

Personal determinants (carers)

- Carers do not want to know some things, e.g. if their partner had epilepsy*
- Carers are not always in the right frame of mind to take on some information whilst the stroke survivor is in hospital*
- Carers are too busy to read written information whilst the stroke survivor is in hospital*
- Carers are too proud to ask for information*
- **Carers do not want to bother professionals for information and support ***
- **Carers assume that information and support will be provided and therefore take a passive approach to gaining this***
- **Carers lack knowledge and skills for being prepared following the transition from hospital to home/ providing practical care**
- ***Carers lack knowledge about who and what to ask regarding support and information****
- **Carers are uncertain about the type of support required and their support needs**
- ***Carers are reluctant to ask family and friends for support due to feeling bothersome, not wanting to disturb them***
- Carers might see it as a weakness to ask for help from professionals, family or friends*
- Carers lack confidence for attending stroke groups on their own initially*
- Carers perceive that going to a group means that they are a failure*
- *Initial anxieties, fears and lack of confidence for coping*
- *Uncertainties about caring abilities, extent of stroke survivors' recovery, managing changes in stroke survivor, life at home and impacts of stroke*
- *Feeling isolated, abandoned, shocked, distraught, stressed, scared, low, depressed*
- Carers have poor or a lack of coping strategies (Stroke, Cancer, Dementia, FTLD- type of dementia) *
- **Carers lack realisation about the changes to their lives, relationships and the extent of the stroke survivors' impairments***
- **Carers lack realisation about how hard things could be***

Personal determinants (others e.g. professionals, services, friends)

- Health professionals are uncertain at stage during the stroke survivors' stay in hospital, therefore providing expectations is difficult*
- Health professionals are too busy to give carers advice in hospital *
- Professionals expect carers to cope if they have a medical background*
- Professionals focus on the physical aspects of stroke, emotion comes second*
- **Professionals focus on the stroke survivor rather than the longer term implications for the carer- wards are often therapy led***
- Professionals may lack the skills to provide support and information to carers if they have been trained medically (too much use of medical language) *
- Health professionals find it difficult to provide reassurance knowing there are poor facilities for carers*
- **Health professionals do not have time to prepare carers, poor timing of visits, limited staff, and short length of hospital stay.**
- *Professionals lack time to involve carers in the stroke survivors' discharge*
- **Health professionals do not see it as their role to seek out carers to provide support once they return home**
- **Professionals lack time to follow up carers when they return home/ provide support in the community***
- Services do not always take a family approach to providing care*
- Services have difficulties keeping staff e.g. volunteer to provide support*
- Services have difficulties getting information to carers quickly*
- Services face financial and resource constraints*
- Friends do not know how to handle the situation and often end up doing nothing*
- *Family and friends feel uneasy about changes to the stroke survivor*
- ***Friends and family struggle to understand the situation***

Behavioural factors

- **Avoiding approaching health professionals for support**
- **Avoiding being active in seeking information (passive approach)**
- Carers do not always make use of information during the stroke survivors' time in hospital *
- Carers do not seek information and support from professionals during the stroke survivors time in hospital *
- ***Avoiding asking for support from family and friends****
- Carers do not attend stroke groups*
- *Carers provide care without preparation (emotional and practical)*
- Carers do not prepare emotionally for the changes to life and relationships etc.*

Environmental factors

- Professionals in hospital do not inform the carers that the stroke survivor may change after their stroke*
- **Poor communication from professionals (e.g. delivery of training, supporting the stroke survivor physically).**
- **Professionals fail to adequately assess whether carers understand the stroke survivors' needs**
- **Professionals fail to adequately teach carers to support the stroke survivor with their rehabilitation**
- ***Professionals do not inform carers about expectations for life at home, available facilities, access to support, cause of stroke and extent of recovery****
- ***Professionals in hospital provide carers with too much information****
- ***Professionals do not provide carers with enough support that is carers specific when the stroke survivor is in hospital (emotional or practical)****
- *Professionals do not provide carers with reassurance about their abilities to care**
- **Professionals do not always include carers in the discharge process***
- **Professionals do not always provide appropriately timed information and support for carers/experience lack of opportunities to provide information**
- **Professionals do not provide carers with enough information when they return home, e.g. benefits, the stroke, groups or services***
- ***Professionals do not provide carers with enough support about how they are getting on once they return home* (influences coping with changed relationships, managing practically).***
- GPs do not provide consistent support once the stroke survivor returns home*
- **Inadequate assessments of carer needs for supporting survivor as part of service provision**
- Services fail to provide adequate home care support once the stroke survivor returns home (Stroke)
- Services failing to provide continuity of rehabilitation in the community and at home (Stroke)
- Services fail to provide psychological support once the stroke survivor leaves hospital- coping general and specific aspects e.g. relationship
- **Services failing to provide appropriate/ accessible resources for information once the stroke survivor returns home***
- **Services failing to provide appropriately formatted and timely information**
- **Services fail to provide available and accessible support in the community**
- ***Friends and family do not provide emotional or practical support (Stroke, Cancer)****

Health problem (burden)

Being/ feeling unprepared before and during the transition from hospital to home

Patient factors

- Changes in behaviours of person with condition – (Dementia, FTLD, MCI, Stroke)- crying, laughing uncontrollably, loss of inhibitions*
- Stroke survivors that lack empathy towards carer*
- Severity of illness (Dementia, MCI, Stroke*)
- Loss of speech*
- *Level of stroke survivor impairment/ extent of improvements over time (Stroke)*

Carer factors

- Young age (Cancer, Dementia, Stroke*), older age (Dementia)
- Gender- mixed findings (Dementia, Cancer, Stroke*)
- Low income (Cancer, Stroke*)
- Poor psychological health e.g. depression (Parkinson's Disease, Dementia, Stroke*)

Other factors

- *Shock, distress when the stroke initially happened**
- Not perceiving themselves as a carer initially and even for continued time following return home*
- *Disruption to their imagined future and relationships**
- Uncertainty around things getting better*
- **Uncertainty around some practical aspects***
- *Difficulties with emotional impacts attached to caring- low and depressed**
- *Entering a role with little choice (obligation to care)*