

Stroke survivors report loss of sexual desire, blurred gender roles, anger and fatigue

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Suffering a stroke can have a profound effect on relationships and lead to significant changes in how couples relate to each other on a physical, psychological, social and emotional level, according a study in the June issue of the Journal of Clinical Nursing.

Researchers from Northern Ireland have come up with four key recommendations for clinical practice after speaking to 16 married stroke survivors, nine males and seven females, aged between 33 and 78.

They found that sexual relationships were significantly affected after a stroke, gender roles became blurred and feelings like anger and frustration were confounded by a lack of independence and ongoing fatigue.

“All the participants perceived stroke as a life-changing event” says Hilary Thompson, who is based at Mullinure Hospital, Armagh, and carried out the research with Dr Assumpta Ryan from the School of Nursing and Institute of Nursing Research at the University of Ulster.

“They faced a continuous daily struggle to achieve some sense of normality and that required huge amounts of physical and mental effort” adds Hilary, a nurse specialist, who earlier this month won the Patient’s Choice Award at the RCN Northern Ireland Nurse of the Year 2009 for the support she provided to the family of a stroke survivor.

Key findings included:

- Sexual relationships changed. A 35 year-old female stroke survivor summed up the general feeling well. “It’s not a husband and wife role anymore” she said. “It’s a carer and a patient and it’s not very pleasant and it’s not fair.”
- All but one of the respondents reported a reduction or total loss of sexual desire after their stroke. Some felt that this was down to medication and fear of another stroke. As one 61 year-old male told the researchers “I want her there now as a friend but not really as my wife.”
- Most of the females lost interest in their appearance, regardless of their age. “No interest in clothes, no interest in make-up, no interest in hair. Weeks go by that I don’t even wash my hair” said one 57 year-old female.
- All the respondents said they had changed since their stroke and irritability, anger, agitation and intolerance were frequently mentioned. “I’m normally easy going, but now the slightest little thing sets off the temper” said one 53 year-old male, adding that his wife would “probably say I’ve turned into a miserable pig.”
- A number said they felt unable to prevent outbursts and this compounded their feelings of guilt, low-esteem and despair. As one 62 year-old female said: “I’d sit back and think why did I do that? But if doesn’t make any difference, I keep doing it.”
- A lot of the respondents said their outbursts reflected their frustration at not being able to perform routine daily activities, such as making a cup of tea. One 67 year-old male said that that his wife was a “reasonably healthy person” and asked “why should she be lumbered with me?”.
- Over-protective spouses appeared to increase anger and feelings of

frustration. One 78 year-old female explained that her husband wouldn't give her time to do the things she could still do because "he's afraid of me falling".

- Being discouraged from doing things they could do before their stroke made survivors feel demoralised and affected their confidence. One 72 year-old male said he was keen to "do the hedges, want to tidy the place up" but if he tried to do anything heavy his wife had a go at him.
- Over-protective spouses also demotivated survivors and made them even more dependant. As one 66 year-old female said "I don't have to so I don't bother".
- Some survivors said that they were unable to continue their traditional male or female role after their stroke and that this challenged their self-perception and identity. "You're not as much a husband as you were before" said one 67 year-old male, while a 66 year-old wife said that her husband didn't do the washing right "but he is only trying to help so I let it pass".
- Survivors said they felt safe and comfortable at home but were reluctant to resume social activities with their spouse because of swallowing problems, anxiety and fatigue. Some came to agreements whereby their spouse would go out alone. "I would be asked enough times but won't go" said a 46 year-old male.
- Fatigue was a real issue for survivors and this was often associated with reduced independence and guilt. It made it difficult to plan ahead because they didn't know how they would feel from day to day. Younger survivors also said it made it difficult for them to return to work. "You plan nothing" said a 46 year-old male survivor.

“There is no doubt that strokes have a profound effect on relationships and our research showed many of the physical, psychological, social and emotional issues a stroke can raise” says co-author Dr Ryan. “It is important to point out that stroke can happen at any age and many of the survivors who took part in our study were relatively young.”

Four were aged between 33 and 43, two between 44 and 54, six between 55 and 65 and four between 66 and 78. The time since their stroke ranged from two months to four years, with an average of 18 months.

As a result of the study the researchers have come up with four key recommendations for clinical practice.

These recommendations are:

- Nurse education should focus on both the physical and psychosocial effects of stroke so that nurses can provide holistic care to stroke survivors and their spouses.
- Health care professionals and service providers must recognise and be sensitive to the profound impact of stroke on sexuality and sexual function.
- Statutory counselling services should be available to people with stroke and their spouses on both an acute and long-term basis to help them cope with the complex issues described.
- Evidence-based guidance is needed to demonstrate how nurses can address the psychosocial needs of [stroke](#) survivors most effectively.

Source: Wiley - Blackwell

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