

EMBED-Care Public Opinion Poll

EMBED-Care
Empowering Better End
of Life Dementia Care

YouGov[®]



EMBED-Care Public Engagement Aim:

To make high quality dementia palliative care visible – in order to demystify the experience, equip audiences with knowledge of services that could support them, and create advocates demanding high quality care for all.

Public Opinion Poll's Aim:

To gain an understanding of public's understanding and perceptions around dementia, palliative and end-of-life care

Findings

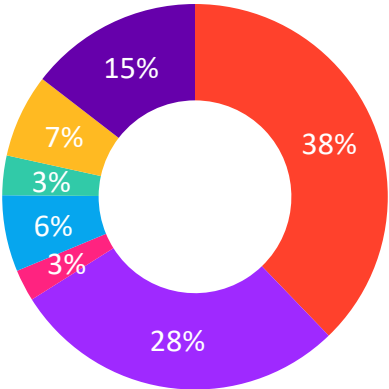
- Current and future level of need
- Research and care funding and charity awareness
- Dementia and palliative care
- Priorities

Current and future level of need

Leading cause of death

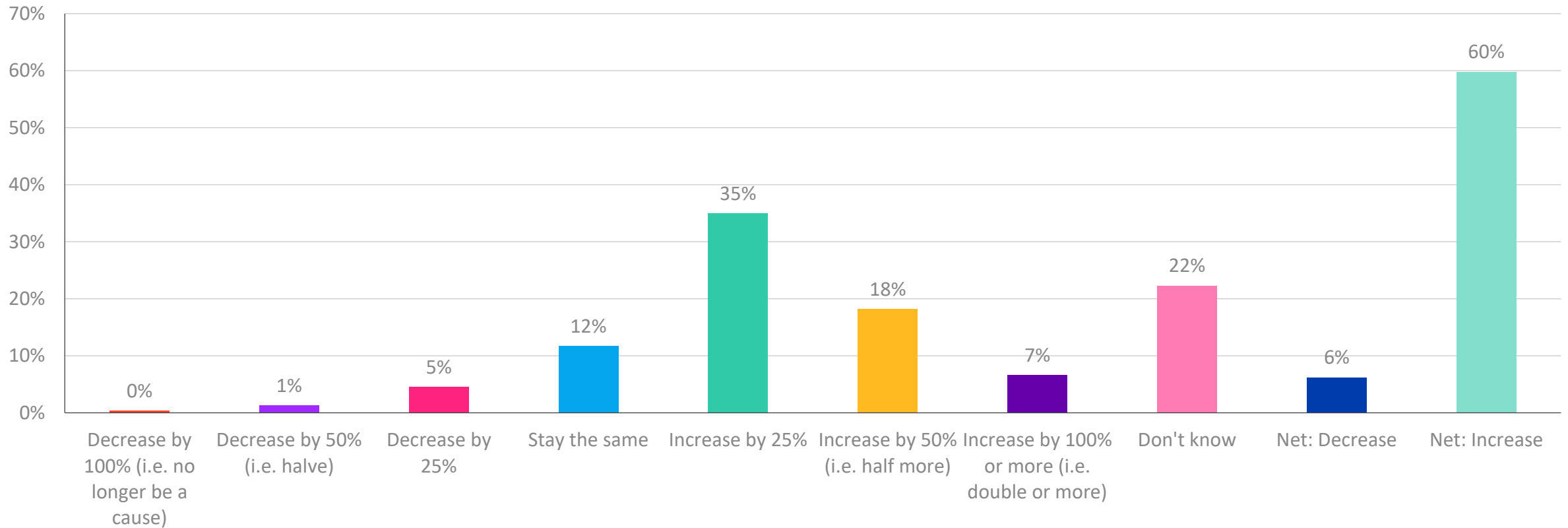
Which one of the following do you believe was the leading cause of death in England between 2015-2019?

- Heart Disease
- Cancer
- Cerebrovascular diseases (e.g. stroke)
- Dementia and Alzheimer's disease
- Chronic lower respiratory diseases (e.g. Chronic Obstructive Pulmonary Disease (COPD))
- None of these
- Don't know



Number of dementia deaths

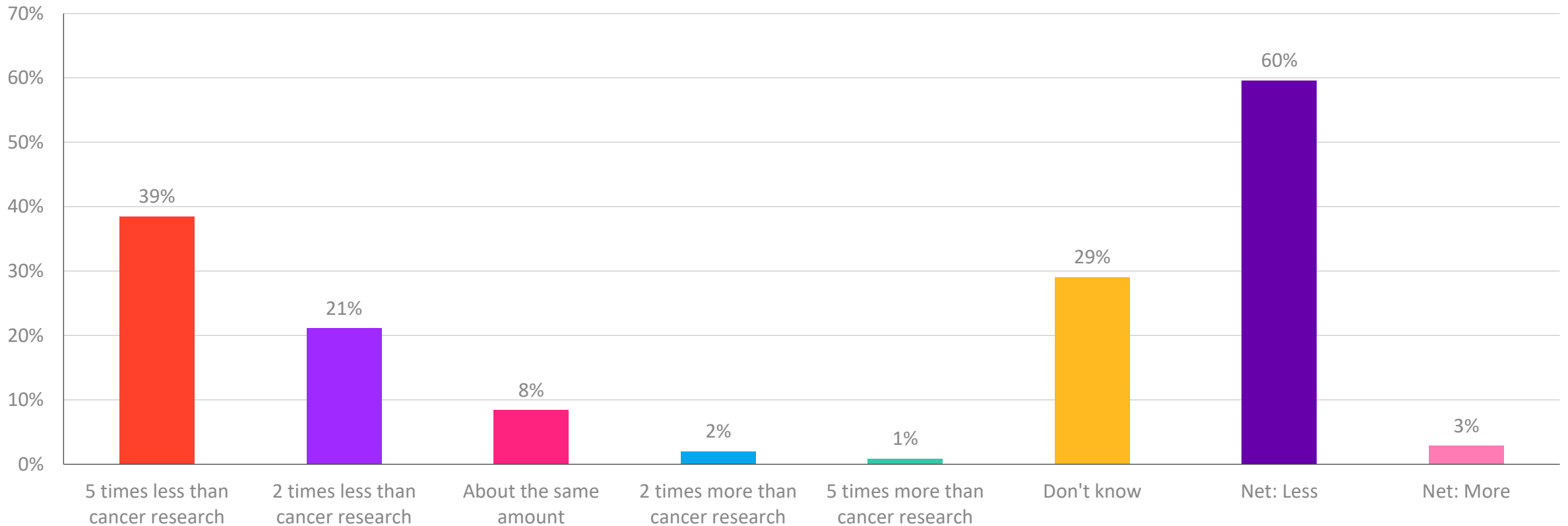
For the following question, by 'dementia deaths' we mean deaths where dementia or Alzheimer's disease is mentioned on the death certificate. Do you think the number of dementia deaths in the UK will increase, decrease or stay the same by 2040? (Please select the option that comes closest to your estimate)



Research and care funding and charity awareness

Dementia research

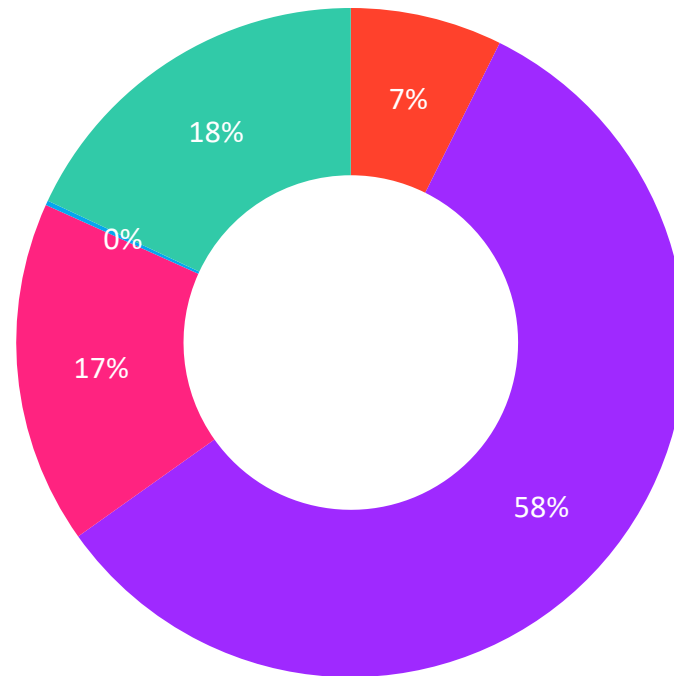
For the following question, by "research funding" we mean expenditures on research that results in new products, processes and understanding. In the UK, how much research funding do you believe is provided to dementia research, as compared to cancer research? (If you are unsure, please provide your best estimate)



Dementia care funding

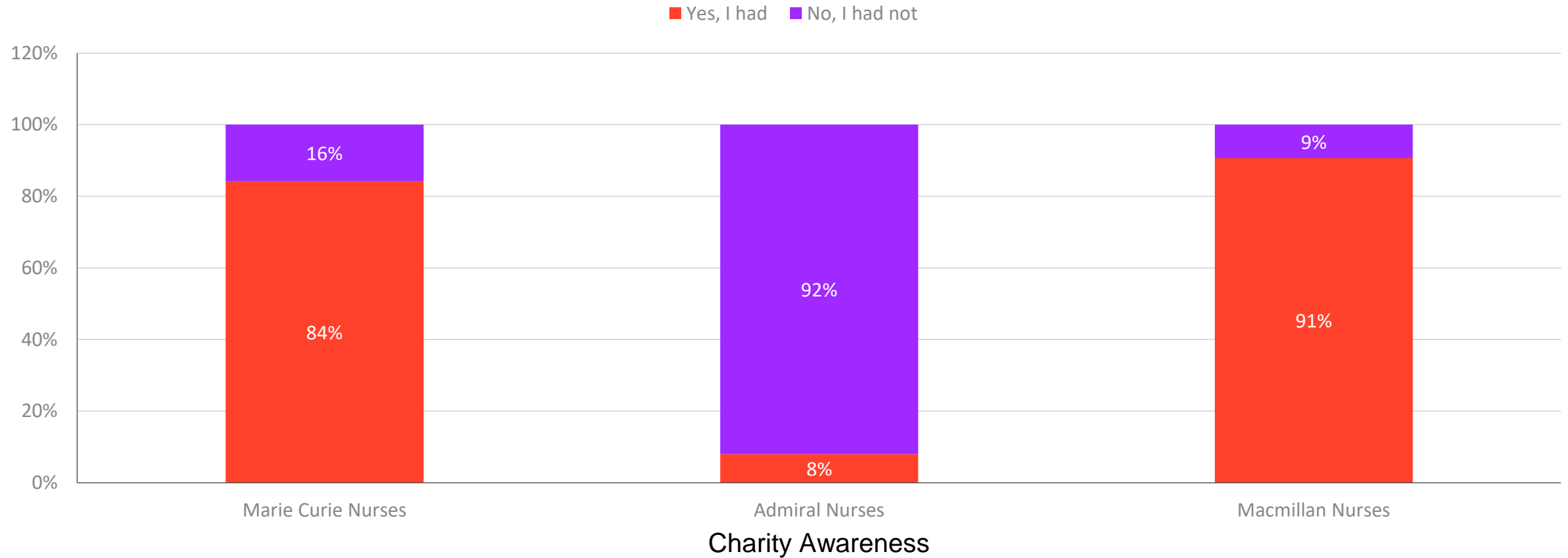
Which one, if any, of the following do you believe funds the majority of dementia care in the UK?

■ The Government ■ Charities ■ People affected by dementia (patients and carers) ■ Other ■ Don't know



Charity Awareness

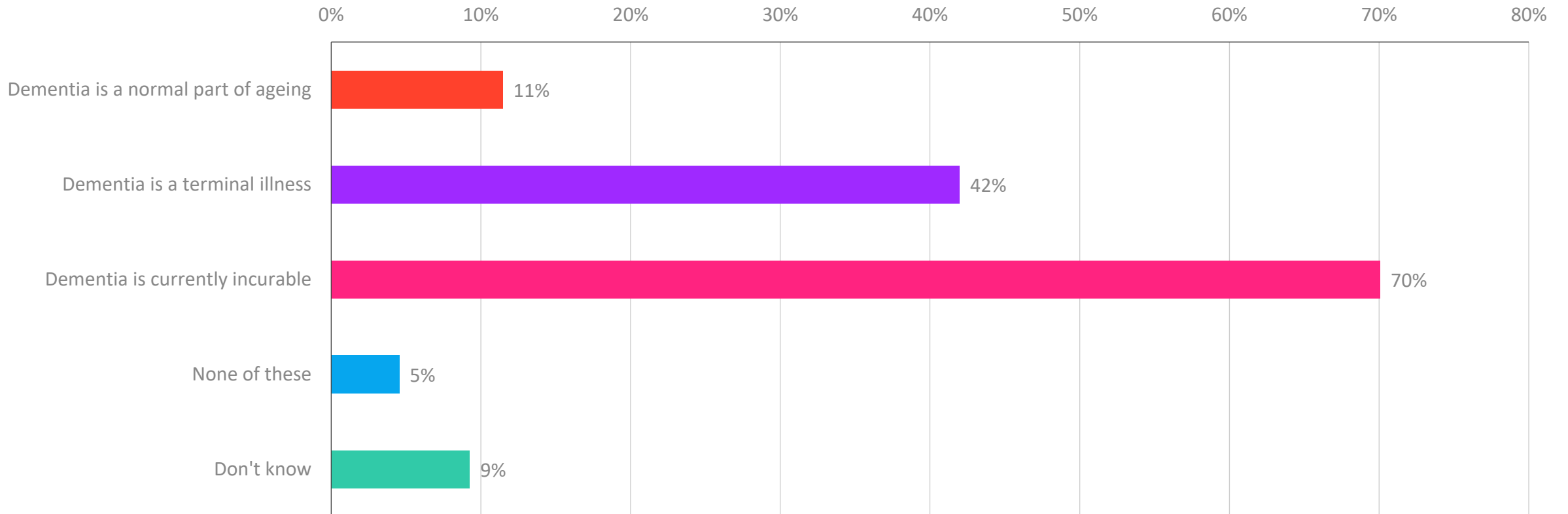
Before taking this survey, which of the following had you ever heard of?



Dementia and palliative care

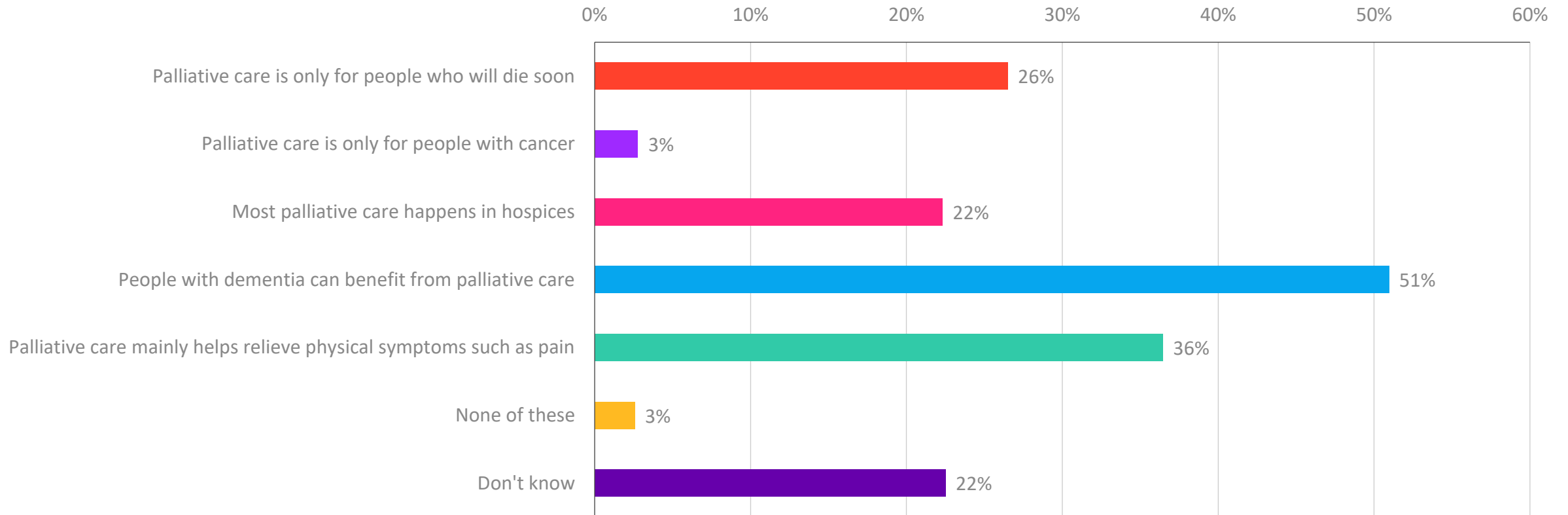
Dementia T/F

Which, if any, of the following statements do you believe to be true? (Please select all that apply)



Palliative care

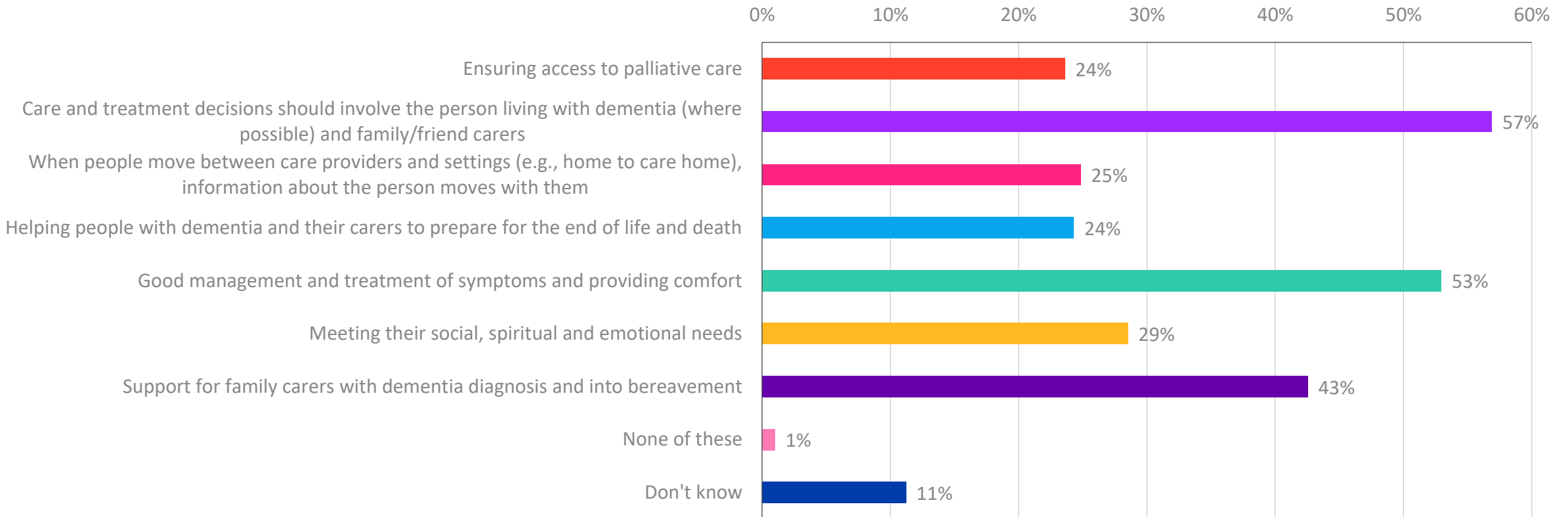
Which of the following statements about palliative care do you believe to be true? (Please select all that apply)



Priorities

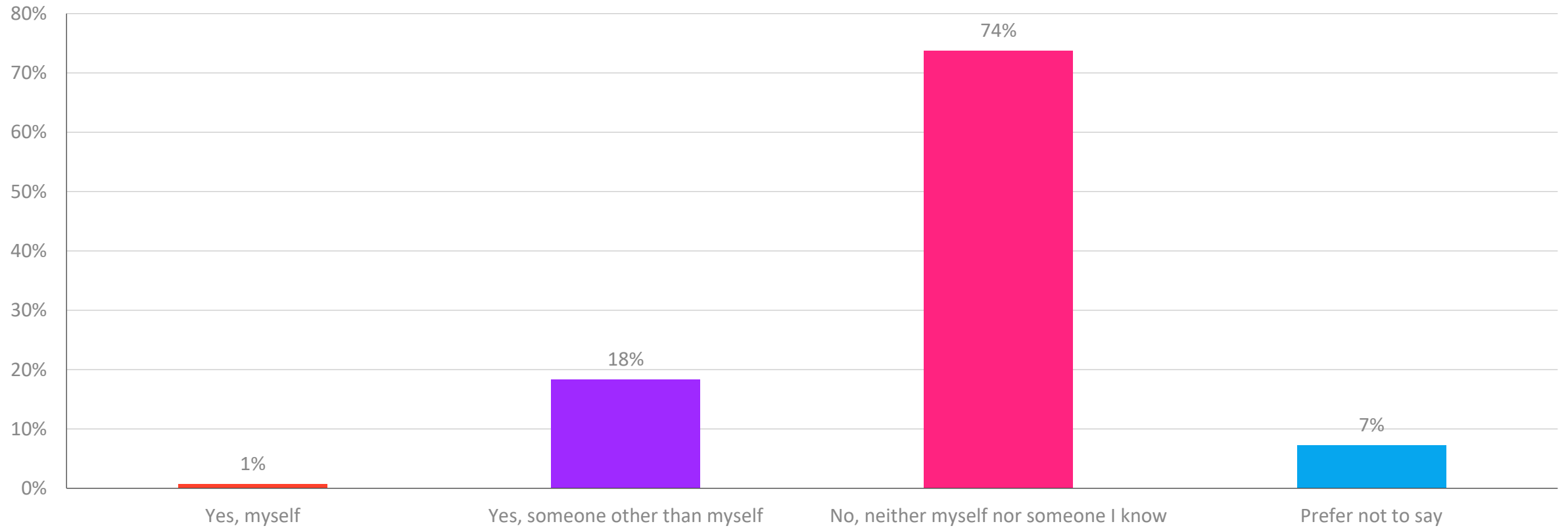
Dementia support and care for patients and family carers

Which three of the following aspects of support and care, if any, do you think are most important to provide to people with dementia and/ or their family carers? (Please select up to three options)



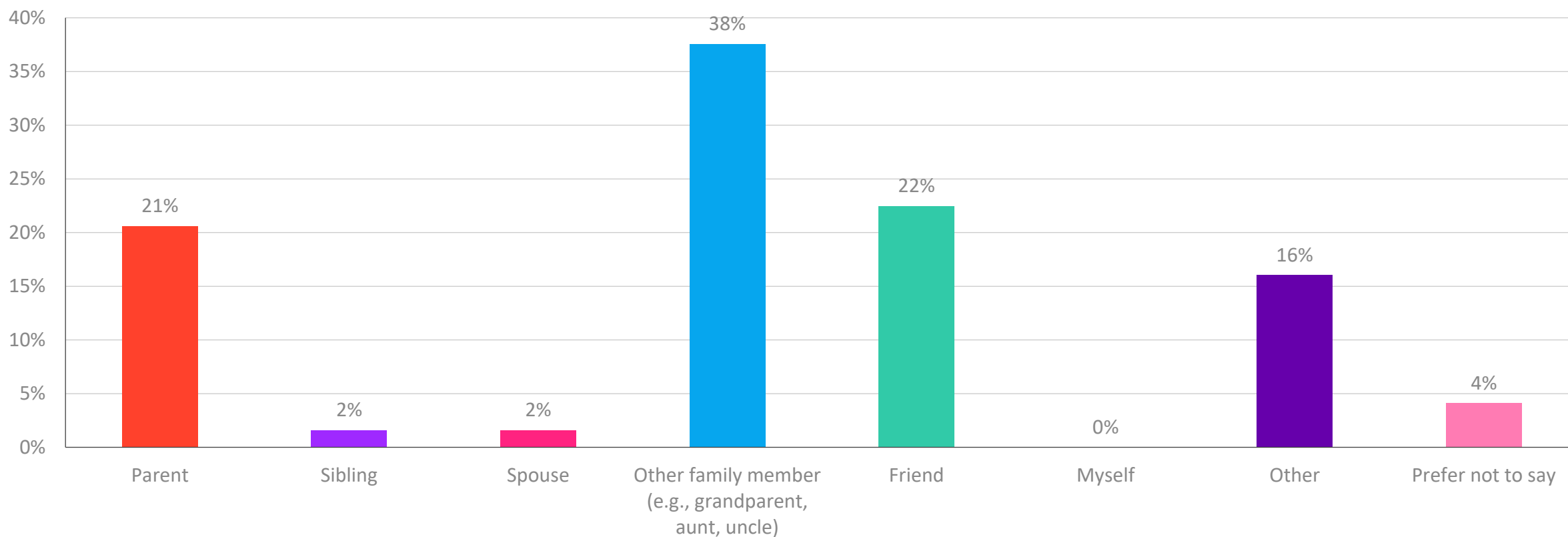
Know someone with dementia

Are you, or anyone you know, currently living with dementia?



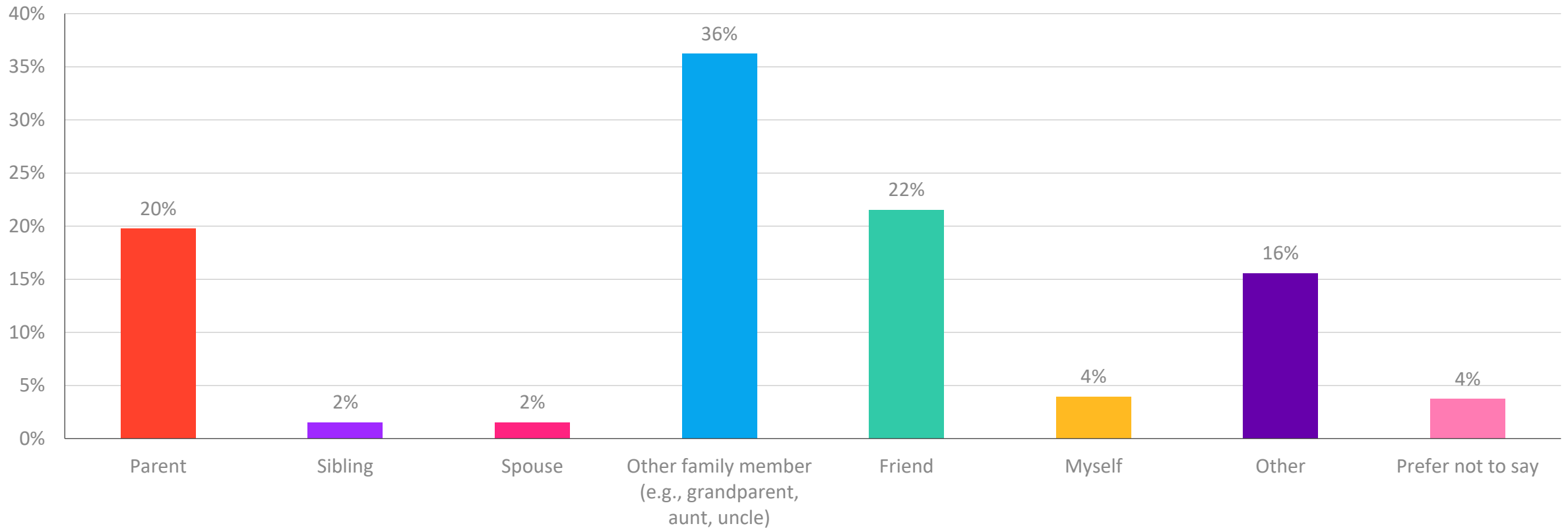
Who do you know with dementia (only other than respondent)

You mentioned knowing someone other than yourself living with dementia. Who is/are the person(s) with dementia that you know? (Please select all that apply. If you would rather not share this information, please select the "Prefer not to say" option)



Who do you know with dementia (including "myself")

You mentioned knowing someone other than yourself living with dementia. Who is/are the person(s) with dementia that you know? (Please select all that apply. If you would rather not share this information, please select the "Prefer not to say" option)



Methodology

- Fieldwork was undertaken between 12th - 13th April 2022.
- The survey was carried out online.
- All figures, unless otherwise stated, are from YouGov Plc.
- Total sample size was **2133 adults**.
- The figures have been weighted and are representative **of all UK adults (aged 18+)**.
- Visit <https://yougov.co.uk> for data access queries.

This survey has been conducted using an online interview administered to members of the YouGov Plc UK panel of 800,000+ individuals who have agreed to take part in surveys. Emails are sent to panellists selected at random from the base sample. The e-mail invites them to take part in a survey and provides a generic survey link. Once a panel member clicks on the link they are sent to the survey that they are most required for, according to the sample definition and quotas. (The sample definition could be "GB adult population" or a subset such as "GB adult females"). Invitations to surveys don't expire and respondents can be sent to any available survey. The responding sample is weighted to the profile of the sample definition to provide a representative reporting sample. The profile is normally derived from census data or, if not available from the census, from industry accepted data.

List of sociodemographic variables about the participants

- Gender
- Age Groups
- Social Grade (binary: ABC1 – upper middle to lower middle classes, C2DE – skilled working class to those at the lowest level of subsistence)
- Region
- Government Region
- Working Status
- Marital Status
- Children in Household Parent/ Guardian
- Who is the person you know who is living with dementia?
- Social Media/ Messaging service (within the last month)

References

EMBED-Care Research Programme:

1 – Sampson, Elizabeth L., Janet E. Anderson, Bridget Candy, Nathan Davies, Clare Ellis-Smith, Anna Gola, Richard Harding et al. "Empowering better End-of-Life dementia care (EMBED-Care): a mixed methods protocol to achieve integrated person-centred care across settings." *International Journal of Geriatric Psychiatry* 35, no. 8 (2020): 820-832.

<https://doi.org/10.1002/gps.5251>

Causes of death in the United Kingdom statistics

2 – England and Wales; Mortality Statistics: Deaths Registered in England and Wales (Series DR) Scotland: National Records of Scotland Vital Events Reference Tables. Northern Ireland; Northern Ireland Statistic & Research Agency Registrar General Annual Report - <https://www.dementiastatistics.org/statistics/deaths-due-to-dementia/>

3 – Office of National Statistics for England and Wales monthly statistics up to October 2022 - https://www.ons.gov.uk/search?q=Monthly+mortality+analysis%2C+England+and+Wales&sort=release_date&page=1

4 – Office of National Statistics for England and Wales <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/dementiaandalzheimersdiseasedeathsincludingcomorbiditiesenglandandwales/2019registrations>

Dementia death projections

5 – Etkind SN, Bone AE, Gomes B, Lovell N, Evans CJ, Higginson IJ, Murtagh FE. How many people will need palliative care in 2040? Past trends, future projections and implications for services. *BMC medicine*. 2017

<https://bmcmmedicine.biomedcentral.com/articles/10.1186/s12916-017-0860-2>

Care costs

6 – Wittenberg R, Hu B, Barraza-Araiza L, Rehill A. Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019–2040. London: London School of Economics. 2019.

https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf

Dementia end-of-life and palliative care

7 – End of life care for a person with dementia. Alzheimer's Society

<https://www.alzheimers.org.uk/get-support/help-dementia-care/end-life-care-dementia>