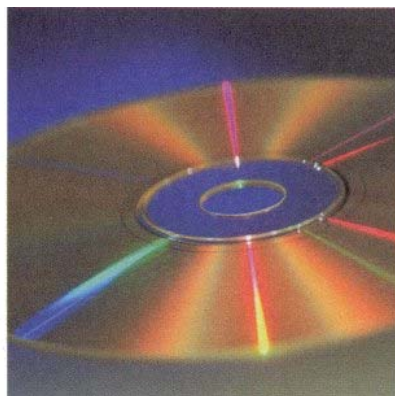
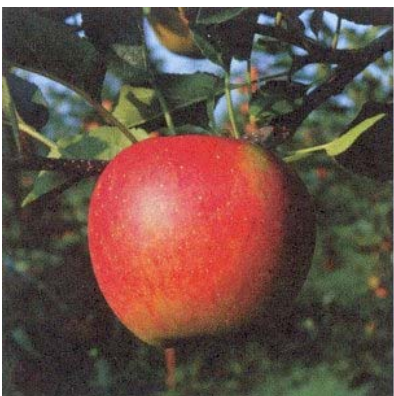


Communicating Information to Stroke Survivors

A Pilot Study



Helen Alaszewski
Annette King
Andy Alaszewski
CHSS

Jonathan Potter
East Kent Hospitals NHS Trust

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Librarian
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George Allen Wing
University of Kent
Canterbury

Tel. 01227 824057

Fax. 01227 827868

chssenquiries@kent.ac.uk

<http://www.kent.ac.uk/chss>

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June 2008

Helen Alaszewski
Annette King
Andy Alaszewski
Centre for Health Service Studies
University of Kent

Jonathan Potter
East Kent Hospitals NHS Trust

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Peta Hampshire
Administrator
Centre for Health Services Studies
George Allen Wing
University of Kent
Canterbury
Kent CT2 7NF

Tel: 01227 824057

E-mail: p.r.hampshire@kent.ac.uk

Fax: 01227 827868

www.kent.ac.uk/chss

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1. Executive Summary

1.1 Introduction

This study explored current approaches to communicating information to stroke survivors and their relatives. The aim of this pilot project was to gain better understanding of information provision about stroke from health professionals by exploring the perspectives of the stroke survivors, their carers and professionals themselves. The study aimed to explore, through qualitative interviews, how such information is provided, what works well in information giving, what the barriers to good information provision are and how these arise. The research provided a step towards developing an information toolkit for service providers, stroke survivors and relatives to engage in effective person-centred communication. The study is based on interviews conducted with health professionals in acute, community and primary care settings in East Kent and with a small sample of stroke survivors and carers. We interviewed 19 stroke survivors, 6 relatives and 23 health professionals (11 individually and 12 in 2 focus groups) involved in their care and support. To protect individual identities, we have changed all names in our report.

1.2 Research questions

The study addressed the following research questions:

- What perceptions do health professionals and service providers have of the information needs of patients and what strategies do they employ to meet these?
- What type of information do health professionals in acute, community and rehabilitation services have on stroke risks and how do they use it to advise on life style adjustments?
- What information needs do stroke survivors and their relatives have about risk factors and how to minimise them?
- What perceptions do stroke survivors and their relatives have about risk factors in stroke?
- How have stroke survivors used information about stroke in their daily lives?
- What are the factors that influence information exchange on secondary prevention, risk and self management of stroke?

1.3 Key findings

Communication of information: professional, stroke survivors and relatives

- Health professionals working in different parts of the care system had varied insights into the information needs of stroke survivors.

- Stroke survivors had changing information needs at different stages of their recovery; therefore timing of information for the different stages is crucial in ensuring that stroke survivors understand information fully and remember it.
- Immediately following a stroke, survivors and relatives can find it difficult to absorb information.
- Initially stroke survivors and relatives are most concerned about what has happened and their chances of survival.
- Memory and communication problems can contribute to difficulties in receiving, understanding and retaining information.
- Members of the stroke team all had different information to give and there is not always overall coordination of information to ensure comprehensiveness.
- Health professionals in acute and community services were aware that there can be gaps in information giving. They also were not always aware of what information others had given.
- Health professionals recognised survivors' needs for emotional support as part of the process of information giving.
- There can be an information overload when stroke survivors are discharged from hospital.

Support and rehabilitation in the community

- GPs saw their role primarily in terms of providing information on secondary prevention, for example, on cholesterol levels or blood pressure, rather than broader information on psychological and emotional aspects of rehabilitation.
- The community rehabilitation team felt there was sometimes a gap in communication between themselves and the hospital. This could result in a delay in care for the stroke survivors and their families.
- The stroke specialist nurse provided a post discharge follow-up phone call as she felt that most problems did not emerge until the survivor was back at home.
- The stroke family support worker saw her job as signposting people to support agencies, tailoring the information to their needs and lending a listening ear.
- Accurate information enables stroke survivors to make informed decisions about treatment and treatment options.
- The provision of information can aid a positive attitude to recovery.
- One stroke consultant felt that information given to stroke survivors and their families which was tailored to their individual needs enabled them to make informed choices within the context of their lives.

Stroke survivors and carers

- Stroke survivors stressed that appropriate and timely information helped them to understand what had happened, how they could reduce the chance it could happen again and how they could make the best use of support and services. Information that survivors and their families wanted depended on their particular circumstances, but also where they were in the recovery process.
- Stroke survivors and relatives did not always want to ‘hear’ information which did not fit with their hopes and aspirations.
- Stroke survivors and families often did not know anything about stroke and information giving therefore needed to start from a very basic platform.
- Stroke survivors and their families did not always know what questions to ask. This was particularly the case immediately after the stroke when they were likely to experience difficulty both in articulating questions and in understanding answers. Stroke survivors and relatives wanted opportunities in hospital and after discharge to ask questions and gain information.
- Information needs are likely to change over time.

Preferences in information communication

- Some stroke survivors may be very proactive in their information seeking, others may not have the capabilities or may not wish to do so. Information about stroke and recovery needs to be offered to survivors and relatives – the onus should not be on them to find out.
- Stroke survivors and their relatives found it helpful when a specific time for information giving with the patient and their relatives was ‘booked’ or set aside. On occasion, information was given in a hurry, particularly in hospital. Stroke survivors found this unhelpful and found it more difficult to ask questions when they perceived that health professionals were rushed.
- For stroke survivors and their relatives, information provision is only one aspect of the stroke experience, but it is pivotal to building a successful dialogue between health professionals and stroke survivor over the longer term.
- Stroke survivors noted and appreciated when health professionals used varied tools and methods to explain information about stroke, including the use of scans, drawings and charts.

TIA or minor strokes

- Survivors and relatives considered there was a gap in the information provided by health professionals and contained in the stroke information leaflets.
- Hospital admissions for TIA or minor stroke were brief and, because the survivors often had no physical needs, they could be overlooked by busy staff and could miss opportunities to access information and ask questions.

- In the community, this group was usually not eligible for services from the rehabilitation team and did not receive sufficient information and reassurance between out patient appointments.

Driving after stroke

- While most stroke survivors thought that there were clear instructions in the written information guidance, for example those issued by the Stroke Association, some stroke survivors found the details vague.
- Losing the right to drive not only created major practical problems but was also a threat to independence and a sense of being a competent adult. Most survivors and their relatives felt that they were well supported by health professionals and given clear advice. However, a small number of participants chose to ignore the advice given about driving.
- Loss of confidence was an issue which concerned stroke survivors in relationship to driving.
- Professionals involved in stroke care felt able to give general information about post-stroke driving but referred the survivor back to the consultant or GP for more specialised advice.

Secondary prevention after stroke

- Most stroke survivors were frightened of having a second stroke and were concerned to prevent it happening again.
- Survivors and their relatives wanted information about aspects of their lives they could take control of to minimise the risks of another stroke.
- Stroke survivors and carers felt the advice they were given was not specific enough in the context of their everyday lives, for example, how strenuously they could exercise at the gym.
- Survivors and relatives obtained their information from a variety of sources, including, information leaflets, the internet, newspapers but face-to-face communication with professional was an important and valued source of authoritative advice.

Information on medication

- Stroke survivors and carers indicated that they often had gaps in their knowledge of the medication they took. This included their role in reducing the risk of further strokes, in managing underlying clinical conditions and information about the potential and actual side effects. Knowing about these was important to stroke survivors particularly when medication was prescribed and had to be taken long-term.
- Stroke survivors and their relatives may find it difficult to recall information on medication because they have not had to deal with it during the hospital stay. They

felt that information on medication needed to be repeated and written down in detail on discharge.

- Stroke survivors and their relatives wanted opportunities to discuss, understand and gain reassurance on the often complex medication regimes early and discuss side effects. They felt that sometimes there was a lack in the continuity of care between acute, intermediate and primary services in relation to medication.
- Individuals who had TIAs and minor strokes in particular did not receive full information on medication and welcomed greater opportunities to discuss their medications and its possible side effects.

1.4 Recommendations

The responses of stroke survivors and carers indicate that they receive a substantial amount of information through various channels, in different ways, and that there are examples of good practice. There remain gaps in the information provision, particularly with regard to information about the personal circumstances and individual information needs, which need addressing.

Overall we would recommend

- That the stroke services in East Kent develop an information provision strategy, which is an integrated part the overall stroke service development across the acute and community and primary care services.
- This strategy should aim for a person-centred approach, which can be responsive to the changing information needs of stroke survivors and their families. It should be based on a personalised approach to information provision, which is tailored to the individual circumstances of stroke survivors.
- The strategy should integrate and expand on the successful local elements of information provision, but also should look outside the area for evidence of good practice.
- The development of the strategy should involve the health and social care and voluntary sector stakeholders, as well as patient groups. Stroke survivors, carers and health professionals should be closely involved in its design and use their experiences and expertise in reviewing it. It should be disseminated widely and proactively across the service area.
- The information strategy should not only provide written materials, but also examples of continuous communication between health professionals and stroke survivors, developing and cascading examples of good practice, training and education, and the use of third party information provision (for example, the use of internet websites etc.).

We would also recommend

- During the hospital stay, the coordination of information provision could be further streamlined, so that all patients and carers are prepared appropriately for discharge and are reassured about their continuity of care when they return home. This is particularly important in the context of shorter hospital stays, which limits the opportunities for information exchange between health professionals in hospital and patient/carer.
- Information provision for patients who had a TIA or minor stroke often do not have the opportunity to discuss their strokes and receive advice and information. Particular attention should be paid to improving information access and continuous support for this group of patients.
- Stroke survivors and carers need the space at different intervals in the recovery process to address their changing information needs. Primary care should assume a greater role in proactively discussing stroke information particularly at later stages of the recovery process.
- We found a number of gaps in the provision of information about medication, particularly on discharge from hospital and in the community. Information about the medication taken needs to be provided in writing and in a way stroke survivors and their families and carers can understand. Developing an effective and innovative solution to this could involve pharmacy services in hospital and in the community.
- Greater emphasis should be placed on detailed and continued advice and information on life style, not only to help minimise the risk of further stroke generally, but also to increase the feeling of control stroke survivors have over their lives. It should include, for example, discussions of relevant aspects of every-day life such as diet, physical exercise and stress, including a discussion of what the stroke survivor already does and what she/he would like to achieve.

2. Introduction

The project on which this report is based was funded by a grant from East Kent Hospitals NHS Trust Charitable Fund. It explored current approaches to communicating information to stroke survivors and their relatives. Our previous research into stroke survivors' recovery identified lack of information as a major impediment to rehabilitation (see Alaszewski et al, 2005-7). A longitudinal study of stroke survivors' experiences indicated that while professionals did provide information there were a number of barriers which prevented survivors understanding and effectively using this information. In this study we wanted to explore what these barriers are, how they arise and how service providers, stroke survivors and relatives¹ can engage in effective person-centred communication. We interviewed 19 stroke survivors, 6 relatives and 23 health professionals (11 individually and 12 in 2 focus groups) involved in their care and support. We have changed any names and some of the job titles in our report to protect individual's identities.

Strokes are a major cause of long-term disability amongst adults and older people and are a major 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 (DH, 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 prevention, rapid diagnosis and early treatment can contribute to reducing both the incidence and severity of stroke, stroke survivors and their immediate families have a key role in rehabilitation and secondary prevention. In this, they need assistance and support from services and professionals through effective provision of accurate and helpful information. For example, if survivors and their families are to engage actively in secondary prevention by making life style changes, they need to have accurate information on risk factors such as smoking and eating fatty foods and information on how to reduce their risks.

Our research on the rehabilitation of younger stroke survivors indicated that there were major shortcomings in the provision of this type of information, and in the way it was communicated. For example, some respondents interviewed for the study were unaware of the restrictions on driving after stroke, while others did not know about the process of regaining safe driver status after stroke. Similarly, some respondents also indicated that they lacked knowledge about risk factors associated with life style. Current guidelines specify that all stroke patients should routinely receive this information. For example the National Service Framework standard for stroke (DH, 2001) clearly specifies that as part of treatment and care professionals should give 'advice to patients and relatives to help them manage the effects of stroke on their lives' (para 5.22) and specifically that 'Patients and their families should be provided with information advice and support to prevent further strokes'" (para 5.26). The evidence from our study suggests that such advice and information is not reaching all stroke survivors and their families.

¹ In this report we use the term "relative" generically to include family and friends who are engaged with stroke survivors and support them in their rehabilitation. Relatives are also sometimes referred to as carers, but we have avoided this term as it may be misleading in terms of the type and nature of the support given.

3. The Research Context

3.1 Policy

Information about prevention and successful illness management are central to minimising the consequences of chronic illness in the population. Good communication in stroke has been recognised as a significant aspect of stroke service provision and is part of the drive to inform patients about their conditions in a way they can understand. The National Clinical Guidelines for Stroke (2004) for example recommend that information provided to patients should take account of the needs of individual patients; that carers and patients should be able to access information specific to ‘their’ impairment; that information needs to be translated into languages other than English; that stroke services should provide ‘education’ programmes to assist patients and carers in adapting to living with stroke (p. 19-20).

The consultation on a new strategy for Stroke (DH 2007) also highlighted the role of information not only in ‘educational’ terms but also as a vehicle for reassurance and for enabling choice in care after stroke. Specific issues highlighted in the consultation included:

- Reassurance about the transition to primary care and social care upon discharge from hospital
- Information about cooperation between secondary and primary and social care
- Information and links to the voluntary sector and stroke organisations.

While these documents demonstrate that there is a growing consensus on the need for improved information and communication as part of the stroke strategy, the recommendations do not contain enough detail on how to approach information provision, what to include and in which form. They also lack a clear definition of what constitutes good stroke information. Responses to the consultation on the new stroke strategy picked up on this (DH, 2007). Respondents highlighted the need to include families in the information context, to provide specific information on preventing stroke and TIA in high-risk groups, and the requirements for continuity of information across all stroke service areas (acute, community and primary care).

3.2 Key points from the review of evidence

One of the problems in developing detailed guidance on stroke information provision is that the evidence on ‘what works’ remains underdeveloped. As part of this study, we conducted a brief review of the literature on the stroke information provision (see Appendix 2). The purpose of the review was to provide a preliminary analysis of the research evidence on stroke information giving, and in particular evidence on good practice, which is evaluated through research.

Overall, the review supported our initial impression that research evidence on information provision is still a developing field, which covers a diversity of issues and factors and that evidence of a systematic development of integrated and comprehensive information provision is limited. Studies covered a range of topics, including identifying current needs and gaps in information provision in different settings (acute care, rehabilitation, community) and at different points of recovery; exploring what contributes to good information flow and

communication and how health professionals and stroke patients think about this; how stroke survivors and carers understand stroke and its causes; what the psycho-social factors affecting communication in stroke are (see Appendix 2).

The project looked at the different perceptions health professionals, stroke survivors and relatives/carers had about information needs and the ways in which these were met. In the review we identified several themes:

- Health professionals and patient/carers reported that there were gaps in stroke information provision. These gaps related to, for example, the provision of personalised information, the quality of information leaflets, access to relevant information in the long-term, continuing access to information after discharge and access to information in the community.
- Studies identified a diversity of information needs for stroke patients.
- Studies highlighted differences in perceptions in what patients and carers perceive as important information and what health professionals think patients and carers need to know. A number of factors, such as gender and age, also played a role in determining information needs of patients.
- Information needs for patients and carers changed over time. This was recognised by health professionals, who may not have been in the position to cater for this changing need adequately, as patients moved into a community setting.

As yet, there are no evidence-based comprehensive interventions which stroke services could use as examples of best practice to guide information provision within the stroke services. Rather, it seems that information strategies need to address the complexity of the stroke experiences, which are highlighted by the changing needs, capabilities and preferences of stroke survivors and their carers.

4. Findings

The findings explore professionals, survivors' and relatives' perceptions of current information needs and how this information is currently communicated. Sections 4.1 and 4.2 consider the professional perspectives since professionals, especially those who specialise in stroke care, have experience of stroke survivors' and relatives' information needs and of meeting them. Sections 4.3, 4.5 and 4.6 discuss survivors' and relatives views especially their perceptions of the strengths and weaknesses of current practices.

Sections 4.7 to 4.9 focus on the provision of information about three specific topics that are relevant to most of stroke survivors and their families: communication of information about driving, secondary prevention and medication. The sections examine the significance of each of the issues in the survivors' lives and the ways in which this shapes the information they need. They consider the survivor and professional perspectives on the ways in which information is provided and the extent to which the information provided meets the needs of survivors and their families.

4.1 Professionals' perceptions of information needs

In this chapter we explore the perceptions that stroke specialists and generic health professionals have of stroke survivors' and relatives' information needs. We will explore the immediate information needs in the hospital, then at discharge and finally in the community. We will then discuss professionals' views of the impact of information, what specific information they provide and finally the issues involved in trying to ensure that survivors and relatives get the information they need.

Hospital and acute care

Communication immediately after stroke It is mainly the medical and nursing staff who are involved with the patient at this very early stage following stroke. Professionals involved in acute care following stroke felt that their patients had different information needs at different stages of recovery. The professionals interviewed noted that at this time the survivors were most concerned about what had happened, where they were and what was likely to happen to them. As the manager of a stroke unit in the multi-disciplinary team focus group explained:

Immediately it's what's happened? Where am I? Can it happen again? Can you tell me what's going on? Will it happen? Am I going to die? Or how quickly can I get out of here?..... Seeing them so acutely though, a lot of them they're not even able to rationalise that far ahead. It's what's happening now? Where am I now? Who is this person? What's going on?

The two stroke consultants in the study also reported that patients wanted to know what had happened and where they were but they stressed that patients were concerned about the future and want to know how long it would take them recover, if they would make a complete recovery and how they could prevent it happening again. One consultant discussed the sort of information that patients wanted in the following way:

Well, I think they all want to know why it happened to them, whether they are going to recover, how long is it going to take, how much is the recovery going to be. Whether they will be able to resume their previous particular and social activities, driving, whether they, especially the younger patients, whether they will be able to return to work. What else do they want to know? Whether it can affect their family, some they asked recently because someone might have had a stroke in the family and they want to know if there are related risks for their siblings or children. They want to know when they will be discharged, stuck in hospital. Some of them want to know more.

Professionals also noted that in addition to the shock of stroke, a number of stroke survivors had residual problems which formed barriers to their ability take in information such as problems in communication either speaking or understanding and memory problems.

A stroke specialist nurse noted that patients' information needs changed over time, describing the recovery from stroke as a 'journey' which patients made in stages:

But I also think that their information needs change depending on where they are in the journey so things that I may tell them in here I may need to reiterate when I

Speak to them on the discharge call but also by then they've got new needs for information.

This nurse explained that timing was very important for information delivery and described how she could spend time showing patients a stroke handbook before discharge and ringing them up later. She found that she often had to repeat information as patients often had no recollection of being given any information.

Communication after the initial shock Stroke survivors stayed in hospital for varying lengths of time and were involved with a number of health professionals and therapists according to their residual disabilities. The members of the multi disciplinary team we interviewed felt that patients wanted both specific technical information and general reassurance. A speech and language therapist noted that she spent time explaining dysphasia and speech problems. Professionals recognised that patients also needed other kinds of support and communication and provided reassurance and hope. A dietician commented:

It depends on what state they are at. There is an awful lot of reassurance they need to be given. There is an awful lot of 'What did I do to get the stroke?' 'What did I do wrong?' 'What didn't I do wrong?' 'If I didn't do this, or did do that, will it stop the stroke or will it stop another stroke?'

Some professionals reported that they were cautious about providing too much reassurance as they felt it could give patients and relatives false hope. They tried to create realistic expectations. An occupational therapist in the rehabilitation team focus group argued that:

I think that people want hope but you mustn't give them false hope, I think, that's my experience of the stroke patients I have had. They want to know what's going to happen, whether they're going to get better and it's quite tricky really to be realistic without taking their hope away.

The ward manager from the stroke unit suggested that nurses differed from the other therapists in that they did not have a specific body of information which they gave, but that they were often there at times when patients expressed anxieties and needed to address these anxieties. She gave the example of night care in hospital:

It tends to be everything that they say to all the other therapists because, you know, it's the middle of the night things, the waking up in the middle of the night with worries, concerns. Usually if they've become unwell with something else it is going to lead to a stroke so the feeling is that everything could turn in to a stroke. And then the things that are unrelated to actual how they are physically feeling, it's worries about work or how they're going to manage their home type of thing as well, it's financial worries

Professionals noted that when they were approaching discharge from hospital, stroke survivors and relatives needed to be given information on a number of issues such as medication, rehabilitation, and further tests. Some professionals expressed concern that there was an 'information overload' at this time. One stroke consultant explained that he preferred to give written information over the course of a patient's hospital admission so that they had time to read it and think about the questions they needed to ask.

Support and rehabilitation in the community

Stroke survivors are cared for in the community by the primary health care team led by the General Practitioner (GP). The GPs we interviewed saw stroke survivors' information needs mainly in terms of secondary prevention, i.e. control of blood pressure, lowering cholesterol and making lifestyle changes. The GPs tended to delegate much of the routine management of longer-term care to practice nurses who monitored patient compliance by measuring blood pressure and cholesterol levels and provided lifestyle advice. The pressures on general practices to achieve government targets meant that there was a strong emphasis on the technical aspects. The key Quality of Outcomes Framework (QOF) targets for stroke relate to discrete physical functions as this GP describes:

Anyone that has evidence through QOF of stroke or peripheral arterial disease or cerebro vascular disease, we attack them and they are on the conveyor belt. They have their regular blood tests, they're on their drugs ... Cholesterol, smoking, oh yes, the full gambit, screening for their diabetes all the time, so that's the main area of activity.

There is no incentive for GPs to recognise and deal with emotional or psychological problems unless the patient is diagnosed with mental illness. Such issues appear to be filtered out of the interaction and seen as the responsibility of other organisations. When asked about the kinds of issues stroke patients raised, a practice nurse replied:

They don't actually, besides the usual, you know, the blood pressure and diet, they don't really bring up diet, I suppose we usually bring that up cholesterol levels and things, they don't really, I think they must be very well cared for, you know, outside hospital, various organisations, stroke association and things.

Stroke survivors who fit the criteria for involvement with the rehabilitation team are eligible for 6 week intensive tailored therapy. However members of the team are not, stroke specialists and people with stroke make up only a small percentage of their client group. In a focus group interview, the rehabilitation team discussed the transfer between hospital and the community and a physiotherapist felt that there was room for improvement in communication:

I feel the communication between the stroke unit and us needs to be better because I feel sometimes if patients come out, they haven't made much recovery and they're not going to make much more recovery and they're going to get this wonderful care in the community.

The team provided on-going information for their clients. An occupational therapist in the team felt it was her job to help clients to accept and manage as they are. The stroke specialist nurse in one hospital provided a two week post discharge follow up phone call and explained that different issues arise when people get home:

It's usually the psycho-social issues and that's why in some ways I strongly believe that people should be ... I personally believe that we should discharge as early as we can because they can't deal with those within a hospital environment which is very false and very much our environment and not theirs.

She also commented on the lack of support in the community:

but at the same time we need to find that balance and get support out there – enough support out there because one family support worker can't do everything in life and also the family support worker isn't always the right person at the right time so at the moment I don't think that we're meeting what we could be meeting in the ideal world.

The family stroke support worker provided information and help to stroke survivors and their families following discharge from hospital, and received referrals from any health professional or self-referrals. She described her role in this way:

Well I work for the Stroke Association and I visit people at home when they've had a stroke and sometimes I'll meet them on the wards in the hospital and I give them information and have a sort of listening ear. I can signpost them to various other voluntary groups as appropriate.

She explained that people's information needs were as diverse and individual as their strokes so it was difficult to generalise but after picking up some individual information from the ward she tried to tailor the information she took with her when visiting a client. Besides checking up on medication issues, she provided information on support groups, respite services, available transport for those no longer able to drive. As well as providing factual information, the supporter worker offered a 'listening ear', providing emotional and psychological support.

Professionals acknowledged that in addition to factual information, survivors and relatives needed emotional support in terms of reassurance and hope. Care and support within the community appeared to focus on secondary prevention, with little provision for emotional and psychological support.

4.2 Professionals' perceptions of the impact of information

The majority of the professionals interviewed stressed the importance of information provision, how it could contribute to survivors approach to recovery and the recovery itself. Talking about the impact of information, a number of practitioners explained that it encouraged a positive attitude towards recovery. For example, a physiotherapist stated:

Information tailored to them as individuals is extremely valuable, so it is knowing perhaps realistically what your limitations are, and then rather than looking at it as a negative thing, trying to see that as a positive. They may not be able to get back to level they were before, however, they may be functioning at a level nevertheless. So it is about finding the positive and then trying to apply that in various contexts, so that they can have a good quality of life.

Professionals described how they tried to find positives for stroke survivors at a potentially negative time in their lives. In tailoring information to individual needs, a practice nurse explained that:

I would never give out just booklets in one go I would always give out an invitation for them to come back if they need to and discuss any issues or anything.....Yes and it gives them control over things.

Information could be given in a number of ways, and this practitioner stressed the importance of information that was tailored to the individual rather than being general. A stroke consultant explained that access to information allowed people to make informed choices about their lives:

It's their life, they have the right to know, and make informed choices about potential operations, whatever it is. I think it is very important.For most people, I find it will need reinforcement and maybe small amounts of information at one time.

A number of professionals felt that information could have a positive impact on the recovery of stroke survivors but it needed to be given in an individualised form which enabled them to make informed choices.

Professionals acknowledged responsibility for imparting a certain amount of information to stroke survivors but were careful to refer them back to another person within the team if they felt it was not in their sphere of practice. For example, a care manager who saw her main information provision as based 'on money and finances', such as provision of benefits advice, explained that she was wary about answering questions on topics outside her special area, such as secondary prevention:

I could answer but I actually feel that as a Care Manager now that, you know, that's possibly either going to be treading on toes or putting me in a little bit of a difficult position really. So I actually try to point them in the right direction, so I would possibly point them back to the nurses or whoever would be appropriate to ask really about that I think.

It was not just a lack of specialised knowledge that prevented her from answering such questions but she was also sensitive about the feelings of other professionals in the team. In a focus group interview, members of the rehabilitation team admitted that there were gaps in who should be providing certain parts of the whole information package:

Nurse A *It's the lack of continuity and not knowing what other people have said...*
Nurse B *Not owning responsibility. You might go and do an assessment and think that someone else is going to tell them. It's not clear whose role it is. There is an assumption that someone else has done that or will do that.*

If information giving is fragmented and professionals are wary of treading on each other's toes, it is likely that survivors and their families will spend a lot of time being referred from one practitioner to another or that things get missed in a pressurised service.

There is a large body of information on different aspects of treatment and recovery which professionals need to pass on when patients are discharged from hospital and because of pressures on staff and receptive difficulties for stroke survivors it is possible that things get missed. Information needs to be given at a time when the stroke survivor is receptive and

may need to be repeated. Personalised information should be provided alongside written and the professional responsible should record what has been given and when.

4.3 Stroke survivors' perceptions of communication

Stroke survivors' and relatives' perceptions of the need for and quality of information

In this section we explore the impediments to successful communication and information exchanges between stroke survivors, their families and professionals involved in their care. In the first part of this section we examine the residual effects of the stroke that impact upon survivors' abilities to take in and retain new information. In the second part we explore how survivors and relatives felt they were given information about stroke and why this was often not satisfactory from their perspective.

Having a stroke is a serious and frightening health event which often results in admission to hospital. The uncertainty which surrounded their future and the likelihood of another stroke made participants and their relatives feel very anxious and the shock made it difficult to "think straight". Mrs Vine, 45, described the ways in which her stroke undermined her sense of security and ability to trust, thus making her feel anxious, vulnerable and not able to rely on her former knowledge and experience:

I've been thinking about things because I think it was just such a shock that I didn't necessarily think about the things that now seem like logical to ask because it's just all so unreal.

Mrs Vine found that her stroke experience undermined her sense of trust and made her anxious about new experiences such as going for a scan:

but things just seem more scary now because it's like not being able to trust anything because this has happened and you don't understand why and everything is so different to what it was before, then anything new just seems as though its not going to be nice. And I knew they wouldn't hurt me but it's just not knowing what is going to happen because everything now is so not real, everything now is not real because I'm not like I was. Everything is just the opposite of what it was before....

Survivors felt it was important that they were provided with information as the hospital was an unfamiliar place that could be frightening if they did not understand what was happening and why. For example, Mr James, 58, became very concerned when, following the insertion of a naso-gastric tube, he was not given any medication for 5 days:

In fact I was scared and I expressed the fact, in fact I really lost my temper with the nurse and it wasn't very nice for her.....I thought they were trying to kill me because I hadn't had any medication and I hadn't had any food for five days and I couldn't understand why.

Thus some survivors felt that their past experience was no longer relevant and did not help them understand the shocking experience of managing their life in the frightening hospital environment. Some of these survivors felt that the experts who were responsible for their

care overestimated their knowledge and expected them somehow to understand what was happening

Barriers in the immediate aftermath of stroke A number of survivors noted that they had experienced problems with understanding, processing information and with communication (speaking and listening) generally immediately after the stroke. Some of the problems related to the consequences of their stroke such as loss of short-term memory, hearing problems and not being able to concentrate and other reasons for not asking for or retaining information. Miss Knight, 78, explained how she had problems retaining information saying ‘*I don’t remember much about it to begin with.*’

These difficulties were exacerbated by the ‘shock’ of the stroke. Survivors described how, in the immediate aftermath, they felt scared, confused and not really able to understand what was going on around them which made them feel vulnerable. Such experiences affected people differently. Mr Norris, 69, reported that he became angry or ‘ratty’ because he could not understand what was going on:

I was a bit ratty at this stage because I didn’t want to be there, I couldn’t understand why I was there and when I can’t understand something I get ratty.

Mr Long, 64, said that he had become passive and did not ask questions. A third stroke survivor reported that could not think logically enough to articulate important questions

You lay there and think ‘What am I doing here?’ and nothing seems to occur to you, you know. To ask any questions, you know.

Mrs Grant, 86, felt annoyed with herself that she had not asked questions but felt that the staff expected her to know about stroke:

They all seemed to take it for granted that I grasped it. You know, I had never had experience, I didn’t know anybody with a stroke. And I didn’t asked questions either, that is what annoys me now. I didn’t ask questions.

While communication could provide explanations and reassurance, it was also important in re-establishing survivors’ sense that they had some influence over what was happening. Some survivors reported that they felt ‘talked over’ by those involved in their care. This not only deprived them of information but also their status as competent adults. Miss Knight, 78, knew she had, ‘all her onions’, but found it difficult to articulate her thoughts and felt patronised when she asked a question and was met with the reply:

I wanted to know what my chances were and I wanted to know what I could do to help myself and I suppose somehow I got the answers but they just said ‘don’t you worry about that – let us worry’, but I did worry really because I wanted to know.

65 year old Mr Harvey commented on the communication at his out patient appointment:

Well, I’ve asked, now and again, is everything alright? I haven’t said, is there anything wrong? You say, is everything alright, and they say, yes. They don’t

actually say, don't do this or don't do that, they just, well, they don't say anything really, just goodbye.

These two survivors felt that their questions had not been answered in a straightforward way and important information had been withheld.

Several survivors felt that a major barrier to effective communication and information giving in the hospital setting was the 'busyness' of staff, which meant they and their relatives were reluctant to take up their time. This left some survivors with an impression that it was their responsibility to ask rather than information being freely given as described by 48 year old Mr Duncan:

You do want as much information as you can to be honest. So I was always... sort of always fishing for it to be honest. They're busy people I know and people are having strokes all the time but I did have to ask.

A number of participants mentioned staff shortages and felt that they had left hospital without discussing their stroke with staff. Mrs Harris, 63, had used alternative sources of information, booklets on stroke, but felt they were not a substitute talking to staff:

Well they were so busy because they're always short of staff and that. There wasn't anything, you know, I did read the booklets there. I made a point of getting them and reading them. No, not really because as I've said they didn't tell you an awful lot. They're too busy looking after you to.

Having a stroke is a traumatic experience that can visibly impair ability to understand and communicate but it also creates less obvious impediments. Since a stroke is a disorienting and shocking experience, individuals wanted information that would help them re-establish their sense of normality and regain control of their lives.

Continuing challenges in communication Information giving is a complex activity which involves not only the functional activity of providing information or specific facts but involves a relationship between the giver and receiver of the information. If the information giver does not develop empathy with those they are seeking to communicate with, then they will have only a generalised understanding of the receivers' situation. As a result the information giver will not be able to adjust either the mode or content to the specific circumstances of those they are trying to communicate with.

Thus stroke survivors felt that information needed to be both understandable and relevant. Since stroke survivors often had continuing cognitive difficulties, such as short-term memory loss, and sometimes found it difficult to understand the terms being used, they might remember that professionals had given them information but could not recollect the precise nature or content of that information. Mrs Turner, 65, who had short-term memory problems commented:

I'm not saying they didn't because I can't swear to it, I can't remember but whatever they told me or didn't tell me, it was no use to me. It wasn't a piece of information I could put in context.

The information given was not useful for her as it was not put into a context which was meaningful for her. Other participants commented on struggling with the language used by professionals. For example, Mrs Vine, 45, explained why she looked up stroke survivors experiences on the internet:

And on some of the websites it's got what happened to other people when they had their strokes and got better and I think sometimes because they are people like me I think you relate to it more than what the doctors say because it's all, I'm not saying they're not giving you the right information or they're misleading you it's just it's more my sort of English, which is idiot English not medical English which I don't always understand.

She went on to explain that she was not being critical of doctors but the information 'sometimes goes over your head a bit'.

Stroke survivors and their relatives were often concerned about their lack of background knowledge. This meant they found it difficult to interpret information or to ask the right questions. A number of participants in our study admitted to knowing nothing about stroke before their own experience and to not knowing anyone who had experienced one. Their lack of knowledge about stroke contributed to their need for effective information giving but also meant they felt at a loss to know what questions to ask. Mrs Carter, 76, stated:

I don't think the public understand enough about strokes and I don't really know what you can actually ask because, you know, you don't know what to do.

Mrs Young, who was caring for her 55 year old husband following his stroke explained:

I think that I, I didn't really take it all properly. I didn't realise how many things it affected. I really was in, I didn't know nothing about strokes. I didn't know, I thought, 'oh, in a few weeks he'll be alright'.

Participants were sometimes given information which they either did not want to accept or found hard to accept. Stroke could undermine a person's sense of security especially if it threatened everyday life, for example information which indicated that recovery was likely to be slow or partial could to undermine their expectation of a rapid recovery and return to normal everyday life. In this study a number of our participants described how it took them time to reach acceptance of what had happened to them, not only to accept the diagnosis of stroke, but to accept living with the consequences. For example, 57 year old Mrs Baldwin listened to the information which was given to her but because of her age thought it would not be applicable to her and therefore disregarded it:

As I said, I didn't necessarily believe any of it was to do with me at the time. I thought I was going to be different and get better much more quickly.

Mrs Vine, 45, found it hard to accept that nobody could tell her how long it would take her to get better:

I think a lot of it is learning to accept what has happened and that it isn't going to happen over night

For a third participant, acceptance involved realising that he had to live with the side effects of the medication he was taking (he did not specify them in the interview) as it was probably the medication that was keeping him alive. Mr James, 58, admitted that he did not like the answers he was getting from the doctor but eventually accepted them. Mr Leeman, 72, described his strategy of putting problems to do with the stroke at the back of his mind and coping by not accepting that he had had a stroke.

Comment The stroke survivors in our study commented on the difficulties they experienced when trying to understand information given to them by professionals post stroke. The reasons for this lack of communication were varied but our research indicated a variety of impediments to effective communication. Some of impediments related to the ways in which professionals presented information. However stroke survivors acknowledged that they were also reluctant to 'hear' information which conflicted with their desire to 'normalise' their lives as quickly as possible.

4.4 Relatives' perceptions of communication

In this section we explore the perceptions of carers of stroke survivors on the information they received and the way in which it was communicated, immediately after the stroke, on discharge from hospital and in the community. There were six carer interviews (plus one other interview with a stroke survivor, where his wife also participated). Carers views were often very similar to those expressed by the survivors but there were specific information needs which the carers felt were not addressed.

Immediately after the stroke Relatives, such as Mrs Yorke, whose husband had previously been fit and well agreed with stroke survivors that stroke is a life threatening event which happens suddenly:

Anyway, but, he's been very healthy, very fit and this stroke came out of the blue.

Carers and relatives had little prior knowledge about stroke and did not recognise what was happening. Mr Dennis explained:

Well, you know, at first you don't know anything about strokes because it happens without your knowing and in fact....., we didn't realise what it was at first.

In the immediate aftermath of the event they were in a state of shock:

Oh dear me. I don't know, I think you're so in shock with it all that you didn't really look into it too much.

This affected both what carers wanted to know about the stroke and how much information they were able to take in. Mr Cameron sought reassurance that his wife was going to be alright rather than details of her condition at this stage.

I don't think there was too much that I wanted to know, I mean apart from was she going to be alrightbecause you don't know what is going to happen, whether

she is going to be alright, whether it's going to be really bad. You're too worried at the time to think about what's going to happen later on.

Mrs Yorke and her son had an interview with the doctor but found it hard to understand everything and would have liked more time:

I found it a bit hard to understand.You know, it feels like sometimes, yes they answer our questions but it feels like sometimes, you'd like to have a little bit longer and slow it down to take it all in but there again, they are busy people and you understand that they've got a job to do but you, know, there are things sometimes when you think, I wish I'd have asked this and at the time, when you are trying to think what you want to ask, you don't always ask it.

During the hospital admission, Mrs Yorke was unhappy about having to seek out information rather than it being offered:

Mrs Yorke:.....you still wonder whether it's possible for it to happen again....

Int: So did you manage to get the information that you wanted from them?

Mrs Yorke: It wasn't forthcoming, I had to push for it.

Two of the six carers we interviewed thought they had been involved in all the decision making and consultations. Mr Dennis whose wife had had a number of hospital admissions before the stroke felt that communication between professionals and patients/carers had become a much more equal exchange:

.....it's been a revolution, as far as I'm concerned, that things are so different now. Doctors talk to patients, doctors talk to nurses and they talk amongst themselves and it's a completely different attitude, I've found - a very welcome one.....I find it's a far more relaxed relationship; doctor to nurse to patient.

Discharge Stroke survivors were sometimes discharged more quickly than originally stated and this left carers feeling a bit uncertain and unprepared. Mrs Yorke had initially been told her husband would be in hospital for 3 or 4 months but he was discharged after 13 days:

I was a little bit nervous about him coming home, you know, wondering what was going to happen, you know, I did wonder what would happen and how things would go. I mean he came home and at the beginning, naturally he was a lot worse than what he is now. He lost all his confidence. I mean he couldn't, there was a lot more that he couldn't do and he needed a lot more help with, I mean, he wasn't talking much then and I suppose really I would have liked at that time perhaps, somebody coming out a bit more to just make sure I was OK.

Mrs Young's husband had had a severe stroke which had left him with a right hemiplegia and dysphasia. She understood that she was going to be part of a discussion before discharge:

I didn't feel, I was lead to believe that you should have, we should have sat round and spoke about what was going to happen when my husband come out which, with the different teams, which wasn't done. They made a decision and after my husband, because of it being just before Christmas, we knew we had the

Christmas period and the New Year. It was all sort of phoning around. Well, you know, my husband was meant to be going to the Day Centre 2 days a week but that hadn't been actually put into place. And the CART Team was meant to be coming in and that wasn't done until I phoned up to try and start getting it on the move so it was all sort of, December 20th you came out and we didn't see anyone until not the first week in January, the second week.

Mr Cameron was getting ready to visit his wife when he received a phone call about her discharge:

I just got a phone call saying, your wife can go home, come and get her and that was as we were getting ready to go up and visit anyway. Going at that time (early afternoon) you don't see anybody to talk to anyway, there's only the nurses, the doctors weren't around and nobody approached us during the 6 hours that we were there visiting, doctor-wise, nobody told us anything, so we just visited, came home and that was it.

Stroke survivors themselves also wanted and pushed to go home. Mrs. Twigg's husband disliked being in hospital so much that they decided to go home earlier:

Yes, they wanted to keep him in for longer, about a week but he fretted so much.....it was difficult but he just had this feeling that the longer he stayed the worse he'd get, that sort of feeling people do have sometimes about hospitals.

With the policy of earlier discharge from hospital, professionals from the rehabilitation team felt under increased pressure and were concerned about the increased expectation of rehabilitation services in the community. A physiotherapist from the rehabilitation team for example was concerned that patients' expectation about community rehabilitation services could not be matched.

I feel the communication between the stroke unit and us needs to be better because I feel sometimes if patients come out, they haven't made much recovery and they're not going to make much more recovery and they're going to get this wonderful care in the community and really realistically whether they've taken it on board or not.

In the community Husbands and wives felt uncertain about how to care for their partners as the problems following strokes were not simply the obvious physical disabilities as Mrs Young described:

I was more concerned about the dysphasia rather than the actual physical side because of the understanding and the writing and I feel that my husband's so cut off, that he knows what he wants to say but to be able to communicate, it is so hard....., which with the stroke it's just not possible because the writing is affected too.

Mrs Young received help and support from the community rehabilitation team but as her husband's discharge was at Christmas the service did not start until 2 weeks after his discharge. Mrs Twigg struggled with her husband's disabilities after his minor stroke

I mean I suppose there were various things I wasn't aware would happen, you know, like this sort of confusion and memory loss and I suppose personality change is putting it a bit strongly but getting so easily frustrated and impatient about things.....

She was unsure about how to manage such changes, whether to be firm or not and if so, would that precipitate another stroke.

and I'm thinking, you know, shall I stand firm or, being a bit nervous about it, will I agitate him so much he has another stroke? So I would have liked some sort of guidance on that

Mrs Twigg was not alone in this dilemma. She sought and received the support of her GP but others felt disappointed and bewildered at the lack of help. When asked about what information would have helped him as a carer, Mr Cameron explained:

And when you come home, if you're able to, that you'll be sent for by the doctor or asked to go to the surgery if you're able and just really for a bit of peace of mind and so the doctor can tell you what's happening and the doctor can get a little bit more involved and give you a little bit more information and reassure you and guide you along . Certainly in the hospital they were taking blood pressure and now it has just stopped and if it was so important then, why have to go to the doctors for at least one reading but if you went to the doctors he would explain why this is important and why you have the tablet.

Comment Families and carers had experienced a traumatic and worrying event but for some, rapid discharge and lack of involvement in such a discharge left them feeling inadequately prepared for life at home with a changed partner. Sometimes the stroke survivor had pressed to be discharged feeling that they would get better quicker at home. Carers did find information booklets on the wards and found these useful but not specific enough to help them in the day to day care and support of their spouse.

The carers of stroke survivors in our study mainly felt ill-prepared to care for their partners when they were discharged from hospital. Unsure of how far they could encourage or push their partners to resume normal activities mirrored the stroke survivors' fears of precipitating another stroke. Lack of information on discharge from hospital and lack of support from GP's resulted in some feeling isolated in their new role as a carer.

There were a number of points and issues raised individually by carers:

- Mrs Twigg felt that a number of issues were 'glossed over' by professionals such as sex after a stroke; what to expect in terms of moods such as irritability, loss of confidence.
- Mr Dennis disappointed that there was a considerable delay in getting the blue disability badge for the car because the GP did not sign the form.

- Mrs Young's GP refused to sign a form about her husband because he had had no contact and did not realise that anything was wrong with him (one month after discharge)
- Mrs Yorke found the local hospital information booklet very helpful for accessing services and the Connect Communication book very useful for helping her husband with his dysphasia.

4.5 Stroke survivors' and their relatives' perceptions of information communication

In this section we examine receiving and giving information within the broader context of communication between stroke survivors and health professionals. From the responses in the interviews, we identified two factors which play a role: the style and strategy in which communication about stroke occurs, and the way information giving is part of the overall relationship between patient and carers and health professionals. Both have an impact on the way information is given and received.

Styles and strategies of communication in stroke

For stroke survivors, health professionals were the most significant source of information about stroke in general and about their own personal circumstances, recovery and long-term prospects. Stroke survivors thought the best strategy for developing a reassuring and informative exchange on their stroke included developing an informed and open dialogue with health professionals about their conditions, based on good relationships and open exchange and comprehensive information about diagnosis, treatment and prognosis. Mrs Grant, 86, summed this up as follows when asked about what would be most helpful for gaining information on stroke:

Through conversation with knowledgeable people who can explain it, through conversation.

Stroke survivors themselves used a number of strategies to initiate and foster this process of communication.

Asking questions A number of stroke survivors had been very pro-active in initiating a dialogue by asking questions persistently in order to gain knowledge and to supplement information. Mr Norris, 69, and Mrs Baldwin, 57, for example, asked many questions and appreciated the patience with which these were answered.

Dr X didn't bat an eyelid at all at the questions I was delving at him about this and about all of the other things and what the chances are (Mr Norris)

But in the main that was explained to me as and when it happened; you know. If I asked a question, I was generally given an answer that satisfied me. (Mrs Baldwin)

Stroke survivors found it particularly helpful when health professionals invited more comprehensive inquiries – this seemed to facilitate asking further questions which otherwise may not have been asked. Mr James, 58, found this helpful.

The consultants asked me every time whether or not I'd got any questions to ask them about what was going on, so they were good as far as I was concerned, yes, they were pretty good.

For other stroke survivors, there was an expectation that information would be provided by health professionals on a regular basis. If this did not happen, questions could become a signal that there were gaps in the dialogue. For example, Mrs Vine, 45, felt overwhelmed by the frequent visits of the rehabilitation team to her home. Only when she started to ask questions about why they were coming, did she get the fuller picture:

Yes, when all these people that come now, this rehab team, this was all a bit, they just said they were coming but nobody explained before I came home, who they were or what they did, all these people just suddenly appeared and I had to ask because one day a nurse came, another day somebody else, so in the end I asked who they were and what's going on.

Creating a dialogue Stroke survivors felt dialogue was important and the responses to questions could help them articulate the issues that were important to them. So when questions were not listened to, not answered directly or were deflected, communication was curtailed. Stroke survivors in our study were quite sensitive to this. They felt undermined and in some cases this created additional anxiety. Miss Knight, 78, wanted to know about the progress on equipment she needed to become more independent, but was gently turned down.

I suppose somehow I got the answers but they just said 'don't you worry about that – let us worry', but I did worry because I wanted to know.

She indicated that she had experienced a number of problems in making herself heard and listened to. Miss Knight anticipated that requests for information might be ignored and developed counter measures:

They don't tell you things and I'm quite ... I've got all my wits about me and I don't like them talking over my head so I get up and I stand and I say ... you know, if people come in and they talk to this person sitting then they talk over your head, so I get up.

Some stroke survivors found it difficult to initiate a discussion directly. Their way of expressing that they wanted further information and dialogue were quite subtle and may be quite difficult to pick up on as Mr. Harvey, 65, noted:

Well, I've asked now and again, "is everything alright?" I haven't said "is there anything wrong" You say, "is everything alright?" and they say "Yes". They don't actually say "don't do this" or "don't do that", they just, well they just don't say anything really, just goodbye.

Comprehensive information Health professionals sometimes suggested additional reading or directed individuals to further sources of information. Mrs Baldwin, 57, and Mr Small, 63, found this helpful.

My partner and I have asked the consultant. He's given me books on it, he's talked it through with me; he's given me things to read and all along the line, whoever I asked, has been quite happy to tell me what I wanted to know. (Mrs. Baldwin)

I think in the main explaining to people what's caused their stroke and then they know. The information is there what's caused it. And how to go about avoiding that in the future and to have areas 'If you do this, this going to cut down your chances of a stroke'. (Mr. Small)

Stroke survivors also found demonstration and talking through practical issues helpful. Mrs Collins, 48, commented that she had not been given enough guidance on what to expect after discharge.

Well I would talk to them and their families before they left so they know what can do and what they can't do, because we didn't know what to do, did we? They just let us come home

Using non-technical language While stroke survivors understood that professionals had detailed technical knowledge of stroke, they wanted them to provide it in a language and form that they could understand. Mrs Vine, 45, explained her need for a lay explanation in the following way:

I think you relate to it [the experience of other stroke survivors] more than what the doctors say because it's all, I'm not saying they're not giving you the right information or they're misleading you. It's just it's more my sort of English, which is idiot English not medical English which I don't always understand" ... "Because sometimes there isn't another word or another way to explain something and I'm not criticising the doctors its just a bit, sometimes it just goes over your head a bit and sometimes if you're not with it, it goes over a head a bit.

Similarly, respondents appreciated it when tests and procedures were talked through in some detail. It helped Mrs Vine, 45, and Mr. Rigby, 73, to understand the procedures and their strokes better.

They always said when I'd had the tests like, well this did not show this and showed this and because this showed this we'll take more blood. And things like that

I was told all of that in fairly clear detail and then of course I had the scan as well which gave further information

Survivors indicated they were able to remember information better and in more detail when the person providing it had used examples or illustrations.

Building a relationship with professionals

The way information about stroke is provided influences the degree of trust stroke survivors will have in the care they receive from health professionals.

Honesty A number of stroke survivors stressed honesty in the information from health professionals as significant for developing trust and confidence in the care they received. Many of the interviewees understood the uncertainties around their stroke, but found it helpful when professionals discussed outcomes in terms of probability or likelihood. Mrs Baldwin, 57, and Mr Long, 64, commented on honesty in the following way:

'I know that when I was on the stroke unit, that the nursing staff were very upfront, I felt that they never fed me any information that I didn't believe in; if I asked a question they were very straight with me. I didn't think they dressed this up particularly. Which they knew I wouldn't have wanted. (Mrs Baldwin)

I asked a nice nurse from xxx at night, I asked her "How am I doing?" and she said "you're going to be alright because your brain is o.k. and you will get better very quickly". And basically that was it. That was very good. She inspired confidence in the future (Mr Long)

Mr Norris, 69, asked his consultant about the probability of having another stroke:

But with Dr. X he got to the stage where he found that "well the best way to talk to this idiot is tell him upfront" and "don't sort of give him the nice bits, give him the badest way that he could". And he did tell me, he said "yeah, it could happen. Yeah it definitely could". And I said "like tomorrow?" He said "in all purpose of things yes it possibly could happen tomorrow, it's most likely not though... They said it could happen if definitely could happen. On the other hand it might not happen for another 20 years if at all. And he made it very clear. I mean no slightly messy words

Sometimes stroke survivors were left with the perception that professionals were not prepared to be as forthcoming with information as they could be, even in response to direct questions. Mrs Deakin, 76, had this experience:

In hospital they were ... they were quite good about getting the physiotherapists and people. I don't think I had that much information really. They may have thought 'Well there's nothing wrong with her, so she'll do alright' – I don't know, perhaps they did.

Sensitive and person-centred information The context in which information about stroke is provided can be as important to stroke survivors as the content of the information given. Stroke survivors indicated that the way and the setting in which information was given contributed to their overall experience of their stroke care and to whether information was remembered. For example, Mrs Inglby, 45, recalled her assessment of TIA in hospital as being both swift and effective; at the same time she also recalls the support and kindness shown to her when she became distressed. For her, the relationship and rapport with health professionals generally was important in shaping how she perceived and remembered the information. Mr Norris, 69, also fondly remembered the way in which his assessment was conducted:

They seemed to react quite quickly and try and sort of assess what the situation was and try and find out what was going on, even though one of the doctors said, sometimes these things happen and we don't always find out why it happens so... and they were very kind to me because, quite often you get emotional and things like that and there was one time when I was just sitting on the bed with the curtains around me and the young doctor came in, he didn't realise I was in there, and I was sort of having a quiet moment. And he said, 'Are you alright?', and I said, 'well, no, not really'.

At this stage she funnily said like "how are you now?" Let me try and see you walking around and she was explaining to me about this. I can't remember all the things that she told me. I know she looked after me but I can't remember all the things ...

The way diagnosis, tests and treatment are explained can have a long-lasting negative impact if these are not handled with great sensitivity and aligned with the expectations of the stroke survivor. Mrs Turner, 65, had a stroke a year before the interview. She had been very dissatisfied about various aspects of the care she had received. In particular, she was bitter and upset about the way she felt professionals had ignored her requests for information and dismissed her efforts in being kept informed about her condition:

I am sure this is not just my bad memory, of anybody speaking with me, they talked about me and over me and round me, but I realise now that once you've had a stroke they don't talk with you, it's considered a waste of their precious and valuable time

She contrasted this overall experience with the way the optometrist had discussed her eye test with her during her hospital stay after the stroke:

Aah, now, to be fair, when they were doing all this testing in the hospital, the woman that tested my eyes was one of the few people that actually talked to me, I mean I can't remember what she said but I appreciate it nevertheless, she showed me the chart, 'and this is gone and that ...' and I thought, its quite extraordinary that it was a woman who talked to me as if I was still human'

Building trust A number of stroke survivors felt that honesty, sensitivity and empathy were important values in building relationships with health professionals in stroke. They saw this process as developmental and the relationship as growing over time, resulting in greater trust in the advice given, more acceptable and easier to follow. Mr Norris, 69, who was quoted above describing how open his conversations with his consultant had been, summed up as follows:

It's like every other relationship you grow into when you meet someone several times ad especially on that type of relationship, it grows in to ... you either get a trust and a bond with a person or you don't' ... 'Oh I trust him totally. I mean absolutely. I mean if Dr. X said to me I want you to go to hospital now I would say "Do you want me to take my pyjamas with me or do they give them to me?" and I'd go'

Other respondents also emphasised the interpersonal aspect and rapport in establishing trust. Mr. Small, 63, expressed this as follows:

I suppose I was lucky in that I know Dr. X We talked at a nice level and I could ask him questions.

Mr Small, and also Mr. Norris, 69, were at the time of interview participating in clinical research studies and would have had additional contact with health professionals.

As the result of building this rapport with health professionals, some of the stroke survivors were able to express more independent views on treatment options and begin to negotiate aspects of their own care. For example, Mr Norris, 69, felt confident enough in his relationship with his GP to negotiate treatment in relation to cholesterol medication.

I said “I can’t have this”. I am not having this because it is just wrong. And quite rightly she said “Well there is no point in us trying to keep you right in one way and do your head in “ I said “Well you’re getting the body right but you’re doing my head in with this pain”. And she said “Well come off it for a fortnight and try and measure how you feel at the end of the fortnight”

Trust in professionals helped survivors make decisions. Mrs Baldwin, 57, for example, decided to take up a gym membership on the advice of the rehabilitation team. It did not work for her on that occasion, but the link to the CART team was invaluable in promoting her proactive stance in improving her mobility.

They asked me whether I’d like to join a, something they set up. It’s where they place you at a gym, which I went to [name of Sports Centre], to their Gym. Unfortunately, I found that not as successful as I’d hoped it to be because. And I decided that was really for me at that stage. So actually that did not work for me. I just did not think it was quite right for me. Or that I was safe doing some of the exercises; and I don’t blame him, and he just hadn’t encountered a person with a stroke before and he knew nothing about it.

Comment Anderson and Marlett (2004) argue that information needs of stroke survivors have to be understood in a wider context of communication, which includes not only information provision about the condition, but also involves other aspects of communicative activities, such as knowledge sharing (p. 441). While the interviews conducted for this study were comparatively early in the recovery stage after stroke, stroke survivors showed in the examples they gave that they wanted the development of a dialogue on their stroke, space for enhancing their knowledge and an opportunity to reflect on their experiences. The examples given by stroke survivors above show that these involve specific styles of communication and also strategies of providing information.

In practical terms, stroke patients appreciated when health professionals ‘translated’ information so that it became understandable. The examples given by stroke survivors and the fact that they could be reproduced in such detail, highlights the fact that information can be ‘packaged’ in such a way that it is memorable. Health professionals clearly already have responded to this preference and developed their own ways of engaging stroke survivors in a

dialogue, which included new ways of explaining issues through examples and comparisons and an imaginative use of charts and drawings, as well as being able to respond to the individuality of the stroke survivor. A number of examples and strategies used by health professionals were referred to in the interviews. Asking open-ended questions such as 'How are you doing?' opened the opportunity for stroke survivors to develop questions. Using analogies and translating the technical aspects of stroke into lay language helped understanding and may help the retention of information in the longer term. Using visual aids, such as pictures and graphs of test results, for example, also helped to promote understanding and knowledge building. Building on this existing repertoire and developing it in a systematic way would go long way to make information giving more successful for stroke survivors. This could be an area which could be developed further and where health professionals could learn from each other.

The other defining factor of successful information provision highlighted by stroke survivors were the values of honesty, openness, empathy and sensitivity, which enabled patients and health professionals to build trust relationship over time. Many of the stroke survivors worked hard at developing this type of rapport with health professionals and often used questions on information as a platform for doing this. They were pro-active in their efforts to open up a dialogue and continued to persist even when the response was not always as they had wished. But even this strategy was of limited success if signs and signals were not recognised or responded to.

And of course, not all stroke survivors are able to be this proactive; they might have communication impairment as the result of their strokes (short-term and longer term) or they may not have the capacity to do so for other reasons. It is often assumed that older people are more deferential and less willing to ask questions. This does not seem to be the case in our study. Most of the older participants in our study stated that if they had questions they asked it. Only one of our research participants, Mrs. Grant, 86, stated that she had not asked the questions that she wanted to ask during her hospital stay. Another older research participant, Miss Knight, 78, said on several occasions in the interview that she had felt spoken down to by health professionals and had to make an extra effort to ensure that her questions were answered.

4.6 Communication with individuals who have had a TIA or minor stroke

In this section we examine the experiences of people who have experienced a Transient Ischaemic Attack (TIA) which can be defined as, 'a less serious or minor stroke where the effects pass quickly and leave no lasting damage' (DH 2007) In this section we examine the effect which TIAs have on stroke survivors and their relatives lives and their experiences of health service involvement. We discuss the current provision of information, follow up services and how the experience has affected their lives.

Stroke survivors and relatives experiences Six of the stroke survivors in our study reported their diagnosis as transient ischaemic attack or a minor stroke. This group varied in age from two people in their 40s, three in their 60s to one person who was 72 years old. TIAs are often seen as 'minor' for individuals who experience them and their families, the TIA was a medical emergency and both the event and its aftermath were significant. While they acknowledged that they were 'lucky' in comparison to others who had had a more serious stroke, the TIA was both frightening and also created uncertainty and fear about the future,

especially whether they were likely to have another more serious stroke and if there was anything they could do to reduce the risk.

The onset of stroke is sudden and often involves a period of time where the person experiences a loss of control or inability to communicate effectively. Even when this has been for a short time, the stroke survivors described how frightening it had been for them. Mr Norris, 69, explained how he been in ‘hairy situations’ all over the world but this was how he felt when he had his minor stroke:

That afternoon I was scared. I never want to go through that again. The fear... fear is terrible thing and that's the first time I recognised it and I had that experience

Having undergone a frightening experience, albeit a short lived event, the stroke survivors and their supporters sought information about stroke, such as its causes, both in hospital and when they got home. In the next section we look at their experience of gathering such information in hospital.

Communicating information about TIA and mini stroke: After the onset of symptoms individuals either arranged to see their GP or went straight to hospital. One person delayed seeking medical care thinking her symptoms would disappear. A second went to the GP on a Friday but was not admitted into hospital until the Monday. Three participants had short stays in hospital of two or three days and one went to A & E but refused hospital admission. He explained that this was a personal reaction and following discussion with the hospital staff he was willing to take the potential consequences of this decision, such as, delays in his tests. Those who were admitted to hospital had varying experiences. Their main contact was with doctors and nurses as they tended not to need therapy input. Mostly they were treated on designated stroke units by specialist staff. Participants described the care as ‘efficient’ but understood the wards were short staffed, staff were busy and short of time. However, they felt neglected at times as staff spent more time with patients who were more disabled. Mrs Collins, 48, felt that because of the minor nature of her stroke she was not given the same degree of attention as those with more visible physical disabilities:

I mean they were very nice in the hospital but they just haven't got the time. I mean they was rushing about all the time and you couldn't really ask them anything really. No, it would be nice if somebody came up to you and said, this has happened, we're going to try and find more out but nothing. I mean perhaps they do with people who can't move, or something but I could get myself dressed and help the lady get the tea so they said you shouldn't really be here now

A specialist stroke nurse agreed with this view:

The systems are there (for information giving) but then everywhere is so short-staffed ... I mean I'm not making excuses but it is the truth that physical care quite often has to come first

There were times when individual staff found time to talk and survivors valued such opportunities to find out more about their situation. For example, Mrs Ingby, 45, who had experienced a transient ischaemic attack felt that a doctor had recognised how she was feeling and gone out of his way to speak to her and it had really helped:

And we had a little chat and he was really kind and that sort of, when you're in a situation like that, even though I hadn't had a proper stroke, sort of thing, it still scares you and you're a little bit vulnerable and just a few kind words help

Mrs Ingby recalled another conversation that she found reassuring, with a nurse who brought her a cup of tea and discussed her situation with her but left her feeling positive. Informal conversations that involved personal attention and kindness gave this participant some pleasant memories from this time of anxiety.

The ward round provided a formal event within which information could be provided. This was generally a weekly event and if it coincided with the hospital stay of the person who had had a TIA it was an opportunity, possibly the only one while they were in hospital, for a discussion with the consultant. Mr Small, 63, described how his consultant broke the news of his diagnosis to him:

[On his ward round my consultant said] 'You had a TI, TIA, which is a sort of, ehm, a stroke' But he said, 'If you describe a stroke as a foot long, you had half an inch'. This is what the consultant said. He said 'Consider yourself lucky.'

This light-hearted exchange was taken in good part but when he received the results of further investigations and a letter which described the blood flow to his brain 'was not as good as it could have been', Mr Small became much more anxious about his health. He was not the only participant to feel that his stroke had not been taken seriously. One participant, Mr Harvey 65, reported that others in the hospital felt care had been 'lackadaisical' and if he had had a heart attack he would have been treated more seriously. Mrs Ingby, 45, had looked at the written information but felt:

a bit of a fraud probably picking it up, if that makes sense. Because they were saying, 'It's only a TIA', whatever, and I thought, well I'll have look in it, there might be some information.

Three of the participants who had had TIAs stated that they left hospital without understanding the cause of their stroke or how to modify their lifestyle to prevent another stroke.

Professionals, such as staff working on the stroke unit, accepted that they could not spend as much time as they wished talking to patients with TIAs and giving them information. The stroke specialist nurse explained how she had developed an information pack and information resource sheet for stroke patients but because of pressure of work within the stroke unit she felt she had to keep giving staff gentle reminders to ensure information was given to patients before discharge. Ward staff did provide patients with stroke packs and Stroke Association information leaflets but participants in this group did not find the information in these packs and leaflets relevant to their particular circumstances. The leaflets did not include symptoms that they could relate to and the younger survivors felt the booklets were geared towards older people's circumstances and recovery.

Follow up services These participants were not eligible for the rehabilitation team follow up services. Out patient appointments took place approximately 3 months after discharge from

hospital and were an important event for survivors and their relatives. Respondents reported investing time and emotional energy thinking about what they might want to ask and compiling lists of questions and issues that they wanted to discuss. People with TIAs and mild strokes might only get one out patient visit so accessing the information they needed in this session was a priority. Two participants were entered into clinical trials and consequently benefited from more consultations with the consultant and more tests. In both cases this resulted in them developing a relationship with the consultant and access to more information about the stroke.

Participants in our study varied in their expectations of their GP's role. Rather than going to their GP as things that worried them cropped up, some participants tended to wait until the out patient appointment and then go with their list of problems. Where the survivor or partner had a 'good' relationship with their GP they felt this was supportive and helpful. There was an expectation amongst some that the GP would visit after a serious event such as a stroke and disappointment when this did not occur. When they arranged to see their doctor it was generally for issues involving medication. One GP we interviewed felt that stroke as a condition did not attract the same attention or resources as other chronic conditions:

We don't have anywhere near the same co-ordination though of patients who have had TIAs and stroke as we do with other diseases which is interesting.....I think they haven't been a priority.

The Stroke Association family support worker provided information about community support and a listening ear. Two of the participants in this group had received such support. In her interview the stroke support worker indicated that GPs generally did not refer any patients to her.

Getting back to every-day life All the stroke survivors in this group were mobile and most felt they had fully recovered their functional skills. However one woman in the study, Mrs Collins, aged 48, was still experiencing memory problems four weeks after discharge and felt unable to go out alone. Her husband reported that his wife's discharge had been very sudden and there had been no staff available to speak to. Despite having picked up the information leaflets, he felt this lack of communication hampered their efforts to work towards recovery:

Once I got home I read the leaflets, that's when she was resting, sleeping and I read them from cover to cover and I didn't read what I should and shouldn't be doing, what I could try and shouldn't try and basically to get me through the first week, two weeks of being home.

Those survivors who felt that they were back to normal did feel that there was a lack of information about how to manage their 'condition', both to how prevent a further stroke and how to resume previous levels of activity. The younger more active people wanted to get back to previous their levels of activities but felt unsure of how far they could push themselves. For example, Mr Small, 63, wanted to get back to going to the gym but had lost his confidence and was worried about having another stroke if he exercised too much. He felt there was a gap in information provided about such activities:

These are the sort of unknown things, you are left with a bit of a limbo on how far to push yourself or how far to go. How much confidence you have in yourself.

Mrs Twigg, one of the relatives, explained how she was worried about her husband doing too much and asked the GP to support her in preventing this.

Comment The people in our study who had experienced a TIA or mild stroke felt that there was a gap in the information provided, both from the professionals and contained within the leaflets. Hospital admission was brief and because they were not in need of physical care their needs tended to be overlooked. In the community they did not meet the criteria to see the rehabilitation team and the written information was not particularly useful or relevant for them. It did seem as if they fell through the safety net.

4.7 Communication about driving after stroke

Stroke survivors' and relatives' information needs Stroke survivors, their families and professionals agreed that driving was major concern post stroke. Losing the right to drive could not only create major practical problems but was also a threat to independence and a sense of being a competent adult. The specialist stroke nurse explained that driving was a 'huge issue' for stroke survivors because of the loss of independence and also that people were desperate to get back into their cars. Lack of public transport in rural areas made driving essential and for some of the younger survivors it was the only way to get to work as described by Mrs Baldwin, 57:

I was very keen to get back to driving, because without driving I can't go back to work. And I live in a village and obviously the roads are pretty poor here. I am pretty restricted to getting out and about and I am very reliant on other people for that and I didn't want to be.

Eleven stroke survivors discussed getting back to driving in their interviews. Five had returned their driving licenses to the DVLA, four had stopped driving for a short period of time and two had not stopped at all. Two of the older people in the study had had their driving licenses withdrawn and both felt the loss as it was something they had really enjoyed doing. One of them had a partner who could drive her around but the other lived by himself and recognized that its loss increased his dependence on others and prevented him from continuing with enjoyable activities such as fishing.

The guidance on driving following a stroke is clear. A person who has experienced a stroke or a TIA should not drive for at least a month after that period should seek a doctor's approval before resuming. The Stroke Association website provides the following guidance on driving after a stroke:

YOU ARE NOT ALLOWED TO DRIVE FOR AT LEAST ONE MONTH AFTER A STROKE OR A TIA.

If after that time, your doctor agrees you are fit to drive **you may do so**. You do not need to notify the DVLA but you should **notify your insurance company**. However, if your doctor feels unable to pass you as **fit to drive**, you **must** then **inform the DVLA** and your **insurance company**. **You are still not allowed to drive.** (Emphasis in the original, reference (see http://www.stroke.org.uk/information/after_a_stroke/driving.html))

After being given the information, it is the stroke survivor's responsibility to inform the DVLA (Driving and Vehicles Licensing Agency) as this GP explained:

The patient has the responsibility to inform so I emphasise that.

Apart from needing to know for how long they were unable to drive, participants and their families had to understand the procedures to follow in relation to the DVLA and insurance. Mr Rigby, 73, felt unsure about who he should contact:

I knew fairly quickly that I wasn't supposed to drive for at least a month but they didn't tell me I should notify my insurers so they halt er ... it's the technical detail there, which was a bit vague and I had to find out myself.

However, in a separate interview, his wife admitted that this issue had caused some tension between them:

Yes, he wasn't given any sort of clear instruction about whether he needed to tell the DVLA and this became a slight point of contention, he said, 'I don't have to', sort of thing, [I said] 'yes you do'.

This couple resolved this problem but Mr Rigby indicated that he was having some difficulty rebuilding confidence with driving. Loss of confidence after a break from driving was a problem for a number of participants. One described how she had lost confidence and slowly taught herself to relax but it was always at the back of her mind that she might have another stroke while she was driving.

Information provision in practice Most participants in our study reported that they had been given the information they needed about driving after a stroke in a clear and comprehensible form. Mrs Yorke, who was caring for her husband explained that driving, for him was, 'one of his biggest things'. They had received clear and concrete advice from the consultant about how they could proceed with a driving assessment, where they should go and how much they would have to pay. One participant, Mrs Baldwin, 57, was trying to get her license back at the time of the study and felt that the occupational therapist at the hospital had been very supportive. She also mentioned that her consultant had written a letter to the DVLA on her behalf and felt he had done so because he understood it was something she was interested in.

However, this was not always the case and sometimes survivors found information unclear or even inaccurate. Mrs Inglby, 45, needed to drive to get to work. She asked the doctor on discharge from hospital and was told that once she could do an emergency stop she could

start to drive. She was quite surprised at this as she felt that her thinking was slowed down at this time and as she reported:

...it did take me probably 2 or 3 weeks before I was even confident to get in the car and think shall I drive round the block.

Another participant, Mr Small, 63, stated that he had asked the consultant if he was fit to drive after his TIA and was told, it was alright, 'Unless you had another'. One of the survivors in our study chose to disregard advice he was given. A man in his 60s, he admitted that he had been informed verbally by a health professional in the hospital that it would be better not to drive for a month, but that he had not told his wife about this and had started driving well before the four weeks were up. He justified his action by saying he had cut down the distances he drove.

Verbal information about driving was given to stroke survivors and their families primarily by medical staff, hospital consultants or GPs. The professionals interviewed agreed that survivors of all ages wanted information about driving. Most respondents felt competent to give general information about driving but would refer patients and their families to their Consultant or GP for more specific information, as this physiotherapist explained:

We can give them general advice, but Dr. xxx would give them specific advice and obviously tell them about the importance about liaising with GPs and about contacting the DVLA

The consultants and GPs interviewed accepted responsibility for information giving on driving. The stroke consultants stated that they routinely discussed driving with their patients. One of the consultants indicated that he gave patients the Stroke Association leaflet and then allow them time ask questions.

The family support worker provided information for stroke survivors and their families in the community. She gave information leaflets and explained about the driving assessment but felt it was 'an issue' with some people, particularly if they were the sole driver. Aware of the importance of transport she also distributed information about alternative travel methods such as the Kent Carrier.

The job of informing someone that they are no longer allowed to drive was not considered a pleasant one. In a focus group discussion with a rehabilitation team, the occupational therapists discussed their role in relation to driving and their guidelines and responsibilities. They explained that they carried out cognitive assessments on their clients but were not able to make a decision on fitness to drive. One of them remarked how she felt it would be to inform someone they would no longer be able to drive:

It is an absolutely horrible thing to have to do really because that's their one lifeline and you're taking that away as well and it is just adding to their stress

Comment Driving is a technical skill and an important part of everyday life. Some participants in the study felt that the information given to them after their stroke was clear and easy to follow. Others, however, received inaccurate information which they also

followed. One person reported that he had been given information that he should not drive and had disregarded it.

Driving is enjoyable and for many people an indication of adult competency. Experiencing an event such as stroke necessitates a break from driving sometimes permanent. It is very difficult for a small number of individuals to accept this situation and despite being given advice, they chose to disregard it and drive. For others, getting back driving is sometimes difficult because of a loss of confidence. They try to rebuild the skill gradually by driving with another driver or driving only short distances. This aspect does not seem to be covered in the leaflets about driving after a stroke or by the health professionals who give out information.

4.8 Communication about secondary prevention

Current Government policy is aimed at reducing the incidence of strokes by reducing the level of stroke risk factors within the UK population. A key aspect of the strategy is the provision of information on such risk factors so that individuals can make informed choices to change their lifestyle and reduce their own level of risk and so reduce the collective level of risk. Such information is provided to the general public (primary prevention) and targeted at those people who have already experienced a stroke to prevent a second (secondary prevention).

In this section we look at the information about lifestyle which is given to stroke survivors and their relatives and how they use it in their daily lives. We also examine the role of the professionals in the provision of this information.

Information needs of stroke survivors and relatives: One of the main concerns of stroke survivors and their relatives in our study was how to prevent a second stroke. Ten participants spoke about fear of recurrence and how they could reduce the probability of it happening again. For example, Mr Long was 64 years old when he had his stroke and when asked about his information needs post stroke he replied:

What are my chances of a hundred per cent recovery, and will I ever recover, and will I have another one. I know I will have another one eventually, but what is my life expectancy and how can I prolong this and things

Survivors and their families wanted information on those factors which they could control and reduce risk, such as changes to their lifestyle. Mr Small, 63, was considering lifestyle changes when thinking about future plans:

When it hits you, that suddenly that is a decision that affects your life, takes time to actually get into your brain, that this is serious. And I immediately thought that somewhere along the line I need to change my life style, you know. Quickly.I think it is very serious in terms of life style, yes. I mean you want, you make plans for retirement.

However, he did not find any professional support in making his decisions:

But there was no way of actually to somebody saying 'Is this something that I should be doing?'. I should have, I wanted to make a decision about life style, but there is no one there to actually say, this is the way forward.

There is clear advice available. For example, a Stroke Association leaflet provides clear and simple guidance:

- stop smoking
- reduce your alcohol consumption
- eat a healthy diet. This means reducing your salt intake, eating lots of fruit, vegetables, wholegrain foods and fish, and less fat, red and processed meat
- take regular exercise and try to keep a healthy weight
- maintain the right blood pressure and low cholesterol levels.
- take your doctor's advice on lifestyle changes (such as **diet, weight, smoking, exercise and alcohol**);

http://www.stroke.org.uk/information/preventing_a_stroke/stopping_stroke.html

The practice of information provision Stroke survivors received their information on secondary prevention from a variety of sources including health professionals and Stroke Association leaflets, other stroke survivors, the internet and newspapers. When asked about the information sources she used, Mrs Baldwin, 57, replied:

Mrs Baldwin Well I suppose I would have to say the main one, for me, I have relied on professionals that I have come into contact with and who have been responsible for my care

Interviewer: *Leaflets?*

Mrs Baldwin Oh yes, I have read every leaflet I have been given. And of course, I explore the Internet.

Most of the participants appeared to have listened to and accepted the general information about lifestyle changes but some felt the need for additional information about their specific circumstances and risk. Mrs Twigg, who was caring for her 73-year-old husband, recounted a discussion about her husband's exercise levels which had occurred during an out patient appointment. The doctor suggested her husband should do some exercise such as swimming or jogging, and Mrs Twigg thought:

Hang on, he's never been jogging, he can't swim, so they were totally unrealistic, just text book ideas rather than based on reality.

She felt it would have been more helpful to ask her husband about what exercise he did first and then to suggest a particular level of activity based on his reply. Participants wished to exercise but also wanted specific advice on how far they should push themselves as we noted above in our discussion of needs of individuals who had had a TIA's and minor strokes. In the absence of concrete or relevant advice some survivors decided to 'play safe' as they were concerned about over stressing their bodies. For example Mr Small, 63, decided to stop going to the gym and instead took up walking.

Like the eating and like the same questions on 'How far should you push yourself'. See, as far as a layman like me understands, is that there has been a sort of clog in the brain, as sort of a block. But if you do a lot of exercise and your blood's rushing, does that help it, hinder it, or does the food you eat help or hinder it. There is nowhere at the moment to get easily that sort of information.

Stroke survivors and their families felt that they had had an opportunity to discuss diet following the stroke. They acknowledged they had received general information about eating a healthy diet, for example, increasing their intake of fruit and vegetables and reducing red meat consumption but again they wanted more detailed and personalized advice and information.

Mr Norris, 69, had discussed his diet and cholesterol levels in great detail in the outpatient clinic following his stroke. He had been advised by the clinic nurse about the amount of cheese he could consume and he added:

And then we went through certain things like greasy foods and frying and things like that and going on to vegetables. But she was the one who actually gave me an indication as to the volume of vegetables and fruit and I thought I was doing well.

Mr Norris was also able to discuss his cholesterol levels and their implications at his outpatient appointments.

Stroke survivors were also concerned about the interaction between their diet and their medication (we will discuss medication in its own right in the next section). Some of the survivors were not used to taking regular medication and were worried about the side and long-term effects of regular medication and wanted more information about alternatives. Mr Harvey, 65, speculated about whether he could control his cholesterol level purely by changing his diet.

I'd rather just let my own system deal with it and the wife does now, she has since that thing, you know, cut out a lot of the foods and all that business which they tell you to lower the cholesterol and thin the blood and all that business, but whether you do enough by yourself without the medication, I don't know, they've not told us.

He and his wife used newspapers as their main source of information about diet and often found such information confusing and contradictory. In her interview his wife explained that they had had cut down on red meat and were eating more fruit but:

We weren't given any advice on any diet or, we still haven't had that. I mean you read the bloody paper and you think, 'We're not having that anymore', and then the next day you can have it and then the next day.... We've basically done it ourselves, haven't we, in cutting down on a bit of...

They had decided that if they ate 'everything in moderation', they would be alright. Other survivors took the same approach adapting the secondary prevention message to their needs by selecting those parts which they felt were most effective and/or the most doable. Mr Long, 64, took one of the secondary prevention messages very seriously and gave up smoking

immediately. However, he was also advised to reduce his alcohol consumption and although he had cut it down, he was finding ways to justify his current intake:

Mr [Consultant] he would like me not to drink at all. Well I've got to get some fluid inside me, I can't drink orange juice and tea all day. I don't think that a couple of pints of Guinness are going to do me an awful lot of harm. I am thinking of changing that to something less, eh, rich, as they say. I might go over to bitter in the near future. But I shall ask him about that again.

He was also struggling with his diet as he was not very keen on vegetables and had taken up eating sweets to combat the loss of smoking.

The role of professionals Professionals recognised the importance of providing information on lifestyle seeing it as an area in which stroke survivors could make a difference to their future lives and take responsibility for themselves and their futures. As a stroke family support worker explained:

Stroke Support Worker: *Everybody wants to talk about food and it's something that people can actually take control of and make a difference to themselves.*

Interviewer: *And cholesterol?*

Stroke Support Worker: *Oh yes we go through the cholesterol and the salt and the food. Yeah. Oh yes. And the smoking and the drinking. Yes. It's all there.*

Survivors, their families and professionals all agreed that it was important that stroke survivors received information on diet, exercise and other ways in which they could reduce their risk of another stroke.

Comment Secondary prevention is high on the agenda of health professionals. The stroke survivors and relatives in our study demonstrated that they were interested in information which would help them reduce their risk factors and they were aware of the broad messages of prevention and lifestyle changes. However the information they received was generic and not tailored to their individual situation. When they could not get the information they wanted from health professionals they used other sources such as the internet or newspapers which are variable in quality. This selectivity related partially to the perceived quality of information but it also related to the acceptability of the information. Survivors acknowledged that they made choices about those lifestyle changes they felt able to make.

4.9 Communication about medication

A significant number of stroke survivors need to take medication as part of the recovery and rehabilitation after stroke and will continue taking medication long-term to prevent further strokes. In this section we discuss communicating information on medication within the hospital context, on discharge and in the follow-up period.

In hospital Health professionals reported that stroke survivors and their relatives and carers can have quite different ideas of what they need to know about the medication they are prescribed in hospital. A community nurse in the rehabilitation team focus group described the situation in the following way:

It's not always the patients, it's often their relatives as well. But they will either want to know everything about their medication or they will sort of just believe that they're being given it and it's right and they don't need to know about it, it will just somehow ... they will just get it.'

Health professionals reported that occasionally stroke survivors or their relatives actively sought discussions of different options for medication, particularly in relation to treatment, and that relatives often used additional sources for information about different treatments and drug options, for example, from the Internet. A consultant gave an example of his response to questions/queries like this.

I can only give such information where there is evidence, clinical evidence. At the end, it's the patient's responsibility to take it or disregard it, whether for example they want aspirin or Warfarin. I can only say 'My choice would be... '. This is the best treatment at the moment.

Occasionally, when a relative had researched and found a treatment option which was not offered, it could lead to tensions. Another consultant described such an incident:

There was a patient whose son wanted to know why this clot busting injection was not given. Because it is given in some hospitals in London so I tried to explain that this treatment, hoping we are able to initiate in the very near future. It is still in the process of negotiation and etc, etc. He still couldn't understand why it's not given.

The stroke survivors and relatives we interviewed did not make any specific comments on the need for information on medication in hospital. It is possible that following the trauma of the stroke patients and their relatives concentrated on immediate survival and the prospects of recovery and that concern about medication only developed later.

On discharge Professionals viewed the provision of medication information as an important part of the discharge process. They were concerned that stroke survivors were not always ready to manage their own medication when they could no longer access professional advice on a daily basis. A nurse in the focus group on the stroke unit commented:

And there's a sudden realisation when they're ready to go home well how am I going to take this? What am I going to do? When do I need to take these ones?

Health professionals agreed that they needed to provide sufficient information so that stroke survivors could understand and manage their medication. A speech and language therapist expressed this as follows:

Well they need to go home with their medication, I think it's one or two weeks supply, but they go home with their drugs so obviously they need to understand what they're taking and when, especially, from my point of view I just check with people that they've got dysphasia and establish that they take their tablets - three tablets once a day and it's potentially dangerous if they get that wrong so double check that they really do understand their medication and if they don't

make sure there's someone around at home who does and give them their medication.

A specialist stroke nurse based in the hospital had developed a discharge card with medication details which she filled in with the stroke survivor as a patient-held personal record:

My target blood pressure is ... and we fill those in for every patient and we also have current medication list on there so they know what their medications are and what they're for and a personal record chart on the back for dates and cholesterol levels that they can get Boots to fill in or their GP. So we certainly do give them information but I think potentially not enough.

Underpinning the concern about adequate information on medication is the worry about inappropriate use of medication and the risks associated with that. One of the consultants recalled an occasion when a recently discharged patient continued taking a medication, despite having been advised to stop taking if he developed a headache:

A good example, we had a patient with a minor stroke, I gave him all the information at the same time because he was discharged the same day. And I gave him all the leaflets. And I got a call from his son-in-law 'Oh, he is asking this thing, can you explain to me ...'. So I had to explain to him, because I had prescribed some for him and had said 'If you have a headache, can you stop taking these'. So the son said 'Oh he had headaches for the last two days'. So I said, 'Can you ask him to stop taking these.' The patient had forgotten.

Some health professionals commented that the best way of preparing patients for self-management was repeating and reiterating information on medication over the course of the hospital stay and even checking that the regime was followed after discharge. In her interview the family support worker said:

I do always check with them that they've got their medication and they are going to renew their prescription because I have come across a couple of people who have come out of hospital with the medicines and finished it, their 2 week supply and haven't go back to get more. So I have to just check that they're going to do that, or they have done.

Stroke survivors and relatives reported varying experiences of receiving information on medication on discharge. A number of survivors and relatives commented that medication had been explained before discharge in detail and instructions had been given on their management. For example, Mr Baxter, a 78-year-old stroke survivor who had regular hospital admissions received a list of medications from the pharmacist which he found very helpful:

The pharmacist in the hospital did it... did me the first one of those [lists] and since then every time I've gone to the hospital and they've come out with the drugs and everything, I say will you give me a patient's drugs sheet and they do.

Others reported that they had received little information on medication and the side effects. For people who had not been used to taking medication, such as Mr Harvey, 65, the prospect of taking a number of drugs for life was alarming:

You hear so much about internal bleeding and all that stuff and then they say, 'you've got to be on it for the rest of your life'. I was on two [aspirin] when I began, I'm on one now, a small dosage. I still worry about it because they give you 1 to stop your stomach being affected and another one for your blood pressure and, you know, does it all work? I mean, is it all necessary?

A number of survivors explained that when they asked about medication they were given their discharge letter which listed the medication; however, the information in these letters is primarily intended for other professionals and for patients and their families may find it difficult to understand. Mr Small, 63, explained the way in which he supplemented his knowledge of medication:

Mr Small: *But when you are talking to a customer you're suddenly find out 'Oh, I'm on these tablets'. 'I'm on these tablets' 'How many are you on a day'' I'm on four' 'Oh I'm on six a day', 'Oh you're lucky, I'm on ten a day'. Yes, this is what you get from customers.*

Interviewer: *Do you find that helpful?*

Mr Small: *Yes indeed, you find out that so many people are in the same boat. You find out 'Oh, yes,' 'Oh, yes, that's normal'.*

Problems also arose in receiving continued medication at home. A number of the stroke survivors reported that they had not had an automatic GP follow-up either through a home visit by the GP or through an appointment at the surgery, where medication was prescribed. Several interviewees reported that they had organised follow-up medication themselves or through their relatives or carers.

One patient group which seemed to receive little information on medication were those with minor strokes or TIA, and stroke patients who had only had short stays in hospital. They reported that there had been no time for discussing medication. As a consequence, stroke survivors and carers reported that they had quite basic information gaps. Mrs Hall whose husband had a mild stroke felt ill prepared for coping with her husband:

Well, we just made sure what medication, in that, appointments were fine, there wasn't really a lot of sort of, 'go home and get on with it sort of thing', but there wasn't any, 'go home and do or don't do this'.

She described how this led her into problems with his medication:

My husband was put on two aspirins when he came out of hospital, then he went, January wasn't it, and they reduced it to 1. Well, the tablet they give you to stop you getting too many tummy problems and I bought this pill dispenser so that we didn't get in a muddle and all that and it was when you run out and I was thinking, why have you run out, I had been giving him two instead of one..

Mr Small, 63, who had a TIA some time ago still did not know exactly what the medication was he was taking for stroke. Although in his case self-management appeared to be working well and he obtained repeat prescriptions at regular intervals.

So, the tablets they put me on, ehm, we assume, that that was going to stop it happening again. You know I have no effects [of the stroke] really. I'd come out of it almost immediately.

Follow-up For health professionals, medication, the choice of drugs and compliance are major issues discussed with patients during follow-up appointments. Primary care professionals such as GPs saw their role as ensuring patients understood and accepted the importance of medication in reducing risks of a further stroke and managing any underlying conditions such as diabetes. One of the GPs we interviewed described his role in the following way:

When patients are discharged, with regard to the medical aspects, and probabilities of recurrence, medication, medication reviews, symptoms and side effects and underlying background illnesses whether its depression or a problem with their blood pressure or whether they're diabetic or all of those.

He saw himself as the first point of contact for patients or their relatives who wanted more information about their medication.

When they come and see me it's usually concerning medication, to be honest, but I think I've probably seen more questions about medications and side effects, more from carers.

A rapid response team working in the community visited people in their homes who had not been admitted to hospital or sometimes became involved after discharge. A nurse in the rehabilitation team focus group explained:

It depends on what stage we've been called in, if we've been called in post-hospital, somebody has been through the stroke protocol, they've been through the hospital then we're assessing their immediate needs in relation to their medication and their symptoms. And we would, perhaps, once we've done the initial problem solving with any issues they've got with their medication, then we might not be involved again.

The consultants felt that their follow-up clinics provided opportunities for stroke survivors and relatives to raise any issues regarding medication, side effects and also to discuss whether medication was still necessary:

In out patients we look at the aetiology of stroke and secondary prevention and advice regarding healthy life style and reducing risks.

Stroke survivors and their relatives often attended out-patient appointments with questions about medication and the side effects; often they hoped of reducing medication. Mrs

Leeman² wanted to talk about her husband's anti-epilepsy medication at the clinic as she felt it was a cause of his fatigue

We are going to see him tomorrow and we're hopefully going to ask him if we can throw all the pills away apart from Epilim and just take one at the time because pills I don't think are cheering up, they're making him very tired.

Talking through medication with health professionals and doctors was the most important source of information for the stroke survivors we interviewed. Mr. Baxter, 78, for example, used the Stroke Association Newsletter to access information on the possible side effects of the medication he was taking but did not think the information was sufficiently detailed and therefore was going to discuss it further at the next clinic appointment. We mentioned above that Mr Baxter found the hospital pharmacists helpful as they printed out information on the drugs. However, none of the other stroke survivors mentioned the hospital pharmacies as a source for information on regular medication.

Being well informed on medication can enhance the confidence in self-management of medication. Mrs Leeman, who we quoted above, had taken independent medication decisions in the past, stopping a drug which she thought made her husband depressed. Stroke survivors sometimes disregarded the advice on medication or even refused it outright. Mr Norris, 69, described his relationship with his GP in the following way

She [his doctor] will never prescribe tablets or that because I won't take them because I always believe if you can stick yourself with tablets nothing will ever happen to you until you die and you'll not know why you've died because you are not in pain. You know, I always believe that the pain is there to tell you something.

While this was an extreme example, participants indicated they found it easier to comply with medication when they were actively involved in decisions about medication in the longer term and if professionals listened to their concerns.

Overall, stroke survivors and relatives relied heavily for the advice on medication from GPs and the hospital consultants. Most of our stroke survivor interviewees reported that they had discussed medication and that opportunity existed to review both dosage and drugs. One informant, Mrs Deakin, 76, however, had not received appropriate information of a drug, which damaged her kidneys.

I wasn't given the information that I probably should have been that the tablets I was on to control urine would destroy my kidneys so I've just got one kidney left and that's working only at 50% of capacity.

Overall, more and open discussion on medication is welcomed by stroke survivors and relatives, as Mr. Harvey, 65, and Mr Baxter, 78, indicated:

² Mrs Leeman was present at her husband's interview and contributed some of her own experiences as a relative and carer.

...discuss it more ... like what the medication does and do you need to take it for the rest of your life or 4 months or 3 months or whatever, Not just left in limbo, take this and go away. (Mr. Harvey)

I said to the doctor, what happens if I stop taking these pills? ... So he said, well you know if you don't take the pills you don't live and he is ...he is very straightforward in what he says. So I just say, if that's the pill you want me to take ... (Mr. Baxter)

Good communication about the possible side effects of drugs seemed particularly important. Early and open discussion of side effects and where necessary a change to a dosage or another medication with less side effects seemed to enhance survivors confidence and trust in the prescribed drug regime. Mrs Inglby, 45, commented:

That's what the doctor put me on whatever tablets to try and manage that because other tablets I was on made me dozy that it was, I was only going into work 2 days a week because I was just so tired and they made me very sleepy

This development of trust through open discussion was a deciding factor in one survivors accepting medication for depression. Mr Leeman, 72, indicated he was willing to consider anti-depressant medication:

Would I like to go on anti-depressant pills, which I wasn't keen on but maybe, I have thought about them again, maybe it's a good idea.

Comment From our small sample, we cannot explain the different perceptions health professionals, stroke survivors and relatives had about how systematic the provision of information on medication was in hospital and on discharge: professionals thought it a priority and that they provided extensive information particularly on discharge, survivors and relatives had more limited and varied recollections about receiving such information. We carried out the interviews several months after the hospital discharge, and it possible that patients and relatives did not recall these issues and other stroke-related issues had become more important. It may also be that the process was so embedded in the hospital routine, that it became part of the time spent in hospital. Of course, some stroke survivors might have slipped through the net and had missed out on information about medication.

The need stroke survivors and carers expressed for continuing advice on medication after discharge highlights the importance of having well functioning transition mechanisms across different care sectors and that self-management of medication is a process of learning, which requires continuous support. While most of our respondents had the necessary follow-up, there seemed to be still gaps, particularly in the transition from acute to primary care. Patients needed to know what would happen to their prescriptions when they were discharged, who would be the contact/liaison to turn to for advice on medication and who would have professional responsibility for the medication. While continuity of care was not only an issue in relation to medication, it was an immediate concern, partly because patients had a limited supply of medication and had to replenish this supply frequently.

A number of stroke survivors found it difficult to take medication correctly because the regime established in hospital appeared quite complex and/or difficult, especially if it was

new to patients or their relatives. Issues highlighted included: when to take medication, how much to take and when to stop. Information about medication reviews was also an issue.

Patients with TIAs and minor strokes, who had a brief or no hospital stay sometimes had missed opportunities to receive information on medication, as they were not part of the hospital system long enough to receive all information regarding their medication. A solution to this potential gap could be a proactive programme of follow-up in primary care, which would include medication advice.

GP medication reviews and follow-ups through clinics are an important part of managing stroke recovery. Survivors have indicated that open discussions and being listened to would enhance their understanding and acceptance of their drug regime and this would enable them to tolerate side effects better. Patients and relatives also indicated that professionals' willingness to accept their accounts of side effects and to change drugs because of these helped to build trust and to develop their ability to self-manage.

5. Conclusion

In our earlier studies, funded by Nunnery Fields Trust and by the Stroke Association, stroke survivors and their families identified limitations in the ways in which professional provided information and communicated with them. This study was a follow-on study which focussed specifically on the ways in which information is currently communicated to stroke survivors and their relatives. The aim of this pilot project was to gain better understanding of information provision about stroke from health professionals by exploring the perspectives of the stroke survivors, their carers and professionals themselves. The study was designed to explore, through qualitative interviews, how such information was provided, what worked well in information giving, what the barriers to good information provision were and how these arose. The research was intended to be the basis for developing an information toolkit for service providers, stroke survivors and relatives to engage in effective person-centred communication. The study was based on interviews conducted with health professionals in acute, community and primary care settings in East Kent and with a small sample of stroke survivors and carers. We interviewed 19 stroke survivors, 6 relatives and 23 health professionals (11 individually and 12 in 2 focus groups) involved in their care and support. To protect individual identities, we have changed all names in our report.

5.1 Research questions

In this study we wanted to examine both sides of the communication, i.e. providers perceptions of the information that they ought to be providing of their success in proving such information and the stroke survivors perceptions of the information they wanted, the potential sources of information and their success in obtaining it. Thus our interview with professionals and survivors and their relatives had similar structures but different emphases. With professionals we focussed on:

- Their perceptions of the information needs of patients and relatives and the strategies they used to meet these needs.

- The type of information which they had on stroke risks and how they used this information to advice patients and their relatives on life style adjustments?

With stroke survivors and their family we examined:

- Their understanding of the risk factors in stroke and the type of information they felt they needed about risk factors and how to minimise them.
- How have stroke survivors embedded information about stroke in their daily lives.
- Their perceptions of the factors that influence information exchange on secondary prevention, risk and self - management of stroke?

5.2 Key findings

It is important to recognise that information provision is part of the general process of communication and that not only do stroke survivors and their relatives communicate with a range of professionals but they also have access to information from other sources especially the internet and the mass media. Stroke survivors and their relatives want clear, consistent and timely information and they did not always receive such information.

General issues

We found that health professionals working in diverse parts of the care system had different insights into the information needs of stroke survivors. Health professionals recognised survivors' needs for specific information on issues such as prevention, lifestyle changes and driving but most also acknowledged that emotional support should be part of the process of information giving. These health professionals were aware that there could be gaps in information giving. They were also not always clear about the information that other professionals had given to survivors and their relatives. Members of the stroke team felt that they had different information to give to survivors and their relatives and there was not always overall coordination of information to ensure comprehensiveness

In their interviews, stroke survivors and their relatives indicated that they needed different information at different stages of their recovery. For example immediately after the stroke survivors and relatives were most concerned about what has happened and the chances of survival therefore. Later they wanted information on practicalities of recovery and what they could do to deal with or minimise residual disabilities. Thus for survivors the timing of information for the different stages was crucial in ensuring that they had relevant information. Immediately following their stroke survivors and relatives can find it difficult to absorb information. Furthermore memory and communication problems could contribute to difficulties in receiving, understanding and retaining information. Survivors and their relatives noted that when they had a confirmed discharge date there was pressure on hospital staff to provide a lot of information quickly and they found it difficult to absorb this information. There was can be an information overload when stroke survivors are discharged from hospital. Thus survivors and relatives felt it was important that they did not receive information just once and had a chance to access information several times both in the hospital and after discharge.

Providing information: staff perceptions

Professionals providing stroke care recognised that good information could contribute to survivors' and their relatives' well-being and information can aid a positive attitude to recovery. There was agreement that accurate information enabled stroke survivors to make informed decisions about treatment and treatment options. For example a stroke consultant felt that information given to stroke survivors and their families which was tailored to their individual needs enabled them to make informed choices within the context of their lives. The community rehabilitation team felt there was sometimes a gap in communication between themselves and the hospital. This could result in a delay in the provision of support services for the stroke survivors and their families.

Professionals in the community tended to focus on the provision of specific types of information. GPs saw their role primarily in terms of providing information on secondary prevention, for example, on cholesterol levels or blood pressure, rather than broader information on psychological and emotional aspects of rehabilitation. The stroke specialist nurse provided a post discharge follow-up phone call as she felt that most problems did not emerge until the survivor was back at home. The stroke family support worker saw her job as signposting people to support agencies, tailoring the information to their needs and lending a listening ear.

Stroke survivors' and their relatives' information needs and preferences for information communication

Stroke survivors stressed that appropriate and timely information helped them to understand what had happened, how they could reduce the chance it could happen again and how they could make the best use of support and services. They indicated that the sort of information they wanted changed over time. Stroke survivors and families often did not know anything about stroke and information giving therefore needed to start from a very basic platform. They recognised that they did not always know what questions to ask. This was particularly the case immediately after the stroke when they were likely to experience difficulty both in articulating questions and in understanding answers. Stroke survivors and relatives wanted opportunities in hospital and after discharge to ask questions and gain information

Survivors and their families acknowledged that information they wanted depended on their particular circumstances, but also where they were in the recovery process. They also recognised that they did not always want to 'hear' information which did not fit with their hopes and aspirations.

Some stroke survivors and their relatives indicated that they were proactive in their information gathering. They looked for and compared different sources and types of information. Others indicated that their neither had the capacity nor interest in doing this. Stroke survivors and their relatives found it helpful when a specific time for information giving with the patient and their relatives was 'booked' or set aside. On occasion, information was given in a hurry, particularly in hospital. Stroke survivors found this unhelpful and found it more difficult to ask questions when they felt that health professionals were rushed.

For stroke survivors and their relatives, information provision is only one aspect of the stroke experience, but it is pivotal to building a successful dialogue between health professionals and stroke survivor over the longer term. Stroke survivors noted and appreciated when health

professionals used varied tools and methods to explain information about stroke, including the use of props, scans, drawings and charts.

Information needs following a TIA or minor strokes

Survivors who had experienced a TIA or minor stroke and their relatives felt that there was a gap in the information provided by health professionals addressing their special circumstances. Furthermore the available information leaflets tended to deal with issues relating to major strokes. Individuals who had TIAs and minor strokes in particular did not receive full information on medication and welcomed greater opportunities to discuss their medications and its possible side effects

Hospital stays for survivors who had had TIA or minor stroke tended to be short. Because they often had no residual or visible disabilities they felt they tended to be overlooked by busy staff and could miss opportunities to access information and ask questions. In the community they were not eligible for services from the rehabilitation team and felt that they did not receive sufficient information and reassurance between out patient appointments.

Driving after stroke

Health professionals involved in stroke care felt able to give general information about post-stroke driving but referred the survivor back to the consultant or GP for more specialised advice.

Losing the right to drive not only created major practical problems but was also a threat to independence and a sense of being a competent adult. Most survivors and their relatives felt that they were well supported by health professionals and given clear advice. However, a small number of participants chose to ignore the advice given about driving. Some stroke survivors felt that they had lost confidence in their ability to drive and did not know how to rebuild that confidence. Loss of confidence was an issue which concerned stroke survivors in relationship to driving.

While most stroke survivors thought that there were clear instructions in the written information guidance, for example those issued by the Stroke Association, some stroke survivors found the details vague and the advice contradictory.

Secondary prevention after stroke

All stroke professionals felt that provision of information on secondary prevention such as life style changes was important. Both stroke consultants and general practitioners saw providing this type of information as a priority.

Most stroke survivors were frightened of having a second stroke and were concerned to prevent it happening again. Survivors and their relatives wanted information about aspects of their lives they could take control of to minimise the risks of another stroke. Stroke survivors and carers felt the advice they were given was not specific enough in the context of their everyday lives. For example while there was general advice to do exercise it was not clear how that related to their particular circumstances and how strenuously they could exercise at the gym.

Survivors and relatives obtained their information from a variety of sources, including, information leaflets, the internet, newspapers but face-to-face communication with professional was an important and valued source of authoritative advice.

Information on medication

Most stroke professionals acknowledged the importance of information on medication especially that designed to control blood pressure and cholesterol levels. Generally it was felt that doctors should provide this information as they did the prescribing.

Stroke survivors and carers indicated that they often had gaps in their knowledge of the medication they took. This included their role in reducing the risk of further strokes, in managing underlying clinical conditions and information about the potential and actual side effects. Knowing about these was important to stroke survivors particularly when medication was prescribed and had to be taken long-term.

Some stroke survivors and their relatives indicated that they found it difficult to recall information on medication because they had not had to manage their own medication while they were in hospital. They felt that information on medication needed to be repeated and written down in detail on discharge. Stroke survivors and their relatives wanted opportunities to discuss, understand and gain reassurance on the often complex medication regimes early and discuss side effects. They felt that sometimes there was a lack in the continuity of care between acute, intermediate and primary services in relation to medication.

5.3 Recommendations

The responses of stroke survivors and carers indicate that they receive a substantial amount of information through various channels, in different ways, and that there are examples of good practice. There remain gaps in the information provision, particularly with regard to information about personal circumstances and individual information needs, which need addressing.

Overall we would recommend

- That the stroke services in East Kent develop an information provision strategy, which is an integrated part the overall stroke service development across the acute and community and primary care services.
- This strategy should aim for a person-centred approach, which can be responsive to the changing information needs of stroke survivors and their families. It should be based on a personalised approach to information provision, which is tailored to the individual circumstances of stroke survivors.
- The strategy should integrate and expand on the successful local elements of information provision, but also should look outside the area for evidence of good practice.
- The development of the strategy should involve the health and social care and voluntary sector stakeholders, as well as patient groups. Stroke survivors, carers and health professionals should be closely involved in its design and use their experiences

and expertise in reviewing it. It should be disseminated widely and proactively across the service area.

- The information strategy should not only provide written materials, but also examples of continuous communication between health professionals and stroke survivors, developing and cascading examples of good practice, training and education, and the use of third party information provision (for example, the use of internet websites etc.).

We would also recommend

- During the hospital stay, the coordination of information provision could be further streamlined, so that all patients and carers are prepared appropriately for discharge and are reassured about their continuity of care when they return home. This is particularly important in the context of shorter hospital stays, which limits the opportunities for information exchange between health professionals in hospital and patient/carer.
- Information provision for patients who had a TIA or minor stroke often do not have the opportunity to discuss their strokes and receive advice and information. Particular attention should be paid to improving information access and continuous support for this group of patients.
- Stroke survivors and carers need the space at different intervals in the recovery process to address their changing information needs. Primary care should assume a greater role in proactively discussing stroke information particularly at later stages of the recovery process.
- We found a number of gaps in the provision of information about medication, particularly on discharge from hospital and in the community. Information about the medication taken needs to be provided in writing and in a way stroke survivors and their families and carers can understand. Developing an effective and innovative solution to this could involve pharmacy services in hospital and in the community.
- Greater emphasis should be placed on detailed and continued advice and information on life style, not only to help minimise the risk of further stroke generally, but also to increase the feeling of control stroke survivors have over their lives. It should include, for example, discussions of relevant aspects of every-day life such as diet, physical exercise and stress, including a discussion of what the stroke survivor already does and what she/he would like to achieve.

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7. Appendices

7.1 Communication and patient education: A review of current evidence

The WHO states that patients have the right to be fully informed about their health status, including the medical facts about their condition, and about the diagnosis, prognosis and treatment. Information must be communicated to the patient in a way appropriate to their capacity for understanding, minimizing the use of unfamiliar technical terminology (1). These recommendations are further supported by the UK National Clinical Guidelines for Stroke. (2)

Current information available to health professionals and information provision to patients

Within the UK the main providers of stroke information comes from the Royal College of Physicians and from The Stroke Association. The RCP provides an extensive booklet on all aspects of stroke including treatment, complications, prevention rehabilitation and long term management. Similar information is available from the stroke association web site, it also provides audio information to patients and relatives. Other formats of information provision are more difficult to come by. There are no recommendations on what is the most efficient way to provide information to stroke survivors.

Despite these recommendations and the apparent abundance of information available, both patients and their care givers are dissatisfied with the information they receive following a stroke (3)

Perceptions of health professionals with regard to type and content of information provision

Health professionals perceived that most information provision was received through communication with doctors, nurses and social workers and that reading pamphlets and participation in support groups were also used but to a lesser degree. (4). With regard to level of information received, approx 77% of health professionals felt that survivors and family members receive only some or too little information about their stroke. (4)

Another study looked at what health professionals thought that stroke survivors should know. Risk factor management, rehabilitation and post stroke problems and treatment of stroke were rated highly. (5)

Information needs of stroke survivors and their relatives as perceived by themselves

The majority of studies would indicate that the information needs of the patient changes over time.

A study from the Netherlands interviewed stroke survivors and their families 12 months following their first stroke. The most desired information was on medical issues regarding cause, consequences, prognosis and treatment for stroke. A smaller percentage of patients and care givers found financial, legal and social issues to be less important. This was found to correspond to the percentage of actual information provided on each topic. Approx half of the patients felt that they were happy to receive the information 1-2 times. Only 22-33% of patients felt they needed to be informed 3-6 times. (6) These findings were replicated in

several other studies, with patients again stressing a need for more information on treatment, causes and risk factors, prognosis in the first few months following stroke. (7)

Another study carried out in New Zealand followed patients for a period of 2 years. Their findings were similar but found that the nature of the questions changed with time following stroke. 10-50% of patients wanted to know about medical issues such as cause, treatment and prevention within the first 2 weeks, this reduced to 4-14% at 2 years. Desire for information on rehabilitation also decreased with time. Desire for information on the role of medication, risk of recurrence, memory and visual problems increased with time. As with the previous study only a small amount of patients wanted information on legal and financial issues, this did not change greatly over time. (8) Age and gender were also found to influence patients' perceptions and type of information desired. Younger patients desired more knowledge about the medical aspects of stroke, post stroke exercise and post stroke sexual activity. Whereas patients with severe motor dysfunction desired more knowledge on items concerning rehabilitation (5)

Information about modification of risk factors were found to differ between sexes, with men desiring more knowledge about smoking and women desiring more knowledge about dietary risk factors (5)

A qualitative study to identify the information needs of stroke survivors and relatives at various stages post-stroke found there was a need for personalised information, and concluded that use of a customised database would improve information provision (23)

Deficiencies in communication, mostly relevant written information were commonly reported by patients and relatives was one of five domains identified in a review of qualitative studies which aimed to identify the most frequent long-term problems of stroke survivors and relatives. (24)

A patient satisfaction survey, part of a study to assess the quality of the discharge process from hospital and follow up services for people with stroke found that levels of communication were poor and only basic care was delivered on discharge with a narrow focus of rehabilitation. (28)

The information needs of the care provider also changed over time. In particular they felt they were not provided with adequate information on services and resources they could access following discharge, especially regarding psychological support. A lack of continuity of care from the rehabilitation to community setting was also reported. (9)

Several studies have also observed that patients and family members felt that they had to look for most of the information themselves or had to demand it (4, 9)

A commentary written by the relative of a stroke survivor suggests that there is a need for better communication and that improved communication would result in better outcomes for stroke survivors, their families and professionals. (29)

These studies demonstrate the wide diversity of desired information and how information needs vary greatly between individual patients and change with time.

Patients' perception and misconceptions

A study published in the BMJ in 2002 compared stroke knowledge between the general public and in patients who have had a stroke. This study revealed that both groups had a similar understanding about the description of stroke and both groups expressed difficulties in recognising the symptoms of stroke. Participants in this study who had had a stroke reported that they had not received enough information during their hospital stay. (10) A similar study was repeated in 2005. This also showed that stroke survivors did not know more about stroke than non-stroke survivors. Both groups had similar good understanding about stroke symptoms, the role of rehabilitation, risk factors including diet, blood pressure and cholesterol, the role of aspirin and other available treatments. Lack of knowledge was demonstrated for risk factors such as smoking, excess alcohol and atrial fibrillation. (although a large portion of the study population were non smokers) (11)

Another study looking at a general population of 150 elderly patients found that a small percentage of stroke survivors within this group did not have up to date information on the medical restrictions to driving (12) 46 participants were surveyed one year post stroke in a study which sought to determine whether stroke survivors received and complied with advice given about driving. Those who had received advice were significantly more likely to obtain medical permission before driving but there were no significant differences in compliance with other recommendations. (26)

These studies further highlight inadequacies of educational programmes following stroke

Factors affecting perception and desired information

Various factors have been looked at as to why patients and care givers are generally dissatisfied with the level of information provision following stroke. These include lack of time or skills on part of the health professional, inability or unwillingness to absorb information on the part of the stroke survivors and their families and lack of good quality educational materials. (13, 9, 4)

Particular attention has been paid to the suitability of written educational material for stroke survivors. Eames et al assessed 53 educational materials and found that 68% were written at a level that exceeded the reading level of both stroke survivor and their care giver. (13). These findings were further supported in several other studies 14, 15. Houts et al demonstrated that information conveyed through pictures was particularly helpful for those patients with lower literacy skills (20).

Another study suggested that excess emotion and distress of the caregiver following the diagnosis of stroke affected their ability to absorb information at the time of admission, they also demonstrated that given time to accept the care giving role, they became more receptive to learning about stroke. (16) This is supportive of the changing information needs with time. Education level also seemed to affect the level of information required and received. Stroke survivors rated as highly educated generally wish for more information and indicate to have received less information than low educated stroke survivors (4). However this observation was not replicated in other studies (5)

Trials looking at different methods of communication

Overall there seems to be a consensus between healthcare professional and stroke survivors that there are gaps and deficiencies in the amount, type and timing of information provision

following stroke. These inadequacies appear to be multifactorial in origin. Recognising these difficulties there have been many trialed interventions to aim to improve information provision and overall patient satisfaction.

One such intervention was design of a computer information system to provide tailored information for patients and their relatives. The system allowed patients to select the topics about which they wish to receive information, the amount of information they wanted and the font size of the printed version. The system also allowed for interaction with health professionals. Although a randomised controlled trial has yet to be completed initial results were promising (17)

A critical review looking at intervention studies for caregivers of stroke survivors was published in 2005 (18) Various interventions were reviewed, services to improve discharge, provision of a stroke family care worker, educational interventions and counselling studies. Despite looking at 22 different studies they were unable to identify any specific intervention that was clearly beneficial for caregivers of patients with stroke. (18) A further review from the Cochrane database concluded that information provision combined with educational programmes improved stroke knowledge. (19)

An Australian study assessed the use of a self management education intervention taking into account the psychological and social needs of stroke survivors and relatives appeared to improve rehabilitation outcomes in the short-term. (21)

A patient education programme using a combination of a stroke information manual plus education meetings every two weeks with MDT members did not result in improved knowledge but did reduce anxiety six months after the stroke. (22)

Another Australian trial looked at a patient education programme which included three visits from a social worker trained in family counselling. The intervention aided family functioning also social and functioning outcome. There were, however, no significant effects on anxiety and depression.(27)

Information sources used by patients

A review to determine the use of the internet by patients concluded that they have become active consumers of health information rather than passive recipients.(25)

Comment

It would seem that to improve information provision following stroke, health professionals should aim to transfer our thinking away from seeing patients as part of a similar stroke population, to individuals, each having the same diagnosis but with different backgrounds and different future needs. Information needs and provision will be different for each individual patient. Future intervention need to bare this in mind. Professionals also need to find more specific and widely accepted outcome measures to assess these interventions.

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7.2 Research plan

Aims and methods

With the proposed pilot study we want to address the issue of communication of stroke information through the following questions:

What type of information do health professional in acute, community and rehabilitation services have on stroke risks and how do they use them to advice on life style adjustments?

What perceptions do health professionals and service providers have on the information needs of patients and what strategies do they employ to meet these?

What information needs do stroke survivors and their family and relatives have about risk factors and how to minimise these?

What perceptions do stroke survivors and their relatives have about risk factors in stroke?

How have stroke survivors embedded information about stroke in their daily lives?

What are factors that influence information exchange on secondary prevention, risk and self - management of stroke?

Project objectives

This project will identify:

- relevant literature on communication in stroke;
- service providers' perceptions of the information needs of stroke survivors and their relatives;
- the strategies service providers use to meet these needs especially with regards to the when, where and the type of information they provide;
- stroke survivors' and relatives' perceptions of the information they need;
- stroke survivors' and relatives' perceptions of the information which they received in the six months following a stroke;
- strategies which stroke survivors and their relative use to obtain information;
- the ways in which stroke survivors and relatives evaluate different sources of information and use it.

Achieving objectives/plan of work

We are proposing to conduct four streams of work in this study:

Literature review The project will conduct a focussed review of the literature on stroke and communication, drawing on existing empirical research evidence, clinical case material and other relevant literature. The purpose will be to gain an overview and summarise the findings of relevant research and to identify best practice in overcoming barriers to communication.

Social survey The study will use a survey design to identify the ways in which different parties in the communication process define information needs, and to draw out perceptions and views on information currently provided, the relevance of different sources of information and their utility. Social surveys are a well-established and cost

effective method of collecting quantitative and qualitative data from a sample of cases selected from a wider population (O'Leary, 2003 and Moser and Kalton, 1971). As this project is attempting to draw out and define relevant issues in communication about stroke, the study will use a qualitative research design focussed on in-depth analysis. In using a small-scale approach, we will be able to retain flexible approach to actively respond to emerging issues.

A survey of patient information literature on stroke in East Kent and other documentary sources used by stroke survivors. We will collate relevant literature and information sources for stroke survivors. The aim is to gain an overview of the information sources available to patients, their quality, their location and ease of access. The documents will also be used in interviews and focus groups to elicit views about their usefulness by stroke survivors, their relatives and service providers.

Preparatory work on developing a larger-scale research project Based on the emergent findings and the experiences of conducting research in this area, we propose to work on an outline proposal for a larger scale study, with recommendations and guidance on research questions to be asked, suitable research designs and models for approaches, funders and outcomes for the research.

7.3 Research participants

Interview participants: Stroke survivors

No	Pseudonym	Age
1	Mr James	58 years
2	Mr Small	63 years
3	Mrs Deakin	76 years
4	Mrs Baldwin	57 years
5	Mrs Vine	45 years
6	Miss Knight	78 years
7	Mrs Carter	76 years
8	Mrs Turner	65 years
9	Mrs Inglby	45 years
10	Mr Rigby	73 years
11	Mr Harvey	65 years
12	Mr Leeman (interviewed with Mrs Leeman, his wife and main carer)	72 years
13	Mrs Grant	86 years
14	Mr Norris	69 years
15	Mr Duncan	48 years
16	Mr Baxter	78 years
17	Mrs Harris	63 years
18	Mrs Collins	48 years
19	Mr Long	64 years
Total		

Interview participants: Relatives and carers

No.	Pseudonym	Age
1	Mr Dennis	75 years
2	Mrs Young	55 years
3	Mrs Yorke	63 years
4	Mrs Twigg	71 years
5	Mrs Hall	65 years
6	Mr Cameron	49 years
Total		

Interview participants: Health professionals

Individual interviews	Focus Groups
GP 1 (pilot)	1) <i>Multi-disciplinary team (hospital based)</i>
GP 2	1 nurse – discharge nurse
Speech and Language Therapist	1 Speech and language therapist
Consultant 1	1 Occupational therapist
Consultant 2	1 nurse-ward manager
Stroke nurse	1 nurse - ward manager
Dietician	
Physio therapist	2) <i>Community Assessment and Rehabilitation Team (CART)</i>
Practice nurse	Physio therapist
Family support worker	2 Occupational therapists
Care manager	2 Rehab Assistants
	2 nurses
Total: 11	Total: 12

7.4 Information letters and consent form

Information sheet and Invitation to participate (Health Professionals) Version 1 June 2006



Research Project Information Sheet and Invitation to participate

Current approaches to communicating information to people after a stroke: a pilot study

Start date: October 2006

End date: June 2007

Would you like to help us with our research project?

Researchers from the Centre for Health Studies at University of Kent and East Kent Hospitals Trust are carrying out a study which we hope will help people recovering from strokes and their carers. The research team has had previous experience of working with people after stroke. This study is supported by funds from the East Kent Hospitals Trust Donated Funds.

What is the study about?

This pilot study aims to pave the way for a larger study to investigate issues with regard to communicating information, including when is communication most effective, who is in the best position to provide information, what is the best way of providing information e.g. by speaking with people, by written information, group sessions or mixtures of various types.

The project follows on from previous work supported by the Stroke Association which showed that communication of information from health professionals to stroke survivors and their families can be quite variable. For example, these two participants in that study had very different views:

Well, actually I can't fault it all, the doctors and the nurses have been very honest with me

If we were talking marks out of 10 I would say 7. I don't think I was given the full information. It was all a bit iffy

The aims of the study are to investigate:

- What information do health professionals have relating to the risk of stroke happening and how do they use this information to advise stroke survivors on life style adjustments
- What understanding do health professionals have with regard to the information needs of stroke survivors and how do they meet these needs
- What information needs do stroke survivors and family/carers have with regard to the risk of stroke and how to reduce these.
- What understanding do stroke survivors and family/carers have about the risk factors in stroke
- How have stroke survivors used the information they have received in making changes to their life style.

How many people will be involved in the study?

We are seeking to recruit 24 people in Kent who have experienced a first stroke within the last six to nine months and 20 carers. We also wish to recruit 20 service providers, 10 of whom are designated stroke workers and 10 generic.

Do I have to take part?

It is entirely up to you whether or not you take part.

If I agree to take part, what would it involve?

The researchers, Helen Alaszewski and Annette King, wish to do a number of individual interviews and focus group discussions. The interviews will take place at a time and place convenient to you and will take up to 1 hour.

With your permission, we would like to tape record the interviews. The tapes will be kept in a locked cupboard and destroyed two years after the end of the project. To protect your confidentiality all names will be changed for any quotes used in the final report.

What will happen if I change my mind and no longer wish to take part?

You can withdraw from the study at any time and will not be asked for an explanation.

Findings from the study

We will write a report at the end of the study and you will be sent a copy if you wish.

Further information

If there is anything else you would like to know about the study please contact the researcher who will be only too pleased to explain in more detail.

Helen Alaszewski

Tel: 01227 827641

Email: h.p.alaszewski@kent.ac.uk

Thank you for taking the time to read this sheet.

The Research Team

Andy Alaszewski is Professor of Health Studies and Director of the Centre for Health Services Studies. He is a social scientist who has been an active health services researcher for over 30 years. He is committed to a person-centred approach to research, to understanding how illness affects individuals and how this knowledge can be used to shape services to be more sensitive to individual needs.

Dr Jonathan Potter has been providing medical input into to stroke unit in Canterbury for 15 years and has been involved in many service developments in the area. In addition he has a long-standing record of clinical research grants and research.

Annette King works in a research and development role in East Kent Hospitals Trust, in the Department of Health Care of Older People. She trained as a social scientist and has worked for over 10 years in a variety of research roles. Annette is particularly interested in how best to use research to improve care and services in the NHS.

Helen Alaszewski is a Research Associate at the Centre for Health Services Studies. She trained as a nurse and worked with people with learning disabilities and older people. She has worked in research for the last 10 years and is just finishing a study supported by the Stroke Association looking at younger peoples' experience of stroke.



Research Project Information Sheet and Invitation to Participate

Current Approaches to Communicating Information to Stroke Survivors: a pilot study

Start date: October 2006 End date: June 2007

Would you like to help us with our research project?

Researchers from the Centre for Health Studies at University of Kent and East Kent Hospitals Trust are carrying out a study which we hope will help people recovering from strokes and their carers. The research team has had previous experience of working with people after stroke. This study is supported by funds from the East Kent Hospitals Trust Donated Funds.

What is the study about?

We would like to find out your views on the information you have been given about the stroke and follow-up support and care. The project follows on from previous work supported by the Stroke Association which showed that communication of information from health professionals to stroke survivors and their families can be quite variable. For example, these two participants in that study had very different views:

Well, actually I can't fault it all, the doctors and the nurses have been very honest with me

If we were talking marks out of 10 I would say 7. I don't think I was given the full information. It was all a bit iffy

The aims of the study are to investigate:

- What information needs do you and your family/carer have with regard to the risk of stroke and how to reduce these.
- What understanding do you and your family/carer have about the risk factors in stroke
- Whether you have used the information you have received in making changes to your life style.

Why have I been chosen ?

This is a pilot study and we hope to use the findings to do a larger study at a later date. We are seeking to recruit 24 people in Kent who have experienced a first stroke within the last six to nine months. We will also seek the views of at least 20 relatives of stroke survivors and a number of health professionals.

Do I have to take part?

It is entirely up to you whether or not you take part and your decision will not affect the services you receive in any way. If you decide to, you will be given this information sheet to keep and will be asked to sign a consent form.

If I agree to take part, what would it involve?

One of the researchers, Helen Alaszewski or Annette King, will come and talk to you in your home, at a time convenient for you. They will be interested to hear about your experience of stroke, in particular about the information you received, how you received it, how useful you found it and whether it influenced your lifestyle. The interview will take about 40 minutes to 1 hour. Helen and Annette will carry ID cards with a photograph that you can check before letting them into your house. Please do not be put off if you are having some difficulty in communicating as we will still be interested in your views.

With your permission, we would like to tape record the interviews. The tapes will be kept in a locked cupboard and destroyed two years after the end of the project. To protect your confidentiality all names will be changed for any quotes used in the final report.

What will happen if I change my mind and no longer wish to take part?

You can withdraw from the study at any time and will not be asked for an explanation. As before, the services you receive will not be affected.

Findings from the study

We will write a report at the end of the study and you will be sent a copy if you wish.

Further information

If there is anything else you would like to know about the study please contact the researcher who will be only too pleased to explain in more detail.

Helen Alaszewski

Tel: 01227827641

Email: h.p.alaszewski@kent.ac.uk

Thank you for taking the time to read this sheet.



Research Project Information Sheet and Invitation to participate for carers of people who have had a stroke

Current Approaches to Communicating Information after a Stroke: a pilot study

Start date: October 2006 End date: June 2007

Would you like to help us with our research project?

You are being invited to take part in a research study. Before you decide it is important that you understand why the research is being done and what it will involve. Please take the time to read the following information and to discuss it with others if you wish.

Researchers from the Centre for Health Studies at University of Kent and East Kent Hospitals Trust are carrying out a study which we hope will help people recovering from strokes and their carers. The research team has had previous experience of working with people after stroke. This study is supported by funds from the East Kent Hospitals Trust Donated Funds.

What is the study about?

We would like to find out your views on the information you have been given about the stroke and follow-up support and care. The project follows on from previous work supported by the Stroke Association which showed that communication of information from health professionals to stroke survivors and their families can be quite variable. For example, these two family carers in that study had very different views:

I think the information she (Family Stroke Support Worker) gave us, and just being able to talk to her. I think that has helped a lot, well it has with me because I just felt that my husband thought he was out on a limb, you know, why me?

I felt that I had to go and knock on doors quite a lot. Everybody was very kind but the advice didn't come really freely.

The aims of the study are to investigate:

- What information needs do you (carer) have with regard to the risk of stroke and how to reduce these.
- What understanding do you (carer) have about the risk factors in stroke
- Whether you have used the information you have received to make changes to your life style

Why have I been chosen ?

This is a pilot study and we hope to use the findings to do a larger study at a later date. We are seeking to recruit 24 people in Kent who have experienced a first stroke within the last six to nine months. We are also seeking to recruit 20 carers of people who have had strokes and number of health professionals involved in the care of people who have had a stroke.

Do I have to take part?

It is entirely up to you whether or not you take part and your decision will not affect the services you receive in any way. If you decide to take part, you will be given this information sheet to keep and will be asked to sign a consent form.

If I agree to take part, what would it involve?

The researchers, Helen Alaszewski and Annette King, will be conducting 8 individual interviews, in participants' homes, and two group interviews at an easy access location. They will be interested to hear about your experience of stroke, in particular about the information you received, how you received it, how useful you found it and whether it influenced your lifestyle. The interview will take up to 1 hour. Travel expenses will be paid to the group interviews and transport could be provided.

With your permission, we would like to tape record the interviews. The tapes will be kept in a locked cupboard and destroyed two years after the end of the project. To protect your confidentiality all names will be changed for any quotes used in the final report.

What will happen if I change my mind and no longer wish to take part?

You can withdraw from the study at any time and will not be asked for an explanation. As before, any services you receive will not be affected.

Findings from the study

We will write a report at the end of the study and you will be sent a copy if you wish.

Further information

If there is anything else you would like to know about the study please contact the researcher who will be only too pleased to explain in more detail.

Helen Alaszewski

Tel: 01227827641

Email: h.p.alaszewski@kent.ac.uk

Thank you for taking the time to read this sheet.

The Research Team

Andy Alaszewski is Professor of Health Studies and Director of the Centre for Health Services Studies. He is a social scientist who has been an active health services researcher for over 30 years. He is committed to a person-centred approach to research, to understanding how illness affects individuals and how this knowledge can be used to shape services to be more sensitive to individual needs.

Dr Jonathan Potter has been providing medical input into to stroke unit in Canterbury for 15 years and has been involved in many service developments in the area. In addition he has a long-standing record of clinical research grants and research.

Annette King works in a research and development role in East Kent Hospitals Trust, in the Department of Health Care of Older People. She trained as a social scientist and has worked for over 10 years in a variety of research roles. Annette is particularly interested in how best to use research to improve care and services in the NHS.

Helen Alaszewski is a Research Associate at the Centre for Health Services Studies. She trained as a nurse and worked with people with learning disabilities and older people. She has worked in research for the last 10 years and is just finishing a study supported by the Stroke Association looking at younger peoples experience of stroke.

7.5 Interview schedules

Interview Schedule 1: For professionals providing health and social care

1. Role

What is your current job title?

Could you briefly describe your role and activities? (prompt context of work, team work, referrals)

What sort of services and support do you provide for patients who have had a stroke. (prompt whether work with a variety of patients and if so what proportion of their case load is made up of stroke patients, approximately how long worked with stroke patients.)

2. Information needs of stroke patients

What do you see as the main information needs of the stroke patients you work with (query should we ask this in a generic or concrete terms)(prompt causes, secondary prevention, work, driving, prognosis, benefits)

What are the sort of questions or issues which stroke patients raise with you? (prompt examples, how do you deal with them, do you refer on)

What are the sort of questions or issues which their immediate family and friends raise with you? (prompt, examples)

In what ways do you think that getting information helps patients and their families (prompt for anxiety, uncertainty)

3. Responsibility for communicating information

In your team/working environment who do you see as having the main responsibility for providing information to stroke patients (prompt overall clinical responsibility, issues of team work)

What do you see as your responsibility for providing information to stroke survivors or carers (prompt in relationship to treatments provided, more broadly)

Do you see it as your responsibility to provide stroke survivors with information about secondary prevention or driving? (prompt if not who should)

Are there any constraints that prevent you providing information (prompt, team structure, time pressure, lack of privacy, lack of knowledge)

4. Current practice

From your experience what is the best way of communicating information to patients (prompt explaining, answering questions, providing leaflets, drawing attention to websites)

Is it the same for their supporters (prompt if different why?)

Are there any specific problems of communicating information (prompt memory problems, stress and anxiety) If so how do you deal with them (prompt, examples)

Can you see any ways in which the provision of information can be improved? (prompt for examples)

5. Survivor and carer search strategies

How do you think patients and carers go about getting the information they want (prompt have they thought about this, do they see themselves as main source information, variety of sources, professionals, friends/family, leaflets, media, internet)

How do you think stroke survivors and carers evaluate the information that they get from different sources (prompt, trust, quality assessment, acceptability of information, query their evidence for this)

What impact do you think this has on stroke survivors recovery and prognosis (prompt risks of driving, failure to change lifestyle)

Interview Schedule 2: For stroke survivors

1. Context

Could you tell me a bit about yourself (prompt, approximate age, where and how living, significant relationship/supporter)

Could you tell me about your experiences immediately after your stroke (prompt, experience of hospital, consultant and nurses, therapists, discharge)

Could you tell me what services you have been in contact since then (prompt outpatients, community team, general practice, specialist therapy, social services, benefits, CAB, DWP)

In relation to your stroke do you see anyone at the moment (prompt outpatients, community team, general practice, specialist therapy, social services, benefits, CAB, DWP)

2. Information needs of stroke patients

When you first had your stroke what sorts of things did you want to know (prompt if clarification requested either in hospital or if not hospitalised in first 6 weeks, prompt causes, prognosis, disability, likelihood of another stroke)

Did you manage to get the information you wanted (prompt sources, difficulties, issues about memory problems)

When you were discharged from hospital what sorts of things did you want to know (prompt causes, prognosis, disability, likelihood of another stroke)

Did you manage to get the information you wanted (prompt sources, difficulties, issues about memory problems)

At the moment are there any aspects of stroke and your stroke experience you do not fully understand or would like more information on (prompt why not got info earlier)

Looking back do you think there have been any inconsistencies in the information which you have received, either between professionals or between the information you have got from professionals and from other sources (prompt, examples)

Looking back do you think the information you received was as specific and concrete as you wanted (prompt for uncertainty, vagueness, unwillingness to make a judgement).

Looking back do you think any professionals took responsibility for giving you information or do you think you had to ask or search it out for yourself (prompt hospital, outpatients, community)

3. Information practices

In comparison to other major life decisions, do you think that making decisions in relationship to your stroke have been any different, if so why? (prompt comparators, buying

house, car, booking holiday, why same or different, trauma, loss of confidence, time pressure, loss of control, defining moment, irreversible, how deal with this, press for comparisons)

What do you see as the main sources of information on stroke (prompt experts/professionals, friends and family, leaflets, media, internet).

Which sources have you found most helpful (prompt why, accessibility, relevance, responsiveness)

Which sources do you think contain the most accurate information (prompt try and elicit criteria used to judge)

Which sources do you trust the most (prompt try and elicit criteria for trust, self interest v disinterest, commercial v public)

4. Advice for the future

If you were given the job of making sure stroke survivors got the best information what would you concentrate on

What advice would you give professionals for improving the way they communicate information.

Interview Schedule 3: For carers

1. Context

Could you tell me a bit about yourself (prompt, approximate age, where and how living, how you provide)

When had his/her stroke were you involved in the decision about diagnosis and treatment (prompt visit hospital, involvement in meetings)

When was discharged from hospital were you involved in the decision (prompt preparation, contact)

Since then have you been involved in care and therapy (prompt different aspects)

2. Information needs of stroke patients

When ... had his/her stroke you, what sorts of things did you want to know (prompt if clarification requested either in hospital or if not hospitalised in first 6 weeks, prompt causes, prognosis, disability, likelihood of another stroke)

Did you manage to get the information you wanted (prompt sources, difficulties, issues about memory problems)

When was discharged from hospital what sorts of things did you want to know (prompt causes, prognosis, disability, likelihood of another stroke)

Did you manage to get the information you wanted (prompt sources, difficulties, issues about memory problems)

At present are there any aspects of stroke and your situation that you do not fully understand or would like more information on (prompt why not got info earlier)

Looking back do you think there have been any inconsistencies in the information which you have received, either between professionals or between the information you have got from professionals and from other sources (prompt, examples)

Looking back do you think the information you received was as specific and concrete as you wanted (prompt for uncertainty, vagueness, unwillingness to make a judgement).

Looking back do you think your specific needs for information were considered (prompt hospital, outpatients, community)

3. Information practices

When you make major life decisions such as buying a house or a car, how do you make sure that you are making the right decision (prompt information strategy, sources of information, assessing the quality of information, press for examples)

Do you think that involved in decisions about X's care and treatment is this different, if so why? (prompt why same or different, time pressure, loss of control, defining moment, irreversible, how deal with this, press for comparisons)

What do you see as the main sources of information on stroke (prompt experts/professionals, friends and family, leaflets, media, internet).

Which of these sources have you used to find out more about stroke (prompt general info about cause of stroke, specific info about personal cause, treatment, advice on lifestyle)

Which sources have you found most helpful (prompt why, accessibility, relevance, responsiveness)

Which sources do you think contains the most accurate information (prompt try and elicit criteria used to judge)

Which sources do you trust the most (prompt try and elicit criteria for trust, self interest v disinterest, commercial v public)

Do you think that you and X use different sources of information? If so why?

4. Advice for the future

If you were given the job of making sure stroke supporters got the most appropriate information what would you concentrate on.

What advice would you give professionals for improving the way they communicate information.

Focus Group 1: Professionals

1. Could you please briefly introduce yourself to the group (prompt what your currently position is and what involvement you have in providing service for people who have had stroke and those who provide informal support)
2. Could we start by discussing what you see as the main information needs of stroke survivors (prompt to you think information needs change over time and if so how)
3. Do you think that people supporting stroke survivors have same or different information needs (prompt, do they change over time)
4. Who do you think has the main responsibility for providing information to stroke survivors and carers (prompt person responsible for care, shared responsibility, varies according to type of information)
5. What do you see your role in providing information for stroke survivors or their carers?
6. What do you think is the best way of providing information (prompt varies according to type of information, problems of personalising information, dealing with memory or cognitive problems)
7. How do you think stroke survivors get information (prompt different sources)
8. Do you think there are problems with providing information? If so what would be the best way of overcoming such problems?

