

# The unmet needs of adults living with grade II and III brain tumours: Implications for supported self-management

Ben Rimmer, Dr Lizzie Dutton, Prof. Linda Sharp,  
on behalf of the Ways Ahead study team

Population Health Sciences Institute, Newcastle University Centre for Cancer,  
Newcastle upon Tyne, UK

**Website:** <https://research.ncl.ac.uk/waysahead/>

**Email:** [waysahead@newcastle.ac.uk](mailto:waysahead@newcastle.ac.uk)



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# Conflict of Disclosure

- The authors declare that there is no conflict of interest.

# Background

Grade II and III brain tumours can have a prolonged, negative impact on quality of life, with inevitable progression and mortality.

- Grade II and III oligodendrogliomas
- Grade II astrocytomas
- Younger adults: 30s and 40s (*Bauchet, 2017*)
- Average life expectancy: 5 to 15 years (*Dixit et al., 2017*)
- Living for extended periods with a terminal condition can affect people's ability to 'return to normal' (*Affronti, 2018*).

## Aim

To understand what problems people living with low- and intermediate-grade gliomas experience following primary treatment.

## Purpose

To inform the co-design of a supported self-management programme for adults living with low- and intermediate-grade gliomas, as part of the **Ways Ahead project**.

# Method

## Recruitment

- The Brain Tumour Charity (UK)
- NHS (UK)
  - ❖ Newcastle upon Tyne Hospitals
  - ❖ The Christie
  - ❖ NHS Lothian
  - ❖ South Tees Hospitals

## Eligibility

- Grade II or III oligodendroglioma or grade II astrocytoma
- Adults aged  $\geq 18$  years at diagnosis
- Completed primary treatment
- Currently stable

## Data collection

- Semi-structured interviews, covering:
  - ❖ Cognitive impact
  - ❖ Physical impact
  - ❖ Psychological impact
  - ❖ Social and role impact
  - ❖ Functional impact

## Proposed analysis

- Thematic analysis (Braun and Clarke, 2006)

# Sample

23 patients interviewed

## Tumour type

- Grade II oligodendroglioma (n=11)
- Grade III oligodendroglioma (n=9)
- Grade II astrocytoma (n=3)

## Treatment

- Surgery (n=22)
- Radiotherapy (n=17)
- Chemotherapy (n=14)

## Years since diagnosis

Mean = 9; Range: 0-18

## Age at diagnosis

Mean = 43; Range: 22-67

## Sex

- Male (n=14)
- Female (n=9)

## Unmet needs

Cognitive

Physical

Psychological

Social and role

### Influenced by:

- Tumour type
- Tumour location
- Disease stage
- Extent of disability

## Cognitive

Speech  
Communication  
Memory  
'Brain fog'  
Slowness  
Concentration  
Personality change

## Physical

Weakness  
Gait changes  
Seizures

## Psychological

Anxiety  
Guilt  
Depression  
Acceptance  
Self-image  
Confidence

Fatigue



# Social and role

**Relationships**

**Work**

**Travel**

**Hobbies and  
interests**

**Caregiving**

**Finances**

# What next?

We are also asking patients about:

- Self-management strategies
- Barriers and facilitators to self-management
- How they would like support to be delivered

Interviews with family members and health professionals are underway to comprehensively understand how these patients can be better supported.

# Ways Ahead study team

Ben Rimmer, Lizzie Dutton, Linda Sharp

Joanne Lewis, Pamela Gallagher, Sophie Williams, Richéal Burns, Vera Araujo-Soares, Tracy Finch

[waysahead@newcastle.ac.uk](mailto:waysahead@newcastle.ac.uk)

<https://research.ncl.ac.uk/waysahead/>

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# References

- Bauchet L. Epidemiology of diffuse low grade gliomas. Diffuse low grade gliomas in adults. Springer, 2017: 13–53. 37
- Dixit K, Raizer J. Newer strategies for the management of low-grade gliomas. Oncology 2017;31:680–2.
- Affronti ML, Randazzo D, Lipp ES, et al. Pilot study to describe the trajectory of symptoms and adaptive strategies of adults living with low-grade glioma. Semin Oncol Nurs 2018;34:472–85.
- Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006;3:77–101.