

UNDER PRESSURE

LIVING WITH MS IN EUROPE

The Under Pressure project focuses on the sharp discrepancies in the treatment, employment and empowerment of people with multiple sclerosis (MS) across Europe. It was carried out by a team of five renowned photographers under the coordination of the European Multiple Sclerosis Platform (EMSP) and with the support of MS societies from 12 countries in Europe.

The dedicated website hosts up to 600 evocative pictures and a selection of powerful video testimonies emphasising the challenges faced by people with MS and their carers.

Under Pressure is also providing MS communities with a photo exhibition and a brochure with facts and figures.

About EMSP

The European Multiple Sclerosis Platform (EMSP) represents more than 600,000 people living with MS in Europe.

2014 marks our 25th anniversary – over the years we have gained the support of 38 member societies from 34 European countries.

Among our other flagship projects: the MS Barometer – a collection of comparative MS data provided by national MS societies; MS Nurse Pro – an accredited online education programme, promoting the role of MS nurses and the provision of care across Europe; and Believe and Achieve – an awareness-raising campaign to improve access to employment for young people with MS in Europe.

25 years, and more to come, as the voice of people with MS in Europe

About MS

Multiple sclerosis is a chronic disease of the central nervous system, amongst the most debilitating neurological disorders for young people. When MS sets in, the body starts attacking itself – the immune cells start destroying the protective sheath called myelin that covers all the nerves in our brain and spinal cord. The result is that messages fail to get through to other parts of the body correctly, or sometimes at all.

No two people are affected in the same way. Symptoms range from fatigue and depression to severe mobility problems and blindness in extreme cases. Most people are diagnosed between the ages of 20 and 40.

There is currently no cure for multiple sclerosis, but the condition can be managed through specialised help, starting with early diagnosis and continuing with person-centered therapies and appropriate medication.

Multiple sclerosis directly and indirectly affects the lives of more than 1,5 million people in Europe.



EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM



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Minsk, Belarus, 10/2011
© WALTER ASTRADA

In the one-room flat he shares with his mother, Andrei Boukatyi (34) practices Qigong every morning to build his strength and improve his balance. He chose this alternative therapy after prescribed MS medications caused

him periods of depression and aggression. Yet his advanced condition makes it almost impossible for him to navigate the stairs in his building. Andrei's disability pension, based on years of study (3) and work (3), is about

50 euros per month; his rent costs about 27 euros. His mother, Tatiana, will soon reach the age of forced retirement and their combined income will decline.



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Minsk, Belarus, 10/2011
© WALTER ASTRADA

Nicolai Kleshchanka (56) is blind and virtually paralysed from the neck down, but MS has had no effect on his mental capacities. Extremely low access to medical treatment and rehabilitation has likely contributed to

his physical deterioration. The MS Society of Belarus estimates that 500 PwMS live in Minsk – and that 430 are too disabled to leave their flats. Like Nicolai, they pass their days (and years) in front of the TV.



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Tallinn, Estonia, 11/2011
© LURDES R. BASOLÍ

When Harry Kestlane first noticed he could no longer see letters printed on a page, he had something of a panic attack and rushed to the window to look at the trees. He still loves to be outdoors, but now relies on other

senses to experience nature. Harry now “sees” only pink, as though a thick fluid has covered his eyes.



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Laagri, Estonia, 11/2011
© LURDES R. BASOLÍ

An adult-sized tricycle allows Piret-Karin Sula to enjoy an evening walk with her children, Alexandra-Elisabeth and Toomas-Gustav, or to carry out errands such as shopping or going to the bank.



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Paris, France, 02/2012
© LURDES R. BASOLÍ

"I was terrified when Marc said he wanted to keep performing after his last relapse. Afraid that people wouldn't know where to look once they saw the wheelchair, or that they would pity him," says Marie-Odile Chantran.

"After a couple of concerts, I understood that they were still coming because he is still Marc Perrone, and he still has something to give them."



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Paris, France, 02/2012
© LURDES R. BASOLÍ

Hitting the bull's eye may be the end goal, but Armelle Bugand finds in archery what other PwMS look for in practicing Yoga or Qigong. Before she releases each arrow, she must achieve the “zen” moment that brings all of

her energy to a single focus. This mental discipline is important to coping with MS and living with a “mind over body” philosophy.



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Freiburg, Germany, 03/2012
© CARLOS SPOTTORNO

Each visit to the neurologist is a time of reflection for Amadou Touré. For three years, they have been locked in a debate over using Mixantrone, a form of chemotherapy, to control his MS. Because it is an aggressive

therapy with potentially serious side effects – including heart attack – it is a short-term, last-resort option. Amadou does not want to take it too early; his neurologist does not want him to wait until it is too late.



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Bad Wildbad, Germany, 12/2011
© CARLOS SPOTTORNO

Ergotherapist Ingrid Weissinger leads Ernst Friedrich Bieringer through a series of exercises to improve his mobility. The Centre's multi-disciplinary approach is driven by the needs and desires of the PwMS.



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Thessaloniki, Greece, 10/2011
© MAXIMILIANO BRAUN

Before the economic crisis hit, Manolis Tsatsiadis used swimming as a form of physiotherapy; after an hour in the water, he could walk comfortably for about 30 minutes. When the pool took measures to

save money on heating, he had to stop: colder water worsens his tremors. Manolis' meagre disability pension barely makes ends meet: his family provides financial help for physiotherapy and household essentials.



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Thessaloniki, Greece, 10/2011
© MAXIMILIANO BRAUN

“One thing changed quickly when I was diagnosed with MS,” says Vasiliki Garopoulou. “The family of my boyfriend at the time couldn’t cope; his mother basically suggested to me ‘You have one option if you want to date my son:

you must be perfect.’ Now, I make a script for myself, and find that I’d rather be thin and have MS and still like to look at myself in the mirror, than to be fat and feel ugly. Especially because I know that having MS is something I can’t change.”



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Reykjavik, Iceland, 10/2011
© FERNANDO MOLERES

Electric scooters provide little protection against foul weather, but more than enough energy to empower Kristján Einar Einarsson, Helga Káradóttir and Jón Þórðarson (right to left). A mentality of independent living

pervades Icelandic culture, and underpins investment in facilities and infrastructure. In fact, with secure financial support for physical care of PwMS, MS-félag Íslands (MS Society of Iceland) feels lucky to be able to offer

services that focus on psychological, social and overall well-being.



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Reykjavik, Iceland, 10/2011
© FERNANDO MOLERES

Steinn Ólafsson believes that being a carer is partly about being an enabler. Guðrún Sigríður Eiríksdóttir works out regularly at the MS Centre (MS Setrið) so she can pursue an active lifestyle. When fatigue and loss of

balance threatened her golf game, the couple began renting a cart and devised a “duck and grab” manoeuvre that keeps Steinn from taking a hit during the downswing and Guðrún from landing face-down on the fairway.



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12/2011, Dublin, Ireland
© WALTER ASTRADA

Since Dixie joined the family, Mary Bartley has noticed a marked improvement in her overall mobility. She has more stamina when walking and knows it is a form of physiotherapy each time she reaches to give the dog a pat. "Dixie

is a wonderful companion and I do believe you need to keep exercising," says Mary.



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12/2011, Trim, Ireland
© WALTER ASTRADA

Looking back, Grace O'Sullivan points to a case of vertigo as her first symptom of MS, but her doctor thought it was a viral infection. Shortly after, she began to notice that her speech was slurred. Subsequent relapses

led to blindness in one eye, which responded to injected steroids in just a few days, and paralysis of her left arm, which gradually lessened over a period of about six months.



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Buonconvento, Italy, 02/2012
© CARLOS SPOTTORNO

Like many PwMS, Martina Vagini loves swimming: it makes her feel light and healthy and, for a time, she can forget about balance and gait problems. But the closest pool is in the village of Buonconvento, several kilometres from

where she lives in San Quirico d'Orcia. Although psychologically uplifting, the work-out leaves her physically exhausted. To support Martina's fitness plan, the local MS Society provides a volunteer who goes along to the pool and then drives her home.



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Aversa, Italy, 03/2012
© WALTER ASTRADA

“At present, I have no problems in terms of getting around: I can drive, I can walk and I can work,” says Stefania Salzillo. “But I can see that if this changes, everything will take more effort. So, I think this should be an

important objective of government policies – to raise awareness of these difficulties and sharpen the focus on solving these problems. Every citizen should be given the same opportunities to live.”



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Warsaw, Poland, 10/2011
© CARLOS SPOTTORNO

Ania Szczepaniak dreamed of being a model and actress; a friend photographed her often to make a portfolio. As it becomes increasingly difficult to move around even inside her flat, Ania must re-evaluate how and

where she can work. She finds it harder to go to students as she did in the past, but hopes to continue teaching Polish at home.



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Radom, Poland, 10/2011
© CARLOS SPOTTORNO

Monika Kladko receives electrotherapy every day for about 30 minutes. The treatment uses a mild electrical current to stimulate nerve fibres, thereby releasing endorphins (the body's natural pain-killing chemicals).

This service is provided by the MS Society in cooperation with the Radom City council.



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Oradea, Romania, 11/2011
© FERNANDO MOLERES

A group physiotherapy class at the MS Centre focuses on flexibility and balance. Lenuta Covășdan credits two people with convincing her that, even with MS, living was worthwhile. "My husband literally saved my life on two

occasions. My priest changed my life: he told me God had allowed this disease to be in my life so I could trust him more and help others. This is what makes me happy now; helping others."



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Turda, Romania, 11/2011
© FERNANDO MOLERES

"Faith is very important to us", says Erika Chirvai. "Dan and I believe that God brought us together and made our union possible." She is deeply grateful for how their marriage changed her life. Paralysed from the waist

down since age 13, she lived for many years with a sister who worked and went out a lot. Erika was trapped in the flat most of the time. Despite struggling with MS, Dan was eager to take her out and show her the world.



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Madrid, Spain, 10/2011
© LURDES R. BASOLÍ

Heads turn at the zoo's amphitheatre as David carries his wife, Almudena, up to her seat. On the platform below, her wheelchair is equally eye-catching among a small horde of baby strollers. Making sure their son has an active

life is more important than giving any serious consideration to how strangers react to the ways they cope with living with MS.



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Madrid, Spain, 10/2011
© LURDES R. BASOLÍ

As Antonio's world becomes more confined by the walls of their apartment, his wife Milagros Albertos feels her role is evolving from wife and partner to nurse or mother. She is losing important elements of her

own identity and is often faced with difficult choices such as going out with friends or staying in to show her support. As their financial situation worsens, they are forced to consider moving in with Antonio's mother.



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Reading, United Kingdom, 12/2011
© MAXIMILIANO BRAUN

Maureen Pankhurst (70) has lived with MS for 50 years, and in the same house almost as long. Over time, the local health council has adapted the home to meet her changing needs. Neil, the next-door-neighbour who

became her second husband, is a retired engineer who cares for Maureen and volunteers almost daily as a driver for the Reading Branch of the UK MS Society.



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Hove, United Kingdom, 11/2011
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Shoshana Pezzaro (32) thought of herself as never having outgrown the awkward stage of being a teen. UK health policy requires that people select a family doctor in the area where they live. Because Shoshana

moved often while in university, each odd symptom or minor injury from a clumsy fall was overseen by different doctor. Unaware that there might be a link between numb legs and loss of colour vision, she never

told doctors about her past medical history. Some 10 years passed between her first symptom and her diagnosis.

Sponsors / Credits

The European Multiple Sclerosis Platform (EMSP) expresses sincere thanks to the network of sponsors and partners that provided support for the UNDER PRESSURE project*, listed below in random order:

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