#### Top questions of Living Well with Progressive MS

1. Helen, in your <u>podcast episode</u> you seemed to have mentioned "hydrotherapy"...what is the meaning of this expression?

It's a good question because 'hydrotherapy' can refer to many different uses of water to relieve pain or other medical symptoms - including water jets to apply pressure, water massage and mineral baths. I was referring to something more specific: namely, physical therapy for people with MS in a swimming pool under the supervision of a neuro physiotherapist (or physical therapist).

By moving out of the gym and into a pool, we can use the buoyancy of water to overcome gravity and support our bodies, as well as provide resistance when we exercise. My biggest challenge (here in the UK) is finding a hydrotherapy pool as part of a physiotherapy service. It would be interesting to hear people's experiences in different countries.

2. You have spoken before about your Electro-Tricycle which one did you go for and would you recommend it?

Buying an electric tricycle is a big investment, but it's the best thing I've ever bought and, yes, I'd certainly recommend trying one. I did quite a bit of online research before going to Jorvik Tricycles in York (in the north of England) where I could test ride a tricycle before committing to buy.

It took a little while to get used to the tricycle, but I am growing in confidence with every ride. It's easy to get on and off because the tricycle is completely stable, and once you start pedalling, the battery gives you as much or as little assistance as you want. It's lovely to exercise outdoors while feeling very safe and stable, and with the option of resting your legs when they feel tired.

3. I have SPMS. I am confined to a wheelchair. I have aphasia speech impairment. Also, problems swallowing, as well as other common MS symptoms like fatigue & bladder issues. What aspects of the OMS program should I focus on for maximum benefit?

I am sorry to hear about these challenges of living with SPMS and I appreciate you asking this important question. To be honest, it's difficult to prioritise one aspect of OMS programme over another, because it's the combination of caring for both our bodies and our minds that is really valuable. But I'd certainly recommend eating well, maintaining a good level of vitamin D, and managing stress and anxiety through mindfulness practice.

I know that exercise can be difficult when you have restricted mobility combined with fatigue, but there are good suggestions for <u>gentle chair-based exercises on the OMS website</u>. Personally, I find breathing practice very helpful, especially when I am feeling tired and stiff: it brings me back into my

body and reminds me that the smallest movement of the breath flowing in and out is nourishing for us.

## 4. Is there anything that one can do to slow down the worsening of symptoms due to neurological damage not relapse?

Yes, and the OMS steps address this. If you look at lifestyle recommendations for common degenerative neurological diseases like Alzheimer's and Parkinson's they all make very similar recommendations to OMS, and typically recommend exercise, a good diet, looking after your mental health, and keeping your mind active. In particular, there is now good evidence that exercise is both neuroprotective and stimulates the creation of new neurons.

#### 5. Have you tried "Oxygen Therapy"?

No, but I have spoken to many who have. Anecdotally some seem to find it helpful, others less so. Oxygen therapy is an example of a complementary therapy, like acupuncture and reflexology, that seem to help some but not others.

There is no clear academic research showing that oxygen therapy is beneficial but, like other complementary therapies, if you personally find them helpful and they do not harm you then you should decide what is best for you.

### 6. Is the low-fat low dairy aspect of OMS relevant for progressive?

Yes, particularly because saturated fat is degenerative and a key component of the OMS diet is low saturated fat. A healthy diet will also help with comorbidities, and this can be critically important for us with the progressive form of the condition.

# 7. I'm experiencing constant issues with mobility and balance which are getting worse over time. Could this be primary progressive MS?

The continuous loss of function is associated with progression rather than relapses, so that does sound like the progressive component of the condition. However, there are lots of things that can be done to recover some function so would recommend finding a neurophysio to work through mobility and balance issues.