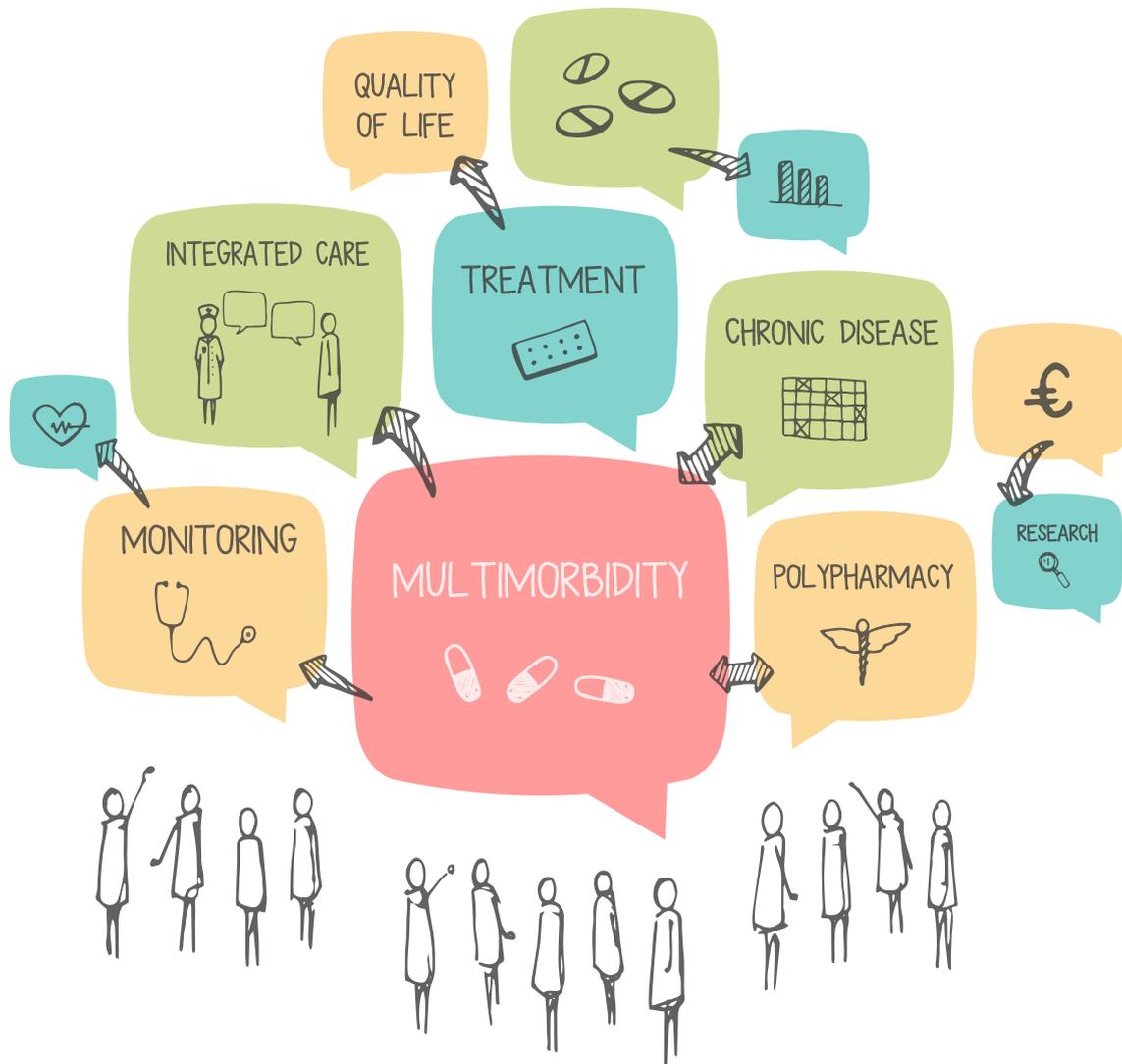




European  
Commission



# Which priorities for a European policy on **multimorbidity** ?

Brussels, 27 October 2015  
Thon EU Hotel

# Foreword by Vytenis Andriukaitis, EU Commissioner for Health and Food Safety



Over the last century, economic development, improved lifestyles and advances in healthcare as well as medicines have contributed to a significant increase in life expectancy across the EU. On the other hand, multiple chronic conditions in one person, also known as multimorbidity has become increasingly common.

An estimated 50 million people in the EU currently suffer from multiple diseases which deeply impacts their quality of life. By 2020, when we expect a quarter of Europeans to be over 60 years of age, multimorbidity will become the norm rather than the exception. This will have significant implications for our economy, labour market, social security and healthcare systems and the quality of life of our citizens.

It is time to start understanding multimorbidity from a research, clinical and community care perspective. This will help us to shift away from a disease-oriented approach towards a patient-oriented approach. We need to reflect on the changes to our healthcare systems necessary to implement and promote patient-centred, coordinated, multidisciplinary approaches that meet the often complex care needs of individual patients.

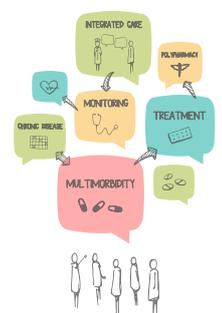
As the patient is central to our discussions today, this booklet gathers testimonials from patients across Europe. These personal stories help us understand the reality of living with multimorbidity today, and can help orient our discussions on how to improve patients' lives whilst making an efficient use of resources.

A European approach to this challenge requires a comprehensive response involving all stakeholders from policy-makers to healthcare professionals, researchers, professionals from the pharmaceutical and ICT industry, insurers and patient representatives.

At today's conference we can discuss best practices, and also identify gaps and uncertainties, so that together we can reflect on a common approach to multimorbidity and help the patients.

Vytenis Andriukaitis

A handwritten signature in blue ink, appearing to read 'Vytenis Andriukaitis'. The signature is stylized and fluid.



# Agenda

27 October  
THON Hotel  
Brussels

**09.00 Registration and Coffee**

**09.30 Opening Speech by DG SANTE Director-General Xavier Prats Monné**

**10.00 Opening session: Sharing existing knowledge**

Five story tellers will share their experiences in dealing with multimorbidity, their successes, problems encountered and outcomes of their interventions or projects. The stories will be followed by group discussions among the participants.

- **Story 1:** A structured approach for multimorbidity in Primary Care: the Exeter experience  
*José María Valderas, Hospital of Exeter – United Kingdom*
- **Story 2:** Developing model-based patient-centred chronic illness care: the Potku example (Finland)  
*Mieke Rijken, NIVEL – The Netherlands*
- **Story 3:** Towards a more effective care model for multimorbid patients under the Joint Action CHRODIS  
*Graziano Onder, CHRODIS Joint Action – Italy*
- **Story 4:** How to overcome acute disease approach and go towards a patient-centred model: the experience of a patient with multiple conditions  
*Regina Roller-Wirmsberger, European Union Geriatric Medicine Society – Austria*
- **Story 5:** The challenge of developing decision-making tools: the NICE example  
*David Haslam, National Institute for Health and Care Excellence – United Kingdom*

**12.30 Lunch**

**13.30 Break-Out session: Defining main elements to build a common framework on multimorbidity**

Interactive session to discuss on the main elements to focus on to establish a common framework on multimorbidity. Participants will reflect on which are the main priorities to address, in particular in scientific research; healthcare system organisation; cost-effectiveness and financing and patient engagement.

**15.30 Coffee break**

**15.45 Break-Out session: Working together to tackle multimorbidity**

An Open Space opportunity for participants to engage in meaningful discussions on topics they consider to be a priority when dealing with multimorbidity. This is a concrete opportunity to hear stakeholders' voices and propose joint activities to tackle the challenge of multimorbidity. Proposals for actions and envisaged achievements will be fed back to the participants to inspire future collaboration.

**17.30 Closing remarks by the Deputy Director General of DG SANTE, Martin Seychell**

# Speakers' biographies

## Professor José María Valderas



He is an Academic General Practitioner, with a commitment to research on patient centred care that is relevant for decision making in clinical practice and health policy. He is a Professor of Health Services & Policy and leads the Health Services & Policy Research Group at the University of Exeter Medical School, where he also leads the patient-centred care theme in the Exeter Collaboration for Academic Primary Care (APEX). He is a member of the Board of Directors of the International Society for Quality of Life Research.

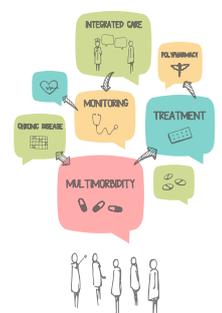
His current research interests focus on the use of patient reports on their own health for decision making in clinical practice and health policy, and the improvement of processes of care (quality and safety), with a particular interest in patients with multiple conditions. In this area, he has completed a review of theories of multimorbidity and implications for health policy and clinical practice (400 citations in Google Scholar), a systematic review of epidemiological studies on prevalence, patterns and determinants of multimorbidity, a systematic review of instruments and measures of multimorbidity (111 citations in Google Scholar), and a series of papers with primary quantitative and qualitative data from European countries (UK, Spain and Ireland) on multimorbidity, later including also Australia. He is one of the founders of the European multimorbidity network Threads and Yarns, a collaboration between researchers in the UK, Spain, Germany, Netherlands, Ireland, and others. He is currently completing an NIHR publicly funded (£1M) 5 year programme of research on the use of patient reported outcomes for priority and goal setting in patients with multimorbidity.

## Mieke Rijken



Mieke Rijken, PhD, trained in health education and health psychology, is a senior investigator at NIVEL, the Netherlands institute for health services research. She has supervised NIVEL's research program on the needs of people with chronic illness for almost 15 years. Her national research projects focus on healthcare organization and quality of care from the perspective of chronically ill people as well as their self-management, quality of life and social participation.

She is currently also coordinating the project 'Innovating care for people with multiple chronic conditions in Europe' (ICARE4EU; co-funded by the EU Health programme 2008-2013). This project aims to contribute to the innovation of person-centered, integrated care services for European citizens with multiple chronic conditions. In addition, she participates in the EU co-funded Joint Action on Chronic Diseases (CHRODIS-JA; work package on multi-morbidity care). Mieke is also a member of the international working group on high needs/high costs patients of the Commonwealth Fund.



## Dr. Graziano Onder



Dr. Onder is Professor of Geriatrics at the the Università Cattolica del Sacro Cuore, Policlinico A. Gemelli in Rome, Italy. He is Fellow of the European Academy for Medicine of Ageing and member of the Geriatric Working Group of the Italian Medicines Agency (AIFA). The main focuses of his research are pharmacoepidemiology in the elderly, including assessment of prevalence and risk factors for adverse drug reactions and inappropriate prescribing in the elderly, sarcopenia and its impact on clinical outcomes, multimorbidity and organizational characteristics of health care systems. He participated in several project funded by public and private institutions including the Italian Ministry of Health (CRIME project), the European Commission through the Seventh Framework Programme (FP7 – AdHoc, SHELTER and IBenC) and through the third Health Programme (Joint Action on Chronic Diseases - CHRODIS). He is author of more than 200 publications in peer-reviewed journals.

## Dr. Regina Roller-Wirnsberger



Professor of Geriatric Medicine and Competence based Curricular Development. Involved into academic research programs in the field of geriatric medicine since 2005, co-applicant of 6 EU funded projects, expert in 2 EU funded projects, chief executive coordinator of 12 national projects (7 finished and in publication) - 10 of them in the field of sarcopenia and malnutrition (coordinator Nutrition Day in Nursing Homes in Styria, RIMO project StGKK and many others), stakeholder in international projects (SENATOR, Shared decision making and many others), stakeholder in guidelines development (Leitlinien zur Ernährung alter Menschen in Österreich des BMG and many others)- Program director for curricular development at MUG for clinical education in undergraduate curriculum, Leader of SIG education in Europe, Program director and coordinator for curricular development in EAMA.

## Professor David Haslam



David Haslam is Chair of the National Institute for Health and Care Excellence (NICE) . He was a GP in Cambridgeshire for 36 years, and is past President of the BMA, past-President and past Chair of the RCGP, and a former National Clinical Adviser to the CQC and to the Healthcare Commission. He is visiting Professor in Primary Health Care at de Montfort University, Leicester, and Professor of General Practice at the University of Nicosia. David has written 13 books, mainly on health topics for the lay public and translated into 13 languages, and well over a thousand articles for the medical and lay press. He was awarded the CBE in 2004.

# Patients' testimonials

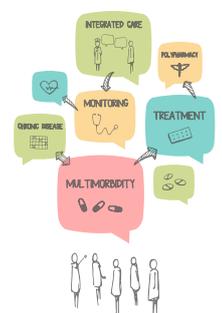
“My name is Amanda Roberts and I have atopy in three manifestations: asthma, eczema and hay fever. Each one of these impacts upon my quality of life and is treated in a hierarchical fashion by my General Practitioner – who takes into account his priorities not necessarily mine – and in a silo by specialists. My asthma has always overshadowed my eczema. With strong, regular medication, my asthma is generally far better controlled than my eczema. But I struggle to get my eczema taken seriously.

When I was pregnant and saw an obstetrician (another silo) I was not given any meaningful information about minimising the risks of atopy and neither were my children monitored as at risk. They have gone on to be diagnosed with eczema, asthma, hay fever, and anaphylaxis. All of which had to be done by different specialists. In the case of the anaphylaxis, this was a particular struggle as our General Practitioner refused initially to accept that my son was reacting to a bag of peanuts being opened in his vicinity – and just told us to go away and stop feeding him peanuts!

So the health system has made my atopy become a multimorbidity where to my life it is just one all-encompassing condition and in doing so has underserved my quality of life and that of future generations.”



**Amanda Roberts, United Kingdom**  
*Asthma, eczema, hay fever*



“My name is Dan Oana Maria, I am from Zalau (Romania) and I am 30 years old. I finished High School ten years ago and did several training courses. I am now working as a secretary for the Romanian Association for Rare Cancers and I am also a volunteer in the NoRo Centre – a Pilot Reference Centre for Rare Diseases in Romania, where I also do therapy.

I am a patient with PraderWilli Syndrome (PWS) – a complex genetic condition that affects many parts of the body – and psoriasis – an autoimmune disease characterized by red, itchy and scaly skin patches. I was diagnosed with PraderWilli Syndrome very late, when I was 18, but I always knew that I was not responsible for some of my health problems because I gained weight and could not stop eating whenever I had food available (as I always felt hungry).

When I was a child I had weak muscles and obesity, I could not walk and talk until I was two and a half, after enduring a rehabilitation program for six months. From childhood I had developed obesity and three years ago I was also diagnosed with psoriasis. Having obesity, my parents thought that it was just an irritation but, I was sure it was psoriasis from the beginning as I had read about it when a friend of mine, who is also diagnosed with epilepsy, had a severe form of psoriasis a few years before.

It is a very unpleasant disease and sometimes it makes my life even more difficult than PWS. I cannot receive some therapies because of PWS and sometimes psoriasis has an impact on my behaviour and attitude in society.

I am on growth hormone therapy but I started it very late as I was diagnosed late. It helped my muscle tone and my breathing. My treatment is free as we have a national program for rare diseases.

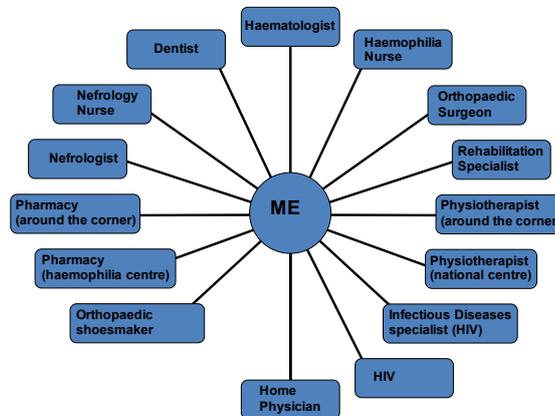
It is very difficult to be in front of doctors or therapists with a problem and to understand that they do not know how to help you or do not understand you. Once, I complained in the centre that I could not exercise as my leg hurt badly but my therapist thought that I was trying to fool her and was lazy. She only later realised that I had erysipelas, an acute infection typically with a skin rash, and I was right.

We can recognise the symptoms, learn from them, and support doctors to help us faster but they have to understand that we have to work as a team. We have to share our experience with other patients and learn how to support each other.”

**Oana Maria Dan, 30, Romania**

*PraderWilli Syndrome, psoriasis, obesity*

“The quintessence of my personal story is that in over sixty years of life, I became a person with multiple chronic diseases (haemophilia and therefore serious orthopaedic problems; HIV; hepatitis C which is now cured; diabetes and renal failure). I have a wide range of healthcare contacts as you can see in the illustration and I believe many other people with chronic diseases have a comparable experience.



While I am getting older, my care-givers are getting younger. By now, I have to deal with the 6th generation of caregivers and most of them have no clue about my medical and social history. When decision-makers are talking about concepts like ‘healthy ageing’ and ‘self-management’, my personal experience is increasing health problems and a decreasing ability to manage my own care in the future. Incorporating the challenge of comorbidities with healthy ageing is a key issue.

Three problems worry me with comorbidity: the lack of coordination between medical specialists; the use of multiple medications and the “fear factor”.

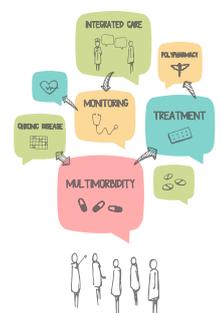
Like other patients with severe haemophilia, I have particular fears: lack of control when you are hospitalised, when you need medical treatment from physicians who have no experience with haemophilia or when you are involved in a serious traffic accident. In all of these cases, you, as a well-educated manager of your disease, may not be able to influence your treatment. The ambulance may take you to a hospital that has beds available but no experience with haemophilia, and valuable time may be lost. Older people with haemophilia are often not in good physical shape due to orthopaedic or viral complications. So when, surgery is proposed we fear the operation, and also the consequences of this operation for total body functioning. Our state of health is a delicate balance.

In rehabilitation, paediatric and geriatric care, a holistic approach has been developed in which the patient is seen as a person in relation to his environment. Care encompasses not just the child/ old person but also the family. This compares with the way I grew up in the hospital setting – at a time when there was no treatment for haemophilia – where the matron regarded her patients as more than their illness. Although for haemophilia this concept already exists since the introduction of specialised comprehensive care centres, I wonder whether it is also possible to introduce a comparable hospital setting for patients with other multiple chronic diseases. This will be in sharp contrast with the way most hospitals are now organised, but it is worth the effort to start piloting this approach.”



### Cees Smit, 60+, The Netherlands

*Haemophilia, orthopaedic problems, HIV, hepatitis C, diabetes, renal failure*



“I am Nina Baláčková, I am 57 years old, I am from the Czech Republic and I live with my husband. I am a member of the European Working Group of People with Dementia and also a member of Dementia Alliance International.

I was diagnosed with Alzheimer’s disease eight years ago. I am asthmatic and I have heart problems too. Which is making me suffer the most is Mr Alzheimer’s, but unfortunately the doctors are not cooperating between them.

When I was diagnosed with Alzheimer’s the doctor told me that I could only expect 5 more years of life! She said that people with a young onset of the disease were ‘going faster’ towards the end their lives. She helped me filling forms for my pension. It helped me with money. But I did not receive any other advice such as going to the Czech Alzheimer Society, training my memory, exercising - NOTHING!

I would like to emphasise the importance of moving, cognitive training and social contacts - family, friends, and neighbours.

Medicine/pills are important, but an active life with a positive attitude is important too. Every person is different!

Many problems of people with dementia are not seen, but there are there for us and for our families.”



**Nina Baláčková, 57, Czech Republic**

*Alzheimer’s, heart problems, asthma*

“I am a 70-year-old man, married with one son. Prior to my retirement in 2008 I was working as an international sales manager. I studied law and later I also did a web-based vocational education programme for business people.

In 2004 I was diagnosed with Attenuated Familial Polyposis (aFAP) of my proximal colon out of clinical sight, which was however not supported by human genetic findings. At the beginning of 2009 I was diagnosed with a 4th stage metastatic colon cancer which took its origin from a hyperplastic adenoma in my caecum and which had grown within 9 months after my previous colonoscopy. Consequently my entire colon was removed and I am now living with an ileorectal anastomosis. Chemotherapy was successful at fighting back my hepatic metastasis and has kept me alive up until now.

Another of my health problems originates from my younger days when, at the age of 30, I was operated from a lumbar subdural tumour. The operation prevented me from sitting in a wheel chair however it did not keep me from having problems with my back and legs. For the last 20 years I have suffered from spinal stenosis which limits my walking range.

Since 2004 I have been actively engaged in patient support groups. This has helped me considerably to cope with my cancer diagnosis and my life afterwards. I am working now in leading positions in different patient advocacy organisations: European Colon, the Familienhilfe Darmkrebs (Family support with hereditary colorectal cancer), Lynch Syndrome International (LSI) and the Patient Advisory Board of the Centre for Rare Diseases at the University Clinics of Bonn.

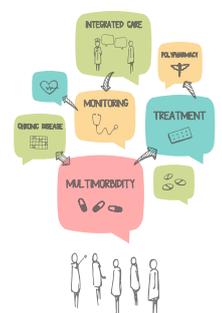
In June this year I had a surgical operation for the replacement of my right hip link by an endoprosthesis. I had been painfully waiting for the operation for the last two years, until my oncologist saw a chance to pause my chemotherapy since such an operation is by no means advisable while running chemo therapy. This was my second operation of this kind since my left hip link was replaced already in 2007.

I am here today because my care was well coordinated, although it was not easy to wait for the hip replacement I needed. The interactions between the doctors were good and I was involved at all points and fully informed. Unfortunately, I know of different experiences than mine, of cases in which patients have experienced much more difficulties.”



**Wolfram Nolte, 70, Germany**

*Colorectal cancer, spinal stenosis, orthopaedic problems*



“My name is Dee. I am in my late sixties, married for over 40 years, mother of five, granny of three (so far!) and a retired community development administrator. I was reasonably healthy (apart from controlled essential hypertension) up to my early 50s, when I developed asthma following pneumonia. By the way, I have never smoked, nor does anyone in our house, though my father was a pipe-smoker.

My asthma was reasonably well controlled for about 10 years with a maintenance inhaler and albuterol as needed, which was very rarely. Then, following an operation, I developed rheumatoid arthritis (RA). I was lucky in that I was referred to a rheumatologist very quickly, who started me on methotrexate, to which I had a life-threatening reaction, then leflunomide, which I could not tolerate either, and on to etanercept, a biopharmaceutical which I inject every week. It has worked very well for the RA; unfortunately, it is an immunosuppressant drug, which means that I am much more vulnerable to infections, especially of the lungs.

After a couple of admissions to Accident and Emergency, my respiratory consultant and I agreed on a protocol for managing my asthma: if my daily peak flow measurements fall below an agreed level over 24 hours, I take prednisone, for which I have a rolling permanent prescription. This saves both time in treating the infection and money – it costs me €60 for a GP visit, as I do not have a medical card. On a daily basis I now use a second maintenance inhaler, whilst I am on the maximum dosage of four separate medications for the worsening hypertension/mild heart failure.

This brings me to the question of overall costs. My RA drug alone is priced at about €2000 a month; thank goodness that under the drugs payment scheme I ‘only’ pay €144 to cover all my medications. The long-term illness list in Ireland does unfortunately not include asthma.

Individually, I get on well with my three consultants (respiratory, rheumatology & cardiology) who deal with me as an intelligent adult and involve me in the management of their particular speciality – but I do query the communication between them. I have had to learn how to balance my asthma and RA, and to be the one who makes sure they all remember all my conditions and their effects on one another. I have taken control as much as possible!”



**Dee Neeson, 60+, Ireland**

*Rheumatoid arthritis, hypertension, asthma*

“My 79-year-old mother is a real poster child for why co-morbidities need to be recognised and acted upon. She was diagnosed with vascular disease 20 years ago. She has also been suffering for many years from hypertension, rheumatoid arthritis, temporal arteritis and severe back and joint pain. She is also obese.

For many years her breathing has been bad (she is an ex-smoker). I said for years that she had COPD but my mother just thought I was being a know-it-all and her doctors just put her awful breathing down to the vascular and heart disease. It was not until she nearly died after contracting pneumonia 18 months ago that I again said that she had COPD and they should test her for it. Again, I was slapped down by her GP who attributed her breathing problems to the pneumonia. I insisted and they grudgingly tested her 2 months later. Guess what - it turns out she has pretty advanced COPD...

They then prescribed medication and she has been seeing a specialist nurse at her GP practice but was only referred to a special exercise class for COPD this summer. The annoying thing is that the class is held across the street from her house and she could have been attending for a couple of years.

Still, I have to say that after her pneumonia, the NHS kicked in and she is now being treated in a very multidisciplinary manner - to the extent that she is at her GP's or at the hospital 2 to 3 times per week now. She has been tested for everything you can think of. That also has its downsides as she is now starting to feel overly medicalised and often the only time she gets out of the house is to go for medical treatment. This, of course, is leading to depression on top of everything else.

I also have to say that I have seen the difference between the UK and poorer EU member states in the last 12 months. About a year ago, the mother of a Bulgarian friend was hospitalised with awful headaches and vision problems. She was investigated for a brain tumour but they found nothing. Her symptoms sounded just like my mum's when she was diagnosed with temporal arteritis so I told my friend to have her mum investigated for that condition. My friend was ignored by the neurologist in Sofia for three weeks who should have referred her mum to a rheumatologist. When they eventually listened to my friend and referred her mother on, she did in fact turn out to have temporal arteritis. But by then it was too late and her mum subsequently went blind days later. In May this year she died.

So, as ever, it is about sophisticated multi-disciplinary systems of care. But it is also about medical specialists who have to listen to patients and carers or refer on to other specialisms when they are getting nowhere and about family members having the confidence to take on the medical establishment.”

### Jane's mother, 79, United Kingdom

*Vascular disease, hypertension, rheumatoid arthritis, temporal arteritis, severe back and joint pain, obesity, COPD*



“My name is Marie Fowley, I am from Sligo, Ireland.

I am married with one child. I had diabetes for 43 years prior to my SPK (Simultaneous Pancreas-Kidney transplantation). I developed diabetes when I was 11 years of age.

As I was a free spirited child/teenager, I did not worry about the future or my health. Medics told me I would not see my 21<sup>st</sup> birthday. I decided to live life to the full causing high blood sugar levels and high blood pressure. Suffering a lot of hypoglycaemia and diabetic comas. I went on with my career and became an SRN (State Registered Nurse) and Midwife even though I was refused at interviews due to my diabetes.

In my early twenties I was diagnosed with kidney disease and I was put on medication which held it for ten years. A bout of food poisoning, ten years later plunged me directly into stage 3 kidney disease, but I did not have any physical signs, only severe weight loss. I was told by my consultant it was the silent killer. I was monitored regularly by my endocrinologist. I was not long slipping into stage 4 kidney failure. I was well aware where this was leading for me and the word that I would never speak about to my family or friends...DIALYSIS!

The nephrology team in Beaumont Hospital in Dublin were excellent and they explained the different types of dialysis and which would be suited best to my busy lifestyle. I choose peritoneal dialysis. I was dreading this but I had no choice, I was scared, either dialysis or death. I was now in end stage kidney failure. My usual positive mental attitude faltered, as each day I had to dress and care for the tenckhoff catheter which was protruding from my tummy. I found this so difficult from a woman's point of view but the excellent team from Beaumont Hospital kept me strong and home visited regularly. They even called me over Christmas.

Due to my underlying diabetes and the high glucose level in the dialysis fluid, my life was a struggle. As I deteriorated I thought that death would be a relief for me and for all those around me. This was so not like me and my positivity. I considered stopping my dialysis and letting nature take its course. Again the Beaumont nurses, my angels kept me going. I had a lot of admissions to Beaumont Hospital due to fluid retention and blisters on my body along with a rash. It was at this point I then turned to prayer.

The call came one Monday night at 1.40am while I was in mid-dialysis. A very fast trip to Dublin saw us in Beaumont Hospital in a very quick time. Tests followed and I was wheeled into theatre at 10.00am, everything matched and ready steady go.

I was returned to my room at 10pm that night and my road to recovery began. I will never forget the words...“your kidney is working perfectly and you no longer have diabetes.”

Oh my God, after forty three years ... a miracle.“



**Marie Fowley, Ireland**

*Kidney disease, diabetes, simultaneous pancreas-kidney transplantation patient*

“My name is Helga Bruggink. I am a nurse (caretaker) and an activities guide. Unfortunately, I was declared unfit for my work because of my health. My health problems started ten years ago, when I had two brain infarcts caused by bosom fibrillations. I have heart failure, kidney failure, rheumatism and diabetes.

At this moment, my life is being hindered most by tiredness and a feeling of fretfulness. I cannot stand too much noise and movement in my vicinity for very long. I start to feel nauseous and I get headaches. When this happens, a three hour resting period, in full silence, gets me through.

My doctors take good care of me. Although I have to add that I am assertive. I ask my cardiologist if he knows I have diabetes. Also, I always ask my doctors whether they are up to speed with the results of certain tests their colleagues performed on me. Thanks to my paramedical background, I am familiar with the medical terms. This facilitates the communication.

Doctors are autonomous. They do not want to interfere with someone else’s working area. But if you do not take the initiative to talk about it, you get very little information. I think it is a good thing when doctors take the responsibility to share more information with one another and with the patient, because if they do not, a lot can go wrong.

When I ask my doctor whether he knows about the result of a specific test, I often get the response that “it is on the computer”. And from the questions I get from my nephrologist and my rheumatologist, I know they exchange results. But I do not know if they actually confer with each other. And as for my cardiologist, I cannot get any insights into his level of knowledge. The other day, I asked my family doctor whether he had sent the results of my diabetes examination to the nephrologist. I knew that the nephrologist was eager to receive them. Only when I explicitly asked him to pass on the results, did he sent them.

I plan the visits to my doctors on the same day as much often as possible. During my latest visits, I had my protein and sugar levels in urine tested by one doctor, and half an hour later by the other one. I indicated that this test had already been performed and that maybe they could share the results. But they all wanted to perform it themselves, and receive the results themselves. I think it is a waste of money, but I leave it at that. I think it is more important that they are all fully informed about my medical situation.”



**Helga Bruggink, 64, The Netherlands**

*Heart failure, kidney failure, rheumatism and diabetes*



“My name is Ine Boys, 57-year-old former psychiatric and independent district nurse, living on disability.

At the age of 30, a blood transfusion following a caesarean caused anaphylactic shock and 42°C fever. This changed my life forever! Being a young, married woman with two small children, a mortgage and a demanding job, I could not find anyone to help me. 17 years and several diagnoses later, a doctor finally acknowledged my illness and was willing to help me.

It became clear my condition was serious and not easy to solve. Taking care of heart and gynaecological problems, a pituitary adenoma was relatively easy in comparison to Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) and years later, late-stage Lyme because of the multi-systemic nature of these diseases. This made it more difficult to manage my condition. Because only part of my diseases could be treated, which meant chances of getting better were jeopardised.

The most difficult aspect of having multiple conditions is not knowing which disease is responsible for which symptoms. On the one hand myalgic encephalomyelitis is a physical, serious and debilitating condition for which little recognition exists but also, having ME/CFS written in my personal health record puts me at risk for having everything assigned to ME/CFS. Clinicians do not take me seriously and send me home without check-up and/or treatment which can be dangerous. Health professionals and the health system have done a correct job in treating and reimbursing my heart and gynaecological problems but for the other three conditions the care was appalling. Once during the weekend, there was a note hanging on the ER-door saying “NOT FOR ME/CFS PATIENTS”. I really felt stigmatised and there was nothing I could do about it!

Little by little my health deteriorates because I cannot access the care I need and my disease has not been taken seriously. Symptom-relieving treatments to alleviate my burden and suffering are inaccessible. Multimorbidity and multi-systemic diseases are apparently very difficult to treat because different medical disciplines do not know how to work together to benefit the patient.

As a patient, I believe that it is very important to organise initiatives to increase awareness and understanding of ME/CFS, to set up inter- and multidisciplinary collaboration among different partners – researchers, clinicians, care facilities, patients, family, policymakers, etc. – and provide appropriate care at all levels, as well as research and training for everyone involved with ME/CFS patients are needed. This could improve the lives of ME/CFS patients and reduce the burden whilst there is no evidence-based treatment available yet.”

### **Ine Boys, 57, Belgium**

*Cardiac patient, pituitary adenoma and myalgic encephalomyelitis patient*

“I have never been happier. I know it sounds strange for someone with multiple sclerosis (MS), but this different life is so much better in ways I did not expect. There is more appreciation for the little things in life, more self-awareness, less pressure to do things „I should do” but do not really want to do.

I would be silly if I said it be silly if I said it has been easy. The truth is that my 86-year-old grandmother is in better shape than I am. It is hard for me to focus or remember details, and the chronic tingling in my fingers makes it difficult to write or use a cell phone. And that is on the best days. Sometimes things just fall out of my hands and break.

Shortly after the diagnosis, when I was numb from toes to the neck, a disc slipped in my lower back. This had happened before, but this time I cloud not walk. I actually could not move. I spent 5 days on my living room floor, trying to watch TV and not to think about the future - not to ask myself if this would ever go away. After a few weeks it did.

So having experienced such overpowering numbness, every day when I walk again is filled with smiles. When walking up the stairs, “normal” people simply just do it. For me - with every step there is the appreciation that I can still walk. Simple pleasures, so taken for granted before.

I got my treatment one month after the diagnosis, in spite of a long waiting list. Pure luck. The Polish law - to refund the treatment not just for a couple of years, but for as long as it works - changed a few weeks before my first shot. Any of us can get sick, but only the luckiest get to be treated. I still spend a fortune on necessary supplements and all sorts of pills though – from dizziness to depression.

What else? I put on 15 kg because I had to quit smoking. The doctor told me it has been proven that smoking accelerates relapses. I have not smoked since.

MS made me crazy - I am not ashamed to say that I need a shrink to keep me away from imminent depression, but it was my choice. When my days got really dark, I walked in and said “Help me out, I do not want to be unhappy”. And I know that one day the reality will overwhelm me, but just not yet.

My family, my friends, my employer - all passed the test for understanding and being there for better or worse. I even got a raise and keep on the good work that I love. Who can say that about their life? Only the luckiest of people.

I am not a believer, but when I recently went to church, just as a tourist, I felt the need to light one of those votive candles. But I didn’t ask for health, I only said „Thank you”. Weird? Perhaps. Am I crazy to be happy? Sure.”

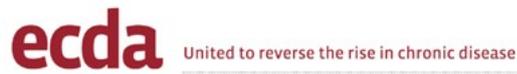


**Marianna Wodzińska, 31, Poland**

*Relapse remitting multiple sclerosis and associated complications*



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