Delivering Psychological Care to Stroke Survivors in Northern Ireland

Briefing Paper

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Briefing Paper

It is anticipated that up to 40% of stroke survivors and their families will need direct access to clinical psychology services at some point in their journey post stroke (NHS Improvement, 2011; 2012).

Providing the right intervention at the right time and place by the right service is vital to ensure effective outcomes and achieve recommendations set out by national drivers and quality standards (DHSSPS, 2017).

Whilst mood disturbance is often considered the most common psychological factor post stroke, there is often a wider range of presenting concerns that can also benefit from specialist psychological formulation and intervention. The aim of which is to support the process of healthy adjustment. Examples include, anxiety, behaviours that challenge, assessment and rehabilitation of cognitive difficulties, capacity assessment, carers' strain, poor engagement with rehabilitation, environmental factors, fear of falling, systemic issues, as well as management of fatigue and pain and risk assessment beyond team screening. These all respond well to evidence-based interventions provided by specialist psychological services (Lincoln et al., 2012; Sharpe & Curran, 2006; Thomas et al., 2012; Wang et al., 2018).

Currently, there is a shortfall in the number of referrals received by specialist clinical psychology services, and this in part reflects the limited capacity of service provision. It is estimated that only 30-50% of stroke survivors and their families who would benefit from direct access to clinical psychology services are currently receiving direct input by the stroke psychologists in Northern Ireland (NI).

1. Introduction

This briefing paper stemmed from discussions with the Regional Stroke Network, who were keen to understand the scope of existing psychological care across Northern Ireland. It has been written with a view to informing the various subgroups of the Regional Stroke Network and facilitating the planning of future service developments. This paper has been ratified by the Regional Clinical Psychology Stroke Special Interest Group (SIG) and endorsed by the Division of Clinical

Psychology for Northern Ireland, British Psychological Society, and the Association of Clinical Psychologists UK.

The current paper provides an overview of:

- National guidelines, quality standards and recommendations from professional bodies for the provision of psychological care to stroke survivors, their families and carers
- Current psychological care provision and providers in NI
- Gaps in service provision
- Key recommendations for service improvement and evelopment

2. Summary of Key Recommendations Proposed by National Guidelines and Quality Standards Relevant to Clinical Psychology

Guideline / Quality Standard	Key Recommendations
The National Service Framework for Older People (DoH, 2001)	• Standard 5 - Clinical Psychologists should be members of specialist stroke services.
Improving Stroke Services in Northern Ireland (DHSSPS July 2008)	• Standard 1 - Organisation of Stroke Services. Access to specialist psychology services is available for those who would benefit. • Standard 5 – Community-based care. Access to appropriate vocational, retraining and counselling, including specialist psychology services and rehabilitation support for stroke patients, where appropriate.
British Psychological Society (2010) Psychological Services for Stroke Survivors and their Families – Briefing Paper 19	• Community rehabilitation - 2.0 wte Clinical Psychologists (one of which should be a Lead Consultant Clinical psychologist and the other a Specialist Clinical Psychologist) and 1.0 wte Associate Psychologist is recommended per 500,000 population. • Routine assessments of mood and cognition are in place for each stroke service.
NHS Improvement (2011) Psychological care after stroke	• 100% of stroke survivors should be screened for mood, cognition and quality of life at various transition points post stroke.

NICE (2013) Stroke rehabilitation in adults	• Emotional functioning should be assessed in the context of cognitive difficulties. • Interventions need to consider the type and/or complexity of neuropsychological presentation and relevant personal history. • Standard 5 - Adults who have had a stroke are offered active management to return to work if they wish to do so. This process requires identification of the physical, cognitive, language and psychological demands of the job, as well as the impact of these on work performance. This will guide tailored interventions to facilitate reasonable adjustments in the workplace.
Camden REDS model of best practice for ESD (as per NICE; 2013)	• 1.0 wte clinical psychologist per 100 ESD referrals.
The Regulation and Quality Improvement Authority (2014) - Review of Stroke Services in Northern Ireland	• All Trusts recognised the value of clinical psychology in the rehabilitation and long-term management of stroke patients. This was an area of major unmet need. • Trusts should increase their provision of clinical psychology services for stroke patients.
Royal College of Physicians Intercollegiate Stroke Working Party (2012; 2016) National clinical guidelines for stroke	• Services for people with stroke should have a comprehensive approach to delivering psychological care that includes specialist clinical neuropsychology/clinical psychology input within the multi-disciplinary team. • Services for people with stroke should include specialist clinical neuropsychology/clinical psychology provision for severe or persistent symptoms of emotional disturbance, mood or cognition. • Stepped, matched and stratified care are considered the main models for psychological care provision. • Hyper Acute and Acute Stroke Units should have 0.2 wte Clinical Neuropsychologists/Clinical Psychologists per five beds.
Reshaping stroke services pre-consultation (DHSSPS, 2017)	• Seamless care pathways that ensure the right support at the right place at the right time.

For over twenty years, key needs surrounding psychological care have continued to emerge in many of the national drivers and recommendations set out for stroke services. In NI, there has been a consistent shortfall in the provision of clinical psychology services during this time, which has never been appropriately resourced or prioritised.

As a result, there has been limited development of the proposed recommendations for psychological care. A level of unmet need continues to exist across all five health Trusts.

A wealth of literature consistently highlights the links between psychological factors (e.g., mood, cognition) and poor functional outcomes. It is also widely acknowledged that poor outcomes after stroke are associated with reduced quality of life (QoL), higher mortality rates and economic costs (Lincoln et al., 2012; NHS Improvement, 2012).

As the gaps and level of unmet need in psychological care provision become more recognised, documented and apparent, the regional Clinical Psychology SIG for stroke welcomes the interest and opportunity within this review to develop services in the near future.

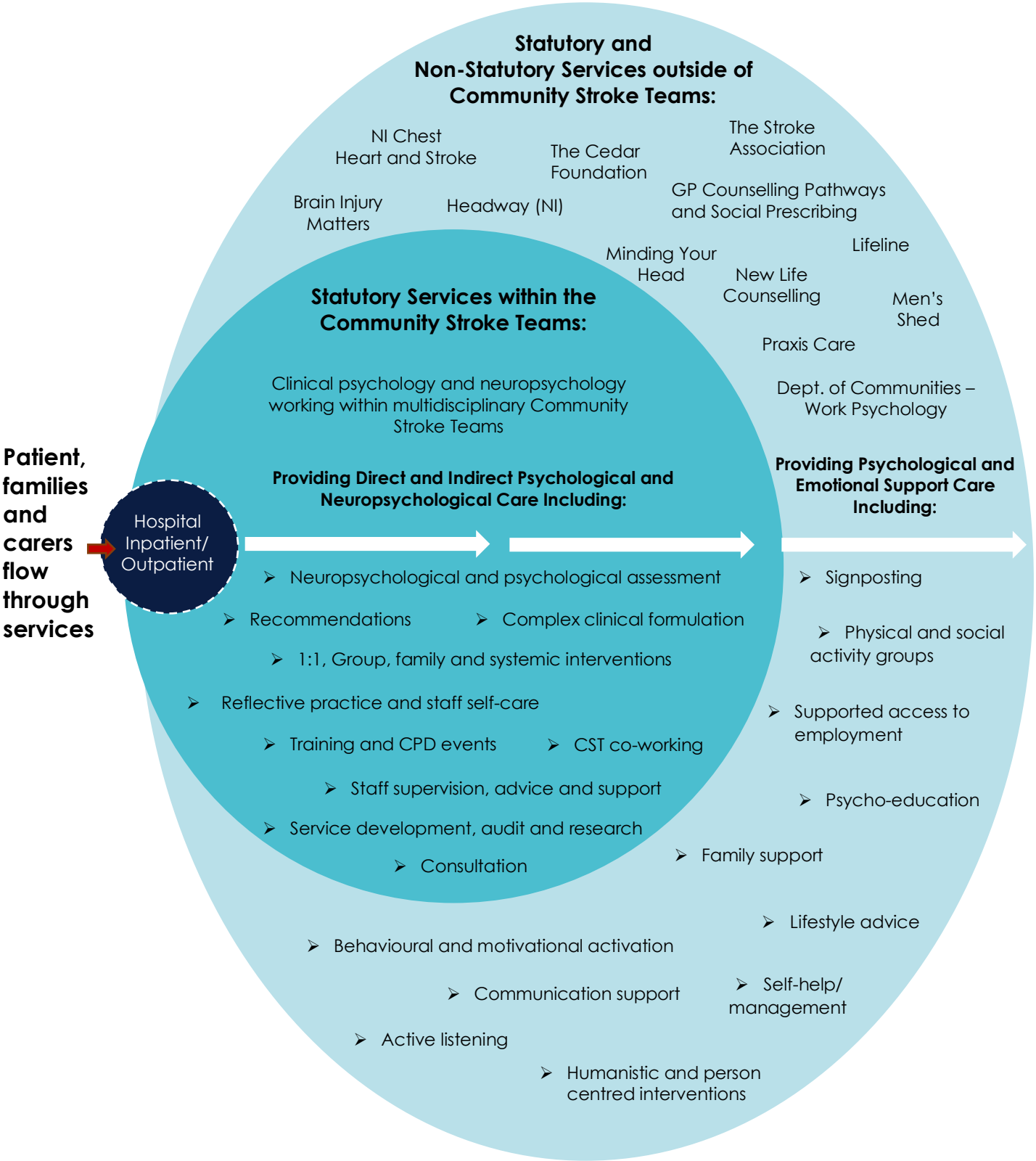
3. Current Psychological Care Provision in NI

Both statutory and non-statutory services provide input to stroke survivors and their families/carers across NI. As is the case for other neurological and long-term condition populations, statutory services are commissioned to provide essential care and services, which non-statutory servicescan build upon in order to promote consolidation, maintenance and longer-term support, including emotional support.

Figure 1 depicts an overview of statutory and non-statutory psychological care providers and services. There may be some local variation and the list is not exhaustive.

3.1. Psychological Care: Flow through Services

Figure 1
Current Psychological Care Providers for Stroke Survivors, Families & Carers in NI



3.2. Statutory Service Provision

Currently each Health Trust commissions Health and Care Professions Council (HCPC) registered and regulated Clinical Neuropsychologist/Specialist Clinical Psychologists to lead on psychological care for stroke survivors, their families and carers. Psychologists are qualified to doctorate level and are accredited and chartered through the British Psychological Society (BPS).

Clinical psychology is best placed for this lead role in contrast to other professions that are not qualified to the same level. Clinical psychology brings a breadth and depth of knowledge and skills that allows the profession to work with complexity on individual and systemic levels; either directly or indirectly. The depth and breadth of training associated with the profession over an average of six to ten years brings an understanding of neuropsychological issues (e.g., the complex interaction between emotional and behavioural needs in the context of cognitive deficits and vice versa) in a wider context of lifespan development, social, systemic, cultural and inter/intra-personal dynamics. This understanding allows highly specialist assessment, formulation and interventions that can be tailored for individuals and family/staff to promote coping, emotional well-being and the alleviation of distress; thus meeting the heterogeneous nature of stroke populations.

Health Trust	Provision
Belfast Trust	**Specialist Clinical Psychologist (1.0 wte)** Clinically supervised by Consultant Clinical Neuropsychologist and professionally accountable to Head of Psychology Services.
Northern Trust	**Consultant Clinical Psychologist (1.0 wte)** Clinical Lead for stroke psychology service. Clinically supervised and accountable to Consultant Clinical Psychologist/Manager Brain Injury Service.
South Eastern Trust	**Specialist Clinical Psychologist (1.0 wte)** Clinically supervised by Consultant Clinical Neuropsychologist and professionally accountable to Head of Psychology Services.
Southern Trust	**Specialist Clinical Psychologist (1.0 wte)** Clinically supervised by Consultant Clinical Neuropsychologist and professionally accountable to Head of Psychology Services.

Health Trust	Provision
Western Trust	**Clinical Neuropsychologist (1.0 wte)** Clinically supervised by Consultant Clinical Psychologist and professionally accountable to Head of Psychology Services.

Clinical psychologists provide services to the community stroke teams and psychological care is provided through direct and indirect services to people with stroke, their families, carers (in some Trusts) and professionals working within Trust stroke services.

Typically, direct involvement from clinical psychology is with those presenting with complex multimodal and/or moderate to severe post-stroke neuropsychological changes (behavioural, cognitive, emotional), and changes that are impacting on rehabilitation, recovery and /or daily life.

In most Trust areas there is no dedicated funding or capacity to deliver psychological input into acute services. Similarly, this is the case in meeting longer term needs at the end of the stroke pathway (e.g., beyond 18-months).

A matched/stepped care model is recommended, with screening for mood and cognition embedded across care pathway (RCP, 2016). There are a few interpretations of these models across various services and health conditions. The stepped-care approach recommended by the Regional Clinical Psychology SIG for Stroke can be found in **Appendix A** of this briefing paper. It is based on recommendations surrounding best practice as well as appropriate knowledge and skill sets (Department of Health, 1989; NHS Improvement 2011; RCP, 2016). **Appendix B** provides a summary of the Management Advisory Service (MAS) framework.

4. Gaps in Psychological Care Service Provision

Nationally, the RCP guidelines (2012; 2016) highlight that access to neuropsychological and psychological care remained inadequate across the acute and community settings. None of the five Health Trusts in NI meet the RCP recommended staffing levels for clinical psychology.

The National Service Framework for Older People (NSF) (DoH, 2001) and BPS briefing paper 19 (2010) both outline a service model, which should address four stages of the care pathway:

- Prevention

- Immediate (Acute) care/first contact
- Early and continuing rehabilitation
- Long-term support and review for the stroke survivor and their carers

Clinical psychology input is appropriate at each of the four stages identified.

As per the NSF/BPS service model, key gaps in clinical psychology provision were identified by the Regional Clinical Psychology SIG for Stroke services in NI. These include:

- **Primary Care and Early Intervention and Prevention**
  - GP surgery and wider community cardiovascular health services
  - TIA clinics
- **Hyper-Acute / Acute Inpatient Services**
  - Family/carer/stroke survivor interventions and support
  - Assessment and intervention for behaviours that challenge
  - Risk assessment and management advice
  - Provision of formal capacity assessment, consultation and recommendations
  - Preparing family and stroke survivors in the transition from hospital to community
- **Community Stroke Services**
  - Interventions for formal carers (e.g., residential/nursing homes, i.e., behaviours that challenge, person centred behavioural analysis, formulation and interventions)
  - Systemic and joint interventions for families and carers to support stroke survivor and family adjustment (including group work)
  - Return to work, including psychometric assessment and compensatory strategies to support return to work (currently this provision remains inconsistent across Trusts)
- **Longer Term Support/Living Well Following Stroke**

Psychological difficulties can occur at any time after stroke and therefore it is recommended that access to clinical psychology should be available to patients at all stages of the stroke pathway (BPS, 2010; NHS improvement, 2011; RCP, 2016; Sarre et al., 2014). This is particularly recommended for persistent mood or cognitive problems (RCP, 2016).

Example of current gaps in clinical psychology provision

- Longer term management of adjustment, coping, cognition and behaviour in the context of environmental, developmental or psychological life changes

and setbacks
- Non-verbal mood management
- Communication partners
- Befriending services
- Socialisation and isolation avoidance programmes
- Return to work

- **Younger Stroke Populations and Return to Work**
    - Psychology services should be commissioned to address the (unmet) specific psychological needs of younger stroke survivors. These include hidden cognitive deficits, identity and adjustment, as well as return to work.
    - Employment is a key psychological outcome and indicator of successful rehabilitation (NICE, 2013). Individuals are entitled to a full neuropsychological (cognitive) assessment to facilitate a return to work. Currently, this provision remains inconsistent across Trusts and is at times provided by non-specialist services or not at all.
- **Working with Staff Groups across the Stroke Pathway (including Acute, Community, Voluntary Sector)**
    - Co-working, facilitating reflective practice and neuropsychological CPD for other professionals.
    - Training across the stroke pathway
    - Training Audit 2019 revealed that between 38% and 49% of community-based staff did not feel competent in working with psychological changes after stroke.
    - Consultation
    - Supervision
    - An interdisciplinary approach to psychological care is integral to the delivery of matched/ stepped care.
- **Service Development**
    - Strategic planning in the development of psychological services
    - Audit
    - Research
    - Workforce planning and recruitment

Further information on the recommended roles, service structure and organisation of clinical psychology in stroke services can be obtained from the British Psychological Society (BPS) Stroke Briefing Paper No 19 (2010) which provides a comprehensive overview.

A number of recent guidelines also highlight the wider impact and role that clinical psychologists can have beyond direct 1:1 patient contact (e.g., Working in Teams, BPS 2001; Inpatient Best Practice, DCP 2017; Psychological Leadership Framework, DCP, 2010; NHS Improvement, 2012).

5. Key Recommendations for Service Development

1. Prioritisation around investment and allocation of clinical psychology resources

- Significant investment is needed to ensure provision of neuropsychology and clinical psychology services across the primary care, acute, community and long-term care pathways. This would help to secure the right support, at the right time, at the right place with the right profession. Clinical psychology has the knowledge and skill set to meet key recommendations from National Guidelines (BPS, 2011; Department of Health, 1989).

Having additional Clinical Psychologists/Neuropsychologists in post will facilitate further development of matched/stepped care referral pathways and allow expansion of indirect clinical work.

2. Recommended staffing level and mix

- Hyper Acute and Acute Stroke Units should have 0.2 wte Clinical Neuropsychologists/Clinical Psychologists per 5 beds (RCP, 2016).
- Community rehabilitation services should have access to 2.0 wte Clinical Psychologists, one of which should be a Lead/Consultant Clinical psychologist and the other a Specialist Clinical Psychologist. An additional 1.0 wte Associate Psychologist is also recommended per 500,000 population (BPS, 2010, 2015).

Potential cost savings in developing psychological services have been well documented (NHS Improvement 2012; BPS 2010). For a review of the key benefits and roles of a consultant led model of care as well as various staffing grades within clinical psychology, readers are directed to the Inpatient Best Practice Guidelines for Older People (DCP, 2017), which provides an overview of the same.

A number of workforce and skill mix planning tools have also been recommended by the National Stroke Service Model – Integrated Stroke Delivery Networks document (NHS England NHS Improvement, 2021). Two key examples include, the Health Education England (HEE) Star Tool and Stroke Specific Education

(competency) Framework (SSEF); both of which could support planning of longer-term workforce needs in order to optimise the delivery of best practice models, such as matched/stepped care across NI.

3. **Ensure emotional, psychological and neuropsychological needs are matched with evidence-based interventions at the right time using appropriate knowledge and skill sets.**

    - Whilst non statutory agencies and charities are well placed to build upon services provided by statutory sectors, they should not be considered as an alternative or substitute option. A summary of evidence-based interventions can be found in **Appendix C**.

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Appendix A

Recommended Stepped Care Model for Psychological Care in NI

A matched/stepped care approach is recommended by professional working groups and national guidelines (e.g., NICE, 2008; RCP, 2016; NHS Improvement 2011). A stepped care model has the potential to deliver a significant financial cost benefit and thus reduce the cost burden of stroke (NHS Improvement, 2012).

The model highlights that all stroke patients will have psychological needs at some point in their journey of recovery, but not necessarily need to see a psychologist. It promotes timely and appropriate access for those (complex cases) that need clinical psychology / neuropsychology directly (step two and three), but also ensures that staff are supported in their recognition and management of neuropsychological changes after stroke (steps 1 and 2). Whilst stepped care is a hierarchical approach that matches intervention to patient need, flexibility is built in so a patient might for example, progress through all steps sequentially or they might come straight from step 1 to step 3 (essentially promoting Matched Care; RCP, 2016).

Successful provision and benefits of the stepped care model require implementation of core recommendations, as proposed by the Stroke Strategy (2008) and wider evidence base provided within National Guidelines (NHS Improvement, 2011; RCP, 2016). The recommendations suggest:

- A matched/stepped care model is adopted.
- Integrated acute, community and social care services
- Access to 6-week and 6-month reviews
- Screening for mood routinely embedded in practice several times post stroke
- Screening for cognition
- Screening is essential to the success of matched/stepped care, as it determines access to direct neuropsychology services if needed.
- The current recommended stepped care model for NI is depicted below.

Screening is essential to the success of matched/stepped care, as it determines access to direct neuropsychology services if needed.

The current recommended stepped care model for NI is depicted below.

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Stepped Model of Psychological Care for Stroke Services

(Adapted from NHS Stroke Improvement-Psychological Care After Stroke, 2011)

Regional Clinical Psychology/Neuropsychology Group for Stroke

Recommended by the Royal College of Physicians (2013; 2016)

LEVEL OF NEED	ROLE OF CLINICAL PSYCHOLOGY SERVICES	TYPES OF INTERVENTION
- Persistent moderate – severe symptoms - Complex multiple presentation - Significant impact on rehabilitation & function - Minimal response to step 1&2 interventions	**STEP 3** **Clinical Psychology** Providing direct neuropsychological assessment, formulation and intervention	- Highly specialist psychological and neuropsychological assessment and management - Individual and systemic/family interventions addressing multiple presentation and need

- Mild-moderate symptoms of impaired behaviour, cognition and mood
- Impact on Rehabilitation and Recovery
	STEP 2
	Interventions
	Clinical Psychology working directly and indirectly
	
	Supporting teams via psychological training, consultation, reflective practice, co-working cases and supervision
		- Screening and routine monitoring of mood, cognitive and behaviour
		- Screening for carers
		- Group interventions (e.g. Guided self-management, ACT, Cognitive rehabilitation)
		- Single stage CBT approaches
		  o Promoting problem solving, solution focused therapies
		  o Motivational goal setting, behavioural activation
		  o Anxiety management
		- ABC interventions for challenging behaviours

- Mild transitory symptoms - Common reactions to a sudden unexpected life transition, distress, tearfulness, disrupted coping, worry, perceived fatalistic consequences - Limited impact on rehabilitation	**STEP 1** **Team Management** Clinical Psychology working indirectly: Providing psychological training, consultation and advice, reflective practice and supervision	- Screening and routine monitoring of mood/cognition - Facilitating staff recognition, responses and reporting of psychological changes after stroke (e.g. mood, behaviour, cognition, pain, fatigue, etc) - Chest Heart & Stroke programmes - Stroke Association programmes - Statutory & Non-statutory services - Watchful waiting – acknowledge, validate & normalise not minimise! - Active listening & information giving - Humanistic & Person Centred Interventions (e.g. counselling) - Basic principles of Cognitive Rehabilitation - Promoting engagement with activities and roles for physical, emotional and social wellbeing, for both stroke survivor and carers support - Psychoeducational, self-help and skills groups

Psychological care us everyone's business!

All stroke survivors and their families will have psychological needs at some point in their journey – but not necessarily need to see a psychologist

Appendix B

MAS (1989) Framework - Level of Psychological Knowledge and Kkills Needed for Stepped Care Model

The Management Advisory Service (MAS) review (MAS, 1989) of Clinical Psychology (CP) services has become the basis of many papers and guidelines today. Most notable is the proposed skills framework which is still applicable today. It provides useful guidance and understanding around psychological knowledge, skills, and levels of intervention and in particular the role of formulation as a skill and intervention in its own right (BPS, 2011).

This framework can be mapped onto stepped care as follows:

Level 1 Skills for Step 1 – typically involves mild 'normal' transient concerns post stroke, which can benefit from supportive relationships/active listening and supportive counselling (e.g., humanistic and person centred), psychoeducation, self-help, behavioural activation, lifestyle advice and support groups. Interventions at this level do not utilise a formulated and/or formal psychological approach. These can be delivered by stroke nurses and MDT under supervision/consultation from CP or non-statutory agencies such as voluntary sector. Patients can also avail of GP counselling and wider services such as Lifeline at this level. This is already the case in a number of Trusts.

Level 2 Skills for Step 2 – moderate impairment in cognition and/or mood/adjustment reactions which benefit from standardised problem specific formulations/circumscribed psychological support, for example (adapted) Cognitive Behavioural Therapy (CBT). These protocol-based formulations and interventions can be provided by qualified Clinical Psychologist and/or associate psychologists (B5) and/or by supporting rehabilitation staff in the application of psychological techniques, under the supervision or consultation of highly specialist clinical (neuro) psychologist. The difference from generic CBT is the added knowledge of brain behaviour relationships and neuropsychological sequelae post stroke that clinical (neuro) psychology can integrate into the formulation and oversee.

Level 3 Skills for Step 3 – severe and complex cognitive/mood/adjustment/behavioural changes post stroke that require level 3 skills – specialist psychological interventions based on multi-modal integrated formulations drawn from a broad theoretical knowledge base.

Whilst a Clinical Psychologist can operate at and oversee all levels, only a Clinical Psychologist can operate at level 3. Within stroke however, step 2 also requires knowledge around brain behaviour relationships and neuropsychological sequelae post stroke that clinical (neuro) psychology can provide. This will ensure structured formulated approaches that can be delivered by CP services.

Appendix C

A Brief Overview of the Evidence Base for Psychological Interventions Post Stroke

Stroke specific research is limited but growing, and therefore many recommendations stem from health psychology, long term conditions (LTC), older people's services and brain injury literature. These populations are closest in nature to stroke, as opposed to what works for patients in adult mental health services.

Working with Individuals

In relation to mood disturbance post stroke, there is good evidence for behavioural activation, which includes patients with reduced cognitive and communication abilities (Lincoln et al., 2012; Thomas et al., 2013).

There is a growing evidence base for adapted and tailored Cognitive Behavioural Therapy (CBT) (Wang et. al., 2018), Motivational Interviewing, Acceptance & Commitment Therapy (ACT) as well as Mindfulness for mood, pain and fatigue management (Lincoln et al., 2012 provides a summary). CBT is effective in managing psychological distress associated with ill health and LTC's but requires at the very least a structured formulation of the problem (step 2 intervention). For significant issues (upper end of step 2 and step 3) evidence highlights a need for anything between 12 and 20 sessions (Sharpe & Curran, 2006).

Further research is required to establish the effectiveness of other psychological approaches in stroke.

Knowing what works for whom and at what point is key – screening and consultation/formulation by clinical psychologists are skilled ways to decipher the same (Lincoln et. al., 2012).

A recent review of non-randomised controlled studies for interventions on cognitive function post stroke highlighted promising evidence for neuropsychological approaches; in particular for the domains of attention and memory impairment (Merriman et al., 2019).

Working Systemically

Panzeri and colleagues (2019) completed a systematic review on psychological interventions for carers post stroke. They concluded that a psychologist-led tailored intervention such as CBT showed more positive outcomes with regards to carers

strain and mood disturbance in informal carers of stroke patients. They recommend that such an approach should be integrated as part of the stroke rehabilitation process to improve carer QoL and well-being, and thus patient outcomes.

Clinical psychologists can play a vital role in upskilling and supervising occupational therapy colleagues in the screening, assessment and management of cognitive difficulties after stroke (Kontou, et al., 2020).

Timing of Intervention

There is evidence to support both early (e.g., motivational interviewing (Watkins et al., 2007) and later intervention CBT (Lincoln & Flanaghan, 2003), with some researchers recommending early intervention and others arguing for later. Key is knowing what works for whom and at what point (Lincoln et al., 2012). Evidence from adjustment models (Ch'Ng et al., 2008) and research regarding interventions for carers (Cameron & Gignac, 2008) suggest that both patients' and carers' needs change throughout recovery: earlier stages tend to be characterised by a need for information, reassurance and practical support whereas individuals may be more focused on emotional adjustment in later stages.