Health problem (burden)

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

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*

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)*

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.*

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, 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)