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EUROPEAN
MULTIPLE SCLEROSIS
PLATFORM

Breaking down the barriers.
Access to employment and the economics of brain health

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Speech

Hello, I'm Shana, I'm 35 and I live in Brighton in the UK. I was finally diagnosed with Multiple Sclerosis 7 years ago Aged 28. By that point I was extremely ill, I had to sell my business and I was signed off of work permanently.

I am not an unusual case. There are 700,000 people living with MS in Europe, and 70% of us are diagnosed in our 20s to 40s. This means MS hits at a time which can have a massive impact on our working lives and careers. Currently, 2 in 5 people with MS aged under 35 are unable to work or study due to our condition.

Early retirement and loss of employment is the biggest economic burden of MS in Europe. But for many of us living with the condition, working not only means financial independence, it's also an important part of feeling part of society.

Working gives us a sense of achievement, worth and self-esteem. Remaining in work helps to fight depression and social isolation.

I was only diagnosed with MS 7 years ago, but my neurological health problems started at 7 years old. By the age of 14, I was missing on average 1 day a week off school.
At 17 I was very ill and nearly died. But I went on to study Drama at The University of Bristol, and I had a great time despite being in and out of hospital a lot. Then I moved to London to work in television as a production coordinator.

I worked for the television company for 2 years. In that time had three severe kidney infections and periods of extreme facial pain when I couldn't speak. I kept falling down stairs, and tripping over, (when I wasn't drunk). At one point my right arm went totally dead and my colleagues had to come to my house every morning to help me do up my bra and help me get dressed. Then they'd take me to work! There were long periods of time when I was well. I could really focus, be creative and dynamic and I was excellent at my job. But there were also times when I was suffering really badly with fatigue and my concentration and focus would really suffer.

Eventually I admitted to myself that I was struggling with the long hours of working in television. Sometimes we worked for 36 hours without stopping. And there was lots of heavy equipment to lift and carry.

My boss and colleagues were really supportive. But it just wasn't the sort of job where you could have days off ill, come in late, or have time off for doctors and hospital appointments. I was responsible for organising film shoots with multi-million pound budgets and the work was very fast paced, high stress and everything had to be done incredibly quickly and accurately. Finally I decided that I couldn't cope with doing that job, in that industry, with my health problems.
So, I decided to move to Brighton and set up a children's stage school and theatrical agency. Being self-employed was so much easier, my health was my own problem and I could manage it. At first I was teaching piano, drama, dance and singing, and I employed part time office staff, so I could go off to doctors and hospital appointments.

Sadly, whilst my business rapidly expanded, my health really deteriorated. I couldn't dance as I was walking very badly and I had two operations on my leg and ankle. I had to stop teaching piano as sometimes my hands wouldn't work and sometimes my vision would blur so I couldn't see to read music. I was having problems singing for long periods and my speech slurred when I was tired. And I would suddenly desperately need the toilet. I remember wetting myself whilst teaching as I couldn't just leave my class of 5 yr olds unattended.

Eventually I couldn't teach, but I could sit at my computer and do all the business admin, organisation and run the very busy agency. I found ways of adapting and changing my role so I could stay working for as long as possible.

However, after 5 years I had 300 students, 13 members of staff and I was very, very ill. I couldn't cope working any more. I was finally diagnosed with MS aged 28 and I sold my business.

So now I work voluntarily when I am well enough. I do lots of Media, Campaigning, Press and PR work around MS, disability, social care, welfare, exercise and health. But the reason I do it is because working is such an important part of my identity. It makes me feel valued and that is crucial for my positive mental health. But fundamentally, I really want people with MS to be supported to stay in *paid* work for as long as possible. And for employers to see people for their talent and ability, not for their MS.

Gaining and maintaining employment is one of the biggest issues facing people with MS across Europe. Many work places are not physically accessible, but the biggest barrier to employment can be employer's negative attitudes to chronic illness. Some employers are absolutely fantastic. But for many others, there is a huge amount of misunderstanding about MS.

Every person with MS has different symptoms. And many people with MS can be extremely fit for many years and just have short periods of relapse where they are affected by their symptoms. But this fluctuating aspect of MS is often misunderstood. Many employers just see MS as potentially highly detrimental to their business but that's why EMSP (and others) are working on showing the reality. The Work Foundation, an EMSP survey of young people with MS last year and research from the International Labour Organisation (ILO) and World Health Organisation (WHO) all repeatedly show the same thing - people with disabilities desperately want to work and while many employers recognise their abilities, there are some employers who simply do not want to risk employing someone with a fluctuating health condition. In reality, if you have MS it can be incredibly difficult to get a job, no matter how much you could contribute to an organisation. We want to support people to go beyond the barriers and preconceived ideas.

The European Union is focussing so much energy and ability on employment. There are national implementation plans under the EU Youth Guarantee Scheme aimed at early intervention and activation for young people who are not in employment, education or training. National funds for the scheme are being topped up by €6bn through the Economic Social Fund. So we really need to ensure some of this money is used to support young people with neuro-degenerative diseases, to give people opportunities to gain skills and build towards their future. It makes financial sense.

Again, employment is the single most important factor in the economic burden of multiple sclerosis. Many people with MS *could* work.

So, what could and should be done to support people with MS to work?

- For employers hiring people with MS, we need to provide education on multiple sclerosis, practical tools and policies that can be implemented and financial support.

- One thing employers seem to be afraid of is taking a person with MS on board, and then being unable to support them if there are changes to the person's condition. Solutions include retention policies that support the company and person to adapt to the changes.

- We need to promote the concept of person-centred participation. The person with MS should be actively involved in identifying issues of concern around employment. And then be supported to work with the employer to find positive solutions.

  And there are some simple changes to work-places which can make a huge difference to someone's ability to stay in work, such as
    - Clear policies and action plans to support staff
    - Open communication with managers/human resources
    - Provision of a quiet area to rest
    - A desk positioned close to the toilets
    - Flexible working hours, or ability to work from home

Finally, I believe that the UN Convention of Rights of people with disabilities is fundamental to the discussions we are having today. It recognises that, "persons with disabilities continue to face barriers in their participation as equal members of society". EMSP shares the common aims of the European Disability Strategy 2010-2020 to empower people with disabilities so they can enjoy their rights and benefit from participating in society and the economy. The support of DG Justice of the Paving the Path to Participation project, we are moving closer to these goals.

We need to ensure that people living with neurological conditions can focus on living their lives, on working, and continuing to be active citizens.

Thank you for your support today.