



Lived Experiences of Cavernoma Patients in Europe



INTRODUCTION

Cavernoma is a neurological condition affecting around 1 in 625 people. The European Cavernoma Alliance (ECA) is a network of patient advocacy associations. Six ECA members came together in 2024 to deepen their understanding of the unmet needs of cavernoma patients, with the aim of advocating for improvements for patients and their families. They launched the first European Cavernoma Patient Survey in five languages on Rare Disease Day (29 Feb 2024) for 1 month. 475 responses were received from a self-selecting group of respondents resident in 23 countries. This first rapid report summarises some of the key findings of this survey.

FINDINGS

Average diagnosis time

from first symptoms, as reported by survey respondents



501 days

People diagnosed **5+ years ago**



382 days

People diagnosed **1-5 years ago**



327 days

People diagnosed **up to 1 year ago**

165

out of the 475 respondents reported that they were first **misdiagnosed**



Reported symptoms

50% Headaches

48% Memory problems

46% Dizziness

46% Balance problems

46% Difficulty concentrating

41% Tiredness

35% Numbness

34% Weakness

28% Haemorrhagic stroke

27% Seizures

27% Double vision

19% Slurred speech

18% Tinnitus

15% Tremors

11% Ataxia

6% Dysphagia

For more info on headaches go to <https://bit.ly/CavernomaHeadaches>



“

The way in which the diagnosis was delivered severely impacted my mental health. The doctors didn't know anything about cavernoma. They told me that I may need to go through brain surgery in the next few days before having the reports... they discharged me without any information whatsoever. I needed therapy... This could have been avoided.

What is cavernoma



Cavernomas are formed of abnormal blood vessels and look like raspberries. They are found in the brain and/or spinal cord. Because they have thin leaky walls, they can bleed (haemorrhage) at any age without warning. 1 in 625 people are thought to have a cavernoma, and whilst most people won't experience symptoms approximately 1 in 2,700 do. Current treatment options are either neurosurgery or stereotactic radiosurgery. However, many patients are told to “wait and see”.

Information sources

49% rated the information received from their primary care clinician as poor or very poor.

55% rated the information from their specialist as very good or good (e.g., neurologist, neurosurgeon).

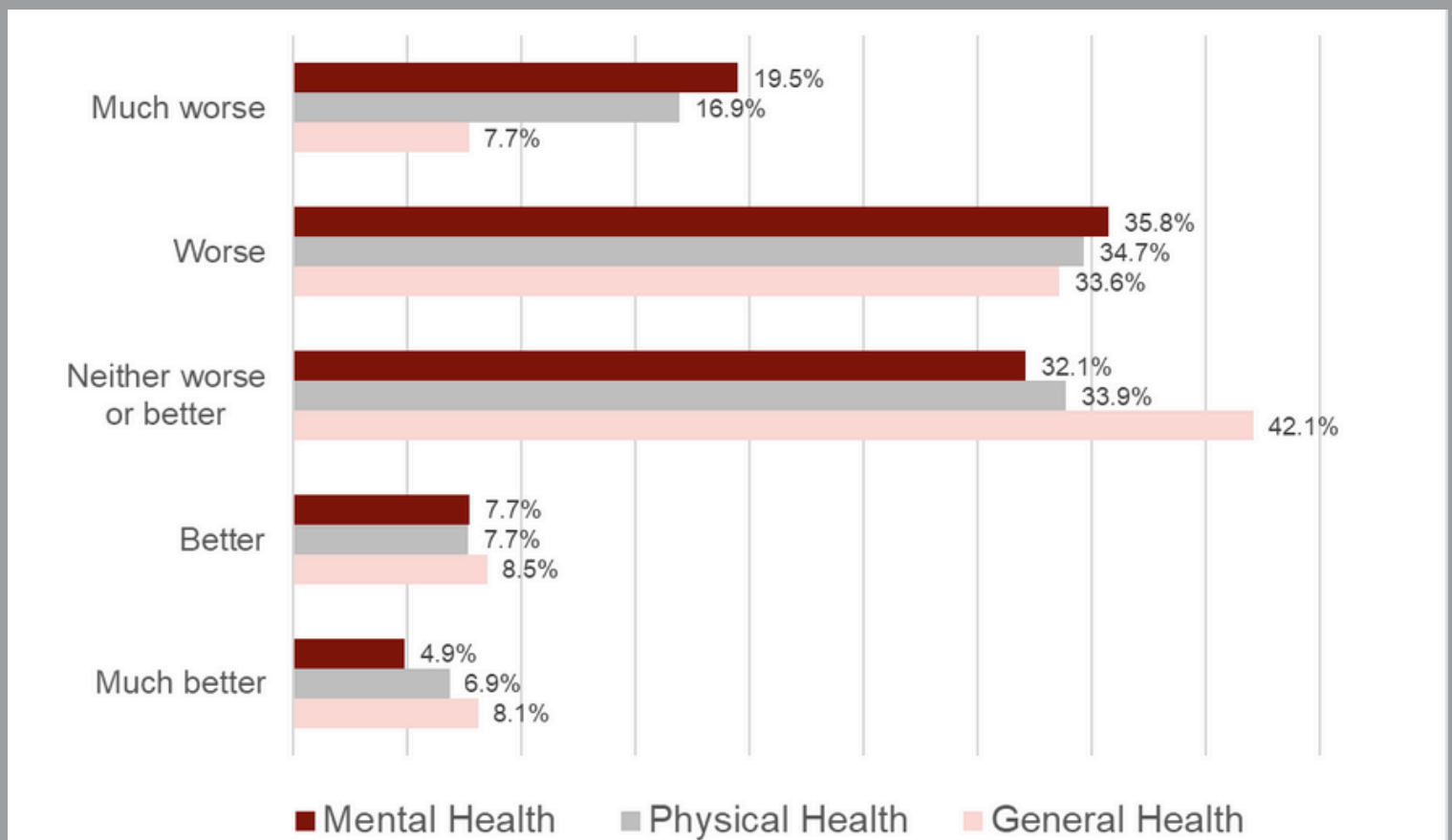


Care and support

24% rated the care and support received by clinicians after diagnosis as very good (33% before/after surgery).

Support from family & friends was rated by 72% as good or very good.

Impact on quality of life



Note: Respondents were asked to compare quality of life now to before cavernoma-related symptoms first-started, or if asymptomatic before first-diagnosed with cavernoma. Data excludes respondents with other health-conditions impacting quality of life

Work and education missed after having a haemorrhagic stroke



398 days

Haemorrhage over 6 years ago



Respondent reported average number of days

266 days

Haemorrhage 2 to 6 years ago



Impact on daily living



1 in 3

respondents spend less time in **paid work** and/or have changed the way they go about it



1 in 5

respondents spend less time on **social activities** or have changed the way they go about them



1 in 10

respondents reported reduced **education** prospects or opportunities

*Cavernoma is often a **hidden disability**, which others don't see or forget you have... There needs to be recognition of the invisible disability as a reality.*



Average respondent



76% women
57% identified as disabled
53% aged 40s/50s
49% living in the UK
34% multiple CCMs
28% haemorrhagic stroke
27% seizures
27% neurosurgery
24% brainstem cavernoma



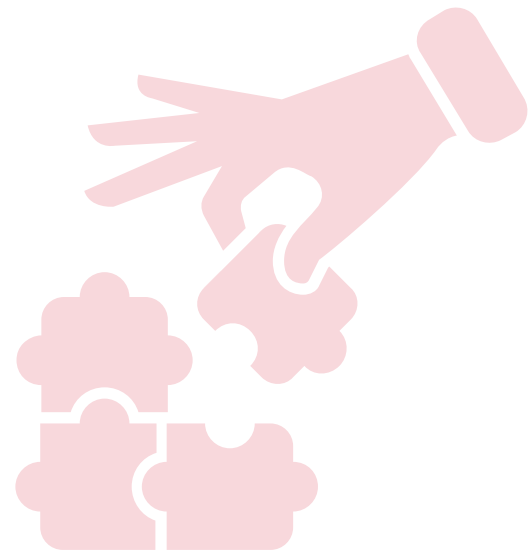
Only...

5% asymptomatic and 4% Gamma Knife

The respondents to the survey were a self-selecting group of people. These results do not reflect the average cavernoma patient. They only reflect the average respondent to this survey.

CONCLUSIONS

Care and support for cavernoma patients in Europe has improved over the past 10 years, but there's still a long way to go before patient needs are being fully met. Improvements are urgently needed with 4 priority areas identified.



Improvements needed

- Time to get an accurate first-time diagnosis;
- Treatment options to reduce the impact on daily living, especially on work for working aged adults;
- Understanding of the impact on mental health and the need to access mental health support;
- Quality of patient information provided by clinicians.