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Purpose of this document

The Integrated Life after Stroke Support (ILASS) model provides best practice guidance on provision of support services required to provide practical, emotional and social input to people affected by stroke. This support is required to rebuild a life after stroke and optimise a person's independence and reduce their risk of further stroke.

As the largest provider of life after stroke services, NHS England has worked in partnership with the Stroke Association, to develop this document. It has been informed by the views and perspectives of a wide range of stakeholders including those with lived experience of stroke, charities providing services to stroke survivors, clinicians and healthcare professionals, managers and policy makers.

This guidance should be used with the National Stroke Service model and National model for an Integrated Community Stroke Service to inform commissioning and provision of care for people affected by stroke.

National guidance for an Integrated Life after Stroke Support model

1. Executive Summary

More than 100,000 strokes happen in the UK every year. With an increasing number of people surviving stroke and an ageing population, by 2035, the number of stroke survivors living in the UK is also expected to rise to over 2.1 million. Personalised life after stroke support is an essential part of the recovery pathway. Life after stroke support is different, yet complementary, to rehabilitation and has a strong emphasis on living well with the effects of stroke; it is about empowering people to take an active part in their own recovery in a way that compliments the way that they want to live their life.

The Integrated Life after Stroke Support (ILASS) model is part of the National Stroke Service Model and the National model for an Integrated Community Stroke Service. It provides best practice guidance on the provision of focused practical, informational, emotional and social input for people affected by stroke that is required to rebuild their life, optimise their independence and reduce their risk of further stroke.

The key features of the ILASS model are that it is integrated in the stroke care pathway and should be pro-actively provided in parallel to rehabilitation and other care; is provided on a needs-based rather than time-limited basis; has a range of overarching outcomes which should be informed by the individual being supported and based on what matters most to them; and should be delivered through dedicated support from a Stroke Key Worker for people affected by stroke, as well as other professionals.

The components of what should be available as part of life after stroke support includes; personalised care and support planning; personalised information provision; holistic six month post-stroke review; emotional support; secondary prevention information and support; communication support; return to work support; peer support; and access to support for unpaid carers of people who have had a stroke.

This document provides the detail on what good looks like when it comes to life after stroke support. It should be used together with the National Stroke Service Model and National model for an Integrated Community Stroke Service as a framework by all of those involved in commissioning and providing services to people affected by stroke, including NHS Trusts and community services.

2. About this document



Integrated life after stroke support is part of the National Stroke Service Model and National Integrated Community Stroke Service model. This document defines and describes the key features of life after stroke support that should be implemented and integrated into stroke care pathways across England.

A stroke happens when the blood supply to part of the brain is cut off, or when there is bleeding in or around the brain. More than 100,000 strokes happen in the UK every year. Over 1.2 million people in the UK are living with the effects of a stroke, making it the biggest single cause of disability. For the best chance of recovery, a stroke needs to be recognised and treated quickly. If symptoms disappear within a few hours, it is known as a transient ischaemic attack or TIA (also called a 'mini stroke') – this can be a warning sign that a stroke will happen in the future.

The cost of stroke to the health economy is considerable and the number of people living with the impact of stroke, often in conjunction with other long-term conditions, is set to rise substantially over the next twenty years. With an increasing number of people surviving stroke and an ageing population, by 2035, the number of stroke survivors living in the UK is also expected to rise to over 2.1 million, having stood at 950,000 in 2015^[2]. Stroke currently costs UK society around £25.6 billion each year, with 29% of this cost borne by the NHS, 11% social care and 3% in productivity loss^[1]. Stroke is also one of a number of long-term conditions which collectively consume 70% of the health service budget^[1].

^[1] NHS (2014) Five Year Forward View <https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>

^[2] Stroke Association (2019) Current, future and avoidable cost of stroke in the UK: Summary report https://www.stroke.org.uk/sites/default/files/jn_1819.144b_current_future_avoidable_costs_of_stroke_0.pdf

3. Population Needs

A stroke is not something anyone prepares for. Yet, in an instant, it changes lives forever.

The impacts often extend into all aspects of a person's life, including but not limited to, their employment, relationships with others, confidence and self-identity, mood, financial situation, housing needs, ability to drive and their social connections. These impacts can last a lifetime, even when an individual's rehabilitation and clinical needs have been met. Stroke can have a significant impact on partners, a person's family unit and social circle and close family and friends may need support too. The Stroke Association has produced a series of publications¹, based on the largest ever survey of people affected by stroke, which evidence the substantial scale and depth of this impact.

From a clinical perspective, a person who has had a stroke or transient ischemic attack (TIA) is also at substantial risk of going on to have a further stroke, with the rate of stroke recurrence at five years standing at 12%². Immediate and lifelong secondary prevention input is consequently vital, for example blood pressure control, cholesterol lowering, blood thinning medication as appropriate.

Personalised life after stroke support is an essential part of the recovery pathway. Using personalised care approaches will support people to make any necessary lifestyle and behaviour changes required in secondary prevention and is an essential part of the recovery pathway. Life after stroke support is different, yet complementary, to rehabilitation and has a strong emphasis on living well with the effects of stroke; it is about empowering people to take an active part in their own recovery in a way that compliments the way that they want to live their life. As Think Local Act Personal³ states, "personalisation is rooted in the belief that people want to have a life, not a service". It recognises that many of the things that drive an individual's health and wellbeing are unrelated to the traditional provision of health and care services but are instead rooted in the person's financial situation, the social connections and relationships they have with others, their self-image and self-esteem, their employment position and the lifestyles they lead. All things which, as described above, are often impacted when a stroke occurs.

The Integrated Life after Stroke Support (ILASS) model ensures that all people affected by stroke and TIA have access to specialist personalised support to help them live their best possible life after stroke. The ILASS supports people affected by stroke through the often complex, practical, social and emotional impacts of stroke, as well as to understand and reduce their risk of further stroke or TIA. Personalised care means people have choice and control over the way their care is planned and delivered, based on 'what matters' to them and their individual strengths, needs and preferences and central to delivering the NHS Long Term Plan as well as engaging people more fully in their own health and wellbeing. The ILASS described in this document reflects existing policy and evidence-based clinical guideline recommendations^{5,6,7}.

4. Key features of the ILASS model

a. Integration

The ILASS model is part of the National Stroke Service Model⁴, a whole pathway approach to delivering high-quality evidenced based stroke care. ILASS provides the focused practical, emotional and social input people affected by stroke require to rebuild their life (many to a 'new normal'), optimise their independence and reduce their risk of further stroke.

The ILASS model provides detail of the types of support that should be provided across the stroke care pathway and should be commissioned alongside recommended community-based stroke care in the National Integrated Community Stroke Service model. Members of the ILASS workforce (e.g. Stroke Key Workers) should be considered core members of the stroke care pathway.

b. Needs-based support

ILASS should be provided on a needs-led, rather than time-limited, basis, with the opportunity for people to re-access support at any stage in their recovery. Details of how and when to re-access support can be described in a personalised care and support plan.

Support should be provided via a blend of face-to-face and remote support options, tailored to personal preferences and needs, particularly those related to accessibility (including accessibility needs arising from communication difficulties and cognitive impairments).

c. Pathway of care

ILASS should be available in parallel to, rather than as a follow on from, stroke rehabilitation, and be fully integrated into hospital discharge and Integrated Community Stroke Service pathways to ensure a seamless pathway of care and support.

It should also be proactively offered, and accessible to, everyone, including those for whom specialist stroke rehabilitation is deemed not appropriate, as well as carers/family members (in their own right) and people who have had a TIA.

d. Outcomes

ILASS sets out to deliver the following overarching outcomes for people affected by stroke:

- Enhanced quality of life
- Increased confidence, self-esteem and self-efficacy
- Increased physical and mental wellbeing
- Reduced risk of secondary stroke and other cardiovascular events

- Increased social connection, participation and involvement in purposeful activity
- Enhanced knowledge, skills and confidence to self-manage ('activation')
- Increased control, choice and independence
- More positive experience of care which is personalised to them, their needs, preferences and individual circumstances.

Outcomes should be measured using a variety of methods, with a particular focus on those that seek feedback directly from the person being supported.

At the level of the individual being supported, these outcomes and how they are achieved will be personalised, based on what matters most to them.

e. Workforce

All people affected by stroke should have access to dedicated support from a Stroke Key Worker. A Stroke Key Worker is a community-facing professional who has sufficient knowledge and skills, following appropriate training, to support the practical, informational, emotional and social support needs of people affected by stroke. Stroke Key Workers make a unique contribution to the multidisciplinary stroke care pathway by delivering elements of the ILASS model, working in collaboration with acute stroke teams, the Integrated Community Stroke Service and wider community-based services.

Stroke Key Worker capacity may be different depending on the model of service delivery. Appendix A details examples of models of care demonstrating these roles in practice.

Other workforce roles (e.g. primary care practitioners) required to deliver elements of the ILASS model will need to be locally defined, taking into account the local context and existing assets.

Volunteers may form part of the ILASS workforce, working as partners with – not substitutes for – paid staff. For example leading on the provision of peer support groups.

f. Education

For those providing stroke-specific support, e.g. Stroke Key Workers, education and training should be developed and provided in accordance with the Stroke-Specific Education Framework⁸. All of the workforce delivering ILASS should be aware of and understand the implications for patients of relevant legislation including the [Mental Capacity Act](#) (2005) and the [Care Act](#) (2014).

Training in personalised care modules is also available through the PCI. [Personalised Care Institute: Log in to the site.](#)

For wider community-based support services, providing support that is not stroke-specific, education and training should be developed and provided to support them to tailor their support to the distinct needs of people affected by stroke, particularly those related to cognitive and communication difficulties post-stroke.

g. Key relationships and partnerships

People delivering ILASS will need to hold key relationships and partnerships with hospital stroke teams and with the Integrated Community Stroke Service. However, they will also need to work in collaboration with a wide range of other community-based support services, and support people affected by stroke/TIA to access these in line with their needs and using social prescribing approaches.

Such community based support may include, but is not limited to:

- Social prescribing link workers, health and wellbeing coaches and care coordinators/navigators
- GPs and other primary care professionals
- NHS community services, including: memory clinics, pain clinics, falls services, continence services, NHS Talking therapies for anxiety and depression services, health promotion services.
- Pharmacies and neighbourhood teams
- Social care providers
- Leisure and exercise providers
- Care and residential homes
- Benefits and finance support providers, including Welfare Rights, Department of Work and Pensions, Citizens Advice and Job Centres
- Carers centres or other support services for carers
- Social groups
- Driving assessment centres and accessible transport providers.

These services will need to be supported to be 'stroke aware', having an understanding of the impacts of stroke, particularly those which may be considered 'hidden' and how their support may be tailored to accommodate these. How this is achieved will need to be locally determined.

5. Integrated Life after Stroke Support

a. Personalised care and support planning

Personalised care means people have choice and control over the way their care is planned and delivered, based on 'what matters' to them and their individual strengths, needs and preferences. It is central to delivering the NHS Long Term Plan, as well as engaging people more fully in their own health and wellbeing.

Personalised care represents a new relationship between people, professionals and the health and care system. It provides a positive shift in power and decision making

that enables people to have a voice and to be heard. It means people have the opportunity to choose how best to live their lives with the support to do so.

Personalised care is delivered through the Comprehensive Model, which has been co-produced and brings together six evidenced based and interlinked components of which the majority contribute and are relevant to the ILASS model in some way. The components are:

1. Shared decision making
2. Personalised care and support planning
3. Enabling choice, including legal rights to choice
4. Social prescribing and community-based support
5. Supported self-management
6. Personal health budgets and integrated personal budgets.

NHSE developed a set of criteria which articulate the definition of a personalised care and support plan (PCSP), and provides strong quality indicators for personalised planning. These criteria have been coproduced with people with lived experience and clinicians and demonstrate what is required from a personalised care and support planning experience rather than seeking to adopt a one size fits all approach. NHS England have a provided guidance and resources which support the planning process and perspectives⁹.

The Personal Stroke Record (developed by the Stroke Association in partnership with people affected by stroke), can provide a starting point for a stroke specific personalised care and support plan.

Throughout the ILASS, and ideally starting earlier in their stroke pathway (i.e. at or before hospital discharge, or upon returning home), people affected by stroke should have access to support to create a personalised care and support plan. This is most effectively done through a series of conversations facilitated by a Stroke Key Worker, focusing on what matters most to the individual in the context of their whole life and family situation. Family members or advocates should be involved as directed by the individual themselves. The plan should encourage self-management, and social prescribing approaches should be used to connect people to community-based support. Implementation of the plan should be supported by the Stroke Key Worker, particularly for those with complex needs. The intensity and nature of support provided should be matched to the person's needs and preferences. The plan should be reviewed and updated at agreed intervals, and people should be given information about how they can prompt review of their plan or access support sooner if required.

For people affected by stroke receiving stroke rehabilitation, rehabilitation goals should form part of the personalised care and support plan. Stroke Key Workers should also be aware of any other support plans that may be in place for an individual (e.g. by social prescribing link workers) and work with the relevant professionals to ensure that plans and support are integrated in an effective way.

b. Personalised information provision

People who have had a stroke should leave hospital with accessible and personalised information about their stroke (e.g. [Personal Stroke Record](#)). This should be completed as part of an active process, involving the stroke survivor and, as appropriate, their family and carer. This can be a starting point for a fuller PCSP to be developed.

ILASS should include support for people to access trusted, accessible, and evidence-based information, tailored to individual need. This should include information to help them understand more about their stroke and its impacts, and about the support available to them, as well as how they can support themselves. Many voluntary sector organisations provide such information, which has also been co-produced with patients and clinical professionals, and existing resources such as these should be used wherever possible to avoid duplication. All information should meet the Accessible Information Standard.

Information should be provided in a timely way, so that people are not exposed to too much information and left feeling overwhelmed and be available in printed and digital formats. Wherever possible, information should be provided as part of an active process to ensure engagement and support understanding.

c. Post stroke reviews

Stroke Key Workers, or a member of the Integrated Community Stroke Service, should provide a holistic six month review of needs and goals, using an evidence-based tool, as well as a stroke review at twelve months. Reviews should be offered to all stroke survivors. Carers, family members and people who have had a TIA may also be considered for a six and/or twelve month review on a needs-led basis.

Where people have a personalised care and support plan, these reviews should form part of the update and review of that plan, rather than operating in isolation.

Six month review data, including the EQ5D-5L, should be entered onto the [Sentinel Stroke National Audit Programme](#) (SSNAP) database.

d. Emotional support

Stroke Key Workers play a vital role in the emotional and psychological support pathway, optimising mental health and wellbeing. They provide essential level one ('sub-threshold' problems) and often level two (mild/moderate symptoms of impaired mood and/or cognition) support¹⁰ for people affected by stroke, at an intensity relative to their needs. This support includes active listening, support with emotional wellbeing and adjustment (including confidence, self-esteem and self-identity), exploring and supporting the impact of stroke, information giving, goal setting, and supporting people to access more specialist psychological support where needed.

This should augment emotional support provided by other elements of the ILASS model (e.g. peer, communication and carer support) as well psychological rehabilitation accessed as part of the Integrated Community Stroke Service model.

Support should be integrated into clear and comprehensive emotional and psychological support pathways (including specialist clinical psychology/neuropsychology and wider mental health services e.g. NHS Talking therapies for anxiety and depression services), with appropriate supervision from specialist clinical psychologists/neuropsychologists.

e. Secondary prevention

Secondary prevention of cardiovascular disease includes rehabilitation, addressing relevant lifestyle risk-factors, and drug treatment. There is evidence that the impact of drug therapy on CVD outcomes can be seen in approximately 6-12 months.

All professionals involved in a person's care and support have a role to play in secondary prevention and previously mentioned personalised care approaches can strengthen these plans and relationships significantly.

As part of ILASS, all stroke survivors/TIA patients should have their risk factors and secondary prevention reviewed and monitored at least once a year in primary care.

ILASS, particularly Stroke Key Workers, should support people affected by stroke/TIA to understand the risk factors associated with secondary stroke/TIA and to understand what they can do to reduce their risk. This includes working alongside others, such as Health and Wellbeing Coaches, Allied Health Professionals and members of the Integrated Community Stroke Service, to support people to understand the role their lifestyle (e.g. diet, physical activity, smoking and alcohol intake) can play in their risk of secondary stroke/TIA, and helping them make changes to reduce this risk and optimise their wellbeing. This support can be delivered in a variety of ways and may range in its approach from the use of 1:1 educational approaches to specific interventions to support behaviour change.

Given the impacts of stroke, especially the physical impacts, ILASS and the Integrated Community Stroke Service, should work together to support stroke survivors to

engage, or re-engage, in physical activity and exercise training personalised to their needs. People who have sustained a stroke often become physically deconditioned and many are unable to participate in the same type or level of physical activity as they did before the stroke¹¹.

f. Communication support

ILASS should include access to opportunities for people with ongoing communication difficulties (e.g. aphasia, dyspraxia, dysarthria) post-stroke to practice their language and communication in a supportive and safe environment and adjust to life. Support should aim to build confidence, self-efficacy and self-esteem, help people adjust to life with communication difficulties and increase life participation. There should also be support available for family and friends to enable them to be effective communication partners.

Opportunities may be provided locally but may also include those available at a national level.

Communication support should be part of a clear integrated pathway of support, which seamlessly connects Speech and Language Therapy delivered by the Integrated Community Stroke Service with participation-focused communication support delivered as part of ILASS for people with aphasia and other communication difficulties post-stroke.

g. Return to work support/Vocational rehabilitation

For people wishing to remain in, return to or commence employment (paid or unpaid) after stroke, ILASS should include information provision and basic conversations around work needs, as well as through social prescribing/signposting to other appropriate services. Support provided at this level should be integrated or complement return to work and specialist vocational rehabilitation provided as part of the Integrated Community Stroke Service model.

h. Peer support

ILASS should include access to a range of peer support opportunities, catering for people's needs, preferences and circumstances.

Quality peer support can take a variety of formats, from remote peer befriending to local stroke support groups, and in some cases be specific to sub-groups within the wider stroke population (e.g. for people of working age, carers or for those with a special interest in a particular social activity). It may also be 1:1 or group-based, and provided face-to-face or remotely, depending on personal preferences.

Many voluntary sector organisations have extensive experience of providing peer support, particularly peer support led by volunteers, many of whom are often stroke survivors themselves and therefore 'experts by experience'. Local teams should make

use of existing peer support opportunities available from the voluntary sector where appropriate and based on needs and preferences. This should include those offered at both a national or local level and available through different channels (i.e. remote or face to face), to augment any support offers provided locally.

I. Carer support

ILASS should include access to support for unpaid carers of people who have had a stroke. While an Integrated Community Stroke Service will ensure that assessment and appropriate training in care tasks (e.g. moving and handling) is provided, ILASS should include personalised support for carers and family members in relation to their own practical and informational needs and emotional wellbeing. This is in addition to the other elements of ILASS described, which should also be accessible to carers.

ILASS, working alongside an Integrated Community Stroke Service, should support unpaid carers and family members to gain an understanding of stroke and its impacts, and the knowledge, skills and confidence they need to meet the needs of the person they are caring for or supporting, as well as their own. This should take a 'whole family' approach where relevant and include information and support for young and teenage children of stroke survivors. To make the best use of resources, the value of existing local and national support available for carer should be optimised before developing bespoke local opportunities.

ILASS should ensure that unpaid carers are aware of, and helped to access, support that enables them to take regular breaks and should ensure that they are made aware of their rights, and supported to access where needed, a formal carers' assessment from their local authority.

6. Accessing ILASS

The ILASS is intended to support the stroke care pathway as a whole. All people affected by stroke and TIA (and their carers/family members where appropriate) should be supported to access ILASS, irrespective of whether they require Integrated Community Stroke Service input. This includes people discharged from inpatient care to care homes and other forms of supported accommodation.

Providers across the stroke pathway should work collaboratively to remove barriers to information sharing to ensure effective coordination of a person's care and support. Information and data should be appropriately shared between service organisations, including the voluntary sector, as well as with people affected by stroke/TIA.

ILASS should work closely with the Integrated Community Stroke Service and inpatient/TIA clinic teams to establish agreed and coordinated referral pathways and

ensure a named person or team is responsible for making the referral to a Stroke Key Worker prior to discharge.

Discussions concerning life after stroke should commence as early as possible in the stroke pathway but contact with a Stroke Key Worker should be facilitated and established for everyone who has had a stroke at the point of discharge from hospital.

Where a person affected by stroke is discharged home with Integrated Community Stroke Service input, Stroke Key Workers and members of the Integrated Community Stroke Service should work collaboratively to ensure that the nature and timing of their support is complimentary and centred on the needs of the person. Collaborative working should be facilitated by Stroke Key Workers attending MDT meetings and participating in joint personalised care and support planning.

In addition, members of the Integrated Community Stroke Service should support direct access to ILASS input, as appropriate. For example, facilitating access to communication support should also be integrated into the speech and language therapy pathway.

Teams providing the initial care for people who have had a TIA, including within a TIA clinic, should routinely assess patients to identify any immediate ILASS needs. If needs are identified, the person should be referred directly to a Stroke Key Worker. If none are identified, the person with TIA should be made aware of how they can access support from a Stroke Key Worker should their needs change.

The Stroke Key Worker should make contact with the person affected by stroke (or their family/carer) within 3-5 days of discharge.

During this contact the Stroke Key Worker should support with any immediate concerns or questions, identify and provide/facilitate access to any ILASS input that is required, and determine an appropriate frequency of follow-up. They should also ensure a personal care and support plan is in place. Clinical concerns should be flagged back to the referring stroke team, or to the Integrated Community Stroke Service if appropriate.

Stroke Key Workers should ensure that people are aware of the package of ILASS available to them at any time, and how they can access this.

Hospital teams may refer family members to the Stroke Key Worker in their own right if ILASS is required, including before the person who has had the stroke has been discharged from inpatient care.

7. Data collection

The standard sets of data for routine collection/recording for audit purposes should be locally determined, informed by clinical guidelines and core datasets included in the [Sentinel Stroke National Audit Programme](#). The collection and use of patient-reported outcome and experience data should also be routinely embedded in service delivery for quality assurance and improvement.

8. References

1. Stroke Association (2019). Lived Experience of Stroke Report (online). Available at: <https://www.stroke.org.uk/lived-experience-of-stroke-report>.
2. Flach et al (2020). Risk and Secondary Prevention of Stroke Recurrence: A Population-Based Cohort Study. *Stroke*, 51(8), pp. 2435-2444.
3. Think Local Act Personal (2021). Making It Real: How to do personalised care and support (online). Available at: <https://www.thinklocalactpersonal.org.uk/assets/MakingItReal/TLAP-Making-it-Real-report.pdf>
4. NHS (2021). National Stroke Service Model (online). Available at: <https://www.england.nhs.uk/wp-content/uploads/2021/05/national-stroke-service-model-integrated-stroke-delivery-networks-may-2021.pdf>
5. Royal College of Physicians (2016). National clinical guideline for stroke (online). Available at: [https://www.strokeaudit.org/SupportFiles/Documents/Guidelines/2016-National-Clinical-Guideline-for-Stroke-5t-\(1\).aspx](https://www.strokeaudit.org/SupportFiles/Documents/Guidelines/2016-National-Clinical-Guideline-for-Stroke-5t-(1).aspx)
6. National Institute for Health and Care Excellence (2016). Quality Standard: Stroke in adults (online). Available at: <https://www.nice.org.uk/guidance/qs2>
7. NHS. Delivering universal personalised care (online). Available at: <https://www.england.nhs.uk/personalisedcare/upc/>
8. NHS Health Education England. Stroke-Specific Education Framework (online). Available at: <https://stroke-education.org.uk/>
9. NHS. Personalised care and support planning (online). Available at:
10. [Personalised Care and Support Planning - Personalised Care Collaborative Network - FutureNHS Collaboration Platform](#)
11. NHS Improvement (2011). Psychological care after stroke (online). Available at: https://www.nice.org.uk/media/default/sharedlearning/531_strokepsychologicalsupportfinal.pdf
12. Billinger et al (2014). Physical Activity and Exercise Recommendations for Stroke Survivors. *Stroke*, 45(8), pp. 2532-2553.

Appendix A – Examples of models of care demonstrating these roles in practice.

Example 1: National Stroke Rehabilitation Pilot: North Central London: Stroke Buddy Role

The Stroke Buddy role was developed and piloted to provide a point of face to face and virtual contact for up to 6 months post stroke or longer if appropriate. The Stroke Buddy facilitates the identification of patient reported barriers to participation and challenges to recovery and help. The Stroke Buddy team also introduce to the stroke patients and their caregivers a validated self-management intervention tool called 'Taking Charge After Stroke' which is a low cost, person-centred, self-directed rehabilitation intervention after stroke that has been shown to improve health-related quality of life and independence.

Between 1st September 2021 and the 31st March 2022, the Stroke Buddy team has offered support for 390 patients (out of a total of hospital discharges since 1 September 2021 of 402) and completed a programme of support in 169.

The Stroke Buddy model has been successful and provides one solution to the perception that care falls away at the end of formal therapy input. A key learning from the pilot to date is that there is a wide spectrum of non-therapy needs amongst the patient group, so the delivered service model needs to be sufficiently flexible to identify issues and coordinate multi-disciplinary expert input that is appropriate for the patient and their family.

Case Study from the pilot

Woman in her 30s with a thriving job in finance was discharged to the community team after a long stay in hospital.

- Experiencing motor and language deficits that meant she could no longer live independently and could no longer work, placing financial strain on her and her family.
- Also, no longer working meant that she was experiencing increased social isolation and anxiety.

The Stroke Buddies aim was to hear what mattered most for the stroke patient and share their 'Taking Charge' conversation through reflective practice to the wider MDT with the aim to support with the things that matter.

- In this case it was support with travel and finance and help with strategies to manage anxiety and fatigue.
- The patient gained confidence through the Take Charge programme and noted improvement in participation and a recovery of self.

Example 2: Oldham Stroke Recovery Service: Provided by the Stroke Association

In Oldham, the Stroke Association provide support for approximately 350 people affected by stroke each year, through the Stroke Recovery Service (SRS). The service provides and coordinates the longer-term personalised support that people affected by stroke need to rebuild their lives after stroke, live full lives in their communities and prevent further stroke.

- The SRS supports all those living with stroke or who have suffered a TIA and their carers living in the Oldham area or those registered with an Oldham GP.
- The team consists of 5 x coordinators and 1 clerical assistant (total 133 coordinator hours and 25 clerical assistant hours) alongside 2 volunteers who support the services group activities.
- Oldham SRS forms part of the Oldham local stroke pathway.
- On a weekly basis a coordinator visits Fairfield General Hospital (FGH) to provide support early and introduce the SRS to stroke survivors and their families.
- The team work collaboratively with Oldham Community Stroke Team (CST), attending weekly MDT meetings to support those affected by stroke.

People referred to the service are designated a coordinator to support them and within five working days the coordinator contacts those affected by stroke to arrange an initial assessment, this can be done face to face, over the telephone or virtually dependent on their individual needs. ***The coordinator works in partnership with the person to understand what matters to them and their current needs and aspirations at this time.*** The coordinator uses a holistic needs assessment tool to support the exploration of potential physical, social, emotional and practical support needs, producing a personalised recovery plan.

In the following weeks and months, this is regularly reviewed, either over the phone or via further home visits and at a frequency tailored to the individual, to ensure that it continues to be effective and focused on the things that are important to the individual during the ups and downs of their recovery journey. The support includes a holistic post stroke review at six months, supported by using of the evidence-based Greater Manchester Stroke Assessment tool, this review is also entered onto the SSNAP database. A further post stroke review at twelve months is provided as appropriate.

The service also directly offers communication support for people with ongoing communication difficulties post-stroke. This support can be provided on a one to one basis or by attending a face to face or virtual communication support group, dependent on the needs of the individual. Groups run in eight week blocks and this provides a supportive and safe environment for people to practice their language and communication, helping to build confidence and self-esteem as people adjust to life with communication difficulties. The service works closely with the Speech and Language Therapist to support those with communication difficulties.

Case Study from Oldham Stroke Recovery Service

Woman in her early 60s had a stroke resulting in right sided weakness and visual issues. It also caused a number of emotional and cognitive issue.

- She presented with problem solving issues and had expressed suicidal feelings and having a very low mood.
- She didn't feel safe to prepare food at home or in and around her home and felt very isolated.
- Her sister who provides help and emotional support was feeling overwhelmed and stressed.

During the initial conversation with a Stroke Coordinator she expressed she wanted to;

- Feel more confident and secure and understand better how to make sense of how she was feeling.
- Feel safer within the home environment.
- Understand why she is feeling unusually tired and wanted to regain energy.
- Live in flat or bungalow in the area she is familiar with which would be easier for her to manage and enable her to be more confident and independent.

Based on the outcomes she wanted to achieve, the stroke coordinator;

- referred her to Oldham CST psychologist for help with emotional/cognitive issues
- referred to the CST Occupational Therapist for advice, help and support with safe kitchen work and general safety in her home environment.
- A referral was made to ophthalmology to support her with the visual issues she was experiencing.
- Discussed strategies of how to cope with fatigue and provided information.
- Provided assistance with and talked through the process of applying for alternative housing with Oldham Council, working closely with the housing at the council.

As a result;

- The sister was also supported, listening to how she was feeling and helping her manage this very difficult situation.
- She continues to receive psychological help from the CST psychologist and is showing signs of great improvement and she is feeling better.
- She has now moved into a new flat, is happy, feels safe and secure and is able to manage the flat, get outdoors, and living a happier life, feeling more energised.
- Kitchen safety is now no longer an issue as she has worked with the OT and has demonstrated safety in the kitchen.
- She has carers who visit twice per day to assist.
- The sister is relieved at the above outcomes. She no longer feels stressed as a result of her sister's situation.

Example 3: Lincolnshire Stroke Recovery Service: Provided by the Stroke Association

The Lincolnshire stroke pathway was redesigned by bringing together health and care professionals from across Lincolnshire to make a real difference to stroke patients. With the patients at the centre of the redesign Individual stroke services became the Lincolnshire Stroke service as collaborative/integrated working became the norm.

Working as one team the SRS receives intelligent referrals from the acute hospital and the community stroke teams at the time when the stroke patients and their families need support. This enables the service to focus on the people that require support during their recovery.

Since the stroke pathway redesign the SRS has seen an increase of stroke survivors accepting the Stroke Association support offer. Between 1 April 2021 and the 31st March 2022 the engaged referral rate was 80% where it had previously been 42%.

The service now employs a total of 4.83 whole time equivalent (wte) stroke coordinators, with an annual referral rate of 742 people, equating to 154 referrals per wte coordinator. The active caseload is 593, meaning there around 124 active cases per wte coordinator.

The community stroke team and the Stroke Association also jointly deliver monthly online stroke awareness and prevention sessions to new stroke patients. With clear patient pathways and collaborative working arrangements in place professional and provider boundaries have been set aside to create a single team who work seamlessly together to support stroke survivors and their families. Improvements have ensured that patients get the support they need at the right time and in the right way, and that those involved in their care communicate with them and with one another throughout the journey.

Case study from Lincolnshire Stroke Recovery Service

58 year old man who was working in a manual job at the time of the stroke lived with his wife and was the sole earner.

- As a result of his stroke he suffered from fatigue, short term memory difficulties, visual problems and word finding/information processing difficulties.
- He was concerned about his recovery, his finances and returning to work.

On referral, the coordinator had an understanding of the client's stroke journey so far and understood which supporting services were involved. On visiting at home his needs were assessed and a support plan established to enable him to achieve the best possible recovery.

- The coordinator was able to support with both practical and emotional support with a blended approach of face to face and remote contact as and when needed.
- He was signposted and referred into the following community services: benefits advice/support, sensory services, smoking cessation service, neuropsychology etc.
- He was also supported with information and advice on returning to work and referred to the CAB and occupational therapy to discuss reasonable work adjustments.

Following support from the Stroke Recovery Service:

- He was able to manage the effects of his stroke, his mood was much improved and he has stopped smoking.
- The client's self-esteem has improved and he returned to work on reduced hours with his original employer in an alternative suitable role.
- He also successfully made a claim for PIP benefit to ensure he was financial stable.