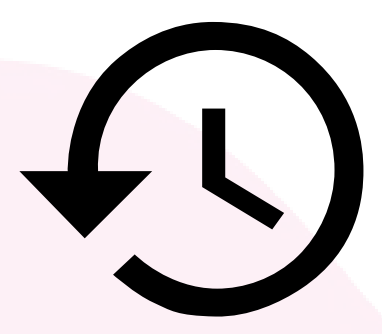


# Careless Whispers

## Do we really hear the voice of the carer? Evaluating the impact of a 6 week yoga course for relatives that care for someone with Multiple Sclerosis (MS).

Barber J (Head of Integrated Clinical Services & Physiotherapist), JodyBarber@chilternsneurocentre.org, and Garner C (Family Support Worker)



### Background and aim

Family members that care for someone with MS are an invisible and unsupported workforce. Rarely acknowledged officially, these carers provide help and support with basic everyday tasks as well as with more complex responsibilities such as providing medical home care. There are benefits to providing care to a loved one, however this informal care can be time consuming and may take a heavy toll on the carer's health and well-being.

Data from recent surveys shows:

"While 51% of carers are looking after a partner with MS, almost a third are looking after either a child or a parent with the condition. As a consequence of these relationships and due to the long-term nature of MS, some carers assume a responsibility which can last decades."<sup>1</sup>

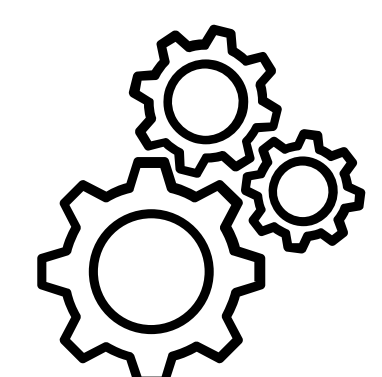
A recent review article on the lifestyle and environmental factors that influence disease progression in MS sites the importance of family. "a multidisciplinary, collaborative and person centred approach to care that encompasses the healthcare team, family members and community support groups."<sup>2</sup>



### Understanding the current situation /problem

The Chilterns Neuro Centre currently supports 535 members with MS. Family members supporting the person with MS can also become members. I had noticed that the membership had significantly increased for carer members by up to 25% some months. MS carers acknowledged the need for support, with this requirement greater at certain times due to the unpredictable nature of MS and the unique way it affects each individual patient.

At the Centre, carers were able to access some advice and educational support from a member of the team employed by the Centre to offer advice and support to families. However I reflected with the team that while I had worked closely with family members who were carers in the community in my previous NHS posts, and often navigated them to information and support, I was aware that I had not really been in a position to have a real impact on the wellbeing of the carer, in the same way I had for the person with the condition. Now working in a charity, I had the skills as a qualified British Wheel of Yoga instructor and neuro physio, and the opportunity to offer more to the carer members.



### What we did:

We wanted to explore breaking down the barriers that relatives who care for someone with MS have to making time for self-care. Promote awareness of the need to take real and positive action to support the health and wellbeing of carers.

The yoga course was delivered at the Centre each session lasted 90 mins

Yoga uses the breath and body movements and postures to help you to cultivate this listening, greater awareness of the body, breath, mind link. Yoga has many reported benefits, including stress and blood pressure reduction.<sup>3</sup> The emphasis was on self-management, giving the carer the self-efficacy and tools to develop a personal yoga practice they could carry out at home on their own.



"Jody has made it easy to use everyday things in the house which has made me more confident."

"The social aspect of these sessions creates friendships amongst the carers who understand each other."

"With a mat and a cushion I could take on the world."



### Evaluation

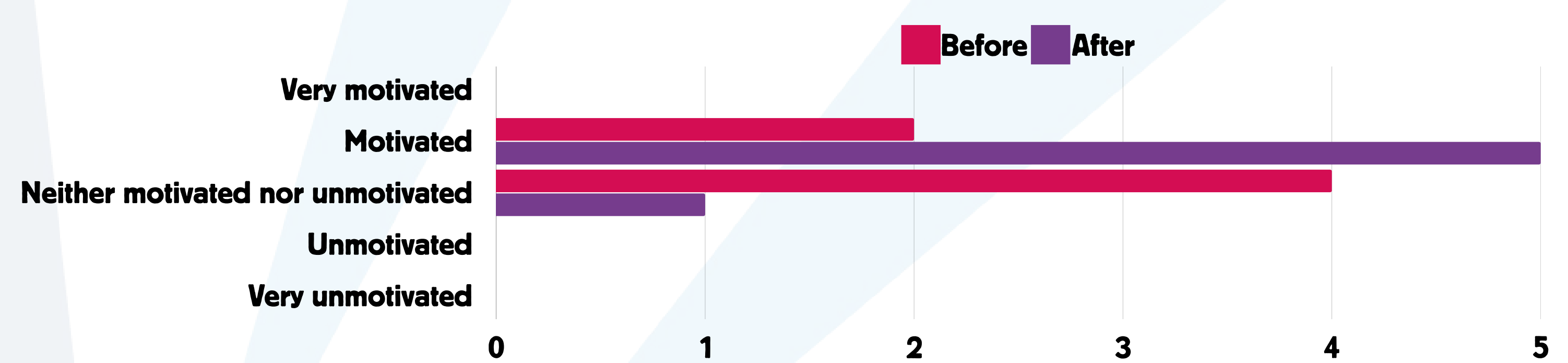
6 people signed up, after the first week, 1 person had to drop out because the person they care for was admitted to hospital. By week 2, another person dropped out as they could not commit to the time.

The Carer Burden Inventory (Novack and Guest 1989)<sup>4</sup> was used to evaluate the impact on the care role for each person.

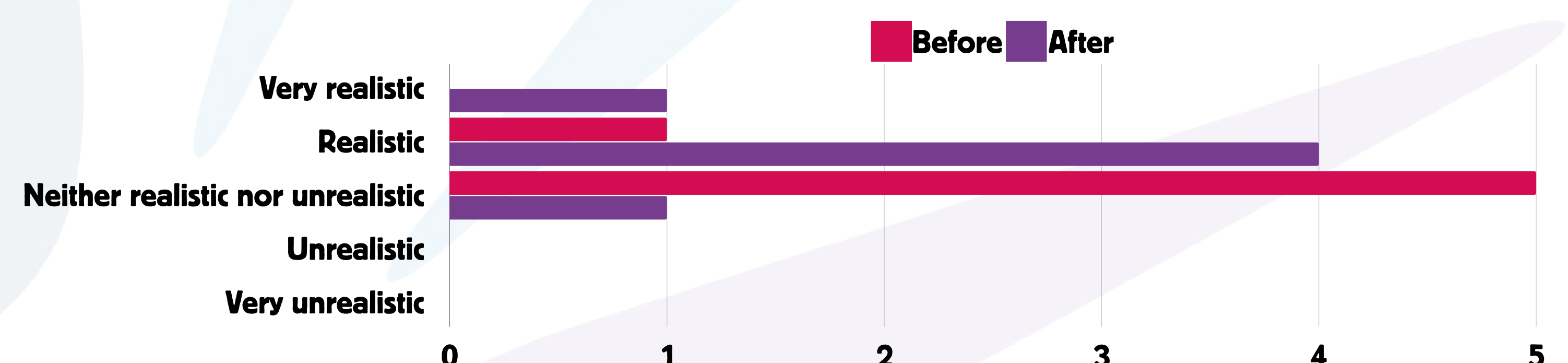
The average score was 42/96, with the scores ranging from 24 to 68. A score near or above 36 indicates a greater need for respite and other services. Anyone who scored over 36 also had additional support from the family support worker.

We also collected some feedback on the carers' experience which is displayed below.

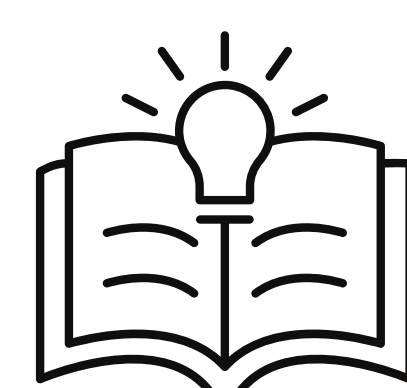
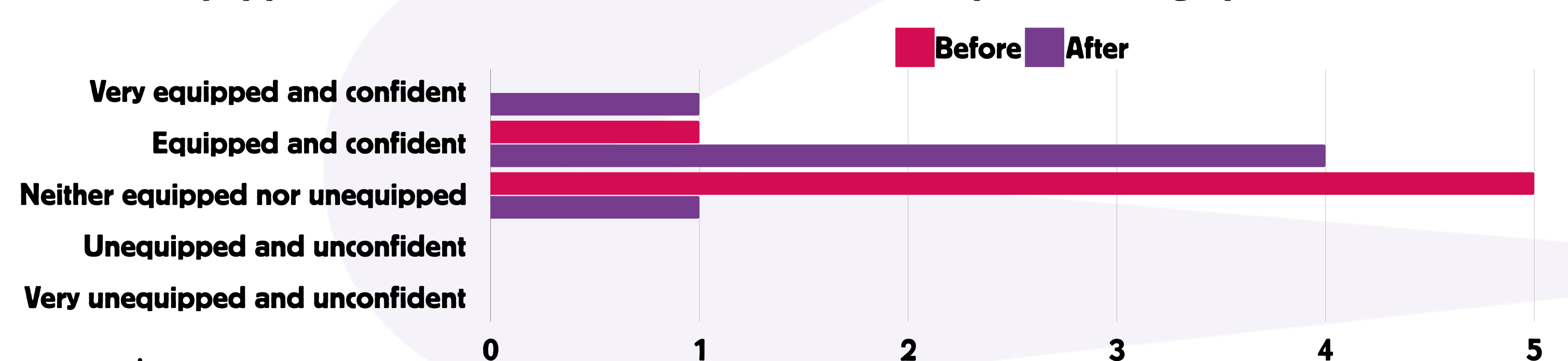
#### How motivated am I to carry out a yoga practice at home?



#### How realistic is it for me to carry out a personal yoga practice at home?



#### How equipped and confident do I feel to carry out a personal yoga practice at home?



### Key reflections, learning and next steps

Spending 6, 90 mins sessions with the people who care for their loved ones without recognition or pay, has been a privilege and widened our personal lenses on the importance of listening to the needs of the carer and working more to explore ways they can be supported in practical and accessible ways. Following the positive feedback. The yoga for carers at the Centre will continue, with a monthly drop-in yoga session. Another 6 week beginners' courses will be running this Autumn and again in the following spring.

"Identifying and meeting the needs of MS caregivers offers the best way of delivering tailored support. Future research should focus on the development of psychosocial supports, while acknowledging the needs of those caring for different MS patient populations."<sup>5</sup>

Anticipatory support for relatives that care is a priority area for the Centre. Following the findings from this small study, we will be building on the support offered to carers, starting with a carers' adjustment to change workshop called Empower. We have gained separate funding of £3,000 to run this new course. The Centre also has set up a carers' education programme with the following topics; coping with fatigue, understanding dementia, how to have healthy relationships, basic first aid, complementary therapies, safe aids for independent living. We will continue to evaluate the impact we are making here and learn from it to inform our future support for carers.

"We feel seen and heard and valued."

"I can fit it into my daily routine and around when I need to help my partner."

"It is so lovely to have something for me and the questions that you have asked me has validated the value of what I do everyday, but why it is important to make time for myself."

"It has made a difference to my body, not being so stiff and painful. When I do feel stiff I know what I can do to help myself."

### References

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5. Rebecca Maguire et al (2020) Caregiver Burden in Multiple Sclerosis: Recent trends and future directions. *Curr Neurol Neurosci Rep*: 20(7): 18