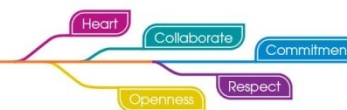


So what is Motor Neurone Disease?

The term covers a group of related diseases that attack the motor neurones. These are the nerves in the brain and spinal cord that control how muscles work. It means that messages gradually stop reaching muscles, leading to weakness, stiffness and wasting.

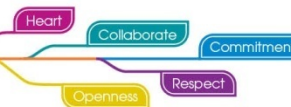
It is usually a rapid progressing disease, affecting how you can walk, talk, eat, drink and breathe.

There is no cure.



Emerging evidence of cognitive impairment in MND and statistics.

- Identification of new genes show that in 15% of people with MND, there will be a form of associated Fronto-Temporal Dementia.
- Up to a further 35% of people with MND will develop some form of cognitive impairment.
- Up to 5000 living in the UK at any one time.
- 1/3 will die within 1 year and 1/2 within 2 years.

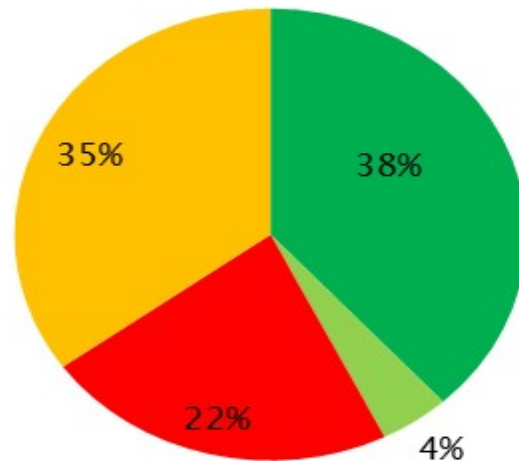


Improving my MND Care Survey. (IMNDCS)

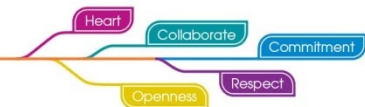
- Survey every 2 years
- 924 responses from circa 2000 sent out.
- 554 chose to answer the End of Life section
- Analysis from the Picker Institute.
- Ability to complete on-line or via postal questionnaire.



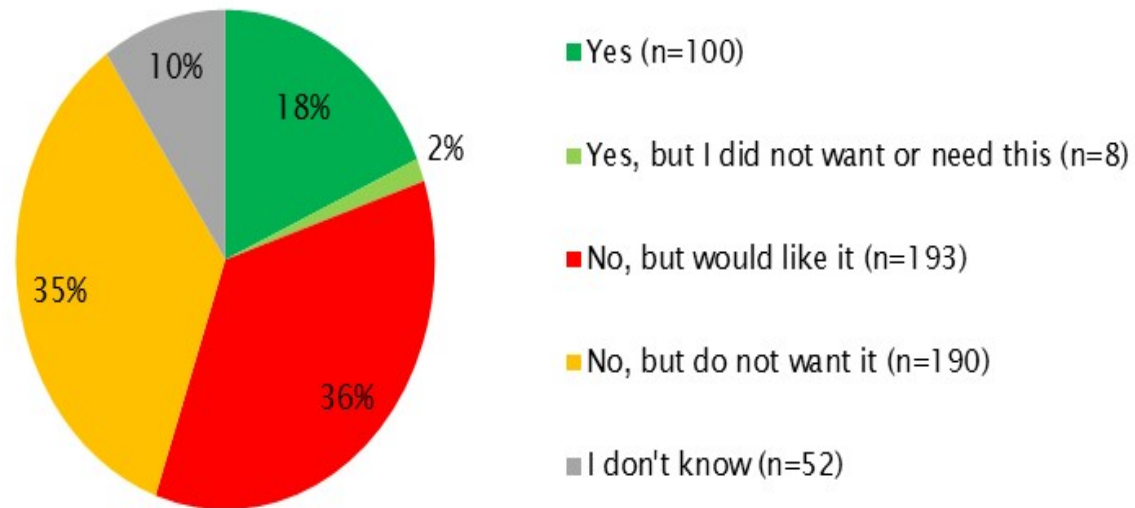
Have you been offered any information about choices and options at end of life?



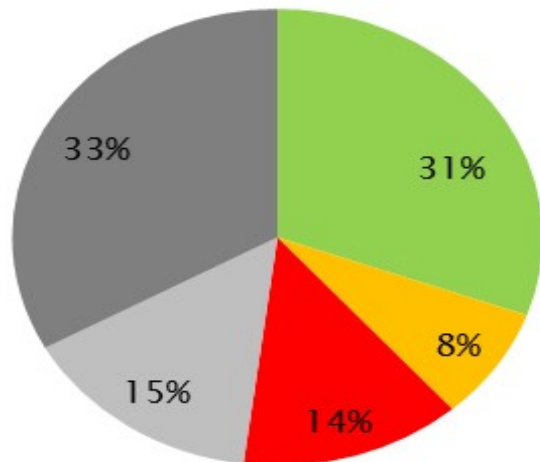
- Yes (n=208)
- Yes, but I didn't want or need this (n=24)
- No, but I would have liked this (n=122)
- No, but I didn't want or need this (n=190)



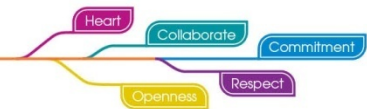
Have you received the MND Association End of Life guide?



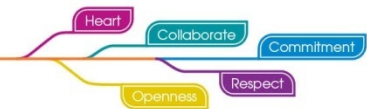
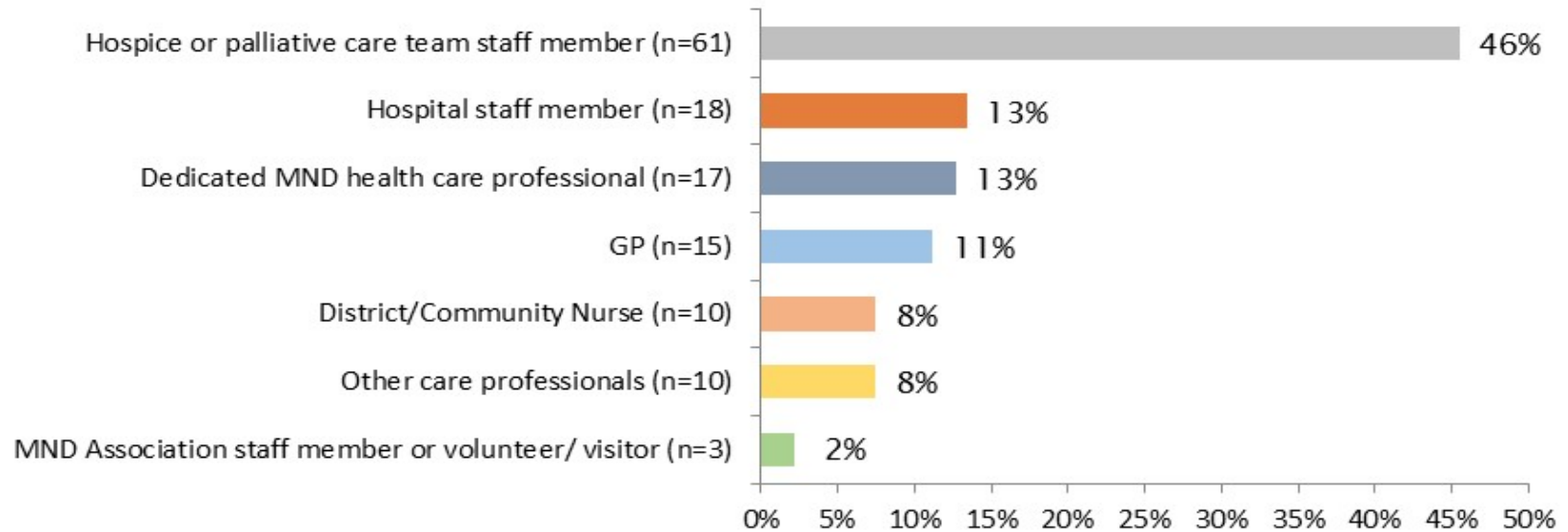
Have you discussed end of life decisions with any care professionals?



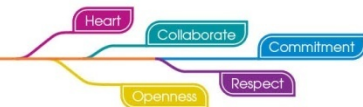
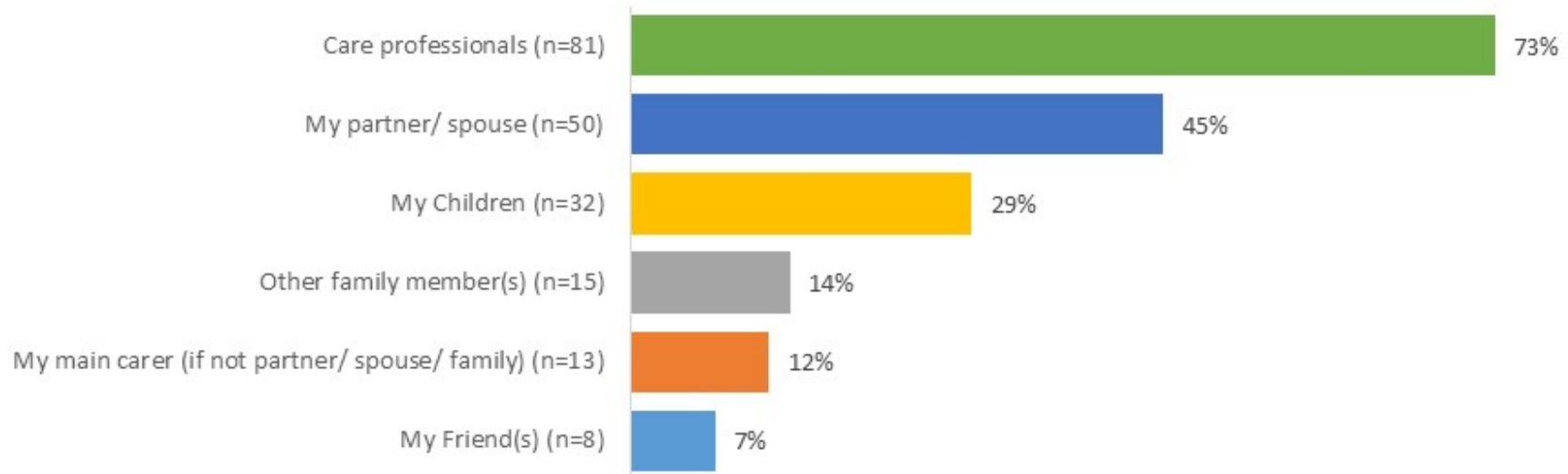
- Yes and I chose to discuss these issues (n=160)
- Yes, but I did not want to discuss this (n=42)
- No, but I would have liked to (n=71)
- No, but I did not want to (n=78)
- I do not feel ready to do this yet (n=173)



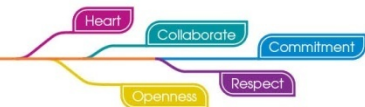
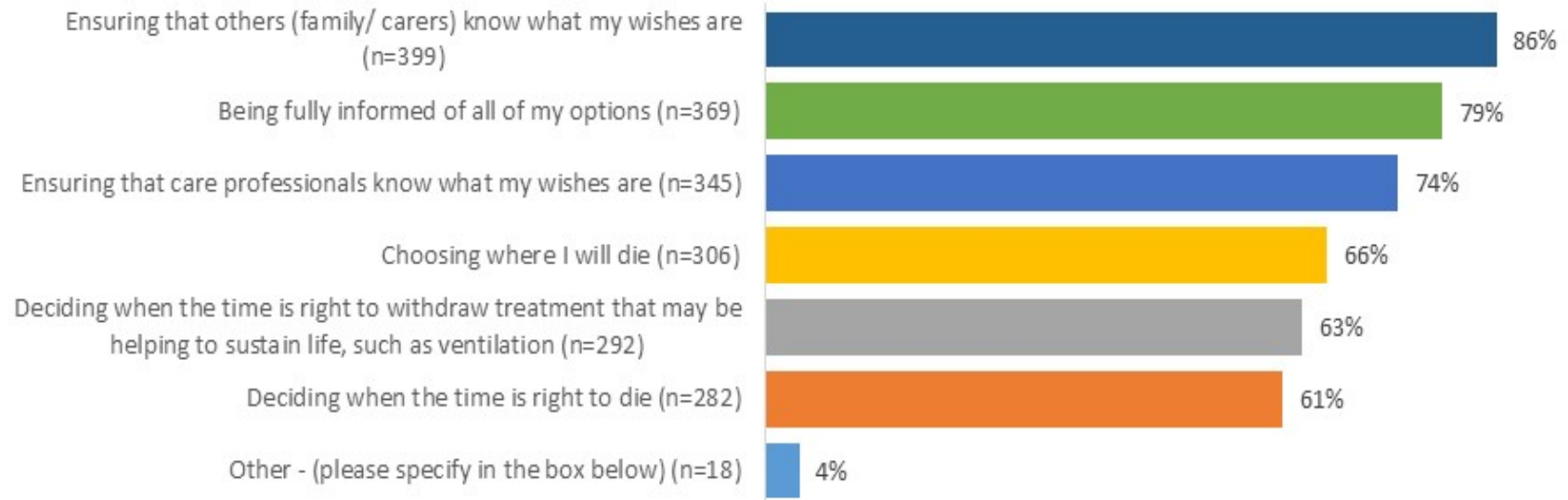
Who is the main care professional that you have discussed end of life with?



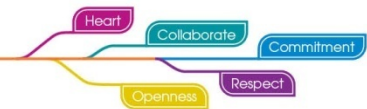
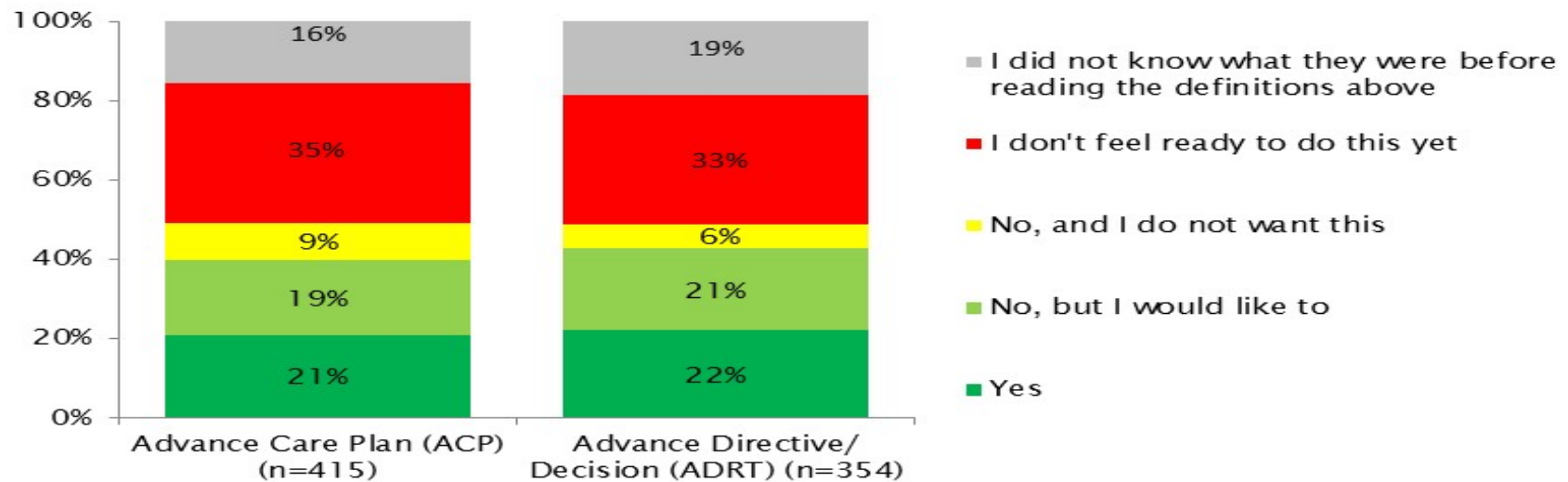
Who do you find it easier to have end of life discussions with?



What does having control at end of life mean to you?



Have you made an advanced care plan and/or and Advanced Directive/Decision?



Were you offered support in doing so?

