



Coma and Disorders of Consciousness
research centre

Why vegetative and minimally conscious patients (and their families) need dedicated case managers



Purpose of this document

To present a summary analysis of family members' experiences drawing out implications for case manager support.

The research

In-depth interviews were conducted with 65 people in the UK who had experienced a relative in a prolonged vegetative or minimally conscious state. For more information about research method see publications (mostly open-access) at www.cdoc.org.uk.

The research findings

Interviewees often praised the dedication and skill of staff, but also identified difficulties including:

- problems dealing with official bodies in relation to their relative's financial affairs (applying for and getting financial deputyships and dealing with benefits, pensions, utilities and bank accounts)
- challenges navigating the health care system including access to information, specialist assessment, rehab and long-term care; lack of continuity of care, breakdowns in communication between services and poor provision in some settings (e.g., on general wards in hospitals).
- the constant threat about whether funding for their relative's care was secure from year to year; lack of access to experts to discuss the situation or advocates to help resolve problems.

Family members often talked about feeling disempowered, isolated, excluded, burdened, exhausted and frustrated in a 'battle for care' and some felt their relatives had been 'abandoned' or 'lost in the system'. Family members sometimes contrasted such experiences with how patients/families are treated in other situations:

'In the cancer field there is a lady that has an idea of all the different sorts of care and solutions that are available. There is nothing there neurologically. There is nobody to go to, to say "what are the options for this?' [Phil]

'When I had breast cancer, they said, "Well, we have an interdisciplinary meeting every Wednesday ...". I think that something like that would've been helpful [with my son], to know more from professional people – some solid information that would help you make better decisions.' [Miggy]

Our research found that family members with active case managers (e.g. assigned by insurance agencies or legal firms) were noticeably less alienated and felt better equipped to act on their relative's behalf. Family members who has access to such a resource (a small minority of those interviewed) gained huge support from having skilled advocates 'on side' who had knowledge about brain injury and the medical/legal system.

'I [had] a firm of solicitors who were specialists in acquired brain injury. And they offered me an all-round care and support package. And without that I don't think as a family we could have survived. They'd seen it all before, they'd done it all before, and they had most of the answers.' [Helen]

'[My case manager] was my rock. She's the only person who I could ring up and say "what about this, what about that?" ... I would get supported or sometimes she used to go against me. Sometimes she said "come on, it's not quite like this." ... If I hadn't had her, that would have been very, very difficult.' [Gordon]

Recommendations

Existing recommendations (e.g. Royal College of Physicians 2013) address some ways in which service provision could be improved (e.g. clear pathways of care and proper consultation with families). Counseling for relatives is also encouraged and there are now support networks for families ('Brain injury is BIG') and detailed online multi-media information for family exploring family experiences and the legal/clinical context (see <http://goo.gl/rwdesg>).

However, our research suggests an additional need. We recommend that dedicated case managers should be provided to advocate for severely brain injured patients (and provide support to their families) irrespective of whether or not there is an insurance claim. The case managers should be attached to the patient – not to the individual organization – and would need to move with the patient through the system. Case managers would need an advocacy background and be available to the family for regular consultation. (Current systems involving funding review managers or an assigned social worker do not seem to address the needs identified above.)

Such provision could be cost-effective insofar as it could help reduce family illness and breakdown, promote improvements in service co-ordination, and pre-empt or resolve conflicts.

For further information and all our research findings see our publications at www.cdorc.org.uk and film clips from our interviews at www.healthtalk.org.

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