

UNDER PRESSURE

LIVING WITH MS IN EUROPE



Warsaw, Poland, 10/2011 •

Ania Szczepaniak dreamed of a career under the bright lights of the catwalk or on the stage of a Warsaw theatre. Now, a short walk on a warm day can be overwhelming. Ania went to university, married and bought a nice flat before learning that she had MS. For 13 years, Ania's father asked the doctor to hide the diagnosis to his daughter – a gesture for which Ania is grateful. Her husband counters that if they had known, the couple would have made different decisions about their future.

Photo: Carlos Spottorno

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CONCEPT AND CREATIVE DIRECTION

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PHOTOS

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UNDER PRESSURE (UP) shows how differences in national policies, culture and services can affect the daily lives of people living with multiple sclerosis (MS) across Europe.

Approximately 600,000 Europeans live with MS, an unpredictable disease that can launch random attacks on the central nervous system. Women are more frequently affected than men. MS can be like a long, slow walk over an unfamiliar landscape where weather patterns are unpredictable and range from mild to extreme.

In late 2011 and early 2012, five renowned photographers went out to meet people with MS in 12 different European countries, capturing their stories through their photographic lenses, as well as through conversations and interviews. Each of the photographers spent up to ten days per country to get to know the individual people, to meet with their families and carers, and to learn what it means to live with MS in places as different as Bucharest, Seville and Berlin.

Fighting for the interests of people with MS across Europe, the European Multiple Sclerosis Platform (EMSP) regularly publishes an MS Barometer, providing data about national disparities but also about progress in managing MS in Europe. Given the inconsistent approach to data in many countries, the MS Barometer is of great importance in the fight against health inequalities.¹

The report age captured in Under Pressure was born by the aspiration to make the findings of the MS Barometer even more tangible, casting a spotlight onto some of the countries, and complementing facts and figures with real-life stories. In doing so, we concentrated on three indicators used in the MS Barometer: equal rights, including access to MS treatment and services; employment and job retention; and empowerment of people with MS.

UNDER PRESSURE tells stories from 12 countries about what it means to live with MS in Europe: from Nilolai from Belarus who is blind, paralysed and effectively trapped in his

1. For insights into the MS Barometer http://www.emsp.org/attachments/article/160/MS_Barometer_2011.pdf. The data in the country profiles stems from multiple sources: the MS Barometer, national MS societies and the research team's conversations with the MS community throughout Europe.

apartment; via Martina from Italy who, despite some mobility problems, works full-time at a hotel; through to Guðrún and Steinn, an Icelandic couple who have developed their very own system for playing golf, despite the toll the disease has taken on Guðrún's health.

The personal portraits are complemented by country spotlights, providing insights into the collective MS story in the respective region. The booklet illustrates how the personal and professional opportunities for people with MS are inextricably linked with the country in which they live.

Access to medication and rehabilitation are key factors in determining people's experience. There is strong evidence that disease-modifying treatments can slow down the progression of MS by many years, yet access to appropriate treatment is not guaranteed for many Europeans with MS. The booklet shows the importance of other factors such as social and employment policies and their enforcement - and how different these are from one country to another.²

It also shows the impact the economic crisis has on the situation of people with MS in some of our member countries. As with MS itself, the very real risk of any economic crisis can be irrevocable, that is to say that, what is lost may never be regained.

Importantly, this booklet also demonstrates that MS means something different for each person living with the disease. No one story in this book is identical to another, but there is clearly a common thread. The whole team working on the project were struck by the strength and resilience of so many of the people who contributed.

By the nature of the project this report focuses on people with visible MS challenges such as mobility problems. What was captured to a lesser extent were the challenges of those living with invisible symptoms. As underlined in the Icelandic profile, many people with MS are forced to stop working due to symptoms such as fatigue and cognitive problems. Importantly,

2. Under Pressure provides commentary, opinions and testimony from individuals, specialists and MS organisations including information on the treatment, care and employment practices in a number of European countries. These represent the views of those contributors and do not indicate endorsement of any particular approach by EMSP.

there are also people who are able to continue living and working without significant problems.

Having witnessed the many different ways in which MS can impact on people's lives, lead photographer, Carlos Spottorno said: *'An active social life, a regular job and goals for the future, make life richer, and happier. A full life makes people with MS no different from anyone else, and that needs to be the ultimate goal of our work'.*

People with MS are and should be in the forefront of this booklet and we would like to thank all those who had the courage to tell their story. We would also like to thank their families, carers and volunteers, as well as the MS societies for their invaluable contributions

to the booklet and their fight against MS in Europe.

There are many others whose commitment and contributions ensured the successful development and completion of this project: Marilyn Smith as the originator of the concept and Creative Director; the photographers; our partners in the European institutions, research and industry; and the EMSP project team.

John C. Golding

President of the European Multiple Sclerosis Platform

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“Multiple sclerosis (MS) is a disease that respects no geographical boundaries and in order to maximise their quality of life, people with MS need access to the best available treatment, care and services as well as having the opportunity to fully participate in work and in their communities. Unfortunately, there continue to be unacceptable disparities in access to these services for many people with MS throughout Europe.

Under Pressure provides, through the medium of bold and evocative photography, a moving and powerful insight into the world of people affected by MS and we hope that this will be used as an effective tool to raise awareness and mobilise support for people with MS and to help reduce some of the inequalities they face.

EMSP, the outstanding photographers, the national MS societies, the project coordinator, and most importantly, the people with MS who participated and gave their time and personal stories so generously are to be commended for this innovative approach to increasing the visibility of MS on the map of Europe.

Prof. Alan Thompson

*Chairman of the International Medical and Scientific
Advisory Board of the MS International Federation
(MSIF)*

Dean of the UCL Faculty of Brain Sciences, London

MS in BELARUS

The Byelorussia MS Society estimates that 500 members of their organisation live in the capital, Minsk – and that 430 of them are virtually trapped in their apartments. Amongst the estimated 10,000 people with MS in Belarus, this is a shocking degree of isolation.

Nowhere within this reportage is the personal impact of ineffective health and social policies more evident. Twenty years after its approval by the US Drug administration, the costs of Interferon-B, the very first disease-modifying drug are still not reimbursed; nor are the other disease-modifying drugs, that are approved elsewhere in Europe. In a country where the average gross income is about €250 per month, who could possibly afford a medication that costs €2,000 every month?

As is expected within a given MS population, many Byelorussians remain in the relapsing-remitting stage. But those whose condition is progressive, experience more advanced disability at younger ages than is evident in other countries.

Public transport is free to many people with disabilities (1st & 2nd group), but neither the subway nor the bus system in Minsk are wheelchair accessible. People with disabilities

who live alone in Belarus are entitled to a 50% discount on rent (only 1st group) and some discount on utilities, but as few residences are accessible, most disabled people are obliged to live with friends or family, thus becoming ineligible for such discounts. A severe lack of independent living opportunities also leaves many people with MS no choice but to live in state-run institutions. Quality of care is reportedly low.

The ratio of neurologists to people with MS is 1:>500. In comparison, the ratio is 1:<100 in Estonia. Practicing general neurologists (not specialised in MS) have insufficient time to devote to each person. The treatments approved by the National Health Ministry are known to cause severe side effects.

By law, people with disabilities are entitled to retain their positions or seek employment. In practice, they are rarely successful in such efforts. Local NGOs report that only 5% of people with MS are employed in full-time positions; approximately 10% work on a part-time basis.



Minsk, Belarus, 10/2011 • Nikolai Kleschenko (56) is blind and virtually paralysed from neck down, but MS has no impact on his mental capacity. Inadequate access to medical treatment and rehabilitation is likely to have contributed to his state of health. The MS society of Belarus estimates that 430 people with MS living in Minsk are too disabled to leave their flats.

Photo: Walter Astrada

MS in POLAND

At just 7% of GDP, Poland's spending on health care is comparatively low for an EU country. This bodes badly for a region that has a very high prevalence of one of Europe's most costly diseases – 120 per 100,000 population are affected by MS, and approximately 500 people are newly diagnosed each year. Insufficient funding ultimately results in worse health and poorer overall quality of life for people with MS.

According to the MS Barometer, in Poland only around 7% of people with MS receive disease-modifying treatment, despite evidence showing treatment can effectively slow down the progression of MS for up to 15 years. To “equalise” access, a limited number of people receive disease-modifying drugs at any one time. After five years, access is transferred to the next person on the waiting list. Withdrawing disease-modifying drugs markedly increases the risk of progression of the disease.

While access to therapy for treating symptoms is relatively high, on average the state reimburses less than 25% of the cost. Poland is one of only three countries, along with Belarus and Ireland, in which the neurologist to patient ratio exceeds

1:500. An estimated 30% of people with MS have access to rehabilitation services but this access is inconsistent and there are long waiting lists for the services.

The law clearly states that employers must not discriminate against people with disabilities who are employed or are seeking employment, and must allow people to request flexible working conditions following diagnosis.

The legal system does not provide personal assistance services and people with disabilities living in a public institution pay 70% of their income for the living facility and the 24-hour care.

Poland scores rather well in terms of empowerment of people with MS. The key achievement is the establishment, in 2011, of an MS Parliamentary Group, comprising 11 Members of Parliament from diverse political backgrounds but united by a common interest: improving the situation for people with MS. As a result, the Parliamentary Health Commission devoted time during one of its recent meetings to the difficult situation of Polish people with MS.



Radom, Poland, 10/2011 • 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. Electrotherapy only solves a small portion of the problem.

Photo: Carlos Spottorno

MS in ESTONIA

Estonia is a player to watch in many ways. The country has one of the most efficient health care systems in the world. Most treatments are accessible to people with MS at no cost; however, access to new medication is comparatively slow.

The ratio of neurologists to people with MS is 1:<100, meaning that neurologists have more time for their patients than in other countries. There are no specific limits to symptomatic treatment in Estonia, and most people with MS are allowed to spend two weeks per year as in-patients at the MS Centre in Tallinn.

On the downside, MS care is neither holistic nor standardised. Individual neurologists determine, for example, how often their patients will receive a brain scan. Some prescribe annual imaging to monitor progression of disease and the effectiveness of the current therapy. Others might prescribe a scan once every 10 years. While health policy supports the prescription of disease-modifying drugs, some neurologists prefer not to prescribe.

Such inconsistencies have an impact on the health of people with MS.

Estonia provides poorly for people with MS in respect of social services, rehabilitation and support for employment. Although there are some positive initiatives, there are still big differences between large organisations and smaller companies when it comes to maintaining employment and offering flexible working arrangements. While there is legal protection for people with MS to remain employed after being diagnosed, it is not unusual for a company to be “restructured” to eliminate the position filled by a person who becomes disabled.

More positively, a person with a disability pension may continue working to the extent that he or she feels able. Earning an income does not have any negative impact on that pension.

Estonia does not yet have a national register for people with MS, which limits the opportunity to influence policies.



Tallinn, Estonia, 11/2011 • MS has left Harry Kestlane both blind and paraplegic. He uses the time spent alone in his home to train his memory by visualising the placement of things in the room around him. Harry now recognises visiting friends and former co-workers by the sound of their footsteps. As the apartment has no elevator, getting out has turned into a major venture for Harry and his helpers.

Photo: Lurdes R. Basolí

MS in ROMANIA

Although only 1,500 people are registered, an estimated 10,000 Romanians live with MS. The subtlety of language deals an additional blow: the first part of sclerozã multiplă is just one letter shy of sclerozat – a term meaning “lack of mind” that is used to denote psychological disorders such as dementia or senility.

Discrimination against people with disabilities remains a problem, and at just 5.4% of GDP, spending on healthcare is extremely low. Although the neurologist to patient ratio of 1:<100 rivals that of Western European countries, neurologists’ ability to provide effective, holistic care is undermined by other aspects of the healthcare system that are seriously deficient. In effect, there is a two-tier system in place, with wealthy people able to access better care. There have been many reports of cases in which people bribe the clinic or hospital staff to get better treatment. One report estimates that such informal payments amount to as much as €300 million each year, equal to the average net monthly income for more than 1.5 million Romanian workers together.

Access to disease-modifying drugs is quite poor, with only one fifth of those who are registered as people living with MS receiving such treatment. On a positive note, there is no

limit to the duration of treatment, as long as the therapy is shown to be effective. In principle, people with MS are able to receive symptomatic treatment. In practice, only 50% of them do so. There is a serious lack of rehabilitation services. Those who can afford it travel to other countries in the hope of getting relief through rehabilitation or alternative treatment methods.

Romania occupies the third-to-last place on the MS Barometer when it comes to reimbursement of costs. In some cases, the cost of medication for symptoms exceeds the person’s monthly pension. People need to be inventive to cope financially with the disease.

Somewhat surprisingly, Romania scores high in the area of employment and job retention – ahead of countries such as Norway, Sweden, and France. Legislation supports the right of people to remain employed following diagnosis. Employers with more than 50 employees are obliged to employ at least 4% of disabled people.

Social stigma continues to have profound implications for employment of people with MS in Romania. Despite incentives such as tax deductions, most employers prefer to pay a fine rather than employing a disabled person.



Bucarest, Romania, 11/2011 • Christian Bunda's MS is aggressive and his disability is advancing quickly. He boards a plane to Serbia to get treated abroad. Just one day before the trip, his neurologist confirmed that his MRI showed many more lesions than expected.

Photo: Fernando Molerés

MS in SPAIN

The economic crisis is taking a harsh toll on people with MS in Spain on many levels: access to rehabilitation is declining rapidly, unemployment is rising and the future of reimbursement is becoming more and more uncertain.

While health care is free in Spain and access to disease-modifying drugs is reasonably good, public hospitals offer little assistance for rehabilitation therapy. To fill the need, a model of self-supporting MS centres has been developed in which communities of people with MS pool their resources in cooperative-type arrangements, most of them with at least some degree of government support. Since the economic crisis hit, governments have slashed contributions and funding from major supporters has fallen sharply. Many centres face the difficult choice of cutting services and staff or increasing the cost of member fees. Access to physiotherapy gets even more complicated than it used to be.

The ratio of neurologists to people with MS is 1<100; by contrast, in Ireland, Poland and Belarus, the ratio exceeds 1>500 people with MS. The ratio in Spain supports rapid access when the need arises, and neurologists are able to spend appropriate amounts of time with their patients

and follow their condition closely. No other health professionals receive certified MS training.

An estimated 50% of people with MS work full-time; another 10% hold part-time positions. Employment policy for people with MS is weak in Spain. A critical factor is the lack of legislation to protect the rights of people with MS to retain their positions after being diagnosed. Similarly, there is no legal means by which a person with MS may request flexible working conditions. The government does, however, offer some incentives to employers to recruit or retain people with disabilities, including MS. In practice, many employers remain resistant. Inevitably, many people with MS will avoid revealing their condition for as long as possible.

Spain guarantees public support for people who cannot lead independent lives for reasons of illness, disability or age, including revenue for families taking care of a person who is unwell. This is another provision under threat with the economic crisis. In addition, reimbursement is almost always insufficient to truly cover the cost to a person with MS.



Madrid, Spain, 10/2011 • Almudena Movilla is doing her weekly yoga class with her teacher Borja Rodríguez at FEMM/FELEM, one of the main centres for people with MS in Madrid. While she is waiting to have access to rehabilitation, yoga works well for her body, as it makes her feel very relaxed. She combines yoga with other therapies.

Photo: Lurdes R. Basolí

MS in GREECE

The number of people with MS has increased from 3 to 11 per 100,000 in Greece over the past years, meaning that Greece is one of the ‘high-risk countries’.

There is a clear gap between a rather favourable legal situation and the increasingly tough reality for people with MS. Recent labour policies support employment for disabled people, and the latest medicines, including disease-modifying drugs, are available at no cost to most people with MS. This could change with the current economic crisis. Yet paying even 10% of the €2000/month required would be beyond the means of most people with MS.

Greek law mandates access to buildings for people with disabilities, special ramps for sidewalks and for means of public transport; however, authorities enforce this law poorly. The general lack of accessibility leads to serious social exclusion. As one MS patient put it: “Do you see any disabled people on the streets of Thessaloniki? No. It’s not that they don’t exist; it’s that they can’t get out of their apartments.”

Many aspects of daily life have become harder for people with MS. Before the crisis, the mere

fact of being diagnosed with MS led to a 67% disability status and related benefits for the person affected. Now, only severely disabled people receive an allowance. And for many of them, this provision is also under threat. Many people try to get by without the equipment they need to maintain their independence.

The ratio of neurologists to people with MS is 1:<300, meaning that doctors have very limited time with their patients. There are only two specialised MS nurses in the whole country. Greece also reports a troubling lack of access to rehabilitation. Physiotherapy is reimbursed only for a period of three months after diagnosis.

It is estimated that 35% of people with MS are employed full-time while another 20% hold part-time positions. Employing people with disabilities continues to be financially supported, but with the economic crisis employers are reluctant to recruit. On a positive note, a person of any age with MS who has worked for 15 years has the right to get an old age pension equivalent to that of a person of any age who has worked 35 years. They don’t have to wait to reach the age of 65 or 67 to get their pension.



Thessaloniki, Greece, 10/2011 • 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.

Photo: Maximiliano Braun

MS in IRELAND

Ireland has one of the highest rates of MS in the world, with limited opportunities for neuro-rehabilitation. Access to disease-modifying therapies is reasonable but provisions for multidisciplinary support are very poor.

A third of people with MS currently receive disease-modifying treatment. There is no policy limitation to the number of people being treated or the duration of treatment. However, while those with private health insurance can access services more quickly, those seeking free services may face long waits.

The ratio of neurologists to people with MS is very low – 1 > 500; only Poland and Belarus report similar figures. As a consequence, neurologists in Ireland can spend only limited time with their patients. A model of nurse-led services may help to provide a solution.

There are no specialised MS rehabilitation facilities in Ireland and access to generic rehabilitation is limited. Moreover, some people with MS would need to travel more than 200 km to benefit from rehabilitation. In contrast, people in Germany with MS have specialised care within 50 Kilometres of where they live.

On the positive side, the Irish health system supports symptomatic treatment for MS and ranks high when it comes to access to new medications. Ireland also scores well in the area of MS research.

The Irish law and social system is forthcoming in many ways, but it is comparatively weak on home adaptation, leaving people with MS to cover a major part of the costs out of their own pockets: many people simply cannot afford the devices that would help them to live independently. Support to keep people with MS in the workplace is slightly higher. It is estimated that more than half of people with MS are unemployed as a result of their MS (64%); another 24% work part-time.

There is important financial support for people with disabilities in place, however this is very low compared to the average income and needs supplementing. Ireland does not yet have a national register for people with MS, limiting the opportunity to influence policy for this group of people.



12/2011, Dublin, Ireland • John Nevin settles into a jacuzzi bath at the MS Care Centre, operated by MS Ireland. The Centre's primary aim is to provide a week of rest, therapy and social interaction for people living with MS. It is well recognised that the visits are equally important for family members, giving them a break from the demands of care.

Photo: Walter Astrada

MS in FRANCE

French neurologist Jean-Martin Charcot was the first to recognise MS as a distinct disease almost 150 years ago. Today, France has a medium to high rate of prevalence of MS. More people are affected by MS in the north and east of France.

France is doing well overall when it comes to policies and provision for people with MS.

The French law forbids discrimination against people with disabilities, and the government generally enforces these provisions quite effectively. The World Health Organisation lists the country as the best overall provider of health care, and care is free for people with long-term conditions.

Access to therapies and treatment is reasonably good for people with MS, 40% receive fully-reimbursed disease-modifying drug therapy. The health system also covers the treatment of specific symptoms as well as rehabilitation.

France is among the 23 EMSP member countries in which the ratio of neurologists to

people with MS is 1<100 – five times better than in countries like Ireland, Poland and Belarus. Neurologists can follow their patients' MS rather closely.

The French MS Society estimates that 25% of people with MS currently work full-time; another 35% work part-time. French law protects people with MS so that they can keep their jobs after being diagnosed. People with MS can also request flexible working conditions. Those who have to retire early are offered a small pension. But even in a country that is ranking almost 'best in class', living with MS poses continued challenges for the people affected.

By contrast, France offers less financial assistance for home and workplace adaptation than other countries – only 50% to 74% of the costs are taken care of.

France is one of just 15 countries with a register for people with MS, offering an important opportunity to influence policy.



Paris, France, 02/2012 • Hitting the bull's eye may be the end goal, but Mel Bugand finds in archery what other people with MS 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 for living with a “mind over body” philosophy and helps coping with physical challenges.

Photo: Lurdes R. Basoli

MS in THE UNITED KINGDOM

There is wide variation across the UK both in access to different MS services and the quality of those services. Last year, two of the UK Government's watchdogs, the National Audit Office and the Public Accounts Committee issued reports into the state of health and social care services for those living with neurological conditions in England. They identified a range of problems, including wide variation in access to services, long times to diagnosis, poor information and a lack of care coordination.

Access to MS medicines is also subject to a postcode lottery yet can be vital in helping to reduce the frequency and severity of relapses and slowing the progression of the condition. In 2011, the UK MS Society reported considerable variation between prescribing practice amongst hospitals and MS specialist centres. Prescribing levels in the UK are amongst the lowest in Europe; the UK is ranked last out of 33 European countries with only 12 percent of people with MS on disease modifying treatments.

In the UK, people with MS have the right to remain in employment following diagnosis and to request flexible working conditions, however significant areas for improvement remain. People with MS have lower participation rates in the

labour force compared to those with other long-term and progressive conditions. Discriminatory attitudes and poor awareness among employers of the fluctuating nature of the condition and many of its unseen symptoms such as fatigue, pain, memory and concentration difficulties, can delay access to workplace interventions and put pressure on working relationships. Lack of systematic advice and information means that many people with MS are unaware of the support available to them.

There are two main disability benefits available for people with MS in the UK – Employment and Support Allowance (ESA) and Disability Living Allowance (DLA). ESA is the new benefit for people who cannot work due to illness or disability, while DLA helps people manage the additional costs of living with a disability. However, DLA is being replaced by the new Personal Independence Payment (PIP) in 2013 and significant cuts are expected to be made to the numbers of people who qualify for the benefit. There is also considerable concern that the tests for both ESA and PIP fail to properly recognise how people with MS are affected by the fluctuating nature of the condition. Care and support services are available across the UK but the qualifying tests and the amount that people have to pay towards this care is different across and within each of the nations.



Reading, United Kingdom, 12/2011 • Maureen Pankhurst has lived with MS for 50 years, and in the same house almost as long. Over time, the local health council has adapted her home to her changing needs. Maureen's next-door-neighbour Neil became her second husband. A retired engineer, he cares for Maureen and volunteers almost daily as a driver for the Reading Branch of the UK MS Society. He is one of the heroes in the background of this reportage.

Photo: Maximiliano Braun

MS in ITALY

Sardinia lies closer to Africa than to the west of Italy and the sun shines, on average, for 300 days per year. Yet, Sardinia has one of the world's highest rates of MS, strangely contradicting both geographical and vitamin D deficiency theories about MS.

Whether in Sardinia or Tuscany, people with MS in Italy are relatively well off compared to many of their European counterparts. The public health care system ranks second-best, and health and social policies broadly reflect the needs of disabled people and others with long-term conditions.

Italy offers important access to treatment and therapy. More than 200 geographically dispersed MS Clinics guarantee access to MS management. Some 65% of people with MS in Italy currently receive disease-modifying therapy. Because of the economic crisis and the high cost of such medication, there has been some attempt to limit treatment at local level. Italy is also lacking adequate long term rehabilitation, but it is one of only eight countries with a specialised palliative care programme.

Half of the people with MS in Italy continue to work full-time – actually, the woman featured in the photo works at a hotel. In most other countries less than a third of people with MS keep full-time positions. In Italy some 10% work part-time. People have the legal right to stay in their jobs following diagnosis and to request flexible working conditions. Importantly, Italian law also offers employers incentives to recruit or retain people with disabilities.

The pension for disabled people is considered to be adequate and Italy also has a provision for paid leave for disabled people and their carers.

Despite Italy's progressive attitude to disability, areas for improvement remain. For instance, the well-meant strict protection of architectural heritage can pose accessibility problems in practice. How to enter a church on Sunday if there's no ramp?

A national register has not been established and it is in this area of data collection that Italy loses its standing among the high-ranking countries on the MS Barometer.



San Quirico D'Orcia, Tuscany, Italy, 02/2012 • Diagnosed at the age of 18, Martina Vagini finished university but then hit a low point. With each relapse, she felt she had to “accept” MS all over again. Joining the Italian MS Society was a turning point: as she learns more about the disease, she finds new ways to cope with it. Now working and living on her own, Martina has made new friends who understand her physical limits. The photo shows her leaving a cinema.

Photo: Carlos Spottorno

MS in ICELAND

Iceland has one of the highest concentrations of people with MS in Europe. In 10% of families, more than one person has MS, compared to only 4% in most other regions, suggesting a genetic and environmental link. Doctors, especially neurologists, in Iceland are very well informed about MS which makes it easier to get an accurate diagnosis. In Iceland, there are probably few people who have MS who are not diagnosed. Due to the small population in Iceland and high representation of people with MS in the MS Society it is relatively straightforward to keep track of numbers.

In the Icelandic welfare model rights arise from citizenship, not employment. Laws support both employment and empowerment of people with MS. Yet unemployment among people with MS is quite high: 35 per cent of the people with MS are not working. Fatigue has a negative effect on endurance, and many people find it difficult to keep pace with workplace demands.

An estimated 40% of people with MS are currently employed full-time, and another 25% part-time. Legislation allows people with MS to retain their positions following diagnosis; they

may also request flexible working conditions.

Despite Iceland's financial crisis in 2008 and modest economic recovery since, the country offers important reimbursement. The health system covers all disease-modifying drugs; treatment of symptoms is fully reimbursed; and people with MS enjoy unlimited access to rehabilitation.

Operated by Iceland's MS Society, the Icelandic MS Centre demonstrates how the needs of people with MS can be met; it serves as both care and community centre. The MS Centre is financially supported by the State and can accommodate forty people with MS every day – and people can come every weekday if they wish.

Iceland also has an exceptionally high ratio of neurologists: 18 specialists serve an MS population of 430 people - by contrast, Ireland has just 27 specialists for an estimated MS population of 7,000. Iceland is also one of eight countries offering specialised palliative care.



10/2011, Reykjavik, Iceland • Steinn Ólafsson believes that being a carer is partly about being an enabler. Guðrún Sigríður Eiríksdóttir works out regularly at the MS Centre 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.

Photo: Fernando Moleres

MS in GERMANY

More than 120,000 people live with MS in Germany - one of the highest numbers in Europe. The country has the world's oldest universal health system, offering important protection for people with disabilities.

The ratio of neurologists to people with MS is 1 < 100, allowing the neurologists to monitor people closely. Treatment is carried out by a team of specialists from various disciplines. The German health system reimburses the full cost of disease-modifying drugs, and does not limit the duration of treatment. The treatment of symptoms is also fully covered, and people have unlimited access to rehabilitation. Germany also does well in providing access to new medications coming on the market. In addition, it is one of the few European countries offering specialised palliative care.

Public transport must be barrier-free in Germany and restaurants with accessibility problems are not allowed to operate. People with mobility problems do not need to pay any motor vehicle tax and are allowed to use special, reserved parking spaces.

Of all countries in this book, Germany scores

best in employment and job retention. Legislation in Germany protects the right of a people with MS to retain their positions after being diagnosed; the individual may also request flexible working conditions. Germany also offers incentives to recruit or retain people with disabilities, using a subsidy to salary costs as a “carrot” and an obligation to employ people with disabilities as a “stick”. However, as fines are low the obligation does not always have the desired effect. Also, if an employer wants to dismiss an employee, they might use economic difficulties or restructuring as a reason. An estimated 32% of people with MS are employed in full-time positions and another 13% working on a part-time basis.

Germany has a pension fund for early retirement for people with MS-related disabilities. Those who need help in carrying out everyday tasks may also receive care insurance payments, as may their carers.

Germany and Poland are the only countries in which the MS Society is part of the decision-making process on reimbursement of new therapies. Germany also scores high on research in MS.



Freiburg, Germany, 03/2012 • Both architects, Amadou and Bettina Touré share a passion for culture; but they are at odds over next steps with regards to MS. Three years ago, Amadou's neurologist recommended chemotherapy to halt, at least temporarily, further loss of function. Amadou believes he can manage MS through a positive attitude and a healthy lifestyle. Bettina worries that he will soon lose the ability to walk at all, which would have dramatic impacts on their lives – together and individually.

Photo: Carlos Spottorno

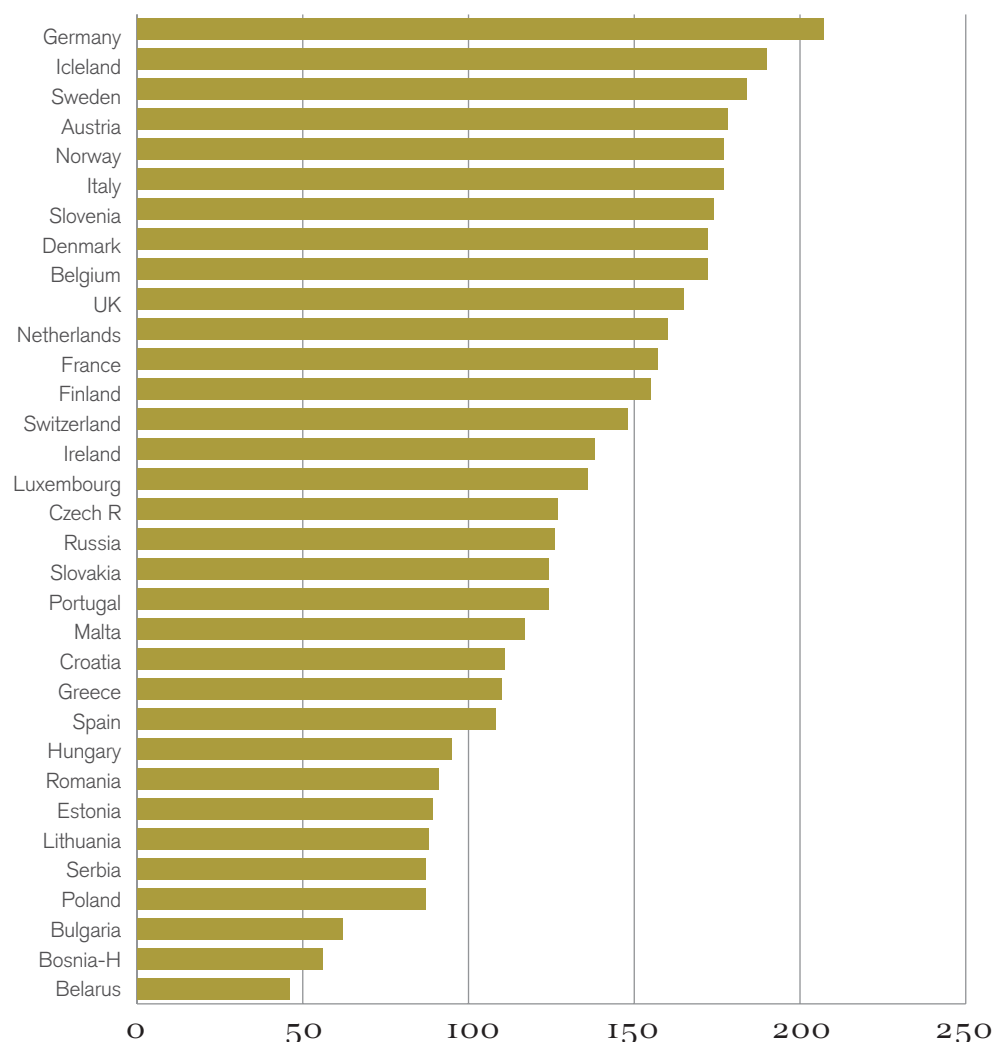
Insights from the MS Barometer

Together with its member organisations, EMSP has been representing the interests of people with MS for more than 20 years. Although during this period there have been many successful projects and activities resulting in tangible achievements – including a European Parliament Resolution on a European Code of Best Practice in 2003 – the situation of people with MS in Europe remains challenging.

Collecting data from 33 countries, the “**MS Barometer**” shows that regrettably little has improved between 2003 and 2011 in how the condition is managed throughout Europe (fig.1).¹

The **Under Pressure** project has focused primarily on three of out of seven areas from the MS Barometer: access to treatment and therapies; employment and job retention; and empowerment of people with MS and their carers in the featured countries. The discrepancies between European countries in all areas remain important.

Fig.1 MS Barometer 2011: overall results

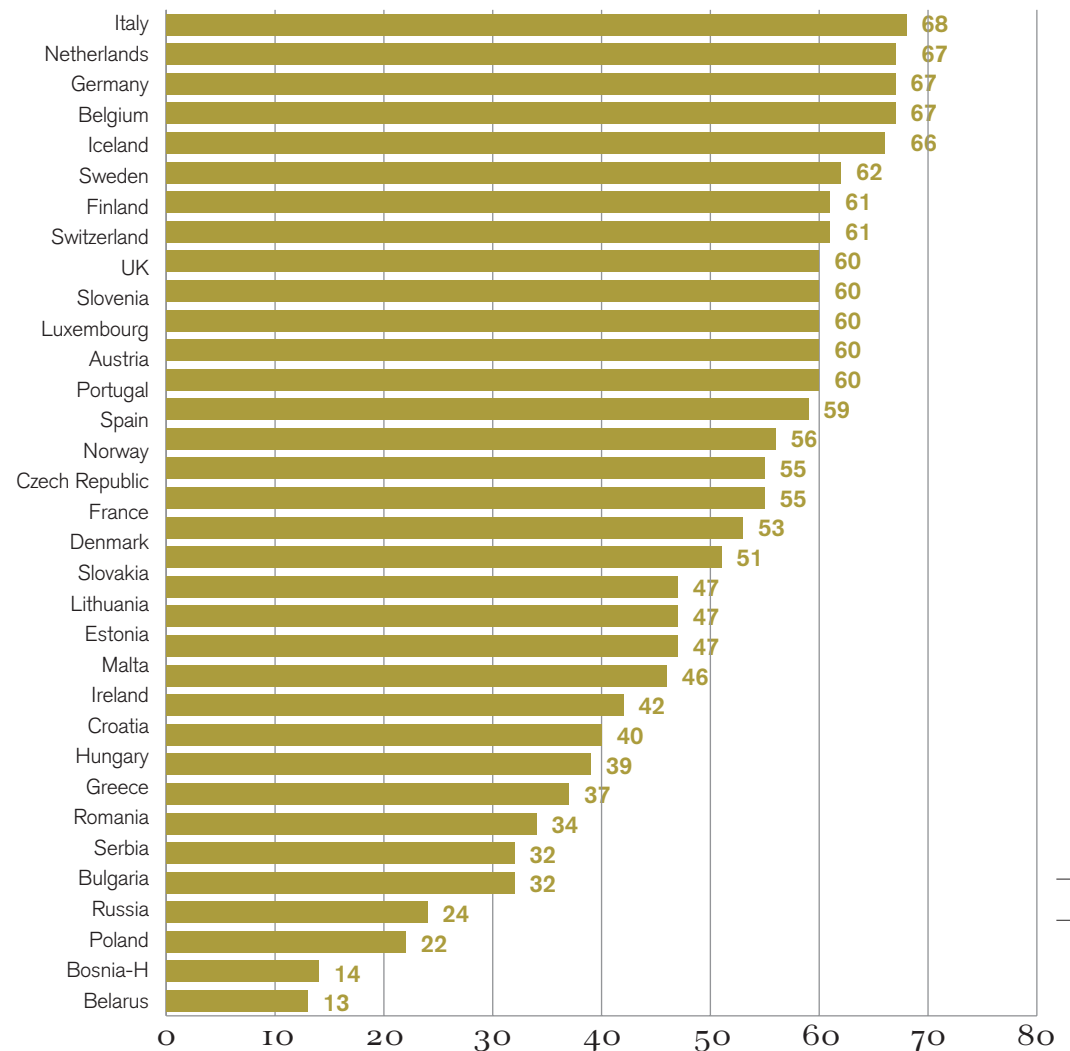


1. This text is based on the findings of the 2011 MS Barometer: <http://www.emsp.org/projects/ms-id/160-ms-barometer-2011>. The country profiles also refer to other data, primarily from the national MS Societies.

The approach to treatments and care varies substantially throughout Europe, (fig. 2): access to disease-modifying drugs ranges from 0% to 80%; symptomatic treatment duration is limited in countries such as Hungary and Belarus; some countries do not have specialised rehabilitation clinics; or the number of clinics available is inadequate to meet the needs of people with MS. These are just a few examples of the existing disparities.

Multiple sclerosis is one of the most common diseases of the central nervous system, but far too little is known about it. Against this background, the lack of public funding for research is noticeable: only 15 countries out of 33 reported receiving public funding for MS research.

Fig.2 MS Barometer 2011: Access to treatment and therapies (max. Score: 70)

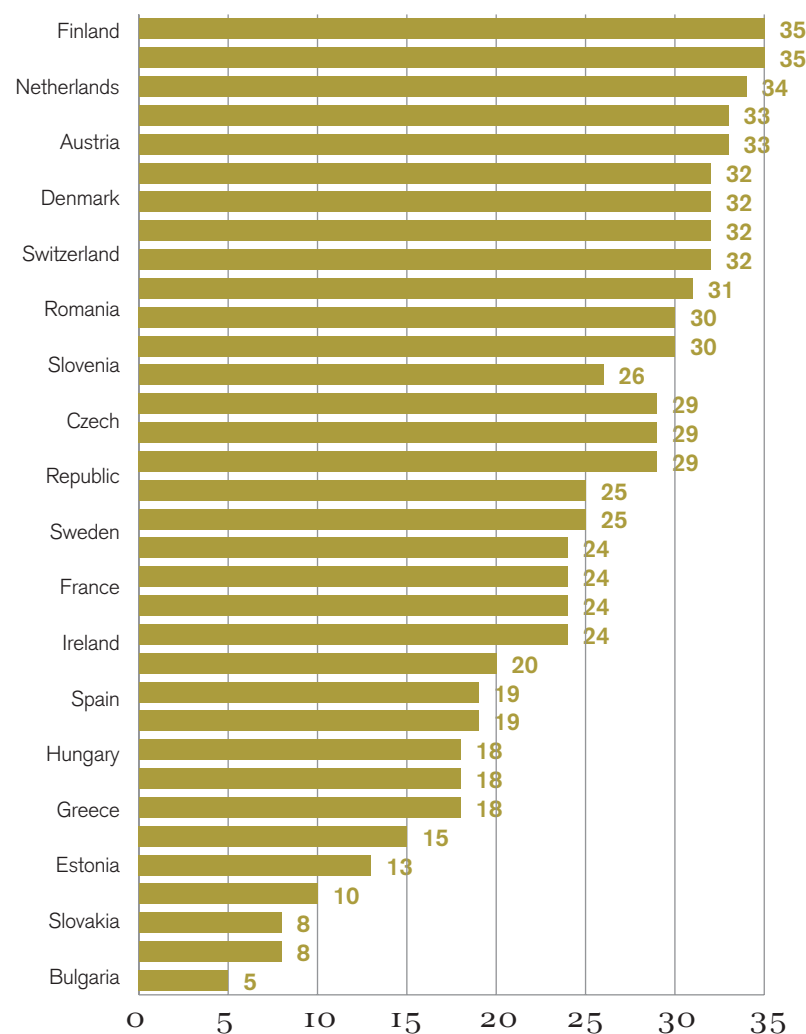


The MS Barometer also shows that people with MS face daily challenges with employment, job retention and securing adequate income (fig. 3). Despite the fact that people with disabilities are legally entitled to remain employed in all European countries, the failure to adapt workplaces and to introduce flexible working practices acts as a significant barrier to people with MS keeping their jobs.

In a number of countries, including Bulgaria and Slovakia, there is no pension fund to support disability-related early retirement. In other countries the funds are insufficient to meet the real needs of the beneficiaries.

Relevant national policies are necessary to enable people with multiple sclerosis to be independent and to participate in an active life with their families and in their communities.

Fig.3 MS Barometer 2011: Employment
(max. score: 35)



A call to action to improve the quality of life of people with multiple sclerosis

EMSP encourages national policy decision-makers to exchange best practice in neighbouring countries with similar socio-economic situations to provide the best possible access to treatment and care for people with MS.

The health and wellbeing of people with MS is a matter of public health concern. Swift action must be taken to ensure that:

- Health professionals are better educated and trained and have the tools they need to treat people with MS;
- Access to appropriate healthcare and support is not hindered by reimbursement costs policies;
- MS research is high on the political agenda;
- Empowerment of people with MS is fully guaranteed through adequate financial support, involvement in decision-making and access to flexible employment.

This course of action would help impact positively on the quality of life of more than 600,000 people affected by multiple sclerosis throughout Europe

Sponsors and 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,¹ listed below in alphabetical order:



A special thank you goes to **Almirall** for making the production and dissemination of this brochure possible.

We would also like to thank 306 Members of the European Parliament for signing a Written Declaration² on tackling multiple sclerosis (MS) in Europe.

1. All EMSP projects supported via unconditional grants from corporate sponsors are subject to the conditions stipulated in EMSP's Code of Conduct.

2. Declaration of the European Parliament of 13 September 2012 on tackling multiple sclerosis in Europe: [http://www.europarl.europa.eu/sides/getDoc.do?type=TA&reference=P7_TA\(2012\)0357&language=EN](http://www.europarl.europa.eu/sides/getDoc.do?type=TA&reference=P7_TA(2012)0357&language=EN)





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