy solo.

Esta es mi historia.

Sweden

Ignorant

Anonymous

To say that my knowledge of cancer in general and of blood cancer in particular was lacking up until about a year ago is not an exaggeration. Honestly I didn't even know what this blood cancer was at all, and in hindsight I have noticed that my ignorance is shared by many within my family and among my friends and acquaintances. "Is it not leukaemia?" is the smartest answer I've had when I tried to explain the blood cancer that is now part of my life. I have stopped spending several minutes explaining my disease. I do not have the energy to waste my time on that, and it is often useless anyway. I simply can't cope...

But still I feel I have to! Many curious questions are asked by friends and other acquaintances. I would almost need a handbook in order to save time. "Blood Cancer for Dummies" or something like that - that would have come in handy. For even if I do have a sort of leukaemia, it still makes a huge difference whether it is "acute" or "chronic" and whether it is "lymphatic" or "myeloid," especially for my family and closest friends. They want to know things that are important to all of us such as "but hey, how about our vacation together?" (the best friend), "how much are you going to be able to work?" (the employer), "how can I best help you?" (the husband) and "are you going to be there to see me graduate?" (the son).

As a newly diagnosed patient there are things you don't have a clue about... Nor do I a year later, have the answers to all questions, but nevertheless I can give an indication about what the future looks like.

> **" Apparently research is moving along in a positive direction, which is good, but uncertainty is still a huge part of everyday life. "**

None of us knows what tomorrow has to offer, this applies especially for us with blood cancer. Apparently research is moving along in a positive direction, which is good, but uncertainty is still a huge part of everyday life. "One day at a time" is thus my life motto right now, where I try to enjoy life even though life doesn't seem to enjoy me being here. But that is not my problem...

So I keep at it... What else can I do? We humans are after all very adaptable, and you don't want to be worse than "the average Joe". To complain doesn't help either, rather the opposite is true in my case, so I prefer to stay away from doing that. Sure it is good and nice to say "no" to cancer on certain days, but considering that I have a chronic cancer diagnosis I might as well just accept the situation. There are always support people whom I can turn to on gloomy days, which I am grateful for. If only the health care centres had the same knowledge as these good-hearted and understanding people, then the future of healthcare would look bright, rather than the opposite.

To sum it up, I really don't know what I would have wanted to say, other than that it can be clever from time to time to have some patience with all the "stupid" questions asked by our near and dear, acquaintances, colleagues and strangers. After all, once upon a time even I was as ignorant and would have continued being so if the cancer had not gotten hold of my body. But the fact that the doctors at the health care centre don't get anything is another thing. There I think that we shall put our foot down and row!!! If we don't do it, who will stand up for us?! If we only stand united and together, for instance with the Blood Cancer Association or some other Patient Advocacy Group, then our voice will be heard. At least that's what I want to believe, since that is the reason I joined the Association a few months ago.

Att säga att mina kunskaper om cancer i allmänhet/blodcancer i synnerhet var bristande fram till ca 1 år sen är på inga sätt att ta i. I ärlighetens namn visste jag inte ens vad det hära med "blodcancer" var överhuvudtaget, och såhär i efterhand har jag märkt att min okunskap delas av många inom familjen och vänner/bekanta. "Är inte det leukemi" är det smartaste svar jag har fått när jag har försökt förklara den blodcancersjukdom som numera är en del av mitt liv. Att spendera flera minuter åt att beskriva min sjukdom har jag nu slutat med. Jag har varken tid eller energin till sånt tidsslöseri, och det är dessutom lönlöst i många fall. Jag orkar helt enkelt inte...

Men jag känner fortfarande att jag måste! Många nyfikna frågor ställs ju av vänner och andra bekanta. Jag hade nästan behövt en handbok för spara tid. "Blodcancer för idioter" eller något i den stilen, det hade varit behändigt! För även om jag faktiskt har en typ av leukemi, så är det ju en stor skillnad på om den är "akut" eller "kronisk" & "lymfatisk" eller "myeloisk". Särskilt för min familj och närmaste vänner. De vill ju veta sånt där som är viktigt för oss alla - ungefär "men du, hur blir det med vår gemensamma semester?" (bästa kompisen), "hur mycket kommer du kunna jobba?" (arbetsgivaren), "hur kan jag hjälpa till på bästa sätt?" (maken) och "kommer du hinna se mig ta studenten?" (sonen).

Frågor man som nydiagnostiserad inte har en susning om. Inte heller vet jag svaret på alla frågorna ett år senare, men jag kan om inte annat ge en fingervisning på hur framtiden blir. Ingen av oss vet ju vad morgondagen har att ge, framförallt inte oss med blodcancer. Forskningen går ju tydligen framåt i en positiv riktning, vilket ju är bra, men osäkerhet är trots detta minst sagt en stor del av vardagen. "En dag i taget" är alltså mitt livsmotto just nu, där jag försöker njuta av livet trots att livet inte alltid verkar njuta av att jag finns. Men det är inte mitt problem...

Så jag fortsätter att gneta på, vad kan man annars göra? Vi människor är trots allt väldigt anpassningsbara, och där vill man ju inte vara sämre än "medelsvensson". Att klaga hjälper inte heller, snarare tvärtom i mitt fall, så det undviker jag helst. Visst är det skönt att säga "nej" till cancer vissa dagar, men med tanke på att jag har en kronisk cancerdiagnos är det bara att gilla läget. Stödpersoner finns alltid att vända sig till vid dystra dagar vilket jag är tacksam för. Om bara vårdcentralen hade samma kunskap som dessa storhjärtade och förstående människor, då hade vårdens framtid sett ljus ut snarare än det motsatta.

Sammanfattningsvis så vet jag inte riktigt vad jag ville få sagt, mer än att det kan vara smart att då och då ha lite tålamod med alla "korkade" frågor som våra nära och kära och bekanta och kollegor och främlingar ställer. En gång i tiden var även jag trots allt lika okunnig, och hade säkert fortfarande varit om nu inte cancern hade rotat sig fast i just min kropp. Men att inte läkarna på vårdcentralen fattar någonting är en helt annan sak. Där tycker jag att vi ska slå näven i bordet och ryta till!! Om inte vi gör det, vem ska då stå upp för oss!? Står vi bara enade och samlas i t.ex. Blodcancerförbundet eller någon annan patientorganisation så kan våra röster höras. Det vill åtminstone jag tro, eftersom det är skälet till att jag gick med i "Förbundet" för bara några månader sen.

" Forskningen går ju tydligen framåt i en positiv riktning, vilket ju är bra, men osäkerhet är trots detta minst sagt en stor del av vardagen."

United Kingdom

Remaining positive

Roger Brown

Waldenström's macroglobulinemia

I am Roger Brown, patient member of the WMUK board and here is my blood cancer story: I was diagnosed with Waldenström's Macroglobulinemia (WM) at 53 (13 years ago) getting breathless learning to tap dance.

My wife Alison noticed night sweats, tiredness and more dimwittedness than usual and thought it might be MS. I then came down with shingles and pleurisy. My doctor said I was depressed and prescribed happy pills, but a blood test produced the diagnosis of WM at a local leukaemia centre. 5 years was quoted as survival time! This necessitated a strong cup of tea. It turned out that breathlessness was due to thick blood and this also explained the lack of brain power. The tiredness could be put down to anaemia. Luckily I had none of the eye damage that sometimes accompanies hyperviscosity. Since then, I have undergone multiple cyles of chemo and relapse, followed by an autologous stem cell transplant.

All through the chemo treatments we kept a spreadsheet of blood tests and treatment so I could compare symptoms with the test results. This really helped. I continued to work and visited places such as Antarctica as a travel photographer, with no problems.

In autumn 2010, red and white cell counts declined again and tiredness took over. So, in January 2011 we decided to go for an autologous stem cell transplant. We put aside most of August 2011 for the transplant. Hopefully this treatment will give me a decent remission until something better comes along. The last effect to disappear (in time for Christmas) was that all red wine tasted like vinegar.

Now five years on, the transplant has relapsed slowly so in the absence of new treatments in the UK, I am having my fifth line of chemotherapy and starting to feel better.

My advice for others with WM is: seek a second opinion, reach out to the IWMF and WMUK, remain positive and get on with your life.

> **"All through the chemo treatments we kept a spreadsheet of blood tests and treatment so I could compare symptoms with the test results. This really helped."**

Thank you

We would like to thank the following Patient Advocacy Groups for their help in collecting stories for this book, and for their ongoing support:

Bulgaria

Bulgarian Lymphoma Association
www.lymphom-bg.com

Croatia

HULL – Hrvatska udruga leukemija i limfomi (Croatian Leukaemia and Lymphoma Patient Association)
www.hull.hr

Mijelom CRO – Udruga za podršku oboljelima od multiplog mijeloma (Multiple Myeloma CRO Patient Association)
www.mijelom.hr

Denmark

LyLe - Patientforeningen for Lymfekræft og Leukæmi (Patients for Lymphoma and Leukaemia)
www.cancer.dk/lyle

France

SILLC - Association de Soutien et d'Information à la Leucémie Lymphoïde Chronique et à la Maladie de Waldenström (Chronic Lymphocytic Leukaemia and Waldenström's Macroglobulinemia Patient Association)
www.sillc-asso.org

Israel

Flute of Light
www.halil.org.il

Portugal

Associação Portuguesa de Leucemias e Linfomas (Portuguese Leukaemia and Lymphoma Association)
www.apll.org

Serbia

LIPA - Lymphoma Patient Association
www.lipa.org.rs

Slovenia

Slovensko združenje bolnikov z limfomom in levkemijo, L&L (Slovenian Association of Patients with Lymphoma and Leukaemia, L&L)
www.limfom-levkemija.org

Spain

LA COMUNIDAD ESPAÑOLA DE PACIENTES CON MIELOMA MULTIPLE (Spanish Community Patients with Multiple Myeloma)
www.facebook.com/pacientesmielomamultiple

Sweden

Blodcancerförbundet (Blood Cancer Association)
www.blodcancerforbundet.se

United Kingdom

WMUK - Waldenström's Macroglobulinemia UK
www.wmuk.org.uk

For further information and support

The following pan-European organisations offer patient support, information about blood cancer and details of relevant patient organisations in your country.

Leukaemia & Lymphoma

CML Advocates Network
www.cmladvocates.net

European Leukemia Net
www.leukemia-net.org

European WM Network
www.ewmnetwork.eu

CLL Advocates Network
www.clladvocates.net

Leukaemia Support Rhein-Main EV
www.leukaemiehilfe-rhein-main.de

Lymphoma Coalition
www.lymphomacoalition.org

Myeloma

Myeloma Patients Europe
www.mpeurope.org

International Myeloma Foundation
www.myeloma.org

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