

Waking up next to a stranger

Do you know what it feels like for me to wake up every morning, look at the man in bed next to me, and wish it was the man I married, not the monster I live with now?



RODGER LL. WOOD discusses how head injury can affect personal relationships.

THIS comment was made by the wife of a man who suffered injury to frontal areas of the brain in a car accident. The couple had been married for 10 years and had two small children. Her husband had been a devoted father and her 'best friend'. Since the accident he had become emotionally aloof and showed no warmth to his wife or children. He had a brief and very obvious 'affair' with an older lady he met in the local pub but appeared sexually uninterested in his marital partner and seemed oblivious to her distress about the pain and embarrassment caused by his infidelity. In contrast to his pre-accident behaviour, he often behaved in a very critical and unreasonable way to his wife and children, yet managed to display a social veneer that concealed his unpleasant character. In the privacy of his home he could be emotionally labile and completely unpredictable in temperament, directing angry outbursts at his wife and children. He was unable to recognise, or unwilling to accept, that his behaviour or personality had changed and would not acknowledge his wife's distress or that of his children, one of whom had begun to wet the bed at night, the other showing signs of behaviour problems at school. He blamed others for problems reported by the family, such as financial hardship (caused by his impulsive spending) and social isolation (because none of their friends were allowed to visit their home).

His wife felt trapped by a moral dilemma. She wanted to love her husband and try to recover something of their lost relationship, yet she hated the man he had become. She wanted to escape him and the

damage he was doing to their children, yet feared the opprobrium from her in-laws and friends who rarely glimpsed the unpleasant side of her husband's character and did not appreciate the problems that daily confronted her. She wanted her 'real husband' back, but felt helpless in respect of her ability to influence any change in the family's circumstances, because her husband either refused to talk to her at all or flew into a rage if she tried to assert herself regarding his unreasonable behaviour.

Her GP was initially sympathetic but then became increasingly irritated with her when her husband refused to attend marital counselling. The GP eventually made it clear that there was nothing he could do to help. She asked to see a psychiatrist, with a view to seeking help for her husband, but the psychiatrist diagnosed stress and depression in her and prescribed medication, making her feel that she was the cause of the problem. Because the

husband would not acknowledge that a problem existed and would not accompany his wife to the outpatient clinic or refer himself for treatment, the mental health team (who knew about his injury) felt unable to intervene. No support or advice was offered to the wife to ameliorate the problem.

There is, as yet, no happy ending to this domestic drama, nor is it a particularly extreme or rare psychosocial legacy of serious head injury. Many relationships are wrecked and many close relatives (especially children) suffer extreme psychological distress when the nature and quality of family relationships is radically altered as a result of behavioural and personality abnormalities that can follow in the wake of serious head trauma.

The psychosocial impact of serious head injury

The incidence of head injury is higher than any other neurological disorder and is

WEBLINKS

Headway – The brain injury association:

www.headway.org.uk

Brain Injury Rehabilitation Trust: www.birt.co.uk

PARAMOUNT/THE KOBAL COLLECTION/ FRANCOIS DUHAMEL

The 1991 film *Regarding Henry* dealt with the aftermath of head injury

probably unique amongst accident injuries, in that its long-term social impact is determined largely by psychological factors, even when there are persisting physical sequelae. The majority of head injuries are sustained as a result of road accidents and involve mechanical (decelerative) forces that principally damage the frontal and temporal lobes, plus subcortical limbic structures important to emotional expression, self-regulation and social cognition (see Levine *et al.*, 2002, for a review). Victims are predominantly male, between the ages of 18 and 35 (Miller, 1993), therefore, the psychosocial impact (as far as relationships are concerned) is mainly experienced by female partners.

A surprising number of such people appear pleasant, rational and motivated when seen by psychologists or psychiatrists in the context of a structured interview, and they often perform normally on a range of cognitive tests, even those specially designed to assess the impact of frontal injury (Shallice & Burgess, 1991). However, information from family members often paints a totally different picture, of someone who may be feckless, capricious, emotionally labile, suspicious of other people's intentions (sometimes to the point of paranoia), rigid (often with marked compulsive or ritualistic patterns of behaviour), emotionally shallow, and egocentric to the point that they may be indifferent to the feelings or needs of those who, prior to their injury, they cherished. If the head-injured person lacks any outward sign of disability and 'performs' well in a structured interview, inexperienced professionals may doubt the veracity of the partner's complaints. This could result in many families experiencing what can be described as a 'double whammy' – not only having the brain-injured person to cope with but also being let down by the system. Partners can end up feeling misunderstood, isolated, helpless and vulnerable – especially when healthcare professionals do little, in terms of practical help, to ameliorate the situation.

Psychologists who have conducted social outcome studies of serious head trauma are unanimous in showing that alterations to behaviour, personality and emotionality are not only a permanent legacy of the injury but also have a greater lifetime impact than cognitive or physical disability (Thomsen, 1992). The greatest impact, of course, is on family life. The

majority of relatives (and other caregivers) report high levels of stress as a result of providing daily support for such individuals, far greater than reported by relatives or caregivers of other disabled groups (Brooks *et al.*, 1986; Lezak, 1978). Parents, especially mothers, seem to cope best with the caregiver role, presumably because they are returning to a former role. This can sometimes be to the detriment of the injured person, who is 'looked after' to the point of being unable to learn from

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experience and develop the ability to look after themselves.

The relative most vulnerable to the complex changes in behaviour, personality and emotional disposition following head trauma, is the spouse or partner. In practice, therefore, it is mostly females that have to bear the brunt of any character changes exhibited by their injured partner. Many have difficulty adjusting to a different role in the relationship, such as when the partner has to make many more (usually all) decisions affecting domestic arrangements, financial decisions, care of the children, and so on, because the injured partner is either unable to make decisions or appears to lack interest and seems content if others shoulder the responsibility of day-to-day planning. Many partners who assume this responsibility gradually adjust not only their role in the family but also their perception of the injured relative, relegating them to the position of a child – 'it's like having another child to look after'. This can lead to feelings of resentment (from either partner), beginning a process of alienation that will affect the bonds of intimacy, respect, trust, companionship, and even the viability of the relationship itself.

Reasons for alienation

There are several levels at which relationships can be affected. Possibly the most obvious level is one of social engagement. Many partners report a sense of isolation as a result of the loss of friendship and peer group involvement. In an epidemiological survey, Dawson and Chipman (1995) found that among couples

where one of the partners had a head injury 90 per cent of the respondents reported a sense of social isolation. This may be attributed to the injured person's loss of social interest, reflecting the apathy, lethargy and reduction in both drive and motivation that is imposed by many forms of frontal injury. Alternatively, social isolation may result from friends and relatives avoiding the injured person who, as a result of altered personality, may exhibit behaviour that is perceived as rude, aloof, disinhibited, embarrassing or irritating. This is more likely in cases where the injured person has no physical disability to remind people that there may be a reason for these character changes.

At another level there is a loss of companionship. Many partners report 'I have lost my best friend' because the injured partner lacks any zest for life, seems unable to share in the planning and organising of family life, show any initiative, or display the kind of social interest or enjoyment that provided an important bond in the pre-accident relationship. Some partners complain about the loss of empathy in their relationship, reflected by the partner's inability to exhibit any kind of concern that recognises when a loved one needs support, help or affection. In some cases the injured partner will acknowledge a recent act of unreasonable behaviour but try to promote the 'funny side' of what was a very distressing incident for other family members.

A frequent legacy of head trauma is emotional lability. Some people exhibit a shallow irritability that results in frequent angry outbursts, some of which escalate out of control and appear quite disproportionate to the incident that provoked the outburst. Many partners express the view that living with someone who lacks inhibitory control is like constantly 'walking on eggshells' because they never know what they might say or do that will lead to an angry and largely irrational reaction. Partners find unpredictable changes in behaviour and personality to be one of the major causes of stress, insecurity and alienation in personal relationships, leading to the frequent comment that – 'it's like living with Dr Jekyll and Mr Hyde'. This unpredictability in behaviour has been identified as a major factor causing the breakdown of relationships (Wood & Lioffi, in press), presumably because a feeling of emotional

insecurity enters the relationship, causing the uninjured partner to withdraw from intimate contact, with the inevitable weakening of emotional and sexual bonds.

Sexual dysfunction is a frequent legacy of head injury, one that can have a major impact on the viability of a relationship. A minority of head trauma victims have increased sexual interest, usually in the context of a general pattern of disinhibition, where sexual interest is not matched by sexual performance. In the majority of cases, however, head injury results in a reduction (or loss) of sexual arousal that can undermine the bonds of the relationship. Many uninjured partners (of all age groups) have difficulty coping with their partner's loss of sexual initiative, equating the lack of physical contact with emotional rejection. Some of them even speculate that their partner might be seeing someone else. However, loss of sexual interest may not always be on the part of the injured partner. Sometimes the uninjured partner reports a reduction in sexual interest, reflecting the altered roles in the relationship. If the uninjured partner has to adopt the role of caregiver, they eventually view the injured partner as dependent (like a child), diminishing the sense of intimacy that characterised the pre-accident relationship.

What can we do to help

There are clear signs that neurobehavioural legacies of brain injury adversely affect both the quality and viability of family life

and the psychological well-being of partners (Hoofien *et al.*, 2001). Neurobehavioural disability after head trauma nearly always involves qualitative changes to the injured partner's personality that are usually permanent and adversely affect the mental health of partners and caregivers. This not only jeopardises the relationship itself but also undermines the injured person's capacity for life in the

'Some partners make surprisingly good adjustments'

community, because the caregiving or social support role assumed by many partners is vital to helping the head-injured person function in society. Therefore, it is important that psychologists involved in primary care and marital therapy, as well as neuropsychologists, understand the complex nature of neurobehavioural disability and its impact on psychosocial functioning.

One successful form of psychological intervention is a modified form of cognitive behaviour therapy, used to help raise awareness of the impact of one's altered behavioural style on others, creating conditions for better self-regulation of behaviour (see Manchester & Wood, 2001). Some cases of unpredictable behaviour change also respond to treatment with anticonvulsants (Eames & Wood, 2003).

However, many disorders of behaviour and personality prove intractable to psychological or psychiatric intervention. In such cases the onus is on the uninjured partner to make personal and family adjustments to minimise the incidents that cause distress to family members. This largely relies on the uninjured partner's coping skills. Some partners make surprisingly good adjustments and learn to cope with the altered family lifestyle imposed by their injured relatives behaviour. Others require a lot of psychological support, shifting the emphasis of 'treatment' from the injured to the uninjured partner, without the former feeling alienated, guilty or deprived of attention, and the latter not made to feel responsible for the problems in the relationship.

However, even with psychological support, many partners fail to adjust to the personality changes displayed by their injured partner, becoming depressed, angry and resentful. Research has shown that many such relationships fail, often after four to five years (Tate *et al.*, 1989; Wood & Yurdakul 1997), by which time individual family members who have been subjected to considerable stress realise that the current (adverse) situation is unlikely to change. In such cases it is often wise to assist the partner to reach a decision that brings the relationship to an end, as soon as possible with as little acrimony as possible. The solution often involves the couple living apart, but within easy reach of each other, so that children have access to the estranged parent and social support can be given, as needed. This bleak prospect is often a practical necessity to minimise the mental health risks to other family members.

More and more health professionals are becoming aware of the often subtle but pervasive changes in behaviour and personality associated with head trauma. Hopefully, this will not just increase opportunities for informed therapeutic support, both for head-injured people and their families, but will also improve methods of therapeutic intervention for people who lack awareness and judgement of 'characterological' changes that turn them into strangers within the midst of their families.

■ Professor Rodger Ll. Wood is at the University of Wales Swansea. E-mail: r.l.wood@swansea.ac.uk.

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