



Ways Ahead

Improving support for people with brain tumours

Summary of interview findings

Thank you very much for your previous participation in the Ways Ahead project. Your participation was very helpful, and contributed to the successful completion of the interview stage of this project. This sheet summarises what we found across the three interview sets and where the project is going next.

What we did... We interviewed 28 people living with a brain tumour, 19 family-members and friends supporting someone living with a brain tumour, and 25 health professionals involved in the care of brain tumour patients. People told us about what it was like living with/supporting someone with a brain tumour and how support for patients could be improved.

We have been presenting findings at numerous conferences and are preparing several papers for publication to scientific journals. All outputs are available on the project website (<https://research.ncl.ac.uk/waysahead>), as and when they go live.

Patient findings

- **Symptoms and impairments included:** fatigue, seizures, physical impairments (e.g. mobility), cognitive impairments (e.g. memory and communication deficits), personality changes, future uncertainty, anxiety, and treatment effects (e.g. hair loss).
- **Social and role implications included:** finances, hobbies and interests, relationships with partners, family, and friends, transport (e.g. driving licence revoked), returning to work, housework, and outlook on life.
- **What helps and hinders self-management:** personal characteristics (e.g. acceptance), environmental characteristics (e.g. location and understanding workplace), resources (e.g. equipment, finances), health status (e.g. fatigue), healthcare system (e.g. awareness of available support and relationship with health professionals).
- **The things that people do to manage living with a brain tumour included:** receiving support from family and friends, monitoring emotions, accepting the tumour and its consequences, and reinterpreting negative consequences. The approaches to self-management most commonly reported were: using support, creating a healthy environment (e.g. acquiring equipment or information), meaning making (e.g. appreciation for life), and self-monitoring (e.g. awareness of fatigue).

Family and friends findings

- **The emotional impact on family and friends included:** distress, helplessness, future uncertainty, fear of progression, changes in family dynamic, living with patient changes (e.g. frustration), need for resilience, feeling responsible, and burnout.
- **Ways in which family and friends helped people living with a brain tumour included:** cognitive (e.g. memory and communication strategies), emotional (e.g. companionship), practical (e.g. personal care, childcare, and housework), and social/role support (e.g. transport and finances), as well as help navigating the healthcare system (e.g. finding information and arranging support).
- **Types of support family and friends received from other people included:** emotional (e.g. understanding from others and opportunities to talk), opportunities for relief, and information (e.g. from support groups).

Health professional findings

- **Perceived patient support needs included:** emotional adjustment, fatigue and seizure management, physical and cognitive support, and help maintaining social roles (e.g. work and transport). Support needs were wide-ranging and often interconnected.
- **Available support included:** fulfilling above perceived support needs, information support, identifying needs, being available for the patient, and integration of family.
- **What helps and hinders health professionals to provide support:** challenges in co-ordination with, and co-operation of, other health professionals; identifying patient support needs; and staff availability, time, training, and facilities.
- **How health professionals think they should be supporting patients to self-manage included:** empowering patients and family, providing the tools and education to promote independence and control, and listening to patients' needs to develop goals.

Next steps... We will now work together with people living with a brain tumour, family and friends, and health professionals to design a self-management programme. This will include what support is desired and how it might be delivered.

We will also apply for more research funding to test whether our self-management programme does help people living with a brain tumour.

For more information or if you have any questions:

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