

# Altered living: coping, hope and quality of life after stroke

Helen Western

## Abstract

This care study assesses how individuals who have had a stroke negotiate loss of functional abilities and disruption to life in order to achieve quality of life. Focusing on a particular individual in a rehabilitation ward, the article discusses how continued problem-solving and goal-setting is imperative to life satisfaction. However, this process is only possible when individuals feel that they have autonomy and mastery over their own existence, and so healthcare professionals must encourage them to make decisions about their care. By empowering individuals to do this they can achieve satisfaction by altering the values they ascribe to different areas of their lives.

**Key words:** Altered living ■ Autonomy ■ Coping ■ Hope ■ Quality of life

Stroke is the third most common cause of death in industrialized countries and is the most common cause of disability (Stroke association, 2007). There are 110 000 first strokes per year in the UK with 30 000 recurrent strokes (Bath and lees, 2000). Eighty per cent of stroke survivors live in the community 1 year after their stroke with one third of these individuals requiring the assistance of an informal carer (Smith et al, 2004). However, the decisions on where individuals are discharged to is based on their level of disability, neurological deficit and older age, as well as the support available at home (Leeds et al, 2004).

An individual has a stroke when the blood supply to part of the brain is suddenly interrupted (ischaemic stroke) (Figure 1), or when a blood vessel in the brain bursts (haemorrhagic stroke) (Figure 2). Brain cells die when they no longer receive oxygen and nutrients from the blood or when bleeding causes pressure to build up, and this affects the entire body. Commonly, individuals who have had a stroke experience hemiplegia (complete paralysis on one side) or hemiparesis (one-sided weakness), and they can experience uncontrollable emotions, cognitive and communication impairment, and pain (National Institute of Neurological Disorders and Stroke, 2007). Recovery from

stroke begins immediately and over months and even years with appropriate rehabilitation, different areas of the brain can learn to do the things that dead parts used to, such as recognizing sensory or motor stimulus from the use of effected areas (The Stroke Association, 2007).

Stroke causes a major upheaval in individuals' lives because any impairment that results causes disruption and often dependence in carrying out the tasks of everyday living, even if the severity of the stroke is not that great (Hanger et al, 2000). Despite this, Hallan et al (1999) found that attitudes to stroke varied widely among stroke patients, with few viewing disability as a fate worse than death. Many stroke patients would be reluctant to have high-risk interventions and would rather adjust their perception of a 'normal life' and cope with any disability associated with stroke (Hallan et al, 1999).

In this care study the author will not be focusing on the pathophysiology of stroke or looking at the mechanics of rehabilitation. Rather, the author will be discussing how individuals cope with a new way of being, in order to gain as independent a life as possible. For this reason the article will examine the idea of altered living as a new way of being with reference to patient Betty (see Box 1 and Table 1). (For the purpose of confidentiality the patient's real name has not been used.)

## Box 1. Care study

Betty is an 86-year-old woman who was admitted to the rehabilitation ward after having a front-parietal intracerebral haemorrhage. This left Betty with right-sided hemiplegia and dysphasia (Table 1). The event was very traumatic for Betty as she was alone in a bus station and had her purse stolen as she lay on the ground. Initially, it was thought that Betty would not make a very good recovery and that she may even die in the weeks following her stroke. Despite the poor outlook and the disabilities that Betty has faced since her stroke, she has impressed the hospital staff in her rehabilitation. This cannot only be attributed to good expert care, but sheer determination and a positive attitude on her part. Betty has continued to make great progress and the professional team has delayed her discharge to a residential care home because it is evident that she is still improving. From the initial prognosis of dependency, Betty has actively gained many skills and re-educated her body so that she can cope with as little help as possible when she is discharged.

Helen Western is Student Nurse, Department of Health and Human Sciences, University of Essex, Colchester, Essex

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**Table 1. Betty's case**

- Eighty-six-year-old female who lives alone
- Admitted to rehabilitation ward from stroke ward
- Has a supportive family who visit her regularly
- Suffered a front-parietal intra-cerebral haemorrhage
- Has severe right-sided hemiplegia
- Dysphasia makes communication challenging
- Eats independently with the aid of modified crockery and utensils
- Currently requires moderate assistance to fulfil hygiene needs
- Learning to mobilize with the aid of physiotherapy and occupational therapy
- Has a positive and determined attitude to challenges
- Enjoys interaction with ward friends, staff and relatives
- To be discharged to a residential care home
- Residential care home proactive in fulfilling the criteria of Betty's care plan

**Coping**

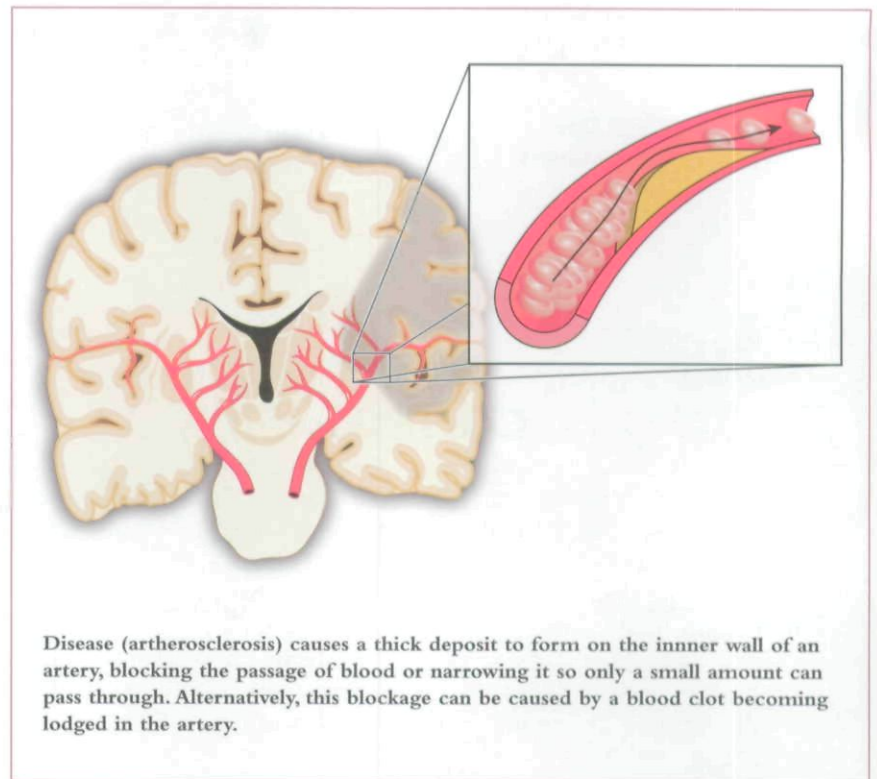
Coping is an abstract concept as it refers to how individuals make meaning and values (Pound et al, 1999), and can be seen as a way of problem solving (Bluvol et al, 2004).

The cycle of coping (*Figure 3*) is drawn from Kübler-Ross's (1969) Grief Cycle and represents the journey of coping observed in patients while on placement in the rehabilitation ward. As in the Grief Cycle (Kübler-Ross, 1969) it seems common for individuals to become stuck at a particular stage when they are negotiating change, or they often appear to move on a stage before they have fully completed the previous one. This means that individuals return to ways of thinking and emotions without ever truly developing their coping skills. For example, after an event occurs it is important that individuals recognize and accept any loss, in order for them grieve. Grieving the loss is significant because it allows the individual to realize how it will impair their quality of life and reveals the problems that they will face. Once they have completed this stage, individuals can begin to actively problem solve and negotiate what they can realistically do and what they cannot, leading them to modify their goals or find alternative ways of achieving them. When this stage is completed individuals reassign their values, meaning that they negotiate what is important to them now and what is less important. For example, achieving a goal becomes more important than the means to achieving it. Becoming stuck in any of these stages means that an individual's sense of quality of life is reduced.

According to Weiten and Lloyd (2006) individuals cope with stressful situations by using one of three strategies:

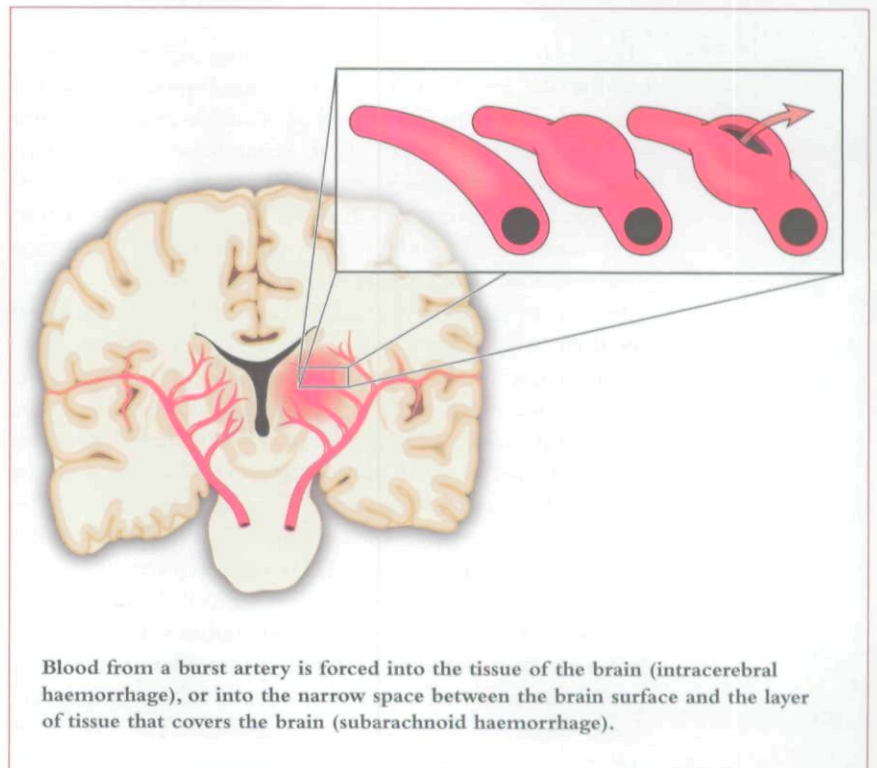
- Appraisal-focused strategies: how individuals change the way they think about things by denial of the issue or distance from the issue. Here they modify their goals and values and use coping mechanisms like humour to change they way they think about a problem.
- Problem-focused strategies: how individuals attempt to deal with the root cause of the problem by acquiring knowledge, learning new skills and modifying how they live to manage their problem.

*Figure 1. Ischaemic stroke.*



Disease (atherosclerosis) causes a thick deposit to form on the inner wall of an artery, blocking the passage of blood or narrowing it so only a small amount can pass through. Alternatively, this blockage can be caused by a blood clot becoming lodged in the artery.

*Figure 2. Haemorrhagic stroke.*

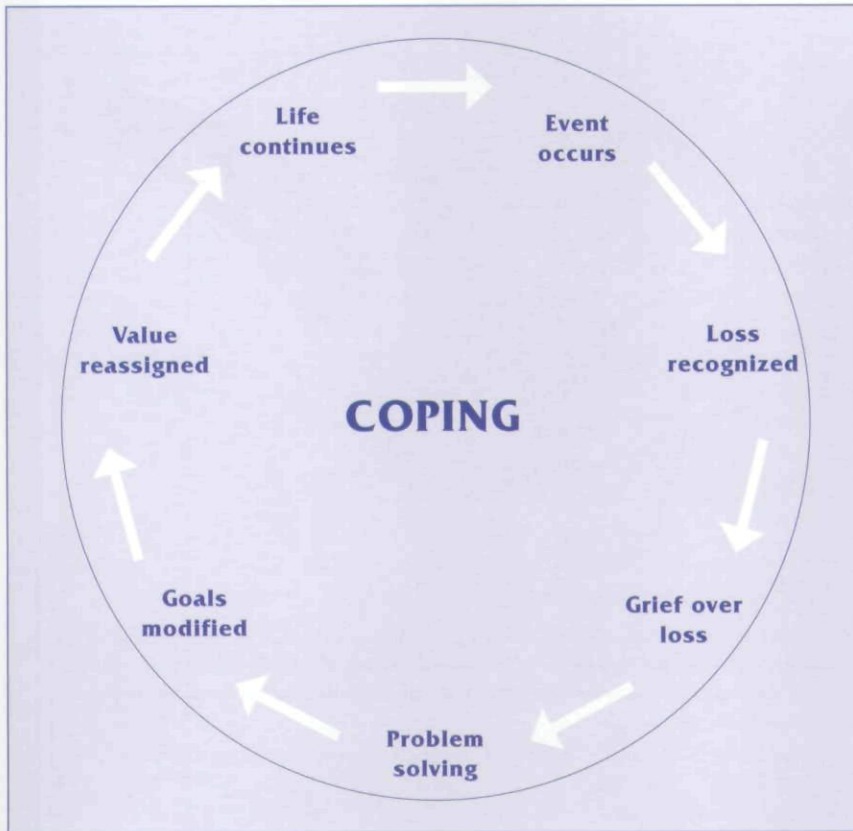


Blood from a burst artery is forced into the tissue of the brain (intracerebral haemorrhage), or into the narrow space between the brain surface and the layer of tissue that covers the brain (subarachnoid haemorrhage).

- Emotion-focused strategies: the management of emotions caused by the problem involving distraction, venting of feelings, managing anger and relaxation strategies.
- In Betty's case she appears to have dealt with the disabilities by using an appraisal-focused strategy. She has been an active participant in her rehabilitation by not accepting the things that she cannot do, and pushes herself to learn new



Figure 3. Cycle of coping. Adapted from Kübler-Ross's (1969) Grief Cycle.



strategies to cope. This is common among patients who have had a stroke who do not seem to accept limitations that the healthcare team informs them of (Folden, 1994). The aim of healthcare professionals is to rehabilitate individuals to cope in the outside environment with their new limitations, whereby patients aim to return to the life they had before their stroke and set their goals higher than is expected (Hafsteinsdóttir and Grypdonck, 1997).

Pound et al (1999) found that individuals actively negotiate new ways of living by organizing support and using imaginative strategies to deal with day-to-day life. It seems unusual then that individuals who have had a stroke are often discussed in negative terms as 'victims'. This term leads us to believe that individuals who have had a stroke are somehow passive receivers of healthcare. This may be because the perception of individuals who have not had a stroke is different to those who have. For instance Hanger et al (2000) found that individuals who had not had a stroke thought that death was favourable to disability. However, for those who had a stroke the views were somewhat different. This is because individuals who have had a stroke and face disability adjust their perceptions and learn to cope, preferring disability to death (Hanger et al, 2000).

As we all seem to cope differently, being perceptive and understanding of the different ways in which individuals do cope would help healthcare professionals to develop strategies to support their patients if they get stuck at a certain point in the cycle of coping (Figure 3). This could be anything from assisting individuals to realize loss, to accepting grief as a natural and necessary reaction, or facilitating the means to solve problems and offering

alternative solutions. By supporting individuals, rather than leading them, healthcare professionals can help their patients to realize their limitations, consolidate loss and empower them to plan for a future that will be satisfying to them. This makes the questions that healthcare professionals need to ask not 'what are we going to do for our patient?', but 'what does our patient want to do?' and 'how can we support them in achieving this?'.

### Hope

The concept of hope can be characterized by an uncertain, but positive, desire to achieve goals that allow individuals to adjust and move goal posts when transformations occur. Hope is important to recovery as it gives individuals the motivation and strength to achieve their goals. Having hope means that an individual is on an ever changing journey towards something. The quality of individuals' lives improves as they focus on getting somewhere. However, when there is no hope of further recovery individuals feel like they have come to the end of the journey and can only focus on problems in the here and now and so quality of life is impaired (Bluvol et al, 2004).

Hafsteinsdóttir and Grypdonck (1997) concur, offering that individuals who have had a stroke often experience depression and loss of hope because they experience humiliation and loss of control. Individuals feel that they are regaining control of their life as they progress and this continues as their rehabilitation continues. However, in periods when recovery plateaus or stops, feelings of dependence and loss of hope can return. Loss of control can be magnified by dysphasia that stops the already disempowered patient from communicating their needs and desires (Hafsteinsdóttir and Grypdonck, 1997).

Empowerment then can be seen as a means of helping individuals to realize and achieve their goals. However, this should not focus on the expertise and knowledge of healthcare professionals, but healthcare professionals should work in more open and responsive ways and assume that they do not always know what is best for everyone (Pease, 2002). This means that empowerment should not be something that is done to the patient, but something that patients to take for themselves.

The person-centered focus of the rehabilitation ward has enabled Betty to take control of her life meaning that she can consolidate loss and hope for the future. By accepting her disabilities, Betty has not given up hope of regaining some function. She deals with the grief of her lost functional abilities by continuing the journey of rehabilitation. She obviously becomes frustrated when she cannot communicate, but instead of withdrawing from conversation she makes regular attempts to speak to her ward mates and staff. Her speech improves daily. This improvement is encouraging. However, Betty may find it difficult to cope if her rehabilitation plateaus and so this hopeful and determined attempt to recover may be her way of coping. It is possible that Betty will continue to hope for further progress even if none is expected, but as long as she still accepts what she cannot do in the present, this is favourable to a state of hopelessness and depression.



### Quality of life

Quality of life can be defined as an individual's contextual perception of self in relation to their social field and what they wish to achieve (Bluvol et al, 2004). The World Health Organisation (WHO Quality of Life Group [WHOQoL Group], 1994) defines quality of life as:

**'An individual's perception of his/her position in life in the context of the culture and value systems in which he/she lives, and in relation to his/her goals, expectations, standards and concerns. It is a broad-ranging concept, incorporating in a complex way the person's physical health, psychological state, level of independence, social relationships, and their relationship to salient features of their environment.'**

This definition attempts to umbrella a vast amount of concepts. The WHOQoL Project has devised tools to assess quality of life that it says are sensitive and valid cross-culturally (Centre for Participant Reported Outcomes, 2007). The WHOQOL-BREF considers 24 facets considered to contribute to quality of life and groups them in four domains and is intended to be self-assessed by the individual or with the assistance of an interviewer. The four domains are: physical health, psychological, social relationships and environment. The scoring of each of the 24 facets is intended to demonstrate in which of the domains an individual is experiencing quality of life impairment and to what extent (WHO, 1996). However, tools like the WHOQOL-BREF can be too limited to assess individual's actual perception of the quality of their own life. This is because it asks individuals to express their thoughts and feelings in terms of numbers rather than allowing them to communicate their experiences in their own words, leading to a loss of context and quality.

Individually, healthcare professionals should take time to reflect on their own perceptions of what they think contributes to quality of life. In doing this they may realize that the values that they hold are completely individual to themselves and are only appropriate until their life changes in some way. Understanding this can help us to engage with our patients in ways that will make their goals and achievements our goals and achievements, and not the other way around.

Jaracz and Kozubski (2003) found in their study that quality of life appears significantly reduced after stroke. This did not mean that individuals were not satisfied with their life; in fact, in certain categories, individuals reported that they were satisfied or very satisfied, signifying that they had found a balance between the things that they can do and those that they cannot. This means that individuals can still enjoy life, adjusting their expectations as their corporeal reality changes (Jaracz and Kozubski, 2003).

However, Leeds et al (2004) found that although participants in their study all had a low level of continuing rehabilitation, those who were discharged to their own homes had more improvement in the activities of daily living and seemed to have a better quality of life than those individuals

who were discharged to a care home. This is because individuals discharged to care homes had higher incidents of depression due to lack of control and independence, which is characteristic of a caring environment (Leeds et al, 2004). There seems a need for the transition between hospital and residential care planning to be seamless, because a sense of independence and psychosocial wellbeing is evidently as important, if not more important, than physical disability. This means that the need to be an autonomous social human being must be recognized as central to a good quality of life (Jaracz and Kozubski, 2003) (achieving quality of life as changes occur, *Figure 4*).

Betty Sky is eventually to be discharged to a residential care home because it will be impossible for her to manage on her own. She is positive about this, and the care home has liaised with the team on the rehabilitation unit in order to offer seamless care. The care home is being proactive in enabling Betty to be as functionally independent as possible and has sought advice from the occupational therapist who has advised the home of any devices that need to be in place to facilitate this. Before Betty is to be discharged the ward occupational therapist will visit the home to reassess the facilities and to hand over the plan of care. It is hoped that Betty will not become a passive individual in her new home as this may lead her to feel dependant, and her quality of life will be impaired.

### Conclusion

From the reading for this care study the author realized that care of individuals who have had a stroke must be a team activity. Without one aspect of care all the others become impoverished (Johnstone, 1987). Included in this team is

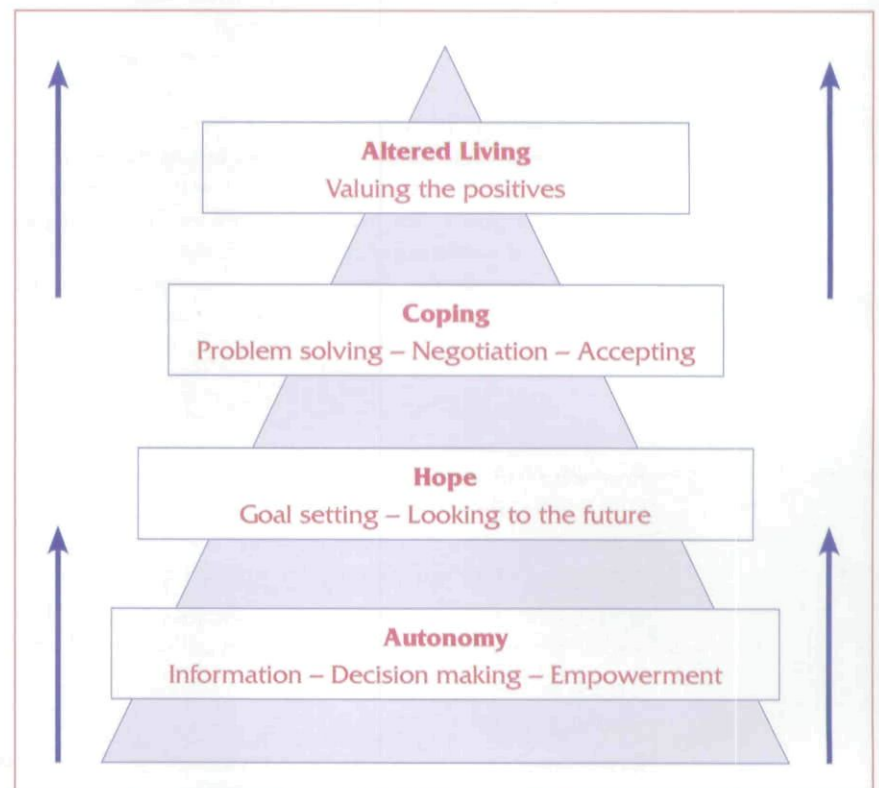


Figure 4. Achieving quality of life as changes occur.



the individual, who must be involved in all aspects of their rehabilitation in order to give them independence. For this reason patients must be empowered to take control (Hanger et al, 2000) and individualized plans must be made where the functional factors of recovery are married with the psychosocial needs of the individual (Hafsteinsdóttir and Grypdonck, 1997).

Smith et al (2004) call for a nurse-led stroke service that is accessible for patients and carers and offers efficient and clinically sound care and advice to combat barriers to help. Although Lincoln et al (2004) found that having this kind of care did not improve the physical and functional outcomes, patients did feel more emotionally supported which is important to promote individuals' wellbeing.

More vigorous interventions and care of individuals who have had a stroke may not necessarily help them to recover sooner or further (Rodgers et al, 2003). It seems that how far an individual will progress is mainly led by them. Apart from the functional disabilities and illness an individual may acquire and the care they receive, the individuals' attitude and how they tackle specific problems predicts how well they will do.

It is common for healthcare professionals, especially nurses, to adopt a caring role where we do things or make decisions for our patients because we feel we are being kind, saving time, or minimizing conflict by doing so. This approach is not appropriate for all patients. Indeed if it is possible that our patients can do, or learn to do these things, we are doing more harm than good by taking this away from them. Being in partnership with patients means that we become their advocate and walk along side them through their difficult journey, acting as a support and facilitating action. By taking this approach we allow individuals to feel empowered to take control of their life as it changes.

By accepting their altered body and creating strategies to cope with their new self, individuals can enjoy life regardless of what quality of life scales identify. It is true that Betty will never again be fully independent in the functional sense, but she has the ability to make choices and with the assistance of tools, mechanisms and healthcare workers, she can live an independent life that has unlimited possibilities for her.

Betty is fortunate in that, although she may be more functionally impaired than many patients on the rehabilitation

ward, she remains positive and determined. Many individuals who have had a stroke are not able to negotiate loss and impairment because of depression and grief and should be helped to overcome this and accept their new way of living not as half living, but altered living. BJN

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### KEY POINTS

- Quality of life is a highly subjective concept based on an individual's sense of autonomy and pleasure, and cannot be measured in terms of functional ability.
- When faced with disruptive life events individuals negotiate new ways of being and cope with limited functional abilities through a process of problem-solving and goal-setting.
- Having hope is as important to individuals' quality of life as functional ability. Hope allows individuals the continued motivation to build and rebuild their lived experience when changes occur.
- Hope can be diminished when individuals feel they have no autonomy and little mastery over their own existence, leading to poor quality of life.
- Allowing individuals to empower themselves facilitates a sense of mastery which will allow them to assign higher values to the things that they can do, meaning that altered living can be quality living.

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