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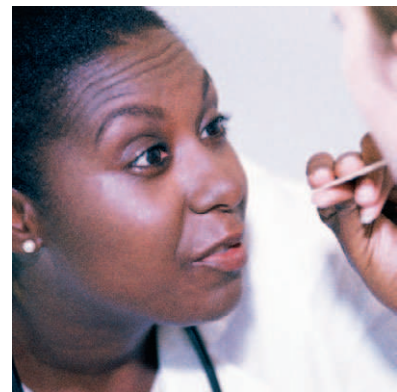
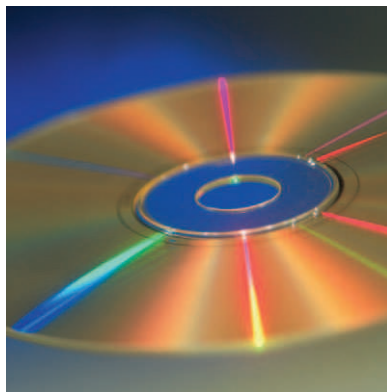
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Life After Stroke: Reconstructing Everyday Life



Helen Alaszewski, Andy Alaszewski,
Jonathan Potter, Bridget Penhale
and Jenny Billings



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Life After Stroke: Reconstructing Everyday Life

Executive Summary

Introduction

The project was funded by a grant from the Nunnery Field Trust Fund. We were very conscious that most research had emphasised the clinical dimensions of stroke and we wanted to do work that enabled survivors to speak for themselves and to use their accounts to enhance understanding of their experience of stroke and how services could be developed to improve their experience. We interviewed a number of stroke survivors in East Kent, their carers and professionals involved in their care support. We have changed any names in our report to protect individuals' identities.

Context

Stroke can have a major impact on a person's life. For example a stroke may leave an individual with residual disabilities such as difficulty with walking or speech that creates considerable challenges to everyday life. While quite a lot of research has been done on how to prevent and treat stroke, comparatively little research has been undertaken on the ways in which individuals respond to strokes and how they reconstruct and manage their everyday lives after a stroke. In this study we seek to understand how individuals identify and manage the challenges and opportunities of every day life and the ways in which professionals can help their development. We are particularly interested in how individuals identify and manage risk, however, our previous research indicated that risk tended to be identified with hazard and danger. We therefore expressed risk as part of everyday life and we provide a general account in this report. We plan to specifically highlight risk in a forthcoming paper.

Aims

The study aims to:

- provide insight into the ways in which people who have experienced a stroke, carers and professionals define the opportunities and challenges of everyday life.
- enhance understanding of the strategies which these individuals and their carers develop to manage such opportunities and challenges.
- identify how professionals and support workers can develop more effective ways of supporting the rehabilitation of individuals who have had a stroke.

KEY FINDINGS

Survivors and their strokes: life changes

- Stroke is a catastrophic event that impacts on all aspects of a person's being, forcing individuals to change their life-style and reconstruct their identity.
- Stroke survivors felt that stroke was unique. Strokes happen suddenly, are often hugely incapacitating and recovery is often a long-term process, even for those people who consider their stroke to be mild.
- Stroke survivors experience physical, psychological and social challenges that are interrelated and impact on each other.
- Survivors may experience psychological challenges such as increased anxiety, fear of having another stroke, loss of confidence and depression. These are often invisible to other people but are major disabling factors in regaining independence and may make people reluctant to go out alone or to go back to work.
- Survivors may also suffer from memory problems, which impact on the ability to perform daily living activities. Loss of control over emotion and feelings of frustration are also common features.
- The residual physical effects often leave survivors disabled, resulting in an altered body image and a far more restricted lifestyle. Speech and language can also be severely affected.

- Survivors may experience extreme fatigue that can affect motivation for rehabilitation and getting back to normal.
- Social life and relationships, both within and outside the family are changed. Partners and children become carers, role reversal often occurs and the difficulties of getting out make social relations and activities hard to continue.

Survivors: getting back to normal

- The stroke survivors set themselves goals and developed strategies to achieve these. For some, these goals were expressed in general terms but other were very specific. Achievement of one goal could often fulfil others, such as getting to the toilet independently, reduced carer stress and burden, reduced dependence, improved self-esteem.
- *Personal Goals* inside and outside the house often related to mobility and getting about independently. Inside the home survivors strove to be mobile and to perform their own personal care and to regain skills and activities such as cooking or gardening.
- Going back to work was important for some of the younger people but they often had to accept shorter hours or a less demanding position in order to succeed. Driving was also seen as an essential skill and loss of this was a blow to independence and identity.

continued...

KEY FINDINGS (CONTINUED)

- *Strategies* Sometimes people used short-term goals to reach their long-term ones, such as breaking a journey up into stages or using a taxi to get to the shops to ensure sufficient energy to do the shopping.
- Survivors often went out accompanied until they gained enough confidence to go out alone.
- Inside the house survivors developed creative strategies to regain former skills, to reduce dependency and minimise disability.
- As well as practical solutions, survivors employed a range of psychological strategies to motivate themselves and make their situation appear better. For example many survivors stated they were lucky, thus comparing themselves with others who were more severely affected.

Professionals view of stroke

- Professionals involved in the care and support of people who have experienced stroke and their carers accepted that stroke has a major impact on all aspects of life and identity.
- Over half of those interviewed explained recovery for the survivor in terms of the model of bereavement and loss, a psychological model of stages of grief that individuals go through after a severe loss.

Professionals and rehabilitation

- Professionals viewed the return to valued activities such as getting about independently, going back to work, return to social activities and hobbies as key aspects of rehabilitation and a return to normal life.
- Two practitioners suggested that adopting the 'stroke identity', by going to clubs and related groups and becoming actively involved was an alternative way of 'adjusting' to stroke and re-constructing individual identity.
- Professionals defined rehabilitation as a process of assisting individuals to reach an optimum level of independence.
- Some practitioners framed their definition in clinical terms that emphasised function. Others used a 'person-centred' definition that emphasised

the social and personal aspects. Professionals negotiated goals with clients and broke these down into small, achievable and incremental units.

- Relationships worked well where the goals were mutual, but when goals were considered by the professional to be unrealistic, this hampered the relationship and also impacted on progress towards recovery.
- Practitioners sought to achieve a balance in goal setting, trying to be realistic without discouraging. They felt that those stroke survivors with carer support often recovered better as did those with more demanding personalities.
- The majority of professionals believed that stroke services for younger people were inadequate.

Survivors' and carers' views of stroke services

- The majority of those interviewed were positive about their initial hospital care, particularly if they had been admitted to a designated stroke unit where they benefited from the assessment and skills of the multi-disciplinary team.
- Survivors and carers also felt well supported during the intensive short-term intervention by the community rehabilitation team or CART Team. However, not everyone was eligible for their support and lack of long-term support resulted in users and carers feeling isolated and abandoned.
- The Stroke Family Support Worker, provided home visits for an unlimited period of time, received much positive comment, particularly from younger stroke survivors who had missed out on specialised hospital care. The worker helped them to normalise their experience.
- The Stroke Discharge Nurse also provided care in the community and a coffee morning she established for survivors was much appreciated and seen as a way of keeping contact with others.
- In some cases, rapid discharges with a lack of support services caused considerable added stress and anxieties for service users and carers as did lack of information both on stroke itself, possible recurrence of the condition and carer education.

Methods

The study built up a picture of the ways in which individuals and their carers perceive and manage opportunities and challenges from a number of sources:

Current research evidence

The research team undertook a review of current research evidence on individuals' response to risk.

A naturalistic study

A naturalistic study of individuals who have been affected by a stroke, their families and professionals who provide support in the community. The research team invited individuals affected by stroke and those involved in providing support to take part in focus groups or individual interviews.

Case studies

A small number of individuals who have experienced stroke were invited to keep a diary of daily events and decisions over a specified period of time.

Outcomes

Participants in the study will be sent a summary of the main findings. The overall findings of this research will be made widely available through publications. It is anticipated that the evidence from this project will improve the overall quality of support provided for people who have experienced strokes and their carers enabling them to maintain their independence.

Suggestions for further research projects

Our study was a pilot study that provided important findings on the ways in which stroke survivors, their informal and formal carers manage the consequences of stroke. There are a number of ways in which this research can be taken forward:

- There is an urgent need for more qualitative work using a person-centered approach which will enable us to gain greater insight into the ways in which individuals respond to stroke and how services can help them.
- While 'one-off' studies can provide insight, it is important that they are complemented by longitudinal studies that show how processes develop.
- While our study has provided some insight into the ways younger people adjust to strokes, given the uniqueness of their situation, it is important that they become the focus of more research.
- Epidemiological evidence indicates that individuals of African Caribbean descent have a higher risk of stroke, however, as far as we know, no qualitative research has explored the distinctive issues affecting such survivors.

1

Life after stroke: evidence from the literature

1.1 Introduction

People who have experienced stroke face a future that is characterised by uncertainties about possible recurrence and about how much recovery they will achieve (Burton, 2000; Ellis Hill, 2000). Current policy on stroke and the majority of the research focuses on prevention and treatment and studies that examine rehabilitation are mainly written from the professional perspective. Few studies have been conducted which explore how people cope with their anxieties and reconstruct their lives following stroke. In this chapter we look at the current literature relating to post-stroke experience.

1.2 Context

Stroke is a major cause of long-term disability amongst adults and older people and a significant factor in the increase in disability associated with ageing. The incidence of strokes increases with age from 2.0 per 1000 for ages 55 to 64 years to 20 per 1000 for those over 85 years (Department of Health, 1999). The prevalence of people who have survived a stroke is 5 to 7 per 1000 population, with at least 50% of those people left with physical disability and many people experiencing a degree of memory impairment (Rudd et al, 1999). While cerebro-vascular accidents can vary from relatively minor events such as transient ischaemic attacks to major life threatening strokes such events have major impact on both the individual and their carers that may include psychological trauma as well as varying degrees of mental and physical disability (see Anderson 1992). However there has been relatively little research into the ways in which people who have had strokes and their carers respond to and manage stroke. Professionals have concentrated on developing effective forms of diagnosis, treatment and support but less attention has been paid to the longer-term support. Little attention has been given to the strategies which people who have had strokes and informal carers develop to manage their every day lives and the ways in which the actions of professionals support or undermine these strategies.

This relative neglect of the longer-term impact of stroke and how effective rehabilitation and supportive care can be provided is evident within current policy. While strokes are identified as a key area for action within the National Service Framework for Older People

(DOH, 2001) given the current evidence base, the emphasis is on prevention and initial treatment with a specific standard of care to reduce the incidence of stroke and prompt access to integrated services for those who have had a stroke. This project is designed to rectify this imbalance by providing an understanding of how people who have experienced stroke manage their lives, the coping mechanisms that they and their carers have developed and the ways in which professional intervention can support such strategies.

1.3 Current approaches to research

The current literature on post-stroke experience is dominated by a service-orientation. The main emphasis is on identifying and evaluating how services especially hospital services respond to and manage stroke (see for example Kelson, Ford and Rigge, 1998 and Clark and Smith, 1998). Even the studies that have examined how people who have had strokes and their carers respond to and manage stroke have been conducted very much within a 'professional' framework. For example studies on older people who have had strokes have explored their and their carers' satisfaction with services they received following the stroke (see for example Wellwood, Dennis and Warlow, 1995, Scholte op Reimer, de Haan and van den Bos, 1996 and Pound, Tilling, Rudd and Wolfe, 1999). Within this framework individuals are seen as users of services and the main emphasis is on their experience of and satisfaction with services.

The limitation of many of the studies of people with disabilities living in the community is that they use survey methodologies to identify need (see for example Wilkinson et al, 1997). This type of research not only emphasises the deficits and difficulties which individuals and their carers' experience, it also tends to provide a static picture. An alternative approach is to use naturalistic methodologies which access survivors and carers experiences. Only exceptionally have researchers explored the longer term implications of strokes. For example Baldock and Ungerson's study (1994) examined the impact of stroke on older people in terms their experiences of hospital, discharge, service provision at home and the ways they adapted after their stroke. Wade, Leigh-Smith, and Langton-Hewer (1986) examined the impact of the 'survivors of stroke' on their carers. Studies of longer-term support have often emphasised the difficulties experienced especially the 'burden of care' placed on informal carers. Such research has undoubtedly drawn attention to the need for continuing care and support. However such studies tend to miss the strategies by which individuals and those caring for them reconstitute and normalise their every day lives by creating mechanisms to manage its uncertainties (see for example Voysey's account of parents caring for children with severe disabilities, 1975).

Studies that focus on how vulnerable individuals and their carers cope tend to find that carers have active and creative strategies for managing every day life (Pound, Gompertz and Ebrahim, 1999). Buri and Dawson examined the ways in which carers support individuals who are vulnerable to the risk of falls. They found that carers:

Used multiple strategies to avoid falls and maintain their precarious position on the brink of chaos, by creating order in their lives. They selectively used *information*, exercised *control*, *redefined normality*, *reconstructed* their *self-identity* and the relationship with their impaired relative. (emphasis in the original, 2000, p. 283)

There is a limited body of research that analyses the experience of stroke from the perspective of the survivor. Anderson (1992) in the Greenwich stroke study examined how stroke changed the lives of individuals and their carers. He interviewed 173 people three times over an eighteen-month period recording chronologically the experience of stroke and the physical, psychological and social impact on their lives. Anderson stresses the need for more research to be conducted from this perspective to inform professional practice.

1.4 Emerging insights into the implications of strokes

While more research is needed to fully explore the individual's perspective, it is possible to identify some emerging themes from the current literature. It is clear that a stroke is a major life event or *defining moment* for individuals who have experienced them. They challenge and *undermine their basic trust* in the world and make them rethink who they are and what they want. Rehabilitation is a complex journey in which individuals *set their own goals* and explore, often slowly and painstakingly, ways and *strategies* for achieving them.

Defining moments and uncertainty Survivors of strokes are increasingly recording their own experiences (see McCrum 1998 and Bauby 1999 Jelks 2000) both in books and by telling their stories using support networks on the Internet. Although there are hi-tech machines to diagnose stroke and medications and life-style changes that can help to prevent its occurrence, doctors are unable to give an accurate prognosis either of the likelihood of another stroke or of the degree of recovery.

Burton (2000) found that each new stage in the treatment, especially discharge home, left survivors feeling unable to plan because of the uncertainty. Thus the survivor is left as unpredictable world that is full of uncertainties and where they can no longer take for granted their own identity and role. For example Nilsson et al (2000) concluded that dealing with the aftermath of stroke 'seemed to embrace and challenge the whole of the individual's 'being''. McCrum describes stroke as an event which goes to the centre of who and what you are, 'the You-ness of you' (p. 172).

While stroke survivors acknowledge the impact which stroke has had on their skills and abilities, they tend to emphasise the social implications of these changes, i.e. the threat which stroke poses to their personal identity. For example Jelks (2000) reflects in great detail upon the experience of having a stroke and then about how he reconstructs his identity:

One of the greatest needs a stroke victim has, after the reality of having part of his body paralysed has set in, is victories — successes. The victim, up to this point, has been completely absorbed in a world made up of things he cannot do. Continuation along this line leads only to frustration, despair and possibly even worse. The victim's world must be changed. At this point his self-esteem has hit rock bottom. When I was at this point I felt I would go crazy if I did not find something I could do as well as or better than the next man. And I might have if I had not succeeded at a task I set for myself.

Dowswell et al (2000), investigating recovery from stroke, found that people measured recovery in terms of their pre-stroke lives and had to adjust to accepting that they will never be the same. Almost all the participants in their study related how the stroke had drastically changed their lives, even those whose stroke had been mild and who had regained full physical function. McCrum reflects on the loss of a former self and the efforts to stick the pieces back together:

the cruel fact is that this former self is irretrievably shattered into a thousand pieces, and try as one may to glue those pieces back together again, the reconstituted version will never be better than a cracked, imperfect assembly, a constant mockery of one's former, successful individuality' (p. 151).

He also stresses the importance of setting oneself short-term achievable goals rather than concentrating on losses and deficits.

Personal goals Reviewing the literature on people's experience of stroke, Hafsteinsdottir and Grypdonck (1997) concluded that survivors set their own goals and measure their recovery in terms of returning to activities which they value. They stress the need for more descriptive studies, particularly those which are conducted some months after the event. Burton (2000) tracked six people over a year who had experienced stroke and describes how re-engagement in the social world is more important to people who have survived stroke than physical function. He suggests that:

Stroke is an intensely personal experience, involving the rebuilding and restructuring of an individual's world ... The social context of recovery was enabling participation in the social world through adaptation and the development of coping skills, rather than improvement in discrete physical function alone.

As professionals providing rehabilitation programmes tend to focus on improved physical function and set goals that relate to achievement of these, they may not recognise or acknowledge that individuals who have experienced a stroke may have different goals and therefore different ways of assessing their own progress. A number of studies have identified a discrepancy between professional and user perspectives in relation to goal setting (see for example Lawler et al, 1999 and Pound and Gompertz, 1998). Recovery of function is of paramount importance for the professional but for the individual who has had a stroke it is only a means to an end. Such survivors are usually more concerned with the ways in which recovered functions enables them to perform valued social activities which in turn are important for their

sense of self and self esteem. Stroke survivors feel that professionals tend to neglect these aspects of their experience (Sabari et al, 2000). Dowswell concluded that current outcome measures are too simplistic to ‘capture patients’ and caregivers experiences’ because of the complex nature inter-related factors.

Strategies Studies of people who have experienced stroke suggest that they develop their own strategies for overcoming challenges. Pound et al (1999) identified five ways in which people respond actively to stroke, by: mobilising informal social support; creating new ways of doing things; taking things more slowly; beginning the process of relearning; exercising; ‘covering up’. They suggest that people who had experienced stroke developed creative ways of managing their lives by devising and employing new strategies to enable themselves to do things. They maintain that far from being victims they employ active strategies to manage their lives. Mr Jelks, who tells his ‘story’ on the internet explains that to stop himself thinking about all the activities he can no longer do he sets himself a task, to plant ten tomato plants, and then breaks activity down into small achievable units. Using his spade as a crutch he dug a hole a day — half in the morning and half in the afternoon. He recounts details of achieving competence at everyday tasks and the importance for his self-esteem.

I can put on my socks (if they have wide tops) as fast with one right hand as I formerly could with both hands — but it took me five months to perfect it. It took ten months to learn how to tie shoestrings, and I still don’t do it well. But I can do it now, and I have regained one more small portion of control, of independence. The road from total paralysis to minimum function is a long and arduous one. It is fraught with defeats, victories, and many innovations — mostly innovations. It seems to me that it is the simple things that are the most perplexing. For instance, you are right-handed, with a left side paralysis, and you are sitting on the john. You find the toilet tissue roll is on the left side. How do you get to it? Even more exasperating is to find it on the right side. You grasp the tissue with your right hand but how do you tear it off? You pull it and it keeps rolling off until the floor is full. Innovation 1: step on this tissue with your good foot and tear with your good hand. Innovation 2: using your good right hand, put the tissue between your teeth and yank downward. Do not drop the tissue from your mouth or you must start all over again. Innovation 3: uses less tissue.

Using the Internet website he describes his personal strategies and passes them on to other visitors to the site.

1.5 Risk in everyday life

The accounts which stroke survivors give can be seen as accounts or narratives which help them explain, make sense of and control the situation. Williams in his analysis of individuals’ accounts of chronic illness argues that such narratives can be seen as:

a process of continuous accounting whereby the mundane incidents and events of everyday life are given some plausible order.

Giddens argues that such narratives are an essential mechanism by which individuals establish and maintain their identity in modern society (Giddens, 1991, p. 243).

However not only have researchers neglected the ways in which individuals perceive and manage the uncertainties of their lives, so also have service providers. Ryan has examined the ways in which individuals with mental health needs and their carers managed the uncertainties and challenges of everyday life (Ryan, 2000a and 2000b). He identified a number of strategies ranging from fatalistic passivity through techniques for minimising harm to active preventive strategies. However he could find little evidence that professionals were aware of user or carer strategies or had assisted or influenced users and carers in the development of such strategies. Buri and Dawson, in their study of carers supporting vulnerable older people concluded that professional interventions designed to help carers should be based on a collaborative approach and that professionals should 'discover individual carers' strategies' for managing risks (2000, p. 291). Our own work with vulnerable adults and their carers (see Alaszewski, Manthorpe and Harrison, 1998 and Alaszewski, Alaszewski, Manthorpe and Ayer, 2000) confirmed that every day life posed considerable challenges to people with disabilities which they sought to actively manage. In some circumstances they experienced professional interventions as a risk in itself which needed to be managed.

While the experience of each stroke survivor is unique, there are common themes within their narratives. It is clear that stroke survivors see their stroke as a defining moment, an event which changes a person's life and after which nothing is the same. It can be seen as a 'fateful moment':

Fateful moments are highly consequential for a person's destiny (Giddens, 1991, p. 112)

Giddens argues that while the individual concerned has to deal with the consequences of a fateful moment, that as in the case of a stroke, experts such as medical practitioners play a key role in identifying the fateful character of the event through process such as diagnosis. The moment or event is fateful because it undermines an individual's basic trust or certainty that things will continue as before. Such trust is an important personal defence mechanism providing a 'protective cocoon' that filters out dangers that threaten the individual:

Fateful moments are threatening for the protective cocoon which defends the individual's ontological security, because the 'business as usual' attitude that is so important to that cocoon is inevitably broken through (Giddens, 1991, p. 114).

In such circumstances individuals are inevitably exposed to uncertainty and risk and need to develop strategies to re-establish as far as possible their protective cocoon so that they can manage uncertainty and risk. The increased vulnerability of individuals means that they need added help in protecting themselves, such help may come from personal contacts for example relatives and friends but can also come from expert or abstract systems. Experts can help

individuals identify risks but the individuals concerned are those that run the risk and experience the consequences if things go wrong.

There is increasing understanding of the importance of effective risk assessment and management to both minimise the harm experienced by vulnerable individuals and maximise the quality of their lives (see for example Kemshall and Pritchard, 1996 and 1997). There is a general acceptance that strokes in particular increase an individual's vulnerability by impairing physical and/or mental capacity. However this has not always extended to the consideration of the ways in which vulnerable individuals and their carers manage their own risk. Indeed to our knowledge nor has there been a study examining risk in relation to individuals who have had strokes and their carers.

Changing patterns of care and support combined with individual preferences for independent living mean that a growing number of vulnerable adults stay in their homes supported by carers, health and social care workers. A Social Services Inspectorate report on services for older people with dementia stressed the importance of risk assessment and management when supporting vulnerable older people in their homes but acknowledged the difficulty of balancing safety and empowerment (1997, para. 8.1). Commentators have identified the benefits of risk taking for older people (Easterbrook, 1999, p. 10) and for other vulnerable adults (see Kemshall and Pritchard, 1996 and 1997). As Brearley noted in his seminal study of risk and older people, professionals caring for and supporting older people have the dilemma of balancing protection and autonomy. He argued that there is a bias towards safety (1982, p. 108) as threats to survival and safety are always taken more seriously than emotional needs. He maintained that professionals 'project negativism' in their work with older people, feeling that there is no point to it. The bias towards safety is particularly marked in the case of older people with mental disabilities. Stevenson argued that if an older person is 'intellectually competent', they are more likely to be supported in their choices even if these pose a risk of significant harm (1999, p. 202).

In our own study of nurses and social workers supporting vulnerable individuals in the community, we also identified a bias towards safety. Professionals supporting vulnerable adults tended to define risk in terms of threat, though a minority did acknowledge the benefits of risk taking (Alaszewski, Alaszewski, Manthorpe and Ayer, 2000). Brooker and his colleagues in their study of the educational preparation of nurses to provide care and support for older people also noted 'the dilemma of balancing safety/risk with a person's autonomy and independence' (Brooker et al, 1997, p. 134). This bias towards safety means that many professionals see their role as first and foremost providing protection and therefore start by assessing dangers and hazard to users (Alaszewski, Alaszewski and Parker, 1999). This approach tends to undermine the main objectives of rehabilitation that are according to the National Service Framework for Older People to:

Help older people regain their independence and confidence to relearn and practice their previous skills in everyday living, and to cope

successfully with increasing threats to the balance and increasingly demanding functional tasks. (DOH, 2001, p. 84)

One way of facilitating more effective rehabilitation is to ensure that professionals' interventions are grounded in a clear understanding of the ways in which users and carers define and perceive risk and the strategies they use to manage it. In particular it is important to see how the risks associated with the management of disabilities are placed in the contexts of everyday life and the range of challenges and opportunities, which users and carers are seeking to manage and at times reconcile. From this basis it should be possible to develop more sensitive and effective ways of providing individuals with enhanced security and rehabilitation. Jones et al (2000) in a discussion paper on control and disempowerment following stroke cite a paper which suggests that if rehabilitation activities are aimed at achievement of everyday tasks such as hoovering and washing up, people will understand the relevance of the task, it will cause less confusion and increase motivation.

1.6 Summary and comment

Stroke is a distinctive and major cause of disability within contemporary society. While it possible to identify the negative and harmful effects which stroke has on the individual and the ways in which services seek to minimise such effects, and indeed much research does precisely this, such a service-oriented approach misses much of the positive and creative work which individuals undertake. The person-centred approach which we will use for our research does acknowledge that stroke has a major impact on the person, it is a fateful moment that undermines an individual's protective devices and their sense of their self. However in such circumstances individuals are not passive recipients of services, they develop personal goals and strategies to achieve such goals to restore their sense of themselves. In this research we plan to explore the ways in which individuals seek to actively manage their situation and the ways in which the experts can understand, support and develop such active management.

2

Researching life after stroke: methods and methodology

In this chapter we discuss the aims and objectives of our project and the methods that we used to achieve these aims. We start with the aims and then describe and justify our methods.

2.1 Aims and objectives

The agreed aims and objectives of the project were to:

- provide insight into the ways in which individuals who have experienced a stroke, carers and professionals define the opportunities and challenges of every day life
- enhance understanding of the strategies these individuals and their carers use to manage the various challenges and opportunities of their everyday lives;
- identify how professionals can develop more effective ways of supporting the rehabilitation of individuals who have had a stroke;

We chose to use a person-centred approach grounded in qualitative research so that allowed stroke survivors and carers tell us about their experience of stroke and its impact on their lives. Pound and Gompertz (1998) in their research on the consequences of stroke used such an approach, ‘to allow people to raise their own concerns and priorities’. We used semi-structured interviews which encouraged users, informal and formal carers to explore a number of general themes. These included the impact of stroke, how people reconstructed their lives and the impact of professional care. We explored the psychological, social and physical impact of stroke on individuals and the coping mechanisms and strategies they created to manage their disabilities.

2.2 Methodology: overall approach

Since we wanted to gain insight into individual life experiences, we were committed to using a naturalistic approach to accessing experiences and understanding of stroke. While research designs such as social surveys provide cost-effective ways of collecting large bodies of data, the explanatory value of these data are often limited. Survey research is good at explaining what people do, but is rather less effective at explaining or understanding why they do it. Accessing

individuals' interpretations of their world is the only way to do this. As Porter has noted in a review of qualitative analysis in nursing research the premise of naturalistic research is that:

the social world we live in can only be understood through an understanding of the meanings and motives that guide social actions and interactions of individuals...Qualitative analysis is concerned with describing the actions and interactions of research subjects in a certain context, and with interpreting the motivations and understandings that lie behind those actions (Porter, 2000, p. 399).

The only way that researchers can obtain this insight is to access the 'natural setting' (Fielding, 1993) by interacting with individuals on an equal and participative basis. The aim of naturalistic research is to study the world, as far as possible in a state that is not contaminated by the research process so that, "natural" not "artificial" settings, like experiments or formal interviews, should be the primary source of data' (Hammersley and Atkinson, 1995, p. 6).

The aim of the researcher is not to impose his or her categories or interpretations on the lives of the other participants in the research but to show them respect for and understanding (Hammersley and Atkinson, 1995, p. 6). Naturalistic researchers are committed to a person centred approach to research, to seeing the world from the social actors' point of view and to do this they seek to access in the everyday life as seen by the people they study. Blaikie described this approach in the following way:

The chief characteristic is a commitment to viewing the social world — social actions and events — from the viewpoints(s) of the people being studied. This commitment involves discovering their socially constructed reality and penetrating the frames of meaning within which they conduct their activities. To do this, it is necessary to master the everyday language that social actors use in dealing with the phenomenon under investigation, in short, to discover their 'mutual knowledge', the concepts, and the meanings associated with these concepts. The investigation of this reality, and the language in which it is embedded, requires extended periods of involvement in the lives of people, by means of participant observation and/or through extensive in-depth interviewing (emphasis in the original, Blaikie, 2000, p. 251)

We defined 'the people in our study' as those who had survived a stroke and the individuals, both family and friends and experts or professionals, who sought to help them. Ideally we would have liked to access experience by talking to people at various stages after they had had a stroke but given limitations of resources we decided to talk to people a year after. We selected this point in time because we felt survivors would still remember the impact of stroke clearly but also still be changing and developing strategies for coping with life. However it did not always work. While all survivors in our study were at least four months post stroke in some cases it was their second not their first stroke. We asked the volunteers if they would assess their degree of disability using a Modified Rankin scale and also offered them the option of a group interview in a convenient location with transport or expenses provided or an interview in their own home.

2.3 Recruiting participants

For researchers using naturalistic research numbers don't really count or matter in the same ways as they do in experimental or survey research. Researchers using naturalistic techniques do not start with a hypothesis to test but usually with something they do not understand, for example a desire to understand how certain events effect individuals and how they make sense of them. Generalisation does not take the form of making statistical inferences about the characteristics of a population from a representative sample but of gaining insight into social processes and the rationality which underpin observed actions and events. In such circumstances it may not be meaningful to talk of sampling, for example Denzin and Lincoln's (2000) text on qualitative research does not have a chapter on sampling. In naturalistic research the concern is to select cases or settings that will provide an opportunity to gain desired insight into and understanding of the puzzle. In their text on ethnography, Hammersley and Atkinson note that in naturalistic research there may be an element of chance about the selection of settings as the research issues and analysis develop as the fieldwork progresses:

even where a setting is selected on the basis of foreshadowed problems, the nature of the setting may still shape the development of the research questions... All this does not mean that the selection of the settings for study is unimportant, simply that the ethnographer is rarely in a position to specify the precise nature of the setting required. It is a matter of identifying the sorts of setting that would be most appropriate for investigation of the research problem, as currently formulated (Hammersley and Atkinson, 1995, p. 37).

In traditional ethnographic research, the research setting was usually defined as a community or culture whose beliefs and behaviours were puzzling. The selection of individuals within the setting to participate in the research was influenced by their potential for providing insight the concern insight into the nature of the community. Indeed in traditional ethnographic texts such as Whyte's Street Corner Society such individuals were classed as key informants as their accounts were seen as providing privileged access to the rationality of the community. More recent development such as grounded theory strategies involve a phased selection of setting with each phase of data collection generating insights which lead to the selection of new settings to test out the insights and to fill gaps in the data and theories (Charmaz, 2000, p. 519), a process called 'theoretical sampling'.

It was neither feasible nor appropriate to use a structured approach to sampling, there was no defined population to sample from and we were not hypothesis testing. We used non-probability or purposive sampling. We included individuals who 'are judged as typical of' (the specific categories which are of interest to the research). Thus our three main categories were individuals who have had a stroke, individuals who provide informal care and support and professionals who assess and provide services:

Stroke survivors Our prime concern was with the longer-term consequences of stroke and rehabilitation rather the immediate diagnosis and treatment. Therefore we only intended to include

individuals who had a stroke at least one year before the start of the study and carers and families and professional who provide rehabilitation services in the community. We had some difficulty with recruitment and following discussion amongst the research team extended the time range from six months to eighteen months post stroke. The majority of respondents fell within this time frame but as databases did not record previous 'events', two people who had had previous strokes were included. Two individuals who had severe speech difficulties wished to be included in the study and were interviewed with carers present. They contributed as and when they were able to and nominated carers to act as advocates for them. We sought recruits during a six month period from three sources, discharges from the local Stroke Unit, referrals from the Stroke Association and from the Stroke Discharge Nurse. Some people were excluded as unsuitable by the stroke discharge nurse because of severe communication difficulties or domestic problems. Altogether we interviewed thirty one stroke survivors, some individually and some in focus groups. Carers were sometimes present at interviews. When carers were present, the researcher was not directive about whether they participated in the interview and most chose to stay and contribute (for further details on participants see Appendix 3).

Table of Interviews with Stroke Survivors

	Interviewed alone	Interviewed with carer	Group interview	Total
Under 65	8	2	0	10
Over 65	5	9	7	21
Total	13	11	7	31

Carers and families unfortunately this group proved more difficult to access than anticipated. There was no specific stroke carers group, only more generic groups and it was difficult to contact carers who were supporting someone who had experienced a stroke in the timeframe. Eleven of the interviews took place with carers present who actively contributed. One interview was carried out separately with a carer and the research team acknowledged that there were sensitive issues, such as intimacy, which will have unfortunately been missed.

Service providers can be divided into professionals who provide support for a range of client groups in the community such as GPs, community nurses and care assessors/managers, voluntary sector groups and professionals who specialise in rehabilitation work such as members of the Community Assessment and Rehabilitation Teams. Interviews were carried out with: 2 GPs, Community Rehabilitation Team (9 people present), 2 Physiotherapists, 1 Occupational Therapist, 1 Speech Therapist, Stroke Family Support Worker, East Kent Young Strokes Organiser, Stroke Discharge Nurse.

2.4 Asking questions

As in survey research, naturalistic researchers use techniques such as interviews and diaries to access information from participants in the

research. The main difference is in the ways in which these techniques are structured. In survey research the concern is to reduce interviewer or observer bias, so the main emphasis is on having a closely structured set of questions or instructions that ensures each participant is treated in exactly the same way. In contrast in naturalistic research the questions or instructions are more of a starting point of guide and the emphasis is on the participants to express themselves. Hammersley and Atkinson describe this 'reflexive' interviewing in the following way:

Ethnographers do not usually decide beforehand the exact questions they want to ask, and do not ask each interviewee exactly the same questions, though they will usually enter the interviews with a list of issues to be covered. Nor do they seek to establish a fixed sequence in which topics are to be covered; they adopt a more flexible approach, allowing the discussion to flow in a way that seems natural... In these senses... ethnographic interviews are closer in character to conversations than are survey interview (Hammersley and Atkinson, 1995, p. 152).

We very much adopted this approach. Our topic areas for survivors and carers focussed on the impact of stroke on life, changes and the ways in which people adapted and reconstructed themselves. Using focus group and individual interviews we explored:

- perceptions of the ways in which stroke changed individuals' and their families or carers lives
- the types of challenges and opportunities which vulnerable adults experienced when living independently in the community
- the strategies which vulnerable adults and their carers developed to manage these threats and opportunities
- how professionals' interventions influence both the nature of the challenges and opportunities and the ways in which professional interventions could facilitate the rehabilitation of vulnerable adults.

The interviews did not have a rigid structure but were based on a number of key or lead questions plus prompts to stimulate or direct discussion. The key questions for stroke survivors and their supporters or carers were:

- Do you think having a stroke has changed your life, if so in what ways?
- Do you still feel able to take life for granted
- What ways have you found of overcoming difficulties and doing activities that you value? Who helped you in this?
- How do you feel about the professional e.g nurses, physios, help you received?
- How do you see the future?
- Where there any activities you felt were particularly important to you to do again to feel that you were getting back to normal?
- Did you set yourself any personal goals?

For example, an interview with a 79 year old lady:

Int: Do you think it (the stroke) has changed your life?

Mrs Dalton: Ooh, I should say. It has very much.

Int: Are you able to tell me in what ways?

Mrs Dalton: Well, I can't walk the distance I used to. I am now not

re-learning but re-practicing bowls and can play nine ends indoors. And I can't drive a car. That's a big loss, a big loss.

Following this the researcher then went on to explore the reasons she could no longer drive and the impact on her social life. We conducted most of the interviews with professionals individually because of difficulties in arrangements and time constraints. However, we held one focus group interview with a community rehabilitation team. In order to include a wide range of formal carers, the researcher conducted three telephone interviews where no other arrangements could be made in the time frame. Individual interviews lasted approximately 30-40 minutes and the focus group nearer an hour. The key topics for these interviews were:

- The stroke experience and normalisation
- Contribution of Services in general, views on rehabilitation
- Specific contribution of particular service

2.5 Self report and diaries

One way of accessing individuals experiences is to ask them to keep a record or a diary.

We have in previous research used a self report technique based on diaries (see Zimmerman and Wieder,1977). The technique involves three elements: an initial interview, the research diary and a debriefing interview. We invited each diarist to complete two trial days so that we could provide them with additional guidance on how to complete the diary. A set of instructions was included in each diary (see box 1).

Only one participant completed the diary and he, sadly, died before he was able to do the de-briefing interview. A short paper is included in the appendix to explain why this approach was not more effective in

Box 1: Diary Instructions

Your Diary

The purpose of your diary is to help us gain greater insight into the way in which you are coping with life and the strategies you are using to develop your independence. We hope that this will help others who have had strokes and their carers.

- Please provide a short account (about 100 words or half a page) of how you spent the day.
- When you have done this could you identify one or two events in the day that were significant to you and describe them in a little more detail.
- Next, it would be interesting if you could reflect on why this event was significant for you, what you

were trying to achieve and how you over came any difficulties. Were any other individuals such as family, friends or carers involved in this event?

- Can you think of any way in which your experiences could be used to help other people who have had strokes and their carers?

If possible we would like you to write the diary for six weeks (not necessarily consecutive weeks). We very much appreciate your help with this project.

When you have finished writing the diary Helen will come and discuss with you what you have written. If you have any problems you wish to discuss please do not hesitate to phone me 01227 827641.

this particular project and how the research team could overcome some of these problems in a future project.

2.6 Data analysis

Naturalistic research is designed to generate qualitative data. In this research these data took the form of written text, transcribed focus group interviews, individual interviews plus one written diary. These data were content analysed, (apart from the diary), using theoretical categories developed from previous research and constant comparison designed to identify new categories. The computer software programme ATLAS.ti was used to organise and support material. For example, the interview transcripts were entered into a hermeneutic unit and coded. The dominant themes and categories were then identified and collapsed by two of the researchers.

2.7 Summary and comment

In our qualitative study we wished to give stroke survivors and their carers an opportunity to talk about the experience of stroke, the impact on their lives and their views on professional help they had received. In order to do this, we reviewed current qualitative research studies and conducted semi-structured interviews with survivors, formal and informal carers. Use of broad topics enabled the participants to direct the discussion in the way they wished and to explore areas of their stroke experience. The focus group offered the opportunity for survivors to meet together, discuss and compare their experiences, strategies and progress. Unfortunately in this study, the self-report diaries were not as successful as in a previous study by the researchers. We also used semi-structured interviews with a range of formal carers, both specialists in stroke care and generic practitioners to gain insight into their views of the impact of stroke, rehabilitation and services.



3

The impact of stroke on survivors and carers

In the first chapter we explored current evidence from the literature on the impact of stroke on survivors and their families. In this chapter we develop this analysis further by examining the findings from our study and considering the ways in which stroke impacted upon the lives of survivors and their family or carers.

3.1 Psychological difficulties — the invisible side of stroke

While epidemiological research has identified risk factors for stroke, these are population factors that predict the incidence in different groups. However, they cannot predict the individual incidence nor the experience of stroke. For individuals and their families, strokes are an unexpected event, a ‘bolt out of the blue’, that leaves survivors and their families with a sense of shock and disbelief. Ms Beaton, a 40 year old interviewee explained,

I had no disposition to having the stroke and I did smoke but I did not have high blood pressure, a bit over weight I grant you, but I couldn't believe I had my stroke.

Survivors can no longer take life for granted and try to make sense of what has happened to them. They also have to develop strategies and relearn skills to re-establish ‘normal life’. However, that ‘normal life’ is unlikely to be the same as the ‘normal life’ that existed prior to the stroke, the boundaries of normality appear to shift with the experience.

Sudden discontinuity The suddenness with which stroke occurs can leave the individual with a sense of fear and uncertainty about the future; nothing will ever be the same for them again, and it is within this context that they have to try and negotiate and reconstruct their identity. Almost all of those interviewed (30, 97%), felt that stroke had drastically changed their lives: ‘completely’, ‘devastated’ it, or created ‘a completely different way of life’. For most respondents this was a major trauma, which affected both the way people were able to lead their lives and their ability to take life for granted. Ms Price, a 38 year old lady who assessed herself as having had a mild stroke described feeling drained both physically and mentally:

... it leaves you completely empty, I was emptied, I was emptied of being able to look after myself, being able to think, I was just emptied, there

was nothing to draw on, it was just as if someone had sucked it out of you, vacuumed it.

The one exception was Mr Green, a 68 year old man who did not feel that his stroke had made a major difference to his life after the initial impact:

Int: Do you think having a stroke has changed your life at all?

Mr Green: No.

Int: Not at all?

Mr Green: Well, I haven't adapted my way of life at all, so, I mean the stroke itself was a major sort of upset but I mean my recovery is such that I haven't changed.

Mr Green's stroke had been mild, the only residual disability being a loss of balance that manifested itself as 'staggering from side to side when I get tired'. Since he had suffered from a similar problem before the stroke he was accustomed to the sensation and did not attribute it entirely to the stroke. He felt fortunate that his stroke had occurred while he was abroad on holiday and had received immediate care and investigations which, he did not think he would have received in this country as promptly. He had been able to return to previously valued activities, such as driving and walking by building up his confidence and stamina levels.

Mr Green was exceptional within our study, most interviewees judged their lives to have been irrevocably changed and they felt deprived of their former lives and abilities. Occasionally, for some respondents, it seemed as if they weren't even the same person anymore.

Undermining confidence Stroke survivors indicated that the sudden disruption of their life had had major psychological consequences. They could no longer take things for granted, indeed since the cause of the stroke could not be identified with certainty they had to address the possibility of a further stroke. Ms Quick, a 51 year old lady who considered that her stroke was relatively minor, indicated that her anxiety about having another more serious stroke had undermined her confidence:

Int: Is there anything specific since you had your stroke that has made you anxious?

Ms Quick: Only the fear that I might have a major stroke. And I think at first, I wouldn't even go out of the house in case it happened again and in the end you just begin to think, ooh this is stupid because I could go out of the house and get run over, you know, I can't let it dominate my life. I've just got to, but that took a long time really, it sounds quite easy to say but it's awful, I wouldn't wish it on anybody. It was the most horrible feeling in the world.

For some respondents even environments that they had previously taken for granted and treated as safe and secure, such as their own homes became threatening and risky. Respondents spoke of dislike of being alone, being frightened to bathe or shower when nobody else was in the house, or restricting themselves to certain areas of the house. In some cases this resulted almost in a form of agoraphobia.

I couldn't sit at the table, for weeks and weeks to eat my food, I had to have it on somewhere like this (the settee in the living room), where it was comfortable, I couldn't sit on those chairs. Because I was used to being in here, so I didn't really like going into other parts of the house (Ms Price, 38 year old lady).

Space outside the house presented an even greater challenge as individuals had to manage not only their anxieties but also had to anticipate and manage the reactions of people they met. Anxieties about the reaction of others was not restricted to individuals with visible disabilities it also affected individuals without apparent disability. Several of the interviewees felt that people they met could not appreciate or empathise with the difficulties they were experiencing. One respondent described the dilemma in this way:

I think it's very hard because I look physically fine; people can't see inside my head, what I am going through ... that it's very hard for people to accept that there is something wrong with you (Ms Quick, 51 year old lady).

Negative affective states The loss of confidence generally undermined self-confidence and was often compounded by short-term memory loss, dysphasia or problems with comprehension. It is therefore hardly surprising that the participants in the study reported negative changes in affective states. A number identified loss of control over emotional reactions as both an unexpected and unwelcome consequence of stroke. They spoke of uncontrollable laughing followed by uncontrollable crying which caused distress and embarrassment for them and their carers. One 76 year old man, Mr Tucker, who understood 'since I was a boy that I wasn't meant to cry', found the lack of emotional control very disturbing, 'like being hit by a squall'. Survivors admitted to having feelings of anger and frustration when they were unable to carry out activities or to express themselves as they wished to. As time passed and improvements were slow to come, depression often ensued, which was frequently experienced as de-motivating. Stroke left some of our respondents with perceptual problems and so they sometimes found it hard to concentrate, felt confused or also had short-term memory problems.

Comment Having a stroke is clearly a defining moment in an individual's life, which creates disruption of previously 'normal' life and a challenge to identity. There are many invisible consequences of stroke that make re-establishing 'normality' difficult, a very slow process. In the next section we look at the physical restrictions and limitations which stroke imposes; these are often the more visible consequences of the stroke experience.

3.2 Physical difficulties — the more visible aspect of stroke

All of the interviewees in our study reported some residual degree of physical disability, and there was often an overlap between the physical, for example, finding something which had previously been easy very difficult and the psychological sequelae such as the way this

made people feel about themselves. One consequence of stroke can be temporary or permanent loss of control over some aspects of the body and bodily functions. All of interviewees reported some continuing form of disability. The majority (22, 70%) of people reported difficulties with mobility. This amounted in some cases to total immobility and in others to a weakness on one side of the body. There were often a combination of problems as, for example, with Mrs James, a 79 year old lady who experienced weakness in her arms, unsteadiness, hearing loss and fatigue.

Mobility difficulties Loss of control over a leg is particularly disabling as it means the stroke survivor may lose the ability to walk and even be restricted to a wheelchair. In such situations, there were invariably implications for all the family with the changes to the living environment and adaptations around the house. One of the younger stroke survivors described how the living room of his house was now like a hospital ward, with a hospital bed and a commode. He described in some detail how guilty this made him feel on behalf of his wife and daughters. For such people, who were no longer able to move or go out as they wanted to, there was a sense of being hemmed in and trapped. One elderly man remarked:

I can't walk, I have to sit in a wheelchair all the time and that irritates me because I talk to you for a while here and I want to get up and walk outside and I could walk outside but I'd fall over (Mr Jones, 77 year old man).

Life for individuals who needed to use a wheelchair was disrupted and disruptive as it lacked spontaneity and needed very careful planning. For those dependent on their spouses or children to push them around, this increased feelings of inadequacy and helplessness. Again, there was the prospect of facing the outside world with a changed body image, and for some survivors, being in a wheelchair made them feel disempowered and stigmatised. Mr Jones summed up his feelings in this way:

Mr Jones: Because I can't get up and go out when I want, I have to stay here. I could go to meetings if I wanted to but I never go to them now, if I went I couldn't take in what they were talking about, well I suppose I could but I would be embarrassed to go and they come up and speak to you and you feel if you go to a meeting and you are sitting in a chair like this (pointing to the wheelchair) and people talk to you, you feel rather weak sitting in the chair and they are all talking to you and standing up and looking at you.

Int: So do you think people speak to you differently now or do you think that's just the way you feel?

Mr Jones: It's the way I feel I think. They don't mean it I don't think but it does happen. Yes I think they, the stroke really affects me.

Losing the use of a limb, albeit sometimes temporarily, often resulted in a partner or carer having to perform personal care that emphasised these 'dependent' feelings. Previously enjoyed activities and hobbies had become far more difficult, if not impossible to perform. Some people felt, therefore, that their quality of life was diminished.

Learning to walk again proved a challenge to many, as balance was often affected and fear of falling made some individuals restrict their activities and appeared to make their carers over protective.

Heightened perception of loss The consequences of stroke were enduring and this made some interviewees feel more disadvantaged than if they had experienced other medical conditions. Ms Beaton, a 40 year old survivor, who had previously been a health worker, described her feelings of being left partially sighted:

I would rather have gone deaf than have lost my sight actually although that is a horrendous thing for people who are deaf. I can understand, my world feels very, very enclosed ... I would rather have had a heart attack. If I had lost a leg I actually would have coped with that much, much better believe it or not. I know that sounds horrendous because that is not the problem but it is not a nice thing to happen but I know that with support, friends and family, I could have still gone back to work.

Her world had been reduced in a way that she felt it would not have if she had suffered from a different illness or condition.

Fatigue: systemic impact Some of the physical consequence of stroke were experienced as affecting the whole body, not just a particular part or function. For example, 11 (36%) of respondents mentioned extreme tiredness and fatigue as an unexpected consequence of stroke which made plans to go back to work or to progress with their rehabilitation much more complex. Mrs Kellor, an active eighty year old, wanted to return to her exercise class but lacked stamina when she did so:

I did go back for the first lesson after the summer break, I thought I might try it but it was too much. I couldn't cope. I could cope with the sitting and the stretching but then you've got to walk around the room and I don't feel as yet, although it seems a year, I'm not strong enough.

Another elderly lady, Mrs James, raised the issue of tiredness in a group interview,

Mrs James: Do you get a feeling of exhaustion at all?

Mrs Miles: I do find that I get tired much quicker than I used to.

Mrs James: And it doesn't matter how light the job is that I do I still feel exhausted afterwards. I make my bed every morning and I'll get into it afterwards, I'm so tired.

Extreme tiredness forced people to slow down and plan even routine daily events very carefully. It was also a problem for the younger survivors and was noticeable when they tried to return to work. Mrs Early, a 40-year old lady wished to return to work as soon as possible but fatigue made this impossible:

... but what it did was leave me thoroughly drained and I went, tried to go back to work in June last year and I could only manage one day, I just couldn't do it. It was just too much for me. So I've been off sick ever since you know, to just sort of regain my strength and that.

Fatigue was an unexpected but frustrating consequence of stroke which prevented sufferers from carrying out desired activities, forced them to do so much more slowly, or experience exhaustion afterwards. Many of our older interviewees had also had additional physical conditions, for example rheumatoid arthritis, diabetes or visual impairment, which they considered made their recovery more difficult and complex.

Comment Residual physical disabilities following stroke had a major impact on survivors and their carers that caused serious disruption to many of our interviewee's everyday lives. Those people who were no longer mobile had to adjust and adapt to a changed identity, that of being a visibly 'disabled' person. Even for those people who assessed their stroke as 'mild', the discontinuity caused by the event resulted in life being carried out at a slower and more measured pace because of the fatigue experienced. It is difficult to explore the physical impact in isolation from the psychological impact as the two overlap and impact on each other.

3.3 The social effects of stroke — changing identity and role

The psychological and physical consequences of stroke can result in major changes in the survivors' social relationship and identity. Almost two thirds (61%) of respondents felt that their family or social life was in some way affected. This was particularly evident for those people whose mobility was seriously restricted and for the few in our study who experienced speech difficulties.

Changes within the family: Relationships, both within the family and externally often changed as a result of stroke, with spouses having to become carers and undertake tasks which were previously the responsibility of a partner, sometimes even having to give up work. This put a considerable financial strain on younger stroke survivors particularly those who had previously been the breadwinner for the family. Marital relations were often put under considerable stress and carers spoke of loss of bonding and loss of closeness.

Mrs Eden: ... But its you drift apart, you do drift apart. You love one another but there's times when you hate one another, you do, you do there's not the, how can I say that

Mr Eden: There wasn't the bonding

Mrs Eden: the bonding's gone (61 year old man and wife).

One carer summarised her feelings in this way:

Mrs White: There is no physical contact as such, all that has gone because I don't know, well I don't know, although we still love each-other, it's not the same. And then I'm having to sleep in the other bedroom anyway ... Which is dreadful. So that's another, a distance away which we've never had ... (wife of 66 year old survivor).

Role reversal Survivors felt that role reversal had sometimes occurred not only in relation to their spouses but also with their children. Where they had provided support for their spouse or children, they now

received such support, sometimes even intimate care. Mrs Dean, a previously active 50 year old woman reflected, *'I'm more dependent on than being depended on'*. Some interviewees felt a loss of status and role within the family, a sense of feeling diminished. An 89 year old lady felt that she had been marginalized within the family and was no longer 'the queen-bee':

Mrs Hunt: I won't be here for years now anyway (laughs). I can't lead the same sort of life as I used to. I can't pass an opinion to anybody like I would do at one time.

Int: Why is that?

Mrs Hunt: Well, because I'm now the one who sits in a corner and does nothing. I've got no control over anything now which was very nice.

Survivors often mentioned 'well intentioned' over protection, which emphasised feelings of child-likeness. During a group interview, an elderly lady described her feeling of over protection:

Int: So do you feel as though you have been over protected a little bit?

Mrs Best: A little bit you know. 'Don't do that', and I just get on with it. It is all behind me what I used to do and I don't want to be, 'Oh you can't do that Mother'. 'Oh I'll do that', and Oh they are good, they are, and never complain, they are very, very helpful, but I just feel that perhaps I should walk and walk better especially if I have been allowed to go out on my own (87 year old lady).

This respondent emphasised the point by commenting that an elderly man in the same focus group interview was lucky because he lived alone and could get on with what he wanted to.

Social exclusion: Some survivors felt that their stroke had undermined their broader relations and social activities and had also resulted in social isolation. Physical disabilities sometimes prevented previous forms of mobility such as driving:

Int: What about your social life, do you feel that has been affected?

Mr Isles: Totally, devastating. I'm totally reliant on people coming here, I can't get out at all. I've got no means of getting out.

Mr Isles lived in a fairly isolated area with minimal public transport and his mobility was very limited until he was able to drive again. He thus experienced exclusion from his local community.

Access to and from the house was a problem for a number of our respondents who were wheelchair users. This effectively rendered them housebound. Mr Tucker, a 76 year old man who was a wheelchair user had stopped going to meetings, *'I can only go out when somebody is willing to drag me out and wheel me'*, and clearly from his choice of the word 'drag' felt like a burden and an imposition on others. Mr Bryant a late middle aged man, who had previously been a musician but could no longer get out or play his instrument, described his losses in this way:

I've played in many bands. They're all very good to me, came to see me so I don't think they can understand playing in a band, it's not like playing music by yourself, you play in a band you're playing in a team and it's wonderful.

He had lost his ability to get out, to play an instrument and the friendships and support that went with this activity. He described his experience of marginalisation and exclusion graphically during his interview.

Comment: The restrictions and limitations on people's lives following stroke both within the family and in their wider social networks and activities can leave people isolated and socially excluded. This can effectively undermine the survivor's identity and sense of self worth. It is also likely to affect the functioning of the whole family and even their position within their local communities.

3.4 Summary and comment

The experience of stroke changes people's lives in profound and fundamental ways. The survivors, their families and carers in our study have had to cope with and adapt to new and often adverse circumstances. For most of the participants this is a continuing process. Although we have chosen to separate the impacts of stroke into three categories, physical, psychological and social, these were often interconnected and did not exist in isolation of the other factors. In addition, there were overarching themes such as disruption of life that challenges identity and consequently all aspects of life. This was accurately reflected in the testimony of Mr Isles when describing the impact of stroke on his life:

Int: Do you think having a stroke has changed your life?

Mr Isles: Absolutely, in every way. I can't imagine any way it's not really.

That's the most devastating thing really, the fact that nothing is the same, you know, even a simple thing like walking up the lane, I have plan it and think about it, work out whether I am capable of doing it.

The enduring effects of stroke and a lack of information about the likelihood of a further occurrence create much uncertainty about the future and possible recovery. In the next chapter, we will explore how people go about re-constructing their lives including their identities and the strategies that they develop and employ to enable them to do this.

4

Life after stroke: goals, strategies and identities

In this chapter we analyse the ways in which the individuals who participated in our study responded to the stroke. We build on the analysis of the impact of stroke by considering the ways in which stroke survivors and carers responded and sought to manage the challenges and consequences of stroke. We start by considering the ways in which survivors reflected on and redefined their life goals. We then explore the strategies that they used to achieve these goals and the ways in which these strategies helped survivors reconstruct their lives and identities and some of the consequences of achieving and not achieving goals.

4.1 Setting goals

In their study of the role of goal setting in stroke recovery, Lawler et al (1999) consider that rather than asking survivors and their carers about their stated goals they would ask them more generally about changes in their lives, hopes and expectations for the future. In our interviews we asked directly about personal goals and the ways in which survivors sought to develop activities and skills, which they valued and considered important. We felt this more direct approach would provide insight into the ways in which people reconstruct their lives. This approach proved a fruitful way of generating discussion and 21 (68%) of the participants in the study were able and willing to share their reflections on their own personal goals.

Although the majority of the respondents accepted that they were not going to get 'back to normal', in the sense that they would never be as they were before, most felt that it was important to try and return to valued activities such as walking and driving. To this end they often set themselves personal goals and developed strategies to achieve these. For three of the interviewees, such goals were quite general and expressed in relatively broad terms of, '*getting over the effects of it*', '*to get back into the normal run of things*', '*being able to do simple things*'. Some individuals discussed their goals in more specific or well defined ways. For example, one survivor preferred to set herself short-term goals everyday such as making the bed or cooking a meal, to ensure that she actually carried out these activities. Most respondents tended to describe their goals more generally. Of particular importance was mobility with 13 (42%) of respondents citing walking or getting out

and about independently as their personal goal and three (10%) driving. For some of those in the study, the personal goals they set themselves centred around their personal space and accomplishment of everyday tasks such as cooking and personal care; for others it involved recovering enjoyment in a hobby or interest and for some of the younger survivors going back to work.

The development of goals was often a complex process. Individuals had final or ultimate goals they wished to achieve, activities or relationships that they particularly valued, but recognised that they had to set themselves intermediate goals. For example Mr Bryant, who was housebound, described the goals he set himself in the following way:

Int: Did you set yourself any personal goals when you were in hospital or when you came home?

Mr Bryant: Yes, my goals I set, I'd try and get myself to walk as far as the computer and as far as the toilet so I could take a wee without my wife having to change the commode for me. That's my goals.

His immediate goal of walking a short distance was in fact the means to an end, a way of achieving other more complex and valued goals. Walking a small distance could achieve a wider range of goals, access to the computer would enable him to have contact with the world outside the house, and access to the toilet would reduce his dependence and stress for his wife. Similarly Mr Tucker had set himself a goal to propel his wheelchair independently. This would enable him to control access to his computer, files and his CD collection. In a group interview, Mr Neville, a 79-year-old man explained the importance of recording his progress on a calendar and how achieving intermediate goals such as walking 400 hundred steps contributed to his ultimate goal, quality of life:

I think from the moment I came round in the hospital my mind told me I was going to get better and I still have a life to live and so I used to keep a record on my calendar every day, like a diary and for improvements and any advances I had made and one day I was able to write down that I had taken four hundred steps and oh it really does something to you when you are able to do that ... so it was very important for me to get back because the quality of life means such a lot. It means such a lot.

Comment: One way in which individuals responded to their stroke was to identify personal goals. Such goals were related to activities which individuals felt were important and valuable, either as a means to an end or an end in themselves. We identified a number such activities including, walking, driving, hobbies and interests, personal care, returning to work.

4.2 Strategies for achieving goals

Three goals featured prominently in our interviews, gaining increased independence in the home, gaining increased mobility outside the home and, for younger people, getting back to work. In this section, we discuss some of the strategies which individuals had devised and

developed to succeed in reaching their goals and how perceived success or failure impacted on their identity.

Increased independence in the home Mobility and related goals inside the house were, as mentioned earlier, often focussed on increasing independence and decreasing carer stress. Falls were a particular problem as there were frequently difficulties with balance and survivors were concerned about their partners or carers abilities to help them up. Mr Eden had been discharged prematurely from hospital before he had been taught how to get himself back up following a fall:

Mr Eden: I've tried to get up, I've done it myself. I've put myself down (laughs), well, you have to laugh, it's frightening. 'Cos I know ,if I can't get up, she can't get me up, you have to work out a way of getting up. I've done that myself so I know if I go on the floor, slip or something, 'cos this leg has got a nasty habit of giving way and I'm frightened that one day it'll go when I can't hold on to anything.

Mr Moore was taught how to get himself up from the floor but as he and his wife explained:

Mr Moore: Well they did teach you in the hospital how to turn over on your side and get up. Only thing is, when you fall its not usually in a place where you can do this sort of thing.

Mrs Moore: You had a fall between the beds, didn't you?

The kitchen and the bathroom are both areas in the home where people are liable to fall and accidents happen and Mrs Dalton described her experience and the impact on her recovery:

... but I've had an unfortunate fall, caused by a trip not a TIA (minor stroke), went across the landing into my bathroom and in my bathroom I've got a blanket box, I went slam against it and I had a bruised breast and cracked ribs.

Following this episode, she suffered from a loss of confidence that impacted on her mobility and she needed to have further physiotherapy to rebuild and restore it. She felt this fall had been a setback for her in achieving her goal.

A number of interviewees, particularly the women, set their personal goals around being in the kitchen and cooking again. The kitchen is often perceived as a 'risky' area, as many of the tasks involve moving hot materials, lifting, being able to concentrate for long enough to complete a sequential task. Those who had experienced a weakness in or loss of use of one arm devised and employed different ways of carrying out activities or improvised, they purchased new equipment, planned more and sometimes tolerated more mess. Getting back to baking and cooking meals required creativity and imagination. Ms Harper explained that she had to be careful with boiling water and breaking eggs and had improvised in the kitchen by buying a utensil that enabled her to peel and chop vegetables. Mrs Garrett still enjoyed baking but had altered her priorities about the importance of mess:

I like cooking, I like making cakes and I was getting in an awful state because I couldn't do it and then I thought, I need it lower, and my friend had an old stool so she bought it along and as I say, I now do all my mixing on a stool. I make a dreadful mess but that doesn't matter, it can be cleaned up but I do it.

Mrs Dawton found that making the casserole the day before and then portioning it out whilst cool solved the problem of lifting full casserole dishes out of the oven. Making a cup of tea provided its own challenges. Survivors became accustomed to not over-filling the kettle and thus being able to lift it safely, and one person bought a small travel kettle. Ms Quick's daughter supported her while she re-learnt the process:

Ms Quick: By, while my daughter was here and just keep on reminding me what I had to do but it was, I could do it but it was just so much effort because I had to think, I've got to put the water in the kettle, I've got to put the kettle on, I've got to get the cups out. I consciously had to think about every step of what I was doing and then just keep doing it and keep doing it eventually I don't have to think about it anymore.

Individuals listed many examples of how they managed to find methods of doing everyday things (and we have used their 'handy hints' in Appendix 1).

Being able to carry out one's own personal care is another aspect of everyday life in which survivors strove to maintain their independence by developing strategies. As with the kitchen, the bathroom is perceived to be a 'risky' area, some survivors were nervous about bathing or showering when they were in the house alone and in some cases had adaptations fitted to make bathing safer. There were delays in getting adaptations and Mrs Kellor's daughter helped her towards independence:

She bought a plastic stool and put it in the bath and she helped me in and I sat there. Then she got my shower on and then I got the poles on and that is just wonderful and that makes you feel as well that you are getting back to normal, having a bath as usual.

Mrs Dalton sent us a letter, following her interview, describing how she had improvised over a number of daily tasks. For instance she had developed a method of washing and dressing herself in spite of the weakness in her arm:

When washing oneself it is easier to make a knuckle to clean the opposite underarm (more pressure) same move for putting on talcum powder.

When dressing with garments that have buttons fasten the middle one and continue downwards because a) you can see and b) it takes the weight.

People used a combination of imagination, creativity, perseverance and determination to achieve their goals and to get some 'normality' back into their lives. Developing increased mobility outside the home and getting back to work were other ways in which this could be achieved.

Gaining increased mobility outside the home Being able to get about independently, whether on foot, in a car or wheelchair was an activity which respondents valued highly but presented them with risks and challenges that they had to manage. Learning to walk was a valued but challenging goal. In the house survivors had to manage the risks of falling and we have described some of their strategies above. Outside the home there were a variety of issues, not only was there the risk of falling but there were also problems linked to challenges of interacting with other people and issues linked to fatigue and the ability to walk far enough.

Survivors developed a variety of strategies to increase mobility. Most sought to build up their skills incrementally developing their strength and stamina by walking a little further each day and by practising, for example on stairs. Some individuals started with professional assistance and supervision but many respondents missed out on such care and had to develop their own strategies. Transferring these skills was a challenge, especially from practice in and around the home to mobility outside the home. Individuals were not easily able to anticipate the level of fatigue they would experience and fear of being outside alone. A number of respondents related how they started by walking short distances, usually accompanied, and built this up slowly until they could reach the shop or the bus stop. Mrs Garrett chose to use a combination of walking and a taxi:

... and my walking wasn't particularly good either and so it was just small distances. What we did to begin with was to just go to the supermarket and then I'd walk round a bit because that's what I could cope with and I could hang onto the trolley and then as I say, I've twice on my own, I'd get the taxi and then have a walk. And before that I couldn't have done, there was always somebody with me (68 year old woman).

One respondent realised that if she walked all the way to the shops she had no energy left to do her shopping and therefore decided to use a taxi to get there.

Fear of being in crowded places and busy shops instilled anxiety in some respondents at first and they coped in various ways. For example, one 55-year old lady, Ms Harper, who had poor balance and a speech deficit, chose to go shopping at 'quiet' times as she felt people jostled her and were impatient with her. Ms Quick explained that she found it hard to admit to herself that there were times when she could not cope, but when the shops seemed too frenetic, she gave the shopping list to her friend and sat outside. Other survivors, who did not have someone to support them, sought the help of agencies such as the Red Cross who provided befrienders for a defined period to accompany them whilst building up their levels of confidence in their mobility or being outside alone. A number of respondents mentioned the hazards involved in crossing the road and how difficult they found mastering this following the stroke. One survivor had a very specific difficulty related to balance:

It's affected my confidence a lot. I go to step down from the kerb and it's only about two or three inches and yet to me, mentally, it seems as if I'm

going down into a well. So I've lost the confidence in stepping off the kerb (Mr Timms 76-year-old man).

However, he persevered and usually managed to find someone willing to help him. He and his carer also explained how they had purchased mobile phones so that they could be in contact with each other when apart and thus minimise any anxieties. Crossing the road involved a number of simultaneous processes, assessing the speed and direction of the traffic and making the decision about when to go. A number of respondents found this very difficult but still persevered, as it was part of their goal of regaining full mobility:

Going out, crossing roads, I still don't like crossing roads, even now. It's just there's too much going on but it's alright if I stand and wait. I either cross the road with somebody else or if there is an island in the middle of the road then I've only got to cope with one lot of traffic and then I can cope with the other lot of traffic, I hate roads that I've got to look both ways. I can't, I still don't like it (Ms Quick).

One 80 year old gentleman, Mr Nail who had a severe speech problem went for long walks everyday but carried a list of important phone numbers with him, as his daughter described:

Jane: ... then he'll go for his walk, a long walk. He always has something inside his pocket with the phone numbers on in case anything happens to him ... 'My name is L N and I am unable to speak properly following a stroke. If necessary please contact my daughter, my son or daughter-in-law' and there are the numbers so hopefully if anything happens they will find that, so that's part of his routine, he never forgets that.

Electric wheelchairs could provide a source of independence for individuals and although Mr Jones's main goal was to walk, he enjoyed the sense of freedom it gave him:

Mr Jones: Yes, I can go where I want in the electric wheelchair. If I want to go from here into another room it is very difficult but if I use the one with the motor, they can push me outside and leave me and I can go off on my own then.

Mobility or the ability to get about independently was important for survivors in a number of ways, it led to increased independence, improved confidence levels and re-gaining some of their pre-stroke identity. Individuals used a number of different strategies to overcome difficulties and achieve personal goals related to becoming mobile again. In the next section we look at respondent's experiences of going back to work and the strategies they developed for coping.

Getting back to work Some of the younger people felt that returning to work was a vital part of regaining their identity, and responded by setting themselves personal goals of set times to go back:

I tried to go back to work in June last year and I could only manage one day, I just couldn't do it. It was just too much for me. So I've been

off sick ever since you know, to just sort of regain my strength and that (Mrs Early).

However, sometimes, as in this case, in trying to go back early, Mrs Early had not fully appreciated her lack of stamina or anticipated the extreme fatigue she would feel. She chose to re-evaluate her decision to return at this time but her ultimate goal of returning to work remained unchanged. Returning to work was a challenge initially for Mr Isles because he felt self-conscious:

I was very apprehensive about it when I first went back, whether, then I started to think, why am I apprehensive about it? I suppose I was thinking that everyone would point to me and say, 'he's had a stroke' or 'he's disabled'.

He felt that as he worked in an understanding environment this feeling was short lived for him. Loss of skills and the inability to do more than one thing at once made Ms Quick feel inadequate:

... I don't think they quite understood why I wasn't quite up to scratch but they just had to accept. I was a bit lucky because I was back on medical grounds, that indicated to them that there was a reason because otherwise you just go back and that's it. It made me feel stupid sometimes.

One individual who was self employed was able to go back to work but took days off when she was 'having a bad day', however, she found the weight of responsibility of running the business was a burden.

Returning to work represented a return to the normal world and was highly valued but it was problematic and had to be managed, sometimes by reducing hours, sometimes by taking a less pressured position. However, not all those in the study were able to return to work nor did they wish to go to take a less demanding and potentially less interesting job.

Comment Stroke survivors set their own goals, many developed strategies to recover control of their lives. We have explored three themes in detail, independence in the house, mobility outside the house, and work outside the house. All of these activities carried risks and challenges that had to be managed in order to succeed and begin the work of reconstructing their lives. In the next section we explore the impact of stroke on identity and the ways in which individuals managed their post stroke lives.

4.3 Impact on identity

Setting goals and developing strategies for achieving them assists individuals in the process of reconstructing their lives after the trauma of the stroke. A younger stroke survivor reflected on how she felt:

I felt very differently and it upset me because I felt it was taking my personality away and I didn't have a choice in it.

Ms Beaton was still very angry and upset a year after her stroke and found it disturbing when she cooked a meal for friends and experienced a feeling of how she used to be:

... but I felt like my old self really but sometimes that is really upsetting because the confidence comes back.

In her interview she recounted how she felt she was 'moving on' because she was not so obsessed with talking about her disabilities but more concerned with her progress. Practical solutions and goal setting formed an important part of restoring identity but individuals also used a range of mechanisms to encourage and motivate themselves. Perceived strength of personality, positive outlook, comparison to others less fortunate and luck provided the stimulus to move on in recovery and rehabilitation.

Mrs Garrett felt that her personality and taking responsibility or control would ensure her success in recovery:

I think it's sheer determination on my part to do things and I will get there because I feel that it's up to me now.

For others a positive outlook seemed to provide the motivation to progress, 'it's not the end of the world', 'you don't give up, you just keep going', 'you've got to be wanting to get better'. Respondents stressed the importance of not giving up and making the most of things. One way respondents did this was by appreciating what they had and feeling fortunate in comparison to others. Mrs Garrett maintained:

And I don't, a lot of people, I know they're in a lot worse state and I think. I don't suppose lucky is the right word or it could be, but I was fortunate enough ...

Luckiness or good fortune came in various forms, the support and love of family or carers, material wealth, counting ones blessings. These mechanisms or strategies appeared to boost people's self-esteem and confidence.

One individual, Mr Neville valued his quality of life and had a very individualistic and almost militaristic approach to his recovery. He devised mental strategies such as pacing himself, planning ahead, proving things to himself by doing them and mental stimulation and applied them to his everyday activities, walking, cooking, gardening, working and decorating. For example, with his mobility, at first he used a walking stick and took a mobile phone out with him. Then he discarded the stick and 'I mapped out staging areas where I could have a seat, you could go somewhere and have a seat and it all fell into place'. He gained the confidence to go out for walks, shop, go back to his voluntary work. Mr Neville applied this strategy to all aspects of his life, paying attention to the detail of his diet and the amount of mental and physical exercise he took. He secured the admiration of professionals involved in his care and members of the focus group in which he participated.

Mr Jones, who had previously led an outdoor life, was supported by his family in his goal of learning to walk again but was not entirely satisfied with his progress. When walking, supported by his wife and daughter, he did not feel that this was 'real walking', and therefore did not value it. He was suspicious of those assessing his progress, such as the physiotherapist, judging that encouragement and praise was not always realistic about his performance and progress. In spite of support and positive re-enforcement and strong motivation on his part, Mr Jones remained unconvinced about his achievements and was left with a feeling of disappointment.

It was difficult for some survivors to re-establish their confidence. For example, Mr Charles, a 72-year-old man was still able to walk and drive and had a supportive family but had suffered from a profound loss of confidence following his stroke. He had stopped going on overseas holidays because he feared having another stroke:

That I might, you know, fall ill again and that's basically it. It is one of these things that has happened, and as I told my doctor, I feel I am living on borrowed time now because I never know when something might happen again and having taken precautions beforehand. I was a bit surprised it happened.

Problems with balance restricted his ability to do some D.I.Y. tasks around the house and his wife discouraged activities that she considered risky. It appeared that he had developed a strategy of shutting down certain areas of his life to try and protect himself from further stroke, but that this was hampering his recovery in other ways.

Two of our respondents had set themselves goals that they were unable, at the present time to meet. This appeared to have a generally de-motivating effect and the development of rather negative coping strategies. The most important goal for Mr White, a 66-year old man was to get back to driving and not being able to do so was a reality he found very hard to cope with:

I can't understand why I can't get any help so that I could drive. I mean I've got my car standing there in the drive doing nothing ... but I could drive if somebody would give me a help because I'm sure a lot of people could help for an automatic drive. I mean I've done it all my life and they tell me I'm too old.

He felt disappointed and let down in his medical treatment, he blamed outside agencies for his lack of progress and in himself he felt degraded, helpless and depressed. Driving and the freedom it offered had been an important part of his pre-stroke life and the loss of it was a big blow. Mr Bryant also felt let down and depressed as he was unable to pursue his pre-stroke plans and because of his domestic circumstances was unable to progress with his current goal of being able to get out of the house.

Stroke clearly impacts on identity and when individuals gain an insight into their pre-stroke self, it can be a disturbing experience. Profound disturbance to sense of self and identity are key features here. In this section we have looked at the different strategies and mechanisms

which people use to re-build their damaged identities. We found that, in addition to setting personal goals, people used various strategies for boosting their motivation and self-esteem and that a positive outlook and a certain type of personality helped. For some, a very structured and measured approach helped them to organise their lives and restore a sense of normality. For others, although not lacking in motivation, the degree of disability following stroke appeared to lead them to defensive and rather negative strategies, even though, in some cases, they viewed their disabilities as mild.

4.4 Summary and comment

Stroke is an illness that affects people suddenly and for many impacts on all aspects of their lives. The physical impact of stroke with its visible disabilities is in some ways easier for survivors to manage and where possible they develop practical strategies for overcoming challenges and risks. However, the psychological overlay, such as loss of confidence and fear of going out alone appear to need more complex planning to overcome, such as going out with somebody, building activities up slowly, using a combination of walking and transport. Getting back to being independent within the home, required adapting the physical environment, developing practical strategies and accepting help and support where needed. For those who are able to go back to work, patience and support are needed in the work environment. Loss of essential life skills can damage identity and affect relationships within the family. Survivors use a range of 'mental' strategies to maintain a positive outlook and boost their self-confidence that enables them to plan their practical strategies. Survivors who are housebound and their carers need far more long-term help and support to ensure that they are given a chance to reach their potential and to try and minimise the stress experienced.

In the next chapter we will explore the support provided by informal and formal carers and discuss comments from survivors describing what they found helpful and unhelpful in professional care.

5

Professionals and stroke: Professionals' perceptions of stroke and user and carers' views of professional interventions

In the last two chapters we have analysed survivor's perspectives of the stroke experience, its effect on their lives and how they try to reconstruct life afterwards. In this chapter, we draw on the data from interviews with formal carers, both generic and specialists in stroke care to explore their perceptions of the impact of stroke on people's lives, how people try to get back to normal. We also consider their views on rehabilitation and how they assist individuals towards recovery. Two of those interviewed worked in the voluntary sector, but only with individuals who had experienced strokes and their families, one solely with younger people. We also look at users and carers' views on the professional help they have received.

5.1 The stroke experience and getting back to normal

Similarities in stroke All our stroke survivors felt that stroke had impacted on their lives in a profound way and forced them to create new ways of managing. Generally, professionals endorsed this view. A number of the professionals considered that stroke was an exceptional illness because of the suddenness of onset, the uncertainty of the future and the length of time it took to make a recovery. The shock of the event itself and the initial residual difficulties made it difficult for survivors to fully understand and appreciate what had happened to them. An occupational therapist who had previously worked in a specialised stroke unit describes the impact from her experiences:

You were a fully, functional individual with no problems, perhaps and no physical problems and something like this happens and it just shatters people's lives ... I think it is that from one day to the next your life has completely changed, that's the devastation ... There is always some individual deficit left, some weakness and there is also this overhanging potential for you to experience another stroke ... Yes it is this complete change in your life role.

Practitioners in five interviews (56%) compared the experience of stroke with bereavement and loss of a former self, and sought to explain the person's recovery in terms of a 'process' towards adjustment. Those survivors who were not progressing as expected with their rehabilitation were viewed as stuck somewhere in the process and until they were able to accept their limitations, were unable to move on. One specialist stroke worker stated:

And it's like a bereavement, they go through the processes of bereavement and until they can move to the acceptance stage they actually don't really do that well. And lots of them are in the anger and denial stage for quite a while ...

Professionals considered that the fear of another stroke and general uncertainty about prognosis and potential recovery made sufferers lose confidence and trust in themselves and their abilities. A community nurse felt that this loss of confidence stemmed from an experience that went right to the core of their being:

most of the patients I deal with say they don't ever feel themselves for quite a while after the stroke whatever 'themselves' is ... I think it is the whole of them really you know. Well yes, yes, who they are and what they are.

She explained that people she visited were adjusting to an altered body image and a changed identity, life with a disability. Two thirds of the practitioners in the study identified depression as a common consequence of stroke that impacted on recovery as it affected motivation. As Dowswell et al (2000) note, the severity of the stroke does not necessarily determine the impact on the person. This view was evident in our interview with a speech therapist who described the impact of a mild stroke on a client:

I've worked with clients with very very mild problems and really on any form of assessment we would do they are very mild and yet, and I'm thinking of one individual in particular, absolutely devastated his life.

As with survivors, professionals felt that stroke led to loss of valued activities, such as working, driving, going out and maintaining social relations. They considered that such people often became socially isolated not only through lack of opportunity, but also because of a reluctance to face others. One participant who ran a voluntary organisation which supported stroke survivors and their families and who himself had also had a stroke, described how a combination of factors could lead to withdrawal:

it (the stroke) drastically reduces one's social life. You do have, people do go out and do have friends but I think the home and the security they have takes on a new sort of importance after a stroke. The tiredness, there is not the motivation for going out of an evening. I think motivation is a big problem you know ...

Professionals identified a combination of factors, which meant that some stroke survivors were reluctant to leave their homes, including the perceived safety and security of the home and the additional challenges of going out such as tiredness and fatigue.

Some of the professionals held the view that loss of social life and outside employment impact on family life in many ways. A number of younger stroke survivors were no longer able to be the breadwinner and consequently became dependent in their relationships. Being able to go back to work was not achievable for many, as one physiotherapist explained:

There's a lot of things it does involve, thinking quickly, perhaps driving to places, I mean it's perhaps elements of the job that you just can't do. So from that point of view very few people really get back to anything like what they were. They have to accept perhaps more menial [employment] sometimes.

Comment The professionals in our study viewed stroke as a major life-changing experience, but also as an illness with some unique and wide-ranging features. Although each stroke was a very individual event, from their perspective, professionals saw similarities in the physical, psychological and social sequelae that were very similar to those expressed by the service users or individuals in our study. While there is a general concordance between the ways in which professionals and survivors viewed the impact of stroke there were also differences in terminology. While some professionals sought to interpret the consequences of stroke within psychological frameworks such as grieving, none of the stroke survivors we interviewed used such a framework although some mentioned losses and depression. In the next section we will explore the ways in which the professionals considered services users 'got back to normal'.

Normalisation Professionals endorsed survivors' perceptions of the importance of valued activities and considered that re-establishing such activities was an important part of getting back to normal. Professionals saw the restoration of everyday routines through working, going out and hobbies as important markers of progress. One occupational therapist described how she encouraged people to carry on with routine activities and also more major ones:

Yes I think it's all about routine. If you took your holiday in the summer then take your holiday in the summer.

Whilst getting back to work, was highly valued and seen as an important step on the return to normal life, unfortunately, in the experience of the professionals very few survivors were able to do this, or if they did, they often had to take on a less demanding role:

I'm trying to think how many people, I can only think, in twenty odd years of three clients who I've handled who I've actually got back to their original job or something like it and there again, they were all young clients. Some get back to some form of employment, if you like, they are going to be defined by work but that's what most of them do ...
(Physiotherapist, Community Team)

Two of those interviewed, a speech therapist and an occupational therapist, wondered if some people adopted the 'stroke identity', in the sense that they attended groups, such as the Stroke Club, and became very involved with the other members and the running of such groups. Some practitioners actively encouraged their clients to attend such groups as they felt it was valuable experience to be with others who had had similar experiences. As one occupational therapist put it, '*so you don't feel that you are this unique individual kind of who has just experienced this*'. The speech therapist felt that a separate group of service users existed who consciously avoided such involvement, they refused all services and thought they would be fine when they got

home, and thus were almost in denial. There was some discussion about whether survivors do actually normalise their lives. A physiotherapist from a day hospital for older people maintained:

I don't know that they do return to their normal lives because they do kind of accept that this is how they are and that they are not going to be able to do things that they did before ...

She considered, especially with older people, that they adapted more, had rather lower expectations of recovery and 'accepted their lot'. However, other practitioners viewed the process of recovery as dynamic and changing all the time, particularly so with younger survivors.

Comment Most of the practitioners interviewed viewed getting back to normal as returning to valued activities such as work, hobbies, going out, re-establishing former routines. However, some professionals argued that the acceptance of a 'stroke identity' provided an option for some survivors although others adopted the opposite approach of denial and rejection of services. One practitioner felt that service users, particularly older people, grew to a state of acceptance of a new way of life that was not the same as 'getting back to normal'. However, we could find little evidence of this in our interviews with older survivors, the majority of older people we interviewed were very determined to live what life they had left to the full and actively sought ways in which to do so, often by setting major personal goals.

In the next section we will examine the ways in which practitioners support clients in the process of achieving their goals.

5.2 Rehabilitation and goal setting

Definitions of Rehabilitation All the practitioners in our study viewed rehabilitation as a process of assisting individuals to work towards an optimum level of independence, enabling clients to fulfil their maximum potential. However, the way they viewed this process differed, with some professionals emphasising functional or clinical aspects while others were more concerned with the social or personal aspects of rehabilitation. The minority of professionals (3) who emphasised the clinical approach used clinical terms, such as 'function' and activities of daily living (ADL):

Well I think rehabilitation is about maximising your functioning, function and your role. It is about being able to reach that maximum degree of function (Occupational therapist)

and:

Getting them back to as near their original mobility and all their functional ADL's but realistically (Physiotherapist from a community team).

Such definitions created an impression of being distanced from the client's wishes and aims, more a process of 'doing to' than 'with'. The

other approach, which was evident in our interviews with four practitioners, tended to frame rehabilitation in non-expert or lay language and emphasised rehabilitation as being person-centred, enabling and encouraging the service user to set the parameters:

I think that [it] is a really personal thing. For me it is where the patient wants to be and where the patient wants to get to you know so you are following and putting in place what they want to do and not what you think should happen along the way ... (Community support nurse)

This support nurse had the benefit of working with service users in their own homes and maintained that until individuals got home that it was not possible for them to decide what was really important for them to achieve.

Two other aspects of this approach centred on returning to normal, 'a process of getting back as far as possible to where you were before' or 'really getting back what you had before'. One therapist who gave a person-centred definition spoke of rehabilitation being a very 'subjective thing' and in her experience, stroke survivors tended to confound the 'realistic' expectation of professionals through their achievements. Professionals using the person-centred approach tended to emphasise broad adaptations to life and achievement of specific goals was a means to this broader end.

In the next section we look at the process of goal setting by practitioners and the challenges that stroke survivors present.

Goal setting and realism Professionals saw goal setting as an important part of the recovery process and created a contract or partnership with the service user:

they are their goals but they are set with us and they know that we are going to push them as much as we possibly can because, you know, one that is what we're supposed to do and two, we're trying to do the best for the. (Physiotherapist).

The therapists in our study approached goal setting in a very similar way to the survivors, setting an ultimate goal, breaking it down into achievable and incremental units and reviewing progress regularly. The process appeared to work well when the therapist and client shared the same perception of goals. However, when there was a difference, survivors' goals were often seen or classified as unrealistic and this created a major problem in the therapeutic relationship. One such example had a profound effect on the morale of the multi-disciplinary team involved:

this patient, he was really aggressive, he was so, at the moment he wanted to walk indoors, outdoors but realistically he doesn't have at the moment enough balance and his insight wasn't as good as it is now, so it was really difficult because he wanted to run before he could walk. So I mean, here the goals were like frustrated because even, he wasn't doing transfers very well, so we were practising transfers, we were trying to improve his balance and even trying to walk here on the ward but that was really, because we have to as well, give them the feedback, and it was

not good. So he was all the time upset and for me, it was quite difficult to say, he's not safe, he's not doing this now (Physiotherapist, rehabilitation unit).

A therapist from the community rehabilitation team which works intensively with the client for a maximum of six weeks, suggested that their role in goal setting was likely to be less problematic because their intervention time was strictly limited:

and the goals we set with the patient, obviously they initially come from the patient, what they want to do but it's got to be realistic within the timeframe as well.

This perhaps helped the client and practitioner to focus upon immediate and important issues.

Some therapists stated that survivors, who in their opinion, were unrealistic in the goals they wanted to achieve, were 'stuck' somewhere in the bereavement process as they were unable to accept the 'loss' implicit in their disability. They maintained that such clients would not progress with their treatment and rehabilitation until they moved on through this particular stage of bereavement or loss. A stroke support worker gave this example:

And lots of them are in the anger and denial stage for quite a while, much longer than you would expect of them. I mean I've got a girl at twelve months down the line who is very very angry and until she moves on from that she's not going to feel the benefits of the service.

We invited practitioners to give examples of specific cases where they felt their intervention had been successful. A specialist community nurse described her input in this case:

She had had a stroke, discharged from the stroke unit and she was very, very anxious. She was a widowed lady and she was literally made house bound within her flat by the stroke. She had a walker but she wasn't very steady plus she was awaiting a knee replacement so she had an unstable knee to complicate things and she was very, very emotional, weepy as well so just by going to visit her made a difference to her, she looked forward to the visit and her daughter had seen her mother as slightly hysterical and Oh she was putting it on and this sort of thing. So I was able to speak to the daughter and explained stroke to her and no she wasn't putting any of this on and no it was all very real and we looked at and from where I was seeing it I thought she really needed company and I think she would really come out of herself ...

The nurse arranged attendance at Age Concern for the lady from which she progressed:

and I actually went back to follow her up last week and she is now walking again in the Age Concern Centre on her own and she gets involved in all the activities. She looks after the more frail ones and she feels really part of that, and that was something very simple.

Although this nurse played down her intervention in this case as 'simple', the nurse's sensitive support for her client demonstrated the

importance of good communication with the family unit and continuity of care in the community. A number of the 'successful episodes', hinged on clear communication with survivors and their supporters. However, balancing realistic goals against discouraging the client was a dilemma that practitioners faced when trying to negotiate with them:

Physio: So junior physios and perhaps junior staff might try to present too positive a picture, which I think is dangerous, a balanced picture is what I prefer to give somebody.

OT: I think that is equally wrong but I think you just have to leave the door open really and say, I'm not sure, that's all you can do really.

Professionals believed that survivors who lived with carers tended to do better in terms of recovery and those who had vocal and articulate relatives were likely to receive better services. Some had also read research studies that indicated that people who had more difficult personalities made better recoveries than those who were 'laid back', as they were more assertive and less passive.

The majority of practitioners believed that the provision of stroke services for younger people was poor and that their needs were different from older users. The individual who provided a support service for younger stroke survivors felt that there should be a separate treatment unit that provided:

... the opportunity to receive all those specialities like physio, speech, OT in a context that's as near as possible to the world that you left and hope to go back to.

He argued that a hospital ward was not an appropriate place for a lengthy rehabilitation and that the needs of younger users encompassed work, finances, relationships and parenting issues which were different in emphasis to older survivors.

Comment Rehabilitation is an important part of the post-stroke experience. When a therapist is fully involved in this process it can be seen as a negotiated partnership. In our research we identified two distinct approaches to rehabilitation, one which was person-centred and one which was more clinically orientated. The process of goal setting was an integral part of rehabilitation and formed the basis of the therapeutic relationship between the client and the practitioner. Practitioners and clients set goals together and broke these down into small achievable and measurable units that were regularly reviewed. However, when professionals perceived client's goals as unrealistic, the relationship was often strained and on occasions broke down. Striking a balance where the goals were realistic but without discouraging the client was sometimes a dilemma. Practitioners recounted cases where they felt their intervention had made a difference to the client and these often hinged on good communication. The support of carers and the personality of the client were both important in the outcome of recovery. Professionals felt service provision for younger stroke survivors was inadequate.

In the next section we explore the services and relationships with professional from the perspective of the survivor and their families.

5.3 User and carer views of stroke services

The majority of participants in the study were satisfied and spoke highly of their initial care in hospital following the stroke. This was particularly evident for the older people with the stroke services and the professional input on the stroke unit. They were especially impressed by the integrated working of the multi-disciplinary team, as Mrs Dalton explained:

No I think it was clever. I think the whole progression of treatment was very clever and the way they just do everything bit by bit to build your confidence and build your balance and everything related to it.

A number of them benefited from the support of the local Community and Rehabilitation Team, known as CART, for an intensive six-week period on discharge and most spoke very highly of this service. Mrs Kellor lived alone and felt that the care and support she had received was invaluable, she noted:

Also knowing how supportive they are from the hospital, I thought that was wonderful to get all that therapy and all that help.

Carers also spoke highly of this service, feeling that it also supported them in their role as carers which was often very new to them. Mrs Eden, whose 63 year old husband had experienced a dense right hemiplegia, described how the team supported her through a very stressful time:

... they were always there for me. Because you're there (points to the edge of the chair), you're ready to drop off because, not realising what it is like and that you have to do and all that ...

To be eligible for a period of treatment with the CART team, survivors had to have two identified therapy needs following assessment, such as nursing and physiotherapy. Often such treatments led on to a period at the day hospital or attendance at an Age Concern Day Centre or the Stroke Club. However, this meant that occasionally older people who lived alone and had quite significant residual disabilities did not receive this service. In a group interview Mrs Miles an 89 year old woman was able to receive support from the CART team but not Mrs James, 75 years old:

Mrs Miles: Yes and when they had finished they arranged for me to go to the Day Hospital and I can't speak well enough of the after service; I thought it was wonderful and yet these two ladies don't seem to have had it.

Mrs James: I was petrified. I couldn't do anything and I was hoping I could have gone out and done ...

When survivors used the services of a day hospital this ensured continuation of therapy, provided a social environment, and, in some situations, a rest for carers. The stroke discharge nurse was part of the

CART team and provided post discharge support to survivors and carers. She had instigated a regular coffee morning for a number of older survivors which they found very beneficial in terms of getting out and keeping abreast of others' progress:

Int: So do you talk about how you are getting on?

Mrs Kellor: Yes, we talk about that and other things as well because otherwise you would be thinking I wonder how so and so is getting on.

Some of the participants in our study accessed services provided by the local branch of the Stroke Association. There was a support worker for all ages and one worker who ran a group specifically for younger people. These support workers provided a highly valued service. They visited users and carers at home for an unlimited period and spent time with them, providing information about stroke and stroke services and discussing any aspect of the stroke experience was asked about. The Stroke Family Support Worker had a broader and more open role than any of the other professionals involved in stroke care and her input provided something distinctive for users and carers. Ms Quick, who had not been admitted into hospital following her stroke, commented on the support she received in the following way:

I think talking to the Stroke Family Support Worker, that helped incredibly and I only wished I had known she had existed right back at the beginning, it was only because of my efforts that I even found out who she was and I think it's a shame that she wasn't there at the beginning because I think I needed someone like that to tell me it was alright that I was feeling like I was.

A number of survivors, particularly the younger people who had missed the support given by other services, commented positively on the ways in which the Family Support Workers reassured them that it was alright to feel as they were and to adjust their expectations. Ms Harper, a 55 year old lady who had speech and balance difficulties, felt socially isolated and welcomed the support worker's visit every six weeks, *'She takes time. How can I say it, she's nice to me'*.

Service users and carers in our study were generally satisfied with the initial treatment they received in hospital, particularly if they were admitted into the specialised stroke unit and with the follow up services if they received them. However, some people's care was characterised by rapid and unplanned discharge, lack of follow up care and, in the long-term, feeling that they had been abandoned by services.

Hurried and unplanned discharges led to increased anxiety for users and carers who were already facing a frightening and uncertain situation. Mr and Mrs Eden described their experience:

Mr Eden: ... what made it worse when I was discharged from hospital, it was a sudden thing. It was over a bank holiday weekend and erm the CART team hadn't even seen me in hospital and er I got up on the Sunday morning, the nurse helped me to the toilet, I came back from the toilet and she just started helping me wash when they came up and said 'you're going home' ...

Mrs Eden: I just got a phone call to say that he was coming home and I went, what, and they said he'd be home within the hour. They said can you come and get him and I said no.

This couple faced the bank holiday weekend with no support services and no training, education or information. It was a dangerous and threatening time as Mrs Eden had received no training in lifting and handling her husband, he was virtually immobile and they had no idea when they were likely to receive support services:

Mrs Eden: But, as I say, the frustration here 'cos I just had to cope.

Mr Eden: I think that started it off, not knowing what was going on.

Int: So, a lack of information.

Mr Eden: Yes, you were left on a limb, not knowing whether to jump off or climb down.

Lack of information about the stroke itself and possible recurrence, was another major problem for service users and carers, particularly those who were not admitted to hospital, as it often took a long time before they had access to a specialist. Many respondents mentioned that they had not received adequate explanation of the condition, services and what to expect in the future. Carers felt unprepared for the role they had to take on:

Mrs White: I know everybody's stroke is different, everybody's relationships are different. Definitely try and get more information, the more information they can get I think, the better for them.

Int: That's information about the nature of the stroke?

Mrs White: And how to deal with things yourself.

There were instances where survivors, particularly the younger ones, appeared to have difficulties with the ways in which their situation was assessed. For example, Mr Bryant found it unhelpful when he was told, 'there's people worse off, it could be worse', his response was, 'to me it couldn't be any worse'. Mr Isles, having asked one physiotherapist if he could have instructions for exercises which he could do at home and been refused, sought help from another who was newly appointed. He felt this new practitioner was like a 'breath of fresh air', because he provided a such a programme and was optimistic and pro-active.

Comment Service users and carers, generally appeared to find the initial hospital experience following stroke satisfactory, particularly those who had been admitted to a specialist stroke unit. In such cases, they benefited from assessment and treatment by the multi-disciplinary team and were able to access support services after discharge. Intensive follow up care was highly valued and often led to attendance at other facilities. However, where discharges were not planned, support services were often delayed or on occasions not provided and this increased the anxiety and stress for everyone. Lack of information on stroke and education on caring for informal carers also added to difficulties. Recovery from stroke is a long process, often taking months and years, and users and carers felt that after a short period they were left to get on with it, leading to feelings of having been abandoned. The worker provided by the local branch of the

Stroke Association gave reassurance to many service users by giving them time to talk about anxieties, listening to them and reassuring them that their feelings and experiences were not abnormal.

5.4 Summary and comment

The professionals involved in the care and support of stroke survivors and their carers recognised the major impact which stroke had on the lives of survivors. Indeed, some of the practitioners felt that the loss was equivalent to a bereavement and used bereavement as a way of explaining aspects of the experience, especially when survivors seemed stuck in a 'stage' such as anger. However, we were unable to find any evidence either from the literature or from our interviews that survivors recognised or found this model helpful. In the best examples of practice, professionals and clients enter a therapeutic relationship or partnership and together set goals and work towards independence and recovery. This appears to work well when the aims are shared, but when the client wishes to achieve a goal which the professionals sees as unrealistic this can put a considerable strain on the relationship and the process of recovery. Some practitioners felt it was important to find a balance, to encourage clients towards recovery and planning short-term realistic goals whilst simultaneously discouraging over optimism and unrealistic goals.

Stroke survivors and carers were generally very positive in their views on the professional help they had received, particularly when they had a period of intensive follow up in the community. However, this treatment was usually very short-term, while the recovery from stroke was not and people were often left feeling isolated and abandoned. There were some survivors in our study who seemed to have fallen through the net, they had not been admitted to hospital, or were admitted to non-specialist areas and discharged without services or were discharged without adequate planning and preparation. These factors appeared to have a deleterious effect on service users and carers and added to the difficulties of adjustment at home. Additionally, some carers did not feel they were given enough information or adequately prepared for their new role. Survivors found that home visits from people attached to certain voluntary organisations were very helpful both in terms of the time they were given and the understanding of specific aspects of their post-stroke experience.



6

Discussion of findings and implications for professional practice

Our research project was designed to give people who had experienced stroke and the people who support them an opportunity to discuss the impact which stroke had had on their lives and in what ways they had coped with the new situation they found themselves in. In this concluding chapter we will discuss what went well and what was not successful, re-visit the key findings and draw out the implications of these findings for professional practice.

6.1 How successful were we?

In the review of current literature we highlighted the comparative lack of qualitative studies of life after stroke that give the survivor's perspective. We invited survivors to participate in our study approximately a year after the stroke event so that they would remember clearly the impact on their lives but also still be in the process of developing strategies to cope with the changes. As agreed with the ethics committee, we approached our volunteers through a third party. We had a much better response rate from those individuals who were approached by a professional who had supported them in the community than with those who were approached from the hospital. We reached our target number of interviews but unfortunately because of the shortcomings of the information from the databases, two of the respondents did not fully fit our criteria and we interviewed them after their second stroke. The interview format, broad topics with prompts seemed to work quite well and most people appeared to appreciate being given the opportunity to talk about their experience. The focus groups worked particularly well, participants commenting that they had found it both an enjoyable and a useful discussion. We were able to include two people with speech difficulties in our research as they had carers with them but as their actual speech was very limited we were only able to count their views statistically. For a future project we are employing the help of a speech therapist who specialises in aphasia, and hope, with her skills that this group of people might be able to take a greater part.

We were not as successful in accessing carers individually and from the interview conducted, the researcher became aware of issues, such as intimacy, which did not arise when both members of the couple were present. However, many carers were vocal in shared interviews and so

we were able to reflect their views on some aspects of life for them. We were able to access and ascertain the views of formal carers, both stroke specialists and generic practitioners.

We were less successful in getting stroke survivors to record self-report diaries, with only one volunteer actually completing a diary. We have not included the data we obtained in the findings for this project but in a future study such records can provide a separate body of evidence on which to draw and may help to reinforce and substantiate other findings. As this was a pilot study we were concerned to test our research methods and learn from our experiences. We have included an appendix that records our attempts to obtain such diaries and the ways in which we could improve our attrition rate.

In the next section we will discuss the key findings.

6.2 Survivors and their strokes: implications for professional practice

In this report we have demonstrated that stroke is a traumatic event for a person, which affects all aspects of their lives. There are psychological, physical and social consequences which are interrelated, impact on each other and force survivors to review and reconstruct their lives. Their role within the family often changes from being a partner and equal to being a person who is dependent on others.

- When considering the care of people who experience strokes it is important that all aspects of their lives are considered and assessed in planning care and that their priorities for recovery are known.

The invisible consequences of stroke were prominent in the interviews, particularly the psychological problems of loss of confidence, fear and anxiety. Some of the residual difficulties such as extreme fatigue and lack of emotional control were surprising and perplexing for individuals. Such disabilities were disturbing even for those people who considered themselves to have experienced a mild stroke.

- Service users and carers want more and accurate information about stroke itself and the possibility of reoccurrence, though it is important to be sensitive to survivors interest in such information, and what they could be doing to prevent such an event.
- Stroke Family Support Workers visiting the home and reassuring individuals by listening to them and normalising their experiences appeared to be providing an invaluable service to some families. This type of support and possibly additional counselling could reduce depression and the need for medication.

Individuals found the services provided by the specialist stroke unit and the community rehabilitation teams particularly helpful in their recovery. However, some of our respondents were admitted to general wards or not admitted to hospital at all and therefore missed this specialist care.

- Care on the Stroke Unit followed by an intensive period of rehabilitation in the community with the CART Team appeared to be the optimal initial support for older survivors and carers.

- Stroke survivors, whether admitted to hospital or supported in the community, need a degree of follow-up in the community to ensure that they are making progress towards recovery.
- Planned discharges should include carer education on managing practically and emotionally.

6.3 Getting back to normal: implications for professional practice

We discussed the ways in which many stroke survivors set themselves goals and developed strategies to achieve these in their efforts to reconstruct their lives. Such goals often related to mobility and getting about independently. Going out of the house presented challenges such as being outside alone, meeting other people, crossing roads and going to the shops. For younger stroke survivors there were issues around going back to work. Inside the house individuals strove to regain independence in personal care and in activities such as cooking and gardening. To achieve goals survivors put strategies in place, often breaking activities down into small achievable units, this strategy was most evident in getting back to going out. Strategies inside the house often involved negotiation around the kitchen, bathroom and stairs. We collected some practical strategies from participants that are included in an appendix at the end of the report.

- Stroke survivors often used goal-setting as a practical way of getting themselves back to normal. They developed creative strategies to achieve their goals often without any outside help.
- Younger stroke survivors felt they needed care which was more tailored to their specific needs such as going back to work or financial advice.
- Survivors who are housebound and their carers need to receive or have access to long-term support.

Most survivors developed mental strategies that they used to ‘boost’ themselves such as comparison with those who were less fortunate or feeling lucky or fortunate about an aspect of their life or recovery. They considered having the right type of personality and a positive outlook as assets in the recovery process. Some survivors were very frustrated at their perceived lack of progress and others literally housebound and they reported feelings of disappointment, isolation and abandonment.

- It is important that information, such as why an individual is no longer able to drive, is explained to them in such a way that they can comprehend the reason.
- Fitting of aids and adaptations should be prompt to enhance independence and allow individual’s access to the outside world.

6.4 Professional view of stroke and rehabilitation

The formal carers involved in the care and support of people who have experienced stroke and their carers accept that stroke has a major impact on all aspects of life and identity. Stroke was perceived as unique in the suddenness of onset, the variety of residual disabilities and the length of recovery time.

- In view of the long-term nature of recovery, there should be a worker or a support service which could provide some minimal support and monitoring for users and carers

Over half of the professionals interviewed explained recovery for the survivor in terms of a model of bereavement and loss, a psychological model of stages of grief that individuals go through after a severe loss. Poor progress towards recovery was sometimes interpreted and understood in terms of the client 'being stuck' at a stage in the process and unable to move on.

- Is the bereavement model evidence-based and does it assist the individual stroke survivor to understand and manage their recovery?

Professionals views resonated with users on return to valued activities such as getting about independently, going back to work, returning to social activities and hobbies as key part of rehabilitation and a return to normal life. Two practitioners suggested that adopting the 'stroke identity', by going to clubs and related groups and becoming actively involved was an alternative way of 'adjusting' to stroke and re-constructing individual identity.

- Formal carers considered attendance at stroke clubs and other outside activities to be very important in the recovery from stroke and reconstruction of identity.

When defining rehabilitation, formal carers agreed that it was a process of getting to an optimum level of independence. However, some practitioners framed their definition in clinical terms that emphasised function. Others used a 'person-centred' definition that emphasised the social and personal aspects.

- Using a person-centred approach to rehabilitation is more likely to be successful as the client sets the agenda in the context of their own recovery

As with stroke survivors, professionals used goals to measure progress and broke these down into small achievable units. Relationships worked well where the goals were mutual but when they were considered by the professional to be unrealistic, this hampered the relationship and progress towards recovery.

- Goals must be negotiated which are relevant to the client's priorities and that they want to achieve.

Practitioners sought to achieve a balance in goal setting, being realistic without discouraging. They considered that carer support was an important aspect of recovery and that those with such support progressed better. Whilst stroke survivors felt that a determined personality and a positive outlook helped, the formal carers believed those survivors with a 'laid back' personality fared less well. The majority felt that stroke services for younger people were inadequate.

- Formal carers could try to balance individuals aspirations and goals with realism, but without discouraging them.
- Professionals considered facilities and services for younger stroke survivors to be completely inadequate and this could be an area for further research.

6.5 Suggestions for further research projects

Our pilot study has identified the need for further qualitative studies into the experience of life after stroke. We were only able to provide a 'snapshot' of a point in time whereas a longitudinal study would demonstrate how things change overtime and also give insight into the way people adapt to such change. There is a paucity of research on younger people and stroke, impact on relationships and work ambitions. Stroke is over represented among people of Afro-Caribbean origin and a qualitative study of their experiences could identify gaps in services.



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Appendix 1

Strategies for Managing

The following are examples of strategies for managing everyday activities suggested by survivors and carers. We thought they might be useful to include here for other stroke survivors and their carers but we do appreciate that every stroke is different and that something which works for one person may not work for another.

Inside the house

i) The kitchen

- Cooking a casserole the day before and leaving it to cool before portioning it out.
- Planning ahead, cooking four meals at a time and putting three in the freezer.
- Carrying cups on a tray or a deep container to prevent spillage and so you don't have to put your hands around things.
- When making cakes, putting the mixing bowl on a low stool so that you can sit down while you mix and you don't have to keep lifting it up.
- Chopping, holding the knife in the left hand and placing the other hand on the object or use a board with a back on it or something similar.
- Using a travel kettle, using a minimum of water in the kettle.
- Using adapted or specialised equipment. Social services provided a spike-board as an aid to chopping. Betterware stock a container with a funnel and grater on the top which can be used for chopping most things.
- Building up gradually, working in the kitchen with someone else there to relearn and gain confidence.
- Sharing the cooking with someone else.
- Doing the bits you can, drying up with one hand and the dish on your lap or wedged between your knees.
- Use of a trolley (with a tray on top) to transport items e.g. cups and plates between rooms. Also provides some support for walking.

ii) Getting washed and dressed

- Organisation and planning is very important.

- Unscrewing the top of the toothpaste tube with your teeth, squeezing a blob of toothpaste onto the basin and scooping it up with the toothbrush.
- When washing, make a knuckle to clean the opposite underarm as you get more pressure and use the same procedure for putting on talcum powder.
- When getting dressed in clothes that fasten with buttons, start on the middle one and continue downwards, as you can see what you are doing and it takes the weight.
- Hitching your foot over your leg to get your trousers, socks and shoes on, the main thing is getting them over the leg.
- Leaving clothes set out either in a way and an order that makes it easier for you. Leaving them over the back of a chair can minimise bending down.
- Using pillows or cushions while sitting for supporting limbs and in bed to prevent rolling out.
- It takes time for carers to learn what is painful for others, particularly with paralysed limbs and for them to learn how much help is needed.

Outside the house

General strategies

- Planning and organisation
- Carrying a mobile phone so you can contact someone if there is a problem.
- Assessing whether or not you feel capable of going out on that day.
- Setting staging posts and building distances and confidence up gradually.
- Knowing where seats are placed (i.e in a shopping centre) so you can plan your route.
- Using a taxi or a bus while building up stamina and confidence.
- Going out with someone else until you feel able to go alone.
- Using a fold up walking stick as and when needed for longer distances.

Shopping

- Going at quiet times until you feel confident with crowds
- Not trying to do too much at once, walking round part of the supermarket and going to sit outside for a break if needed.
- Going with somebody else until you feel confident, a friend or relative, or using a support service such as the Red Cross. A bus service, the Kent Carrier, serves older and disabled individuals in rural community in East Kent and takes them into the city and home again and takes the shopping in to the house afterwards.

Crossing the road

- Using a crossing where there is a traffic island so you only have to consider the flow of traffic in one direction.
- Finding someone to cross with or asking somebody for help.

Appendix 2

Research Diaries

This appendix reviews the use of research diaries and describes the successes and problems encountered in our pilot study.

1. Methods and rationale

In research, it is difficult to observe every day life as the presence of an observer is intrusive and distorts activities and interactions. We have in previous research overcome these problems by using a self report technique based on diaries (see Zimmerman and Wieder, 1977). The technique involves three elements: an initial interview, the research diary and a debriefing interview.

The case study component of the pilot study involved the completion of diaries by individuals who had experienced a stroke in the previous nine to eighteen months. After an initial interview, we invited individuals to complete a diary of six-week duration. Prospective diarists were asked to make an entry at the end of each day and to record any 'significant' event that took place during the day. The initial interview avoided using the term risk as in this context it has been associated with critical incidents (Alaszewski et al, 1998). We invited each diarist to complete one or two trial days so that we could provide additional guidance on how to complete the diary. The content of each diary is to be analysed to identify the range of risk issues, the strategies used to manage them and the involvement of professionals. In our debriefing interviews we will focus on one or two examples of significant events and explore both the nature of the threats and opportunities, the strategies used to manage them and the involvement of professionals.

The use of diaries enabled the researchers to capture real life decisions and explore the implications of these decisions with diarists. The approach had three stages:

Briefing Interview: This initial interview was used to explain how the research diary was to be completed.

Diary: The participants who agree to complete a diary were given a diary and at the end of the interview and asked to provide a short

record of daily events and to pick out one or two incidents/situations in the day which have been significant to them for example — if they have attempted anything new, done anything differently, been out anywhere or had a particular treatment.

De-briefing interview: When the participant has completed the agreed number of entries the researcher will collect the diary and through identifying themes and classifying the entries, identify two experiences to explore in more detail. For example, if they decided to try walking without a stick, why they decided to do this and how it made them feel, would they have been encouraged to try and do this by support services.

The diary included the following written instructions:

Your Diary

The purpose of your diary is to help us gain greater insight into the way in which you are coping with life and the strategies you are using to develop your independence. We hope that this will help others who have had strokes and their carers.

Please provide a short account (about 100 words or half a page) of how you spent the day.

1. When you have done this could you identify one or two events in the day that were significant to you and describe them in a little more detail.
2. Next, it would be interesting if you could reflect on why this event was significant for you, what you were trying to achieve and how you over came any difficulties. Were any other individuals such as family, friends or carers involved in this event?
3. Can you think of any way in which your experiences could be used to help other people who have had strokes and their carers?

If possible we would like you to write the diary for six weeks (not necessarily consecutive weeks). We very much appreciate your help with this project.

When you have finished writing the diary Helen will come and discuss with you what you have written. If you have any problems you wish to discuss please do not hesitate to phone me 01227 827641.

2. Recruitment

Following the initial interview the participant was invited to complete a diary if the researcher considered the circumstances were appropriate, for example if the participant did not appear too ill or distressed. Initially there seemed to be a great enthusiasm and willingness to write diaries and the researcher recruited seven individuals. Details of the experience with each of these people had been included in an effort to try and understand some of the difficulties of the process.

Mr Eden: A 63-year-old man who had experienced a stroke fifteen months before and had moderate disabilities. He couldn't write but his wife said that she would be happy to write if he dictated to her. They felt it would be good for them to do the diary. The researcher telephoned after a week to find out how things were going and spoke to Mrs Eden who said they hadn't made a start because nothing of any significance had really happened. In the course of the conversation Mrs Eden mentioned that the occupational therapist had just visited to measure up for adaptations and how frustrated they felt about the length of time they had waited for this. I suggested that this was a good starting point for the diary and that we really were interested in the everyday things. She said they would have another try. About a week later I received the diary back with an apologetic note from Mrs Eden describing her husband's usual day and hoping that things would improve for them when the weather did.

Mr Charles: A 72-year-old man with mild disabilities following his stroke eighteen months before. He filled his diary in for two weeks before unfortunately experiencing a further stroke. His wife sent the diary back and explained that he had really enjoyed writing it but the second stroke had affected his sight and cognitive ability so she did not think he would be able to carry on when he came home.

Mrs Best: An 89-year-old woman who had mild disabilities following a stroke a year before. She contacted me about a week later and said that she had a new problem with her sight that meant that she would have difficulty in writing the diary. She also commented, as she had in the interview, that she felt her life was very boring and that there would be nothing of interest to write about.

Mr Neville: An 80-year-old man who had mild disabilities following his stroke fifteen months before. He was enthusiastic about keeping the diary and had kept a list on the calendar of his activities that he photocopied and sent. After a couple of phone calls Mr Neville sent me a couple of pages he had completed. I commented that as well as describing the activity of the day it would be helpful if he could reflect a little on what sort of day it had been. I rang a few weeks later to see how he was getting on and he said he hadn't written anything else because nothing unusual had really happened. I explained again what we wanted but he said he would only write again if he considered that anything interesting had happened.

Mr Jones: A 77-year-old man with moderate disabilities. He already kept a diary but wanted to write one for the project as he hoped his handwriting would improve. He sent me his entries for a couple of days and I again commented on reflection. He wrote his diary for about five weeks and then returned it having included a section at the end of each day which he called his 'important point' e.g. 'Getting the wheelchair out of a rabbit hole and got away by myself as it made me feel independent'.

Mr Tucker: A 76-year-old man with moderate disabilities following his stroke. I was a little concerned when he offered to do a diary because he seemed to find things quite a struggle but he wanted to write it on

the computer and e-mail it over to me. He said he would do a couple of days and then send it over for comment. He eventually sent over a couple of days that were written in great detail, one about going to the day hospital. I have received nothing else despite phoning and emailing. Mrs Tucker explained that they had had to put the house up for sale and that her husband was busy sorting out the legal issues. She also said that he only got to the computer about twice a week.

Mrs Dean: A 50-year-old woman who had slight disabilities following her stroke. I did not approach her about the diary at interview but phoned her later when other people seemed to be dropping out. She said she felt it would do her good to write a diary and that it might 'get her going'. She agreed to send me a couple of days entries when she had written them. I waited about two weeks before I contacted her and she said she had not started. I asked her why and she explained that she could not get herself motivated. From her voice she sounded very 'down'. I thanked her and said that if she did feel like writing we would still be interested to hear from her.

3. Lessons to be learnt

- i) The word 'significant' was a mistake as it gave the impression that we were only interested in 'important' events. I think a better way of approaching it might be to ask whether it had been a good or bad day and what made it good or bad. In their interviews people often speak of having good and bad days.
- ii) The instructions must be much tighter and reinforced by contact at regular intervals. I was surprised that some of the participants agreed to do the diary to the format suggested and then did not. I was also surprised that they offered to write it and then did not and did not contact me to say they were not going to do it. I wonder if there was a lack of realism and insight.
- iii) We need to be more imaginative about how people can record their diaries — e.g. supplying dictaphones, use of computers.
- iv) Need to ask everyone in a future study if they are willing to write a diary hoping that over recruitment will ensure an adequate number are completed.

Appendix 3

Study Participants

	Pseudonym	Age	Sex	Disability level (Modified Rankin)	Lived with	Interviewed with
1	Mr Eden	63	M	Moderately severe	Wife	Wife
2	Mrs Roberts	72	F	Moderate	Partner	Partner
3	Mrs Gordon	80	F	Moderately severe	Husband & daughter	Husband & daughter
4	Mr Moore	79	M	Moderate	Wife	Wife
5	Mr Tucker	76	M	Moderately severe	Wife	Wife
6	Mrs Arnold	74	F	Moderately severe	Husband	Husband
7	Mrs Early	50	F	Slight	Husband	Husband
8	Mrs Best	89	F	Slight	Daughter	Group
9	Mr Neville	80	M	Slight	Alone	Group
10	Mr Charles	72	M	Slight	Wife	Group
11	Mr White	66	M	Moderately severe	Wife	Alone
12	Mrs Hunt	89	F	Moderately severe	Husband	Husband
13	Mrs Kellor	80	F	Moderate	Alone	Alone
14	Mr Green	68	M	No significant	Wife	Alone
15	Mr Nail	81	M	Moderate	Daughter	Daughter
16	Ms Beaton	40	F	Moderate	Alone	Alone
17	Mr Jones	77	M	Moderately severe	Wife & daughter	Wife & daughter
18	Mr Timms	77	M	Moderate	Wife	Wife
19	Ms Quick	51	F	Slight	Daughter	Daughter
20	Mrs Dean	50	F	Slight	Husband & son	Alone
21	Mrs Garret	69	F	Slight	Partner	Partner
22	Mr Peters	43	M	Moderate	Alone	Carer
23	Mr Davies	73	M	Slight	Alone	Group
24	Mrs Kilby	66	F	Slight	Husband	Group
25	Mrs Miles	89	F	Moderate	Son	Group
26	Mrs James	79	F	Moderate	Alone	Group
27	Ms Harper	55	F	Slight	Alone	Alone
28	Mrs Dalton	79	F	Slight	Husband	Alone
29	Mrs Price	38	F	Slight	Husband	Alone
30	Mr Isles	54	M	Moderately severe	Alone	Alone
31	Mr Bryant	57	M	Moderately severe	Wife & daughter	Alone