

If you've got MS, exercise means much more than moving

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For people with multiple sclerosis, the meaning of exercise stretches way beyond health and keeping fit, shows new research revealing what life's really like with the condition.

From a way to cope and a road to freedom, through to sparking a sense



of loss, for people with MS the idea of exercise and <u>physical activity</u> is shown to signify several things.

Two and a half million people worldwide have the condition, which damages nerves in the brain and spinal cord. And exercise and physical activity are shown to ease symptoms.

Researchers at Brunel University London carried out in-depth interviews with people with MS to find out how they really think and feel about exercise and physical activity.

"Everyday life with a deteriorating condition such as MS results in a multidimensional view of exercise and physical activity," said Brunel researcher Dr. Andrea Stennett.

"Exercise and physical activity is a way of coping with the condition and a key to maintaining their identity beyond their diagnosis – for example, as a mother, grandmother, or breadwinner."

Many people put hanging on to their identity or role above physical activity in a queue of priorities competing for limited energy reserves. They plan and organise exercise and physical activity around energy, time and priorities. "This is important because fatigue is one of the most reported symptoms of MS," says the study, out today in *Disability and Rehabilitation*.

"My focus is getting all the stuff done for the family, and then any extra energy I can use on physio," said Jill, 47. "It's extremely frustrating to get to the end of the day and think I just haven't got the energy."

The physical and psychological benefits of exercise and physical activity for people with MS are widely reported. But this study is one of few looking at the social payoffs. Understanding the thought patterns people



with MS have around exercise and physical activity may help health workers help them more.

Everyone who was questioned shared the notion that while both exercise and physical activity mean movement, physical activity means day-to-day tasks such as vacuuming or mowing the lawn. Exercise, on the other hand, was largely something structured they need to take time out to do.

Losing the ability to do physical activities such as walking, driving and painting, was likened to the grieving process and meant some people had to give up their jobs. But despite this shared sense of loss, exercise and physical activity emerged as way to cope with the condition. "Because I am not working now," said Bev, 55, "I didn't have that structure to my day... I could see the whole thing sort of falling apart."

The study enriches and extends existing evidence about the complexities of <u>exercise</u> and physical activity for people with MS who live in the community.

"These movements extend beyond the confines of body structure, function and disability," said Stennett. "They are embedded into everyday life as strategies for coping and living life in the community with a progressive neurological condition."

More information: Andrea Stennett et al. The meaning of exercise and physical activity in community dwelling people with multiple sclerosis, *Disability and Rehabilitation* (2018). <u>DOI:</u> 10.1080/09638288.2018.1497715

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