



Lizzie Dutton, Ben Rimmer, Joanne Lewis, Richéal Burns, Pamela Gallagher, Sophie Williams, Vera Araujo-Soares, Tracy Finch, Linda Sharp
Find out more @ research.ncl.ac.uk/waysahead/
Get in touch: lizzie.dutton@newcastle.ac.uk

Self-management support needs and barriers for adults living with grade II and III brain tumours: *findings from the Ways Ahead study*

Aim

Ways Ahead aims to develop a supported **self-management intervention** for people living with grade II and III gliomas to enable them to manage their **health** and **wellbeing** following primary treatment.

Motivation

Grade II and III gliomas are treatable but **incurable**.

Life expectancy approximately **5-15 years**.

Typically diagnosed in **working age adults**.

Quality of life is often adversely effected.

Ongoing symptoms can include: **seizures, fatigue, cognitive impairment, communication** difficulties.

Patients want increased support post-treatment.

Supported **self-management** interventions can enable people to better manage chronic illness.

Method

Qualitative, semi-structured **interviews**

24 adults with grade II or III **oligodendrogliomas** or **grade II astrocytomas**

Thematic data analysis (Braun and Clarke, 2006)

We asked ...

What difficulties participants experienced following primary treatment.

What barriers to managing their health and wellbeing they experienced.

Conclusions

Grade II and III glioma specific interventions are required

Interventions must adapt to individuals' needs priorities

Interventions should ensure support is accessible

Results*

Support needs

Needs covered four, interrelated areas.

Common problems:

Fatigue

"I try to be normal and I get up and get on with stuff, but come three hours later, I'm ready for a nap. It's ridiculous." – Grade III oligo

Cognitive impairments

"My short term memory is bad... I started reading a book again. I had to keep turning back a chapter to see where it had gone." – Grade III oligo

Anxiety about tumour progression

"I worry more about the impact it has had... the possible progression, and the impact it will have on my life in the future. And it is, kind of, mentally draining." – Grade II oligo

Managing return to work or ill-health retirement

"I was obviously on long term sick leave. I did go back to work under the... with advice from occupational health for the best part of a year." – Grade II astro

Managing changing relationship dynamics

"I suppose I used to sort a lot of stuff out and my wife has to do it now, sort the bills out and the electric out." – Grade III oligo

Support needs vary greatly, depending largely on the extent of tumour- or treatment-related limitations

Common barriers to self-management:

Lack of awareness of available support

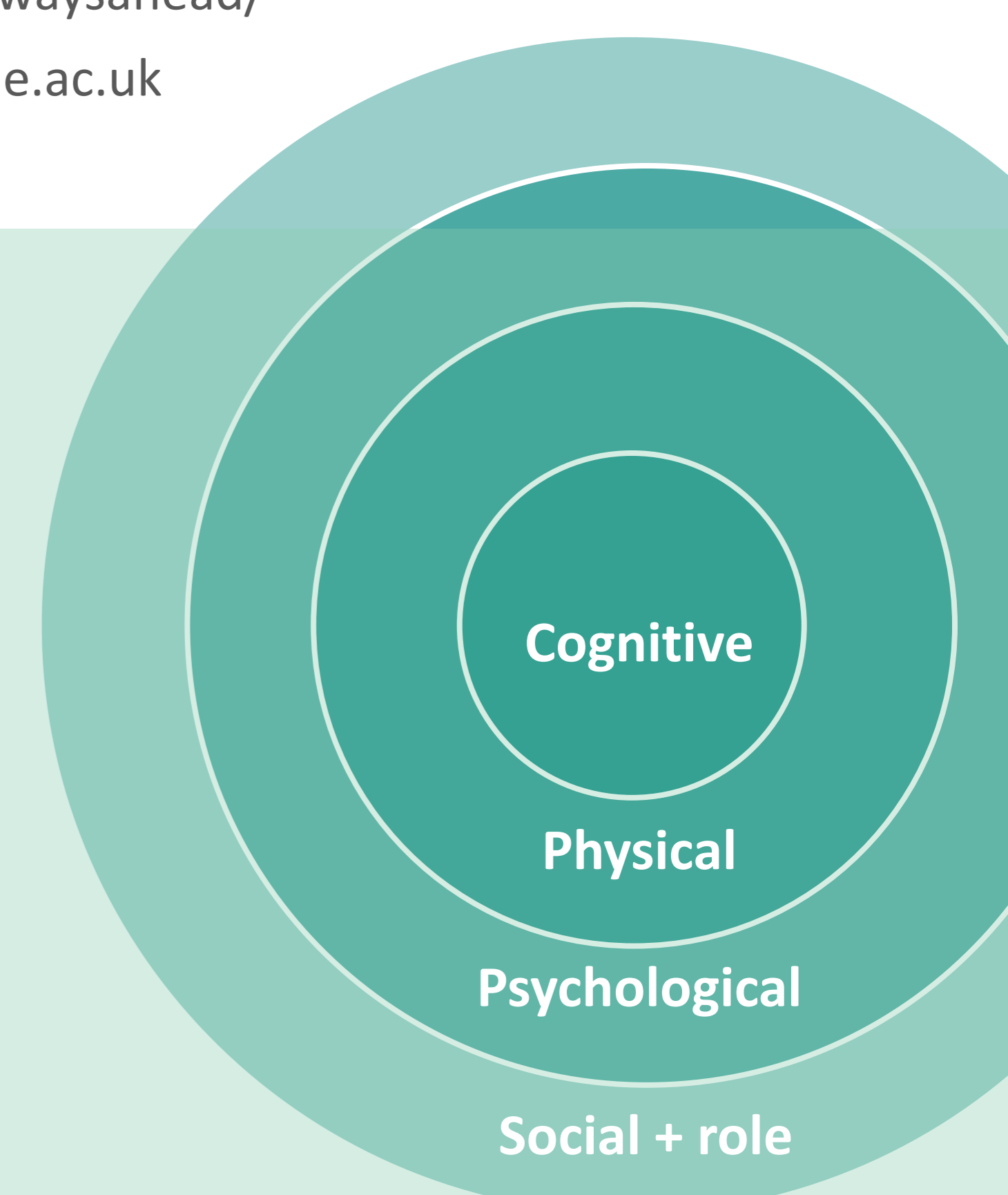
"I don't know what support there is actually. I don't know what support there is for that side." – Grade III oligo

Lack of a support network

"I have to travel to work, and it was just lucky I had friends around us that would give us a lift to work and giving us a lift back." – Grade II oligo

Acceptance and adjustment

"If you dwell on things, they get you, you go downhill with it, but I just get on with life as best you can." – Grade II oligo



*Analysis is ongoing. Findings detailed are preliminary.

