Psychological and emotional issues after stroke explores these symptoms in great detail. These symptoms are common, disabling, and increase the costs of healthcare. Psychological conditions can occur at any age, and a person’s age is just one of many factors to be considered when assessing, formulating, and treating these complications. The commonest and most salient psychological conditions after stroke are anxiety, depression, fatigue, and emotionalism. Other more subtle presentations include low self-esteem, low confidence, reduced self-efficacy, altered identity, and post-traumatic stress. In approaching psychological conditions, it is important to be mindful that most are not limited to the acute phase. The delivery of psychological care is not necessarily the domain of specialists alone; service models such as stepped care may engage a range of staff in helping with less severe presentations. The ubiquitous nature of psychological conditions requires approaches that enable large numbers to be assessed and treated cost-effectively. Group-based approaches and self-management are particularly important additions to resource-intensive one-to-one therapy.

Chapter 26

Psychological and emotional issues after stroke
The focus of this book is stroke in older adults. The psychological, mental health, and social care needs of older people may, on average, exceed those of younger adults in numbers and complexity. But while the perception of psychological well-being and the expectations of psychological health-care may be partly shaped by age and experience, psychological adjustment, and perspectives are immensely variable and flexible. Moreover, few, if any, psychological conditions are the exclusive preserve of one age-group. Age-blindness in practitioners would be counter-productive, but above all, psychological care requires consideration of unique individual characteristics and needs, of which age-related needs and attributes form but one dimension. We should also exercise caution in assuming that outcomes and experiences following stroke are necessarily different in younger and older stroke survivors. Older and younger survivors share many of the same needs and issues. In one study, age predicted functional scores at discharge, but the effect of age alone on improvement in functioning, after adjustment for initial level on admission, was small and accounted for less than 2% of variation.

There is relatively little research into age differences in psychological conditions after stroke, but most people who have strokes are...
over 65 and consequently most research is conducted with typical stroke patients. Therefore, most of the evidence presented below will necessarily apply to older stroke patients. Where specific evidence about age difference is available it will be discussed, especially where it has implications for treatment.

Overview of psychological conditions

This chapter covers a selection of common psychological conditions after stroke, fatigue, cognitive problems, and apathy being covered in other chapters. Psychological conditions such as anxiety, depression, and fatigue are the most commonly reported problems following stroke in patients and carers, being seen in around two-thirds of patients and in carers. They hinder functional recovery and present substantial additional costs to health services. However, psychological conditions frequently go unrecognized and untreated in the United Kingdom. Specialist psychologists to assess and treat psychological conditions remain limited in hospitals and are even more scarce in the community settings.

Common psychological conditions following stroke

The first three conditions described will be familiar to all those working in stroke services, including those working in hospital services with patients soon after stroke. While emotionalism is usually a feature of
the first few weeks or months, depression and anxiety can emerge at any stage, even up to 10 years or more after the stroke event.

**Depression**

Depression is common after stroke and is found in around one-third of stroke patients at any one time. Moreover, the risk of depression remains constant in the years after stroke and 55% of stroke patients experience it at some stage. The prevalence of depression has not declined over the past 20 years, despite increased awareness and therapeutic attention. Depression is a significant factor for all age groups but is more common in those under 65.

Depression after stroke predisposes to poor outcome. It is associated with poorer functional recovery and lower quality of life. It also impacts on the use of services, including impaired engagement in rehabilitation; increased outpatient visits after discharge; increased rate of readmission; greater risk of institutionalization.

To avoid such negative outcomes, it is vital that depression is identified soon after it occurs and that patients are offered appropriate treatment. It is not sufficient to screen only in the early stages of recovery; screening must be repeated at intervals over the succeeding years. This is best accomplished using a brief validated self-rating instrument such as the
PHQ-9 or, when there is communication impairment, an appropriate version of the carer-completed SADQ. These screening instruments can be used by staff without specialist training. They can then refer on for specialist assessment and treatment where necessary, according to a screening protocol about which all relevant staff have received training from a psychologist.

In the United Kingdom, evidence-based guidelines for depression in the mental health context emphasise stepped care and cognitive behaviour therapy (CBT). However, extrapolation from general mental health to the stroke population requires caution. To date there is no evidence for the effectiveness of CBT or stepped care after stroke, but brief psychological interventions, such as acceptance and commitment therapy, motivational interviewing or behaviour therapy may be helpful. There is evidence that selective serotonin reuptake inhibitors (SSRIs) can reduce depression and combining psychological treatment with antidepressant drug treatment may have some advantages. But evidence for pharmacological therapy in the prevention of depression after stroke is equivocal.

There is a self-management text, *Rebuilding your Life After Stroke*, based on acceptance and commitment therapy that includes advice and practical exercises to manage depression after stroke. In England it is...
Anxiety prevalence estimates after stroke range from 18% to 38% and during the first 10 years after stroke the cumulative incidence is 57%.

Anxiety is persistent, more so than depression. Anxiety is associated with poor social functioning, lower quality of life and poorer functional ability.

Anxiety can be screened with the self-report anxiety scale of the Hospital Anxiety and Depression Scale or the Geriatric Anxiety Inventory or the General Anxiety Disorder 7 Item measure. Where there are communication problems an alternative screen is the Behavioural Outcomes of Anxiety scale which uses carer ratings.

Psychological interventions and/or drug treatments (SSRI or buspirone hydrochloride) may be useful in treating anxiety. SSRIs reduce anxiety, but no one SSRI is superior to any other. Small randomized trials of a self-help relaxation CD have demonstrated benefit for anxiety after stroke, but further research is needed with a large representative sample.

For people with anxiety after stroke approaches to self-management may be found in the book, "Rebuilding your Life After Stroke."
Emotional lability, or ‘emotionalism’, is excessive crying, or sometimes laughing, disproportionate to the emotional stimulus. It often occurs at the mention of personally significant people or events, or when family members visit. It affects about 20–25% of patients in the first 6 months after stroke but declines in frequency and severity so that by 12 months only around 10–15% of patients are affected. A small number continue to experience symptoms beyond 12 months. But many of those affected at 12 months will not have experienced it for the whole year after stroke; few have persistent and severe problems. Emotionalism is distressing and embarrassing for patients and their families, and can interfere with rehabilitation and result in avoidance of social situations.

There are no specific assessments for emotionalism, and perhaps the most important indicator of severity and impact is the extent to which it produces distress for the individual and their immediate family.

Antidepressant drugs may reduce emotionalism, but the evidence is not conclusive and there is no basis to recommend choice of antidepressant.

The UK’s Clinical Guidelines for stroke make recommendations for emotionalism based on consensus opinion. These propose specialist assessment (e.g. by a psychologist) and distraction from provoking stimuli with antidepressant treatment only if emotionalism is severe and
Patients with emotionalism, and their families, can be helped psychologically by explaining that it is a neurological consequence of the stroke and does not signify distress in the same way as ‘normal’ crying. This can help to alleviate distress and embarrassment. In addition, clinical experience suggests that training in controlled, regular breathing may be helpful in cases where severe bouts of crying persisted over several months. This may achieve its effect through distraction from the provoking event, or because controlled breathing is incompatible with crying. However, to date there have been no studies of psychological treatments for post-stroke emotionalism and controlled research trials are needed. As for anxiety and depression, the self-management book *Rebuilding your Life After Stroke* offers guidance on how to manage emotionalism.

We will now consider some less well-delineated and researched areas that are nevertheless important aspects of psychological adjustment following stroke and have been identified by stroke survivors as areas particularly requiring assistance and support.

Self-efficacy, self-esteem, and confidence

Self-efficacy has been defined as confidence in one’s ability to perform a task or specific behaviour.
Self-esteem on the other hand is a person’s sense of self-worth and confidence has been defined as the belief one has in one’s ability to do the things one tries to do. Self-esteem has been shown to be impaired after stroke. Although there is a validated measure of self-esteem after stroke, at the time of writing there is no satisfactory measure of confidence after stroke, but Horne et al. have identified its constituents in preparation for developing a measure.

Self-efficacy has been found to be positively associated with mobility, activities of daily living, and quality of life, and negatively associated with depression after a stroke. Self-efficacy assumes importance due to its link with self-management which is a key approach for long-term conditions: self-efficacy is a crucial element in the success of programmes that support self-management. Self-efficacy in stroke patients can be measured by the Stroke Self-efficacy Questionnaire or the daily living self-efficacy scale. It can be increased by interventions enabling people to challenge assumptions about threat and failure, identifying and challenging self-defeating strategies for compensating for poor self-esteem, and combating self-criticisms and enhancing self-acceptance by fostering a more positive self-percept. Furnishing examples of success and encouragement to strive to achieve goals are also helpful. Many useful techniques for building self-esteem and confidence are outline in self-help text, Overcoming Low Self-Esteem.
The self-management text ‘Rebuilding your Life After Stroke’ offers guidance on valued-based living which is a key factor in the development of a positive self-image.

**Itered self-identity or self-concept**

Horne et al. (2014) found that confidence, self-efficacy, self-esteem, and identity are closely associated constructs in the minds of stroke survivors. All are certainly aspects of the perception of self. However, identity is more closely aligned with global perceptions of personality and values than the other three constructs which are more concerned with capabilities and performance.

Reports of change or ‘loss’ of identity following brain injury, including stroke, are common and the experience may persist over many years. Identity change is the ‘subjective discontinuity in their felt, embodied or social experience of who they are’. Following stroke, it has been described as ‘loss of me’ and feeling distanced from the new self, which is perceived as strange and unfamiliar. The self is often viewed more negatively after stroke to a degree unrelated to physical impairment. Identity change crucially concerns brain injury survivors and their families. It engenders discomfort, grieving for the lost identity, and a striving to construct a new identity which can be experienced as a struggle that distracts from rehabilitation. Change
in identity, like identity itself, is associated with emotional problems,[468,69–71] social isolation,[472,71] pessimism about the future,[62] and poorer quality of life.[68,70] Conversely, maintenance of social identity predicts well-being [72,77] and higher quality of life following brain injury.[73,74]

Identity after stroke can be assessed with Head Injury Semantic Differential Scale–III.[75] And change in identity can be gauged by asking patients to complete the scale as they were before stroke and comparing this with how they complete it for after their stroke.

Interventions such as mindfulness based cognitive therapy[76] may be helpful in reducing discrepancies between current and pre-stroke self. Vickery et al. (2005)[74] described a self-concept group intervention for people with brain injury which produced significant overall improvement in self-concept. Narrative therapy approaches are yet unproven but have been proposed as an approach to issues of identity after stroke. For example, a person might be encouraged to construct their life story while highlighting valued aspects of themselves that are preserved following stroke,[72] or they might be helped to develop new self-narratives that emphasize positive aspects of their identity after stroke.[78,79]

Throughout the goal should be to rebuild a sense of identity based on new possibilities, rather than to restore the pre-injury self.[80] These approaches seem intuitively plausible, but caution should be exercised in
the absence of evidence of effectiveness. More research into these important aspects of adjustment after stroke is required.

Post-traumatic stress and post-traumatic growth

A account of psychological adjustment to stroke would be complete without some reference to post-traumatic stress and the somewhat paradoxical related phenomenon of post-traumatic growth.

Stroke bears the hallmarks of a traumatic event, being unexpected, uncontrollable, and potentially life-threatening\(^1\).\(^2\) and 10–31% of stroke survivors experience post-traumatic stress symptoms after stroke.\(^3\)\(^4\)\(^5\)\(^6\)\(^7\)\(^8\)\(^9\)\(^10\). Post-traumatic stress reactions can be debilitating and include: re-experiencing (spontaneous memories of the traumatic event, recurrent dreams related to it, flashbacks); avoidance (distressing memories, thoughts, feelings, or external reminders of the event); negative cognitions and mood (persistent and distorted sense of blame of self or others, estrangement from others, diminished interest in activities, inability to remember the event); arousal (aggressive, reckless, or self-destructive behaviour, sleep disturbances, hyper-vigilance).\(^11\)\(^12\)\(^13\)\(^14\)\(^15\)\(^16\)\(^17\) Post-traumatic stress can be assessed with the post-traumatic diagnostic scale (PDS).\(^18\)\(^19\)\(^20\)

It is important to be aware of post-traumatic stress since it has been related to non-adherence to medication and adverse clinical outcomes in heart disease.\(^21\)\(^22\)\(^23\) Merriman et al. (2007)\(^24\) found that symptoms
decreased naturally over time and therefore NICE guidance suggests that it is prudent to wait to determine if post-traumatic stress symptoms resolve before intervening. However, in cases where symptoms persist this NICE guidance recommends a course of trauma-focused cognitive behavioural therapy or eye movement desensitization and reprocessing.

The other side of the post-traumatic stress coin is the paradoxical but robust finding that posttraumatic growth (PTG) commonly follows trauma and can create ‘an increased appreciation for life in general, more meaningful interpersonal relationships, an increased sense of personal strength, changed priorities, and a richer existential and spiritual life’.

It represents an experience of profound positive change which goes beyond pre-trauma levels of psychological functioning, and is commonly found following illnesses including stroke. It can be assessed with the post-traumatic growth inventory.

The literature on positive psychology suggests that the kinds of positive emotions found in PTG confer benefits other than just ‘feeling good’, and include improved health, success, and social engagement. It has been suggested that PTG should be considered in clinical practice through increasing awareness of the potential for PTG, listening out for news of growth when working with stroke survivors, and using reflective listening skills to focus on narratives of PTG during therapy. There is also
emerging evidence to suggest that peer support, for example through peer support groups, can facilitate the development of PTG after illness.\textsuperscript{99}

Delivery of psychological care

When to assess psychological factors

Stroke services, with their emphasis on rapid response and early intervention for physiological damage, can facilitate a similar approach to psychological problems. But, while there are undoubtedly psychological conditions that are a direct and immediate consequence of stroke, such as communication and cognitive impairments, most psychological conditions are secondary consequences of the impact of stroke on a person’s experience, relationships, and life. As such they do not necessarily require the same emphasis on early assessment and intervention and can emerge at any stage after stroke. For example:

- Depression/absence of depression early on does not predict later depression (between one-3 and three-3 months after stroke).\textsuperscript{100}

- Anxiety occurs at different times after stroke\textsuperscript{35,41}; 40% of those who experience anxiety at some time in 10 years are not anxious at three-3 months\textsuperscript{35,54}.

- Cognitive function does not remain stable after stroke.\textsuperscript{101,40}
Patients often report that psychological problems start after discharge.\textsuperscript{102,111}\textsuperscript{111}\textsuperscript{111} In fact, in the case of cognitive impairment as well as mood, early assessment may not be predictive of subsequent psychological status and early screening may be counter-productive.\textsuperscript{102,104,121}\textsuperscript{121}\textsuperscript{121} and watchful monitoring of psychological state may be the optimal strategy.

**Models of psychological care**

Here are several models for the delivery of psychological care:

- *Stratified or matched care* is hierarchical, moving from low- to high-intensity interventions, but patients’ needs determine the initial intervention level.

- *Collaborative care* has four key elements: collaborative patient and professional identification of problems; collaborative goal-planning; self-management training and support to facilitate the success of interventions, behaviour change, and emotional coping; active follow-up.

- *Stepped care* involves all individuals starting treatment with the lowest intensity interventions (‘least intervention first’). The system allows individuals to be ‘stepped up’ to more intensive or comprehensive interventions if they do not respond to lower intensity interventions.
Stepped care has been recommended for stroke\textsuperscript{49,105,48}. In practice, stepped care requires a level 1 in which the whole stroke team, including ancillary staff, are trained in the management of basic psychological reactions. At level 2 assistant psychologists or other therapists in the stroke team, trained in specific psychological therapies, work under the supervision of a psychologist to deliver therapies for those patients who require more than level 1 support. Finally, at level 3 a psychologist or psychiatrist manages the more complex cases who do not respond at level 2. However, no stroke-specific evidence for the model exists. Although evidence from general mental health suggests that stepped care may be effective, even in this context the evidence is limited and inconclusive\textsuperscript{105,107,46}.

Moreover, it has been suggested that stepped care is:

- Overly rigid and prescriptive and does not allow patient choice about treatment.
- Psychologically harmful for those with more complex problems through the demoralizing experience of failure at the lower levels before being ‘stepped up’.
- Impracticable to implement in stroke services unless there is funding for: (a) psychological therapist training and time at level 2; and (b) for specialist psychology input at the higher level—which is only available at all in around
60% of stroke units in the United Kingdom, and even then, is usually part-time.\cite{10,11}

Approaches to meeting demand for psychological care

The issue of providing psychological care to meet the immense level of demand amongst stroke patients\cite{4} and to reduce the social and economic impact of psychological morbidity\cite{7,8} is challenging.

Clearly an initial step is to ensure that the guidelines for the inclusion of psychologists in the stroke team are followed.\cite{4,8,9,10} The British Psychological Society recommend one consultant and one junior psychologist and one assistant psychologist post dedicated to stroke in each typical general hospital catchment of 500,000.\cite{10,8} With these levels of staffing, a psychology service would deliver a net saving of around £39,000 to the NHS and adult social care over two years.\cite{8} This equates to a saving of around £10 million over two years for the NHS and social care across the United Kingdom, while improving services.

In planning the services that psychology provides, it is important to consider the very high level of need and demand. Based on a stroke prevalence rate of 2% and an annual incidence rate of 135 per 100,000 with 75% of patients surviving stroke and 60% having a carer, we can make some predictions for a catchment area of 500,000. There will be:
• 16,000 people affected by stroke (10,000 patients and 6,000 carers).

• 800 carers and survivors will be adjusting to a recent stroke (within one year).

Based on the prevalence figures available, within the 10,000 stroke survivors:

• 3,300 will have clinical depression at any one time\(^{13}\) and 5,000 at some point after stroke\(^{14}\).

• 2,000 will experience clinical anxiety at any one time\(^{34}\) and 5,800 at some time after stroke\(^{36}\).

• 3,800 will have other emotional problems (e.g. anger and frustration)\(^{13}\).

• 5,000–6,000 will have fatigue; about 1,900 will need help with it\(^{1,10,9}\).

• 4,000 will have significant cognitive problems\(^{13}\).

Even allowing for multiple problems in the same individuals, we can expect around 5,000 to have psychological problems at any one time.

If only 20% of the 6,000 carers have psychological problems at any time\(^{4}\) there will be 1,200 carers with psychological problems. So, in total there will be 6,200 people affected by stroke with psychological problems at any one time.
Service demands of this magnitude require innovative approaches, and it is arguable whether one-to-one therapy, except in the most serious cases, is a good use of psychologist’s time. In England government funding has been forthcoming for a scheme called ‘Improving Access to Psychological Therapies’ (IAPT). This uses a stepped-care approach (with elements of matched care for more serious conditions) and most treatment is provided by graduates who have been trained in low or high-intensity therapies based on the cognitive behavioural approach. It has been successful in several mental health contexts\textsuperscript{11,12} and it may be appropriate to refer some less severe stroke patients with less severe psychological problems into such schemes. However, the practitioners will have training in general mental health, principally in treating depression and anxiety with cognitive behavioural therapy and will not have knowledge of how to adapt approaches to the needs of the stroke population.

Another strategy is for psychologists to train and supervise other stroke team staff in the delivery of psychological care. This is the approach used in stepped care for stroke\textsuperscript{10} and has potential for the management of milder psychological problems at level 1 of stepped care. It may also be possible to develop level 2 of stepped care for more serious psychological problems that do not respond at level 1. But unless there is additional
funding for this it would deplete other functions of the stroke team if, for example, physiotherapists or nurses delivered psychological therapy.

Alternatively, psychologists may develop psychoeducation and therapy programmes that can be delivered in a cost-effective group format. Controlled studies have shown that group interventions after stroke can be both effective in terms of outcomes and reduced costs. In the current climate of economic stringency in healthcare, there is increasing interest in group delivery and it is finding application in areas other than psychology (e.g. physiotherapy). A promising therapy that can be delivered in groups is acceptance and commitment therapy, which is a transdiagnostic approach that can help both patients and carers with a range of different symptoms such as anxiety, depression, emotionalism, or low self-esteem. Acceptance and commitment therapy teaches patients that acceptance is sometimes a better strategy than struggling to ‘fix’ symptoms or to get back to how they were before the stroke. It helps them to combat thinking errors that make life seem bleak and empty and distorts their experience and mood. It teaches techniques such as mindfulness for dealing with stress and anger, as well as helping patients and their carers to identify their core values and translate these into goals for recovery and life after stroke. Variants of acceptance and commitment therapy have been shown to be beneficial in other health conditions, including epilepsy and for dementia carers and can be
delivered in a cost-effective group format and it has now been demonstrated to be effective in improving mood in a stroke population. Recently, forms of self-management for stroke, that require only limited staff time, have become popular and may encompass goal setting, skills training, action planning, and monitoring, and educational programmes with follow-up and support. Self-management has been defined as:

"The actions individuals and carers take for themselves, their children, their families, and others to stay fit and maintain good physical and mental health and maintain health and wellbeing after an acute illness or discharge from hospital." Self-management programmes empower stroke survivors and carers to improve outcomes, quality of life, and experience through education or training to improve skills, knowledge, attitudes, and access to resources. Self-management has a growing evidence-base in stroke. Interventions aimed at promoting self-management may take several forms and encompass aspects of many current intervention programmes such as education and provision of support workers. De Silva (2011) identified four key targets that self-management programmes should address; information provision, development of skills, promotion of self-efficacy.
and support for behaviour change. Lorig and Holman have complemented these proposals by identifying five key elements that facilitate self-management: problem solving; decision-making; resource utilization; forming partnership with healthcare providers; and taking necessary actions. Bolstering self-efficacy or confidence, is a core component of any programme designed to promote self-management.

One highly cost-effective self-management approach is book prescription or ‘bibliotherapy’. As noted above, there is a now a self-management book based on acceptance and commitment therapy specifically designed for stroke survivors and carers that is available through the books on prescription scheme in England [https://reading-well.org.uk/books/books-on-prescription/long-term-conditions/stroke/16840135](https://reading-well.org.uk/books/books-on-prescription/long-term-conditions/stroke/16840135). In addition, there are over a dozen books written by stroke patients or carers providing accounts of recovery from stroke. Many of those affected by stroke find reading these engenders hope and offers practical tips for dealing with the aftermath of stroke. National stroke charities in the United Kingdom and elsewhere publish inspiring patients’ and carers’ stories on their websites and may also provide booklists including stroke patients’ and carers’ books which are also available on their websites (e.g. The Stroke Association).

Other promising general approaches include the use of peer support; former stroke patients and carers join groups of more recent
stroke patients to offer psychological and practical support. In this way the experiential knowledge of the former patients, sometimes referred to as ‘experts by experience’, is harnessed in helping more recent patients to address their own psychological issues. Initial qualitative results suggest this is a feasible and helpful strategy, but properly controlled clinical trials are required as well as a greater theoretical understanding of the mechanisms and principles by which peer support achieves its benefits.

Summary

This selective overview has covered some of the most common psychological conditions after stroke. Others such as fatigue and cognitive problems are covered in other chapters. A range of screening and assessment tools exist for each of the conditions, as well as several approaches to treatment. Treatments for anxiety and depression have the best evidence-base, whereas treatments for other conditions tend to be based on expert opinion. When considering psychological conditions, it is important to realize that many develop some time after stroke. In addition, the high prevalence rate requires psychological treatments that can be delivered in a cost-effective manner.

References


What does confidence mean to people who have had a stroke?—a qualitative interview study. *Clin Rehabil* 2014;28:1125–35.


