NHS

South East Coast Strategic Clinical Networks

South East Coast

Strategic Clinical

networks

Life After Stroke

Commissioning Pack for Clinical Commissioning Groups and Local Authority Commissioners

Authors:

Dr David Hargroves Stroke Clinical Lead SEC CVD SCN

Mark Trickey Quality Improvement Lead SEC CVD SCN

www.secscn.nhs.uk

E mail: england.secscns@nhs.net

Version Control			
Version	**Date**	**Sent to**	**Comments**
1.0 Author M Trickey	11.08.14	J Huddleston and D Hargroves	Comments by J Huddleston
2.0	13.08.14		Revisions includes J Huddleston comments
3.0	14.08.14		Further revisions
4.0	15.08.14	J Huddleston and M Trickey by D Hargroves	Revisions and additions made by D Hargroves
5.0	22.08.14	D Hargroves and J Huddleston	Includes revisions made by D Hargroves and M Trickey
5.1	09.09.14	Task and Finish Group	PDF Version
6.0	14.10.14	J Huddleston and D Hargroves by M Trickey	Incorporates comments from Task and Finish Group members
7.0	15.10.14		Revisions and corrections to new sections
8.0	21.10.14	D Hargroves and J Huddleston	Incorporates further revisions by M Trickey
9.0	23.10.14	D Hargroves and J Huddleston	Summary of recommendations added
10.0	24.10.14	J Huddleston and M Trickey by D Hargroves	Revisions and corrections made
10.1	27.10.14		PDF version
10.2	04.11.14	Task and Finish Group	Hard copy with revisions following comments from group
10.3	06.11.14	M Trickey to D Hargroves	Revisions incorporated after meeting of the Task and Finish Group held on 05.11.14
10.3	07.11.14	Circulated to Task and Finish Group for final comments by 10.11.14	Approved by D Hargroves
10.4	10.11.14	Circulated to the SEC CVD Stroke Clinical Advisory Group and CVD Steering Group	Approved subject to final revisions from Task and Finish Group and proof reading
10.5	13.11.14		Formatting
10.6	5.11.14		1st Proof Read by Laura Ansboro. Amended by M Trickey
10.6	8.12.14		2nd Proof Read by J Huddleston Tracked Changes
10.7	12.12.14		Amended. Incorporated contents page. SCN template applied.
10.7	15.12.14		J Huddleston minor changes
10.8	19.12.14		
11	30.12.14		Pdf

Table of contents

Executive Summary……………………………………………………………………………………………………5

Summary of Recommendations to Commissioners……………………………………………………6

1 Introduction and Purpose ……………………………………………………………………………………10

2 Background………14

3 The Case for Change……………………………………………………………………………………………17

4 The Scale of Need in South East Coast……………………………………………………………20

5 Meeting the Need – Regular Reviews and Needs Assessment……………………………23

6 Information and Signposting for Stroke Survivors and Their Carers……………………26

7 Emotional Support…………………………………………………………………………………………………31

Psychological Care……………………………………………………………………………………………………31

Improving Access to Psychological Therapies………………………………………………………33

Peer Support and Information…………………………………………………………………………………35

Parity of Esteem between Physical and Mental Health…………………………………………36

8 Empowering Stroke Survivors to Take Control……………………………………………………39

Harnessing Technology to Give Patients Control……………………………………………………41

Telecare……41

Personal Health and Social Care Budgets……………………………………………………………42

9 Supporting Carers and Families………………………………………………………………………………45

10 Promoting Independence - Helping Stroke Survivors to Get Involved in Community Life……………………………………………………………………………………………………50

11 Joint Commissioning and Audit………………………………………………………………………………58

Joint Commissioning………………………………………………………………………………………………58

Planning and Audit……………………………………………………………………………………………………....58

12 The Evidence Base……………………………………………………………………………….…………………….…..61

Appendices

1 List of useful websites…………………………………………………………………………….…………………..63

2 Acknowledgements……………………………………………………………………………..…………………………...64

3 My Personal Health Plan…………………………………………………………………………………………….65

4 South East Coast Parity of Esteem…………………………………………………………….…………….…65

5 The Stroke Care Navigator Role…………………………………………………………………………….…….65

Executive Summary

‘’Stroke has a major impact on individual lives and on the nation’s health and economy. Strokes are a blood clot or bleed in the brain which can leave lasting damage, affecting mobility, cognition, sight or communication.’’ National Stroke Strategy, 2007

Despite an improving picture of stroke care in hospital and from supported discharge teams, many people report feeling abandoned by the health and social care system within a short time after returning home. There is clear evidence that services to support stroke survivors are variable and may be disjointed.

Recent guidance and national surveys have shown that stroke survivors have an improved quality of life when they are supported to take control of their symptoms. Empowering stroke survivors and their carers to manage their care, with the help of appropriately skilled staff, is a key theme of this guidance. With an increasing focus on self-management schemes, peer support groups and the introduction of Integrated Personal Commissioning (IPC), stroke survivors may be enabled to control the care they want and need and this guide is intended to help commissioners respond to this.

Commissioners should consider how their services improve the quality of life of the stroke survivor. This means that some services may need to be targeted towards supporting individuals to continue to live a fulfilling life following a stroke, despite any lasting impairments. Although physical improvement may plateau following an acute event, from a social perspective, gains may continue as patients learn effective ways of adapting and creating coping strategies to deal with residual disabilities. Emotional and psychological problems are extremely common in people who have had a stroke. Assessment and receiving appropriate psychological support is crucial to improving the quality of life of stroke survivors and this guide outlines the economic case for ensuring this is in place.

There is a moral and economic argument for supporting unpaid carers. People who may be sacrificing their own hopes and dreams in order to care for a friend or relative who has suffered a stroke deserve help and support to maintain their own health and wellbeing and thus continue to provide a valuable social and economic resource to the community.

As many of the needs of stroke survivors are met by several organisations operating across health, social care, the third sector and others, the case for joint commissioning is made, with a strong track record of success in caring for people with long term conditions including stroke.

The aim of this guidance is to support commissioners, who through their social and health care providers may enable stroke survivors to re-engage 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. There are a cohort of people living with stroke, who despite having made considerable progress in their rehabilitation, never find themselves properly reintegrating with society and daily life. Commissioners should ensure that all elements of the stroke clinical pathway are designed and managed in a way to help people get back to living full and active lives and reintegrating with society as they desire.

Summary of Recommendations to Commissioners

Meeting the Need – Regular Reviews and Needs Assessment

- In line with national and recent guidance issued by the South East Coast Cardiovascular Strategic Clinical Network (CVD SCN) all stroke survivors should be offered a comprehensive review at 6 months
- In addition and in line with national guidance all stroke survivors should be offered a comprehensive annual review
- 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

The Provision of Information

- A whole pathway approach is recommended
- Commissioners should ensure that health and social care professionals know where to access information on local services
- Commissioners are encouraged to compile or commission a directory of services that can be made available to professionals and stroke survivors, their families and carers
- Commissioners should work with the voluntary sector where specialist sources of information may be obtained
- Information should be shared across the entire team and with the stroke survivor and their carers
- Commissioners should support the stroke care ‘‘Navigator role’’ as a valuable resource for stroke survivors and carers

Emotional Support

- All stroke survivors should have access to a comprehensive emotional review and treatment and support regime
- A stepped approach to psychological care is recommended by NICE and should shape psychological commissioning for stroke services
- Commissioners should ensure that those working with stroke survivors have the details of the local IAPT(Improving Access to Psychological Therapies) service so that those that need it can access the service
- Stroke survivors should be seen as a resource for other people with stroke through formal and informal peer support
- Commissioners should evaluate whether there are sufficient and appropriate peer support opportunities for stroke survivors

Empowering Stroke Survivors to Take Control

- Stroke survivors, carers and health and social care professionals should be fully informed 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 and returning to paid or unpaid employment
- Commissioners should recognise and encourage technological initiatives that support stroke survivors

Supporting Carers and Families

- Stroke education, along with advice and support should be provided for families and professional and unpaid carers
- Carers and families should also have their needs assessed at regular intervals by social services or health care organisations
- Carers and families should be provided with clear guidance on how to find help if problems develop
- Carers and families should have the opportunity to access long-term emotional and practical support thought peer support groups facilitated by charitable or voluntary groups

Promoting Independence - Helping Stroke Survivors to Get Involved in Community Life

- 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 therapist, stroke survivor and carer
- Commissioners should ensure a clear pathway is available for referral into the appropriate stroke skilled range of therapies or psychological services where patients or their relatives or carers have concerns
- As part of regular reviews, commissioners should ensure that stroke survivors have access to expertise to address problems with their language skills and communication
- A clear pathway for access into, and funding for, vocational rehabilitation should be agreed with health and social care commissioners
- Education and liaison with local transport providers should be provided
- 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

Joint Commissioning and Audit

- Commissioners should strive to commission joint planning and delivery of health social and voluntary provision of support
- Commissioners should regularly audit the provision of services to stroke survivors

- Commissioners should ensure that all community stroke providers they commission services from are entering data into SSNAP

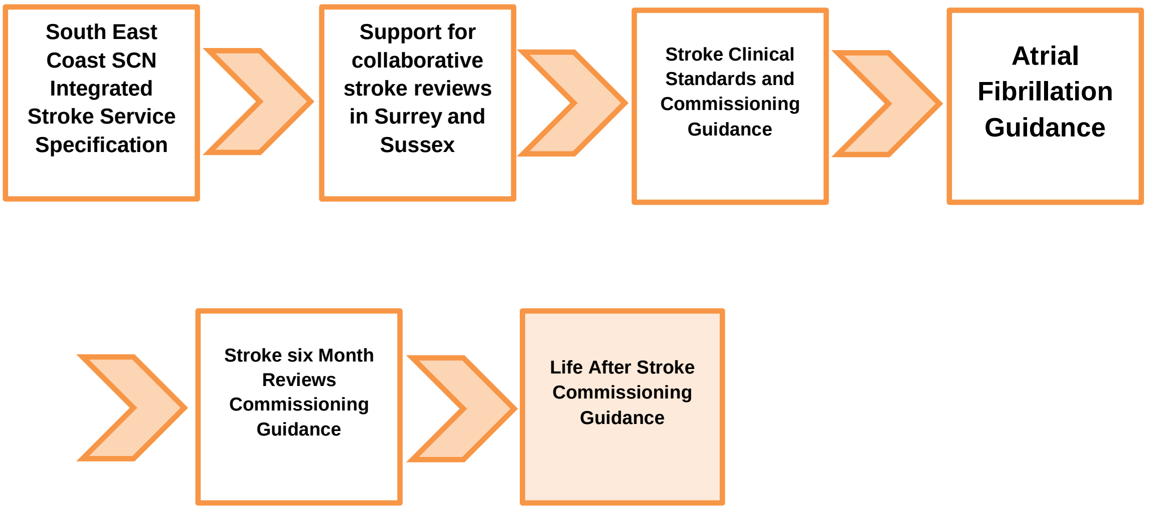
Introduction and Purpose

1. Introduction and Purpose

The Life After Stroke commissioning guidance represents another phase of work, carried out by the South East Coast Cardiovascular Strategic Clinical Network (SEC CVD SCN), with the aim of supporting commissioners to improve stroke care across the South East Coast Region.

Following the publication of The NHS SEC Integrated Stroke Service Specification[1] in 2012, and continuing support for stroke reviews across Kent, Surrey and Sussex, this year saw the publication of the Six Month Stroke Survivor Reviews Commissioning Guide and Service Specification[2]. This guidance sets out standards to which six month stroke review services should be commissioned to. This document focuses upon 'life after stroke' and is a term used to describe how services can be configured to support stroke survivors in the period of their lives following their acute rehabilitation.

The Series of Work Undertaken by the South East Coast CVD SCN Stroke Subgroup



Since the publication of the National Stroke Strategy in 2007[3], there has been considerable work undertaken to improve stroke care and services. Much of the effort has concentrated on prevention, emergency care and the acute components of the care.

---

[1] NHS South East Coast Integrated Stroke Care Services Specification 2012 (2014 update)

[2] SEC CVD SCN Stroke 6 month reviews specification and commissioning guidance. www.secscn.nhs.uk/our-networks/cardiovascular/stroke-clinical-advisory-group/

[3] National Stroke Strategy. DH/Vascular Programme/Stroke. 5 December 2007

Recent estimates indicate that about a third of stroke survivors are left with long-term residual disabilities and needs which can persist for many years following the stroke event. The term 'Life after stroke' encompasses the multitude of services needed to support people to recover from, and live with, the effects of stroke in the longer term.

Following discussion at the SEC CVD SCN Stroke Clinical Advisory Group, a Life after Stroke Task and Finish Group evolved, comprising commissioners, patients and carers, statutory and third sector providers of stroke care and the CVD SCN support team. The group have sought information upon and reviewed local examples of ways in which person centred services can be established, to support stroke survivors to have a positive engagement with their physical, personal and social environment. This work and the resulting guidance are intended to support CCGs and local authority commissioners to commission person-centred services, so that stroke survivors may engage positively with their physical, personal and social environment by providing information, addressing practical, emotional and financial matters that arise as a result of stroke.

Stroke survivors have a broad set of needs and require coordinated support from a number of health and social care providers. The purpose of this document is to provide those commissioning services with clear, succinct guidance and examples of what a comprehensive quality service should look like.

Included are a series of examples of good practice. This is not an exhaustive list and should not be seen as an endorsement of these services over others not mentioned. Commissioners are encouraged to compile or commission a directory of services that can be made available to professionals, stroke survivors, their families and carers and directed to relevant or existing services, where appropriate. Long term dependency is expensive and helping stroke survivors to access available services may deliver cost savings to both health and social care.

There are specific subgroups of the stroke population that may have additional barriers to accessing services. Attention should be paid to ensure that services are equitable, especially for people living with:

- A disturbance of communication
- With English as a foreign language
- Multiple long term conditions
- Co-existent mental health issues and substance misuse ensuring peoples physical and mental health needs are met
- Older people and other potentially isolated groups such as those from travelling communities
- Working age adults with families and dependents
- Expectant mothers

- Younger people in need of signposting to appropriate service or in transition to adult services
- Psychological needs as a result of stroke
- Other associated cardiovascular conditions

Background

2. Background

The National Stroke Strategy 2007 characterised Life after Stroke with 7 quality markers addressing:

- Ongoing rehabilitation
- End of life care
- Seamless transfer of care
- Long-term care and support
- Assessment and review
- Participation in community life and
- Return to work

The strategy states that not all these elements are consistently available and individual stroke survivors experience variable access and limited choice.

In March 2013 the government launched a new Cardiovascular Disease Outcomes Strategy[4]. This document is aimed at helping people working within the NHS and local authorities in England to understand what actions they should be taking to help prevent and treat cardiovascular disease (including stroke). In response to the problems that stroke survivors and carers often encounter when they leave hospital the Strategy also includes recommendations to help improve the longer term experience of people who have had a stroke. This includes making sure that people have their longer term needs assessed and reviewed and that they receive a written care plan. Particular areas of support such as emotional and psychological support are also addressed by the Strategy. This new strategy does not supersede the National Stroke Strategy 2007 which is a 10 year programme and is still active.

In England, the seamless transfer of care has been addressed in both the Acute and Early Supported Discharge (ESD) Standards and reviews at 6 months post stroke but there is a lack of structure thereafter. Patients and carers frequently have no clear lines of communication or pathways to follow.

Although there are no specific figures in England to quantify stroke survivors and their needs, there is evidence of unmet need in nearly 50% of stroke survivors, between 1 and 5 years after stroke[5]. Surveys from the Stroke Association Needs Survey[6] and the Care Quality Commission[6] confirm that stroke survivors and their carers experience unmet needs particularly in terms of information, further assessment and access to community

---

[4] Cardiovascular Disease Outcomes Strategy. DH Cardiovascular Disease Team Publication date 05 March 2013

[5] McKevitt et al 2011

[6] McKevitt, C. Fudge, N. Redfern, J. Sheldenkar, A. Crichton, S. Wolfe, C. The Stroke Association UK Stroke Survivor Needs Survey 2010

services. The Care Quality Commission also found that even when services were available, access could be confusing and complicated.

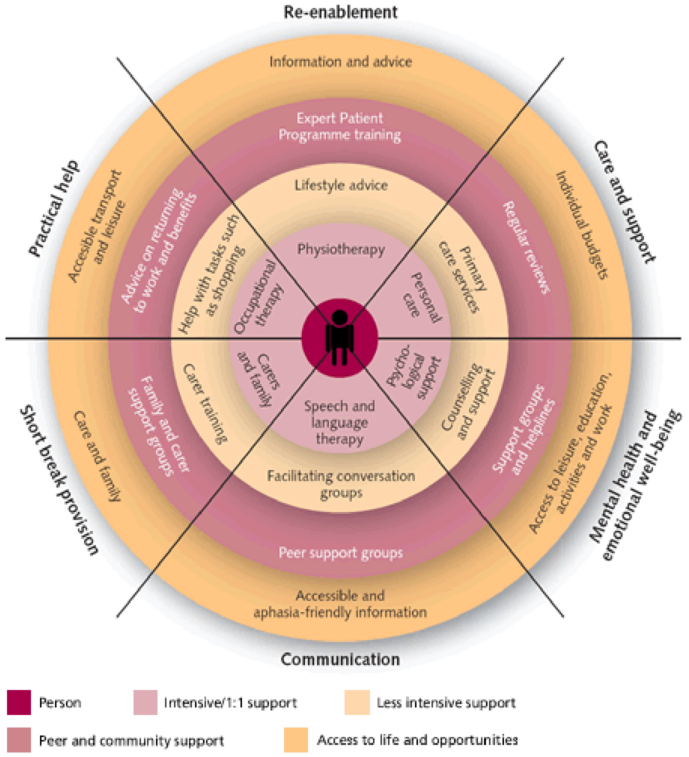
It is possible that these deficiencies are in part a result of the many service guidelines which focus on the early stages of care. For example, the Royal College of Physicians, NICE and the National Service Frameworks all allude to longer term needs but their specific recommendations do not go beyond six week, six month and yearly reviews post discharge from hospital.

The Case for Change

3. The Case for Change

It is clear from the evidence that the needs of stroke survivors and their carers cannot adequately be met by any one group alone and there is a requirement for cooperation and complementary working across health services, social care and the third sector. The level of support model recommended in the National Stroke Strategy 2007 demonstrates this visually.

The Range of Support Someone May Need After a Stroke



There is no recent history of measuring or improving services in this area whereas the measurement and reporting for acute services have been well established for several years through the Royal College of Physicians Sentinel Stroke National Audit Programme (SSNAP)[7]. From an economic point of view it is also important to retain the investments we are currently making in acute stroke services after hospital discharge. Every patient who is able to go back home after a stroke and is fully independent in his/her daily life saves taxpayers' money[8]. However recent estimates indicate that up to half of stroke survivors are left with long term residual disabilities and needs that can persist for many years following an acute stroke event. The appropriate solutions in a given setting will depend on local constraints and opportunities. Stroke survivors, their families and carers will play a major part in determining how needs are met. These needs will cross

---

[7] Royal College of Physicians Sentinel Stroke National Audit Programme (SSNAP)
[8] Kaste, A M. Palomäki, H. Sarna, S. Where and How Should Elderly Stroke Patients Be Treated? 1995

organisational boundaries in different ways and although a standardised delivery model of care may not be the goal in bringing about improvements, a regular review and needs based approach has been identified as a priority in the delivery of care and support for stroke survivors and their carers.

The Scale of Need in South East Coast

4. The Scale of Need in South East Coast

It is important to understand the relative incidence and prevalence of neurovascular disease. There are currently over 81,000 people in Kent, Surrey and Sussex registered with a GP as having had either a stroke or transient ischaemic attack, based upon 2013 QOF data.

People on Stroke/TIA register as a percentage of practice list size *Latest data from QOF 2013*

CCG	Sum of People on GP Stroke and Transient Ischaemic Attacks (TIA) Registers	Sum of practice List sizes	Prevalence
NHS ASHFORD CCG	2202	122614	1.80%
NHS BRIGHTON AND HOVE CCG	3815	300503	1.27%
NHS CANTERBURY AND COASTAL CCG	3990	214771	1.86%
NHS COASTAL WEST SUSSEX CCG	10710	491884	2.18%
NHS CRAWLEY CCG	1805	127278	1.42%
NHS DARTFORD, GRAVESHAM AND SWANLEY CCG	3890	250681	1.55%
NHS EAST SURREY CCG	2769	172367	1.61%
NHS EASTBOURNE, HAILSHAM AND SEAFORD CCG	4780	187058	2.56%
NHS GUILDFORD AND WAVERLEY CCG	3151	216037	1.46%
NHS HASTINGS AND ROTHER CCG	4483	183555	2.44%
NHS HIGH WEALD LEWES HAVENS CCG	3342	166603	2.01%
NHS HORSHAM AND MID SUSSEX CCG	4023	227353	1.77%
NHS MEDWAY CCG	3725	284552	1.31%
NHS NORTH WEST SURREY CCG	5333	353222	1.51%
NHS SOUTH KENT COAST CCG	4124	201092	2.05%
NHS SURREY DOWNS CCG	4924	293020	1.68%
NHS SURREY HEATH CCG	1412	91427	1.54%
NHS SWALE CCG	1527	107556	1.42%
NHS THANET CCG	2790	141762	1.97%
NHS WEST KENT CCG	8263	467773	1.77%
SOUTH EAST COAST (KENT SURREY & SUSSEX)	***81058***	***4601108***	***1.76%***
ENGLAND	***951469***	***56012096***	***1.70%***

The prevalence ranges from the lowest at 1.27% in Brighton Hove and highest at to 2.56% in Eastbourne, Hailsham and Seaford. Overall in South East Coast 1.76% of patients registered with a GP have had either a stroke or TIA.

Nationally there would appear to be a combined prevalence for post TIA and stroke of approximately 1.7% of the population registered with a GP. The population in South East Coast for 2013 is calculated as 4,601,108, as the number of people registered with a GP. This table does not show how many stroke survivors need ongoing community support nor does it provide a measure of unmet need. It is possible that this is an underestimation; some people may not be registered with a GP or may not have been entered on the register for various reasons. There are 6009 patients discharged annually who suffer a stroke in South East Coast[9]. With improvements in acute stroke care and an increasingly ageing population commissioners can expect the above figures for stroke survivors living in the region to gradually increase.

Section 11, Joint Commissioning and Planning, discusses how this information can be used by commissioners when planning the level of service to stroke survivors.

---

[9] Surrey 1885, Sussex 1828, Kent 2296; SUS data Patients Discharged 1/12/12 to 30/11/13 *Epsom data - patients discharged from November 2012 to October 2013 HES data.

Meeting the Need – Regular Reviews and Needs Assessment

5. Meeting the Need – Regular Reviews and Needs Assessment

The National Audit Office's report Progress in Improving Stroke Care[10] highlighted the contrast between improvements made in acute stroke care with poor quality of life after stroke care. This report made particular reference to review processes which showed significant national variation in practice and coverage of 6 month reviews for stroke survivors.

The 2011 CQC review of stroke services[11] found that most Primary Care Trusts had systems in place for reviews at six weeks, but that systems for reviews later in the pathway were not well developed. They noted that even where such systems are in place, it was not always clear who was responsible for ensuring that reviews took place. As of August 2014, across South East Coast there are no services in twelve of the twenty Clinical Commissioning Groups (Excludes NE Hants & Farnham). Where CCGs do have policies in place for six month reviews these tended to reflect good practice.

The CCG Outcomes Indicator Set for 2014/15 detailed a requirement for all stroke survivors to receive a follow up assessment between four and eight months after initial admission to hospital following a stroke. In response to this requirement the South East Coast Cardiovascular Strategic Clinical Network issued commissioning guidance and a service specification to support the commissioning of six month reviews[12]. It is hoped that CCGs will utilise this to ensure standardised, effective and best practice six month reviews are commissioned across South East Coast.

Quality Marker 14 in the National Stroke Strategy states that stroke survivors should have an annual health and social care check. This was endorsed by the National Audit Office in 2010[13]. Rehabilitation and the needs assessment process is a continuous process. Problems are initially identified, analysed, goals set, intervention agreed between provider and patient, intervention delivered and reassessment of impact made. This cycle may be repeated many times for different aspects of need, as existing problems are resolved, and new issues are identified.

The offer of an annual review is of particular importance to stroke survivors as it enables them to stay in contact with health and social care services. An analysis of the London Stroke Register (the largest data base of stroke survivors in the UK)[14] found that individual needs changed over time, particularly in relation to emotional wellbeing and physical activity.

---

[10] Department of Health Progress in improving stroke care. NAO 2010

[11] Care Quality Commission Supporting Life after Stroke review 2011

[12] South East Coast Strategic Clinical Networks 6 Month reviews commissioning pack http://secscn.nhs.uk/

[13] Department of Health Progress in Improving Stroke Care National Audit Office
29 January 2010

[14] Commissioning Support for London Life after Stroke: commissioning guide October 2010.

Regular reviews form the hallmark of a quality stroke service – Commissioning support for London

The Life after Stroke Task and Finish Group has summarised a needs driven support model for stroke survivors as a priority. It incorporates a six month and yearly reviews. Reviews do not, in themselves, meet the required need. Regular reviews offer an opportunity to assess needs and to support dialogue and planning as to how individuals' needs may be met. They also offer an opportunity to make wider assessments about service needs and gaps in provision across a particular geography.

Case Study - Information, Advice and Support and six month Review Service

This service commissioned from the Stroke Association provides a seamless support for both the stroke survivor and their family. A named coordinator will contact stroke survivors on discharge from hospital and offer information, advice and support. This includes navigation services available and signposting to organisations which can support the service user and their family.

At six months an appointment is made and the coordinator will visit the stroke survivor's home and undertake a six month review using the GM-SAT. From this, unmet needs are identified and appropriate referrals made. The GP receives a copy of the assessment
outcome and the data entry to SSNAP will be made.

Contact Sandra Field - ***Sandra.Field@stroke.org.uk***

Meeting the Need – Regular Reviews and Needs Assessment

Recommendations to CCGs and Commissioners

- **In line with national and recent guidance issued by the SEC CVD SCN all stroke survivors should be offered a comprehensive review at SIX months**
- **In addition and in line with national guidance all stroke survivors should be offered a comprehensive annual review**
- **In order to provide a responsive needs-based service, commissioners should ensure that a clear pathway is available for stroke survivors who wish to access a review at other times if change in their needs determines this**

Information and Signposting for Stroke Survivors and their Carers

6. Information and Signposting for Stroke Survivors and their Carers

The availability of information plays a crucial role in patients' recovery and long-term well-being; but many stroke survivors manage without adequate information. The consequences of not having information may be detrimental for the stroke survivor and costly to the health economy. Patients may not avail themselves of essential services, such as physiotherapy, occupational therapy or speech and language therapy. This may delay recovery, increase disability, lead to a loss of independence and self-esteem and reduced employment prospects. A lack of information may also result in unnecessary financial hardship where benefit entitlements are not claimed, which may place an additional burden upon carers.

If patients are not told how to prevent further stroke disease or why it is important to carry on taking their prescribed medicines, compliance may be compromised. Armed with timely information, survivors may manage their condition effectively and gain ownership of their treatment and health decisions.

The provision of information should not just be about handing out leaflets and information sheets but about engaging with people who have had a stroke, their families and carers. There will be a need for information in all forms of media whether paper or web based to be accessible to people with communication difficulties including aphasia[15].

The information that people need may change with time and will depend very much on their current needs and circumstances. Strategies and tools that actively involve stroke survivors and their carers in acquiring knowledge, has been shown not only to improve confidence but to have a positive effect on mood[16].

Signposting and Stroke Care Navigation

The provision of information to stroke survivors and their carers is closely linked to their needs and care so advice and information is ideally coordinated through a single point of contact for specialist stroke advice and signposting. Advice can be given either face to face, or over the telephone, according to which is best suited for the individual stroke survivor and/or carer. The Life after Stroke Group consider this role to sit with the 6 month and annual review team provided the reviewer had received adequate training as outlined in the South East Coast CVD SCN commissioning pack. It is recognised however that other models may be employed depending on the local circumstances. Some local authorities are employing people in the role of Stroke Care Navigator, trained to provide secondary prevention advice to stroke survivors and training for carers and care home staff (see Appendix 5).

---

[15] The Stoke Association Accessible Information Guidelines. Making Information Accessible for People with Aphasia. http://www.stroke.org.uk/

[16] Forster, A. Smith, J. Young, J. Knapp, P. House, A. Wright, J. The Cochrane Library, Issue 1. Information provision for stroke patients and their caregivers. (2003).

One solution to reduce the burden of an increasingly older population with long term health needs is by establishing successful networks and partnerships with the third sector, social care and user organisations[17]. By ensuring that the navigator works collaboratively between all sectors in health, social care and third sector care this will align with this model of care. By putting the stroke survivor at the centre it supports the principles of empowerment and citizenship. These concepts are discussed in more detail in section 8 *Empowering Stroke Survivors to Take Control*.

Specialist teams may be more important in the early stages of rehabilitation, while generic teams can be appropriate for the later stages. However, the configuration of community teams is less important than ensuring that these teams are multidisciplinary and all staff have the right specialist skills to help rehabilitate people who have had a stroke[18].

Case Study - Kent County Council – Care Navigators

The Care Navigator offers free and impartial advice aimed at people over 50 who may need extra support to remain independent in their own home. They will discuss individual needs and support to residents of Kent to find the best way forward, offering options. They provide support and help by making contact and referring to other professional organisations and agencies.

Support and advice includes:

- **Benefit awareness**
- **Care service provisions**
- **Home maintenance**
- **Housing choices**
- **Safety in the home**
- **Self assessments**
- **Adaptations and Equipment**
- **Help in planning individual support**

www.kent.gov.uk

Sources of Information

Professional staff seeing stroke survivors should know where to obtain information that supports the current need of the patient and their carer. This will include information on local health, social care, support groups and charities. In addition stroke survivors may need access to information on financial and vocational support.

Stroke survivors may be a good source of information to others. Their experience, having navigated their own way through health and social care systems may empower them to be

---

[17] House of Commons Health Committee Managing the Care of People with Long–Term Conditions, Second Report of Session 2014–15

[18] National Stroke Strategy 2007 QM10

experts in this process. Locally there will be many groups that can facilitate advice, support and information for stroke survivors and their carers. Often stroke survivors cite the lack of easy access to a one stop source of information as a barrier to them gaining access to services in a timely manner. Commissioner web sites are ideally placed to provide this service and direct stroke survivors to the range of directories and information sites available to stroke survivors (see Appendix 1).The voluntary sector is a rich source of information on many aspects of life after stroke and may act as a source of specialist information and support, e.g. living with aphasia[19].

Case Study CSH Surrey – *My Personal Plan Following My Stroke*

In partnership with Epsom and St Helier University Trust and Surrey County Council, CSH Surrey's specialist neuro-rehabilitation service provides a range of information for stroke survivors in the form of a personal stroke record with information about the details of the individual's stroke and signposting to local stroke services. Included is details about a series of monthly life after stroke group meetings for people registered with a mid-Surrey GPs. ***my personal plan holds*** **6 week and 6 month review information and contact details.**

Contact: Fiona Mooney Clinical Manager, Community Integrated Teams and Rehabilitation Services, Professional Lead for Physiotherapy. CSH Surrey

Case Study - *In-Reach into hospitals in Kent, Surrey and Sussex*

The Stroke Association provides monthly in-reach services to the majority of hospitals across Kent, Surrey and Sussex. Set up initially by a Stroke Association member of staff, then run by trained volunteers, this provides current information to relatives, stroke survivors, visitors and staff. Based, in most cases, in the hospital entrance, information about stroke and what is available locally is displayed with the opportunity for questions to be answered and further information sent on to those requiring ***it.***

Contact Sandra Field **-** ***Sandra.Field@stroke.org.uk***

---

[19] http://dyscover.org.uk/

For stroke survivors who have financial issues, the Direct.gov.uk website may be may be used to access information on benefits including incapacity, disability and mobility allowances can be found.

More information on the various sources of information can be found in the appendices to this document.

Sharing Information

In order to provide continuity of care commissioners and providers of reviews will need to agree arrangements for patient information to be shared between providers to facilitate a seamless pathway of care and this will be essential in ensuring that all patients who are eligible are able to access a review. The service providers of reviews will require discharge information from the last service to support the patient – whether that is acute, Early Supported Discharge (ESD) or community rehabilitation. At each stage of the process the patient should be fully informed and it is good practice to copy stroke survivors or their carers where appropriate, into correspondence so that they are fully informed about what has happened and what has previously been agreed.

Whilst this guidance concentrates on the longer term needs of stroke survivors, a lack of provision of information in the early stages of recovery, possibly following early discharge from an acute setting, may inevitably have consequences for patients in the longer term. Consideration about patient information needs should therefore be given to every stage of the pathway and commissioners should consider a whole pathway approach whilst considering the specific long term information needs of stroke survivors.

The Provision of Information and Signposting Recommendations to CCGs and Commissioners

- **A whole pathway approach is recommended**
- **Commissioners should ensure that health and social care professionals know where to access information on local services**
- **Commissioners are encouraged to compile or commission a directory of services that can be made available to professionals and stroke survivors, their families and carers.**
- **Commissioners should work with the voluntary sector where specialist sources of information may be obtained**
- **Information should be shared across the entire team and with the stroke survivor and their carers.**
- **Commissioners should support the stroke care ''Navigator Role'' as a valuable resource for stroke survivors and carers**

Emotional Support

7. Emotional Support

Psychological Care

As many as 40% of stroke survivors experience a degree of cognitive loss, behavioural problems or disorder of mood, with as many as a third experiencing a severe depressive illness after stroke. Meeting these needs will bring benefits not only to people with stroke and their carers, but evidence suggests that financial sustainability of services can be achieved. The Cardiovascular Disease Outcomes Strategy 2013 sets out the importance of emotional and psychological support in improving patient experience and outcomes, and suggests that commissioners will want to pay particular attention to this area in developing their future arrangements for long term support of those with CVD and their carers.

Mental health issues can cause enormous personal, social and economic cost. In their 2010 report on the Economic and Social Costs of Mental Health Problems, the Centre for Mental Health estimated that in economic terms the cost to the economy is around £105 billion annually[20]. The National Institute for Health and Clinical Excellence (NICE) recommends that psychological therapies be made available on the NHS as first-line interventions for a number of conditions. NICE guidance sets the standards for high-quality healthcare and encourages healthy living. NICE guidance can be used by the NHS, Local Authorities, employers, voluntary groups and anyone else involved in delivering care or promoting well-being[21].

While the economic cost of supporting unaddressed mental health needs is high, there is also evidence to support the argument that investment in mental health services, and psychological therapies in particular, can lead to significant economic savings[22][23] [24].

> ***‘’Between £8 billion and £13 billion of NHS spending in England is attributable to the consequences of co-morbid mental health problems among people with long-term conditions.’’***
>
> **Improving workforce planning for the psychological therapies workforce, a review 2013. www.cfwi.org.uk**

---

[20] Centre for Mental Health The Economic and Social Costs of Mental Health Problems in 2009/10

[21] NICE (2011). *Common Mental Health Disorders: Identification and Pathways to Care*. Clinical Guideline 123. London, UK: National Institute for Health and Clinical Excellence. Available at www.nice.org.uk.

[22] The Depression Report: A New Deal for Depression and Anxiety Disorders (LSE, 2006)

[23] We Need to Talk MIND, 2010

[24] How Mental Illness Loses Out in the NHS LSE, 2012

There is a range of evidence to demonstrate the importance of emotional and psychological support throughout the care pathway, but particularly for those with long term care needs, for example:

- health care costs for patients with long term conditions who also have depression are typically 45% higher than for non-depressed patients;
- depressive symptoms are associated with significantly higher cardiac and non-cardiac NHS service utilisation following heart attacks; and
- NHS Improvement work on stroke has shown the cost-effectiveness of psychological care – see economic model below[25].

Economic Model for Impact of Psychological Care for People Who Have Had a Stroke

Stroke services which incorporate psychological care according to national clinical standards and NICE guidance deliver best outcomes for people who have had a stroke. A stroke service where psychological care is led by a clinical psychologist using a stepped approach is cost effective, with savings to the NHS recovered in around two years. Equally, there are anticipated economic benefits to social care which are more difficult to establish with the current available evidence but which are expected to be of a similar magnitude. This modelling demonstrates that an investment of around £64,000 in a clinical psychologist led service for psychological care, which includes multidisciplinary team training and clinical psychology assistant support could reap financial benefits of around £108,300 to the NHS and social care in around two years and around £126,000 in two to three years.

The outcomes of such service for patients should also be positive and well beyond those expected in terms of the criteria set by the National Institute for Health and Clinical Excellence (NICE) – yielding a ten-fold benefit measured in terms of 'Quality Adjusted Life Years'. To deliver these benefits the stroke service needs to operate within the National Stroke Strategy recommendations and the evidence based national guidance; that patients are routinely screened for mood and cognition several times after their stroke, that acute and community and social care services are well integrated, with access to six week and six month reviews, and a stepped approach to psychological care is used.

Box 8 of the Cardiovascular Disease Outcomes Strategy

Improving Outcomes for People with or at Risk of Cardiovascular Disease. 2013

---

[25] Department of Health Cardiovascular Disease Outcomes Strategy Improving Outcomes for People With or at Risk of Cardiovascular Disease. 2013

"If local NHS commissioners want to improve their budgets, they should all be expanding their provision of psychological therapy. It will save them so much on their physical healthcare budgets that the net cost will be little or nothing."
Professor Lord Layard (2012).

Improving Access to Psychological Therapies (IAPT)

The Improving Access to Psychological Therapies (IAPT) programme pilot was established following the 2007 Comprehensive Spending Review to support the NHS in delivering NICE approved clinical interventions to people with depression and anxiety disorders. Its purpose is to offer patients a realistic and routine first-line treatment, combined where appropriate with medication which traditionally had been the only treatment available[26]. Additionally, the idea is to help people to return to (or stay in) employment who might otherwise have been prevented from doing so by readily treatable conditions.

The IAPT programme supports the frontline NHS in implementing National NICE guidelines for people suffering from depression and anxiety disorders.

CCGs are important local leaders in the NHS specifying how psychological therapies and other services should be delivered and promoting health and wellbeing through strong partnerships with professionals, local government, employment services, people who use services and those who support them.

The IAPT programme gives commissioners a good opportunity to collaborate with providers from all sectors and find genuinely innovative ways of meeting local people's common mental health needs and the routine collection of outcomes data ensures they can demonstrate progress quickly and clearly.

A stepped approach to psychological care is recommended by NICE guidelines for people suffering from depression and anxiety disorders. The IAPT programme stepped care model aims to offer patients psychological care in a hierarchical approach, offering simpler interventions first and progressing on to more complex interventions if required. However, not all patients will progress through the system in a sequential manner. Over the course of their recovery, patients may move in and out of this system several times and at different levels and commissioners and providers should consider how access to therapies for patients with particular disabilities such as aphasia and other communication problems can be improved. This approach makes best use of the skills of the multi-disciplinary team and utilises more specialist staff for the patients with complex problems that require this

---

[26] http://www.iapt.nhs.uk/about-iapt/

level of help[27]. Having a clinical psychologist as an essential member of the stroke team supports education and support for the team to provide psychological care for patients as well as working directly with the patient and families. Psychological care should be part of the care culture for stroke patients. Establishing routine psychosocial education groups for stroke survivors and carers can provide very effective psychological support[28].

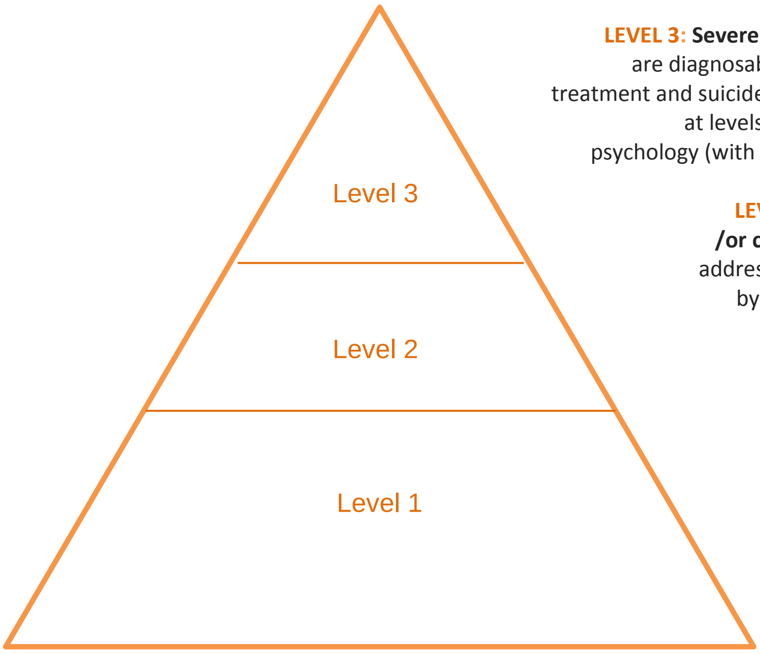
The Stepped Care Model for Stroke (Gillam & Clarke, 2011)

Tier/Step 1: All stroke survivors screened within 6 weeks of diagnosis, with a validated tool, to identify mood disturbance. 'Sub- clinical problems' are common after stroke; support can be provided by peers, and general stroke staff.

Tier/Step 2: survivors with Mild/Moderate problems with mood that interfere with rehabilitation/living offered further assessment (past history, potential causes and impact, and treatment preferences). These problems addressed by trained non-psychology stroke staff, supervised by a psychologist with expertise in stroke.

Tier/Step 3: survivors with severe or persistent disorders of mood that are resistant to treatment at levels 1 and 2 may require specialised assessment, intervention and medication. These require the intervention of a psychology specialist and/or psychiatry.

A Stepped Care Model for Psychological Interventions after Stroke[29]



LEVEL 3: Severe and persistent disorders of mood and/or cognition that are diagnosable and require specialised intervention, pharmacological treatment and suicide risk assessment and have proved resistant to treatment at levels 1 and 2. These would require the intervention of clinical psychology (with specialist expertise in stroke) or neuropsychology and/or psychiatry.

LEVEL 2: Mild/Moderate symptoms of impaired mood and /or cognition that interfere with rehabilitation. These may be addressed by non-psychology stroke specialist staff, supervised by clinical psychologists (with special expertise in stroke) or neuropsychologists.

LEVEL 1: 'Sub-threshold problems' at a level common to many or most people with stroke. General difficulties coping and perceived consequences for the person's lifestyle and identity. Mild and transitory symptoms of mood and/or cognitive disorders such as a fatalistic attitude to the outcome of stroke, and which have little impact on engagement in rehabilitation. Support could be provided by peers, and general stroke staff.

---

[27] Connect: The Communication Disability Network, Impacts and Effects: Information about what it is like to live with aphasia, https://www.ukconnect.org/impacts-and-effects-of-aphasia.aspx

[28] Improving Access to Psychological Care After Stroke. NHS Improvement- Stroke, January 2012 http://www.improvement.nhs.uk/stroke

[29] Psychological Care After Stroke: Improving Stroke Services for People With Cognitive and Mood Disorders. Publication Ref: IMP/comms022 - August 2011. www.improvement.nhs.uk/stroke

Peer Support and Information

There may also be a need to focus on non-clinical support for emotion and mood. After a 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 standalone 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).

The Royal College of Physicians recommend that commissioners should ensure that between health and social services there are sufficient peer-support programmes available to enhance and maintain the wellbeing of stroke survivors[30]. Where there is an identified gap, commissioners should investigate the possibility of establishing this kind of support.

The majority of long-term stroke survivors with emotional needs report that they do not receive adequate help to deal with them *(Intercollegiate Stroke Working Party, "National Clinical Guidelines for Stroke," Royal College of Physicians, London, 2012.)*

Case Study - Aphasia Cafes

In East Sussex support for people with aphasia following a stroke is provided through a network of Aphasia Cafes. The service is commissioned by the Local Authority and the CCGs and a Coordinator receives referrals from professionals and also self-referrals. A network of cafes where stroke survivors can receive support both from the Coordinator and from others survivors in the form of Peer support have been set up across the county.

The groups meet in cafes which have agreed to support the meetings when approached. It gives those attending the opportunity to undertake communication in a safe supportive environment which is also part of the community, rather than in venues where they do not interact with the public. It means they can buy their own drinks, have the conversations they want to with their peers, as well as developing their expertise in using ramps which facilitate and increase their communication skills. The gatherings last for one and a half hours, but people may come and go as they wish. This has enabled people of all abilities to participate, where ever they are in their communication journey. It has also enabled people to meet locally near to where they live with the coordinator setting up the cafes where there are two to three people as a minimum. Those attending are therefore not tired out or stressed by the need to travel.
This has had a knock on effect by the staff of the cafes increasing their understanding of communication skills with people with aphasia.

Contact Sandra Field - Sandra.Field@stroke.org.uk

---

[30] Royal College of Physicians. Commissioning Concise Guide for Stroke Services 2012

Parity of Esteem Between Physical and Mental Health

No Health Without Mental Health[31], the Government's strategy paper for mental health, makes a commitment to 'parity of esteem between mental and physical health services' and pledges significant investment in psychological therapies.

Stroke brings with it a wide range of psychological issues including emotional and intimacy problems, clinical depression, low mood, apathy and issues with controlling anger and aggression. Cognitive and communication problems such as aphasia make assessment and treatment challenging and often mask mental health problems that can go undiagnosed for months or years. Left untreated these issues impact on the survivors and their family and carers. Survivors are often unable to engage with rehabilitation due to mental health issues which leaves them dependent on others.

Across Surrey, Sussex and Kent there is recognition that physical and mental health issues should carry equal status. Quality of life after stroke is not only influenced by physical impairment but by an individual's mental and emotional state which can in turn have an impact on their physical health. Around a third of stroke survivors will suffer from depression and this figure may be as high as 61%[32]. There are a variety of consequences of stroke, such as functional impairments or disability that greatly increase the risk of depression among stroke survivors.

People with poor physical health are at higher risk of experiencing mental health problems.

Diabetes	***Hypertension***	***Stroke***	***Cancer***
27%	***29%***	***31%***	***33%***

Percentage of people affected by depression with various illnesses. NHS England. http://www.england.nhs.uk/ourwork/qual-clin-lead/pe/

Parity of esteem is defined as 'making sure that we are just as focused on improving mental as well as physical health and that patients with mental health problems don't suffer inequalities, either because of the mental health problem itself or because they then don't get the best care for their physical health problems'(*Source: NHS England, 'Everyone Counts: Planning for Patients 2013/14'.)*

In order to meet this objective, South East Coast SCNs have been working with CCGs, the public and providers. At a recent conference Valuing Mental Health: A Change of

---

[31] No health without mental health Department of Health 2011

[32] IAPTS Long-term Conditions Positive Practice Guide Department of Health 2008

Perspective in Kent, Surrey and Sussex, delegates discussed the key principles for commissioning mental health services (Appendix 3).

Emotional Support
Recommendations to CCGs and Commissioners

- **All stroke survivors should have access to a comprehensive emotional review and treatment and support regime**
- **Stroke services which incorporate psychological care according to national clinical standards and NICE guidance deliver best outcomes for people who have had a stroke.**
- **A stroke service where psychological care is led by a clinical psychologist using a stepped approach is cost effective, with savings to the NHS recovered in around two years. These considerations should shape psychological commissioning for stroke services**
- **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**
- **Commissioners should evaluate whether there are sufficient and appropriate peer support opportunities for stroke survivors**

Empowering Stroke Survivors to Take Control

8. Empowering Stroke Survivors to Take Control

The House of Care Model

The House of Care model encompasses all people with long-term conditions, not just those with a single disease or in high-risk groups and it assumes an active role for patients, with collaborative personalised care planning at the heart of this approach. Implementing the model requires health care professionals to abandon traditional ways of thinking and behaving, where they see themselves as the primary decision-makers and instead shift to a partnership model in which patients play an active part in determining their own care and support needs[33].

Personalised care planning is at the centre of the House of Care. This is a collaborative process designed to bring together the perspectives and expertise of both the individual and the professional(s) involved in providing care, offering tailored personal support to develop the confidence and competence needed for effective self-management. A growing body of evidence highlights the importance of effective self-management of long-term conditions[34].

Enhancing the Quality of Life for People Living With Long Term Conditions – The House of Care NHS England[35]

The foundations for the House of Care are commissioning enablers. Planning, securing and monitoring investment on behalf of the individual and population to secure the best

---

[33] The Kings Fund Delivering better services for people with long-term conditions Building the house of care. Coulter, A. Roberts, S. Dixon, A. October 2013
[34] Epping-Jordan et al Improving the Quality of Health Care for Chronic Conditions 2004
[35] http://www.england.nhs.uk/house-of-care/

possible outcomes. The House of Care takes a whole system approach to long term conditions such as those experienced by stroke survivors. It makes the person central to care. It is about aligning levers, drivers, evidence and assets to enhance the quality of life for people with long term conditions no matter what or how many conditions they have.

Stroke Survivors on average spend only a few hours each year with a health care professional. For the majority of the time they look after themselves, sometimes with the support of carers. Traditional practice styles create dependency and discourage self-management but by placing stroke survivors at the centre of their health and social care experience it helps them to be better informed about their health condition. They become 'co-designer' of their care plan and collect and share information about their condition. In planning their own care they become informed from the outset and help set their own goals, and agree their own care plan.

Case Study - *Encouraging Self-management - Sussex Community Trust Befriending Scheme for People with Stroke and Aphasia*

Speech and language therapy teams are under considerable pressure to discharge patients from their case load after 4 months. This leaves many people with aphasia isolated at home. Training and supporting people with aphasia to befriend other people is an efficient way of tapping in to a highly skilled workforce. Their experience as 'experts' in living with stroke and aphasia along training in Befriending is the focus of an innovative befriending service developed by the trust.

Ten Befrienders were initially trained by Connect, the communication disability network. Healthcare staff were also mentored by Connect and given a comprehensive resource pack produced by Connect (www.ukconnect.org/developmentpackages.aspx) in how to set up and run the scheme. Ongoing support for those running the scheme is also available from Connect if needed. Those running the scheme are now able to train further befrienders and support those volunteers at support groups which are held every six weeks. Referrals are made from the local area and befrienders are then matched to befriendees. Each befriender visits between 1-2 befriendees.

The befrienders have recently set up a peer led 'Drop in' group for people with aphasia in Hove. It currently has 30 members and is growing.

Contact: Kirsty Maguire Sussex Community NHS Trust

"My befriender saved my life. I was doing nothing. I couldn't see a future. I can now"
"You have helped me get my best friend back. Thank you" (carer of person with aphasia)

Harnessing Technology to Give Patients Control

The provision of information has been emphasised throughout this guide and is key to giving people empowerment by allowing then to understand about their condition and the options available to them. Technology has in many areas of daily life enabled people to take control of their own interests from banking, through the convenience of online shopping to knowing when the next bus will arrive in real time. Patients, through access to online information are now more informed than ever and professionals have used this to support the provision of information and access to personal health records and information. Providing patients access to their online records by 2015 is a specific commitments in the government's NHS information strategy[36]. There are now a number of different technologies that are helping people to check and monitor their own health as well as access care resources with little effort and cost. The South London and Maudsley NHS Trust have since 2012 provided an online tool called myhealthlocker. This allows patients to have control over their health information. It enables them to access care plans, keep track of how they are feeling, access resources and tips on staying well and manage their health and wellbeing[37].

In future the government has committed to expanding a set of NHS accredited health apps that patients will be able to use to organise and manage their own health and care; and the development of partnerships with the voluntary sector and industry to support digital inclusion[38].

Case Study

My Stroke Guide

The Stroke Association is building a digital self-management tool to support people in their recovery following a stroke.

My Stroke Guide has been designed by stroke survivors and carers. My Stroke Guide will help stroke survivors with self-management after a stroke, enabling them to monitor and improve their own health and well-being, as well as support others to do the same.

The personalised care that My Stroke Guide offers will mean users receive the right information, at the right time, in the right format for them. All of this information will be streamlined so that it is relevant to the user, their stroke, their local area and their support network. My Stroke Guide can also act as a communication channel between user, carer, health care professional and community.

My Stroke Guide is currently being piloted. For more information contact; Kristina Barrack Stroke Association

---

[36] Department of Health. The Power of Information: Putting all of Us in Control of the Health and Care Information We Need 21 may 2012.

[37] www.myhealthlockerlondon.nhs.uk

[38] NHS five year forward view. Chapter 4. October 2014

Telecare

Interest in telecare is driven by a number of factors including concerns about how public services are going to meet the needs and expectations of an ageing population and how health and social care resources can be used most effectively to enhance Independent living in the community. Remote monitoring devices can be a cost effective solution to helping people remain safe and independent in their own homes. Telecare is intended for use by disabled or vulnerable people of all ages, as well as those with long term conditions. Telecare can work in one of two ways:

- Linked Equipment which can generate an alert when there is a problem and help is required and
- Stand Alone Equipment such as easy to read clocks, pill dispensers and calendars which can help with everyday tasks.

Case Study - Telecare

A woman aged 70 lives alone. TWO years ago following a stroke, a fall detector was added to her Lifeline to manage her daily living risks. The control centre is automatically alerted when she has a drop attack' without warning. A private care provider visits both am and pm daily. She also has a close friend who walks her dog and does her shopping.
Telecare equipment used: Lifeline 400 home unit with a pendant Fall Detector

Partnership working: Warden Service, Private provider, care agency, Friend

Performance: The Telecare enhanced package of care has enabled this lady to continue living safely and independently at home delaying the need and expense for residential care at the point of discharge.

Efficiencies: The Telecare has enabled this lady to remain in her home removing the need to be moved to residential care, saving £410 per week (£21k per annum).

Outcomes: She has been enabled to will continue to live independently in her own home with the support of the Lifeline and warden service.

Contact: Angela Yphantides Angela.Yphantides@eastsussex.gov.uk

Personal Health and Social Care Budgets

Personal Health Budgets have been introduced by the NHS to help people manage their care in a way that suits them. They have been piloted in a number of areas across England and from April 2014, anyone receiving NHS continuing healthcare will have a right to ask for a personal health budget. The 'right to ask' will become a 'right to have' from October 2014.

Personal health budgets work in a similar way to the personal budgets that many people are already using to manage and pay for their social care. In many areas, local authorities are offering carers and people who need care the option to decide what care services they receive. These options support people and their carers by giving them flexibility, choice and control of the social care funding available. The options include direct payments, personal budgets and individual budgets. This allows eligible people to design their own care plan for the year based on the amount of money allocated to them. A personal health budget is an amount of money to support identified health and wellbeing needs, planned and agreed between the patient and local NHS team. The aim is to give people with long-term conditions and disabilities greater choice and control over the healthcare and support they receive. The NHS Five Year Forward View[39] further supports this approach with the introduction of integrated personal commissioning (IPC). IPC will provide an integrated, "year of care" budget that will be managed by people themselves or on their behalf by councils, the NHS or a voluntary organisation.

Empowering Stroke Survivors to Take Control Recommendations to CCGs and Commissioners

- **Stroke survivors, carers and health and social care professionals should be fully informed 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 recognise and encourage technological initiatives that support stroke survivors**

---

[39] NHS Five Year Forward Review. P14, October 2014

Supporting Carers and Families

9. Supporting Carers and Families

Education and Support for Carers and Families in Stroke

There are 6.5 million carers in the UK. This unpaid care is estimated to be worth £119 billion with 45% of carers known to have given up work to care. As many as 61% have faced depression as a result of the caring role and worry about the person they are caring for and 49% are estimated to be struggling financially (information from Carers UK). Carers are entitled to receive a carers allowance and may also be entitled to other benefits from the Government and some may be entitled to council tax rebates. The benefits system is complicated and claiming can be frustrating and time consuming. Carers often report emotional distress and feel undervalued in their role[40]. Commissioners should ensure that carers have access to the help and support they need. Carers of stroke survivors should be provided with a named point of contact for stroke information (Stroke Navigator role), written information about the patient's diagnosis and management plan, and sufficient practical training to enable them to provide care[41]. Many carers may be older and may have health and social care issues of their own. Carers should be integral to the review process and should be offered a review of their own need and get support identified as necessary. Voluntary sector organisations are a good source of information and offer services specifically to support families and carers of stroke survivors (Appendix 1). The Stroke Association offers a carer support service. Stroke Care Coordinators offer a home visiting service that helps everyone in the stroke survivor's household to understand the physical, cognitive and psychological effects of stroke. The stroke Care Coordinator provides practical advice about caring at home and information about groups and local services.

---

[40] Greenwood, N. Mackenzie, A. Cloud, G. C. & Wilson, N. Informal Primary Carers of Stroke Survivors Living at Home – Challenges, Satisfactions and Coping: A Systematic Review of Qualitative Studies. Disability and Rehabilitation, 31(5): 337-351. 2009

[41] NICE Quality Standards [QS2] Quality Statement 11: Carer Provisions June 2010

Case Study

Stroke Specialist Nurse Kent

I do have a patient that I see every 2 to 3 months and have been seeing him for the last 6 years since his stroke. His wife is caring for him at home and has had problems adjusting to a new life, one that they did not envisage – he had his stroke at 55 and lost his job. Despite lots of input from other services, she feels that she needs my support on a regular basis, and so I provide it. She wants to look after her husband at home but declines practical help, because she likes the freedom to be able to take him out as and when he is well enough. Unfortunately because she has no family or friends to off load her frustrations she tells me. Both my patient and his wife have been referred to psychology and have been discharged, and I feel that she needs my service as I am the one that has seen him from the beginning and I know their journey the best. I don't think she will ever come to terms with what has happened and despite counselling and support; she needs to know that I am interested and empathetic of their situation.

Case Study

Sussex Community Trust – Carers Health Team

Working directly with carers in West Sussex, the Carers Health Team promotes the importance of health and wellbeing. The team provides health screening and where appropriate access to NHS health checks is available for all. Individual strategies are developed for each carer with an aim to reduce the strain of coping with their caring role. The carer wellbeing clinicians will work in partnership with carers to provide personalised one to one advice and information. This could include:

- **Practical advice and training to help in the caring role, such as safe moving and handling techniques and managing medication.**

- **Information and advice on other services to help care for loved ones and lead a healthier lifestyle.**

- **Advice and information to help plan for the future and guide the carer through the complex health and social care system.**

www.sussexcommunity.nhs.uk/Downloads/service

Case Study –
Kent County Council Carer Assessment and Support Services

During Carers' Week (9 to 16 June 2014), Kent County Council launched a new information booklet for the more than 150,000 people who care for relatives and friends in Kent. Kent County Council and NHS commissioners have invested in new carer assessment and support services. In the first year (2013/4), 3563 new carers have been identified and 1070 of those have been assessed to see what services they can access.

These include:

- **Free Caring with Confidence courses to help carers identify their strengths, look after their health and well-being, develop coping strategies, and, by sharing ideas with others, help make a positive difference to your life and that of the person you care for.**
- **Health checks**
- **Something for me payments which allows a carer to pay for something which would make their life easier. In the past year, 937 carers have received these payments.**
- **Short Breaks which offer respite care for the person who is being cared for, whether to go on holiday, visit loved ones or just to take a break from caring.**

The new booklet has important information about support, assessment, health checks, financial and legal advice, employment rights, and important contacts for carers.

www.kent.gov.uk

Stroke Education for Providers of Adult Care Such as Residential and Nursing Homes

Between 5% and 15% of stroke survivors that are discharged from acute and rehabilitation care are transferred into residential or nursing home care[42]. Those residing in institutional care should also receive or be offered reviews. In addition, staff working in these homes

---

[42] Royal College of Physicians Intercollegiate Stroke Working Party. National clinical guideline for stroke, 3rd edition 2008.

should be trained to be familiar with the common clinical features of stroke and the management of common impairment and activity limitations, e.g. Aphasia. This population of stroke survivors may be older and frail and vulnerable to being excluded from access to quality stroke and social care services. Some specialist residential and nursing homes have recruited clinical staff that specialise in many long term conditions including stroke and commissioners should organise services to ensure that stroke survivors in residential care receive the care that they need.

Case Study – Training for Residential Care Staff

The Stroke Association training courses have been awarded Skills for Care Innovation Grants to provide residential care home staff with stroke specific training. This has allowed them to expand the training they can offer. As a result of the funding, the training team have created bespoke QCF Level 2 in Stroke Awareness and Level 3 in Stroke Care Management - and have become an accredited provider of these courses by NCFE. These courses link directly to the National Stroke Strategy and Stroke Specific Education Framework (SSEF).

www.stroke.org.uk

Supporting Carers and Families
Recommendations to CCGs and Commissioners

- **Stroke education, along with advice and support should be provided for residential and unpaid carers**
- **Carers should also have their needs assessed at regular intervals by social services or health**
- **Carers should be provided with clear guidance, via the stroke Navigator, 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**

Promoting Independence - Helping Stroke Survivors to Get Involved in Community Life

10. Promoting Independence - Helping Stroke Survivors to Get Involved in Community Life

Five years after a stroke, a third of people are likely to remain severely or moderately disabled[43]. Loss of confidence is a common problem after a stroke which compounded with reduced mobility, problems using public transport and being unable to drive can make getting out of the house a challenge for many[44]. For stroke survivors to be able to return to a community and take a place in society they need to be able to get out and about as independently as possible.

Community Groups and Peer Led Services

Stroke survivors are experts in life after stroke, their experience in living with stroke, the issues the condition presents and navigating the health and social care system puts them in a unique position to provide support for other stroke survivors. In a time where finances must deliver maximum benefit, commissioners should look at new ways of using resources effectively to build capacity into services in innovative ways. This may include peer support initiatives and professionally supported self-care schemes that have been shown to be potentially cost effective and may reduce GP and outpatient visits[45]. Community based exercise and education schemes for stroke survivors have been shown to improve physical integration and psychological wellbeing. There are many good practice examples of these schemes operating in the South East Coast region.

Case Study - Stroke Association - Exercise and Education Programme

This service, which is jointly funded by the Local Authority and CCGs, provides, in conjunction with the Stroke Association and the local leisure centres, a 10 week programme of exercise and education offering chair-based and circuit work. All trainers have undertaken the stroke-specific 'later life' training.

Following on from the 10 week course there is the option for participants to join a weekly group that continues with exercise. This increasing group of people have moved on, in some cases, to using full gym equipment.

Contact Sandra Field - **Sandra.Field@stroke.org.uk**

---

[43] Royal College of Physicians Intercollegiate Stroke Working Party 2012

[44] Barnsley, L., McCluskey, M., Middleton, S. What people say about travelling outdoors after their stroke: A qualitative study. Australian Occupational Therapy Journal 2012.

[45] The Wanless Report. Securing Our Future Health: Taking a Long-Term View. 2002

Case Study – The Phoenix Stroke Club

The Phoenix Stroke Club is run for its members and aims to be the first choice social club for people who have suffered a stroke or other neurological disorder in and around Horsham, West Sussex. The Club organises activities that aim to restore its member's confidence which has usually been shattered by their illness thereby assisting their social and speech rehabilitation. The Club provides a stimulating environment where Members can receive specialised physical and mental exercise including interaction with others.

In contrast to other day care centres and respite clubs for the elderly and infirm, the Phoenix Stroke Club specifically caters for people with disabilities arising from a neurological disorder.

The Club is affiliated to the nationally organised Stroke Association.

Members continually express their appreciation for the efforts of the Manager and her volunteers.

Vocational Therapy and Returning to Work or Volunteering

Many stroke survivors will experience social exclusion and low self-esteem. They may want and need to have productive roles within their community. People living with the effects of stroke frequently find it difficult to go back to work or venture into volunteer roles for a number of reasons, including low confidence and motivation, difficulties adapting to environments, skills deficits and fear of stigma. There is substantial national and international evidence identifying the importance of vocational interventions leading to productive roles for people living with stroke.

The National Stroke Strategy (2007) and NICE guidelines for stroke rehabilitation (2013) state that stroke survivors should have access to vocational rehabilitation services, enabling them to participate in paid, supported or voluntary employment. Not everybody can access this type of service. Where it is provided, it may not be organised in a way that maximises survivors' opportunities to work with their existing employers[46]. Survivors are often discharged from hospital without advice about work, and those with severe disability may be overlooked by health professionals who may assume returning to work means returning to the same job with the same responsibilities[47]. A different role with different responsibilities can be negotiated with an existing employer, provided that the employer's door is kept open so that all options can be explored.

---

[46] Playford et al, Mapping Vocational Rehabilitation Services for people with Long term neurological conditions: Summary report. Department of Health. March 2011. 2011

[47] Coole, C. Radford, K. Grant, M. Terry, J. Returning to Work After Stroke: Perspectives of Employer Stakeholders, a Qualitative Study 2012

Occupational therapy and vocational programmes focus on supporting stroke survivors to get back into work or into unpaid voluntary activities and tend to have a highly individualised approach to the client particular needs. Ensuring stroke survivors have the opportunity to work is the responsibility of the whole health and social care team. Without timely referral for support to keep the stoke survivor in their existing job and to enable then to make informed choices about work, their options may be greatly reduced. Vocational rehabilitation needs to start at the point of stroke and continue into the community and beyond[48].

Effective rehabilitation enabling return to work typically results in psychological benefits, including improved self-esteem and mood. However the tangible benefits are seen with reduced levels of social care and welfare subsidies, as well as increased central revenue through earnings. Currently there is no consistent approach to commissioning services within in a stroke pathway in the NHS. The RCP has suggested that this presents a clear case for joint health and social care commissioning[49].

Case Study – Supported Volunteering Esher, Surrey.

The ASPIRE project is designed to help and support anyone who faces challenges in their life into voluntary work.

A dedicated support worker works with the potential volunteer in a non-judgemental and supportive manner. They can provide support with attending interviews, helping with journey planning and accompany client's onsite in the early days of volunteering and can bring structure and routine to a person's life. The volunteer will feel part of a team, will gain confidence and improve their self-esteem.

There is a vast and diverse choice ranging from dog walking, helping at retirement centres, gardening to shop work.

eamonn@vae.org.uk

Transport

Many stroke survivors have great difficulty in travelling outside of the home. Some community transport services are provided in partnership with local authorities in South East Coast while others are independently run by organisation such as Age Concern and the Stroke Association. Some peer led services and stroke clubs can also organise transport for stroke survivors. The provision of information about transport services to

---

[48] Promoting rehabilitation for stroke survivors Nursing times vol. 108 no 47/ 20.11.12

[49] Commissioning volume1 issue 4 2014 Commissioning Stroke Services Royal College of Physicians

enable people to know how to access them is one issue stroke survivors commonly raise, another is gaining the confidence to use public transport.

Case Study

Stroke Association Sutton – Help with Using Public Transport

The Stroke Association Sutton has received a local Authority funding for a 3 year project to support an exercise programme, utilising a local gym and fitness centre. Stroke survivors are referred by the rehabilitation centre at St Helier Hospital. When the fitness centre were no longer able to support the project, self-help groups were set up and the association is recruiting a stroke support coordinator to support this initiative. Stroke association volunteers are now helping people with hobbies they had previously been unable to continue due to stroke. Stroke survivors have gained the confidence and independence to go out of their home, resume some pre stroke activities and to use public transport, sometimes with the support of other stroke survivors.

Contact - Jane Turner Assistant Manager – London.

Contact Jane.turner@stroke.org.uk

Stroke survivors often 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, a referral to occupational therapy to address lack of confidence and issues such as cognitive difficulties, balance and falls should be considered. An individualised occupational therapy programme incorporating strategies to build confidence and increase use of public transport may help stroke survivors regain their confidence, and leave the house on a more regular basis. Carers, families, other stroke survivors and peer support groups also have a crucial role to play as they too can help build confidence and should be encouraged to do so.

Driving

There are risks associated with driving after stroke, and the DVLA has criteria for people with impairments post stroke in order to regain their licences[50]. Health and social care professionals, the Stroke Navigator and the voluntary sector should be able to advise how and where to obtain local information on this and refer stroke survivors to organisations that can help them to apply or reapply for their driving licences. Some organisations can provide driving assessments or training where adaptations have been made to the stroke

---

[50] https://www.gov.uk/driving-medical-conditions/telling-dvla-about-a-medical-condition-or-disability

survivor's car to enable then to drive. Being able to drive a car is of great value to many stoke survivors because of the great independence it offers and the ability or desire to return to driving should be evaluated on a regular basis.

Access to Therapies

Easy access and re-referral to therapy based rehabilitation services may reduce the risk of further deterioration, increases the ability of stroke survivors to undertake personal activities and deliver cost savings through reduced hospital admissions[51]. The purpose of providing community based rehabilitation is not only to see marked improvement in functionality but to facilitate independence, functional mobility and prevention of further deterioration.

The Moving On Report[52] by the Stroke Association and the Chartered Society of Physiotherapy provides the guiding principles through eleven recommendations in four key areas:

- Community based physiotherapy must be available on the NHS to all stroke survivors who need it
- There must be an end to fragmented transitions into community based physiotherapy
- All stroke survivors must receive community based physiotherapy individually tailored to their needs
- The vital role of carers must be recognised and valued throughout the physiotherapy journey

NHS Community based physiotherapy should be available to stroke survivors anytime post stoke if indicated by clinical presentation. Recovery of cognitive impairment is key to supporting stroke survivors to return to society[53]. If cognitive impairment is identified, cognitive rehabilitation may be appropriate.

Communication Problems Following Stroke

Normal communication is a combination of verbal and nonverbal expression and comprehension and includes reading, writing and using a keyboard. Communication problem following stroke are very common. About a third of stroke survivors have aphasia an impairment of language that can affect speaking, understanding others, reading, writing and understanding body language and gestures. Aphasia can be extremely isolating and make previously simple everyday tasks feel impossible, leading to a lack of self-confidence

---

[51] Legg, L., Langhorne, P. et al. Rehabilitation therapy services for stroke patients living at home: systematic review of randomised trials. The Lancet, 363: 352-356(2004).

[52] Moving On a Vision for Community Based Physiotherapy After Stroke in England. The Chartered Society of Physiotherapy and The Stroke Association

[53] Patel M Coshal C Rudd A. Impact of Cognitive Impairment on Functional Outcome in Stroke 2010

and wellbeing. People with aphasia have been shown to be at increased risk of depression and experience more difficulty in engaging in rehabilitation activities[54]. Evidence shows that for people with aphasia a return to the same level of work as pre stroke is rare. Additionally, participation in many other social roles including household management and recreation has been widely found to be negatively affected by aphasia[55]. The risks of non-treatment are that the individual with aphasia is unable to participate in family life and society, leading to unemployment, family breakdown, and psychological challenges, all of which have an ultimate cost to health and social services[56].

The availability of intervention in the long term is emphasised in the National Stroke Strategy (2007) which states, “For months or even years after a stroke, there may be a need for specialised, therapeutic help – for example to improve speech or mobility”

Outcomes for people with aphasia are significantly improved if services ensure people with aphasia have appropriate support[57]. Typically an effective model of support includes:

- Peer support groups supported and managed by specialist Speech and Language therapists for optimum outcomes (refer to section 8 case study)
- Volunteer conversation partners, trained and supported by specialist SALTs, working within the concept of the group and outside in the community
- Active linkages and referral pathways with speech and language therapists

Case Study - TALK Surrey - Charity Supporting People with Aphasia after Stroke

Since 1998 TALK has been helping stroke recoverers with aphasia to regain lost skills. Weekly meetings enable members to practise their communication skills in a supportive and sociable environment.

Talk Surrey - The Charity to help stroke recoverers with aphasia to regain lost skills. TALK works closely with local speech and language therapists who help to train our volunteers. Each recoverer is helped by a volunteer on a one-to-one basis. TALK received the Queen's Award for Voluntary Service for 2005, in recognition of the outstanding contribution made by our volunteers www.talksurrey.org.uk

---

[54] Code, C. & Herrmann, M. The Relevance of Emotional and Psychosocial Factors in Aphasia to Rehabilitation. Neuropsychological Rehabilitation, 13(1 & 2): 109-13 2003

[55] Hinckley, 2002, cited by Royal College of Speech and Language Therapy: RCSLT resource manual for commissioning and planning services for SLCN Aphasia 2009

[56] Enderby, P. Pickstone, C. John, A. Fryer, K. Cantrell, A. Papaioannou, D. Resource Manual for Commissioning and Planning Services for SLCN RCSLT 2009

[57] Van der Gaag, A. Davis, S. Moss, B. Cornelius, V. Laing, S. Therapy and Support Services for People with Long-Term Stroke and Aphasia and Their Relatives: A Six-Month Follow-up Study. Clinical Rehabilitation, 19(4): 372-380 2005

Promoting Independence - Helping Stroke Survivors to Get Involved in Community Life
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 therapist, stroke survivor and carer**
- **Commissioners should ensure a clear pathway is available for referral into the appropriate stroke skilled range of therapies or psychological services where patients or their relatives or carers have concerns**
- **As part of regular reviews, commissioners should ensure that stroke survivors have access to expertise to address problems with their language skills and communication**
- **A clear pathway for access into, and funding for, vocational rehabilitation should be agreed with health and social care commissioners**
- **Commissioners should promote the greater use of therapies to help people to return to work and stay in employment. An annual audit of people returning to work can identify the economic case for investing in this service**
- **Education and liaison with local transport providers should be seen as a legitimate role**
- **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**

Joint Commissioning and Audit

11. Joint Commissioning and Audit

Joint Commissioning

Commissioning is the process of assessing need, identifying resources available, planning how to use the resources, arranging service delivery, reviewing the service and reassessing need. Joint commissioning can bring greater innovation, value for money and improved services that cut waste and duplication. The benefits of joint commissioning are that it helps agencies to work together to:

- Target services to give the greatest impact on outcomes
- Avoid duplication of services
- Ensure value for money & efficiency
- Develop coordinated services
- Share best practice
- Share expertise
- Share intelligence about needs

Planning and Audit

As part of the GP Quality and Outcomes Framework (QOF), GPs are required to keep a register of individuals from their practice that has 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. The register should include reference to significant impairments that a stroke survivor may have, including cognitive issues, aphasia or significant physical disability. With no central record of stroke survivors across particular locality commissioners should consider the development of a local stroke survivor register. The data could 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 by the data then, commissioners could link with GPs in the area to identify areas of unmet need.

The Sentinel Stroke National Audit Programme (SSNAP) is the most comprehensive and reliable source of information about the performance of stroke services in England, Wales and Northern Ireland. SSNAP aims to improve stroke care by measuring the quality of stroke services against evidence based standards and supporting staff to make improvements. In due course SSNAP will not only be able to report on the care of all stroke patients admitted to hospital and define the care they received but will also be able to report on outcomes such as mortality and disability as the programme develops.

Commissioners should ensure that all community providers are entering data into SSNAP so that life after stroke services can be audited when this data comes on line. SSNAP currently identifies where 6 month reviews are being provided and commissioners should consider working with 6 month review providers to audit 6 month review data and assess service needs and gaps in provision across a particular geography.

Joint Commissioning and Audit Recommendations to Commissioners

- **Commissioners should strive to commission joint planning and delivery of health social and voluntary provision of support**
- **Commissioners should audit on an annual basis the provision of services to stroke survivors**
- **Commissioners should ensure that all community stroke providers they commission services from are entering data into SSNAP**

The Evidence Base

12. The Evidence Base

Brighton and Sussex Knowledge and library service were commissioned to provide a search of published articles upon life after stroke using the key terms:

Title/Abstract: stroke* "cerebral vascular accident" CVA "quality of life" QoL "daily activit*" "daily living" activit* "activities of daily living" community "community rehab*" "community support*" "community care" work employ* job driving aphasia Major Descriptors: *STROKE/ *CEREBROVASCULAR ACCIDENT/ *QUALITY OF LIFE/ACTIVITIES OF DAILY LIVING/ *HUMAN *ACTIVITIES/ *LEISURE ACTIVITIES/ ACTIVITIES OF LIVING MODEL/ *SOCIAL SUPPORT/ *CAREGIVERS/ *COMMUNITY BASED REHABILITATION/ *COMMUNITY CARE EMPLOYMENT/ *EMPLOYMENT, SUPPORTED/ *RETURN TO WORK/ *AUTOMOBILE DRIVING/ *CAR DRIVING/ *DRIVING ABILITY/ *APHASIA/
Date of completion*:* 11th July, 2014

Sources searched:
EMBASE (7)
MEDLINE (11)
UpToDate (0)
CINAHL (6)
Best Practice (0)
Google Scholar (3)
Cochrane Database of Systematic Reviews (4)
Evidence Search (2)

Date range used (5 years, 10 years): Last 10 years

Appendices

Appendix 1 – List of Useful Websites

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

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

Dyscover: A Surrey based charity providing long-term specialist support and opportunities to people with aphasia and their families. Dyscover is led and run by speech and language therapists

http://dyscover.org.uk/

Carers Support West Sussex: is a voluntary organisation providing a wide range of information and advice for carers and ensures each carer knows what support is available

www.carerssupport.org.uk/

Carers Support East Sussex:

www.cftc.org.uk

Carers Directory for Kent:

www.kent.gov.uk/social-care-and-health/caring-for-other-people

Carers Directory for Surrey:

www.surreycc.gov.uk/social-care-and-health/information-for-carers

Connect: is a charity whose aim is to improve the lives of people living with aphasia and communication disability, equipping them to re-connect with life

www.ukconnect.org/

TALK Surrey - Charity Supporting People with Aphasia after Stroke

www.talksurrey.org.uk

East Sussex 1 Space: General information on personal care, accessing services information and advice to coping with ill health

www.eastsussex1space.co.uk/

East Sussex Communication Directory: It is a computer database of local and community information developed and managed by the Library and Information Services of East Sussex County and holds information about organisations based in East Sussex and Brighton and Hove www.escis.org.uk/

Appendix 2 – Acknowledgements

We would like to thank

Commissioning Support for London. Their Life after stroke commissioning guide provided some of the content, structure and approach to this document.

The members of the **South East Coast CVD SCN Life after Stroke Task and Finish Group** who contributed to the development of this work.

Sally	Allen	QIL SEC SCN
Caroline	Bates	Maidstone Hospital
Norah	Bessant	Stroke-Specialist Physiotherapist Community Stroke Service East Sussex Healthcare NHS Trust
Lilian	Bold	Patient Representative
Tony	Bundock	Patient Representative
Viv	Cooper	Sussex Community NHS Trust
Sarah	Crouch	East Sussex County Council
Ann	Curtis	Virgin Care
Sandra	Field	Stroke Organisation
Michelle	Gatehouse	Stroke Service Co-ordinator DVH
John	Gooderham	Patient Representative
Jude	Gunasegaram	Crawley CCG
David	Hargroves	SEC SCN Clinical Lead (Chair)
Sarah	Jones	Sussex Collaborative Delivery Team
Emma	Jupp	East Sussex County Council
Simone	Lane	Brighton and Hove CCG
Fiona	Mooney	Professional Lead for Physiotherapy CSH Surrey
Paula	Parker	Kent County Council
Sara	Pledger	GP CWS CCG
Mala	Rai	Kent Community NHS Trust
Elaine	Randall	NHS Coastal West Sussex CCG
Graham	Roberts	Patient Representative
Pam	Stone	Patient Representative
Julie	Thomas	Patient Representative
Rosemary	Townsend	Dyscover
Mark	Trickey	Quality Improvement Lead SEC SCN
Hester	Wain	Surrey CCG's Collaborative
Jaqueline	West	Kent CC
Jane	Whitcher	NHS Crawley CCG and Horsham and Mid Sussex CCG
Melanie	Woollaston	Kent CHT

Appendix 3 – My Personal Plan Following My Stroke

Available as a separate document on SEC SCN website:

www.secscn.nhs.uk/our-networks/cardiovascular/stroke-clinical-advisory-group/

Appendix 4 - The Sussex approach to parity of esteem

http://www.sussexpartnership.nhs.uk/about/news/articles/873-valuing-mental-health

Appendix 5 - The Stroke Care Navigator Role[58]

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 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.

---

[58] Commissioning Support for London Life after stroke: commissioning guide, 4.1 The Stroke Care Navigator Role. 2010