Keeping Stroke Recoveries in Mind

Our calls for increased prioritisation of psychological care within stroke services in Scotland

Rebuilding lives after stroke

Stroke Association

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Executive summary

You can't always see the damage a stroke causes. It's hidden inside. But we know it's one of the biggest issues for people and their families. Emotional and psychological wellbeing for someone after a stroke is just as important as their physical recovery.

The problem is known about but not being dealt with by our health boards. The forthcoming revised Stroke Improvement Plan must be a point for change.

Emotional and psychological care should start as soon as someone is diagnosed with a stroke. A model to deliver this has been developed by the Scottish Stroke Psychology Forum. It's a four level, tiered approach involving all stroke nursing and health care staff, with a clinical psychologist overseeing things.

This is what we need to see happen.

Foreword

Having a stroke is a life-changing event. It affects around 10,000 people every year in Scotland and there are more than 128,000 people in the country living with the long-term consequences of their stroke.

Rehabilitation is a vital, and an often overlooked, part of the stroke pathway. While having a stroke is a devastating event in itself, the recovery period and process of adjustment for stroke survivors can be long and challenging.

We know that the physical impact of stroke is huge with around two-thirds of people leaving hospital with a physical disability after their stroke. However, a person's thinking, behaviour and emotions are also significantly impacted too but often overlooked.

We are now presented with an opportunity to change this. The imminent Stroke Improvement Plan presents an opportunity to create services that are fit for purpose in meeting people's needs after their stroke. Striving for holistic rehabilitation means incorporating good psychological care into core Clinical practice. To achieve this, those working in stroke care must be given the appropriate education and training as well as feel supported in their roles to deliver this holistic model of care.

This is not about having lots and lots more psychologists - at it's core, it's about stroke being seen and treated differently by everyone working in stroke care.

This report provides a model which will help alleviate pressures in this ever-growing area and I know the Cross-Party Group on Stroke will do whatever it can to make sure the change that is required, happens.

Gillian MacKay MSP

Convenor of the Cross-Party Group on Stroke

The Cross-Party Group on Stroke is formed of MSPs, clinicians, third sector organisations and individuals with an interest or lived experience of stroke. The group meets throughout the year to discuss relevant issues and drive forward improvements in stroke treatment and care throughout Scotland.

Background and context

A stroke happens when the blood supply to part of the brain is cut off, killing brain cells. Damage to the brain can affect how the body works. It can also change how you think and feel. The effects of a stroke depend on where it takes place in the brain, and how big the damaged area is.

Stroke is a leading cause of death and long-term disability in Scotland, as well as a driver of large lifetime care costs[1]. There is overwhelming evidence that the economic burden of stroke is rising[2]. Recent projections suggest the health care spending on stroke in Scotland is likely to rise by 280% or £402 million between 2015 and 2035[3]. If we can improve both the physical and psychological outcomes of stroke in Scotland then we can reduce the economic burden of the condition.

Having a stroke is a distressing experience for individuals and their families. It affects every aspect of their lives, what activities they can engage in, the nature of their relationships and their sense of identity. Traditionally services have focused on physical health, but rehabilitation that fails to incorporate meeting psychological and emotional needs results in poorer outcomes, greater physical disability and increased costs of care for society.

For years, campaigners have advocated for parity between physical health and mental health. In some areas, advancements have been made. It was encouraging when the Scottish Government published its Mental Health Strategy in 2017. This 10-year plan looks to tackle prevention, access to treatment and long-term planning of mental health services amongst other things.

Awareness of psychological needs and its impact is crucially important within the clinical setting. Effective psychological care involves all health care professionals understanding and integrating the psychological and emotional needs of survivors and their loved ones into all clinical practice. It involves understanding how these needs impact on rehabilitation and how services can enable and facilitate an individual's adaptation to the emotional, cognitive and behavioural changes brought about by a stroke, such that they can recover effectively.

In stroke care, we do not have parity between the physical and psychological care offered to people after their stroke. But now we have an opportunity to change this.

Improvements in survival rates have been made over the last decade. We must ensure we have adequate services in place to ensure people can live well after their stroke too.

> **"Emotional and psychological wellbeing for someone after a stroke is just as important as their physical recovery."**
>
> **John Watson, Scotland Director, Stroke Association**

What does the evidence tell us?

A breadth of evidence exists which confirms that people's psychological needs are not met after their stroke. Much of this evidence comes from before the pandemic. In our 2019 UK wide report Lived Experience of Stroke[4], we found that 44% of people experienced anxiety and 44% experienced depression after their stroke. While the NHS has faced the biggest challenge in its existence in the form of Covid-19, we cannot allow ourselves to think that the situation was any better beforehand.

93% experienced mental health issues following a stroke, including lack of confidence, anxiety, depression, mood swings or suicidal thoughts

9 out of 10 stroke survivors experience at least one cognitive effect. This is the same number as those who experience at least one physical effect.

During the pandemic, the psychological and emotional needs of stroke survivors grew. Our 2020 UK-wide report, Stroke Recoveries at Risk[5], found that 69% of stroke survivors reported feeling more anxious or depressed during the pandemic. More concerning, 59% of stroke survivors also said they had received less support from health and social care services than usual.

We also know through our work with the James Lind Alliance[6] that "psychological and emotional" problems are an area that is viewed as a priority for research too by both people affected by stroke and health and care professionals.

We know that psychological care is an area where stroke patients are being let down. We can change this.

Policy context

The Stroke Improvement Plan[7], published in 2014, outlined the Scottish Government's priorities and actions for stroke to deliver better prevention, treatment and care. Although the Government acknowledged that: "Patients with stroke are assessed for visual, cognitive, emotional and psychological issues and have access to services" we have not seen required significant improvements in this area. The latest Scottish Stroke Care Audit figures show that only one Health Board had completed and embedded in practice "access to specialist clinical neuro-psychological services". The audit data tells us that access to psychological care is the poorest performing category of all of the stroke improvement priority categories.

In March 2022, the Scottish Government published the Progressive Stroke Pathway[8]. This sets out a vision of what progressive stroke care in Scotland should comprise. In the document they acknowledge the need for holistic, person-centred rehabilitation and state that:

"In the aftermath of stroke, patients and families experience a wide range of psychological, cognitive and emotional difficulties which impact profoundly on function and rehabilitation.

Stroke services should implement a documented programme for promoting awareness of, screening for and treatment of psychological consequences of stroke, led by a specialist clinical psychologist or neuropsychologist as detailed in the National Model of Psychological Care for Stroke. Psychological care should be available to all patients in line with local delivery plans."

We are encouraged by this and want to do all we can to ensure it becomes reality. We are calling on the Scottish Government to commit to a number of recommendations in the upcoming Stroke Improvement Plan to make psychological care a priority in stroke treatment and care.

Paula's story

"All I needed to be asked was how I was feeling"

Life was pretty normal for Paula, 41 from Glasgow. Married to Gerry, working full-time with a list of fun challenges planned, it was like a bolt out of the blue having a stroke.

Paula was admitted to hospital after a series of seizures, and was diagnosed with a haemorrhagic stroke due to a cavernoma – a cluster of abnormal blood vessels.

Whilst the stroke left Paula physically unaffected, her mental health had been severely affected. Her anxiety was completely different to any other anxiety she'd experienced before, leaving her feeling scared and alone, unable to process information and have a conversation.

Fortunately, the hospital staff were kind and empathetic and had identified Paula's low mood and anxiety. They helped her to understand and process what was going on. This really helped. However, Paula did come across some professionals that wanted to treat Paula's physical problems, without taking account of her anxiety. Paula then met a doctor who could describe exactly what she was feeling, and that it was a common and debilitating effect of the stroke. She was put on a waiting list for psychological support and referred to a mental health nurse in the community.

Paula returned home still struggling to cope emotionally and felt unable to do almost anything. Friends and family were a huge support and eventually Paula started to have some good days.

Paula feels that her family and friends have been her mainstay for coming to terms with the impact of her stroke. She knows this isn't an option for everyone.

"I believe empathy and kindness showed towards me in hospital really helped guide me in the early days of my recovery. If people at every level working in stroke, understand and are trained to identify the emotional symptoms of stroke, then everyone will benefit."

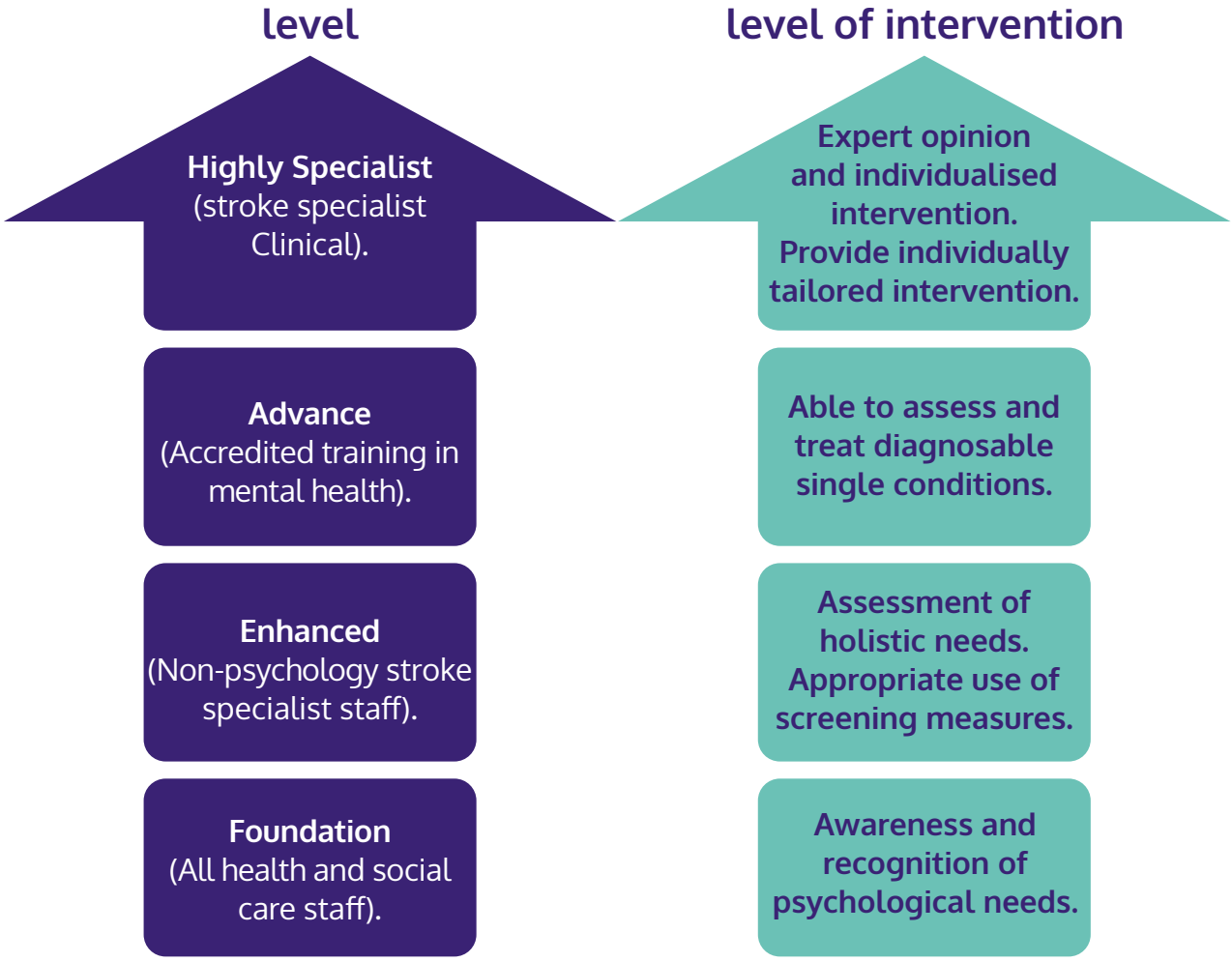
National Model of Psychological Care in Stroke Services in Scotland

The Scottish Stroke Psychology Forum (SSPF) developed the National Model of Psychological Care in Stroke Services (Scotland) (NMPCS).

The model provides a framework and pathway which defines the appropriate assessment and intervention of psychological need that should be available to those affected by stroke. The NMPCS-Scotland is consistent with approaches developed for psychological care in stroke in England[9] and for other clinical populations with long term health conditions[10,11,12,13,14,15].

The model recognises the roles that all members of stroke teams can play in providing psychological care, acknowledging the training and clinical supervision needs of staff to ensure that the psychological care provided is safe and effective. Included in this model is both the emotional, and cognitive effects from a stroke and the relevant assessment and interventions required.

This model is closely aligned with the vision and principles of the National Clinical Strategy for Scotland[16], which are: a focus on quality, change guided by evidence, allowing people and communities to manage their own health, new models of community-based provision, equitable access, encouraging collaboration and the implementation of Realistic Medicine[17].



Amy Mulroue, Clinical Psychologist

Sometimes people don't fully understand what a stroke is or are distressed by feeling a burden to their families. Some want to return to work or are concerned about looking after their young children. Some are struggling to understand why they feel so upset when they've been told they've made a 'good recovery' and know other people are worse off after stroke. Some are trying to 'just get on with it' but are finding it difficult to look in the mirror at how their body has changed. Everybody's experience of stroke is different, and that is reflected in the breadth of the role of a clinical psychologist working in stroke.

We work with people who have had a stroke, and their families to help them understand the cognitive, emotional and behavioural changes they may be experiencing. Clinical psychologists administer standardised cognitive assessments to get an understanding of the strengths and weaknesses in thinking skills and to identify strategies which can help the person to engage in the activities that are important to them. We use adapted evidence-based therapies to help people after stroke to understand their emotional reactions, to what is a sudden, very frightening, and sometimes traumatic experience, and to make sense of and manage the other 'hidden' difficulties after stroke, such as pain and fatigue, as well as mood and cognitive changes.

These hidden difficulties can prevent people from feeling able to engage in their rehabilitation, so clinical psychologists join multi-disciplinary team discussions, across different teams, to share and aid psychological understanding of what may be going on for that person. Clinical psychologists work with someone 1:1, facilitate groups, and provide consultation to other professionals. We work with the team members who already have good relationships with the person, to support psychological interventions to help engage with activity, manage changes in personality, or manage distress associated with limited recovery. Providing regular teaching and supervision to other professions involved in stroke care to is essential to build and support skills in providing psychological care.

Furthermore, because there aren't many clinical psychologists working in stroke, it is important to evaluate and develop services, to try and make the limited resource spread as widely as possible. This involves engaging with and collaborating in research and audit to improve the quality of care experienced by individuals and their families.

Dr Amy Mulroue,
Clinical Psychologist and member of Scottish Stroke Psychology Forum

Prioritise: Psychological care

The tendency to think of stroke as a condition that only affects someone's physical health is contributing to people not receiving the psychological care they need.

For the 10,000 people in Scotland who have a stroke every year, the physical severity will vary. However, we must not underestimate the huge emotional impact this major event could have on them. We consulted with over 100 stroke survivors across the country to better understand this crucial area.

94% of people said that they experienced at least a mild impact on their psychological and emotional wellbeing after their stroke

39% reported either a severe or very severe impact on their mental or physical health after their stroke

¾ of respondents report that they didn't get enough support in hospital

68% of people did not feel they got enough support once they were home from hospital

87% of Stroke survivors in Scotland report they want to see equal access to physical and psychological care within their rehabilitation

Despite this, only **25%** report to have received enough mental health support once they were home from hospital

"I felt after one conversation 'you look well and have no lasting physical aftereffects so get on with it'." **Survey Respondent**

"I had very little support in hospital and the week after I got home Covid rears its head and I saw no one for 10 weeks." **Survey Respondent**

"[patients] need to be made aware of how anxious you become e.g. panic attacks and how to manage them." **Survey Respondent**

"6 months after my stroke and after quite serious depression, low mood, anxiety and behavioural changes I was referred to a psychiatrist but only after my after intervention and advocacy on my behalf by my family. Prior to that I paid privately to see a specialist neuropsychologist because I was told there was no provision in my local area. Had my family not proactively advocated on my behalf there would have been nothing?" **Survey Respondent**

"No one prepares you for the devastating changes to your life that lie ahead." **Survey Respondent**

It is important that we raise awareness of the psychological (cognitive and emotional) impact of stroke to build momentum for change to how care is delivered.

Awareness raising must be achieved both on the ground within stroke teams but also within health board senior leadership. Without awareness at leadership level, funding and resource will not be directed to this area and as such services will be underfunded and cease to exist. As a result, people will continue to suffer after their stroke.

This is not a new problem. Almost 10 years ago, in 2013, we asked stroke survivors similar questions. The results were equally as poor. Almost two-thirds agreed or strongly agreed that their emotional needs were not looked after as well as their physical needs. Similarly, although 67% had experienced anxiety and 59% felt depressed, over half of those who responded to the survey did not receive any information, advice or support to help with anxiety or depression. Almost 10 years has passed and the picture is equally as shocking.

Recommendation 1:

Health boards to implement the National Model of Psychological Care in Stroke Services (Scotland).

Prioritise: Workforce

To be able to improve any stroke service effectively, an appropriate staff resource is essential. Currently, stroke psychology provision is an area of critical concern. In some NHS health boards, it is non-existent.

The Progressive Stroke Pathway makes clear that psychologists are core members of the multi-disciplinary team (MDT). However, there are only 7.8 whole time equivalent psychologists with stroke services in Scotland.

The value of psychologists to patients, families and services goes beyond direct therapy with a patient. By being embedded within MDTs, psychologists can then begin to work within the team to support them to integrate physical and psychological factors into their recovery and rehabilitation, thus becoming holistic practice. They do this by being present and available for training, supervision, and consultation, by modelling ways of working and by sharing formulation and a holistic understanding of the impact of stroke for that individual.

Currently, no health board has a staffing level that is meeting clinical guidelines. And as there is no adequate mechanism for auditing the pathway of psychological care for services that sit out with the stroke pathway, there is no way to fully understand how many people are being offered the care they might need.

Stroke care guidelines state that it is vital that clinical psychologists with expertise in stroke or clinical neuropsychologists must be embedded within the stroke MDT[19]. This applies to teams in acute, post-acute rehabilitation and community settings to develop, apply and promote the proper application of psychological knowledge, skills and expertise during direct and indirect clinical work (i.e. consultancy, supervision, teaching, research and audit)[20].

However, even with this being adopted into clinical guidelines, the provision of clinical and neuropsychology services has lagged behind the provision of new stroke units and services, resulting in significant unmet psychological needs of individuals and families.

Despite the brilliant and determined efforts from stroke doctors, nurses, AHPs, paramedics and their teams to care for patients, psychological care across Scotland is patchy due to challenges which includes lack of suitably qualified staff and training opportunities.

Whether you receive the care you need depends on where you live and who treats you.

The SSPF undertook a scoping exercise (2020) to ascertain which health boards in Scotland had dedicated psychology resource and found that over half did not[18].

Recommendation 2:

Ensure there is an appropriately resourced workforce to enable Clinical Psychologists to lead on the implementation of psychological care model.

Prioritise: Education and training

Underpinning this model is the belief that all members of stroke teams have a role in assessing and managing psychological care. It's widely recognised that psychological care should be provided as part of the normal course of holistic post-stroke care. To enable this to happen, all members of the stroke team must be giving relevant training, development, and ongoing support to ensure they are able to carry out assessment of someone's psychological needs.

The model has 4 levels which allows all health and social care staff to be proactive in enquiring about an individual's emotional and cognitive needs and assess any psychological distress. The aim is to build, support and maintain a psychologically skilled workforce that is able to provide effective psychological care which is intrinsic to rehabilitation intervention.

> **"You have to find your own resources and that puts a lot of pressure on the carer. You are just left to your own devices."**
>
> **Janette, Stroke Carer**

It is estimated that by increasing the Stroke clinical and neuropsychology resource to 25% of the recommended provision would enable implementation of an evidence-based education and training programme for all staff working in stroke services. It is anticipated that this would also impact on the waiting times for psychological assessment and intervention, therefore providing a more timely and equitable service for those in need post-stroke. Often, family and third sector services can also have a significant role in providing psychological care. Central to this is making sure that the individual and their carer or family member know where to go to access these services. This should all be built into their personalised rehabilitation plan.

Recommendation 3:

Develop and implement evidence-based education and training programme about psychological care for all staff working in stroke services.

"You don't need to pamper people but help them to understand what might happen to them. Offer more emotional and psychological support."

Ted, stroke survivor

"Being given information at the start would have helped me to understand, it was only when the psychologist started to talk about the stroke as going through the grief process and it was when she was explaining that, I could see the patterns. You need to be told that this is how things might affect you, it would give people an understanding of what might happen to them."

Lesley, stroke survivor

"The recognition of psychological needs in stroke care has been extensively documented over the past 15 years. This recognition however has not translated into clinical practice with patients and their families consistently reporting a lack of psychological care. Whilst the physical care of stroke patients has improved significantly over the years, the dualism of physical and mental healthcare continues to exist in the organisation of services and in the way healthcare workers are trained, posing a barrier to the delivery of holistic rehabilitation. Psychologists are trained in the integration of bio-psychosocial information and are well placed to lead and support stroke teams to deliver on the provision of holistic care. As such I welcome the Scottish Government's recognition in the Progressive Stroke Pathway that psychologists should be core members of stroke teams."

Dr. Luke Williams, Consultant Clinical Psychologist

Prioritise: Data

To support quality improvement and reduce unjust variation of psychological care we must ensure we are gathering the right data to monitor progress and identify where change may be needed. We must change how we collect data across the pathway, but especially in rehabilitation – both in community and primary care settings – to include patient reported outcomes.

In Scotland there is currently very limited data collected for rehabilitation, especially in relation to psychological care. Whilst we recognise that there has been commitment to "revise and expand" performance targets to reflect the priorities in the revised Stroke Improvement Plan there must be specific focus put on patient reported outcomes across the full rehabilitation pathway. This auditing process should ensure staff are fully committed and supported to this delivery of care and allow for best practice to be learned from across the country.

Only patients can tell us if they have felt an equal partner in their rehabilitation.

Only they can tell us if they have felt empowered and supported.

Only they can tell us if their psychological needs have been met.

Recommendation 4:

Pursue a broader approach to service evaluation. Develop a model alongside the Scottish Stroke Care Audit team so that patient reported outcomes and experiences can be captured and used within model evaluation.

"Having worked in Stroke care for over 15 years, one area that is repeatedly mentioned by patients and relatives is the lack of psychological services in treating and supporting stroke survivors and their families.

Although the wider stroke team all have a role to play in providing psychological support, we particularly note the insufficient NHS funding and provision of clinical neuropsychologists. I also work as a Neurologist, and have seen first-hand the benefit of a dedicated neuropsychologist service to inpatients with neurological problems. This brings better and timely assessment of patients with neurological problems, but also benefits the wider clinical team and relatives of patients to understand and support patients. The lack of such a service for stroke patients in many areas in Scotland needs to be urgently addressed and properly funded."

Dr John Reid, Consultant Neurologist, Aberdeen Royal Infirmary

Ruth's story

"I had two strokes when I was 30. The effects were worse with the second one. It affected my walking, my speech and left me with depression and anxiety. My emotions were overwhelming, and there were times when I couldn't cope.

Peoples' awareness of the psychological effects of stroke is important, yet they often go unnoticed. I'm working with the Stroke Association to highlight that a stroke can affect people in lots of different ways, especially their emotional and psychological wellbeing.

I would also like people to understand that a stroke does not affect peoples' whole self. I'm still a person, still need to work, still have fun, still see my friends. Being three seconds slow at remembering something doesn't make you stupid, or quiet, it just means your stroke takes a little bit longer to get through. We're not just people affected by stroke – we're real people."

My family share my thoughts. Mum said that although she was impressed in the way the healthcare professionals worked together, she feels there is a need for better psychological care in hospital following a stroke.

I'm fortunate to have made the recovery I have, and am back working, enjoying my hobbies and proud to be fundraising for the Stroke Association. Not everyone is as lucky as me. We need to do all we can to help others."

Researcher: Dr Terry Quinn

Dr Terry Quinn is a Reader and Honorary Consultant Physician based in the University of Glasgow. Terry's research looks to improve how clinicians look for, and look after, the emotional, psychological and cognitive problems that can follow stroke. Terry's research helps clinical teams give the best care to their patients, assists policymakers in developing stroke services and helps researchers plan future studies. All these activities ensure that we continue to drive forward improvements in the care we offer stroke survivors.

Speaking on this issue, Terry said "We are all aware of the physical issues that can be caused by stroke, such as difficulty walking or speaking. However, there are many other stroke problems that are less visible but just as important. People living with stroke often say that their biggest issues are psychological – in particular feelings of depression or anxiety. These 'unseen' problems can have a massive impact on a person's recovery from their stroke. This report highlights the importance of emotional problems and reminds us that we should be assessing for these problems so that people living with stroke and their families get the support they need."

Summary of Recommendations

Main ask: NMPCS-Scotland model included within Stroke Improvement Plan and implemented across all 14 health boards

Recommendations: ensure right conditions are in place for the model to be effective:

Recommendation:

1. Health boards to implement the National Model of Psychological Care in Stroke (Scotland).

Recommendation:

2. Ensure there is an appropriately resourced workforce to enable clinical psychologists to lead on the implementation of psychological care.

Recommendation:

3. Develop and implement evidence-based education and training programme about psychological care for all staff working in stroke services.

Recommendation:

4. A broader approach to service evaluation. Develop a model alongside the SSCA team so that patient reported outcomes and experiences can be captured and used within model evaluation.

Glossary of terms

- **Psychological Care:** Psychological care is an umbrella term that incorporates any care, treatment, or intervention provided that has a focus on improving psychological well-being.
- **Clinical Psychologist:** A clinical psychologist working in stroke is concerned with understanding the many biological, psychological and social factors that contribute to how a person experiences their stroke and its consequences. The integration of this information supports patients, families and healthcare workers towards a comprehensive rehabilitation programme, which includes the provision of psychological care.
- **Clinical Neuropsychologists** are clinical psychologists who have further specialist knowledge, training and qualification in applied clinical neuropsychology.
- **Psychiatrist:** a medically qualified doctor who deals with mental illness, as well as the interaction between physical and mental illness.
- **A Neuropsychiatrist** is a psychiatrist with subspecialist training in treating patients with mental disorders related to brain damage or disease.

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When stroke strikes, part of your brain shuts down.
And so does a part of you. That's because a stroke happens in the brain, the control centre for who we are and what we can do. It happens every five minutes in the UK and changes lives instantly. Recovery is tough, but with the right specialist support and a ton of courage and determination, the brain can adapt. Our specialist support, research and campaigning are only possible with the courage and determination of the stroke community. With more donations and support from you, we can rebuild even more lives.

Donate or find out more at **stroke.org.uk**

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