



NHS Improvement - Stroke

Psychological care after stroke

Improving stroke services for people with cognitive and mood disorders



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Foreword



If you want to
heal the body,
you must first
heal the mind.

Plato (427-347 BC)



We're not just legs and arms and a mouth...we are human beings with a mixture of emotions. All these feelings...self esteem, self worth, confidence, identity ...they're all under attack after a stroke...you can feel vulnerable, frightened and you can lose yourself. Psychological support puts you back together again - especially psychological support from someone who's been down that road before. The timing can't be predicted...sometimes it's when you come out into your real world after hospital or it may be two - or more - years later when you discover that you will not make a 'full' recovery...it's about reinvention and finding direction.

Harry Clarke , Counsellor at Connect who has aphasia

I am particularly pleased to commend this document to you which brings together available evidence, guidance and experience from experts and our national projects to provide a single resource to support services in a very pragmatic way. Many of you will know that we have made significant progress in the delivery of stroke care in recent years and outcomes for patients have been improving. Most of this improvement has been from advances in acute care and we must now increase our focus on the post acute part of the stroke pathway. After all, this is, as the National Audit Office noted in its 2010 follow up report on stroke (Progress in improving stroke care), where most people will spend most of their time.

Of particular importance is access to the high quality, appropriate, psychological support that is vital from at least two perspectives. On average one third of people who survive a stroke experience depression. Furthermore, between 35% and 60% of people experience cognitive impairment after stroke. Perhaps less well known, is that the risk of developing cardiovascular disease in people with depressive disorders can be at least one and a half times greater than that of the general population and all patients with cerebrovascular disease are at risk of cognitive loss. Every patient seen after a stroke should be considered to have at least some cognitive losses in the early phase. These figures emphasise the need for psychological wellbeing to be integral to stroke care from prevention through to care for people who have been discharged from hospital.

We know that psychological and behavioural support are not well provided in the NHS but through the efforts of those implementing the Accelerating Stroke Improvement programme we also know that significant improvements can be made to help people achieve the best quality of life they can, often within already available resources and contributing to the Quality, Innovation, Productivity and Prevention (QIPP) agenda.

Professor Sir Roger Boyle

National Director for Heart Disease and Stroke

Executive summary

The National Audit Office (NAO) report of stroke services in 2010 highlighted the widespread lack of provision of psychological care after stroke. A driver for improvement was created by the Department of Health with the development of Accelerating Stroke Improvement, a programme to expedite rapid improvement in aspects of stroke care identified in the NAO report. Stroke services were asked to aim for the achievement of a national measure for 40% of their patients to receive psychological support within six months of their stroke. This national focus has provided a driver for improvement in psychological care with services looking to significantly improve provision of psychological support for people with stroke.

This publication aims to act as a practical guide to support the establishment and development of services for psychological care of people following stroke in which they can implement evidence based guidance and treatment. It brings together summaries of national guidance, standards, and related evidence and shares the learning from seven national projects to provide a single resource to assist stroke providers to implement and improve these services. The guide should be used in conjunction with existing more comprehensive national clinical guidance, literature and research evidence.

Psychological care for this group is as essential as physical rehabilitation, particularly as people with stroke and their families endeavour to manage the impact of stroke on their lives in the longer term. Guidance is given for establishing pathways and processes to assess and manage the psychological impact of stroke for both emotional and cognitive disorders.

The guide covers the stepped care model to manage patients and psychological assessment. There are sections on implementation of care pathways and improving services for people with impairment of mood and cognition. The final sections on training and sustainability provide information about UK-wide education and training programmes for staff, and development of a stroke-skilled workforce and on how to maintain improvements made in services for psychological care.

The key points of the guide are:

- Views of stroke patients and their families about their psychological care should be sought and changes made in the light of this
- Services for stroke should be commissioned with the same emphasis on provision of psychological care as for physical care and rehabilitation
- The whole multidisciplinary team need to be able to identify psychological issues and know how to manage these issues, even where their role is simply to recognise problems and refer on to others using the identified pathway
- Addressing psychological need should be accepted as an essential part of the culture of stroke services
- Regular and ongoing training of multidisciplinary staff is essential. This applies to both the training of stroke staff for better understanding of psychological issues, and the training of mental health staff to understand the needs of people with stroke
- Psychological care is best delivered in a service with full access to clinical psychology; however, in the absence of a psychologist, improvements can still be made

Introduction

Stroke is one of the leading causes of morbidity in the UK, with over 100,000 people experiencing a stroke each year. It is characteristically considered to be a condition causing weakness and paralysis. In fact up to 20% of people have no weakness, and a further unknown number of people have clinically silent stroke. More importantly, all patients with cerebrovascular disease are at risk of cognitive loss and some cognitive loss is probably present in almost all patients.¹ Up to 75% of patients will have significant cognitive impairment², including problems with memory, attention, language and perception as well as organisation of movement and thoughts. Mood disturbance is common after stroke and may present as depression or anxiety.¹ Psychological mood disturbance is associated with higher rates of mortality, long term disability; hospital readmission; suicide and higher utilisation of outpatient services if untreated.^{3,4,5} 30% of patients will suffer from depression at some point post-stroke⁶ and a significant proportion these remain undiagnosed or inadequately treated⁷. In addition, serious psychological problems and strain are common in carers of people with stroke¹.

Psychological care is best delivered in a service with full access to clinical psychology; however, in the absence of a psychologist, improvements can still be made. Provision of psychological care after stroke is multifaceted, involving many professions and agencies (health, social care and voluntary), and a clear jointly developed pathway of care is essential to optimise service delivery. Significant improvements in psychological and emotional care after stroke can be made, by ensuring psychological support is considered by the multidisciplinary team (MDT) to be as critical to recovery from stroke as physical rehabilitation.



The National Institute for Health and Clinical Excellence (NICE)⁸ and the Royal College of Physicians (RCP) National Clinical Guidelines¹ recommend routine assessment and management of mood and cognition after stroke. The National Stroke Strategy⁹ recognises the central importance of a psychological pathway of rehabilitation that addresses the psychological changes which can occur following a stroke. A key recommendation of the National Sentinel Audit (2010)¹⁰ was that commissioners “find resources that enable the service to provide clinical psychology expertise to acute and rehabilitation stroke patients”.

Stepped care approach

A stepped approach to psychological care is recommended by NICE guidelines for people suffering from depression and anxiety disorders, by the Department of Health (DH) Improving Access to Psychological Therapies (IAPT) programme¹¹ and the Stroke Improvement Programme (SIP)¹² improving psychological support after stroke consensus group. Stepped care 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. This approach makes best use of skills of the multi disciplinary team and utilises more specialist staff for the patients with complex problems that require this level of help.

An adapted model to this approach with information about how it can work in a stroke service is shown in figure 1.



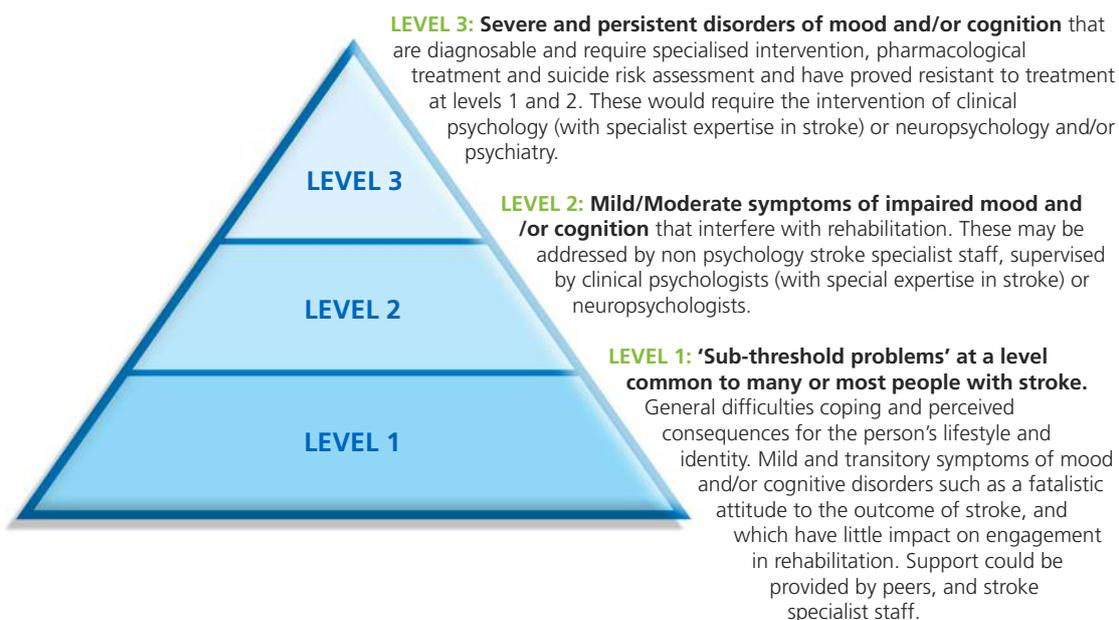
When you realise (in my case in hospital) what's happened you are still scared, but now other emotions come into play; anger, sadness, depression, low self esteem, just to mention a few. To be able to try to express your feelings to someone who appears to understand, is in my opinion vital to the recovery process.

Person with aphasia.

Connect - the communication disability network¹³

Figure 1: Stepped care model for psychological interventions after stroke.

Adapted from IAPT model with input from Professor Allan House and Dr Posy Knights



Psychological needs are not defined in relation to time post-stroke. The support mechanisms therefore need to be flexible to support self referral back into the system at any time.

Getting started

Patient and public involvement:

Find out and act on what stroke survivors think about the emotional and psychological support they were given in your service. Use aphasia friendly questionnaires and communication supported focus groups to identify likely needs of patients across the whole pathway right at the start.

Improve general awareness of multidisciplinary team (MDT):

Focus attention on day to day emotional support that the team can deliver with existing staff competence.

Don't reinvent the wheel:

Look on the SIP psychology webpages¹² for examples of how other services have improved psychological care in different settings and with limited resources.

Clearly defined pathways:

Develop a pathway for psychological care on which the whole team agree a planned resource and which includes routine screening and discussion of psychological issues at the MDT meeting.

Make links with existing services:

Clinical psychologists and clinical neuropsychologists specialising in stroke should be an integral part of the stroke team. In addition to direct assessment and treatment, the clinical psychologist can support the MDT in guiding patient management.⁶

The stroke specific voluntary sector, can offer excellent support from family and carer support workers, stroke co-ordinators and groups.

The local IAPT service may supplement services for people with level 2 mood difficulties. Staff in these services will need to have additional training in stroke and work closely with the stroke service before the pathway to incorporate IAPT is established.

Make use of all avenues for psychological care

Services should be stroke specific and provided under the guidance of a clinical psychologist. Whilst working towards this national recommendation, links can be made with other organisations that may, with additional stroke training and close working, be able to support psychological care of people with stroke.

Key messages for commissioners

The clinical psychologist is a key member of the stroke MDT and provision of their services is a recommendation of national clinical guidance^{1,6,12}. Commissioners should "Find resources that enable the service to provide clinical psychology expertise to acute and rehabilitation stroke patients."

RCP National Clinical Guidance for Stroke (2008)

Community mental health trusts often operate separately to services for physical health. Engagement, shared training and collaborative working can join up disparate services to support patients with stroke.

Social care aims to provide personalised services and is likely to have a longer term involvement with patients. Social care staff may be in a position to offer psychological support throughout the pathway and would benefit from involvement in stroke training.

IAPT services are being tasked to support people with stroke in the new Mental Health Strategy 'No health without mental health'.¹⁴

The strategy has funding to implement improved access to psychological support for people with long term conditions and recognises this group are more likely to suffer from anxiety and depression.

Learning from the Dorset national project

Getting started:

- Real and meaningful involvement of stroke survivors and carers at the outset is essential to understanding patients' perceptions of current services and is paramount to the success of the project
- Work in the months prior to the project to engage the local primary care mental health service was incredibly helpful in gaining support for the project
- Clinical leads were selected from both specialist mental health services and the community rehabilitation team to reflect the collaborative nature of the project. Involvement of the Stroke Association and Adult Social Services helped ensure the wide range of staff involved in stroke rehabilitation were included
- This collaborative approach meant that for the first time in Dorchester, a structured pathway was established to meet the psychological needs of people with stroke

Detailed information about this project including the pathway can be found on the SIP website.¹²

Assessment principles

Throughout this publication the term assessment is generally used in preference to the term screening which is often used to refer an initial vetting process of patient selection for further assessment or intervention. Assessment in this context refers to the process of identification of psychological need, through the validated measures, interview and observation, and can be carried out by any competent member of the multidisciplinary team.

There should be a clear policy and pathway for recognition and assessment of cognitive and emotional needs, which includes the choice and timing of the assessment measure and the recording and communicating of results.

Assessment using standardised measure and interview, should take place routinely on at least three occasions:

- **One month after stroke or just before discharge, or at six week follow-up**
- **Three months after stroke, usually post-discharge to judge persistence of early-onset problems and emergence of new problems**
- **Six months after stroke when much physical and social recovery has stabilised and likely longer-term problems can be assessed**
- **Assessment at six month and annual reviews will allow identification of those with long-term problems**

If there is cause for concern at any other point in the pathway the patient should be reassessed.

Initial assessment should only be carried out by staff trained to administer the tests and the test selected according to the training and qualifications of the assessor. Where language impairments exist, assessments could be carried out in conjunction with the speech and language therapist (SALT).



Aim to use measures validated for use with people following a stroke including those with aphasia.



Patients with mild/moderate symptoms need a further assessment, ideally within days of the initial assessment. This can be conducted by additionally trained MDT members, ideally supported in the administration and interpretation of test results by the clinical psychologist.

Comprehensive neuropsychological assessment (involving psychological and cognitive components) should only be undertaken by qualified clinical psychologist/clinical neuropsychologists.

Assessment of mood

People who may have depression receive an assessment that identifies the severity of symptoms, the degree of associated functional impairment and the duration of the episode.

NICE Quality Standard for Depression 2011¹⁵

LEVEL 1

All patients should be assessed for mood disorder with a simple brief standardised measure eg GHQ-12, BASDEC, HADS, PHQ9. Participatory measures such as the DISCs or observational measures such as the SAD-Q may be used in patients with more severe communication or cognitive difficulties.

In all cases this standardised assessment should be followed up with an interview to check for reasons that the assessment may be unreliable, for distress not asked for in the assessment, and to ask about the patient's view of their current emotional state.

LEVEL 2

Patients with mild/moderate symptoms need a further assessment to seek information on:

- Onset and duration of symptoms
- Episodes and treatment of mood disorder prior to the stroke
- Wider emotional problems e.g. apathy, irritability, fear of falling
- The patient's perception of their symptoms
- Associated health-related behaviours and attitudes

The main carers psychological needs warrant consideration for patients with symptoms at level 2.



Written information should be available to support the verbal messages about the psychological impact of stroke and the support available.



I don't mind who asks me (what profession) or how they ask (using which assessment), but ask me from the start and keep asking me.

Stroke survivor from Dorset

LEVEL 3

Patients with severe symptoms should be considered for referral for specialist assessment and treatment by mental health services (clinical psychology or psychiatry) if:

- They score in the severe range on the standardised measure, or
- They have specific negative cognitions and especially suicidal thinking
- Mood disturbance is having an obvious negative impact on rehabilitation, for example through avoidance of or refusal to participate in, rehabilitation activities
- They are not responding to level 1 or level 2 care

Learning from the York national project

Do not avoid starting to make improvements in the quest for the perfect assessment measure. Make a start with a measure applicable to the majority of patients then refine the pathway as the service develops.

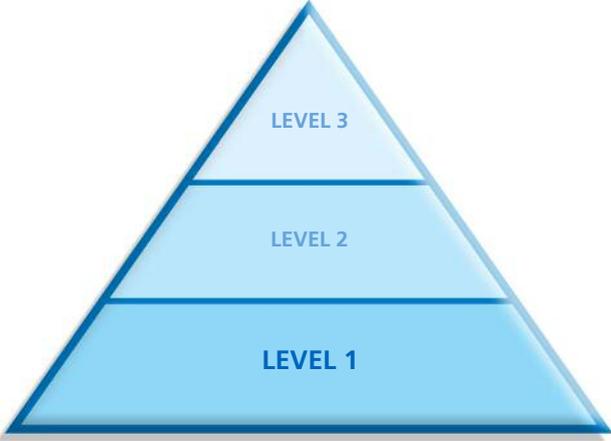
See the York national project approach on the SIP website¹².



Depression is common, but for some patients it may be short-lasting and can remit as the patient recovers function^{5,7}.

See glossary of abbreviations on page 25.

Implementing services for patients with level 1 (sub-threshold) mood or anxiety difficulties



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 stroke specialist staff

LEVEL 1:
Key points for psychological care

- Ensure routine assessment is in place for mood and cognition
- Raise awareness of post stroke psychological issues with the MDT
- MDT members need to be competent in psychological screening
- The MDT need to be competent to provide low level psychological care such as:
 - Active listening
 - Normalising not minimising patients issues
 - Providing advice and information for adjustment, goal setting and problem solving
 - Signposting for informal support and further professional help when required
- Ensure psychological wellbeing is reviewed at MDT meetings and post discharge stroke reviews
- Provision of a single point of contact for the family and stroke survivor on transfer of care from hospital is seen by patients as a critical factor to feeling supported

Learning from the Nottinghamshire national project - Making psychological care part of the culture

- It needs to be acceptable for staff to spend time with patients, exploring and supporting the impact of the stroke. This should be acknowledged as a valid use of clinical time
- Psychological care needs to be embedded into team routines - regularly considering psychological aspects of care in discussions, including it in paperwork and involving patients in service improvement
- Development of psychological skills throughout the MDT is crucial in providing psychological care to all stroke patients seen by the teams
- Skills development focused on understanding adjustment after stroke, identifying psychological difficulties and providing compassionate caring. This was important as psychological care needs to be provided by the whole team, not just by the clinical psychologist

For further information about this project see the Nottinghamshire national project on the SIP website¹².



Addressing psychological need stroke should be accepted as an essential part of the culture of stroke services and equivalent to the management of physical need.

Learning from the Connect national project - People with stroke really value peer support and befriending

People have reduced isolation and greater feelings of support - people with aphasia who have joined conversation groups, or received a conversation partner or a befriender feel greatly supported. They enjoy the understanding that comes from peer support and feel less isolated.

There is support at every stage - with the potential for people to be seen from an early stage in hospital, right up to being seen at home, potentially years after their stroke.

Support is available for years after stroke - This support can involve those who are years post stroke. Prior to the project some people with stroke had been wanting more support or greater involvement but had been unable to find it.

Greater confidence for people with aphasia - taking on active roles helps to develop confidence and this informal support is very accessible to those with communication difficulties.

Therapists feel happier about discharging patients - knowing that there is a long term service that they will be able to access after therapy.

Peer support and befriending can be invaluable for carers and families too.

See how the York national project also implemented a befriending service on the SIP¹² website.

Useful resources can be found on the Connect¹³ website.



Being able to talk to someone in the early days who really knows what you're going through helps to stop you having to go to a psychiatrist six months later.

Person with aphasia - Connect

Key messages for commissioners

Pathways for psychological care should include peer support and befriending services.

Service specifications should include:

- Investment in MDT training and ongoing access to updates so that staff have the ability to assess for emotional distress and provide low level psychological support for patients and carers
- Investment in MDT training related to stroke and communication access, for mental health teams

See how the Dorset national project had its training endorsed by the UK Forum for Stroke Training⁷ on the SIP website¹².



Psychological care is less about 'fixing' and more about understanding and offering timely support.

Dr Posy Knights

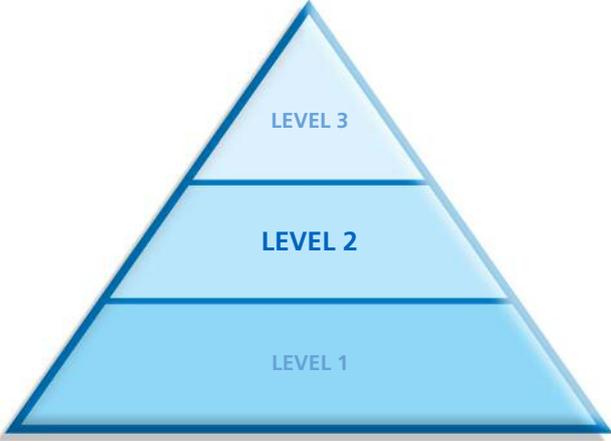


People with stroke value active roles and feel they reduce the possibility of psychological issues. Active roles might include befriending, volunteering, creative activities, group attendance going to the gym etc.



Aim to ensure that equivalent levels of informal support are available for those with communication impairments.

Implementing services for patients with level 2 (mid/moderate) mood or anxiety difficulties



LEVEL 2: Mid/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 2:
Key points for psychological care

- Clear pathways for referral to clinical psychology need to be in place
- The MDT need awareness of optimal utilisation of clinical psychology
- MDT members with additional competence in psychological care can provide:
 - Brief psychological interventions
 - Advice and information for adjustment, goal setting and problem solving
- Signpost to informal support or refer on for further professional help if needed
- Consider the use of psychosocial education groups
- Antidepressant medication should be considered with clearly defined and accessible management plans to review or stop medication

People with moderate depression and a chronic physical health problem receive an appropriate high intensity psychological intervention.

People with persistent subthreshold depressive symptoms or mild to moderate depression receive appropriate low level psychosocial interventions and are prescribed antidepressants only when they meet specific clinical criteria in accordance with NICE guidance.

NICE Quality Standard for Depression 2011¹⁵



There was some evidence of benefit of pharmacotherapy in terms of a complete remission of depression and a reduction (improvement) in scores on depression rating scales, but there was also evidence of an associated increase in adverse events.¹⁴

Learning from the Croydon national project - Establishing a psychosocial education group

- People with stroke may want to access support in the form of meeting other people with stroke, or receiving information and advice. This may include groups developed for people with stroke and their families; for stroke education, psychological wellbeing, information giving or 'telling your story'
- Groups can be run as a one off - such as a stroke education session on an acute ward open to family members and stroke patients. The role of such a group is to provide basic important stroke education (causes, physical and psychological effects, and treatment approaches) and to describe local care pathways and what to expect next
- Groups comprising several sessions can have a more supportive and therapeutic function. The aims of these groups are to educate people on the impact of stroke on functioning and coping. They can devote more time to explaining practical coping strategies and have a good peer support function
- Groups can be open (no fixed attendance) or closed (the same people attend for a course of sessions). Closed groups allow more sharing of problems, whereas open groups meet the needs of a wider group of people
- Resources and educational materials should be accessible for people with communication, visual and cognitive impairments and backed up with information people can take away from the group
- Always ask for feedback from those who attend and act on it
- Publicise groups widely using local clinicians, voluntary agencies such as The Stroke Association, GP surgeries etc.
- Use existing endorsed or recommended training materials where possible

Useful resources can be found on the SIP website¹² in the Bournemouth stroke service example and the Croydon and St Georges national projects summaries.



Ensure ongoing supervision and support is available for those providing brief psychological interventions. This could be in the form of a reflective practice group. See SIP website¹² for information about how the Bassetlaw and Nottinghamshire national projects did this.

Ensure referral pathways to access step down services are available once health care support is no longer required. A route to self refer is essential and pathways should include those provided by the voluntary sector.

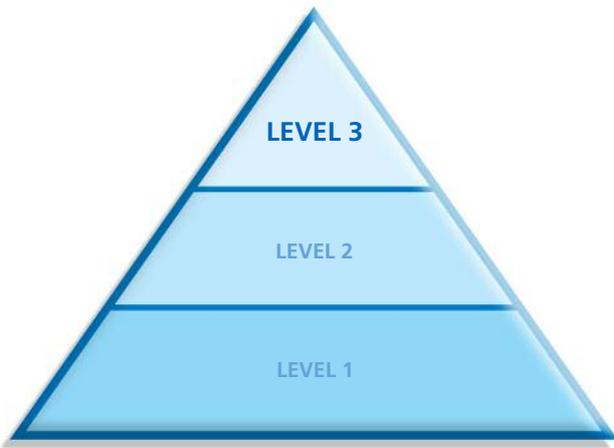
Ensure mood and cognitive assessment is included in six month and annual stroke review paperwork and is appropriate for people with or without a communication impairment.



It was good to have the information talked through, rather than just getting a leaflet.

Person with stroke, Croydon

Implementing services for patients with level 3 (severe/persisting) mood or anxiety difficulties



LEVEL 3:
Key points for psychological care

- Clear pathways for referral to clinical psychology need to be in place with a fast track route for urgent support
- Timely suicide risk assessment and prevention plan needs to be carried out by the clinical psychologist followed by a mental health referral if there are complex or potential risk issues
- Antidepressant medication should be considered with clearly defined and accessible management plans to review or stop medication
- Psychological needs should be considered in the ongoing management and joint care plans
- The six week and six month reviews should be used to monitor progression
- Develop and enhance relationships between mental health teams and the stroke service
- Include in the pathway a route for ongoing support by stroke service teams or the voluntary sector once the patient is subthreshold

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

People with moderate to severe depression and a chronic physical health problem with associated functional impairment, whose symptoms are not responding to initial interventions receive collaborative care.

Practitioners delivering pharmacological, psychological or psychosocial interventions for people with depression receive regular supervision that ensures they are competent in delivering interventions of appropriate content and duration in accordance with NICE guidance.

NICE Quality Standard for Depression 2011¹⁵



- Ensure there is a process for assessing risk
- Ensure there are clear and quick referral pathways to specialist services which are accessible to all staff
- Consider how to support staff working in community settings and lone workers such as stroke coordinators
- See SIP website¹² for examples of business cases for clinical psychology and how to integrate a new psychology role in an MDT

Evidence for interventions

Evidence and value based interventions are recommended in all areas of healthcare delivery. There is evidence for psychological interventions and pharmacological treatment in the general population but less which has been directly researched for people following a stroke. Evidence based NICE quality standards exist for stroke (2010)⁸ and for depression (2011)¹⁵.

The available evidence has been reviewed by the Stroke Improvement Programme steering group. The paper can be viewed on the SIP website¹².

A British Psychological Society paper discusses psychological impact of stroke, the role of clinical psychologists and the evidence for psychological approaches to intervention⁶.

Systematic reviews of clinical studies are available from the NHS evidence review library and the Cochrane library (eg treatments for depression, anxiety and emotionalism after stroke, prevention of post stroke depression).



Key messages for commissioners

Appointing clinical psychologists to the stroke service meets the recommendations of national clinical guidance.^{10, 23}

The main focus for resources for psychological care should be after the first few days following stroke and spread across the whole pathway with more of an emphasis on longer term support.

Services should be commissioned from and coordinated across all relevant agencies encompassing the whole mood care pathway.

Effective mechanisms should be in place to optimise exchange of information across the care providers.

Reviews at six months can provide a safety net for patients with psychological issues not previously identified.



Ideally, services need to develop long term psychological and emotional support, with co-ordinated programmes starting with psychological support in hospital and longer-term support involving the voluntary sector.

National Stroke Strategy (2009)⁹.

Assessment of cognition

Thanks to Professor Nadina Lincoln and Dr Jamie Macniven

All patients after stroke are screened within six weeks of diagnosis using a validated tool, to identify mood disturbance and cognitive impairment.

NICE Quality Standard for Depression 2011¹⁵

The purpose of assessment

The aim is to quickly identify the key areas of need and therefore target interventions accordingly to improve the rehabilitation outcomes after stroke. The purpose of cognitive assessment should be explained to the patient.

Cognitive assessment should be conducted as part of a comprehensive clinical assessment and not as an activity isolated from clinical decision making and treatment.

The pathway

In an ideal service, a brief screen such as the MoCA or ACE-R would be undertaken in the first few weeks in combination with a functional assessment by occupational therapists.

Following initial assessment, rehabilitation should be targeted to where there is a defined quantifiable need. If cognitive problems are obvious from functional assessment then only domains where there is no obvious deficit should be tested further. In services without access to psychologists, therapists may wish to complete further assessments in conjunction with functional evaluation to clearly identify areas for targeted focus and to provide a baseline measure.

After the first few weeks post stroke most patients will have stabilised to the point when it becomes appropriate to undertake more detailed cognitive assessment.

Clear pathways for referral to clinical psychology/neuropsychology need to be in place with a fast track route for urgent support.

If the patient requires ongoing support by social service teams or the voluntary sector a management plan should be developed to align with neuropsychological rehabilitation.

The six week and six month reviews should be used to monitor progress, update risk assessments and review service provision.



I couldn't understand why things were so much harder... I couldn't follow things. I worked before my stroke and was...am... an intelligent man, but didn't feel that way anymore. The tests were interesting for me... some bits were so easy, other bits just made me unravel... things I knew I should be able to do. It really helped me and my wife that the girls explained why this was happening... that it was the stroke, not me. I guess I felt it gave me some control to understand it... now I just hope there will be some improvement.

Person with stroke from Dorset

Routine assessment should be undertaken to identify the range of cognitive impairments that may occur, using simple standardised measures. Any patient not progressing as expected in rehabilitation should have a more detailed cognitive assessment to determine whether cognitive losses are causing specific problems or hindering progress. The patient's cognitive status should be taken into account by all members of the multidisciplinary team when planning and delivering treatment.

RCP national clinical guideline 2008¹

Learning from the Bassetlaw national project - Turning strategy into clinical practice

Find champions at ground level. Establishing a relationship with one or two members of staff that are interested in and motivated by the topic, can allow establishment of a 'lead' for assessment and awareness raising on the ward.

Invest time in educating and supporting the MDT to help them to understand the importance of checking all patients for problems with mood, anxiety and cognition.

Find what works for staff routine. Discussion with ward staff revealed that they wanted assessments they could complete alongside their existing daily care plan routines.

Allow the care pathway to evolve. Establishing a pathway takes time to embed and several revisions before it becomes common practice. Regular auditing of the care pathway is useful way of facilitating its development by comparing what actually happens to the original intention.

More information about how the Bassetlaw national project implemented a new service for routine mood and cognition assessment and psychological support can be found on the SIP website.¹²

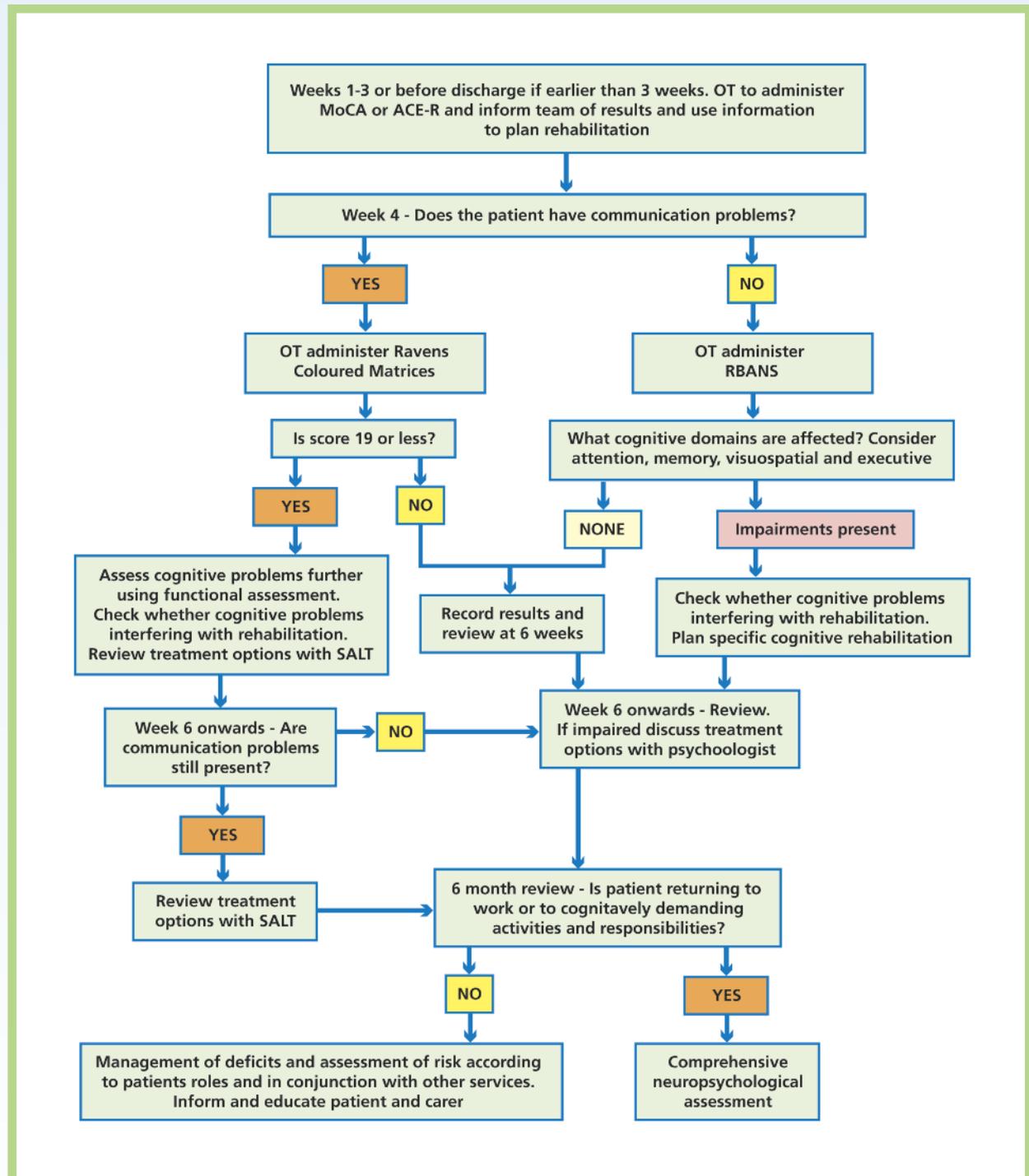


A key consideration is the impact of the acquired cognitive difficulties on the patient's activities of daily living, working life and family and social relationships.

Cognitive difficulties should be considered as part of the ongoing management and joint care planning across the whole stroke pathway.

Aim to use measures validated for use with people following a stroke, including those with aphasia.

Cognitive assessment pathway



Which cognitive assessment tools to use?

- Assessment measures should only be carried out by staff trained to administer these tests
- Some assessments require specific training from the company who provide the assessment, such as the AMPS
- Assessment tools vary in purpose and should be selected according to need. Some assessment tools aim to give a broad picture of cognitive ability such as the MOCA, ACE-R or RBANS. Other assessments are targeted at specific cognitive skills for example:
 - Attention: TEA,
 - Memory; Rivermead Behavioural Memory Test,
 - Perceptual skills; BIT, RVPB,
 - Executive Functions; BADS

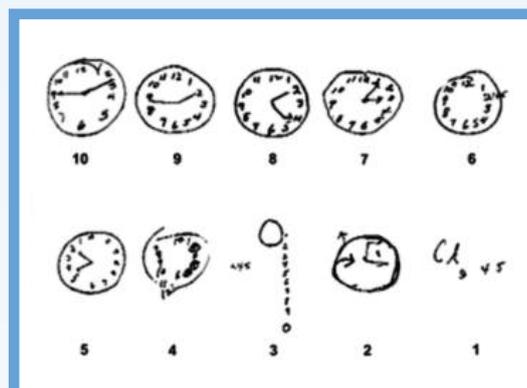
Using the results of assessment

- Assessment results should be used to assist the individual and carers to understand their difficulties, communicate with the MDT to inform management and as an outcome measure
- Assessment results should be considered in the context of psychological comorbidity, visual and language impairments
- Rehabilitation for cognition should be planned according to the problems identified
- Nothing will be gained from identifying cognitive problems without the development of a management plan
- Clinical neuropsychology provision should be targeted for those people who are most likely to benefit, those who are returning to cognitively demanding roles or where risks are unable to be sufficiently minimised
- All patients should receive education, support and coordinated care planning to minimise risks and maximise function and participation



Evidence regarding interventions:

Cochrane reviews conclude that there is currently insufficient evidence to support or refute cognitive rehabilitation approaches in relation to improvements in attention, memory, spatial neglect or function.



Information and education should be offered to people and families of those with cognitive difficulties post stroke. Information should be offered in a format and manner which is accessible. Consider delivering education in psychosocial education groups for appropriate patients. See how the Croydon and St Georges national projects did this on the SIP website.¹²

Further detailed assessment and specialised intervention should be considered for people who are at risk due to their impairment, who are considering returning to work or driving.

Training

Thanks to Professor Caroline Watkins



Implementing better psychological care requires enhanced awareness, knowledge and competence to recognise and manage psychological issues after stroke

Patients treated by stroke-specialists, and others with relevant stroke-specific knowledge and skills, are more likely to survive their stroke, to return home, and to become independent^{20,21,22}. Yet “staffing numbers and skill-mix profiles are insufficient to deliver the required input in stroke care pathways”⁹. This is a particular problem for the delivery of psychological and neuropsychological aspects of care, and the infrastructure for local service provision varies significantly¹⁰. Until now, there have been no clearly defined UK-wide, education and training programmes for staff, nor clearly defined care pathways for people affected by stroke; in particular relating to psychological care. Further development of a stroke-skilled workforce can emerge with the National Stroke Strategy⁹, the UK Forum for Stroke Training (UKFST)²³, the Stroke-Specific Education Framework²⁴ and the Stroke-Specific Role Profiles²⁵. Together these initiatives can contribute to the delivery of high quality comprehensive stroke care through multidisciplinary working, and a commitment to the future further development of stroke services.

Training will be required at all levels throughout the MDT for all organisations involved in the stroke pathway:

- All staff need to be competent in communication access to support people with aphasia
- All staff need to be comfortable discussing emotions. Patients often disclose how they feel to the staff they spend a lot of time with; this may be health care assistants or domestic staff
- Identified staff will need to be competent in first level assessment using agreed validated assessment measures and interview
- Additional competence in higher levels of psychological care will be needed by key identified staff
- Staff carrying out reviews will need to be trained in psychological assessment and be familiar with the pathway for referral onwards if a problem is identified
- Training and competence need to be embedded in team objectives, job roles, and rolling programmes
- Stroke specific training for IAPT staff will be needed to develop joint services
- Training resources and competencies can be found on the following websites:
 - Stroke Specific Education Framework website¹⁹ for endorsed psychological care and training materials
 - The STARS website²⁵ for psychological care training competencies
 - The SIP website¹² for information about shared training between stroke and IAPT teams by the Dorset national project

Learning from the Dorset national project - Developing a collaborative training approach with the primary mental health team

- Joint training enabled primary care mental health practitioners to develop competence in managing patients with mild/moderate aphasia and community teams to develop skills in recognising and managing psychological problems
- Reflective practice sessions for staff with the clinical neuropsychologist and IAPT clinical lead, supported case discussion to consolidate and enhance learning
- Results from the staff surveys completed six weeks after their training demonstrated learning was being translated into practice with patients
- Primary care mental health staff who attended the better communication training improved their knowledge and understanding of aphasia
- Stroke survivors with aphasia helped deliver the training and were enthusiastic about the experience

See the SIP website¹² for the costs of implementing the Dorset training package and how to apply for UKFST endorsement.

Making sustainable changes

Measurement is essential to understanding whether a service is effective and meeting the needs of patients. Ensure that psychological care provision (in all its forms from all professions) is included in routinely collected data which can be used to feedback to teams and to illustrate how the service is improving.

Psychological care is delivered through a network of professions and organisations with different methods of psychological support. The local pathway of care, its structure, roles and methods of referral should be clearly communicated to all who need to access the services. This joined up approach is aided by using common terms of reference and assessment measures.

Identifying and consulting partners/stakeholders at an early stage increases the sustainability of change. New systems and processes should be developed with all involved. The style of consultation needs to be tailored to the degree of impact of the proposed changes on each partner.

Improvements in psychological care after stroke need to be supported at all levels of the service across the whole patient pathway, including by commissioners, managers, health care professionals.

Psychological care needs to adopt a joined up approach with health, primary care, mental health and physical health, social services, and the voluntary sector all working together.

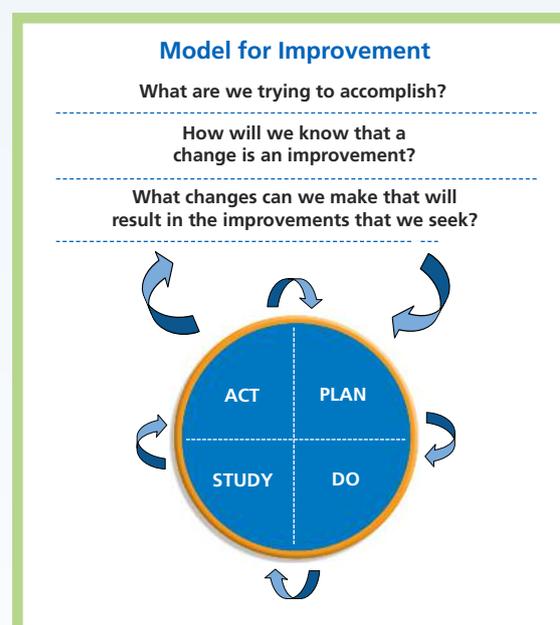
Patient and public involvement is essential.

Gaining the service user perspective through (communication accessible) focus groups, questionnaires or discovery interviews, ensures improvements are targeted appropriately and resources are invested into areas which service users are most likely to access. Involvement should be seen in service development and monitoring and but also in delivery of services such as peer support.

Clearly defined referral criteria for specialist services such as clinical psychology, protects the often limited resource, ensuring access for patients whose needs are unable to be managed by other methods.

Staff support and supervision from psychologists is essential to help the MDT understand how to manage and cope with people in distress or who are cognitively impaired. Consideration should be given to regular formal supervision, peer support and peer reflection for those delivering psychological support.

Consider using service development methodologies such as Review, Assess, Implement, Demonstrate (RAID) or Plan-Do-Study-Act cycles (PDSA) to guide and structure service development and maintenance of improvement.²⁶ The NHS Institute sustainability model²⁷ defines the key areas of the service change which need attention to optimise sustainability.



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Glossary of abbreviations

NICE - National Institute for Health and Clinical Excellence

MDT - Multidisciplinary Team

OT - Occupational Therapist

SIP - Stroke Improvement Programme

SALT - Speech and Language Therapist

SSEF - Stroke Specific Educational Framework

STARS - Stroke Training and Awareness Resources

Mood assessment measures

BASDEC - Brief Assessment Schedule Depression Cards

DISC - Depression Intensity Scale with Circles

GHQ-12 - General Health Questionnaire 12 item

HADS - Hospital Anxiety and Depression Scale

PHQ-9 - Patient Health Questionnaire 9 items

SADQ-H10 - Stroke Aphasic Depression Questionnaire Hospital Version -10 item

Cognitive assessment measures

ACE-R - Addenbrooks Cognitive Examination - Revised

MoCA - Montreal Cognitive Assessment

RBANS - Repeatable Battery for the Assessment of Neuropsychological Status

TEA - Test of Everyday Attention

BIT - Behavioural Inattention Test

RPAB - Rivermead Perceptual Assessment Battery

BADS - Behavioural Assessment of Dysexecutive Syndrome

Notes



NHS Improvement

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