Life after stroke: commissioning guide

A guide for commissioners in the NHS and local authorities to develop and improve their service to stroke survivors living in their communities

October 2010
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1 Introduction and purpose

This commissioning guide represents the next document in a series of work looking at improving stroke care across London. Following the publication of The London Stroke Strategy\(^1\) in 2008, and subsequent public consultation in 2008/09\(^2\), London’s acute stroke care has now been reconfigured. This means that patients across the capital can all access the highest quality care for stroke. Last year saw the publication of the Acute Rehabilitation Commissioning Guide\(^3\), which set out the services should be configured to support stroke survivors in the period of their lives following their acute rehabilitation.

Since the publication of the National Stroke Strategy\(^4\) in 2007 there has been a huge amount of work undertaken to improve stroke services with much success. However, much of the industry in stroke has focused on the acute and emergency components of the care pathway. This commissioning guide begins to redress the balance between acute care and life after stroke. This means having person-centred services to support stroke survivors to have a more positive engagement with their physical, personal and social environment by providing information, addressing practical, emotional and financial matters that arise as a result of stroke.

Recent estimates indicate that about a third of stroke survivors are left with long-term residual disabilities and needs which

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can persist for many years\textsuperscript{5,6} following the acute stroke event. Annually in London there are around 11,000 strokes\textsuperscript{7}, meaning that there are over 3,500 people per year added to the population of stroke survivors in the capital that will require some sort of ongoing support.

There are specific subgroups of the stroke population that may have additional barriers to accessing services. Therefore, throughout this guide commissioners will need to assure themselves that services are equitable, especially for people living with:

- Aphasia
- English as a foreign language
- Dual diagnosis such as vascular disease and multi-infarct dementia
- Co-existent mental health issues

Stroke survivors have a broad range of needs and require support across a range of different areas. The purpose of this commissioning guide is to provide those commissioning services for stroke survivors with clear, succinct guidance on what a comprehensive quality service should look like. Much can be done for stroke survivors by reorganising existing services and refocussing work rather than spending more money. Long term dependencies are expensive and changing some of the ways that services are delivered can deliver cost savings to health and social care in the long term.

This document is guided by three core principles that commissioners should consider about all services they commission for life after stroke.

Firstly, how do the services commissioned aid the stroke survivor to reengage in active citizenship, such as returning to work, establishing links with support groups or regaining autonomy, control and a positive sense of identity following a stroke. One of the biggest challenges faced today for stroke services are the cohort of people living with stroke, who despite having made considerable progress in their rehabilitation, never find themselves reintegrating with society and daily life. Commissioners should ensure that services are designed and managed in a way to help people get back to living their lives and reintegrating with society.

Secondly commissioners should consider how their services improve the quality of life of the stroke survivor. The most important factor for any service should be how that service is perceived by the end user, and the positive effect that the service has on them and their life. This means that some services need to be targeted towards how an individual can continue to live a fulfilling life, despite any lasting impairments. Although from a strictly clinical perspective gains may plateau, from a social perspective gains will continue as people find more effective ways of adapting and creating strategies to deal with residual impairment. Commissioners need to ensure that quality of life is not solely measured by clinical outcomes, but services are assessed against metrics agreed by the commissioners and provider services.

This guide also addresses the way in which stroke survivors should be empowered to take control of their care and manage their own condition. With increasing focus on self-management schemes, peer support groups and personalised care budgets, stroke survivors will have a bigger say than ever in the care they want and need. This guide will help commissioners respond to this trend.


The scale of need in London

There are almost 90,000 people registered with a GP in London as having had either a stroke or a transient ischaemic attack (mini stroke). The prevalence ranges from 1.6% of patients on GP registers in Bromley to 0.8% of patients in Tower Hamlets, Newham, Lambeth, Southwark and Wandsworth. Overall in London, 1.0% of patients registered with a GP have had either a stroke or transient ischaemic attack.

Table 1: Quality and outcomes framework data showing the number of patients registered at GP practices in London with a diagnosis of either stroke or transient ischaemic attack in 2008/09

<table>
<thead>
<tr>
<th>London Borough</th>
<th>Number of GP practices</th>
<th>Sum of list sizes</th>
<th>Sum of stroke and Transient Ischaemic Attacks (TIA) on register</th>
<th>Prevalence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barnet</td>
<td>72</td>
<td>353,716</td>
<td>4,503</td>
<td>1.3%</td>
</tr>
<tr>
<td>Enfield</td>
<td>62</td>
<td>298,918</td>
<td>3,351</td>
<td>1.1%</td>
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<tr>
<td>Haringey</td>
<td>54</td>
<td>262,946</td>
<td>2,312</td>
<td>0.9%</td>
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<tr>
<td>Camden</td>
<td>40</td>
<td>225,833</td>
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</tr>
<tr>
<td>Islington</td>
<td>38</td>
<td>206,977</td>
<td>2,282</td>
<td>1.1%</td>
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<tr>
<td>City &amp; Hackney</td>
<td>45</td>
<td>262,300</td>
<td>2,262</td>
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<tr>
<td>Tower Hamlets</td>
<td>36</td>
<td>241,028</td>
<td>1,989</td>
<td>0.8%</td>
</tr>
<tr>
<td>Newham</td>
<td>64</td>
<td>323,827</td>
<td>2,448</td>
<td>0.8%</td>
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<tr>
<td>Redbridge</td>
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<td>265,322</td>
<td>2,345</td>
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</tr>
<tr>
<td>Barking &amp; Dagenham</td>
<td>43</td>
<td>179,073</td>
<td>1,734</td>
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</tr>
<tr>
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<tr>
<td>Lambeth</td>
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<td>366,664</td>
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<tr>
<td>Southwark</td>
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<td>309,666</td>
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<tr>
<td>Lewisham</td>
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<td>296,735</td>
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<td>Croydon</td>
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<td>Wandsworth</td>
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</tr>
<tr>
<td>Richmond &amp; Twickenham</td>
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<tr>
<td>Hammersmith &amp; Fulham</td>
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<td>185,351</td>
<td>1,672</td>
<td>0.9%</td>
</tr>
<tr>
<td>Ealing</td>
<td>81</td>
<td>349,976</td>
<td>3,595</td>
<td>1.0%</td>
</tr>
<tr>
<td>London Borough</td>
<td>Number of GP practices</td>
<td>Sum of list sizes</td>
<td>Sum of stroke and Transient Ischaemic Attacks (TIA) on register</td>
<td>Prevalence</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>------------------------</td>
<td>------------------</td>
<td>------------------------------------------------------------------</td>
<td>------------</td>
</tr>
<tr>
<td>Hounslow</td>
<td>55</td>
<td>242,239</td>
<td>2,459</td>
<td>1.0%</td>
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<tr>
<td>Brent</td>
<td>70</td>
<td>350,850</td>
<td>3,365</td>
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<tr>
<td>Harrow</td>
<td>38</td>
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<td>2,901</td>
<td>1.2%</td>
</tr>
<tr>
<td>Kensington &amp; Chelsea</td>
<td>43</td>
<td>185,302</td>
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</tr>
<tr>
<td>Westminster</td>
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<tr>
<td>England</td>
<td></td>
<td></td>
<td>901,323</td>
<td>1.7%</td>
</tr>
</tbody>
</table>

2.1 Interpreting the statistics correctly

It is important to interpret this data in the correct way. Firstly, this table does not show how many stroke survivors need ongoing community support. It simply shows the number of individuals who have had either a stroke or transient ischaemic attack and are registered at a GP surgery. It does not provide an indication of need. Secondly, it is likely the data shows fewer stroke survivors than are actually living in London, as there will be individuals who have either not registered at a GP practice or for whatever reason have not had this condition recorded on the register. Thirdly, the London Stroke Strategy\(^8\) stated that there are approximately 11,000 strokes in London per year. With the improvements made to the acute models of care for stroke, commissioners should expect the figure of 88,348 stroke survivors living in London to gradually increase.

2.2 Using the information

This data should be used by commissioners when planning the size of their service to stroke survivors, and provide an indication as to whether or not their current service is likely to be reaching everyone that it should be. If an analysis of their service shows that the service is reaching a significant smaller number of people than indicated here, commissioners should link with GPs in the area to identify areas of unmet need.

**Recommendations to commissioners**

- Those likely to experience additional barriers in accessing stroke services and support (e.g., those with aphasia) should be identified and their experiences of the services monitored

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8 London Stroke Strategy, op. cit
3 Regular review and needs assessment

In June 2010 the National Institute for Clinical Excellence (NICE) published 11 quality standards for stroke care. Within these standards NICE state that stroke survivors should be “screened within six weeks of diagnosis...to identify mood disturbance and cognitive impairment.” The Accelerating Stroke Improvement Programme and National Stroke Strategy also emphasise the importance of regular review. From April next year, NHS organisations will be asked to report on the proportion of stroke survivors who have had a six month review, and quality marker 14 in the National Stroke Strategy states that stroke survivors should have an annual health and social care check. This was also endorsed by the National Audit Office report in February this year.

The rehabilitation process is cyclical. This is to say that problems are initially identified, then analysed and it finishes with a comparison of the end state to the goals set. This cycle will repeat several times over for different aspects of the stroke as existing problems are resolved and new issues are identified.

The offer of an annual review is particularly important for those stroke survivors that do not have an advocate for them. There will be a cohort of individuals that will need to be actively sought out at regular intervals so that care can be offered to them. Often these are the most vulnerable in society and need the most support.

Evidence about to be published from Kings College London underlines the importance of annual review. In an analysis of the South London Stroke Register (largest database of stroke survivors in the UK), they found that individual needs changed over time, particularly in relation to their emotional wellbeing and physical activity. Regular annual reviews form the hallmark of a quality stroke service.


3.1 What should the annual review consist of?

Stroke survivors are not a homogenous group. The more time that passes from the stroke, the more an individual’s needs can diverge from other stroke survivors who are in the more acute phase. The review therefore needs to be tailored to meet the specific needs of the individual. Services need to recognise the variability of needs and aspirations among stroke survivors.

All stroke survivors entering a period of rehabilitation should be screened for common impairments using locally agreed tools and protocols. At this stage of care, the process should be to engage in meaningful dialogue about what is hoped for and what may or may not be possible and focus on how the individual can be supported to return to meaningful activities and roles. Person-centred goal setting is about negotiating what someone wants and finding a solution that could work; being positive and working together to find an acceptable outcome.

A good review will involve a multidisciplinary person-centred assessment of the individual’s needs and aspirations, and will include information on how to access other services. The review can be conducted by an NHS, social service or third sector organisation, which also has an excellent understanding of the non-clinical issues affecting stroke survivors. An example of a good review process is the Single Assessment Process (SAP)\(^\text{14}\). SAP aims to ensure that the NHS and social care services treat older people as individuals and enable them to make choices about their own care. These approaches work to use resources flexibly, designed around what is important to an individual from their own perspective and work to remove any cultural and organisational barriers. People are not simply placed in pre-existing services and expected to adjust, instead the service strives to adjust to the person.

Stroke survivors should continue to be offered annual reviews until such a time that they either don’t want it or are gaining no benefit from it.

3.2 Who should undertake the annual review?

The review needs to be person-centred and have a range of options so that it can be tailored to the needs and aspirations of the individual. This means that the review should be done by the most appropriate key worker, which could mean a social care worker, GP, therapist, stroke navigator or as part of a structured social group. The key issue is that the person doing the review is able to conduct the review with sensitivity and competence, act on the results of the review, either by delivering the care and support themselves, or helping the stroke survivor to arrange it for themselves.

3.3 Joint decision making

Throughout the process of review and accessing of services, the stroke survivor’s views on the involvement of their family and other carers should be sought to establish the extent to which they want family members involved. This process of engagement with family and carers should start in the hospital and continue into the community. Once agreed, the carer and family can provide valuable insight and information about the stroke survivor, their habits, aspirations and relationships. This added information is an extra resource on the progress of the stroke survivor from both a clinical and social perspective, which means that a more personalised service can be developed around the individual.

3.4 Developing a local stroke survivor register

Stroke survivors often report feeling isolated and abandoned from both society and local health and social care services\(^\text{15}\).

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\(^{15}\) Hilari, K., Northcott, S., Roy, P. & Marshall, J. (2010). Psychological distress after stroke and aphasia: the
For many individuals, this occurs during the first six months following a stroke when the acute phase of care ends. It is these people that are lonely, housebound and lacking in confidence, that require regular reviews. However, the continued pressure of new stroke survivors, coupled with poor local record keeping, means that even if these people could be followed up, this would not be possible as there is no central record held across many boroughs or PCTs.

As part of the GP Quality and Outcomes Framework (QOF), GPs are required to keep a register of individuals from their practice that have had a stroke. This register is regularly updated and GPs are assessed against it prior to receiving any payments linked to it. Local commissioners should tap into this resource and work with GP partners to collate details of people in their community that has had a stroke and would therefore benefit from a review. The register should include reference to significant impairments that a stroke survivor may have, including cognitive issues, aphasia or significant physical disability.

### 3.5 Acute stroke rehabilitation guide

NHS Commissioning Support for London produced a guide for commissioners at the end of 2009 relating to rehabilitation needs of stroke survivors during the acute phase of care. The guide reiterated the need for scheduled regular needs reviews at three, six and 12 months post stroke. In addition the guide makes several recommendations:

- A support worker such as a family support worker or community matron to provide longer-term support
- A designated person for the patient and carer whilst in each care setting, such as a therapist, social worker or nurse
- Every PCT should work collaboratively to develop support roles that

The guide also states that the timeframes set out for review are the minimum number of reviews that should take place. A review should be considered whenever there are significant changes to the stroke survivor’s circumstances or condition. In line with developing a service and review around the needs of the stroke survivor, reviews should take place as often as they are required by the individual. It is important to make the route back into services accessible, flexible and transparent.

#### Recommendations to commissioners

- In line with national guidance and best practice, all stroke survivors should receive a multidisciplinary review at six weeks, six months, 12 months and then annually to assess their needs and aspirations
- In order to provide a responsive needs-based service, a review should take place at other times determined by the needs of the stroke survivor
- An accessible, flexible mechanism should be in place for stroke survivors to access the review system easily such as through a stroke navigator
- Stroke survivors should be screened and reviewed for common impairments in line with locally agreed protocols and have goals set accordingly
- Commissioners should work with local GP practices to access data they have on their QOF registers about stroke survivors

(from previous page)

first six months. Clinical rehabilitation, 24: 181-190

Stroke survivors and their carers often cite the lack of information as being a major barrier to engaging in active citizenship. Studies have shown that there remains a strong desire for better understanding of the causes of stroke, prevention strategies and the availability of local support agencies. People who have had a stroke also continue to need reiteration of what has happened, and what might happen for months and years after their stroke.

Commissioners need to ensure that staff seeing stroke survivors know where to go to obtain information on issues such as other local services, charities in the area and how the stroke survivor may access financial, emotional, social, and vocational support. The provision of information is not just about handing out leaflets and information sheets. It is about engaging with people who have had a stroke and their carers to ensure that they can access the information relevant to them now and in the future. The information they need will change with time and circumstance and is often unpredictable. For many, this involves ensuring that the information and the process of giving the information is ‘aphasia friendly’. Strategies that actively involve stroke survivors and their carers in acquiring knowledge, has also been shown not only to improve confidence, but also to have a positive effect on mood.

18 See www.ukconnect.org for more information

4.1 Stroke care navigator role

Across the country, some local authorities are employing someone in the role of a stroke care navigator. The purpose of the role is to provide a single point of contact for stroke specialist advice. Advice and information can be given either on a face to face basis or over the phone – as per the needs of the stroke survivor and their carer. The presence of an individual in this role also makes it less likely that the stroke survivors will become “lost in the system”.

The stroke navigator can also play a direct role in delivering care. They should be trained and able to undertake regular (including annual) reviews and can help coordinate complex discharges where packages of care can require input from several different agencies. They should also be trained in secondary prevention, so that they can advise stroke survivors appropriately and train carers and potentially care home staff. The navigator works collaboratively between all sectors in health, social and voluntary care. This serves to make accessing support simple and gives the stroke survivor confidence that there is someone available to listen to their needs and aspirations. The full service model for the stroke care navigator for a London borough is included in Appendix 1.

The role of care navigator also aligns with the principles of empowerment and active citizenship. Stroke survivors and their carers are better able to manage physical, psychological and social aspects of their stroke and related disability, and can take an active role in preventing further stroke. The navigator should also help address feelings of isolation, help promote confidence and support the learning of new skills.
“I wanted to be told what was going on. I felt lost going home to live with no support.”

Person with stroke and aphasia

4.2 London stroke directory

Stroke survivors need to have information on which social and community programmes are available locally. The London Stroke Directory website contains details of hundreds of community and voluntary clubs and groups focussed on stroke survivors. This site should be promoted to stroke survivors and their carers to encourage and empower them to take responsibility for their own care and access support themselves. The decision to access services or groups on the site could be discussed with the stroke care navigator for the stroke survivor.

4.3 Other stroke survivors as a source of information

Other stroke survivors are experts on life after stroke and how people can adapt and move on from its effects. Commissioners should support the notion that stroke survivors are the experts in their condition, and groups should be facilitated to offer support, advice and information to stroke service providers and each other.

A programme such as the Expert Patients Programme20 puts those living with a long-term condition in the driving seat, and supports them to make decisions about their care. The programme delivers free self-management courses to anyone living with a long-term condition and can make a real difference to stroke survivors.

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**CASE STUDY: Expert Patients Programme**

The Expert Patients Programme provides those living with a long-term condition, such as stroke, with the tools and techniques to help them take control and manage their condition better on a daily basis. Courses help to build confidence and allow people to share similar experiences.

**Elaine from Birmingham attended a course with others who suffer from chronic fatigue:**

There were fifteen people in our group, and all of us had different conditions but all suffered fatigue, so we knew what it was like to experience this little understood symptom. The course was scripted and we had ‘free think’ sessions where all of us contributed to self-managing our conditions.

We learned how to manage fatigue, and deal with communication problems. Healthy eating played an important part of self-help.

Each week we had to ‘action plan’ and have a goal set, so we could report the following week how we all got on and if we managed to achieve our goals. This could be anything and it was amazing to see people who had such disabilities make a tremendous effort to do something that was important to them and then go on to achieve this.

By the end of the six weeks we had all gained so much more confidence, and felt less pain in our bodies, as we had learnt cognitive techniques and many people like myself had now stopped their medication… the course is a must and it comes with the highest recommendation!

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20 www.expertpatients.co.uk

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4.4 Direct.gov.uk website
The direct.gov.uk website should be the first port of call for information on benefits and other sources of financial help that the stroke survivors are entitled to. This includes information on benefits such as incapacity benefit, disability living allowance (including a mobility allowance) and employment and support allowance. The site also has the facility to apply online for benefits and assistance, as well as providing telephone contact details so that applicants can discuss their case over the phone.

4.5 Sharing information across the team
Continuity of care is a key part of a quality service. When a member of staff is involved with delivering an aspect of the stroke survivors’ care, it is imperative that they are informed about what has happened previously with other services. Information about the stroke survivor therefore needs to be shared across the team and between agencies – to the benefit of the stroke survivor. Where barriers to sharing information exist, commissioners should work with their team and other agencies to remove these barriers for the benefit of those receiving the care.

Recommendations to commissioners
- Commissioners should ensure that health and social care professionals and stroke survivors know where to get information on what is happening locally
- Information from reviews should be shared across the entire team involved in delivering care to the stroke survivor, including with the stroke survivor themselves
- Commissioners should support initiatives to ensure that information and information processes are accessible to all, especially those with cognitive impairments
- Commissioners should link with voluntary sector organisations who act as specialist sources of information and support
- People who live with stroke and aphasia should be supported to be an information resource for other stroke survivors
- Commissioners should support the stroke navigator role in their area as a vital resource for stroke survivors
5 Empowering stroke survivors to take control

Empowering stroke survivors and their carers to play a greater role in making decisions about their care is an important theme of this guide. In order for stroke survivors and their carers to be really empowered, they need to have a good understanding of their condition and the options available to them. This means that the provision of information is key to giving people real empowerment. Similarly, stroke service providers need to have the skills and insight to support people with stroke and have a sound understanding of their needs. To be active citizens, people with stroke need structured support and a sound understanding of the opportunities available to them.

5.1 Self-management strategies

Commissioners must embrace new ways of organising and supporting people living with the effects of stroke, rather than looking for a “cure” or commissioning a new expensive service. The extent to which a stroke survivor believes they can control their activities and their autonomy is a critical factor in both their emotional state, their reported quality of life and their belief that they can live successfully after stroke.

Successful chronic disease self-management programmes can include a behavioural approach, which actively supports the development of skills such as problem-solving, individual target setting, self-exercise and medication management. Interventions can be disease-specific, delivered by professionals or lay experts, and individualised or group based.

CASE STUDY: Greenhill Aphasia Group

Greenhill Aphasia Group, an independent peer support group, is run by people with aphasia for people with aphasia. They meet weekly in a social services day centre with support from volunteer communication supporters trained by local speech and language therapists.

The group provides its members with an opportunity to develop confidence and engage in an active life after their stroke. The group is recognised as an important resource for Newham’s Integrated Stroke Steering Board, providing an easily accessible group for consultations on service developments.

In addition, members of the group have contributed to education programmes by training as “Better Conversations Trainers” in a project led by local speech and language therapists and Connect. The trainers with aphasia help to provide communication skills sessions for people who come into contact with stroke survivors such as health and social care professionals.

Arvinda, an experienced trainer, said of the project: “I felt very nervous initially about the training sessions, but at the end of the day I felt very confident.”


In essence, these person-centred approaches can be tailored to the exact needs of the stroke survivor. Commissioners should work to offer stroke survivors training in self-management, goal setting and problem solving skills\textsuperscript{23} and preliminary evidence has shown the benefit of these approaches\textsuperscript{24}. Commissioners should support stroke survivors in this process by outlining the options available and assisting with budgeting etc. This is especially important for those that may not have an advocate or direct carer to help the stroke survivor make decisions. This choice offered to stroke survivors should not be a one off. At each review, those receiving care from social services should be made aware that this choice is still available to them. As needs change, the support options need to change around the stroke survivor too.

CASE STUDY: The Bridges Self-Management

Training
The Bridges service runs accredited workshops and support for stroke practitioners to enable the learning of effective skills, theory and research relevant to stroke self-management. These are delivered via a series of one-to-one self-management sessions with a stroke survivor.

Workbooks
Trained practitioners are given personalised, interactive stroke workbooks to work through with the stroke survivor to support their self-management. The stroke workbook comprises individual stories and strategies suggested by stroke survivors, together with a diary section to record personal targets and successes.

72\% of participants stated that their practice had changed since the introductory workshop. The areas they felt had changed were their approach to goal setting, with a change towards a more person-centred approach, letting stroke survivors have hope with their goals and awareness of promoting self-efficacy.

5.2 Personalised budgets
All individuals accessing social care services should now have access to a personal budget\textsuperscript{25} to be used to purchase services and basic equipment\textsuperscript{26}. The aim of having a personalised budget is to enable people needing social care and associated services to design support for themselves and to give them the power to decide the nature of the support they want. Empowering people to decide their own support requirements is an important shift in responsibility.

Stroke survivors should have their needs assessed by the social services team. A package of care should then be agreed on and this package should then have a value allocated to it. Stroke survivors and their carers should then be given a choice of either accepting the package of care as set out by the social services team, or to take the equivalent value to arrange a package of care that they feel better suits their needs. Commissioners should support stroke survivors in this process by outlining the options available and assisting with budgeting etc. This is especially important for those that may not have an advocate or direct carer to help the stroke survivor make decisions.

This choice offered to stroke survivors should not be a one off. At each review, those receiving care from social services should be made aware that this choice is still available to them. As needs change, the support options need to change around the stroke survivor too.

The Putting People First initiative is a national programme to improve people’s experience of adult social care. The programme represents a commitment to

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26 www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/LocalAuthorityCirculars/DH_095719
make sure anyone who needs care and support can exercise choice to live their lives as they want. It’s about delivering high quality services tailored to individuals’ wishes, and ensuring better health and wellbeing for everyone, including families and carers. The initiative also provides support for commissioners to help increase the uptake of individualised budgets.

5.3 Adaptations to homes and environments

Having a living environment adapted and suited to the needs of the individual is vital to facilitate autonomy and help stroke survivors take control of their day to day lives. A review of the home and subsequent adaptations needs to be undertaken rapidly to facilitate discharge and promote independent living as soon as possible.

Commissioners should ensure that referrals into social services can be made by anyone; an open referral system needs to be standard. Referrals should then be screened and based on need, stroke survivors should be allocated a team with the appropriate skills to work with them to help provide the adaptations and equipment as needed.

The provision of equipment is not routinely reviewed unless it is deemed to be a “complex” item (eg hoists, bathlifts) or where there is a significant risk to issuing a particular item. Simple equipment does not need to be reviewed regularly, but it should be easy and clear to those using the equipment how to return it once it has served its purpose.

Commissioners should also ensure that where schemes exist for people to either purchase their own equipment in shops or online, those that are unable to get out or use a computer are not disenfranchised. Service should be set up to ensure equity of access for all those who need a service.

Recommendations to commissioners

- Commissioners should ensure that there is an open referral system in social services for assessments of home adaptations and equipment needs
- Stroke survivors, carers and health and social care professionals should be fully informed regarding the personalisation agenda and understand how individual budgets can enhance independence and increase choice in care provision
- Commissioners should support initiatives that foster active citizenship including self-management programmes
- Commissioners should strive to commission joint planning and delivery of health social and voluntary provision of support

27 www.puttingpeoplefirst.org.uk
For stroke survivors to achieve active citizenship, and take up their place in the community, they need to be able to get out and about. It is well reported that stroke survivors do not get out of the house as much as they would like to. Typical barriers to achieving this include a lingering physical disability, anxiety or lack of confidence, poor provision of information on local transport arrangements and the loss of an ability to drive. Services themselves need to be focussed on supporting access to everyday activities such as leisure, adult education, and work (paid and unpaid). This is especially important in the light of both preventing more serious psychological consequences of stroke and in fostering self reliance and healthy living after stroke.

6.1 Therapy based care

A targeted therapy-based rehabilitation service reduces the risk of further deterioration, increases the ability of stroke survivors to do personal activities and delivers cost savings through reduced hospital admissions and more intensive community support.

6.1.1 Physical therapy

Where a stroke survivor has an ongoing physical impairment, physical therapy is shown to be effective at preventing further deterioration and promoting autonomy.

Commissioners should be clear that the purpose of providing community-based therapy is not necessarily to see a marked improvement in functionality or deliver significant health gain. The aim of a physical therapy programme is to facilitate independence, functional mobility and prevention of further deterioration.

Commissioners should also be aware that physical therapy provided for the very elderly or for those in long-term care appears to have the same effect as on younger populations. Provision of long-term physical therapy is worthwhile, safe and reduces disability in all stroke survivors, across all ages.

The Moving On report by The Stroke Association and The Chartered Society of Physiotherapy provides the guiding principles around which a community physiotherapy service should be aimed. These include:

Physiotherapy individually tailored to the needs of the stroke survivor
Recognising the valuable role of carers in a physiotherapy programme

6.1.2 Cognitive therapy

Recovery of cognitive impairment is associated with lower institutionalisation and better functional abilities one year after stroke and remains key to supporting


stroke survivors’ return to society. As many as 20% of stroke survivors suffer from a so-called “silent stroke”\(^\text{35}\). This means that a person does not have any obvious physical weakness or paralysis, but may still have underlying cognitive deficits. Better understanding and vigilance by stroke service providers about the pervasive and potentially damaging nature of silent impairments is crucial.

If cognitive impairments are identified, cognitive rehabilitation may be appropriate. This should be carried out by a person with the skills appropriate to the needs of the stroke survivor.

6.1.3 Aphasia

Aphasia relates to impairments of language. It affects everyone differently; some people cannot speak at all, some may have just a few words, others may no longer read, write or use numbers. Intellect is largely unaffected. It is an invisible condition that can have a huge effect on self-confidence, wellbeing and identity. Its significance lies in the fact that it can pervade all aspects of living with stroke. People with aphasia have been shown to be at increased risk of depression, loneliness, ability to engage with rehabilitation\(^\text{36}\) and diminished social networks\(^\text{37}\).

Outcomes for people with aphasia are significantly improved if services ensure people with aphasia have appropriate support\(^\text{38}\). The model of community support for people with aphasia that has shown itself to be most effective is typically:

- A peer support group focusing upon communication that is guided and facilitated by a third sector organisation
- Volunteer ‘conversation partners’ working with stroke survivors both within the context of the group and outside in the wider community
- Active linkages and referral pathways with speech and language therapists

CASE STUDY: Cognitive Rehabilitation, Warwickshire

Warwickshire College of Further Education in Leamington Spa provide cognitive rehabilitation in a mainstream college environment. The course is designed to help people with cognitive impairments resulting from acquired brain injury (including stroke). It offers participants educational and vocational opportunities with clear progression routes for those wishing to develop their confidence and acquire new skills. It covers modules that include: ceramics, horticulture or conservation, photography, art or craft, computing and communication skills.

(from previous page)

after stroke and factors associated with its recovery. Clinical Rehabilitation, 17: 158-166


Effective community provision of aphasia support should be:

- **Dynamic**: in that service users are encouraged to develop their communication skills and confidence
- **Functional**: relevant to stroke survivors’ own personal circumstances, interests and needs
- **Accessible**: widely promoted and able to accommodate the needs of all potential users
- **User led**: guided by the issues and interests of service users
- **Mainstreaming**: wherever possible, be leading service users into mainstream community activities and reducing the marginalising influence of their stroke and impairment

**CASE STUDY: Communication Plus Training**

The Stroke Association’s Communication Plus service is a communication programme that provides stroke survivors the opportunity to develop their communication skills by attending communication modules over six to eight weeks. At the end of each module, further goals are identified or discharge occurs if no further benefits can be attained.

Communication Plus always operates in parallel with a peer support group where participants can find more informal social interaction and companionship on an ongoing basis.

**CASE STUDY: The Access to Life Project**

The project aimed to extend and enhance opportunities for people with stroke and aphasia living in Cornwall. The project aimed to identify where there was the potential to be innovative with local service models and put those with aphasia in the driving seat in deciding what services should look like.

People with aphasia and those working with aphasia were recruited through a series of events, and began to determine the direction of future service provision. Inspired by peers in London, activities were customised for their local context and it was agreed that the main aim of the project should be around engagement with people with aphasia. People with aphasia who wanted to be trainers or group facilitators were brought together and undertook training programmes.

With more people trained, the group commenced setting up even more local hubs and a home befriending scheme. The group also began to make links with the local media, to promote awareness of aphasia and inform people of where they could go for support. Services run for people with aphasia by people with aphasia such as this are now contracted in many regions of the country.

[www.ukconnect.org](http://www.ukconnect.org)
6.1.4 Continence therapy

Incontinence has been shown to effect up to 15% of stroke survivors one year on from the onset of stroke\(^{39}\) and has a marked effect on both quality of life\(^{40}\) and reported psychological wellbeing\(^{41}\). Although not discussed as openly as perhaps it should be, incontinence has a huge impact on the reported quality of life of stroke survivors and should form part of the regular reviews. Until the individual is confident that they are able to manage their incontinence, return to life roles and integration into social activities will be difficult.

Professional input, through structured reviews and management and specialist continence nursing, appears to be one factor important in helping stroke survivors manage their condition. There are a range of potential interventions available, which need to be discussed during review.

6.2 Transport

Getting about on transport services needs to be recognised as a right. Many stroke survivors have great difficulty getting around outside their home\(^{42}\). There appears to be three key issues for commissioners; provision of transport services and informing people of how to access them, building the confidence of stroke survivors and helping them adjust to new ways of getting around, and ensuring stroke survivors have access to the financial support they need.

Most local authorities run a dial-a-ride service, which usually needs to be booked a couple of days in advance. This means that stroke survivors cannot routinely go out if the weather is good or if they are having a good day. Commissioners should work to ensure that services are as flexible as possible, so that stroke survivors can use the services at short notice. Stroke survivors also report that they are sometimes unsure as to whether or not they are eligible for these services\(^{13}\). Information around how to access services and who is eligible should also be available and clear.

Many stroke survivors cite a lack of confidence as the reason for not using more public or social transport. Fear of injury or embarrassment from falling while walking are factors in keeping stroke survivors isolated. As part of their regular review, an intervention that combines information-giving with skills training in these areas could be helpful. A simple occupational therapy service, coupled with improved information on local transport services has been shown to be successful in helping stroke survivors regain their confidence, and leave the house on a more regular basis\(^{14}\). Carers, families and other stroke survivors also have a crucial role to play as they too can help build confidence and should be encouraged to do so.

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6.3 Driving

Being able to drive is often essential for practical reasons and because it influences self-esteem and mood. There are risks associated with returning to driving following stroke, and the DVLA have set stringent tests for people with impairments post stroke to pass in order to regain their licence. Those involved in caring should be able to advise individuals where to access more information on this and help them, where necessary, to reapply for their licence.

Health and social care professionals should ensure that they are up to date with the latest requirements from the DVLA prior to advising stroke survivors. Those who have suffered cognitive or physical impairment following stroke must inform the DVLA of this at their earliest convenience and follow up proceedings from that point onwards with the licensing authorities. Given the value of independence to stroke survivors, a return to driving (or possibly the use of a scooter) should be evaluated on a regular basis.

6.4 Community leisure and exercise groups

People who have had a stroke need to be enabled and empowered to live a full, autonomous life in the community. Following stroke, many people experience a loss of much of their natural physical fitness. Regaining that fitness is important not only to continued health, but also to helping them play an active role in society. Leisure and exercise groups are particularly important to help support people regain the fitness they once had and then maintain it so they pursue a life in the community.

Social groups have a vital role to play in getting stroke survivors back to being active citizens in daily life. High levels of support, both physical and emotional, are associated with progressive improvement of functional status (especially in severely impaired

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CASE STUDY: Travel Training

As part of a Stroke Association Communication Service in Wandsworth, a volunteer was paired with Aneesha, a stroke survivor who had become isolated and reluctant to venture outside since her stroke. The volunteer was able to support Aneesha to use public transport to make the trip to her local high street where she spent the afternoon ordering coffee and cakes and catching up with old friends. This was the first time Aneesha had been able to use public transport since her stroke, and with a little more help and encouragement from the volunteer, she was soon able to make trips on her own.

Some stroke survivors may be entitled to financial support to help them get around. Commissioners should ensure that stroke survivors are clear about eligibility criteria for any benefits as well as where to source information on this issue (see section 4 on provision of information). It is not that commissioners need to invest more money into this area, it is about linking up services, ensuring that transport planners and providers are aware of issues relating to stroke (aphasia, fatigue, cognitive deficits etc) and that if people require financial support, they know what is available and where to access it.

www.direct.gov.uk/en/motoring/driverlicensing/medicalrulesfordrivers
stroke survivors), and there is also a positive effect on the individual’s psychosocial status\textsuperscript{45}. The relationship between social support and improvements in functional status also exist in the other direction. That is to say that those individuals that receive little or no social support are at particularly high risk of attaining a poor function recovery following their stroke\textsuperscript{46}.

Some leisure classes are set up specifically for stroke survivors to attend. This is not universally the case (nor need it be), however individuals involved in running leisure classes should have some formal training, which will include knowledge of:

- Changes to the individuals’ life roles and relationships
- Possible changes to a person’s identity and self esteem
- Psychological and physical wellbeing
- Cognition and language impairments
- A person’s occupation
- A sound understanding of issues relating to secondary prevention

6.5 Peer-led services

Community-based services for stroke survivors are not just about what a PCT or local authority happens to commission for people in a given area. It is also about the support that stroke survivors can provide for each other – no-one understands life after stroke better than the stroke survivors themselves. In a time where finances are tight, commissioners need to look at new ways of using their resources effectively to build capacity into services in innovative ways and this should include integrating peer support initiatives.

Commissioners should be assured that

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CASE STUDY: Connect-ed

Connect, the communication charity, ran a three year project called “Connect-ed” led by people with aphasia for people with aphasia. The project devised three types of activities; a drop-in session, trips and a quarterly newsletter. Together, this portfolio of activities promotes independence, boosts confidence, allows people to be socially active, offers support, teaches new skills and promotes a sense of community. The cost associated with these activities is also modest. The drop-in sessions reached over 100 people for a cost of less than £10,000. There is also evidence to show that group therapy and counselling for stroke survivors with aphasia and their relatives significantly improves their reported quality of life and communication skills. Connect also provides a counselling service for people with stroke and aphasia run by a professionally trained counsellor who also has aphasia himself.


CASE STUDY: Different Strokes

Different Strokes run a range of different classes and services, primarily aimed at younger stroke survivors. They run exercise groups throughout Great Britain and Northern Ireland and this includes sessions run by professionally trained stroke survivors. New groups continue to open and group coordinators are actively involved in the national management of the charity.

The Different Strokes telephone helpline, ‘StrokeLine’, receives an average of 75 enquiries each week ranging from questions about benefits, counselling and tips on improving rehabilitation to simply providing a listening ear. To talk with someone who has been through similar experiences is an opportunity that we know stroke survivors value highly; often the helpline provides this first point of contact with a fellow stroke survivor. The service is run by stroke survivors who understand the needs of the callers.

www.differentstrokes.co.uk

CASE STUDY: Lambeth Stroke User Involvement Network

The Lambeth and Southwark Stroke User Involvement Network is a project which started in April 2008 coordinated by The Disability and Advice Service Lambeth (DASL) and funded by Guy’s & St Thomas’ Charity with further support from NHS Lambeth PCT and London Catalyst.

The Network is coordinated by DASL but it is led by users. It organises meetings and events, provides information and support to people who have had strokes and provides a peer support (befriending) service. Users deliver key services including peer support and contribute to the planning and design of stroke services in the area.

A key service of the network is the Stroke Peer Support Scheme. Through the scheme, trained volunteers who have had a stroke meet with people living with stroke to share experiences, tips and information. The service is free and available to anyone who has had a stroke at any time who lives in the borough.

www.disabilitylambeth.org.uk
6.6 Returning to work

People who have had a stroke should be able to undertake paid, voluntary or supported employment. Repeated studies have shown that working is good for both your physical and mental health. The 2005 publication of the National Service Framework for Long Term Conditions included a quality requirement on vocational rehabilitation:

“People with long-term neurological conditions are to have access to appropriate...support to enable them to find, regain or remain in work and access other occupational and educational opportunities.”

Organisations such as Connexions and Job Centre Plus accept self referrals and referrals from community based social services teams. Where a full return to the same life the person had prior to the stroke is not possible, programmes need to work with the person’s wider social networks and where appropriate, support them to adapt to a changed way of life. At Job Centre Plus, Disability Employment Advisors can help advise and support stroke survivors to find employment that is suitable to their needs. They can also advise on how the individual might need to tailor their package of care to help them get back to work. Disability Employment Advisors can also help advise on available benefits and financial support packages. They also offer a service to employers, particularly to smaller employers, to help them adapt their working environments and work roles to help facilitate the return of the stroke survivor to work.

CASE STUDY: The Wolfson Vocational Rehabilitation Programme

The programme has been running since 2005. During this time, of those supported by the team, 50% have returned to their previous roles with minor adaptations, 3% have returned to their old employer but in a new role, 18% have started new positions at new employers and 29% have commenced voluntary work.

In 2008, Ken suffered a right hemisphere stroke and other than mild upper limb weakness, he made a good physical recovery. Nevertheless, he struggled to return to work in IT because of cognitive difficulties affecting his memory and concentration, as well as a marked loss of confidence. In the course of the programme, he was taught a range of strategies to manage his forgetfulness, and had psychological support to prepare him for returning to a previously stressful role. His key worker liaised with his employers and visited the workplace to address his manager’s concerns where he developed a return to work plan. Before the programme, he had been off work for a year, his confidence had declined and he had few expectations of working again. He is now back at work at 75% of his previous hours and he and his company continue to work with the team on further increasing his hours.

6.7 Occupational and vocational therapy

Occupational and vocational therapy programmes focus on providing support for stroke survivors to enable them to obtain and stay in work. This could include paid work, voluntary activities and/or educational activities. Programmes therefore involve a highly individualised approach to the client’s particular needs and circumstances.


50 www.connexions-direct.com/

6.8 Stroke survivors in nursing homes

Somewhere between 5% and 15% of stroke survivors are discharged into residential or nursing home care and, conversely, about 25% of nursing home residents have had a stroke\(^2\). At present these stroke survivors rarely receive any attention from rehabilitation services and some nursing home residents are not even provided with standard wheelchairs by the NHS.

In order to address these issues, the Royal College of Physicians recommends that:

- All patients in nursing homes, care homes and residential homes should be able to receive review and treatment from specialist rehabilitation services.


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**Recommendations to commissioners**

- Health and social care professionals should ensure that they are up to date with the current guidance from the DVLA.
- Physical goal setting is important and needs to be a partnership between physiotherapist, stroke survivor and carer.
- As part of their regular review, commissioners should ensure that stroke survivors have access to expertise to address problems with their cognitive skills.
- A clear pathway for access into, and funding for, vocational rehabilitation should be agreed with health and social care commissioners.
- Specialist continence services should be available to all who need them.
- Education and liaison with local transport providers should be seen as a legitimate role for stroke service providers.
- Commissioners should ensure that community leisure and exercise classes are available and promoted to stroke survivors, who are then supported to attend as appropriate.
- Those responsible for running community leisure classes should have basic training in stroke awareness including communication access training.
- Commissioners should see training and education of community based organisations (including communication access training) as part of their remit to support active citizenship and promote wellbeing and prolonged healthy living after stroke.
- Those residing in nursing and care homes should also receive reviews, and staff working at these homes should be familiar with stroke care strategies and options, and the needs and aspirations of those in their care.
Emotional support

In a large review of 500 stroke survivors, almost 40% of respondents said that their largest area for concern was the social and emotional consequences of stroke. Reintegrating people into social networks and supporting them to adapt their lives to accommodate the consequences of stroke help people address reported feelings of isolation and loneliness. Supporting those around the person with stroke to alter their attitudes and practices also contributes to improving how effectively someone with stroke copes with life after stroke. Addressing this and supporting people to become engaged in meaningful activities and roles is important to avoid the slide into isolation and depression.

7.1 Mood and emotional issues

Large scale literature reviews show that depression is present in at least a third of stroke survivors and that complications such as emotional ability and anger proneness are also commonplace. The stressful anticipation of future harm, loss or negative consequences of the stroke continue to contribute to worsening depression, especially between one and four months post stroke. When stroke survivors are asked to rate their morale following stroke, a low rating seems to be strongly linked to the presence of depression. The importance therefore of detecting and treating depression can have a huge influence on the stroke survivor’s motivation to access support services and thus to engage in active citizenship and improve their quality of life.

Stroke survivors should have access to a review of their emotional needs from a qualified mental health professional, such as a clinical psychologist or psychiatrist, and, if needed, a treatment regime can be implemented. The treatment should be person-centred and focussed on the needs of the stroke survivor. It may involve medication and/or psychological therapy which have both been shown to have a positive effect on emotional problems.


57 Johnson, E. A. (2008). Factors associated with post-stroke depressive symptoms and quality of life. School of Nursing, University of Indiana. (Also available at: https://scholarworks.iupui.edu/bitstream/handle/1805/1701/Dissertation_Final_5.27.08.pdf;jsessionid=23D73E05D1E4965161AD5DFDC568E0E0?sequence=1
7.2 Peer support and information

There is also a need to focus on non-clinical support for emotion and mood. After stroke, an individual’s emotional stability can be supported by them feeling part of a community of people who understand stroke issues, and to feel a sense of purpose that comes from engaging in meaningful activity. This kind of ‘lifestyle support’ can best be achieved through peer support which may come from activities unrelated to stroke (like a neighbourhood, sports or church group) or a stand alone peer support group (as in a stroke group or club) or from engagement in a group focusing on other issues (aphasia support or fitness group).

Commissioners should evaluate whether there are sufficient, appropriate peer support opportunities available to stroke survivors locally, and where there is an identified gap, investigate the possibility of establishing this kind of support, either as an adjunct to an existing service, or as a service on its own.

“I saw a clinical psychologist early on but it was too soon, so no good to me. I wanted to get physically better first. Counselling after 14 months was not useful – I was too busy ‘coping’ with life. I want to generally be around others who understand.”

Stroke survivor with aphasia

7.3 Improving access to psychological therapies (IAPT)

The Improving Access to Psychological Therapies (IAPT) scheme supports PCTs to commission evidence-based, NICE compliant, interventions for people with symptoms of depression and anxiety. The service
adopts a collaborative way of working between different health professionals, including high and low intensity therapists, a GP champion and employment advisors. IAPT is strongly endorsed for people with depression and/or anxiety issues and long-term physical health problems.

The service is already operating across most of London and by October 2010 nearly every borough will have an IAPT service. Since 2007, the unique make up of the team has already helped over 1,000 people move off welfare benefits and supported them back into work. The service also accommodates self-referrals, and referrals from individuals who may have stopped using the service but find that they subsequently require further support.

The IAPT service is managed by different organisations across different London boroughs. This means that commissioners need to be clear who, in their area, is responsible for running the service. This information needs to be passed onto those working with stroke survivors to enable them to make a referral as and when the need arises. Stroke survivors too should have access to these details to allow them to manage their own care.

CASE STUDY: Connect For A Day

Connect for a day is a series of themed information and support days for people who have stroke and aphasia and their relatives. The themes covered have included:

- What’s new in stroke and aphasia
- Better conversations
- Caring and coping with aphasia
- Parent with aphasia
- Ideas and inspirations
- Computers and aphasia, and
- Arts access

People with aphasia can be an active citizen through being a member of the ‘expert panel’ or a volunteer helping to run the day, or they can be participants. Connect for a day helps people with aphasia and their relatives realise they are not alone. They share experiences and glean information with others who may be at different stages of recovery. They gain confidence, learn new skills, and are supported, informed, advised and inspired by others to see a future for themselves to live well with stroke and aphasia.

CASE STUDY: Befriending Service in Tower Hamlets

Tower Hamlets stroke team have developed an innovative ‘Home and Hospital Befriending’ service. The project has enabled a group of people living with stroke and aphasia to provide practical and emotional support for new stroke survivors. Trained volunteers are matched with stroke survivors and visit them once or twice each month for up to six months. The visit helps to bridge the gap between inpatient rehabilitation and returning home by providing better access to information, reducing the risk of isolation and raising self-esteem of the participants. One of the befrienders says of the project: “This is a good thing. [A befriender] has been through the same thing; they are the experts. It is useful to hear what they have been through and how they got through it.” Local stroke service staff have been trained to deliver befriending training to enable continuous recruitment of volunteers, ensuring sustainability and growth of the newly developed peer support network.
CASE STUDY: Access to Psychological Therapies

The Stroke Association have a service within the IAPT scheme, where stroke survivors can access cognitive behavioural therapy from a qualified and accredited counsellor. The service is available to stroke survivors as part of a suite of life after stroke services, and strong linkages with local stroke pathway clinicians and third sector providers ensures all those who could benefit from this service do so.

www.workingforwellness.co.uk

Recommendations to commissioners

- All stroke survivors should have access to a comprehensive emotional review and treatment and support regime
- All stroke survivors should be aware of and offered a menu of options to promote wellbeing, including peer-led support groups, engagement in community activities and professional psychological therapies
- Commissioners should ensure that those working with stroke survivors have the details of the local IAPT service so that those that need it can access the service
- Stroke survivors should be seen as a resource for other people with stroke and aphasia through formal and informal peer support
- People with stroke and aphasia should be properly supported to advise on service planning and delivery
Supporting carers and families

Based on their particular needs, the term carers can relate to those in a paid role as well as those who are unpaid, such as family and friends. Their role and their involvement with the person with a stroke is vital from the outset. Carers usually have the longest and the only constant and continuing relationship with the stroke survivor and remain in a supportive role often long after most other services have stopped.

The role of a carer can be a fulfilling one, bringing families together and helping all parties realise what is really important to them. It can also be an incredibly tough, demanding role. Many carers report emotional distress and feel undervalued in their role. Commissioners should ensure that carers, especially those in unpaid roles have access to the help and support they need.

8.1 Educating carers and families in stroke

It is common for carers to identify a lack of training and information about caring for those with stroke as a real challenge in being able to provide the level of care they want. Training and education for carers is shown to improve the knowledge of stroke for both carers and stroke survivors, have a positive effect on satisfaction scores and have some impact at alleviating the effect of depression in the stroke survivor. The way this information is retained is also important. Strategies which actively involve stroke survivors and carers and include planned follow ups for clarification and reinforcement should be used in routine practice.

Commissioners should ensure that carers have access to the following information:

- The nature and consequences of stroke
- Education around secondary prevention of stroke
- How to provide care and support
- Information concerning financial entitlements
- Local support services
- Common feelings and emotional consequences of stroke

Voluntary sector organisations provide useful leaflets that supplement support given through training (see information section). These include information for children of those who have had a stroke.

8.2 Supporting carers

Family members or friends who may be taking on a caring role are also entitled to a review of their needs in their own right. Many carers are elderly themselves and may also have social care requirements. At the time of transfer of care to the home setting following their review, carers too should be offered the support identified as necessary. They should also be provided with clear guidance on how to seek help if problems develop. Joint reviews and commissioning of services in this situation is absolutely crucial.

Charities, such as The Stroke Association, offer a service specifically designed to support families and carers. The Family and Carer Support Service is a home based service for carers and families caring for someone who has had a stroke. It involves face-to-face appointments with a specialist nurse at the care home, a nurse review at the care home, a nurse review at the care home, telephone follow up, and a meeting at the care home.

61 Greenwood et al. op. cit.
63 See www.stroke.org.uk for more information
visiting service, whereby a care coordinator talks to everybody in the household to help them understand the physical, cognitive and psychological effects. They also provide practical advice about caring at home and can facilitate links to other groups and local resources.

CASE STUDY: Volunteers Supporting Carers in Newham

Annette has worked as an independent volunteer in Newham with the Greenhill Aphasia Group in East London since 2005. In response to carers’ requests for a carers support group, Annette worked with her local church and community centre to establish Newham Carers’ Association. Newham Council provided a small grant to help cover basic costs. She describes the group as “a small friendly network of local volunteers and carers who provide each other with informal support”. The group provides an opportunity for carers to share useful information as well as socialise with others who understand their caring commitments and the impact of stroke. Angie, a founding member of the group joined when her sister had a stroke almost four years ago. Angie said: “The carers’ group provides me with real companionship. It works because I can relate to the other people in the group who all have the same or similar problems as me. I can relax in the group and say what I want to say and how I am feeling. I don’t have to be the “perfect carer”. I like that the group is run by volunteers. I feel they are there because they really want to help and not because they are being paid to do it...I can get professional help elsewhere if I need it.”

Recommendations to commissioners

- Stroke education, along with advice and support should be provided for carers in a way that actively involves them in the learning process
- Carers should also have their needs assessed at regular intervals by social services
- Carers should be provided with clear guidance on how to find help if problems develop
- Carers should have the opportunity to access long-term emotional and practical support thought peer support groups facilitated by charitable or voluntary groups
Conclusion

This document is not intended to be a series of tasks and services that commissioners should look to buy on behalf of their population. The work here should provide a principled framework, within which commissioners can assess their services and ensure that stroke survivors in their area receive the support they need. Services should develop the capacity of individuals to engage in an informed and competent way with stroke. This is done partly through developing individuals working in local community services, and partly through empowering stroke survivors to be able to make more informed decisions about the support they access and how they manage their lives.

As many of the needs of stroke survivors are met by several organisations operating across health and social care, the third sector and other sectors, commissioners should note that joint commissioning between PCTs and local authorities have a strong track record of success. By having a comprehensive portfolio of services in one place service duplication will be reduced and lines of accountability and reporting will be more straightforward for all organisations.

Commissioners themselves are a vital part of the service to stroke survivors. The panel felt strongly that commissioners should be encouraged to attend local stroke implementation team meetings, and engage with service users and staff. A team approach to providing services will only serve to benefit the stroke survivor and help them to achieve their goals.
Appendix 1 – NHS Camden stroke care navigator service model

1 Purpose

1.1 Aims

i To provide a single stroke specialist advice and reviews service which can signpost stroke clients and their carers to Camden life after stroke services

ii To conduct specialist health and social care client reviews on a regular basis to all those with new strokes with a Camden GP

iii To support annual reviews of identified clients with complex health and social care needs as a result of a stroke which took place in previous years. These stroke survivors will be identified in partnership with GPs, Camden’s Adult Social Care Reviews Team and the Camden REACH team (including stroke survivors from the Community Rehabilitation Team (CRT) pathway and Camden Physical Disabilities and Brain Injury Team – (PD&BIT) pathway), Camden community and voluntary organisations, as well as through self referrals from stroke survivors and their carers. This will need to be evaluated and discuss with the provider and commissioning in regards to governance, management, financial and service delivery implications

iv To provide telephone advice and general support to stroke survivors, their carers and front line staff

v To assist in co-ordinating, where appropriate, complex discharges, acting as a single point of contact in the community whilst the client settles into their new environment

vi To work within a collaborative approach between health and social care to reduce staff and client confusion regarding access to and eligibility of community rehabilitation and long term care well-being services and support

vii To provide clarity on the local stroke care pathway to health and social care staff, clients and carers

viii To provide training, where appropriate or where there is an identified need, on stroke and secondary prevention to staff in care homes, stroke survivors and carers groups in Camden

1.2 Evidence base

The Camden Stroke REDS register contains approximately 178 people who have survived a stroke in 2009. Although 57 people from the register will have or have had 6 month reviews conducted by Stroke REDS, 121 people are highly unlikely to have participated in any formal review processes post their period of rehabilitation.

The Camden Stroke Reviews Project (NCL Cardiac and Stroke Network and NHS Camden, 2010) provided formal reviews capturing and reviewing the 121 Camden stroke survivors in terms of their needs, opportunities to participate in community life and return to work if appropriate as per the National Stroke Strategy Quality Markers 10, 13, 14, 15, 16.

The project found:

- 13% of the cohort had not had their blood pressure or cholesterol reading (31%) taken post stroke by their GP
- There was a need for case management (particularly where there are cognitive and social problems identified as a result of a stroke)
- A lack of education about stroke and secondary prevention in this group
- Some clients could have benefitted from specialist Physical
Disability and Brain Injury longer term case management.

The Stroke Rehabilitation Guide for Commissioners (Healthcare for London, November 2009) states every stroke survivor is to have access to rehabilitation review at defined points during the first 12 months following their stroke. Stroke survivors must have their rehabilitation needs reviewed at three, six and 12 months following their stroke. In addition, a review should be considered whenever there are significant changes to the stroke survivor’s circumstances (e.g. bereavement).

Benefits of the review include stroke survivors progressing further than expected in rehabilitation, the avoidance of hospital admission, the modification of risk factors, increased quality of life, and compliance with medications.

1.3 General overview

- Stroke survivors may experience significant changes (both positive and negative) in function for an extended period after hospital discharge, and therefore every stroke survivor should have their rehabilitation needs reviewed at defined points during at least the first 12 months following their stroke. Quality Marker 14 in the National Stroke Strategy stipulates: “People who have had strokes and their carers, either 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.”

- The assessment will identify any outstanding issues and support needs as a result of their stroke. This could include the need for further rehabilitation; practical support in managing at home or getting the right access to statutory help, or emotional support to the stroke survivor and family. A plan will then devised to address these needs.

- A stroke survivor must have access to a named support worker who takes full ownership of the individual’s case. Support workers operate on an in-reach basis, first visiting survivors during their acute inpatient rehabilitation on the stroke unit. Support workers will have the experience and training to carry out the role, particularly with regard to communicating with those who have suffered a stroke, and will be focused on the stroke survivor’s agenda.

- Support workers will be focused on facilitating a seamless transfer from one care setting to another, providing continuity of contact across the patient pathway, and providing support for patients, family and carers in the form of navigation and advocacy. The support worker will also play an important role in ensuring that the stroke survivor has access to the information and services that will facilitate their return to work, should they so desire. They will monitor the implementation of the agreed care plan including the defined review.
1.4 Objectives

a) To assist in facilitating a seamless transfer from one care setting to another, providing continuity of contact across the stroke pathway, and providing support for patients, family and carers in the form of navigation and advocacy.

b) To play an important role in ensuring that the stroke survivor has access to the information and services that will facilitate their return to work, should they so desire.

c) To conduct:
   (i) Six week, if appropriate, and six month reviews post hospital discharge for all new strokes for all clients not on the Stroke ESD pathway
   (ii) Annual reviews of all new strokes and,
   (iii) If appropriate, work alongside Camden Adult Social Care to support the annual reviews of people who had a stroke in previous years with complex health and social care needs.

   The aim of these reviews is to facilitate a clear pathway back to further specialist review, advice, information, support and rehabilitation where required.

d) To monitor the implementation of the agreed care plans including the defined review

e) To help improve the knowledge of front line staff and clients in their understanding of stroke and secondary prevention of strokes.

1.5 Outcomes the service will be working towards:

**Stroke survivors, their families and carers**

- Feel well informed with appropriate information and emotional support
- Feel better able to manage the physical, psychological and social aspects of their stroke and related disability
- Feel more in control of their lives and feel able to exercise more choice regarding their ongoing care and support needs
- Feel less isolated as a result for receiving appropriate support
- Have built up social contact with others who share similar interests either through one-to-one support or by attending small groups (networks) of peer support
- Are now able to access facilities and services in their community again
- Feel more confident about returning to work, education or regaining independence or new skills
- Have an increased knowledge of how to prevent further stroke and feel empowered to make changes to their lifestyle

**Staff in health, social and voluntary organisations**

- Through provision of specialist advice on complex cases by the Stroke Navigator, front line staff are better informed of community options for secondary prevention and long term rehabilitation
- Improved knowledge and understanding of stroke and secondary prevention of strokes

2 Scope

2.1 Service description

To be a named contact as well as the GP to all Camden stroke survivors and their carers, helping plan and organise their care after returning home and investigate and rectify any arising problems (e.g. access to services). The Service is to act as an independent advocate for stroke survivors in discussion with services, coordinate services for the individual and be proactive in helping stroke survivors manage their care. The Service is to undertake these responsibilities in coordination with health services, adult social services, stroke
specific community services, training and volunteering services, community transport, leisure services, welfare/benefits services and end of life services.

- To lead on the development and review of the Camden Life After Stroke Care Pathway and policies, ensuring involvement and sign-up by all relevant partners

- To develop a pathway for people who have had a stroke which covers (i) strokes occurring to people in care homes (ii) when an adult with children has a stroke and (iii) work with Children’s Services to ensure there is a clear pathway for children who have a stroke. To be done in partnership with primary care and secondary care clinicians.

- To develop a simple and responsive referral pathway to signpost Camden stroke survivors to the stroke care coordinator

- To develop and maintain a client database or a stroke register. This shall include those survivors that may not present at main hospitals, be out of area when had the stroke, or only presented through A&E

- To be a point of contact for acute/inpatient rehab therapists and hospital social workers during the discharge planning process

- To offer support where deemed appropriate for hospital MDT and social work teams to coordinate complex discharges, acting as a single point of contact in the community while the client settles within a new environment

- To develop a strong relationship with GPs, to ensure stroke prevention/management and the review process occurs smoothly. To liaise and communicate with GPs changes to client circumstances, once reviews have been conducted, and to work collaboratively with GPs assisting stroke survivors to engage in secondary prevention

- To provide education to stroke survivors and their carers at an early stage – focusing education specifically about stroke and suitably appropriate services in Camden

- To provide stroke training to staff working in care homes caring for people who have had a stroke

- To assist in ensuring clients are referred appropriately to inpatient rehabilitation, early supported discharge services, CRT/PDBIT, and other locally available support services such as stroke clubs, carers support groups, home visiting/befriending support, stroke psychology service, vocational rehabilitation and memory assessment

- To assist in identifying clients who would benefit from neurological stroke speciality rather than generic rehab (inpatient or community based)

- To review clients post-discharge, including identification of particularly vulnerable clients (e.g. – living alone, complex presentation, co-morbidities) and follow-up early

- Plan to review clients with ‘no residual deficits’ early by phone to ensure this is actually true. This is a vulnerable group of stroke survivors who are likely not been referred anywhere and may only have GP contact

- Provide further education about stroke, risk factors and secondary prevention

- To network within Camden across the entire stroke pathway including focusing establishing links with services that provide services for addressing longer term needs arising from living one’s life after stroke (please refer to 2.3 for a description of the services)
2.2 **Accessibility/acceptability**
Stroke survivors of all ages (18 years of age and above) and their carers registered with a Camden GP and/or living in Camden.

2.3 **Whole system relationships**
The service will work closely with the local stroke acute units, GPs, residential and nursing homes, Camden REACH Stroke REDS Team, Camden Adult Social Care Reviews Team, Adult Social Care Occupational Therapy Service, Camden Housing Department, Camden REACH Physical Disabilities and Brain Injury Service, Camden REACH Community Rehabilitation Team, Camden Memory Service, Camden Stroke Psychology Service, Kingsgate Stroke Club, Millman Street Stroke Club, Different Strokes Central London Young Stroke Survivors Group, Stroke Association Communication Support Group, DISC Stroke Advocacy Service, Camden Carers Centre.

2.4 **Interdependencies**
The Service will be dependent on referrals from GPs, Adult Social Care, PD&BIT and stroke rehabilitation services for reviews of stroke survivors.

3. **Service delivery**

3.1 **Service model**
The stroke navigator post will be based within the Camden Provider Services REACH team, currently located in the 2nd floor South Wing office at St Pancras Hospital. This is so that the stroke navigator can be based with the other stroke pathways and also with the single point of access, CARIC.

Consent
Consent will need to be sought prior to referral to the stroke navigator service. The stroke survivor will need to be made aware of the service and information should be provided by the referrer through the information leaflet describing the service. The stroke survivor will be made aware that within Camden this Service forms part of their standard care post stroke. Referrers will be asked if consent was gained prior to acceptance of referral and will also be asked for written consent to share the stroke survivor’s information as required amongst stroke service providers including the stroke navigator service.

*Referral into the service*
Ideally, referral into the Service will be made once the Camden stroke survivor enters the HASU as per the stroke navigator pathway below (see 3.2). It can be made by any team member from the HASU assuming consent has been gained. It may be that Camden stroke survivors present at different acute units, or are repatriated from different acute sites within London and the UK, back to their Camden stroke units. Therefore referrals can be made to the Service by calling, emailing or faxing the stroke navigator directly or by contacting CARIC.

*IN REACH Model of practice*
The stroke navigator will operate an in-reach model of practice by: communicating formally and informally with the acute stroke unit and inpatient rehabilitation settings, in person on the wards and or via other communication channels. The stroke navigator will potentially be seeing stroke survivors in acute and inpatient settings in person if appropriate; and also in their usual place of residence or discharge destination within the community, after their standard NHS period of rehabilitation.
3.2 Stroke Navigator Care Pathway(s)

4. Referral, access and acceptance criteria

4.1 Geographic coverage/boundaries

The Service shall be available to stroke survivors and their carers with a Camden registered GP and a Camden residential address, or a Camden residential address only (where the stroke navigator will encourage registration with a Camden GP).

4.2 Location(s) of service delivery

The Provider shall have an office base for the Service, within Camden REACH – for provision of telephone advice and support – but this is not intended to become a client base for provision.

Assessments and reviews to take place usually in the client’s usual place of residence. This may include in care homes and long stay hospitals out of borough if appropriate.

4.3 Days/hours of operation

Monday to Friday 9.00am-5.00pm

4.4 Referral criteria and sources

Referral criteria

- Stroke survivor consent provided. In certain circumstances consent will need to be sought or gained from the next of kin or immediate family, if appropriate.

- Confirmed diagnosis of stroke, ischemic or haemorrhagic, made by a neurologist or stroke physician at an acute setting, HASU or stroke unit, local or national.

- Camden resident and or under a Camden GP.
Referral source

- Any acute inpatient MDT members on the HASU, acute stroke units, or inpatient rehabilitation facilities. In particular it is envisaged that potentially a substantial amount of referrals may be received from the stroke coordinators due to periods of high patient turnover and fluctuating periods of stroke admissions and discharges into the community.

- Camden REACH stroke pathways
- CARIC
- GP
- Family members or carers, both formal and informal
- Community stroke service providers including but not limited to Stroke Clubs, Camden Carers, Social Services etc.

For information, signposting and care navigation to existing stroke survivors living in the community and their carers (this could be for clients who had a stroke more than 12 months ago):

- Self referrals for navigation, information and signposting only. This does not include formal reviews but is focused on the navigation aspect of the service
- Telephone support via Stroke Navigation Telephone Line

For reviews, care navigation and advice service for new strokes:

- Potential referrers: HASU - UCH, ABIU - NHNN, RFH, St Pancras Inpatient Rehabilitation, GP (once client has been discharged with no referral), Camden REACH, Social Services

For reviews, care navigation and advice for stroke clients without a social care package:

- Community health services (e.g. GP, District Nursing, Podiatry, REACH)
- Social Services
- Camden Stroke Clubs
- Community and voluntary organisations
- Self referrals

4.5 Referral route

Phone call, email or fax, to stroke navigator number direct line or if unavailable or unreachable to CARIC single point of access to pass on information of referral.

4.6 Exclusion criteria

- No diagnosis of stroke, ischemic or haemorrhagic, from a neurologist or stroke physician
- Patients who have died during their inpatient admission
- Stroke survivors who decline the Service after information was provided to them by the stroke navigator
- Are medically unwell and thus review needs to be rescheduled

4.7 Response time and detail and prioritisation

Prioritisation of reviews will be assessed on a needs basis based on discharge plans and destination, history of current admission relating to stroke, and any identified risks by the stroke units and community teams. Every stroke survivor discharged home should be referred to the telephone navigation service for future information and signposting requirements.

In regards to the reviews, the service shall complete six week, six month and annual stroke reviews as follows:

- 6 week review (completed if stroke survivor is at home otherwise if still under secondary care it may be more appropriate to make contact with the team providing care to conduct a phone interview only)
- 6 month review (completed with the 6th month post stroke (this could fall the month before or after the anniversary i.e. anytime between the 5th and 7th month post stroke)
- Annual review (completed on the
12th month post stroke (this could fall the month before or after the anniversary i.e. anytime between the 11th and 13th month post stroke).

Telephone queries for support with information, guidance, care navigation and signposting will be responded as follows:

1. Query acknowledged and logged immediately
2. Query responded to depending on the urgency of call. Urgent queries responded to within 1 hour. General enquires responded to within 24 hours
3. Discharge criteria and planning

Potentially a stroke survivor may have three spells of involvement from the Service at the following intervals: six weeks post stroke, six months post stroke and one year post stroke.

There may also be an involvement from the Service around discharge planning from one setting to another, i.e. stroke unit to home, and also through referrals from the community.

Discharge criteria should focus on the navigation service meeting the needs of the stroke survivor by completion of review, communication of information and appropriate referrals being made. Once this occurs the stroke survivor exits the navigation service and may not present till next review – although still contactable at all times by phone to provide information, stroke education, signposting and care system navigation to carers and the client.

As referrals may also arise to the service through non formal pathways, such as review pathway not appropriate as stroke survivor out of area or re-referred to navigation service, once the needs are met then the stroke survivor is discharged from the service. These needs may be based on stroke education, sign posting to appropriate services, advice and carer support. These will be addressed on an individual basis and once met will allow for discharge from the navigation service.

6. Prevention, self-care and patient and carer information

The service shall:

- Run a minimum of three stroke awareness training events a year to staff in commissioned and in-house residential and nursing care homes
- Produce service literature and widely promote the Camden Stroke Navigation Public Telephone Support Line
- Contribute to the improvement of the Camden Stroke Patient Handbook and Camden Stroke website
- Actively encourage and refer clients to participate in secondary prevention programmes e.g. NHS Health Checks, smoking cessation programmes, exercise programmes, stroke club activities, healthy eating programmes, expert patient programmes etc
- Work closely with the REACH health promotion officer to contribute to the planning and delivery of stroke prevention talks to clients and carers in community settings
- Provide telephone information, guidance, care navigation and signposting to all new and existing stroke survivors, carers and front line staff via the operation of the Camden Stroke Navigation Public Telephone Support Line.
Appendix 2 – List of useful websites

The following list of websites may service as a useful resource to commissioners looking to develop their life after stroke services.

London Stroke Directory: provides information on groups and services for stroke survivors across London
www.londonstrokedirectory.org.uk

Stroke Association: The Stroke Association is the only UK wide charity solely concerned with combating stroke in people of all ages
www.stroke.org.uk

Connect: Connect is a UK-wide charity for people living with aphasia, a communication disability. At Connect people with aphasia are active collaborators - informing, driving and improving all Connect does to support people with aphasia to re-connect with life
www.connectuk.org

Speakability: Speakability is the national charity dedicated to supporting and empowering people with aphasia and their carers
www.speakability.org.uk

Different Strokes: Different Strokes is a charity set up by younger stroke survivors to support younger stroke survivors
www.differentstrokes.co.uk

Headway: The charity that works to improve life after brain injury. Provides information, support and services to people affected by brain injury
www.headway.org.uk

Transport for London: Information on all forms of public transport in London, routes, maps, journey planner and online tickets sales
www.tfl.gov.uk

Directgov: The official UK government website for all citizens. Contains information on all government services, including allowances, benefits, motoring and much more www.direct.gov.uk

Connexions: Offers advice on education, careers, housing, money, health and relationships for 13-19 year olds in the UK
www.connexions-direct.com
Appendix 3 – Acknowledgements

CSL would like to thank the following individuals who contributed to the development of this work and sat on the expert reference group.

<table>
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CSL intelligence
Increasing efficiency and reducing duplication

CSL service design
Transforming frontline services and driving up standards of care

CSL support
Providing training and development opportunities for NHS commissioners

Commissioning Support for London
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