Researchers produce first physiotherapy guidance for Huntington's disease

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Professor Monica Busse. Credit: Cardiff University

Cardiff University researchers are part of a global consortium who have published the first clinical guidance for the management of Huntington's disease through physiotherapy.

It follows more than a decade of ground-breaking collaborative research led by the Cardiff team into how to manage the devastating and life-

limiting neurodegenerative condition.

There is no treatment to halt or reverse Huntington's, which damages nerve cells in the brain affecting movement, memory and behavior and affects 6-13 people in every 100,000.

This means physiotherapy is one of the few routes to offer a better quality of life for those with the inherited disease.

A joint review by researchers at Cardiff, Columbia, Ohio State and Wayne State universities looked at previous research in this area, analyzing data from 26 separate studies.

The review found physiotherapy was critical to improve motor impairments, such as dystonia or chorea (uncontrollable movements), rigidity, gait or balance issues in people with the disease.

And in a study, published in the journal *Neurology*, the researchers outline the first global evidence-based guidelines, welcomed by clinicians, physiotherapists and patients.

Professor Monica Busse, of Cardiff University's Huntington's Disease Centre, said: "The impact of Huntington's disease is devastating, in large part because of the increasing social isolation and loss of independence that comes with walking difficulties and mobility problems.

"People with Huntington's need physiotherapy to help them cope with their changing physical function—but tell us that they struggle to get expert input within the health service and there has been little to date to guide physical management in practice.

"These recommendations have the potential to really help those living with Huntington's to keep mobile—and ultimately to keep them

interacting in daily life."

"Huntington's disease has devastated my whole family'

Ian Brooks, 53, first realized something was wrong when he started to struggle to remember place names while at work as a lorry driver. He gradually began to experience mood swings and became increasingly agitated and confused.

Initially he was sent for counseling but after five months it had had little effect.

Ian knew there was a 50/50 chance he could have Huntington's disease because his father, who passed away in 2010, had battled the condition.

He decided to have the test for Huntington's and in February 2019 was given the news that he too had the incurable disease.

Within five days his driving license had been taken away—an abrupt end to a 30-year career as a professional driver and to the things he enjoyed, like driving his granddaughter to school and riding motorbikes.

The impact on his family life has been devastating. His three siblings were later diagnosed with Huntington's. He also has three daughters who have chosen not to be tested, for now.

Ian is still in the early stages of the disease; he's able to go out walking every day with a friend, sometimes for up to two hours.

But he struggles with involuntary movements—rocking, shaking and jerking—almost constantly and knows this will only get worse.

"I always have a positive outlook on life—I take each day as it comes," says Ian, from Preston in Lancashire.

"My body clock is still in work mode, so I'm up at 4-5am every morning, then I go out with the neighbor and his dogs for a long walk."

As well as keeping active, he is taking part in a two-year trial in Manchester which is investigating the efficacy and safety of a potential new drug.

Ian's partner Nicolette King says watching someone live with Huntington's can be frustrating, upsetting and relentless.

But for Ian exercise is a release; it helps him physically and mentally.

"To anyone struggling with this disease, I would just say keep yourself active—go to the gym, go to physiotherapy, go on long walks," says the care home support worker.

"There's nothing more you can do—you've just to live each day as it comes."

The new guidelines recommend:

- Physiotherapy assessment advice from the point of diagnosis
- A lifestyle that builds regular aerobic exercise, such as swimming, brisk walking, cycling or dance into each week, ideally daily or a minimum of twice a week
- A focus on improving or maintaining fitness early on, in combination with strength, balance and flexibility exercise (such as a structured gym program or yoga)
- Practice of activities to help maintain independence in daily life (sitting down and standing up, or getting up from safely from the

floor in the event of a fall)
- Advice and strategies for caregivers to maintain involvement in physical activity as the disease progresses
- Breathing exercises and advice on how to sit comfortably in more advanced cases of the disease
- Clinicians should consider the patient's impairments, goals, disease stage, and any potential for harm and provide specific interventions to target walking, posture and balance problems in the later stages of the disease

The user-friendly guidance will be distributed via global Huntington's disease and neurology networks, along with clinicians and third sector groups, and there are plans for it to be adapted for use by families.

Natalie Beswestherick, director of practice and development at the Chartered Society of Physiotherapy, said: "This devastating disease slowly strips away a person's independence and physiotherapy is vital in helping a person to fight against this.

"It is the key intervention throughout all stages of this disease; to support people to stay mobile for as long as possible, to manage symptoms and later on to ensure the person is comfortable, when simply getting out of bed becomes a struggle."

Trained physiotherapist Ruth Abuzaid, who is head of service development for the Huntington's Disease Association, said keeping active was also an important aspect for mental wellbeing.

"The more people can do in the early stages of the disease, the better they will be prepared for the journey ahead," she said.

The researchers believe their guidance could also have wider benefits as increasing evidence suggests physical activity is important across all

types of neurological diseases.

Professor Busse said: "In future, more work could be carried out to look at a broader spectrum of rare neurological diseases to understand whether our guidance—or something similar—might be applied more widely."

More information: Lori Quinn et al. Clinical recommendations to guide physical therapy practice for Huntington disease, *Neurology* (2020). DOI: 10.1212/WNL.0000000000008887

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