

*“It is impossible for anyone who has not experienced a stroke to understand how it feels for the person and their family. You are devastated, life is over as you knew it...”*

# Stroke Survivors

*Our stories,  
in our words*

*2007 EHSSB Stroke Strategy  
Implementation Project*

# Stroke Survivors - Our stories, in our words

## Stroke Survivors and Carers Recommendations for Improvement of Services



Supported by



A report from the EHSSB Stroke Patient and Carer Reference Group

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## ***10 things you should know about stroke***

1. Every **2 hours** someone in Northern Ireland has a stroke.
2. A stroke is a **brain attack**. A stroke happens due to a clot or bleed in the brain, which causes brain cells to die.
3. The signs of a stroke are:
  - Facial weakness
  - Arm or leg weakness
  - Speech problems
  - Test all three

*These signs may only last a few hours (called a Transient Ischaemic Attack – TIA) but must not be ignored.*

4. **A stroke is an emergency**. If you see the signs of a stroke act quickly and call 999. Early treatment saves lives and increases the chance of making a better recovery.
5. Stroke is the **third biggest killer** and the leading cause of severe disability in Northern Ireland.
6. 40% of strokes are **preventable**.
7. More than **three times** as many women die from stroke than breast cancer in the UK.
8. Unacceptable inadequacies in stroke care and research exist. For every £50 spent on cancer research and £20 on heart disease research, **only £1 is spent on stroke research**.
9. Eating healthily, taking more exercise, not smoking and ensuring blood pressure is normal, can all **help to prevent** stroke.
10. The **Stroke Strategy Implementation Project** is working in partnership with the EHSSB and NI Chest, Heart & Stroke to develop services for stroke survivors and their carers.



## Foreword - from the Director of the EHSSB Stroke Strategy Project .....



*"Every two hours someone in Northern Ireland has a stroke. It will happen to a quarter of all those over the age of forty five."*

Having a stroke is one of the most devastating things that can affect a person, and it will happen to a quarter of all those over the age of 45. Every two hours one person will have their life changed forever as a result of a stroke and over a year this totals 4,000 new strokes in Northern Ireland.

Recent years have seen major advances in stroke management. We know that in the region of forty percent of strokes are preventable, and that fast effective acute treatment of stroke, and high quality rehabilitation can significantly reduce death and disability.

Northern Ireland stroke services have improved significantly in the last decade and many of these improvements are evident across the Eastern Board area, with an average of seventy two percent of stroke patients receiving care on a specialist stroke unit.

Despite this progress there is evidence that much more can be done within the Eastern Board area to improve the quality of stroke services. This is not just about leading edge evidence based care but also about improving patient experience.

Service user involvement is central to the delivery of stroke services that truly meet the needs of patients and their carers. The inside story can only really be told by those who have had first hand experience either as a person with stroke or someone close to them.

We must develop effective ongoing partnerships with stroke survivors and their families ensuring that their experiences, both good and bad are used to improve services in the future.

This is the first time in Northern Ireland that a group of stroke survivors and their carers have come together to write and make public a report on their personal experience of the stroke care they received,

and to make recommendations on how services could be improved.

Although this is a small group, the themes which emerged from their experiences echo those expressed by stroke patients participating in national surveys and expressed through voluntary agencies including NI Chest Heart & Stroke and the Stroke Association.

The recommendations which the patient and carer group have made are both practical and achievable. If implemented, they would make a huge difference, in the management of stroke and ultimately in patient outcomes and quality of life.

Although the report has been written from the perspective of stroke survivors and their carers, some of the recommendations focus on the fundamentals of care, which will be relevant to any condition and are not necessarily resource driven.

This document I hope, will be used as a resource to support policy makers, commissioners and health professionals in delivering equitable, evidence based care in partnership with service users which reflects the needs outlined in this report.

I would like to thank the Belfast and South Eastern Health & Social Care Trusts for their support with this work and look forward to a continued partnership to ensure that the recommendations in this report are central to the development of stroke services across the Eastern Board area.

It has been a pleasure and a privilege to work with the Stroke Patient & Carer Reference group and to facilitate them in telling their stories and identifying their recommendations for improvements in service delivery. I look forward to working with this dynamic group in the future and to ensure that the voice of stroke survivors and their carers continues to be heard.

A handwritten signature in black ink that reads "S. Aitcheson". The signature is fluid and cursive.

Sandra Aitcheson  
Stroke Strategy Project Director

## Context

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This report will be of interest to anyone affected by stroke but particularly to policy makers, commissioners of services for stroke, health and social care trusts, individuals working with stroke survivors and their carers.

A number of stroke survivors and carers from across the Eastern Health & Social Services Board area have come together, facilitated by the EHSSB Stroke Strategy Implementation Project to form the EHSSB Stroke Patient and Carer Reference Group (see Appendix 1 for further details).

The group's work to date has focused on discussing the members' personal experiences of stroke and stroke services. These experiences were varied and a number of areas of good practice came to light alongside a number of areas for improvement.

Detailed in this report are recommendations for service improvements in stroke prevention and management based on the group members' personal experiences.

The report is structured according to key themes which emerged over the many group meetings. Each section aims to highlight some personal experiences, summarise the issues and make recommendations for improvement.



## Background

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A stroke is the brain equivalent of a heart attack and a type of brain injury. It happens when part of the brain tissue is deprived of blood. Blood carries essential nutrients and oxygen to the brain tissue without which brain cells can be damaged or die.

The brain controls everything the body does, including, moving, walking, swallowing, speaking, writing, understanding words, dressing and eating. It also controls bladder and bowel function, mood and emotions. Damage to the brain will affect how the body works.

The symptoms at the onset of a stroke, the damage done and recovery vary tremendously depending on the area of the brain which is affected.

Stroke is the third main cause of death in Northern Ireland and the greatest cause of adult disability. It is estimated that there are 4000 new strokes in Northern Ireland each year of which 1500 are within the Eastern Health & Social Services Board area.

About five percent of the overall NHS budget is spent on providing care and support to stroke sufferers. Of those who have a stroke each year in the Eastern Board area, one third will die within the first month, one third will have a significant disability and one third will make a full recovery.

A recent survey (CHS News) found that there was public ignorance in recognising stroke and meagre knowledge of the risk factors.

Nearly forty percent of strokes are preventable through addressing the known risk factors including: smoking, hypertension, atrial fibrillation, high cholesterol, poor diet and lack of exercise. This would equate to 600 fewer strokes per year in the Eastern Board area.

Increased levels of research over the last decade have led to significant clinical, technological and organisational developments in the area of stroke care, such that there is now compelling evidence for effective interventions for the prevention, treatment and rehabilitation of stroke patients.

Services for stroke within the Eastern Board area have developed through the dedication and commitment of individual professionals. So much so that we now have specialist stroke units in the majority of acute hospitals and a number of community stroke teams.

The 2006 NI Stroke Sentinel Audit results however, clearly identify major gaps in our current stroke service with significant variation and inequity in the standard of care delivered throughout the Board area.

In light of the evidence base for the prevention, treatment, and ongoing management of stroke, a greater focus on delivering good practice in stroke care in the Eastern Board would save lives, reduce disability and allow for more effective use of resources.

*"If all stroke patients in the Eastern Board area were treated in a specialist stroke unit it would save approximately 110 lives per year and potentially save more than 1300 bed days which equates to more than £150k which could be spent on service improvement."(Cochrane Stroke Trials)*

This does not reflect the immeasurable personal cost to individuals and families.

Stroke services need to be provided to the same high standards throughout the Board area ensuring equity to our diverse population.

***The following sections highlight the personal experiences of the service users and carers within the group.***

***They summarise the issues discussed and make recommendations for improvement.***

## Section 1: Primary Prevention

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*“Can stroke be prevented?  
...then that’s where we need to start.”*

*“It was horrendous to have a stroke but it made me feel even worse to know it could have been prevented.”*

*“I would rather have had another heart attack,  
we knew nothing about stroke.”*

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The group discussed the issue of public awareness of stroke which they all agreed was very poor. Most members knew very little about stroke before they were personally affected by it. Everyone was living with the consequences of stroke and felt that had they known more about stroke and how it can affect your life they would have been much more proactive in managing the risk factors.

It was agreed that information about stroke should be made widely available not only to those who have been personally affected but also to the general public. The group felt it was vital to increase awareness of stroke, how to prevent it, what the signs and symptoms are, and also to improve the general

public’s understanding of the impact of stroke on the stroke survivor and their carers and family.

The aim of increasing awareness is to, as far as possible, prevent strokes, ensure that symptoms are recognised and treated immediately, and also to help address the public ignorance of disability following stroke.



### **Recommendations:**

- 1.1 *A public awareness campaign specific to stroke should be developed to increase knowledge of the risk factors for stroke, the signs and symptoms and the impact of stroke on both individuals and their families and carers.*
- 1.2 *There should be a specific emphasis on encouraging young people to adopt healthy lifestyles at a young age.*
- 1.3 *Individuals with risk factors for stroke should be more aggressively managed in order to prevent stroke.*
- 1.4 *GPs should support individuals to address their lifestyle risk factors for a stroke and not solely focus on prescribing medications.*

## Section 2: Emergency Management of Stroke .....



*"The hospital consultant said to me the day after my stroke – what a pity we didn't know that you had a clot or we could have had you on your feet by now!"*

*"When my partner collapsed we immediately rang an ambulance which came quickly and rushed us to A&E. When we got to A&E it felt like the clock stopped... nothing happened."*

*"I contacted the out of hours doctors – one diagnosed 'an inner ear viral infection', a second diagnosed 'dehydration'. The stroke occurred on a Thursday, it was Monday before hospital admission."*

*I felt dizzy and unwell but thought a good nights sleep would sort me out. I had no idea I was having a stroke so I waited overnight before seeking help."*

The group's discussions reflected the variety of symptoms experienced at onset of stroke. There was confusion as to what was happening and what the best course of action was. Most individuals experienced delays in gaining access to specialist stroke treatment due to a variety of factors. Some decided it was best to wait and see and sought treatment sometime after symptom onset. Some contacted their GPs and were given varying advice. There was no clear understanding among stroke sufferers, their families or the GP service in terms of firstly recognising a stroke and secondly the action that should be taken in the event of a stroke occurring.

On arrival at A&E most of the group members received little information and had long delays before getting any diagnosis. In many cases there

appeared to be a lack of understanding among A&E staff as to the symptoms and diagnosis of stroke. Where a diagnosis was made, often this was not communicated to the patient or carer, until much later.

Once a diagnosis of stroke was made most of the group members were not made aware of their need for specialist stroke care, or indeed that there was a specialist stroke service within the hospital. With hindsight most members felt it was too long before they received stroke specialist treatment or access to a stroke unit bed. This was a particularly difficult time for carers and family as many felt the responsibility of acting as an advocate without having any information.

***Recommendations:***

- 2.1 A stroke is a medical emergency and should receive the same emergency response as for a heart attack.*
- 2.2 There must be a recognised emergency response to stroke symptoms both among the public and among healthcare professionals including GPs, the ambulance service and A&E staff.*
- 2.3 All individuals with symptoms of stroke should have rapid access to stroke specialist treatment. Access from A&E to on-call stroke specialists should be available at all times.*



## Section 3: Specialist Stroke Treatment

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*“How much do the staff know about stroke?”*

*“Even though they knew I had visual problems they still gave me out menus that I couldn’t read to pick lunch.”*

*“On the stroke unit I had physio and speech therapy every day and the therapists really motivated me.”*

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The group felt that it was crucial that all stroke patients should be treated by stroke specialists in a dedicated stroke unit.

Among those group members who were treated in specialist stroke units there was still concern that more education and better awareness of stroke among all levels of healthcare staff was needed.

Many of the group members experienced occasions when the staff were not as aware of their needs and stroke-related problems as they expected them to be. Stroke survivors reported feeling confused and uncertain about what was happening to them, and this was compounded by instances where it

was felt that the staff didn’t have an appreciation of the wide range of problems they were experiencing.

Stroke survivors with visual problems reported being given menus which they could not read to choose their meals and those with a range of communication difficulties reported occasions when staff did not seem to be aware of this.

Awareness of the possibility of visual and perceptual problems following stroke is lacking, this results in poor diagnosis and management of these problems, which subsequently has a major long-term impact on rehabilitation and quality of life.

### *Recommendations:*

- 3.1 *All acute stroke patients in the hospital setting should be cared for in a specialist stroke unit.*
- 3.2 *All individuals providing a service to stroke survivors, including healthcare assistants, nursing home staff and those who deliver care in the patients own home should have training in stroke care.*
- 3.3 *Greater awareness among staff of the impact of communication difficulties on patients and carers is vital for patient safety and good quality care.*
- 3.4 *Greater awareness of the potential for visual and perceptual problems post stroke is necessary, and the appropriate support should be put in place.*

## Section 4: Emotional Support

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*“The psychological support was so important because I always felt I was just one step away from total despair.”*

*“So hard to accept –I never realised that my life had changed.”*

*“The emotional side of stroke is very neglected. It seems to be accepted that it’s natural to feel down when you’ve had a stroke. It is impossible for anyone who has not experienced a stroke to understand how it feels for the person and their family. You are devastated! Life is over as you knew it. This feeling of despair and hopelessness affects everything you do. You can’t concentrate on your therapy, you do not remember information that you are given and planning for the future seems hopeless.”*

*“Trying to maintain a positive mental attitude was the toughest part, luckily with support I did manage to find the resources within – your state of mind is crucial to recovery.”*

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It is estimated that up to forty percent of stroke survivors suffer from clinical depression and many more will suffer from a range of emotional issues: anxiety, anger, fearfulness, low self esteem and loss of self confidence. These emotional problems may also affect relationships with partners and children.

Despite all of this only one member of the group had any professional counselling or psychology

service. The service provided to that individual was regarded as a crucial part of the recovery process.

All members of the group agreed that the current lack of access to professional psychology services for both stroke survivors and their carers was a serious concern which must be addressed urgently.

### **Recommendations:**

- 4.1 *There must be greater awareness and recognition among staff of the psychological and emotional problems which stroke survivors and carers frequently experience and the impact which this has on recovery.*
- 4.2 *All stroke survivors and carers must have timely access to clinical psychology services to help them cope with the emotional and psychological issues which are experienced following a stroke. These services should be easily accessible at any stage of the stroke survivor’s journey.*

## Section 5: Stroke - not only an illness of older people .....



*"I was 48 years old when I suffered a severe hemorrhagic stroke, I will never forget the events of that day, I was at work as usual on a perfectly normal day ...when I came around I gradually realised that my left arm, hand and leg were paralysed and that I would remain profoundly disabled for a long time."*

Though it is more likely in later years a stroke can happen at any age, and twenty five percent of strokes occur in people below the age of 65.

However, stroke survivors and their carers felt that regardless of their age they were viewed and treated as "elderly" throughout their experience.

There have been major developments in the understanding and treatment of stroke in recent years, yet it is still seen by many as an inevitable condition of old age. The group felt that this had

the potential to negatively impact on the service they received.

Group members also experienced variations in access to services dependant on age, which they felt was unacceptable. The group advocated the provision of a person-centred service and not one dependant on age.

With regard to access to services, one group member said *"When you are 65 they show you the door."*

### ***Recommendations:***

- 5.1 *Stroke is not only a disease of the elderly. Healthcare staff and the public must be re-educated to think of stroke as an acute neurological condition.*
- 5.2 *Stroke units should be part of acute medical services and not aligned with services for older people.*
- 5.3 *Services for stroke survivors should not be offered according to age but should be accessible to all according to need.*



"I really appreciated how the nurses would come in in the morning and motivate me, switch the lights on and tell me to move it – there was work to be done."

"The worst thing of all was the lack of privacy. My husband was hoisted with very little clothes on and the curtain left half open – everyone was watching."

"Five days without any nutrition due to swallowing problems. He was so tired and weak, how could that help his recovery?"

"Having a shower and getting his hair washed after so long confined to bed made him look and feel so much better."

"Whenever I arrived to visit my husband the staff always brought me out a cup of tea and it just made me feel supported."

"Care in hospital and community has been 110%"

Much of the group's discussion focused on the importance of person-centred care and the need to preserve the stroke survivor's privacy and dignity. There were some very positive experiences of high-quality nursing care, however there were also many examples of situations in which the group members felt that person-centred care was not delivered.

Person-centred care in this document refers to care which is delivered in partnership with patients and driven by their needs, care which ensures that

patients are treated as individuals, kept fully informed, listened to and treated with dignity and respect.

There were many examples of this level of care, where staff sensitivity and support had a positive impact on not only the individuals' experience of the service, but also on their recovery. There were also occasions when individuals felt their dignity and privacy were not respected and this left them feeling angry, vulnerable and dissatisfied with the quality of their care.

## Section 6: Person-centered care

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Particular elements of person centred care which were of concern included nutrition and feeding processes, personal hygiene care and the management of continence problems.

The perception of the group was that registered nurse staffing levels were not always sufficient to allow staff to spend the necessary time with patients.

As a consequence of this, they felt supervision of unregistered staff was very difficult, which in turn impacted on the quality of the service.

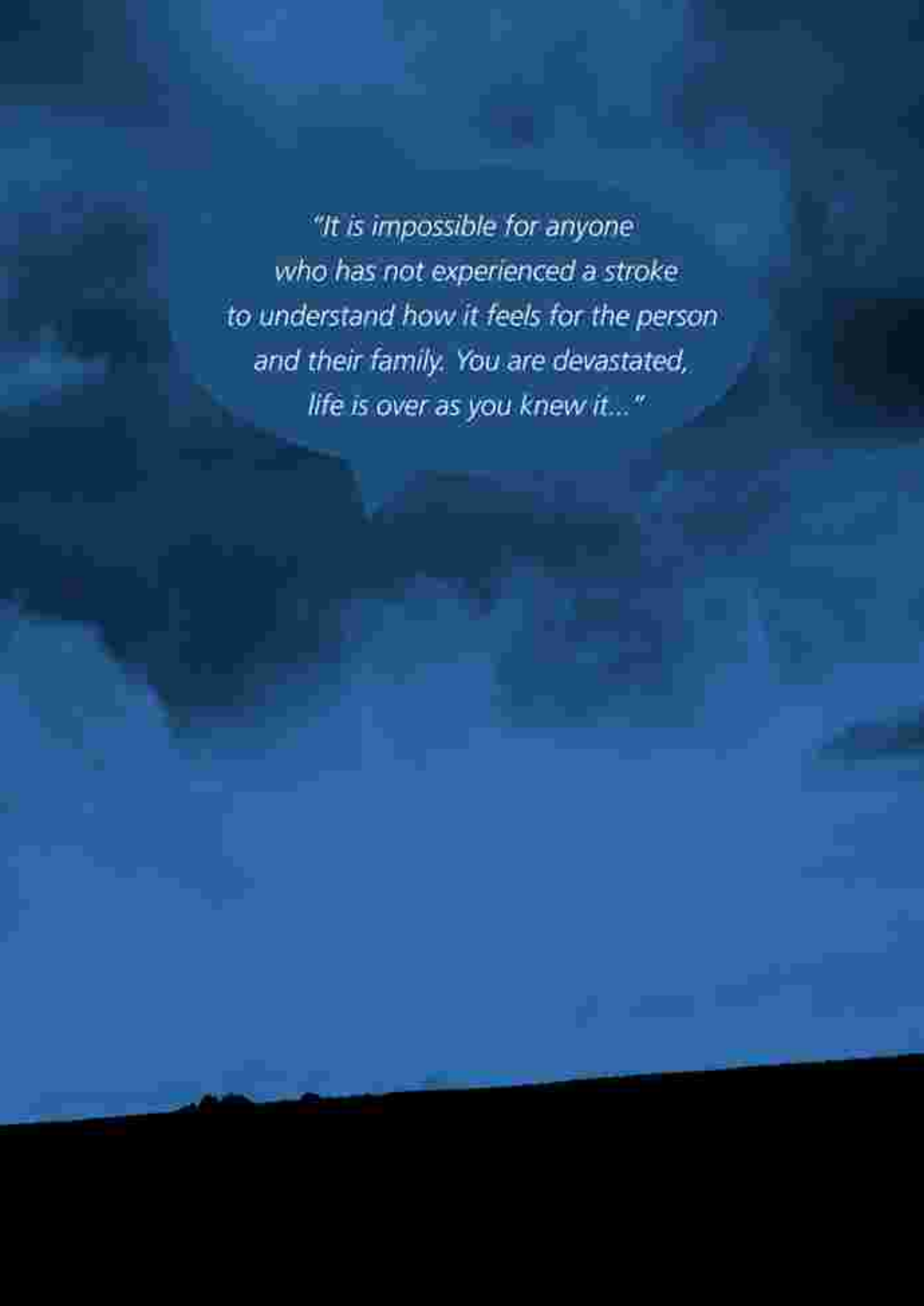
Communication between staff about patient care was felt to be poor resulting in variations in the quality of care.

### *Recommendations:*

- 6.1 *All healthcare staff should provide person-centred care, focused on preserving the dignity and privacy of patients and carers.*
- 6.2 *Improvements should be made so that more emphasis is given to stroke survivors nutritional needs and appropriate feeding support should be available.*







*"It is impossible for anyone  
who has not experienced a stroke  
to understand how it feels for the person  
and their family. You are devastated,  
life is over as you knew it..."*

## Section 7: The environment of care .....

*“John was moved down to a bed near the window and he was in much better form when he could see what was going on outside.”*

*“The electric wheelchair was tremendous – it made such a difference, it gave my husband freedom and independence.”*

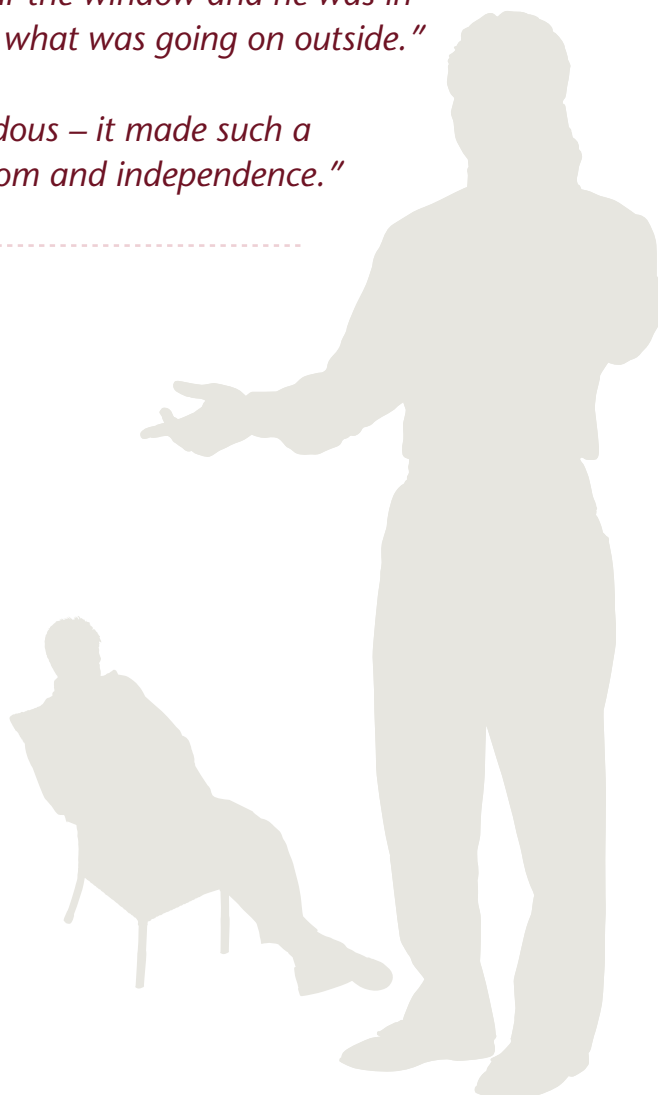
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Many stroke survivors spend significant time in hospital during their acute treatment and rehabilitation. The environment in which they are cared for has a significant impact on their mood and their recovery.

The experience of a long stay in hospital presents a number of challenges and the greatest of those for many of the group’s members was boredom. Long days are spent in hospital and outside of the focused rehabilitation sessions there is little else to occupy the time.

For those who could shower without assistance they felt facilities were very poor and lack of access to showering facilities had a drastic effect on their mood and motivation for rehabilitation.

Single rooms were thought to be desirable by some of the group’s members to ensure privacy. A significant number of stroke survivors found that they were particularly sensitive to noise following stroke and single rooms would help reduce the issue of noise on the ward.



### ***Recommendations:***

- 7.1 There should be access to a range of recreational activities which are appropriate to stroke survivors during their hospital stay.
- 7.2 Single rooms should be available particularly for those with sensitivity to noise following stroke, and for patients who are very ill.
- 7.3 Stroke survivors and their carers should have access to social spaces while in hospital where they can socialise, while in hospital.
- 7.4 Stroke survivors should have good access to showering facilities throughout their hospital stay.



*“The community stroke team was excellent. They saw my husband on the ward, they sorted out his discharge and provided us with care and treatment when he went home. I know it’s not like this for everyone, and it should be.”*

*“His first day home was a big day of adjustment trying to see just how much he could or couldn’t do on his own.”*

*“There was no home visit carried out before I was discharged and I was worried about how I would cope.”*

This was an anxious time for both stroke survivors and carers. Some individuals felt ill-prepared for the problems of adjusting to life after stroke at home, and carers were concerned about lack of support. Some group members experienced delays in discharge due to lack of community care packages and poor communication across service providers.

Many of the group members struggled to get relevant information about the services that were available to them in the community. It was felt that there was not enough preparation of carers for taking on the caring role.

### **Recommendations:**

- 8.1 Communication between healthcare professionals and between hospital and community care providers should be improved to enhance the discharge process.
- 8.2 A comprehensive directory of relevant community services which stroke survivors and carers can access after discharge should be available.
- 8.3 Carers should be particularly supported at this time with information, a support package and training to help them fulfil their caring role.
- 8.4 A specialist coordinator should be in place to support the move from hospital to community, and to be a key contact for stroke survivors and carers in the longer term.

## Section 9: Carers' needs

"My husband was my main carer and it put an awful strain on our marriage, at one stage I told him to just leave me, as I hated how he had to do things for me. Eventually I got some help at home and it made a huge difference."

"I always need my make-up on, so that I can convince the world and my family that I am coping – even when I'm not."

"You feel as if you have to constantly fight for everything you or the person you're caring for needs."

"I had my carers assessment with the social worker over three meetings and just to be able to discuss my needs and have them recognised by someone was a relief – even if they couldn't meet all my needs."

Carers felt that there was little recognition of their role and the hugely daunting experience it is for them. Many reported feeling isolated and frustrated at the lack of freely available information especially when they are often expected to act as the patient's advocate. They expressed the importance of health care professionals recognising the pressure they

were under. They felt their lives were changed forever and most were not given a choice as to whether or not they wanted to become a carer.

Improved communication and information and greater recognition of the carer's role is vital.

### **Recommendations:**

- 9.1 The implications of becoming a carer should be discussed and potential carers should be allowed to decide what level of caring support if any, they can offer at any particular time and be fully supported in their decision.
- 9.2 All carers should have an initial assessment of their needs (Carers Strategy) and ongoing assessment as circumstances change.
- 9.3 From the outset staff should recognise and respect the invaluable role which carers can play in recovery, both in hospital and at home. Carers should be given the opportunity to be involved in the care and rehabilitation of the stroke survivor as much as possible.
- 9.4 Carers should be consulted with the patients consent on matters relating to their care.
- 9.5 Appropriate support should be offered to carers from the outset in terms of provision of information, training, availability of respite and supportive care packages.
- 9.6 Carers should have more control over the quality and flexibility of the home care services of information, training, availability of respite and supportive care packages.

*The availability of the Direct Payments Scheme which allows carers to be provided with the monetary value of the care, so that they can make their own arrangements for care was discussed. Many group members were not aware of this option but those who were felt that while the principle of the scheme was useful it was difficult to take up and manage.*

## Section 10: Information and communication needs

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*“When you don’t know anything – how can you know what to ask?”*

*“There was a nurse who was great and I knew I could ask her to explain anything I didn’t understand.”*

*“The CHS Family Support worker was a great support and made us aware of support groups that were really helpful.”*

*“I was told I’d had a stroke, keep taking my medication, and because I could walk and talk I was just sent home. No-one noticed that I had major problems with seeing. I couldn’t find the edge of the seat to sit on, I fell off pavements. This went on for six months before somebody actually saw me again.”*

*“At the least, tell me and my carer that I have had a stroke, what it means and what you are going to do.”*

*“Hope has got me through – give people some hope!”*

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The provision of information and communication practices was the area of greatest concern to stroke survivors and carers. When information was provided face to face in an understandable way with supporting materials and in an open manner, it was much appreciated and resulted in a better experience for both stroke survivor and carer. Some examples of this positive type of communication were delivered by stroke specialist nurses, the CHS Stroke Family Support Worker and Community Stroke Teams.

Unfortunately, there were also many experiences of little or no information being available, and communication between staff, stroke survivors and carers being very poor. There was also concern that sharing of information between healthcare staff and across hospital, community and primary care was often poor resulting in avoidable problems and mixed messages being given to patients and their carers/families.

The reference group agreed that a positive culture of providing information should be in place. Healthcare professionals must always take a person-centred approach and assess information needs on an individual basis.

Information should be provided as soon as possible and should be ongoing to reinforce what has been communicated and to update as circumstances change. The need for ‘check-points’ and to recap on information is important throughout.

When possible information should be given in a private area not in the middle of an open ward, and on a one-to-one basis. Some members reported staff talking about patients in front of them but not ‘to’ them, and emphasised the importance of directly addressing the patient.

The point was also raised that staff should address people using their title, until the patient indicated

## Section 10: Information and communication needs

otherwise. This was thought to be crucial in maintaining a sense of identity despite this life-changing event.

It is best to try to give a balanced view of both worst and best case scenarios. Professionals should avoid the use of jargon and ensure that information is kept simple and in lay person's terms. It was felt to be equally important to tell patients and carers if there is no information or why answers are not available.

The group agreed that the following were the key areas where information should be provided as a minimum:

- *What could potentially be wrong, if it is not possible to give a definite diagnosis.*
- *Explain clearly what a stroke is and explain what the diagnosis actually means.*
- *What caused the stroke and what the prognosis is.*
- *Explain why things were/were not happening. (e.g. not being given a drink)*
- *Need to be told why certain tests, are being carried out, eg: scans, blood test.*
- *How to prevent further strokes.*
- *What community services are available.*
- *Advice about financial support and benefits.*

### *Recommendations:*

- 10.1 There must be a positive culture among healthcare professionals of proactively providing information to patients, carers and their families.
- 10.2 Information should come from the best possible and most appropriate source e.g. speech & language difficulties should be explained by the Speech and Language Therapists, mobility issues from Physiotherapist etc.
- 10.3 There should be one key contact for further information which stroke survivors and carers can contact at any time especially post discharge from hospital.
- 10.4 Information should be provided face to face with supporting materials provided as a back up.
- 10.5 Where prognosis and recovery potential is not clear it is best to provide the best and worse case scenario.
- 10.6 Information and assistance on accessing financial support and benefits must be available to all stroke survivors and their carers.
- 10.7 Those who have been through the experience, both stroke survivors and carers, should be used as a resource, and supported to provide information and advice to individuals currently going through the journey.
- 10.8 Stroke survivors and carers need to be supported to raise any concerns or issues with healthcare staff about the care they are receiving.

## Section 11: "The rest of my life" .....



*"I was in a stroke unit with 24/7 care for six weeks and then discharged to live with the results of the stroke for the rest of my life with no support."*

*"Meeting people at the NICHS support groups helped me get my confidence back."*

*"With a stroke it's not just the individual who is affected sometimes the carer and family and children are affected every bit as much."*

Stroke survivors and their carers require access to life-long support to enable them to maximise their quality of life. The type of support needed will vary from individual to individual and will depend on their stage in the stroke journey.

In the early days post stroke and following discharge from the hospital setting, stroke survivors and their carers will require considerable input to help them adjust to a new way of life. This help may include personal care, ongoing rehabilitation, information about the management of their condition, advice on financial support and benefits, psychological support and support for carers.

The role of the Community Stroke teams was discussed and felt to be extremely valuable in providing this type of comprehensive post-hospital, person-centred service. Only a small number of the group received this service with the majority not having access to any specialist stroke services after discharge. The group agreed that all stroke

patients should have access to a specialist community stroke service.

The group felt it valuable to have a specialist review at three months post discharge, as a means of maintaining motivation for rehabilitation goals and lifestyle changes. In addition, an annual assessment and review for both patients and carers should be carried out, so that need can be assessed on an ongoing, individual basis.

Some of the groups that are available to support patients once back at home were found to be very useful. These included North & West Belfast Looking Ahead Group, Chest Heart and Stroke family support workers, who also act as a signpost for other services, and the Community Stroke Teams where they are available.

The impact of stroke is felt not only by the individual and their main carer but throughout the entire family. Roles and responsibilities may change and

## Section 11: "The rest of my life" -----

there will be considerable adjustment required for all affected. Children may find it difficult to understand what has happened to their parent and why the lifestyle they used to have has changed. Support services should take account of the impact of stroke on the family and offer appropriate support.

The group also identified a need for better access to public facilities and more cross-organisational

co-operation to provide a range of services which will help to re-enable stroke survivors e.g. transport, leisure facilities, education and training and vocational opportunities.

They also considered that a general support worker/befriender who could help with shopping, taking to appointments and helping in the home would be of value.

### ***Recommendations:***

- 11.1 All stroke survivors should be able to self refer to a community stroke support service as they need it to help them maintain their condition at an optimum level.
- 11.2 All stroke survivors should have a specialist stroke review at 3 months and 12 months post-discharge from specialist services.
- 11.3 Stroke survivors should have access to re-enablement services to help them and their family maximise quality of life and return where possible to social and vocational activities.

## Section 12: Nursing home care

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*“Our experience of three nursing homes was that stroke improvements were never maintained and there was little to stimulate either physically or mentally. Deterioration, falls and loss of dignity always followed at which point I chose to bring him home.”*

*“Falls are a big problem especially in Elderly Mentally Impaired homes where restraint is not allowed. After a fractured hip and loss of mobility and dignity I brought him home with a good care package”*

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It is estimated that ten percent of stroke patients are admitted to long-term nursing care and that twenty five percent of nursing home beds are occupied by stroke survivors.

This clearly shows that stroke patients make up a large proportion of nursing home residents in Northern Ireland.

Stroke clients in nursing homes often do not have access to any form of specialist stroke intervention and can therefore be disadvantaged. Stroke clients in nursing homes should have access to the same level of specialist stroke service as people living in their own homes.

Stroke survivors in nursing homes should also have the same access to voluntary services such as NI Chest Heart & Stroke as those living in their own homes.

Staff in nursing homes require specialist education and support from the health service to ensure the delivery of evidence based stroke care to their stroke clients. Simple interventions should be put in place to address quality of life issues including, psychological issues, positioning and handling, swallow assessment, communication needs, preservation of dignity and self esteem. All of these will significantly improve the quality of life of a stroke survivor.

### **Recommendations:**

- 12.1 There must be equity of access to specialist stroke services for those stroke survivors in nursing homes including specialist stroke review.
- 12.2 Staff within the private sector who work with stroke survivors should have training specific to stroke care.
- 12.3 There should be better information and more advice and support for stroke survivors, carers and their families to choose care homes and facilities.
- 12.4 There should be access to a range of recreational activities which are appropriate for stroke survivors in nursing homes to improve their quality of life.
- 12.5 Care should be taken to treat stroke survivors in nursing homes in a manner that preserves their sense of identity, dignity and self esteem.

## Section 13: Complimentary & Alternative medicine

*“I had aromatherapy treatment while in hospital and also for quite a while after discharge. I found it really calmed me and helped me to relax.”*

Individuals with chronic conditions are among the biggest group of users of complementary and alternative medicine (CAM). Members of the reference group discussed the benefit of many types of CAM including aromatherapy, hydrotherapy, acupuncture and homeopathic medicines. These

treatments were also thought to be hugely beneficial to carers.

The group agreed that more information should be available on the potential benefits and accessibility of these types of treatments to complement conventional medical treatment.

### **Recommendations:**

- 13.1 Information should be provided to stroke survivors and carers on how to access appropriate complementary and alternative therapies and where appropriate should be available as part of the health service care.

## Section 14: Research

*“If we don’t do more research how will stroke care ever improve?”*

*“Why is there not more research on the things that matter to us?”*

The lack of high level evidence for effective management of stroke survivors in the longer term was an issue discussed within the group.

Many members felt there was a great need for extensive research into stroke, both its causes and its management. Research into the benefit of some level of ongoing rehabilitation to maintain function and to maximise potential recovery was a particular area of interest.

The group also identified a need to involve and inform stroke survivors about the research studies under way including its outcomes and implications. This was regarded as important in giving stroke survivors hope for the future.

The group were also aware of audits of stroke services which are carried out and emphasised the importance of acting on this data and ensuring it is used to help develop services.

### **Recommendations:**

- 14.1 Further research into the prevention, treatment and management of a stroke is essential and particularly into the provision of care in the longer term after a stroke. Stroke survivors and their families should be involved in deciding priority areas for research.

## Gearóid Ó Cairealláin - a personal story

I was 48 years old when I suffered a severe hemorrhagic stroke on Monday 31 July 2006. I will never forget the events of that day. I was at work as usual, on a perfectly normal day. At around 4.10 in the afternoon I was standing in my office speaking on the phone to a journalist in Dublin, in the course of the conversation I heard my own voice getting very strange. The words were coming out 'fat', slow and distorted. I remember struggling, trying to make my mouth and lips form the words properly – oddly, I have no recollection now of what the subject of that telephone conversation was. When I finished the conversation, a colleague of mine who was in the office with me and who was startled by the sound of my voice said 'What the hell is wrong with you?' In reply I said 'I don't know and took two steps forward. And just fell...I fell forwards and downwards. I still recall the feeling of losing control of my body and falling. If it was not for the floor I would still be falling. Actually, I landed on our office's wire waste paper bin. Needless to say that was the end of said waste paper bin. It now resembles a waste paper concertina. As I lay on the floor, another colleague, realising I had suffered a stroke, promptly called an ambulance. In no time at all the ambulance men were standing over me and I was arguing with them, 'Its okay lads, nothing serious. All I need is a cup of coffee.' 'We'll take it from here' was their reply. I have no recollection of being brought downstairs, nor of my journey in the ambulance to A & E. I do know, however that I was quickly admitted to the Intensive Care Unit. My family were informed that I was very seriously ill, and would most likely be left with serious disability. In the event, I remained in the I.C.U. for eight weeks before being transferred to a neurology ward and from there to a specialist unit for intensive rehabilitation in mid October. I was eventually discharged on February 7 and then commenced my course of treatment as an outpatient.

For the first two or three months in hospital I was unconscious, heavily sedated and suffering from the after effects of the stroke - the insult to my brain. When I came around I gradually realised that my left arm, hand and leg were paralysed and that I would remain profoundly disabled for a long time. Instinctively, I told myself, my family and friends that I would retain a positive outlook and that I would definitely improve and recover – no matter how long it would take. However, I found it difficult, if not downright impossible to find anyone within the senior medical team who would agree with my opinion, let alone encourage it. The best I was told I could hope for was to become competent in the use of a wheelchair. Walking again, although not ruled out completely, was so far down the road that it was not worth discussing in any serious fashion, even though walking again – running, cycling, and swimming were the only targets I was really interested in. It did not take the team in the rehabilitation unit too

## Gearóid Ó Cairealláin - a personal story

long to help me realise that achieving an independent and satisfying life was a realistic target that could be achieved while still in a wheelchair, and so we focussed on transferring from bed to chair and chair to bed. Similarly, another achievable target is learning to transfer from chair to commode and back again.

Unfortunately my own mid-terrace house in South Belfast could not be modified for wheelchair users, so I was forced to rent. In early April '07 the Housing Executive came up with a purpose built bungalow, where I know I will live happily with my partner, Bríd. We decided to get married on 31 July 2007, exactly one year to the day after my stroke - always was fond of symbolism and appropriate dates. Hopefully, now the last day in July will always be remembered as a happy occasion, rather than the disaster of 2006.

I have nothing but the highest of praise for the medical and nursing staff. They saved my life and helped me retain a positive outlook. However, from the earliest days in hospital until now, I have longed to meet someone who suffered a stroke similar to mine, and while still relatively young, and who recovered. There must be someone out there who regained their health after a serious stroke, even if it took years and a trip to Lourdes! I have not given up the struggle yet. There seem to me to be two schools of thought for stroke recovery, those who say that after six months you've gotten all you're going to get and those who firmly believe that recovery can go on for years. I'm believer in the second school of thought..... because as I read recently false hopes are dangerous, but false despair can be just as destructive. Some day I hope to be the person to share my experiences of recovery following a stroke with other stroke survivors.

Gearóid Ó Cairealláin  
Belfast, 25 April 2007

## Heather McKeown - a personal story

On August 11th 2002 my husband Alfie, aged 58, had a severe stroke in bed around 6am on a Monday morning and two weeks after having had a heart attack. I had no idea what was happening to him but knew it was an emergency and to act quickly rather than wait a while. Turning on the light I could see that he was pale, his eyes were staring and he was making a gurgling noise.

I rang the emergency doctor, his number was at the bedside and he arrived quickly and said immediately that it was a stroke. The ambulance arrived to take him to hospital and I asked if I should travel with Alfie but was advised to drive there and leave it till later that morning.

What was a stroke? I really did not know. I had heard of it, but knew nothing of the cause or symptoms. My immediate thoughts were "Was he going to die, what will I do if he does?" "How will I cope without him and manage the house and finances etc?" I did not cry strangely enough, but felt so scared, not knowing what was ahead of me and feeling I had no control over the outcome. I was unable to think of the things Alfie would need in hospital, a razor, face cloth, towel etc. I needed to write all these things down and leave by the front door in case I forgot them.

On arriving at hospital Alfie was in casualty on oxygen and wired up. I am not sure if he knew I was there so I held his hand. I tried to speak to the doctor on casualty but I assumed he did not know at that stage just how seriously ill Alfie was and we were awaiting a brain scan. I felt I needed some reassurance but the staff were so busy and therefore there was no feedback.

There had been no information since 6am and I was unable to tell my family what was going on. I sat waiting and wondering. It was at that time I needed to know all about a stroke and what was involved. I wanted to talk to somebody and be prepared for the worst case scenario. I was trying to stay calm and focussed. We all find some inner strength to keep going but I felt so vulnerable and not in control of my emotions. I felt life had come to a standstill but for how long I did not know and maybe it was just as well.

Alfie eventually was moved to the stroke unit and staff, although rushed off their feet were friendly and attentive. The recovery process was to begin over a long period of time and that is another story. When Alfie came home I had wonderful support from

## Heather McKeown - a personal story

the Community Stroke Team. They helped me through the first three months. We expected Alfie to be in a wheelchair but he persevered with physiotherapy and can walk using an aid.

Five years on and life has improved, we have learned to accept his disabilities and the changes to our lives. There is no choice, so we manage as best we can. It can be frustrating, not being able to do as you wish. I take Alfie out in the car and occasionally we eat out, go to a show or meet up with other people.

It would be so much easier to stay in the house, with everything at hand but we are not old and life is for living despite our restrictions.

Heather McKeown

22nd August 2007

## Appendix 1

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### *Stroke Strategy Implementation Project:*

The Stroke Strategy Implementation Project (SSIP) is a partnership project between NI Chest Heart and Stroke and the Eastern Health and Social Services Board. The project was set up in 2004 and funded by the Big Lottery Fund to progress the implementation of the 2001 NI Stroke Strategy within the EHSSB but its purpose can more generally be considered as being to pursue service improvement in the area of stroke care.

The SSIP is governed by an EHSSB wide steering group and reports to the Eastern Board Stroke Group. The Project Team work across statutory, private and voluntary sectors to raise the profile of stroke care, and to develop an equitable, person centred, evidence-based service for stroke survivors and their carers.

Local Stroke Task Forces have been established in the four localities of the EHSSB with multi-disciplinary, multi-agency membership, to develop services at a local level. These groups have been tasked with reviewing their local stroke service from prevention through to long term community care, identifying the gaps in their service provision and developing local action plans to address the areas of need.

The Project Team facilitates this process and supports teams to complete this work through raising the profile of stroke, gaining support for the work at commissioning and service provider levels, identifying best practice and up-to-date evidence, sharing information and project managing the process to ensure measurable outcomes.

### *About the EHSSB Stroke Patient and Carer Reference Group:*

The EHSSB Stroke Patient and Carer Group was established by the Stroke Strategy Implementation Project (SSIP) in November 2005 to ensure that

stroke patients' and carers' experiences and views were central to the work of the project in developing services for stroke across the EHSSB.

Membership of the Reference Group includes stroke service users and carers from across the EHSSB locality, along with representation from some of the voluntary agencies and the Stroke Strategy Implementation Project Team. Recruitment into the Group is ongoing, to ensure as representative a group of patients and carers as possible.

The reference group as of August 2007 has thirty members. The age range of the members is from 46 years to 78 years. The members of the group have had varying levels of care and time since stroke for the group varies from one year to eight years. Terms of reference, working methods and the group's work plan have all been developed by the members, facilitated by the SSIP team and are subject to ongoing review and revision as appropriate. The SSIP supports the group with information on stroke services, evidence for care and the organisation of health services to aid their discussion as necessary.

### *Purpose of the Group:*

The group's purpose is to work in partnership with the SSIP, their steering group, the EHSSB and the local Stroke Task Forces, to raise their issues and concerns about stroke services based on their own experience and to promote service improvement. These issues and concerns along with the various reference materials help to shape the priorities of the Project Team and the local Stroke Task Forces.

The group acts as a resource for the four Task Forces to ensure patients' and carers' involvement in all aspects of the work of the Task Forces. Members of the group are involved in ongoing evaluation of its efficacy.

### *Aims and Objectives*

- *To ensure the voice of the stroke patient and/or their carers are heard in the development of services through the Stroke Strategy Implementation Project and the Local Stroke Task Forces.*
- *To ensure meaningful engagement between Local Stroke Task Forces and service users and their carers, with the aim of providing a greater understanding of the needs of the stroke patient among health professionals.*
- *To receive feedback from the Task Force chairs, the SSIP steering group and the EHSSB on actions which will be taken as a result of the Reference Group's work.*

#### *Structure and Frequency of Meetings:*

The EHSSB Stroke Patient and Carer Reference Group meetings are facilitated by the SSIP project team and a consultant from the Beeches Management Centre. Meetings are held every two months and last for approximately two hours. These are currently held in the afternoons, but this arrangement is open to change as the membership dictates.

The group's discussions were facilitated in differing ways including process mapping workshops, focus groups and discussions with service providers. The themes which emerged from the group's discussion of their experiences with stroke are summarised in this report along with their recommendations for service improvement. For further information in relation to this report specifically, the user group or the project more generally, please contact:

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