

## **'This is my journey' – people with MND and their carers share their perspectives**

Below are the questions that were asked of the MND patient group by Pauline Callagher – MND Care Centre Co-ordinator, Preston MND Care and Research Centre, Lancashire Teaching Hospitals' Foundation Trust.

In addition, we have included the background provided to the interviewee group as to why we chose the questions.

### **Questions**

#### **1. What do you wish professionals understood or knew about MND?**

MND is an uncommon condition that requires input from a team of specialists and a GP.

As MND is a progressive condition, a person's care needs will greatly increase over time, and they will need more support from others who may not be familiar with MND.

Health and Social Care professionals cannot know everything about every disease or condition, however, we wondered if there were some things people living with MND would like all professional to understand about MND in order that care provided can be improved.

#### **2. What would your advice be for other people living with MND?**

People living with MND and their carers are very resourceful and often find novel ways of adapting to their changing condition. Here the interviews gave some tips. We hope you find some of these tips useful to pass on to your patients/clients.

#### **3. What would you like professionals to know about or ask about?**

In order to treat people holistically it is important to ensure patients and their families have confidence in those who care for them. Consultation time can be limited for many reasons and effective communication can take a long time.

We wondered if there was anything that people with MND would like professionals to ask about in addition to standard questions in a consultation.

#### **4. What does hope, mean for you?**

There's no cure for MND, but treatment and support can help reduce the impact the symptoms have on daily living.

Low mood is a natural reaction to a serious diagnosis such as MND. Understandably, many people have feelings of intense sadness, and feel hopeless, especially straight after the diagnosis. Over time, these feelings may become less intense, or not at the forefront of their minds, but they can still become emotional very easily. Living with MND can cause frustration and sadness, and many are concerned about the future. MND has been described as 'a series of losses' and people living with MND can grieve for the loss of physical functions and the life they had expected to have. We asked our interviewees what hope means to them when living with MND.

## **5. What activities do you like or have you participated in that have helped you?**

Many people living with MND have had led very active lives but as the disease progresses and function changes.

We wondered if there were activities people found that they could still enjoy as the disease progresses and they are less able to participate in their normal activities.

## **6. What bits of equipment and or gadgets do you have that have been really helpful?**

Many people living with MND and their carers are very resourceful in helping maintain their independence. There are many pieces of equipment available which some people find useful, and people often buy or make their own aids to daily living.

## **7. What services and or support groups or alternative therapies have you found beneficial?**

Many of our patients access complimentary therapies offered at the hospices or privately, we were also interested to know if people living with MND found alternative therapies that they may choose to access which may be less well known, researched, or endorsed by the NHS or the MND Association.

Many people like to attend support groups, but others do not find them useful as they sometimes worry about seeing others with MND who may be further along the disease trajectory.

## **8. Recommendations for holidays or experiences?**

As disability increases and adaptations are made in the home, many worry about how they will cope in a different environment without some of the adaptations and equipment.

However, for many it is still important to have holidays or experiences to look forward to and to make memories.

## **9. Benefits of having a multi-disciplinary professional team who understand MND?**

The needs of People living with MND are complex and usually involve assistance from lots of health and social care professionals from a variety of different specialists and services.

Changes in condition can often be rapid, with individuals having little time to adjust to one aspect of the illness before another presents. Due to so many health and social care professionals being involved in an individual's care, there is a high risk that there could be lack of coordination between services.

## **10. Is there anything that health care professionals don't ask about that you wish they would?**

With so many health and social care professionals involved in their care we wondered if patients and carers had issues that were not addressed as standard.