

People-centred health systems
in the WHO European Region:

VOICES OF PATIENTS AND CARERS



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PREFACE

This publication is a collection of personal stories describing experiences in health systems associated with improved health and well-being. While these examples are not intended to replace technical guidance on how to organize, finance or deliver health and social services, they emphasize people-centred approaches from the perspective of patients and carers.

The motivation for presenting these stories is to strengthen the voices of those directly impacted by the workings of the health system and to give a snapshot of what people-centred health services mean to them in practice. In doing so, the WHO Regional Office for Europe aims to encourage policy-makers and health professionals to take the perspective of service users and to see through their eyes what works and what needs improvement.

Actively listening to patients, families and communities in order to design health systems that are more responsive to people's needs is a growing priority for governments worldwide. This publication serves as an open invitation to health leaders to embrace an inclusive approach that harnesses feedback from citizens to drive system-wide improvements.

Modernizing pharmaceutical policies to make high-cost medicines and technologies affordable reduces health disparities and leads to improved outcomes for people with chronic or costly-to-treat conditions

“I was one of the lucky few who were getting an expensive targeted treatment while many others were not. I was going to the hospital every month to do a blood test and was witnessing the deteriorating health of other patients who were diagnosed around the same time as me. I thought it’s not ethical for doctors to be forced to choose who should get modern treatment and who should receive outdated therapies.”

Name: **Šarūnas Narbutas**
Country: **Lithuania**
Health experience related to:
chronic myeloid leukaemia



In 2006 I was diagnosed with chronic myeloid leukaemia – a type of blood cancer. At that time I was 18 years old and about to graduate from high school. When I heard my the diagnosis, the doctor said there were two treatment alternatives: chemotherapy or bone marrow transplantation. My sister had Googled the day before to see if other treatment options existed and found that there was a targeted medicine that was effective in treating my particular disease. But my doctor said, “Well, that’s not on the table, because our country is underfinanced and we cannot afford it.”

In 2007 16.5% of patients were receiving the targeted treatment, so only about one in six who would have benefitted from it was getting it. The treating haematologist was facing an ethical dilemma to decide which patient should receive the modern treatment and which should undergo chemotherapy. When no matching donors were found for a bone marrow transplantation, we thought I would be going for chemotherapy. Then my doctor made a special recommendation due to my young age at the time, and the alternative treatment was granted to me free of charge.

“There was a targeted medicine that was effective in treating my particular disease. But my doctor said, ‘Well, that’s not on the table, because our country is underfinanced and we cannot afford it.’”

I was one of the lucky few who were getting an expensive targeted treatment while many others were not. I was going to the hospital every month to do a blood test and was witnessing the deteriorating health of other patients who were diagnosed around the same time as me. I thought it’s not ethical for doctors to be forced to choose who should get modern treatment and who should receive outdated therapies. So I was getting a targeted treatment and was responding very well to it, but I was feeling bad about receiving this treatment while other patients were not – and were dying. I understood that it was a purely economic problem, because the targeted treatment was expensive.

When I did the math, it showed that one could take these medicines for five years, and only then would they equal the

cost of the bone marrow transplantation. The Government was already reimbursing any needed transplantation but was selective about reimbursing patients for this treatment.

“I was getting a targeted treatment and was responding very well to it, but I was feeling bad about receiving this treatment while other patients were not – and were dying. I understood that it’s a purely economic problem because the targeted treatment was expensive.”

In 2007 I created a blog to share my story – that I was getting reimbursed for an expensive experimental treatment, but that at the same time many others were not. I invited people to sign a petition asking the Government to reimburse the modern therapies to all patients who need them.

I mobilized my friends and some local politicians and journalists to help me spread this message. To my surprise the message went viral. In the first month I collected 15 000 signatures and it caught the attention of the mass media. In three months I had collected 80 000 signatures and hosted a press conference in the Lithuanian Parliament, stating that this call to action was supported by the society – their constituents. In the next two months, it went from 80 000 to 180 000 signatures, which equalled 6% of the total Lithuanian population in 2007.

In the 2008 budget, the Government doubled the funding for this disease and already half of patients could receive reimbursement for this innovative therapy. I got a letter from the health minister pledging that his cabinet would work to get it reimbursed for up to 100% of patients. They reached that goal in four years. From 2007 to 2011, coverage was increasing and eventually all patients were covered for first-line, second-line and third-line therapies.

My experience, however unusual, shows that it is possible for one person to bring change in the society and in the political process, even regarding economic decisions that influence the ability of providers to practice people-centred health care.

Training and empowering health workers to attend to evolving population health needs and preferences leads to improved trust and satisfaction with the health system

“Our Health Board put together a focused home birth team of two midwives who would serve as ‘ambassadors’ for home birth and make sure that women were being supported if that was the choice that they had made. I think the real benefit to that comes from providing women with a choice of where they wish to give birth: in the midwifery unit, in the consultant unit or at home. Every woman should have the ability to decide what’s right for her.”

Name: **Leah Morantz**
Country: **Wales,
United Kingdom**
Health experience related to:
childbirth



I gave birth to my second son last year. He was born at home and that was a choice that I had made and worked very closely with the midwives in my maternity services unit to achieve. My first birth experience in a hospital was quite traumatic and that was central to my decision to have an undisturbed home birth the second time.

“There was a situation where if you were a prospective mom and wanted a home birth, you might have a community midwife who was supportive of it or you might have one who wasn’t. And that would potentially have an influence on whether you could have a home birth in the end.”

The Welsh Government decided some time ago that they wanted the maternity services units across Wales to improve home birth rates overall. Here in Cardiff and Vale, our Health Board put together a focused home birth team of two midwives who would serve as “ambassadors” for home birth and make sure that women were being supported if that was the choice that they had made. It was definitely a new way of working.

Prior to the introduction of this policy, pregnant women in the area who wanted to have a home birth were not always being supported in the right way, and I think that was because home birth wasn’t sanctioned as openly as it might have been. So there was a situation where if you were a prospective mom and wanted a home birth, you might have a community midwife who was supportive of it or you might have one who wasn’t. And that would potentially have an influence on whether you could have a home birth in the end. The Health Board made an active decision to promote home birth as a choice.

I think the real benefit to that comes from providing women with a choice of where they wish to give birth: in the midwifery unit, in the consultant unit or at home. Every woman should have the ability to decide what’s right for her.

In my particular case, I had many of my antenatal appointments at my house. That was extremely valuable, because it helped me develop comfortable relationships with the midwives, who were seeing my home as the place where the baby’s birth was going to happen.

Midwives are not just doing the role of a traditional midwife anymore. In today’s context they have to look at the whole woman. They have to be able to help women with substance abuse problems and physical abuse problems, as well as with physical problems related to the pregnancy. Midwifery is more than the training that you get from a clinical perspective; I think it’s a very holistic role and it’s a very special role in the context of health care.

The two things that were most important to me were the feeling that I was listened to at every step of the way and that my wishes and the planning that I had put into the birth were being respected. At all times I was part of the decision-making process.

I received exactly the care that I wanted and that was the right care for me. The only improvement I would like to see is for the National Health Service to offer the same options to every woman who wants to have a home birth, and also to every woman who wants to have a birth in the hospital.

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Educating patients to participate in care delivered across settings and supporting them to take an active role in managing their disease increases autonomy and commitment to a healthy lifestyle

“The nephrologist and the nurse have prepared me physically and psychologically for the treatments and for anything else that may lie ahead. They informed me about eating a healthy diet, explained to me how dialysis works, and taught me how I would need to take care of myself between treatments.”

Name: **Humberto Balantzategi Basaguren**

Country: **Spain**

Health experience related to:
heart attack; kidney failure



I had a heart attack several years ago. I was feeling pressure in my chest, which at first I thought was just a bit of anxiety, but finally I went to the emergency unit and there I was told that I had had a heart attack. I have been living with kidney problems since I was 18 and now I have renal failure as well. My kidney function is very low and I expect to start peritoneal dialysis sometime in the future.

For the time being, my cardiologists and nephrologists are closely monitoring my conditions and helping me control them. They have vaccinated me against pneumococcus, tuberculosis and tetanus in order to avoid possible infections should I have to start dialysis on short notice.

The nephrologist and the nurse have prepared me physically and psychologically for the treatments and for anything else that may lie ahead. They informed me about eating a healthy diet, explained to me how dialysis works, and taught me how I would need to take care of myself between treatments. One remarkable thing the nurse did was introduce me to another patient who had been on peritoneal dialysis for 10 years. That person talked with me about his health experiences and advised me what to expect when I enter treatment. I saw that he was doing quite well and that gave me hope and courage.

“My family doctor follows my health very closely. She asks that I keep her informed of any changes to my condition or medications each time I visit the hospital. I take nine pills a day and sometimes the nephrologist changes the mix, so informing my doctor allows her to immediately adjust my prescription.”

My family doctor follows my health very closely. She asks that I keep her informed of any changes to my condition or medications each time I visit the hospital. I take nine pills a day and sometimes the nephrologist changes the mix, so informing my doctor allows her to immediately adjust my prescription. She works closely with a nurse, who assists me with setting up appointments in case I need to see other specialists besides the nephrologist and cardiologist. If I have a sudden health problem or need to change an appointment, I can call her and she would help sort it out.

Although I am usually treated in Vitoria, at one point I needed to undergo surgery for herniated disks in San Sebastian. It was remarkable that the surgeon not only managed to access my medical record electronically, but also cared enough to learn about my medical history. When we met he asked me right away, “Which battle are you coming from?”

With respect to the treatments I received, the doctors always discussed the options with me. In the case of my kidney problem, I could choose between peritoneal dialysis or hemodialysis, and they communicated to me the advantages and disadvantages of each. I chose the former.

“After my heart attack the cardiologist advised me to start attending an outpatient cardiac rehabilitation centre... In the end I went from feeling very unwell to wanting to take up sports for the first time in my life! Now I jog with a heart rate monitor, do gymnastics, and walk regularly. I also abandoned my habit of social drinking.”

After my heart attack the cardiologist advised me to start attending an outpatient cardiac rehabilitation centre. I did that three times a week for three months and the sessions included physical exercises and discussions with a psychologist, social worker, and a nutritionist. They helped me learn how to manage my health better. In the end I went from feeling very unwell to wanting to take up sports for the first time in my life! Now I jog with a heart rate monitor, do gymnastics, and walk regularly. I also abandoned my habit of social drinking.

Last year I was offered an opportunity to participate in an educational course on self-care called Active Patient. Each session in this course is led by a team of one patient with a chronic illness and one healthcare professional. The course taught me how to prepare and take my medication and, in the end, it enabled me to take control of my condition. This autonomy meant the world to me.

Comprehensive health and social services planned around people's functional needs and delivered as close as possible to their home allow patients to recover at their own pace and reduce the stress of the hospital environment

“When it was time to discharge me from the hospital, a nurse phoned my husband to make sure that I had everything I would need at home. My bed is upstairs, so she made sure that we had another bed for me downstairs, as well as all the equipment I would need. They arranged for meals to be brought in to me and my husband, and for a home aide to come in and help me out of my bed. From the doctor's office they even sent a nurse to give me injections. I got all this attention!”

Name: **Olive Cassidy**
Country: **Scotland,
United Kingdom**
Health experience related to:
femur fracture



I broke my leg one day while I was watering the garden. The water was running onto the grass, and I slipped and fell. I couldn't move; I was lying in water and my husband, who is almost 84, called for an ambulance.

The ambulance came within 10 minutes. They got me onto a stretcher, made sure that I was comfortable and helped to reduce the pain right away. When we got to the hospital, I was taken right in. I'm afraid from then on I don't know what was going on, because I was unconscious for a few hours.

"The doctors and nurses were kind and looked after me so well; they all called me by my first name and made sure that I was given their names as well".

When I woke up it was quite late, so they made me comfortable for the night. In the morning the doctors and nurses were kind and looked after me so well; they all called me by my first name and made sure that I was given their names as well. After the operation I was taken to another ward. All my belongings were brought in and were waiting for me. My medication was on time; everything was ok.

When it was time to discharge me, a nurse phoned my husband to make sure that I had everything I would need at home. My bed is upstairs, so she made sure that we had another bed for me downstairs, as well as all the equipment I would need – a commode, wheelchair and walking aide. When I was discharged from the hospital, they arranged for meals to be brought in to me and my husband, and for a home aide to come in and help me out of my bed. From the doctor's office they even sent a nurse to give me injections. I got all this attention!

After six months I felt that I could manage by myself. They showed me how to get in the shower with a step, and they also installed a handle in the shower for me. After a few more months in rehabilitation, I was allowed to put my foot down to some extent and they gave me a new walking aid. I can't tell you how much was done for me! And they gave me the

telephone numbers of people who could help if we needed other things.

So I had a doctor, a home nurse, a physiotherapist and an occupational therapist. It's a mixture of health and social services. When social services take over, the hospital allows you to go home so that you free the bed for somebody else who needs it. I presume that's the idea.

The thing that got me was I never needed to ask for anything; they knew what I wanted. They saw that I couldn't carry anything and was just holding on to my walking aid and my sticks. So they got me a three-wheel trolley with a wee basket in the middle that I can push when I go shopping, which I hope to do in not too long.

They even have a special bus in East Ayrshire for people like me. If you are going somewhere within the area, you phone up and they come and collect you at a set time. They give you time to do what you have to do and then take you home.

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I feel so much better from what a shock I was in when I fell and broke my leg. I had a very good experience and I'm still getting a good experience. I really appreciated everything that was done and I'm looking forward to getting on with my life!

Involving people in self-managing their health and empowering them to peer mentor other patients increases well-being and engagement with the health system

“I assist other patients with mental health problems when they need help filling out paperwork, making appointments with specialists or managing their condition. I understand that other people’s psychological health needs are just as serious as mine was and that I have something to give back that can help them deal with difficult diagnoses.”

Name: **Georgi Hristov**
Country: **Bulgaria**
Health experience related to:
paranoid schizophrenia



I have a condition called paranoid schizophrenia. My health is relatively stable and for that I am grateful for the therapy I receive from my treating physician. There is coordination of services between him and other doctors, and I participate in learning modules on self-management at a community health centre. My part-time job as an operator at a laundry service keeps me active. The contacts with my family also sustain me and keep me in good health.

I receive ongoing support at a multiprofile hospital for active treatment in neurology and psychiatry. I feel confident about the treatment plan recommended by the doctor there, in part because of his open and positive attitude. I am well cared for and my symptoms are carefully analysed by the health team. Beyond the hospital, the social workers at the Global Initiative on Psychiatry (GIP)-Sofia community centre helped me adapt to the real world and gain control of my disease. They also invited me to participate in educational modules on healthy lifestyle, conversational skills and English as a second language.

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There is still a heavy bureaucracy with regard to services for people with mental health problems in Bulgaria. Although a referral from my family doctor to see a mental health specialist is good for up to six months, I may have to wait a long time to see my family doctor in the first place. There is no mechanism to access the physician in case there is something urgent. The health system should find a more flexible solution in case of urgently needed consultations by people with mental health issues. The doctor himself is very responsive to my needs. During my most recent visit he told me, “You can come by any Tuesday. I like talking with you about your life situation.” We talk about things that I don’t discuss at length even with my own family. I’ll go and see him again soon.

My family doctor also helps me in other situations. Some time ago I needed to see a dentist and she gave me a referral. The case manager at the mental health community centre further motivated me to get some additional dental work done. Now I can eat, smile and feel comfortable around people.

“The case manager at the mental health community centre further motivated me to get some additional dental work done. Now I can eat, smile and feel comfortable around people.”

In addition to my job at the laundry service, I work as an expert-by-experience at GIP-Sofia. There I assist other patients with mental health problems when they need help filling out paperwork, making appointments with specialists or managing their condition. I understand that other people’s psychological health needs are just as serious as mine was and that I have something to give back that can help them deal with difficult diagnoses.

This work has enabled me to see life in new ways and taught me to be more tactful and tolerant. I have gained confidence and become a more positive person. I also receive a modest salary for my work as an expert-by-experience, as well as from the laundry service. This shows me that from the lowest to the highest level, people’s efforts are appreciated when institutions are honest.

Physician-provided information on services to help people manage their health improves their capacities to cope with disease psychologically, as well as physically

“I am glad that medics work together with nongovernmental organizations that support patient interests. It means a lot – not only to talk about the medical side or to do exercises but also to get emotional support from other patients.”

Name: **Līva Brizga**
Country: **Latvia**
Health experience related to: **pulmonary hypertension**



I have a genetic disease called cystic fibrosis. I have to use medicine every day to keep my condition more or less stable so that I can move, walk, talk, breathe and do the things that normal people do.

After graduating from high school, I moved to Liepaja and started my studies. I thought that being close to the Baltic Sea and breathing fresh air would help my health condition. But it got worse and worse. I felt that I should be looking for causes other than cystic fibrosis.

One day while I was waiting for the bus, I noticed a poster. The face of the woman in the poster seemed to be sad; her lips were kind of blue and there were some descriptions of symptoms. I asked myself – do I feel the same? Do I have these symptoms? I had noticed that my lips were a bit blue as well, especially when I get tired at work or if I have had a lot of things to do. I understood that I should check whether I have the disease shown in the poster: pulmonary hypertension.

“The cardiologist talks to patients like people; he understands their wishes, problems, difficulties and needs. He has a great attitude and communication skills. You go to him as a friend to share information and experience, and to find the best solution – and not just to get a prescription.”

When I came home, I searched for information on the internet about pulmonary hypertension. I knew that my symptoms were respiratory failure, high blood pressure and physical failure, which made it hard for me to do anything. On my next visit to the family doctor, I decided to ask her to give me a referral to test for this disease.

My doctor was surprised and, at the same time, pleased that I notice campaigns like the one with blue-lipped women. Usually people notice posters with discount products on them, but not ones with information about health. But I noticed, because I was worried about my health at that moment. The doctor referred me to a cardiologist, one of the only two specialists in Latvia who treat patients with pulmonary hypertension. The cardiologist talks to patients like people; he understands their

wishes, problems, difficulties and needs. He has a great attitude and communication skills. You go to him as a friend – to share information and experience, and to find the best solution – and not just to get a prescription. I think that it is really important.

Pulmonary hypertension is a rare disease and in Latvia, there is no uniform compensation scheme for all patients. The cardiologist helped me write an application to the National Health Service to see whether I could get my treatment paid by the Government. They gave me a positive answer within a month and I got my medicine.

“Pulmonary hypertension is a rare disease and in Latvia, there is no uniform compensation scheme for all patients. The cardiologist helped me write an application to the National Health Service to see whether I could get my treatment paid by the Government. They gave me a positive answer within a month and I got my medicine.”

Although I have to write this application every year and the Government approves or rejects compensation for every twelve-month period, it is worth it. Even though you see that this medicine is not on the list of compensated medicines, the Government is trying to find a solution for every case.

I also got information from the cardiologist about how to contact the patient society, which helps and supports people with pulmonary hypertension. I can go to the Association of Pulmonary Hypertension as well if I have questions about everyday situations, such as how to live and help myself, and what kind of help I can get from the Government – not exactly the kind of questions I should be asking my doctor. That was really good advice. I am glad that medics work together with nongovernmental organizations that support patient interests. It means a lot – not only to talk about the medical side or to do exercises but also to get emotional support from other patients.

I really like that nongovernmental organizations have more and more influence, which helps people get more interested in their health and not only by doing internet searches and going to doctors.

Structured education sessions for people living with long-term chronic pain can foster coping mechanisms that reduce dependence on medications and improve quality of life

“One of the best things that happened to me was taking a pain management course and having just one lecture by a consultant anesthesiologist on the effect of drugs on the body. That was extremely useful in helping me reduce my use of opioids.”

Name: **Jay Flood-Coleman**
Country: **Northern Ireland, United Kingdom**
Health experience related to: **chronic pain**



I suffered two brain haemorrhages in the early 1990s. After the second one, I lost a quarter of my brain and about 50% function of my body and have spent many years since trying to rebuild both.

“The goal of a pain management course is to help people understand and manage pain better including through changes in their lifestyle or the home environment. It allows them to discuss their individual pain with medical professionals and others, which can help with developing coping strategies.”

At the rehabilitation unit, there was a review team that asked me questions about my recovery. It became apparent to them that not being able to pick up my newborn daughter due to my disability was causing me a lot of distress. They sent me to a medical engineering firm that made a special harness designed around the baby’s dimensions that would help me lift her up. That service gave me hope. Individuals cannot recuperate properly until they find some degree of hope and that certainly provided hope for me. The rehabilitation unit also had a staff psychologist who helped people with their mental recovery. This is the kind of service that focuses on the future rather than just looks at physical care.

A few years later, I started having chronic pain. The more I was trying to regain my mobility, the more pain I was in, so I went up higher and higher on pain medication. I was concerned that I could become a prescription drug addict, but since I didn’t know a better way to manage the pain I was dependent on the drugs. Eventually I began using opioids. The high dosages affected my home life, because I couldn’t focus on my family properly.

There has to be a way for people who experience chronic pain to be more educated about what the source of their pain is and what they can do about it. Chronic pain is not always being assessed properly and is often seen only in relation to another condition.

One of the best things that happened to me was taking a pain management course and having just one lecture by a consul-

tant anaesthesiologist on the effect of drugs on the body. That was extremely useful in helping me reduce my use of opioids. The goal of a pain management course is to help people understand and manage pain better. Two aspects of this are making changes to their lifestyle and home environment. It allows them to discuss their individual pain with medical professionals and other people experiencing chronic pain, which can help with developing coping and planning strategies.

The most important thing about managing chronic pain as a patient is being believed. That means having a care provider who is willing to listen and say, “Yes, I understand your experience and pain, and we need to do something about it.” And on the patient’s side, it’s important to have an outward focus in order to find a way to move forward in your life through the pain by understanding what triggers or makes it worse.

Self-determination is important, but sometimes you need people to help you see the light at the end of the tunnel. So being believed about your pain, being educated about what you can do about it, and having a good rapport with health professionals are extremely important.

“What I would like to see established in Northern Ireland and elsewhere is locally supported chronic pain clinics facilitated by people who have chronic pain and are experts-by-experience.”

What I would like to see established in Northern Ireland and elsewhere is locally supported chronic pain clinics facilitated by people who have chronic pain and are experts-by-experience. That would help the community come together locally and understand pain better through improved information. For the health system, it would free up significant amounts of money.

I am inspired by seeing that the issue of chronic pain is finally being taken up as a national issue. That has given me hope. As long as you give a person hope, they can change their life and maybe change others’ lives for the better. In this way we can perhaps also see how weaknesses we experience in our lives can be turned into strengths.

Timely attention and empathetic bedside manner by health care staff improve people's experience of care and lead to better compliance with prescribed treatments and medications

“The nurses at the hospital were really comforting and polite, and I appreciated how they talked to me and treated me – and not only me; they behaved the same with all the patients. Indeed, the nurses were great.”

Name: **Maria Anghel**
Country: **Romania**
Health experience related to:
diabetes mellitus



Ten years ago I was diagnosed with diabetes. I found out about it when I went to the hospital for a consultation regarding a problem with my heart. I had told my family doctor my symptoms and she referred me there. I had some tests done then and was hospitalized for a few weeks.

“I go once a year to the hospital for check-ups and once every two months to my doctor, who is very accommodating and supportive. I make appointments for routine check-ups with her, but if necessary she sees me even outside office hours because she understands the problems of sick people.”

The nurses at the hospital were really comforting and polite, and I appreciated how they talked to me and treated me – and not only me; they behaved the same with all the patients. Indeed, the nurses were great. The doctor who was in charge of my case gave me a detailed discharge letter to take to my family doctor, so that she would make sure I stay on the prescribed treatment. Since that moment I have been taking all my medications.

I have no trouble following the treatment, although it is a little expensive, especially one of the drugs. But what can we do – for our health we spend even the last penny. I'm happy I'm feeling good! From time to time I grab a bite of sweets or some cake. But it really makes me feel ill, so I do my best to follow the diet that has been recommended to me.

I go once a year to the hospital for check-ups and once every two months to my doctor, who is very accommodating and supportive. I make appointments for routine check-ups with her, but if necessary she sees me even outside office hours, because she understands the problems of sick people. Until recently I could make appointments one or two weeks in advance, or even just a few days in advance in case of an emergency. So the waiting time was quite short.

Lately it has been a bit more difficult to make an appointment to see my doctor, as I and other patients have been told we have to request a time one or two months in advance. I understand this is not the choice of the doctor but rather a result of the number of people who ask to be seen and her capacity to see them. I told the medical staff at the practice that I would pay if necessary to make an appointment sooner, and they replied that they could do nothing about it, because they are understaffed.

“I have had the same family doctor for more than 25 years. She vaccinated and treated my children when they were small. She also treated my husband for pneumonia, rheumatism and liver problems. Now my children are grown up and my son has a boy of his own. He takes his family to my doctor when they need care.”

The most valuable part of the treatment for me was the services I received at the hospital. I still go there for check-ups and it's quite difficult, because the hospital is far from where I live. I have to take the bus or share a car with somebody from my village, in which case I pay for the gas. But all the effort and expense are worth it, because the doctors and nurses are good and treat everybody with the same care and respect. The hospital was renovated recently and is clean and luminous. They have good diagnostic equipment and a laboratory.

I have had the same family doctor for more than 25 years. She vaccinated and treated my children when they were small. She also treated my husband for pneumonia, rheumatism and liver problems. Now my children are grown up and my son has a boy of his own. He takes his family to my doctor when they need care.

Providing physical and behavioral health services in one location enables patients and their families to form relationships with providers and to engage more fully in their own care

“My son received comprehensive medical care. There was a psychologist, a speech therapist and a special educator working with him. Now he goes to school and receives good grades. He is self-aware and has good eye contact with people, and his behaviour is appropriate to the specific situation he is in. He enjoys playing chess. I believe his progress is a result of their team work.”

Name: **Nikolay Gevorgyan**
Country: **Armenia**
Health experience related to:
autism

(As told by Nikolay's father, Yerem Gevorgyan.)



When he was three years old, my son was diagnosed with autism. We had started noticing changes in his behaviour about a year and a half before that, but despite visiting a lot of specialists we could not get a clear diagnosis. Fortunately we learned that a regional branch of a child rehabilitation centre was established in Gavar, a district town about 70 km from the village where we live. So we went there and finally he got diagnosed.

Nikolay went through two courses of treatment, each of a few months duration. We see obvious changes compared to the situation before. My son received comprehensive care there. There was a psychologist, a speech therapist and a special educator working with him. Now he goes to school and receives good grades. He is self-aware and has good eye contact with people, and his behaviour is appropriate to the specific situation he is in. He enjoys playing chess. I believe his progress is a result of their team work.

Although we have stopped visiting the centre now, we maintain contact with the team of specialists who cared for him. They call to see how he is doing and visit us at home once every three months. Those consultations help us manage his health, which is very valuable to me as a father.

“The rehabilitation centre occasionally involves us in different educational programmes and seminars on care for children with neurological and developmental disorders. This engagement was very important for us, because for my son the most crucial problem now is social inclusion.”

The rehabilitation centre occasionally involves us in different educational programmes and seminars on care for children with neurological and developmental disorders. The children can attend some of these courses. This engagement was very important for us, because for my son the most crucial problem now is social inclusion.

We also received a lot of help from social workers at a local nongovernmental organization and from our family pediatrician. Their advice helped us plan our family life and adapt it to Nikolay's treatment goals. The individual attention we received from everyone involved in my son's care has made me more aware of my responsibilities for my children's health and for my own health. I can say that it pushes me and my wife to model healthy lifestyles for our children.

“The individual attention we received from everyone involved in my son's care has made me more aware of my responsibilities for my children's health and for my own health. I can say that it pushes me and my wife to model healthy lifestyles for our children.”

I have to mention that although the rehabilitation centre works in our society, which is transitioning to a market economy and has some deficit of humanism, in this facility we were met with the kindest, most unselfish attitude.

Here is Nikolay. When we began attending the centre, we planted a small sapling in their yard. We've seen it grow and become the same height as Nikolay. Everyone should strive to make things beautiful for the children visiting the centre.

Nikolay: I planted the tree myself.

Early diagnosis and timely treatment of illness relieve anxiety and physical suffering for patients, while personalized case management leads to increased trust in providers and in the health system

“I am thankful that if I have an arthritis outbreak, which is highly painful, I have my doctor’s number where I can reach her right away, explain what is wrong and get her advice on what to do.”

Name: **Teresa Capell Torras**
Country: **Spain**
Health experience related to:
arthritis



I have been living with arthritis for the last five years. It all began when one day I found myself unable to walk. I got to the emergency department of my local hospital where the attending physician told me he could not determine the cause of my pain and that I had to do further testing. He referred me to another hospital for a magnetic resonance imaging (MRI) and a bone scintigraphy – a type of bone scan – then bandaged my knee and sent me home. I had to wait a whole month in this condition, which was very painful and stressful, before I could be seen for tests.

As I learned afterwards, neither the MRI nor the bone scan were particularly useful for diagnosing my arthritis. When I went back with the test results to the hospital, the treating rheumatologist and the head of the rheumatology unit said they still could not determine a diagnosis based on those results. A third rheumatologist was called in, who suggested that we do an ultrasound scan, which immediately identified that I had an outbreak of arthritis.

Despite the delay in diagnosing my illness, I was pleased with the way the physician treated me, because he seemed genuinely interested in my condition and sent me to do other tests that he believed were necessary.

I understand that if the hospital where I received first aid does not have the infrastructure to perform the tests that I needed, then I had to go to another one. The problem was that the other hospital was 50 km away from where we live, and my husband had to take unpaid time off work to drive me there.

“Despite the delay in diagnosing my illness, I was pleased with the way the physician treated me, because he seemed genuinely interested in my condition and sent me to do other tests that he believed were necessary.”

A month after receiving my diagnosis, we discovered that the arthritis had moved to my hands. The arthritis affects different parts of my body. Sometimes I have pain in my hands, other

times in my feet or knees. At the moment I have arthritis in my shoulders. I go for follow-up once every 6 months and everything is perfect. I get blood tests, ultrasound scans and x-rays done to make sure that the disease has not spread to the bones.

“My doctor knows that I don’t like to take medication, partly because I have problems with my liver. She agrees that I can take the medication only when my arthritis flares up. She also knows which medications I can tolerate and which I can’t.”

Since I received the diagnosis, the doctor explains everything to me about the disease and the prognosis. She knows that I don’t like to take medication, partly because I have problems with my liver. She agrees that I can take the medication only when my arthritis flares up. She also knows which medications I can tolerate and which I can’t, so she says to me, “Teresa, take what you need when you have acute symptoms and if there is any problem, call me.” I am thankful that if I have an arthritis outbreak, which is highly painful, I have my doctor’s number where I can reach her right away, explain what is wrong and get her advice on what to do.

Once she prescribed to me a new drug that had recently come on the market. When I got home and read the contraindications, I called her to say that I was worried about taking it. She said that if I would be taking this medication in fear, it would be better not to take it.

Because arthritis is a disease for life, I think there should be treatments based on complementary medicine. In my case if I take too much cortisone, it can affect my liver. There has to be an alternative.

When I go for my next follow-up visit, I will ask the doctor about the possibility to refer me to physiotherapy services, which may be covered by the social security system. At the moment if I were to use such services, I would have to pay for them myself, but that is very expensive and I cannot afford it.

Ensuring coordination across the continuum of care, from diagnosis and treatment to rehabilitation and follow-up care, improves health outcomes and satisfaction with the health system

“My treatment can be divided into two stages. The first one, before proper diagnosis, was an example of lack of coordination between general practitioners and specialists, which resulted in a worsening of my condition. The second stage, after the diagnosis of cancer, can be described as a prompt reaction, precise and on-time treatment. I was informed about patient rights, provided with an exact plan for my treatment and warned about its potential consequences. I really appreciated the care by the physicians and nurses – I think it was of the highest quality.”

Name: **Szymon Chrostowski**
Country: **Poland**
Health experience related to:
cancer



I was diagnosed with testicular cancer with metastasis to the kidney 12 years ago. It took nine months from the first contact with the general practitioner to the final diagnosis of cancer. During this period the cancer was spreading. Once I was put in contact with a doctor from the polyclinic of urogenital systems in Maria Skłodowska-Curie Memorial Cancer Centre and Institute of Oncology, the cancer was diagnosed. An immediate treatment followed and after one month I was operated on. Today I am cancer-free and go for follow-up examinations only to confirm that everything is ok.

For those reasons, my treatment can be divided into two stages. The first one, before proper diagnosis, was an example of lack of coordination between general practitioners and specialists, which resulted in a worsening of my condition. The second stage, after the diagnosis of cancer, can be described as a prompt reaction, precise and on-time treatment. I was informed about patient rights, provided with an exact plan for my treatment and warned about its potential consequences. I really appreciated the care by the physicians and nurses – I think it was of the highest quality.

“I was really happy with the information and attention that was individually provided to me. The medical staff gave a lot of attention to my needs, such as my sleeping difficulties, feelings of pain and dizziness.”

I was really happy with the individual information and attention that was provided to me. The medical staff gave a lot of attention to my needs, such as my sleeping difficulties, feelings of pain and dizziness. Due to the type of cancer I had and my young age, they informed me precisely about possible complications in the area of reproductive health, highlighting that at the moment I should postpone plans to become a father. The information was provided in a clear and easy-to-understand manner, and in an intimate environment with face-to-face contact.

“I think that timeliness and coordination of care were significant in my case. Luckily I was treated at a complex institute, which showed me the importance of network coordination of facilities and skills of specialists.”

As a non-medical person, I didn't have enough knowledge to decide on what would be the best treatment and my only option was to agree with the doctor or resign from the treatment. I fully trusted my doctors; therefore, I had no doubt about the correctness of the treatment.

For the first nine months, I had to cover some of the costs before my disease was diagnosed. These expenses were later reimbursed by the National Health Fund. After becoming a patient at the Institute of Oncology, I didn't bear any costs. I was really happy to see the improvement in the coordination of care. Recently, during my stay at the hospital, I was provided with care by a psycho-oncologist. Additionally there were rehabilitation services.

I think that timeliness and coordination of care were significant in my case. Luckily I was treated at a complex institute, which showed me the importance of network coordination of facilities and skills of specialists. At the Institute of Oncology, I had easy access to a variety of treatments, including rehabilitation and a psycho-oncologist, which gave me confidence that the care provided to me was composed of all essential features.

Despite the difficulties I faced at the beginning of my treatment, the great knowledge, engagement and dedication of the doctors that I met at the Institute inspired me to commit myself to help other patients defeat their illnesses.

Rapid access to health professionals in critical situations prevents injuries and stabilizes health, while patient–provider relationships built on trust and empathy strengthen people’s resolve to stay involved in their care

“My relationships with the psychotherapist and the psychologist were a lifeline, and my psychotherapist certainly kept me alive many times. I had easy access to him that enabled me to reach him in times of crisis. I feel very lucky to have had such good providers, and the fact that they worked so well together for my health was key. That strengthened my resolve and determination to stay well.”

Name: **Caitriona Cassidy**
Country: **Northern Ireland, United Kingdom**
Health experience related to: **emotionally unstable personality disorder; mood disorder**



I have experienced suicidal thoughts and self-harm behaviour since I was 13 years old. For the past 12 years, I have been receiving continuous psychotherapy and psychological help. Recently I asked my psychiatrist whether I have an official diagnosis, and he explained that I do – emotionally unstable personality disorder – but could not tell me exactly when my condition had developed. I began visiting him several years ago, after the antidepressants and anti-anxiety medications I had been taking stopped working. The psychiatrist helped with adjusting my medications and linked me to other psychological services.

“I was really unwell and was calling the helpline up to 90 times in a month. They eventually assigned me to a key counselor, and she called me once a week so that I could talk things over with her, hopefully to prevent crises from happening in the first place. She became a stable and close presence in my life.”

The most stable period of my life was during the 10 years I was receiving psychodynamic psychotherapy. I started seeing a psychologist in the past year, and my condition is vastly improved now. That has been very stabilizing to me and I continue to work with her once a week.

My relationships with the psychotherapist and the psychologist were a lifeline, and my psychotherapist certainly kept me alive many times. I had easy access to him that enabled me to reach him in times of crisis. I haven't self-harmed or attempted to end my life since 21 October 2014. Before that I tried to self-harm often, sometimes up to three times a week.

There is a crisis response helpline in Northern Ireland where one can call and talk to qualified counselors. They keep a record of patients' notes, so they do not have to repeat their whole psychiatric and social history every time. They do check-in calls and update your general practitioner or send an ambulance if you are in crisis. It's an amazing service.

I started using the helpline in August 2013. During that time I was really unwell and was calling them up to 90 times in a month. They eventually assigned me to a key counselor, and

she called me once a week so that I could talk things over with her, hopefully to prevent crises from happening in the first place. She became a stable and close presence in my life.

Helplines have a statutory responsibility to inform callers' health care providers of all risks. So if I call them and say I have self-injured, they would phone my general practitioner or my psychologist straight away, and one of them would call me back and invite me to visit her that day. That was great, because it took the pressure off from me having to explain, and sometimes I didn't remember the details about what I had done to myself. Whenever I was admitted in the hospital, I could keep in touch with the helpline from the ward by phone.

However, the helpline and the psychologist are secondary services. What could have helped me even more would have been a place where I could go before I would injure myself. Having a safe place as an alternative to the hospital, where one could go and have a cup of tea and a face-to-face talk with a counsellor at the precise moment when one is in crisis, could help de-escalate the situation.

I don't want to be self-harming and be a danger to myself. I am compliant with treatment and am prepared to try anything that the providers recommend, because I trust their judgment. I think it takes as much work from the patient as it does from the providers. It's a two-way process.

I feel very lucky to have had such good providers, and the fact that they worked so well together for my health was key. That strengthened my resolve and determination to stay well. As an extension of the excellent professional services and encouragement I received, I made a safety plan with my friends in order to help me stabilize and recover further.

“What would have helped me even more would have been a place where I could go before I reached the stage where I would injure myself. Having a safe place as an alternative to the hospital, where one could go and have a cup of tea and a face-to-face talk with a counselor at the precise moment when one is in crisis, could help de-escalate the situation.”

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