The effects of stroke on families are considerable. Family members may struggle to adapt to a care-giving role, and relationships between stroke survivors and their families are often altered by the illness. This article provides an overview of the effects of stroke on family dynamics and identifies interventions to support stroke survivors and their families during this difficult time.

**Effect of stroke on family carers and family relationships**


**Summary**

The effects of stroke on families are considerable. Family members may struggle to adapt to a care-giving role, and relationships between stroke survivors and their families are often altered by the illness. This article provides an overview of the effects of stroke on family dynamics and identifies interventions to support stroke survivors and their families during this difficult time.

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**Effect of stroke on family carers**

The first few days and weeks after a stroke can be stressful for families as they deal with the shock of the event. Typically, stroke occurs suddenly and most families will experience anxiety about prognosis and uncertainty about what the future holds (Greenwood et al 2009). Spouses of those who have had a stroke are at risk of developing depression and other types of emotional distress in the weeks and months after the event. In one of the earliest studies identified, Carnwath and Johnson (1987) reported that spouses of stroke survivors were more depressed and generally less happy with their lives compared with a control group matched for age, sex and social class. Other negative outcomes for spouses of stroke survivors were more depressed and generally less happy with their lives compared with a control group matched for age, sex and social class. Other negative outcomes for spouses of stroke survivors include high levels of strain (Blake and Lincoln 2000, Draper and Brocklehurst 2007, Green and King 2009), perceived burden (Thommessen et al 2002), dissatisfaction with life as a carer (Visser-Meily et al 2009) and anxiety (Wilz and Kalytta 2008).

Although similar negative outcomes have been reported in studies of mixed carer samples (spouses, adult children and siblings) (Anderson et al 1995, McCullagh et al 2005), little research...
has been undertaken to investigate the possibility that different family members might experience emotional distress for different reasons. Spouses may experience loss of intimacy as they move from a mutually supportive partnership to a relationship defined by providing care (Coombs 2007), while adult children may face particular challenges in balancing responsibilities to their own children and to their parents. Gender differences in care provision have also been reported. Women caring for a family member following stroke tend to experience greater psychological distress and lower quality of life than men (Dennis et al 1998, Bugge et al 1999, Larson et al 2008). The influence of ethnicity on caregiving for patients with stroke has not been investigated.

In addition to their emotional distress, family carers may have to deal with change in other aspects of their lives, and healthcare professionals need to think broadly when assessing the effect of stroke on family members. One of the most common changes is disruption to social and leisure activities (Anderson et al 1995, Pound et al 1998, Greenwood et al 2010). Simon et al (2009) found that co-habiting carers were able to do less than half of their usual activities six weeks after the stroke survivor returned home. Anderson et al (1995) found that 79% of carers experienced negative social changes a year after stroke, and in another study, 62% of carers had limited informal support from family and friends (McCullagh et al 2005). It is not surprising that social disruption occurs given that family members typically spend long hours carrying out care-giving tasks: daily averages reported in community studies range from 4.4-14.8 hours (Reese et al 1994, Bugge et al 1999, Smith et al 2004).

Other changes for family carers reported in the literature include loss of freedom and restrictions on movement (Greenwood et al 2010), dissatisfaction with care arrangements (Kerr and Smith 2001) and unmet information needs (Wiles et al 1998). There is a lack of research about physical health outcomes in carers of stroke survivors. However, Anderson et al (1995) found that carers (particularly older individuals) experienced exacerbation of existing health conditions, such as arthritis and cardiac disease, after a family member’s stroke. Greveson et al (1991) reported increased fatigue in individuals who had taken on a care-giving role for stroke survivors.

It is important to consider whether the negative effect of stroke on families diminishes or increases over time. Carnwath and Johnson (1987) reported that depression was more prevalent in spouses three years after stroke than after the first year. Bugge et al (1999) found an increase in the proportion of family members experiencing significant strain (defined as a score >6 on the Carer Strain Index) between one and six months after stroke. The timing of assessment is an important consideration because there is evidence that the emotional wellbeing of those who care for stroke survivors changes in a dynamic fashion, perhaps as the physical and functional abilities of the stroke survivor improve or fail to improve over time. Forsberg-Warleby et al (2004) found that although there was an initial increase in carers’ psychological wellbeing after the first few chaotic weeks of their partner’s stroke, positive and negative changes were identified during the remainder of the first year. Carers experienced improvement, deterioration and relative stability in their emotional wellbeing in equal measure.

Although most attention has been given to the negative effect of stroke on family members, there is evidence from the qualitative literature that carers of stroke survivors experience positive outcomes. Greenwood et al (2009), found that carers identified both relative positives (for example, comparing their family member with individuals who had higher degrees of disability) and absolute positives (for example, being brought closer to other family members, appreciating their inner strength and taking better care of their own health). Haley et al (2009) attempted to quantify the benefits of caring for a family member who had had a stroke. More than 90% of individuals reported that their experience as a carer had increased their appreciation of life, 81% felt caring helped them feel good about themselves and 67% reported that their experience had encouraged them to learn new skills (Haley et al 2009). It is therefore important to acknowledge that family members also experience perceived benefits from caring for stroke survivors.

Effect of stroke on family relationships

Although less attention has been given to the effect of stroke on family relationships, some conclusions can be drawn from the literature. Clark et al (2004) found significant family dysfunction in the first nine months after stroke: 32% of families were classified as having ineffective family functioning, using a structured interview schedule, and significant conflict was reported in 66% of families. Similarly, in a population-based study of 84 families in Australia, 35% of carers reported adverse effects on family relationships for a range of reasons, including misunderstandings and displacement of anger about the stroke to others (Anderson et al 1995).
More attention has been given to adjustment of couples after stroke, including the ways in which their relationships change over time. Although high levels of relationship satisfaction have been reported (McPherson et al. 2010), most evidence suggests increased stress on relationships following stroke. For example, Pound et al. (1998) reported that one in four stroke survivors experienced problems in his or her relationship with his or her partner. In addition, the evidence suggests that relationship satisfaction tends to diminish over time (Green and King 2009, Visser-Meily et al. 2009).

The literature, however, is not entirely negative and some relationships strengthen after stroke, possibly as individuals reassess their priorities and place greater importance on family life. In one study, approximately one in six carers reported that their relationship with the stroke survivor had improved since the stroke (Draper et al. 1992). Coombs (2007) found that most spouses indicated that they were committed to their partners and their role as carers, despite the wide range of everyday problems they experienced (Coombs 2007). Data concerning the protective factors for relationships are lacking, although one study of aphasic stroke survivors and their partners found that the more knowledge spouses had about their partners’ language problems, the higher their marital satisfaction (Williams 1993).

**Challenges for family carers and families following stroke**

Many families experience psychosocial difficulties following stroke. If a stroke survivor experiences physical impairment or functional disability, he or she may need the assistance of others to meet his or her basic needs. Approximately half of all stroke survivors require assistance from family members with activities of daily living (Sturm et al. 2002). This can involve long hours providing care, leading to fatigue and burnout (Anderson et al. 1995). However, carers do not only provide physical assistance and hands-on care; they also provide emotional support and help with a range of stroke-related difficulties. Indeed, evidence suggests that it is a survivor’s non-physical impairments – for example, problems with cognition, behaviour and communication – that present the greatest challenges to family carers.

Cognitive impairment is a common consequence of stroke, and several studies have shown that the degree of cognitive deficit is related to carer outcomes such as psychological wellbeing, and perceived stress and burden (Anderson et al. 1995, Forsberg-Watelby et al. 2004, Haley et al. 2009). Greenwood et al. (2010) highlighted the far-reaching consequences for family members of post-stroke cognitive losses, particularly when behavioural changes were also present. Many carers felt unable to leave stroke survivors alone at home because of safety concerns, and some were even unwilling to leave survivors alone in a room, particularly if the person was impulsive or had poor awareness of his or her limitations. Some carers described feeling trapped in their own homes. Other research also suggests that the overall burden of care is high for family members of stroke survivors with aphasia because they may be required to take on a wide range of roles and responsibilities as the person with stroke cannot communicate easily with others (Christensen and Anderson 1989, Draper and Brocklehurst 2007).

Family members are often not given information about stroke-related impairments, and knowledge gaps can lead to stress and frustration. In one study, 57% of individuals were dissatisfied with the information they had been given about their role as a carer (Simon et al. 2008). Carers in another study reported that information about how to prevent future strokes, and about community services and benefits to which they might be entitled, was particularly lacking (Wiles et al. 1998). These information needs may be unmet because healthcare professionals lack the time or skills to give adequate information, or may give information at an inappropriate time. Furthermore, family members may lack information and knowledge because they are reluctant to ask for help. Many individuals feel they are inadequate or are failing as a carer if they do not know something or have to ask for assistance (Anderson et al. 1995).

Stroke carers’ dependence on others for their own practical and emotional support was a theme identified by Greenwood et al. (2010). It is not always easy for families of people with stroke to enlist the support of others and dissatisfaction with social support is common (Baillie et al. 1988, Tomkins et al. 1988). Family members may have given up jobs to provide care, leaving them without sufficient money and sometimes without sufficient energy to maintain social ties and engage in social activities. Sometimes friends stay away because stroke survivors have problems communicating or have diminished interest in socialising (Anderson et al. 1995).

It is important to be aware that family members may consider it unfair or selfish to go out and enjoy themselves if the stroke survivor can no longer do so, and may therefore choose to forego social opportunities (Greenwood et al. 2010). The result is isolation from family and friends,
and sometimes guilt and resentment at enforced restrictions. However, these changes are not inevitable. Carnwath and Johnson (1987) found that individuals who maintained regular contact with friends and neighbours were protected from depression. Good social support is particularly important for family members at the outset of their care-giving role (Simon et al 2009).

**Importance of family carer functioning for stroke outcomes**

It is essential that nurses and other healthcare professionals are concerned about carer and family wellbeing, even though the stroke survivor’s many rehabilitation needs may be their primary focus. There is compelling evidence that psychological and functional outcomes of people with stroke are influenced by family functioning. For example, when carers are depressed, stroke survivors are more likely to be depressed (Carnwath and Johnson 1987). Friedland and McColl (1987) found that social support from friends, community sources and close relationships had a beneficial effect on the stroke survivor’s ability to perform activities of daily living.

In addition, researchers have investigated why some stroke survivors maintain improvements in rehabilitation after discharge while others deteriorate – one third of patients deteriorated between discharge and 12 months following stroke in one study (Paolucci et al 2009). It has been suggested, in explanation, that it is difficult to tailor intervention to the specific difficulties family carers encounter (Mant et al 1999). These findings have important implications for healthcare professionals. In addition to the direct rehabilitation work they undertake with stroke survivors, clinical staff should work with families to ensure survivors’ newly acquired skills continue to be used in the long term. This can be achieved by reinforcing to carers the need for stroke survivors to practise their skills regularly, and by encouraging carers to allow their relative appropriate levels of independence. Current UK recommendations to support patients and family carers following stroke are outlined in Box 1.

**Methods of support**

Interventions to support family carers of stroke survivors have been reported in the literature and are categorised as follows:

- Specialist service provision.
- Information provision, education and carer training.
- Counselling and psychotherapy.

The evidence for the effectiveness of each type of intervention will be reviewed briefly, before guidelines for nurses and the multidisciplinary team supporting family carers are outlined.

**Specialist service provision** The most common type of specialist service, usually used to improve carer and patient outcomes, comprises regular home visits by healthcare professionals with specialist stroke knowledge, such as family support workers (Dennis et al 1997, Mant et al 2000, Lincoln et al 2003) or outreach nurses (Burton and Gibbon 2005). The support they offer to individuals generally consists of empathic listening, provision of information and emotional support, and identification of unmet needs. Positive results have been reported relating to carers’ mood, levels of strain, satisfaction with services and knowledge (Dennis et al 1997, Mant et al 2000 and Burton and Gibbon 2005). Positive results have not been associated with carers’ psychosocial outcome (Lincoln et al 2003).

**Information, education and carer training** Information and education sessions are commonly provided to patients and family members in stroke rehabilitation settings. A Cochrane review found that carers’ knowledge increased after information provision, but found no evidence for improvement in broader carer outcomes, such as mood or subjective (perceived) burden (Smith et al 2009). It has been suggested, in explanation, that it is difficult to tailor information to the specific difficulties family carers encounter (Mant et al 1998). Clinicians should be aware that many carers will struggle to balance their care-giving duties with attendance at educational sessions, particularly after the stroke survivor has been discharged from hospital. For example, only 22% of carers who were invited to a community-based education programme were able to attend (Rodgers et al 1999).

In hospitals, however, attendance is likely to be higher and education sessions more feasible. One randomised controlled study provided...
family members with hands-on training (between three and five sessions) with regard to patients’ walking, sit-to-stand transfers, performance of activities of daily living and communication (Kalra et al 2004). An additional follow-up session was carried out following discharge so that skills could be adapted to the home environment. Carers who received the training had improved mood, lower subjective burden and higher quality of life. Patients also benefited because they achieved independence sooner. Smith et al (2009) recommended that strategies that actively involve carers, and include planned follow up to reinforce learning, should be used routinely during rehabilitation.

**Counselling and psychotherapy** There have been some promising results from talking-based therapies for carers of stroke survivors. Evans et al (1988) reported a counselling intervention, based on problem-solving principles, in a group of 61 patients who had had a stroke and their carers, and found clinically significant improvement in family functioning. Specifically, families communicated better and solved problems more effectively, and treatment gains were maintained for at least one year. A similar, although less intensive, intervention was offered to family members of stroke survivors (Clark et al 2003). The intervention consisted of three home visits shortly after home discharge designed to teach practical coping strategies and promote family cohesion. Clark et al (2003) reported more stable family functioning in those families who received the intervention. Wilz and Barskova (2007) offered stroke carers group cognitive behavioural treatment over 13 sessions, which had a positive effect on carers’ mood and quality of life. However, there have been few studies of talking-based therapies for stroke carers, presumably because specially

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**BOX 1**

**Recommendations to support patients and family carers following stroke**

*National Clinical Guideline for Stroke (Royal College of Physicians 2008):*

- Carers of patients with stroke should be involved with the management process from the outset.
- During the rehabilitation phase, carers should be encouraged to participate in an educational programme that:
  - Explains the nature of stroke and its consequences.
  - Teaches them how to provide care and support.
  - Gives them opportunities to practise care with the patient.
  - Emphasises and reiterates all advice on secondary prevention, especially lifestyle changes.
- Hospital services should have a locally negotiated protocol to ensure that before discharge occurs:
  - Patients and families are prepared, and have been involved fully in planning discharge.
  - Patients and families are given information about and offered contact with appropriate statutory and voluntary agencies.
- Patients and their carers should have their individual practical and emotional support needs identified:
  - When they leave hospital.
  - When rehabilitation ends.
  - At regular intervals thereafter.
- After patients return home (or to residential care), carers should:
  - Have their need for information and support reassessed whenever there is a significant change in circumstances (for example, if the health of either the patient or the carer deteriorates).
  - Be reminded on a regular but not frequent basis of how they may seek further help and support.

*Management of Patients with Stroke (Scottish Intercollegiate Guidelines Network 2010):*

- Patients and carers should have an early active involvement in the rehabilitation process.
- Information should be available to patients and carers routinely and offered using active information strategies, which include a mixture of education and counselling techniques.
- Information should be tailored to the information needs of individual patients and carers, followed up to check understanding and ensure clarity, and repeated as appropriate.
- Carers should be invited to attend therapy sessions at an early stage.
- Conferences between the multidisciplinary team and the patient, carers and family should be arranged to discuss setting goals.
- Appropriate referral to health and clinical psychology services should be considered for patients and carers to promote good recovery or adaptation and to prevent and treat abnormal adaptation to the consequences of stroke.
- The pre-discharge process should involve the patient and carers, the primary care team, social services and allied health professionals as appropriate.
- NHS board areas should consider developing specialist stroke nurse-led support services that include education, information provision and liaison in the community for people who have had a stroke and their carers.

Only the key family carer recommendations are included here. The reader should consult both guidelines for other references to family carers.

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trained personnel are required to deliver them, and psychological therapy can be labour-intensive. Many carers experience clinically significant levels of emotional distress, and so a wide range of evidence-based treatments should be available to them.

**Providing support to families along the care-giving pathway**

The stroke care-giving pathway has three distinct stages: hospital stay, transition from hospital to the community and community living. Families’ needs differ during each stage, as do the types of practical support that best meet these needs.

**Hospital stay** At this early stage in the care-giving pathway, families need regular, direct contact with nurses and other healthcare professionals caring for their relative (Smith et al 2004). Early contact with families is recommended to meet a family’s basic information needs and establish an atmosphere of open sharing. Families may need support to understand the effect of stroke. Some individuals may struggle to identify their role as carers and others may have unrealistic expectations of rehabilitation and recovery.

Regular contact with families and carers gives the clinical team invaluable insight into a family’s needs and the steps the family has already taken towards early adjustment. Basic reassurance can be offered, and early expectations managed and supported by providing information in an accessible and sensitive way. Families benefit from feeling involved, having their role in the stroke survivor’s rehabilitation acknowledged and from being given the opportunity to think positively about the future (Banks and Pearson 2004).

Carer support need not be viewed as a formal process; it can take place on an informal ‘checking in’ basis. Healthcare staff may find it helpful to use an exploratory style of questioning – for example, ‘have you thought about asking your neighbour for help with transport?’ or ‘how are you coping with things this week?’ – to support carers in developing an awareness of their needs, and to help them focus on solutions. Healthcare staff should record the outcomes of these conversations. A range of practical suggestions to support families during the hospital stay are summarised in Box 2.

**Transition from hospital to the community**

Supporting the patient’s successful transition from hospital to the community requires commitment from healthcare staff to work with stroke survivors and their families as well as careful planning as this can be a stressful time (Kerr and Smith 2001, Smith et al 2004) (Box 3). Ideally, planning should begin as soon as the patient starts rehabilitation in hospital. Families

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**BOX 2**

**Practical suggestions to support families during the hospital stay**

- Allow some flexibility in visiting hours to accommodate other commitments that family members may have, for example work.
- Speak regularly to family members to find out how they are coping.
- Although brief questionnaires exist to assess the impact of caring, for example the Carer Strain Index (Robinson 1983), it is also important to speak to family members on an informal basis to understand any issues that they may need help with.
- Provide basic information packs that can be personalised to the needs of each family.
- Provide in-house education and support sessions for families.
- Encourage family members (with the stroke survivor’s consent) to participate in therapy sessions to help them become aware of the stroke survivor’s abilities.
- Support families in talking about recovery and future care requirements.
- Incorporate discussions about family issues during multidisciplinary team meetings.

**BOX 3**

**Practical suggestions to support transition from hospital to the community**

- Offer opportunities for family involvement in care-giving tasks on the ward to increase the responsibility of family members gradually.
- Involve stroke survivors and families in considering the options available for community living, for example home living or supported accommodation.
- Encourage discussions about the effect of stroke on carers after hospital discharge.
- Address any specific fears a family member may have, for example coping with falls or the risk of another stroke.
- Develop a resource pack for family carers providing details of community services and benefits available.
- Give details of social support groups available in the community, for example voluntary sector support groups.
- Ensure good links and information sharing between the hospital and community teams, and between health and social care providers. Arrange opportunities for stroke survivors and families to meet key community staff such as district nurses and stroke liaison nurses before discharge.
should prepare themselves to take on care-giving tasks previously dealt with by hospital staff, and to learn how much independence to expect from the stroke survivor after hospital discharge so that rehabilitation is maintained (Clark and Smith 1999).

**Community living** Supporting families and carers in recognising their needs, developing their own solutions where possible and asking for help when it is needed are vital to the sustainability of the care-giving role. When active rehabilitation is no longer taking place, families frequently require support to recognise that asking for help at this stage is a positive move towards improving their own wellbeing and that of the stroke survivor. The availability of social support should also be considered when supporting long-term adjustment to stroke. Family carers need encouragement to develop a support network in their wider family and social circle to prevent the negative outcomes associated with social isolation (Carnwath and Johnson 1987). The provision of group support can provide carers with the opportunity to share advice and support (Smith et al 2004). These should include services that provide respite for carers. Families frequently require support to recognise that asking for help at this stage is a positive move towards improving their own wellbeing and that of the stroke survivor. The availability of social support should also be considered when supporting long-term adjustment to stroke. Family carers need encouragement to develop a support network in their wider family and social circle to prevent the negative outcomes associated with social isolation (Carnwath and Johnson 1987). The provision of group support can provide carers with the opportunity to share

**References**


experiences and solutions and develop a new network of social support. The authors of this article have experience of developing a stroke support group for carers in Edinburgh and have outlined some guidelines for others who may wish to do the same in Box 4.

Conclusion

This article has reviewed the evidence for the effect of stroke on family carers and family relationships, and outlined evidence-based interventions to support family carers overcome any difficulties. In addition, suggestions have been provided for nurses and other healthcare professionals to incorporate into their practice. Supporting stroke survivors and their families in achieving optimum long-term adjustment should be a fundamental aim of all good stroke services.

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**Box 4**

**Developing a community-based stroke support group for carers**

- Find out about local support groups already in existence.
- Talk to family carers about what they would like, and invite them to be involved in the planning and administration of the group.
- Identify a suitable location, taking into consideration issues of transport and accessibility.
- Identify local sources of funding to help with group running costs.
- Develop links with local respite and sitting services to enable carers to attend.
- Encourage open-door access in addition to a referral system to the group.
- Consider whether a family member may benefit from being accompanied by a nurse or other stroke professional to his or her first attendance at the group.
- Education opportunities should be combined with informal social support.
- Consider the use of newsletters, digital media and social networking to engage families and carers who are unable to attend group meetings.

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