Moving on

A vision for community based physiotherapy after stroke in England

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Care of stroke patients in hospital is now better than ever. Stroke survivors, carers and health professionals have all welcomed improvements made in the last few years as stroke care in England has risen up the political and public policy agendas. The National Stroke Strategy (NSS) for England in 2007, the National Audit Office reports of 2005 and 2010 and the work of the Royal College of Physicians (RCP), through their Clinical Guidelines for Stroke and Sentinel Audits, have all been crucial to this process.

However, the picture is quite different when stroke survivors leave hospital. We believe that the improvements made in the acute phase must now be replicated in what we call the ‘life after stroke’ phase. This is the time when a person leaves hospital and adjusts back to life either at home or in a care institution.

Without doubt, many people are receiving an excellent service from the NHS that allows them to achieve some or all of the skills they had before their stroke. Unfortunately we have found that a significant proportion of others may not be receiving the help they need to move on from this life-shattering experience.

Our Moving on report outlines a four part vision for community based physiotherapy care. We feel, if implemented correctly, this vision could improve the lives of many people after stroke; enhance the quality and productivity of services; and help make long-term cost savings. Our vision includes universal access to NHS care; an end to fragmented transitions into community care; achieving an individually tailored service and valuing the role of carers.

When two organisations that represent different sides of the same story – in this case patients and health professionals – explore together an important issue, there can often be divergent experiences and thoughts on the best way forward. However on this occasion, we found a huge similarity between experiences when consulting both sets of our stakeholders.

Stroke care in acute settings is improving in the UK, and a focus on this can sometimes obscure the critical role of health and social care professionals, especially physiotherapists, in supporting stroke survivors when they leave hospital. Their dedication to their role continues to be one of the key aspects of life after stroke, enabling stroke survivors to move on positively with their lives.

Foreword

‘Our Moving on report outlines a four part vision for community based physiotherapy care.’

Jon Barrick
The Stroke Association

Phil Gray
The Chartered Society of Physiotherapy
When a stroke happens its impact can be devastating both emotionally and physically. Many people survive but are left with a range of impairments. These include paralysis, problems with movement, balance and posture, weakness, spasticity and pain. These physical and emotional effects are often still present when a stroke survivor leaves hospital and physiotherapy can help manage or overcome them.

Moving on provides a four part vision for physiotherapy services which must be implemented in the next few years. Our vision is for a community based physiotherapy service which provides NHS funded care to all those who need it, ends fragmented transitions of care, meets personal need by individually tailoring care and recognises the vital role of carers. This vision could be realised by implementing 11 recommendations.

1. **Community based physiotherapy must be available on the NHS to all stroke survivors who need it**
   - **21%** of stroke survivors who felt they needed community based physiotherapy did not receive any on the NHS.

   **a)** All stroke survivors must receive a written and comprehensive care plan before leaving hospital. This should include reference to continuing physiotherapy or reasons for its discontinuation.

   **b)** All stroke survivors must receive a six week review following discharge. Then at least another review within six months and one year.

2. **There must be an end to fragmented transitions into community based physiotherapy**
   - **25%** of stroke survivors had to wait longer than one month for their first session.
   - **38%** of stroke survivors felt that there had been a delay in receiving community based physiotherapy.
   - **83%** of physiotherapy staff believe that the process of transfer of care for stroke survivors could be improved.

   **a)** All stroke survivors who have been assessed as requiring ongoing physiotherapy after leaving hospital should be allocated a date for their first appointment before they are discharged.

   **b)** All stroke survivors assessed as benefiting from ongoing physiotherapy should access this service within one day of transfer from hospital, where this is appropriate – ranging to a maximum of one week.

   **c)** All stroke survivors must receive a six week review following discharge to identify any delays in physiotherapy.

3. **All stroke survivors must receive community based physiotherapy individually tailored to their needs**
   - **22%** of physiotherapy staff reported that they had been enabled to fully meet their client’s goals.

   **b)** All stroke survivors must receive a six week review following discharge. Then at least another review within six months and one year.

   **a)** All stroke survivors assessed as benefiting from ongoing physiotherapy should access this service within one day of transfer from hospital, where this is appropriate – ranging to a maximum of one week.

   **c)** All stroke survivors must receive a six week review following discharge to identify any delays in physiotherapy.

   - **52%** of physiotherapy staff indicated that the outcomes for about half of their clients could have been improved if greater personalisation of services had been made possible.

Executive summary

To identify a snapshot of current experiences, The Stroke Association and The Chartered Society of Physiotherapy surveyed 1160 stroke survivors and physiotherapy staff in the Summer/Autumn of 2009. Based on the results of both surveys, we have identified a number of areas surrounding community based physiotherapy services which need improvement.
28% of physiotherapy staff felt that their client’s goals had not been achieved because they had been unrealistic.

a) The goal setting process must be a partnership between the physiotherapist and stroke survivor – which enables personal, realistic and flexible goals to be agreed and monitored.

45% of physiotherapy staff reported that almost half (49%) of stroke survivors did not receive the services that would enable them to achieve the best possible outcome.

35% of stroke survivors were either unsatisfied or very unsatisfied with the length of their community based physiotherapy course.

56% of stroke survivors reported receiving less than three months of physiotherapy.

b) Community based physiotherapy must only be discontinued once all achievable goals have been met and no new attainable goals can be set.

c) All stroke survivors who could benefit from exercise classes should have the opportunity to join a class as part of an integrated stroke care pathway.

74% of physiotherapy staff indicated that personalisation of services for stroke survivors could not be achieved within current resources.

d) More research must be carried out into the benefits and relative cost effectiveness of long-term physiotherapy as part of an integrated programme of care.

48% of stroke survivors who indicated a positive experience of community based physiotherapy felt that it had helped them to be less reliant on carers.

40% of respondents who indicated a negative experience (for example, if they had not received any physiotherapy) said that it contributed to them being more reliant on carers.

a) Health professionals and commissioners must recognise that stroke survivor independence should be maximised not only to benefit the stroke survivor but also the carer.

84% of physiotherapy staff, when asked what the key factor is in a stroke survivor achieving the best outcome, indicated ‘support from carer/family/friend’.

b) Health professionals and commissioners must, where appropriate, promote the benefits of including the carer in the rehabilitation process.

The vital role of carers must be recognised and valued throughout the physiotherapy journey

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Health professionals and commissioners must, where appropriate, promote the benefits of including the carer in the rehabilitation process.
Introduction

‘Services should be person-centred, seamless and proactive. They should support independence, not dependence and allow everyone to enjoy a good quality of life, including the ability to contribute fully to our communities.’

*Our health, our care, our say – Department of Health (2006)*

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**The impact of stroke**
When a stroke happens its impact can be devastating. Many people survive but are left with a range of physical impairments. These include paralysis, problems with movement, balance and posture, weakness and in some cases secondary problems such as spasticity and pain.

Whilst in hospital, many people tell us that once they have come to terms with this life-changing incident, their next thought is how they can regain the ability to move and walk independently again. Both the acute and rehabilitative phases in hospital are crucial to recovery and generally there appears to be a positive experience of physiotherapy here. However the most difficult time can be when stroke survivors come out of hospital and try to return to a ‘normal’ life.

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**The role of physiotherapy**
The importance of physiotherapy in helping stroke survivors to regain movement, balance, posture and strength (and in learning how to manage any functional difficulties associated with these impairments) is well documented. There is a wide consensus, detailed in the Royal College of Physicians *National Clinical Guidelines for Stroke (RCP Guidelines)*, about the beneficial impact of physiotherapy on the physical effects of stroke.

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**The current position**
In 2006 the Healthcare Commission (now the Care Quality Commission) undertook a survey of over 800 stroke survivors and found that 28% felt that they had not received enough treatment from the NHS to help improve their mobility after leaving hospital.
For this report, The Stroke Association and The Chartered Society of Physiotherapy surveyed 1160 stroke survivors and physiotherapy staff to identify progress since the publication of the National Stroke Strategy (NSS) for England in 2007. The results show us that whilst the situation has improved slightly, the speed of development must be quickened.

The vision
Based on the results of both surveys we have identified a number of areas which need improvement and this report provides a four part vision for community based physiotherapy services which must be implemented in the next few years. Our vision is for a community based physiotherapy service which:

• Provides NHS funded care to all those who need it
• Ends fragmented transitions of care
• Meets personal need by individually tailoring care
• Recognises and values the vital role of carers.

These are challenging areas to get right. However, we are optimistic – as the presence of the NSS Quality Markers and the RCP Guidelines means there is a general consensus around questions of policy. When community based physiotherapy services fail to meet the quality markers and guidelines, what can result is a generic and fragmented service which may react to problems too late and does not enable stroke survivors to feel they have achieved a good quality of life. We are therefore campaigning for speedy and effective implementation of the policies that exist.

Who should read this report?
This report will be useful to health and social care commissioners, policy makers and health professionals who are involved in organising stroke care. We urge you to support our vision and implement the eleven recommendations contained in this report, in conjunction with the new guidance for commissioners, Aspiring to excellence (for further information see page 19).

Methodology
The Stroke Association surveyed 663 stroke survivors in England (who had their most recent stroke less than two years ago) about their experiences of community based physiotherapy. The Chartered Society of Physiotherapy surveyed 497 physiotherapy staff who work with stroke survivors to find out about the patient experience from their professional perspective. 85% of these physiotherapy staff worked in England. Both surveys took place in Summer/Autumn 2009.

Case studies
All of the case studies in this report are people who have completed our stroke survivor survey. Interviews were undertaken in November 2009 and the information we report is correct to that date but may have changed since.
Community based physiotherapy must be available on the NHS to all stroke survivors who need it

- 21% of stroke survivors who felt they needed community based physiotherapy did not receive any on the NHS.

Working proactively and in partnership
Not every stroke survivor will leave hospital requiring ongoing physiotherapy and it is important that the NHS directs limited resources to those who will benefit. However, by encouraging proactive information sharing and partnerships between stroke survivors and health professionals, service commissioners will promote more understanding of community based care decisions and reduce anxiety over discontinuation of therapy. This approach will also encourage better self management after stroke by empowering stroke survivors.

Current RCP Guidelines on the provision of information about discontinuation of therapy and self referrals are clear and should be fully implemented across all community stroke teams (see A clear discharge plan, page 8). All patients must be provided with information as part of a comprehensive care plan before they leave hospital, especially those who have been assessed as not requiring any community based physiotherapy. It is also important that this plan is written to avoid confusion or doubt in the future. Issues around discontinuation of therapy and shared decision making should be improved once everyone with a long-term condition is offered a care plan by 2010 – as pledged in Our health, our care, our say and reaffirmed in the NHS Next Stage Review.4

Recommendation 1a
All stroke survivors must receive a written and comprehensive care plan before leaving hospital. This should include reference to continuing physiotherapy or reasons for discontinuation.
Robert Veasey, Boston, 57

'I had my stroke when I was only 55 years old. I had been a keen driver before the stroke but had suffered from arthritis which prevented me from working.

In April 2007 I had a minor stroke which led to a major one in November 2007. It left me with paralysis on my left side and I was unable to walk. I was in the stroke unit in Boston Hospital and felt my progress was quite good. I did see a student physiotherapist from time to time who helped with my left arm. At the beginning of the therapy I could pick up some bricks but I could not let them go. My goal was to be able to let them go, which in time I achieved. I was also told that once I could wash myself and walk to the toilet on my own then I was ready to go home.

I don’t remember being given any information on leaving hospital. My wife says that we received some paperwork at my discharge but it was not relevant and did not mention physiotherapy.

Once I came home all I received was one phone call around two weeks later which was from a health worker at the hospital. She asked me whether I was ok and that was pretty much it. It’s now two years later and I have not received any more help from the NHS with my coordination and balance.

All the physical improvements that I have made have been down to me and the support of my wife. I feel I could have achieved more if they had just sat me down and listened to my problems. They never fully understood that my arthritis dates back to before the stroke and maybe this affected the decision on whether I could have physiotherapy. Unfortunately I don’t think I will ever know.

On the positive side I have been attending a communication group run by The Stroke Association. This has really helped my problems with speaking. I have also been able to drive again and had to undergo a specific course to allow me to do so.'
Follow up reviews
Where the in-hospital assessment has revealed ongoing physiotherapy is needed but no follow up has taken place, it is essential that community teams are more proactive. We are therefore calling for the NSS recommendations around follow up reviews (see Review process (1) below) to be fully implemented so that any existing or new needs can be identified.

Recommendation 1b
All stroke survivors must receive a six week review following discharge. Then at least another review within six months and one year.

Rationing
Finally, a real concern for many stroke survivors is what is perceived as arbitrary ‘rationing’. This includes those who live in care homes, those who are elderly and those who live where resources appear to be scarce. It is therefore essential that all decisions on community based physiotherapy are based solely on the stroke survivor’s need, not on where they live, their age or the resources available.

A clear discharge plan
Royal College of Physicians, National Clinical Guidelines for Stroke
‘When a therapist or team stops giving rehabilitation, the therapist or service should:
• Discuss the reasons for this decision with the patient
• Ensure that any continuing support that the patient needs to maintain and/or improve health is provided
• Provide clear instructions on how to contact the service for reassessment
• Outline what specific events or changes should trigger further contact’

National Stroke Strategy – Quality Marker 12
‘A workable, clear discharge plan that has fully involved the individual (and their family where appropriate) and responded to the individual’s particular circumstances and aspirations is developed by health and social care services…’

Review process (1)
National Stroke Strategy – Quality Marker 14
‘People who have had stroke and their carers, living at home or in care homes are offered a review from primary care services of their health and social care status and secondary prevention needs, typically within six weeks of discharge home or to care home and again before six months after leaving hospital. This is followed by an annual health and social care check which facilitates a clear pathway back to further specialist review, advice, information, support and rehabilitation where required.’
There must be an end to fragmented transitions into community based physiotherapy

- **25%** of stroke survivors had to wait longer than one month for their first session (this figure goes up to 62% if it includes those who waited two weeks or more).
- **38%** of stroke survivors felt that there had been a delay in receiving community based physiotherapy.
- **83%** of physiotherapy staff believe that the process of transfer of care for stroke survivors could be improved.

Our survey indicates that many stroke survivors have to wait too long for their first session of physiotherapy after leaving hospital. Therefore, we are calling for an end to fragmented transitions into community based physiotherapy.

**Seamless care**
Quality Marker 12 of the NSS states that there should be a ‘seamless transfer of care’ and a smooth return home. It also states that ‘where health and social care services work together to facilitate a smooth return home it can help people recover quickly, reduce the pressure on the individual and their family and prevent unnecessary readmissions to hospital or care homes’. The RCP Guidelines (see Transfer of care, right) make clear that delays should be minimised and we believe transition arrangements from hospital to home must be tightened up.

Proposing a specific time limit is not simple as any definition of delay is subjective. However, we know that the quicker someone receives physiotherapy the more likely they are to achieve better outcomes. It would also mean that the progress made whilst in hospital is not squandered as soon as a person leaves. Seamless transitions will result in better outcomes for stroke survivors and reduced readmission rates to other health and social care services.

**Recommendation 2a**
All stroke survivors who have been assessed as requiring ongoing physiotherapy after leaving hospital should be allocated a date for their first appointment before they have left hospital.

We believe that where physiotherapy is a key part of a stroke survivor’s care plan it should be delivered on a continuous basis. Therefore if the stroke survivor is happy to do so, the first session should start on the day after they leave hospital. However we recognise that sometimes it may not be appropriate for such continuous physiotherapy, for example where someone has minor mobility problems.

**Transfer of care**
Royal College of Physicians, *National Clinical Guidelines for Stroke*

- a) All transfers between different teams and between different organisations should occur at the appropriate time, **without delay**
- b) Hospital services should have a locally negotiated protocol to ensure that before discharge occurs any continuing specialist treatment required will be provided **without delay** by an appropriate specialist service.
Recommendation 2b
All stroke survivors assessed as benefiting from ongoing physiotherapy should access this service within one day of transfer from hospital, where this is appropriate, ranging to a maximum of one week.

Reviews
Where stroke survivors are due to receive continuing physiotherapy it is still essential for them to be subject to follow up reviews (see Review Process (1), page 8). The six week review in particular will highlight if anyone has experienced an unacceptable delay in receiving their initial session of physiotherapy.

Recommendation 2c
All stroke survivors must receive a six week review following discharge to identify any delays in physiotherapy.

Resources
A lack of resources was perceived by many stroke survivors as a reason for their delay in receiving physiotherapy. We do not underestimate the challenge faced in allocating funding to these types of services. It is clear, however, that where delays are occurring to community based physiotherapy, resources must be either increased or redirected to prevent unnecessary negative impacts on quality of life, speed of recovery and the likelihood of health and social care readmissions.
Maureen Bailey, Northamptonshire, 73

‘Before my stroke I was an active and independent mother, grandmother and great grandmother. I enjoyed going shopping and was a member of the local Women’s Institute. However in February 2009 I had a stroke and spent six and a half months in hospital. The stroke left me with very little mobility. I don’t remember receiving much rehabilitation whilst I was in hospital even though I was in a stroke unit.

There was not much communication with a physiotherapist whilst I was in hospital and I can’t remember being given an assessment for any physio once I left hospital. I just felt that myself and my husband were left on our own. We felt isolated. Even my GP did not know that I had suffered a stroke when I visited him a few months later!

I came home in August and did not have a great deal of help from anyone for a few weeks. I did not have any kind of review about my needs, or any goals set, after coming home. I do remember a visit from an occupational therapist and I received six weeks of morning care straight after I came out of hospital. This helped me to dress myself and make meals but was very basic and did not address my mobility problems. I was also referred to the head injuries charity Headway, where I attend three days a week to help with my short term memory loss.

However, in late November I received an appointment completely out of the blue where I may be receiving some physiotherapy through my GP. This was around three months after I had left hospital and came from Northampton General Hospital.

My mobility is gradually improving but it makes me feel that if I had received the physiotherapy sooner my mobility would be a lot better now. I shuffle along as best I can. I also experience a lot of pain in my leg and knees. I have lost most of my independence and have not been to the WI since my stroke. I also miss being able to drive myself around.’
All stroke survivors must receive community based physiotherapy individually tailored to their needs

The impact of stroke varies hugely and support in the long-term must be tailored to meet individual needs.

*National Stroke Strategy – Department of Health (2007)*

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**A personal goal partnership**

Many stroke survivors feel they need physiotherapy on an ongoing basis and the RCP Guidelines make clear that assessment of need should be based on a goal attainment strategy. However our survey shows that only 22% of physiotherapy staff reported that they had been enabled to fully meet their client’s goals. We are concerned that so many stroke survivors are completing their course of physiotherapy without having achieved their goals. 52% of physiotherapy staff indicated that the outcomes for about half of their clients could have been improved if greater personalisation of services had been made possible.

A common concern is that goals are often professionally driven with little input and ‘buy in’ from the stroke survivor. We believe that the goal setting process must be based more on a partnership between the physiotherapist, stroke survivor and (where applicable) the carer. 28% of physiotherapy staff felt that their client’s goals had not been achieved because they had been unrealistic. Therefore, it is important that goals are realistic (possibly taking into account short, mid and long-term goals) and do not raise expectations too much whilst also being ambitious. It is also important for the goals to be flexible and regularly monitored as they may need to be amended (see *Review Process (2)*, page 14).

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**Recommendation 3a**

The goal setting process must be a partnership between the physiotherapist and stroke survivor – which enables personal, realistic and flexible goals to be monitored.

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**Ongoing physiotherapy**

45% of physiotherapy staff surveyed told us that almost half (49%) of stroke survivors did not receive the services that would enable them to achieve the best possible outcome. The NSS clearly recommends that stroke survivors should receive support when they need it, for as long as they need it (see *Quality Marker 10*, page 14). However, 35% of stroke survivors were either unsatisfied or very unsatisfied with the length of their community based physiotherapy course. 56% of stroke survivors reported receiving less than three months of physiotherapy with many referring to a standard 6–8 session allocation. This suggests a pre-determined and arbitrary amount in some areas. A person-centred service including personal goals should result in the length of the course being tailored to individual needs, alongside other aspects of the physiotherapy.

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**Recommendation 3b**

Community based physiotherapy must only be discontinued once all achievable goals have been met and no new attainable goals can be set.

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**Exercise classes**

Once a stroke survivor has achieved their personal goals it is important that they maintain their improvement. Evidence shows that exercise
Bob Yexley, Dorset, 68

'I had worked as a businessman most of my life including being a director for a major supermarket chain. Becoming bored with retirement, I set up a small handy man business to ensure that I kept active and was still working at the age of 66. Then on Boxing Day 2007 I had a stroke which kept me in hospital for two months.

I received some physio whilst in hospital but it did not start until I had been there for three weeks. There was a planned programme but sessions were often cancelled and there was nothing at weekends. The occupational therapist assessed whether I should return home, but I can’t remember having an assessment for a continued physiotherapy programme. On leaving hospital I still suffered from pain mainly in my shoulder and I could not walk very well at all. Then two weeks after coming home I was visited by a local occupational therapist who told me that I could go to the local hospital to get some physiotherapy if I needed it.

So for about four weeks I went to the hospital once a week and was given half hour physiotherapy sessions which seemed to really help both the pain and walking. However, the gym where I did the physiotherapy was pretty old and ill-equipped.

Then after four weeks I was told that I would not be able to have any more physiotherapy. The only reason given was that there was a lack of resources to give me any more. I’m certain that with more physiotherapy I could now be walking much better than I am.

I walk down to the shops every day to buy a paper, am a member of a gym and go swimming as often as I can. I try to keep active but feel a bit let down by the NHS because the physiotherapy I received seemed like a ‘one size fits all’ approach where you have to work around them rather than them working around you.

I’ve got no complaints about the staff though as I felt that they gave 100% effort at all times.'
classes are beneficial to stroke survivors\textsuperscript{7,8} and are also a relatively inexpensive way to practise exercises that have been advised by a physiotherapist. Unfortunately, feedback from stroke survivors indicates that many areas do not have these classes specifically for them even though many are keen to join one. We are recommending specific exercise classes to be available for all stroke survivors. However, these should augment physiotherapy services and not replace them.

**Recommendation 3c**
All stroke survivors who could benefit from exercise classes should have the opportunity to join a class as part of an integrated stroke care pathway.

**Research**
74\% of physiotherapy staff indicated that personalisation of services for stroke survivors could not be achieved within current resources and, again, we do not underestimate the challenge in this area. However we believe that with innovative commissioning, significant improvement can be made within current resources. There is a growing body of evidence to suggest that therapy continued after discharge, and long after stroke, can bring about improvements in mobility, activities of daily living, social and leisure activities and quality of life\textsuperscript{9}— all of which can reduce the financial burden on health and social care services.

Ineffective commissioning may be a result of the lack of evidence of the effectiveness of ongoing physiotherapy in improving health and social outcomes. Studies have shown that an experienced physiotherapist can improve mobility and reduce disability in patients seen late after a stroke\textsuperscript{10} and in future we believe that the RCP Guidelines recommendations on long-term management must be strengthened.

**Recommendation 3d**
More research must be carried out into the benefits and relative cost effectiveness of long-term physiotherapy as part of an integrated programme of care.

**Quality Marker 10**

**National Stroke Strategy**
‘People who have had strokes access high quality rehabilitation and, with their carer, receive support from stroke skilled services as soon as possible after they have a stroke, available in hospital, immediately after transfer from hospital and for as long as they need it’

**Review process (2)**

**Royal College of Physicians, National Clinical Guidelines for Stroke**
‘Every patient should have their progress measured against goals set at regular intervals determined by the patient’s rate of change, for example using goal attainment scaling.

The rehabilitation process is a re-iterative cycle, starting with problem identification, analysis and understanding (i.e. diagnosis of the problems) and ending with comparison of the end state against goals set. While the cycle may reiterate several times, as existing problems are resolved and as new problems are identified, it is appropriate for the cycle to end when all achievable goals have been achieved and no new attainable goals can be set.’
The effects of a stroke can be devastating for both the person who experienced it and their immediate family. Many wives, husbands, partners and children become carers to their loved ones 24 hours a day, seven days a week. This can place a huge physical and emotional strain on them.

The rights of carers have been strengthened by the Carers Strategy that enables them to have their own needs assessed and receive necessary support[1]. Furthermore the NSS and RCP Guidelines recommend that carers are provided with information and support to enable them to help the stroke survivor and also lead as normal a life as possible (see Carers, right). Therefore, we are calling for the vital role of carers to be recognised and valued throughout the physiotherapy journey.

Social impact
We asked stroke survivors about the social impact of either positive or negative experiences of physiotherapy. **48%** of stroke survivors who indicated a positive experience of community based physiotherapy felt that it had helped them to be less reliant on carers. **40%** of respondents who indicated a negative experience (for example, if they had not received any physiotherapy) said that it contributed to them being more reliant on carers. In both questions, these were the most popular answers. Consequently, stroke survivors overwhelmingly feel that their reliance on carers – and therefore their independence – is the most important goal of their therapy.

**Recommendation 4a**
Health professionals and commissioners must recognise that stroke survivor independence should be maximised not only to benefit the stroke survivor but also the carer.

**Carer involvement**
Our survey of physiotherapy staff also highlighted the importance of carers in supporting the stroke survivor. **84%** of physiotherapy staff, when asked what the key factor is in a stroke survivor achieving the best outcome, indicated ‘support from carer/family/friend’. It is important to make clear that a proactive carer should never take the place of a multi-agency stroke community team. Nor should it necessarily be presumed that the stroke survivor would want their carer to be involved. However where the stroke survivor does want or need their carer to be involved then it is important that health professionals encourage them, whilst also ensuring that the carer receives the proper support they require.

**Recommendation 4b**
Health professionals and commissioners must, where appropriate, promote the benefits of including the carer in the rehabilitation process.

**Carers**
*National Stroke Strategy*
‘Carers are vital in providing support for people who have had a stroke and medical professionals and providers must acknowledge this when looking at the long-term support for people who have had a stroke’

*Royal College of Physicians,*
*National Clinical Guidelines for Stroke*
‘With the patient’s agreement, family carers should be involved in all important decisions, as the patient’s advocate, if necessary.’
Before Nick’s stroke we were a normal family with three children. I was a full time mum and Nick was a director of a company. Nick went on a skiing holiday with our two eldest daughters in 2008 whilst I stayed at home with our youngest. However he had an accident and a few days after coming home he had a stroke as a result of a damaged carotid artery. He was only 43 at the time.

He spent six months in hospital and had regular in-house neuro-physiotherapy. Once he came out he continued to receive a lot of occupational therapy and physiotherapy – usually around two to three times a week. This has lasted for over a year and I feel that it has been hugely beneficial to Nick.

I have been heavily involved in Nick’s care and often talk to his therapists. I have been involved in Nick’s goal setting and at the moment his goal is to walk around the house using a stick. He is close...
to achieving this but our next step is to do this without the stick. He is some way off from achieving this but our physiotherapist is realistic but ambitious for Nick and pushes him a lot. She also makes sure that the goals are practical and revolve around family life, which is important when you have three young children.

I am also involved in Nick’s case conferences every three months. This is where his key worker who is a Senior OT gets together with other professionals involved in his care including the physiotherapists. We discuss Nick’s progress and plans for the future.

Overall the physiotherapy that Nick has received has greatly improved his movement and independence. He now can get down to the shops to get a paper and can get on a bus on his own. Although he has lost his ability to speak, in terms of mobility, Nick is far less dependent on me which I feel gives both of us a better quality of life than we had anticipated following the stroke.
Other issues highlighted by our surveys

Both of our surveys identified a number of other issues, which we outline briefly below.

**Workforce**
98% of physiotherapy staff indicated that an effective multi disciplinary/multi agency approach was key to the achievement of the best possible outcome for stroke survivors. It is also best practice for physiotherapy to be performed by practitioners who specialise in stroke. 46% of stroke survivors told us that they had seen a stroke specialist with 21% saying they had not and 33% not knowing.

**Self referral**
Physiotherapy staff reported that self referral to accessible services improves outcome and prevents negative impact on quality of life. 14% of stroke survivors reported that either they self referred or a family member or carer referred them to community based physiotherapy services. 6% were referred by their GP.

**Different treatments**
Many different treatments have been mentioned by stroke survivors which have enabled them to achieve their goals. Some mentioned classes specifically aimed at improving balance. Botulinum toxin treatment was also mentioned, which helps with spasticity problems and is included in the RCP Guidelines.

**Consistency of physiotherapist**
Many stroke survivors mentioned that they had an excellent relationship with their physiotherapist and thought that having the same person for each session was a huge advantage. Those who were critical of their physiotherapist tended to experience a lack of continuity in the professional they saw.
Conclusion

The overall aim of the *Moving on* campaign is to raise awareness of the vital importance of physiotherapy to stroke survivors once they leave hospital. We believe this joint report from The Stroke Association and Chartered Society of Physiotherapy will provide health and social care commissioners with the evidence that more must be done to meet the needs of stroke survivors in this area and to realise the vision of where services should be in the future.

Our campaign does not advocate revolution but implementation. Due to the huge strides seen in recent years, initiated by the Department of Health, the Royal College of Physicians and the National Audit Office, there are no longer divisive questions over the direction of policy. However there remain large variations between stroke survivors’ experiences of community based physiotherapy.

The vision set out in this report could improve the lives of many people after stroke, reduce the dependency of individuals, enhance the quality and productivity of services and help to make long-term cost savings. We urge anyone involved in the provision of community based stroke services, including health professionals and commissioners, to read this report as a starting point. You can then refer to the new guidance for commissioners (see Aspiring to excellence, right) which outlines the practical steps to achieve a high standard community based stroke care pathway that includes a proactive, seamless, person-centred and outcomes-based physiotherapy service.

It is our strongly held belief that by working together, commissioners, physiotherapists and stroke survivors can achieve a model for community based physiotherapy that enables more people living with stroke as a long-term condition to achieve a better life and truly move on after their initial trauma.

Aspiring to excellence: services for the long-term support of stroke survivors

The Chartered Society of Physiotherapy and The Stroke Association recognise that achieving excellence across the whole service will not be immediate. There are however some key activities that can be undertaken that will change the experiences of living with a stroke for service users, their carers and families.

Aspiring to excellence, the new guidance for commissioners, is about whole system commissioning – putting the user at the heart of the provision. The guidance is aimed at enabling the best decisions to be made to work towards excellence in service provision. To order a copy please contact the CSP on 0207 306 6666 or go to www.csp.org.uk or www.stroke.org.uk/campaigns
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