

# **Neuropsychological Rehabilitation**

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## **A Resource for Group-Based Education and Intervention**

Andrew J. Champion

*Health Psychology Department, Gloucestershire Royal Hospital*



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## **About the Author**

Dr Andrew Champion has worked in NHS inpatient and outpatient neuro-rehabilitation settings since qualifying as a clinical psychologist in 2001, most recently working as part of a multidisciplinary Head Injury Team and contributing to the work of inpatient and community stroke services. As well as specialising in the assessment and subsequent rehabilitation of people who experience acquired brain injury, Dr Champion teaches on these topics at both doctoral and postdoctoral diploma level, and is a Full Practitioner member of the British Psychological Society's Division of Neuropsychology.



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# Chapter 1

## Information Provision in Neuro-rehabilitation

For me, information is absolutely the most important thing. No-one told me, or my family, about the radical emotional and behavioural changes that a brain injury would force on me.

(Headway: the Brain Injury Association, 2005)

While for many people involved in the field of brain injury – professionals, carers and patients alike – it seems intuitively correct that the provision of information relating to such a sudden and potentially life-changing event should be an important part of after-care, in today's evidence-based and financially restricted context for clinical practice, this falls far short of constituting a sufficient rationale for investing resources such as healthcare professionals' time and room space (such a precious resource in so many NHS settings) into group-based education interventions. An indication of how low down the list of priorities systematic information provision often falls is provided by the results of a recent survey of approximately 100 healthcare professionals (including nurses, neurologists and therapists) working with people who have neurological conditions. In only one per cent of the neurological settings investigated were any financial resources available for education and information interventions (Brain and Spine Foundation, 2005).

This chapter is intended to summarise the evidence-base supporting such a use of resources, with the aim of assisting the practising clinician to justify the implementation of group-based education and rehabilitation sessions to those in the management hierarchy who may hold sway. This aim has an effective ally in the recently produced *National Service Framework for Long-term Conditions* (Department of Health, 2005), and this document will be considered in some depth.

### Information provision in neurological settings

Irrespective of the nature of an individual's condition, there are established findings suggesting that equipping people with information relating to their health condition has beneficial effects. In a concise overview of such findings, Barton, Levene, Kladakis and Butterworth (2002) cite studies spanning the past few decades. Ley (1988) notes that increasing patients' knowledge is associated with increased adherence to health regimes, as well as with increased patient satisfaction. Furthermore, adjustment to illness has been linked with increasing patients' access to relevant information (Reynolds, 1978).

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Neurological conditions are no exception to this. Morrison, Johnston, MacWalter and Pollard (1998) evaluated a workbook-based intervention and found that such an educational approach was associated with significantly reduced levels of depression and anxiety following stroke, while Kelly-Hayes and Paige (1995) linked the provision of information relating to stroke with strengthened social support systems.

Despite the evidence relating to the benefits of providing information to patients with neurological conditions, it is apparent that the provision of such information is often lacking in either its quantity or in the way that it is presented. Barton et al. (2002) identify two potentially problematic elements to the provision of information to people who have had a stroke, in that either health professionals do not communicate the relevant information, or that it is presented in such a way that the people who have had a stroke are not able to assimilate it. In the Brain and Spine Foundation's (2005) study, a major reason given by health professionals as to why they were often unable to provide information regarding people's conditions was shortage of time, a situation that will be familiar to the majority of health-care professionals in the NHS. One hope for the material provided in the following chapters is that the time-consuming preparation stage of structured information provision will be shortened considerably by the collation of information and resources into one volume.

Barton et al. (2002) go on to cite two studies to demonstrate their assertion that there are inadequacies in the quantity or the nature of information provision in settings that have a neuro-rehabilitation component. Gariballa et al. (1996) investigated patients who had either had a stroke or had ischaemic heart disease, and found that 86% of the people in their sample were unable to recall receiving any information or advice regarding their condition during the time that they were in hospital. The conclusion was that the methods of providing the information were not proving successful. Hanger and Mulley (1993) examined the nature of enquiries received by the UK Stroke association over a period of four months, and found that almost a quarter of all enquiries related to fundamental information about stroke that could or should have been provided by health professionals involved in the care of the individuals concerned. The conclusion, as above, was that either information was not being given to patients and their relatives/carers, or that it was not being given in an accessible form.

Further weight is added to these concerns from the findings of a Cochrane review carried out by Forster et al. (2002), which related to information provision for stroke patients and their caregivers. Forster et al. begin by acknowledging that provision of information and advice relating to stroke is recommended as a central aspect of care, citing the King's Fund (1988) and HMSO (1999). Despite this, they contend that the level of understanding of their condition remains poor in patients who have had a stroke, using a number of studies to support this claim. For example, Wellwood, Dennis and Warlow (1994) surveyed UK patients who had recently been discharged from hospital following a stroke and found that approximately one in four was unable to describe the difference between a stroke and a heart attack. Similarly, Drummond, Lincoln and Juby (1996) found that approximately a quarter of patients discharged from a stroke unit were unaware that a stroke involved damage to the brain.

Forster et al.'s (2002) review highlights some of the benefits of information provision, including improved quality of care after discharge from hospital following information

provision to carers (Evans, Bishop & Haselkorn, 1991) and compliance with secondary prevention (O'Mahoney, Rodgers, Thomson, Dobson & James, 1997).

One finding from Forster et al.'s (2002) Cochrane review is that information provision in the context of educational sessions does improve knowledge and is more effective than information provision without the educational session component (for example, issuing leaflets to patients). Although Forster et al. (2002) did not conclude that information provision had an effect on mood for patients or carers, more recently Young (2004) evaluated the provision of a short educational programme for carers using a randomised controlled trial, and concluded that it was associated with a significantly greater reduction in anxiety levels. The emphatic opinion espoused in this study is that patient education is a crucial element in the management of chronic disease (Young, 2004).

Clearly the presence of cognitive impairment is a challenge to effective communication that is particularly relevant to neurological conditions. If individuals lack insight into some aspects of their condition or its consequences, then this can pose a major obstacle to any rehabilitation attempts. If this is the case, then the focus of education about a condition can be shifted towards the family/carers of the individual. It is also becoming increasingly recognised that family members and carers should be given information about the condition and any associated difficulties; indeed this is specifically referred to in the National Service Framework for people with long-term neurological conditions (Department of Health, 2005).

## **Family and carers**

Family members are the most common providers of ongoing care for people who experience a brain injury (Jacobs, 1988, cited in Hayes & Coetzer, 2003). Liamaki and Bach (2003) considered the utility of group-based intervention with the carers of brain-injured relatives, focusing on the qualitative feedback that they received from their group of six attendees. The three main benefits that were highlighted related to normalisation of their experience, validation of the burden of caring and their attempts to cope with difficulties, and the knowledge that there were avenues of support available.

It has been established that one of the most important perceived needs of family members and carers of people with brain injury is for accessible, clear information (Sinnakaruppan & Williams, 2001, cited in Hayes & Coetzer, 2003). More generally, carers tend to report that two elements of information provision are of most value to them; namely, information about the nature of the condition itself, and information about how to obtain support (Zarit & Edwards, 1999). As regards information pertaining to the condition, it is a robust finding that cognitive, emotional and behavioural changes have the most impact on carer burden (e.g. Oddy, Humphrey & Uttley, 1978; Knight, Devereux & Godfrey, 1998), and this tallies exactly with the content of the sessions included in the session plans described in the following chapters. Knight et al. (1998) go on to report some benefits of systematic education programmes for family members of people with traumatic brain injury in terms of their understanding and subsequent management of ongoing difficulties. Crucially Knight et al. (1998, p. 479) conclude that 'where carers are confident in their ability to cope, burden is reduced'. Providing understanding and strategies

to help manage the cognitive and emotional changes is an essential part of increasing carers' perceived ability to cope.

## **The national service framework for long-term conditions<sup>1</sup>**

The National Service Framework for Long-term Conditions (NSF-LTC) has a particular focus on people with neurological conditions and one of its intended outcomes is to improve health outcomes by bringing about systematic approaches to the delivery of treatment and care. It consists of 11 'quality requirements', and the very first of these is of great relevance to the provision of information to those with neurological conditions. This quality requirement is headed 'a person-centred service', and is described as being an essential prerequisite for the remaining 10 quality requirements. 'Providing information' is mentioned specifically as a key element of the first quality requirement under a heading of 'improving services' (Department of Health, 2005, p.13). A second area in which the NSF-LTC refers specifically to the provision of information is in quality requirement 10, in which 'the need to offer information, advice and support to families and carers' is emphasised (Department of Health, 2005, p.17).

In the expanded notes relating to quality requirement one (QR1), the NSF-LTC cites two publications based on expert professional and/or expert service user evidence, and one randomised controlled trial, to support its statement that 'providing good information and education benefits the person by improving opportunities for choice and levels of independence and can reduce consultation rates' (Department of Health, 2005, p.22). Two of the three publications cited relate to 'patients' in general rather than to specifically neurological populations (Department of Health, 2001; 2004), while the third (the randomised controlled trial) relates to the provision of written information in the form of a booklet for patients experiencing back pain (Roland & Dixon, 1989).

It is stressed that, in order for such input to be effective, it must be designed and provided in a way that renders it accessible to the target population. At this point, the NSF-LTC highlights the ongoing need for staff throughout the disciplines and at varying levels of experience to undergo training in order to communicate effectively with people who may have cognitive impairments, citing as support the NICE (2003) National Clinical Guidelines for Multiple Sclerosis. This recommendation supports the provision of information regarding the consequences of brain injury to healthcare professionals, a third intended population (in addition to service users and their families/carers) who may benefit from structured information provision, for example in the form of attendance at a series of group sessions.

The NSF-LTC suggests that a range of formats is beneficial when presenting information for people with neurological conditions and their carers. The advantage of a group setting (for those who are able to engage in such a setting effectively) is that such a range is pos-

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sible. Group settings lend themselves well to the use of visual aids, including prepared slides and handouts containing written summaries, while other accessible formats will include functional examples generated by other attendees, demonstration and rehearsal of particular strategies within the sessions, as well as the spoken verbal content of the session.

The NSF-LTC acknowledges the importance of the timing of information provision. While this is considered in more depth in Chapter 2, there is some consensus that information provision in the post-acute time period is recommended (e.g. Barton et al., 2002). The notion that there is a ‘window of opportunity’ for information provision is one that can be particularly compelling when seeking to provide such input in, for example, an inpatient post-acute rehabilitation setting.

The first quality requirement identifies a range of ‘markers’, which serve as objective indices of whether or not good practice is being observed. One such marker is that ‘people receive timely . . . information . . . on the condition and how best to manage it’ (Department of Health, 2005, p.23), and this is supported by, among other publications, a systematic review relating to the information and counselling needs of people with epilepsy (Couldridge, Kendall & March, 2001). A second marker is that ‘people with long-term neurological conditions and their carers can access education and self-management programmes’ (Department of Health, 2005, p. 23), a marker based on a range of quantitative and qualitative research (e.g. Darragh, Sample & Krieger, 2001; O’Hara, Cadbury, De & Ide, 2002).

The central importance of providing information is highlighted by the fact that QR1 is referred back to throughout the other 10 quality requirements. For example, in QR2 (which relates to ‘early recognition, prompt diagnosis and treatment’) it is stated explicitly that inherent within receiving a diagnosis of a long-term condition, ‘people need information about their condition and an opportunity to talk through the implications for them’ (Department of Health, 2005, p.25), and attendance at courses run by healthcare professionals is included as an example of such good practice. The importance of ‘specialist advice from people who understand their condition’ is mentioned, with particular reference to conditions including multiple sclerosis, for which input from specialist nurses has been well documented in terms of clinical and cost effectiveness (e.g. Johnson, Smith & Goldstone, 2001).

QR3 deals with emergency and acute management, a stage in which structured provision of information regarding long-term consequences is less relevant, although it is of note that even at this stage there is an acknowledgement that staff need to be well-informed about conditions, and also that patients and their families are to be kept informed about the current condition, with care taken to avoid breakdowns in communication, particularly if the patient is transferred between settings.

QR4, dealing as it does with ‘early and specialist rehabilitation’ cites references that recommend the provision of information (e.g. Turner-Stokes, 2003), and clearly emphasises the utility of a multidisciplinary approach. Having more than one professional discipline present in structured group settings has a number of benefits (see Chapter 2), which overlap with the generation of a cohesive multidisciplinary goal-driven approach to an individual’s rehabilitation.

QR5 focuses on ‘community rehabilitation and support’. Essentially, this quality requirement demands that patients can access continued rehabilitation, advice and support after their discharge from an inpatient setting, with a view to enhancing independent living. The range of areas which this should cover is summarised in the NSF-LTC as including ‘physical, emotional, psychological and social’ (Department of Health, 2005, p. 35), and evidence is cited linking decreased community participation with a range of neurological conditions, including stroke (Drummond, 1990), head injury (Oddy, Coughlan, Tyerman & Jenkins, 1985) and spinal injury (Tasienski et al., 2000). Other consequences that can arise if some or all of these needs are not addressed are highlighted, including social isolation, anxiety and depression. Studies cited in the NSF-LTC relate these sequelae to various conditions including spinal cord injury (Kennedy & Rogers, 2000), multiple sclerosis (Nicholl, Lincoln, Francis & Stephan, 2001) and Parkinson’s disease (Raskin et al., 1990). Crucially for the provision of structured condition-related information in this setting, it has been demonstrated that improved adjustment to a condition ‘lessens the burden on carers and reliance on services, prevents unnecessary hospital admissions and can lead to substantial savings over the long term’ (Department of Health, 2005, p.35). The last two elements from this statement in particular are likely to be of use when attempting to access resources to run structured multidisciplinary patient information groups, and the NSF-LTC refers particularly to a study by Malec, Smigielski, Depompolo & Thompson (1993) in justifying this stance.

Within QR5 there is further support for running courses aimed at increasing the expertise of healthcare professionals, particularly generic community teams. Providing knowledge relating to some of the consequences of long-term neurological conditions to these professionals is described as a ‘key issue’ in developing ‘responsive and high quality rehabilitation in the community’ (Department of Health, 2005, p.36).

Furthermore, mention is made of the need to provide information and education alongside practical advice and skills to people with neurological conditions, their family and their carers. Specific publications are cited that refer to conditions including stroke (Kersten, Low, Ashburn, George & McLellan, 2002), spinal cord injury (Boschen, Tonack & Gargaro, 2003), and multiple sclerosis (Freeman et al., 2002). One of the evidence-based markers of good practice for QR5 is that people with a long-term neurological condition, their family and carers will ‘develop knowledge and skills to manage their condition’ (Department of Health, 2005, p.38). This is supported by three studies relating to acquired brain injury; one comprises a two-year follow-up relating to social adjustment (Weddell et al., 1980), while the second and third relate to evaluation of community-based rehabilitation (Pace et al., 1999; Powell, Heslin & Greenwood, 2002), the most recent being a randomised controlled trial (Powell et al., 2002).

QR6 relates to vocational rehabilitation. In practice, for many people with long-term neurological conditions such as acquired brain injury, it is in the work setting that the impact of more subtle cognitive sequelae becomes apparent, as the workplace is often characterised by multiple demands and time pressures. Indeed, as Lezak (1995) notes, after a ‘mild’ head injury, which does not require an extended admission to hospital, but may lead to an individual taking a few days off work, it is not uncommon for some cognitive difficulties to remain undetected until the individual begins to challenge themselves

cognitively – often this means on returning to work where skills such as divided attention, prioritisation and flexible thinking are at a premium. Normalising such difficulties and suggesting management strategies (both ‘internal’ and relating to environmental modification) can equip people to reduce the impact of cognitive difficulties on their daily work activities, and can facilitate productive discussions with employers regarding reasonable adjustments that can be made in the workplace. The long-term effectiveness of providing such information early has been demonstrated in the literature relating to mild head injury (e.g. King, 2003).

QR7 deals with the provision of equipment and accommodation, and incorporates assistive technology to support independent living. While this encompasses sophisticated equipment such as environmental modifications and communication aids that can have marked implications for quality of life, it must also cover the various ‘cognitive prostheses’, from diaries to paging systems. For people to implement such strategies they need to be aware of them, and also aware of the rationale for their utility, as would be predicted by the Theory of Planned Behaviour (e.g. Ajzen, 1985). Once again, education about the nature of cognitive deficits and information regarding rehabilitation strategies is a prerequisite for this.

Within QR8, which relates to ‘providing personal care and support’, there is an essential place for ensuring that – in whatever setting an individual may choose to live to meet their ongoing needs – care staff are familiar with the range of difficulties that are common in long-term neurological conditions. Two ‘key elements of successful home care’ (Department of Health, 2005, p. 48) related to the provision of information are explicitly recommended in the NSF-LTC. Firstly, those who are providing the direct day-to-day input should receive training in order that rehabilitation becomes inbuilt into an individual’s daily routine. Secondly, in a very similar recommendation, professionals in rehabilitation should provide training in the needs of people with long-term neurological conditions. While these two recommendations can seem somewhat duplicative, on closer reading it seems that the first relates more to specific interventions that need to be maintained on a daily basis for their benefit to be gained (such as wearing splints, or using a whiteboard), while the second is intended to provide care staff with a broader understanding of the rationale for some of the interventions recommended in order to facilitate understanding of individual needs. The provision of such information (as would be provided by a structured education/information package) is one of the evidence-based markers of good practice for QR8.

QR9 is headed ‘palliative care’. While specialist palliative care services emphasising quality of life are well developed and implemented by a range of specialist professionals, including nurses, social workers and hospice staff, some neurological conditions present with specific features in their more advanced stages (e.g. cognitive impairment) that may be less familiar to these staff. It is for this reason that QR9 suggests that in some situations, staff working in a palliative care setting may benefit from training regarding some of the consequences of neurological conditions such as cognitive changes (e.g. Kite, Jones & Tookman, 1999). Matters of capacity to make decisions can become particularly pertinent in palliative settings, and providing information relating to cognition to those involved in such situations can be an important element in demystifying some of this sensitive decision-making process.