Chest
Heart &
Stroke
Scotland

NO LIFE HALF LIVED

1 IN 5 APHASIA REPORT

No Life Half Lived

OUR VISION:

Welcome to a Scotland where people with our conditions can live their lives well. Full lives, with the right support, at the right time, and in the right place. A place where people can shape their future and live the life they want to lead.

OUR MISSION:

Every person with our conditions should have access to quality, supported self management and community recovery. We will deliver an approach to this that is designed by people with our conditions and puts what matters to them at the heart. We will work to develop the partnerships that will enable this to be available across Scotland – for everyone, no matter where they live.

Introduction

One in five (1.1 million) people in Scotland live with one or more of our conditions. If you are not directly affected yourself, you will know someone living with a chest, heart or stroke condition or Long Covid.

The voice of people affected by our conditions is critical to how we develop and deliver our services, and how we advocate with them on the care that matters to them.

Five years ago, we conducted the most comprehensive survey we had ever undertaken with people living with our conditions. This helped us set out our vision of No Life Half Lived in Scotland for the first time.

Now, five years later, we have conducted an even larger survey through an independent research company to find out how people's experiences have changed over the last five years, and to include Long Covid for the first time. The 1886 responses to the survey tell us that people with our conditions are continuing to struggle with loneliness and their mental wellbeing, and that opportunities are still being missed for them to get the support they need to live their lives to the full.

We know that living with a long-term health condition is life-changing for the person affected and their family, friends and the people around them. And aphasia, which is a communication disorder that affects 1 in 3 stroke survivors, affects people's lives instantly and brings challenges that can seem insurmountable. Imagine not being able to speak or understand what other people are saying or not being able to read and write. Not being able to communicate with those around you is devastating and leads to feelings of isolation, loneliness and mental health issues.

In this report, we have put a spotlight on the issues that people with aphasia are struggling with most. Issues such as isolation, depression and mental wellbeing are significant for people with aphasia, but so too is the impact on their relationships with family and friends, every day social interactions and access to work. For many people, aphasia means they cannot work as before. They feel they can sometimes be treated negatively and experience stigma as a result of their condition, and many have experienced difficulties in accessing key services in Scotland.

We have been supporting people with aphasia in Scotland for many years and have developed services and resources that focus on communication difficulties. Our Aphasia Strategy which was co-produced with people with aphasia and their carers is focused on supporting more people in Scotland who have post-stroke aphasia and communication difficulty. It is in place so we can do more and do better for people affected by aphasia and their families, building upon our reputation for excellence in community-based services for people with aphasia. A vital part of this strategy is to raise awareness of aphasia and what support is available. Too many people in Scotland are missing out on the emotional, social and rehabilitation support that could provide them with the best possible recovery and quality of life for their futures.

Through this report we want Scottish Government, NHS health boards and other key organisations to be better informed about aphasia and better understand the reality of living with this long-term health condition.

People with aphasia need more support and we are calling on Scottish Government and our partners to help us to make sure they get what they need to live their lives well. The provision of broader rehabilitation, community support and speech and language services should be increased and accessible at all stages of recovery, so that the thousands of people living with aphasia get the help and support they need to connect with family and friends and get back to activities and employment if possible.

Key Findings

HALF (50%)
said there was **support they needed but weren't able to access**

Nearly
(48%) **HALF**
with aphasia said they **experienced loneliness as a result of their condition**

More than
HALF (52%)
of people with aphasia said that **their condition affects their mental health**, but only 8% have accessed psychological or emotional support

2 in 5 (43%)
said **it impacted on their ability to work** as before

(67%) **TWO THIRDS**
of people with aphasia experienced some kind of **difficulty in accessing services**

What is Aphasia?

Aphasia is a communication disorder caused by damage to the language centres in the left side of the brain. Aphasia is most common after a stroke, but can occur with other neurological conditions or head injuries. Around 1 in 3 stroke survivors experience aphasia.

Aphasia can affect speech production, understanding speech, reading and writing, and using numbers. People with aphasia can have one or more of these impairments, or all five, and the level of impairment differs from person to person, from mild to severe.

All people with aphasia will have difficulty finding the right words to express themselves. Aphasia does not affect intelligence.

Aphasia is one of three types of speech impairment that can be experienced after a stroke. The others are dysarthria (weakness or paralysis of the muscles of the face, lips, tongue and/or voice box needed for speech) and apraxia (difficulty coordinating the movements of muscles needed for speech).

People with aphasia may find that they:

- Find it difficult to think of the right words
- Use the wrong word, or put words in the wrong order
- Struggle to understand what people are saying
- Slur or mumble
- Spell words wrong, or mix up similar words

How we heard from people with aphasia

> *"I am not able to write any more."*

We wanted to hear from as many people with aphasia as possible, so it was important to make the process as accessible as possible. We co-produced a questionnaire with people with lived experience of aphasia including our Aphasia Reference Group. We started by asking people with aphasia what questions we should ask. We asked them to try out a pilot questionnaire to see if the questions worked.

250 people with a wide range of post-stroke communication difficulties took part in the survey. We provided this survey both as an online questionnaire and in printed hard copy, in a format that was accessible and easy for people with aphasia to understand. Some people were able to fill in this questionnaire without support. Some people were supported by a family member or friend, or CHSS staff member where we are already providing them with support. Everyone included in this report described themselves as having aphasia.

We have produced an aphasia-friendly summary of this report, which is available online at www.chss.org.uk/aphasiareport

What Matters to You?

We asked people with aphasia what mattered most to them. Specifically we asked them which aspects of life they were most concerned about.

- Over 4 in 5 **(83%)** said their **speech was affected**, while over a third, **(69%)** said their condition affected their **ability to communicate with others.***
- Almost three quarters **(72%)** of people with aphasia said **communication was one of their biggest concerns.**
- 2 in 5 **(40%)** said they were concerned about cognitive challenges, such as **memory loss or confusion.**
- Over a third **(36%)** of people with aphasia said they were concerned about **having another stroke** (or a recurrence of another health event).
- A third **(36%)** said they were concerned with **losing their independence.**
- A quarter **(26%)** said they were concerned with **rebuilding their confidence.**

Communication affects every single aspect of our lives. It is central to how we build relationships, connect with others and live independently.

When we asked people with aphasia which parts of their life were impacted by their condition:

- 3 in 5 **(61%)** said it impacted their **sleep or fatigue level.**
- 3 in 5 **(60%)** said it impacted **being physically active.**
- 3 in 5 **(60%)** said it impacted their **personal independence.**
- Nearly 3 in 5 **(57%)** said it impacted their **ability to pursue hobbies and interests.**
- Over a half **(52%)** said it impacted their **ability to get out.**

** People with aphasia who said their speech was not affected will be those who have recovered speech through rehabilitation.*

Mental Wellbeing

Not being able to communicate means not being able to connect with others. Aphasia's impact on building and maintaining connections with others as well as the opportunities to do the things that matter most to those affected means the condition can have a significant impact on wellbeing.

- More than two thirds **(68%)** said their condition impacted on their **self confidence.**
- More than half **(52%)** said the condition affected their **mental health.**
- More than half **(51%)** said the condition affected their **self esteem.**
- Half **(50%)** said they experienced **anxiety and stress** because of their condition.

> *"It is seven years since my stroke and despite wonderful inpatient rehabilitation, there was no mental health specialist. My wife and I have tried to self help with books but I have not adjusted to my changes. My mood is often low, I am angry and resentful."*

Mental Health

Some people needed additional support around their mental health. Only one in 12 (8%) had accessed mental health support or psychological support.

However, mental health services often need to make adjustments to their services if these are to be meaningful or accessible for people with aphasia This can contribute to problems with access.

- One in seven **(14%)** said that they **needed specialist mental health support** because of their condition, however had not been able to access it.

> *"Wanted to talk with a clinical psychologist about my condition, but told the waiting list could be anything up to two years."*

Loneliness

Difficulties in communicating can have an impact on our friendships. People may not know how to support a conversation or friendship with someone who cannot speak or communicate. It can be difficult to make plans to see friends, or to go out when it is necessary to rely on someone else to make the arrangements..

People with aphasia were much more likely to say they experienced loneliness than other stroke survivors. Nearly half **(48%)** of people with aphasia said they experienced loneliness as a result of their condition, compared to a third **(34%)** of all stroke survivors.

> *"I miss going to the shops, swimming, going to church, meeting friends."*

Many people specifically said that they would benefit from more friendship in their lives.

> *"I would like a friend to arrange a run or outing, or chat."*

Stigma

Nearly 2 in 5 people with aphasia (38%) said they been treated negatively because of their condition.

Worryingly, a third of stroke survivors who experienced stigma (38%) said it made them less likely to seek help. Our 1 in 5 report, which looked at the experiences of nearly 2000 people with chest, heart and stroke conditions and Long Covid, found that the biggest impact of this stigma was to make people feel overlooked or unsupported. More than half of people with those conditions who had experienced stigma said that this impacted on their social life or relationships. Others said this treatment made them feel isolated, embarrassed and impacted on their self esteem.

> *"I now stutter and stammer over words and forget what I was saying midsentence, although I know what I want to say. It makes me feel stupid and despondent. I just want to be treated as normal again the way I once was."*
>
> *"Post Stroke Aphasia needs more acceptance amongst the NHS and other bodies."*

Access to Services & Support

REHABILITATION

Rehabilitation (or rehab) covers a wide variety of support, from speech and language therapy, physiotherapy, occupational therapy to emotional support and peer support groups. Rehab covers all the services people need to make the most of life with their condition, to be as healthy, active and independent as possible.

Speech and language therapy is particularly important for people with aphasia, in improving their ability to speak or communicate.

A third of people with aphasia **(67%)** accessed NHS Support.

Of those who accessed support,

- Three quarters **(74%)** of these had accessed **Speech and Language Therapy.**
- More than half **(56%)** had accessed **Stroke rehabilitation services.**
- **(42%)** had accessed **physiotherapy.**
- Nearly 2 in 5 **(39%)** had accessed **occupational therap.y**

Only **8%** had accessed **mental health support.**

However, the need for support is often greater than what is available. Half of people with aphasia **(50%)** say there was support they needed but weren't able to access. Of these, the biggest need was for more speech and language therapy **(24%).**

> *"I would like more speech and language therapy. I find it hard and tiring to motivate myself. If I had regular therapy, I would push myself to do more."*
>
> *"I need more speech therapy. One-to-one sessions were very helpful."*
>
> *"I have been assessed quite a lot by NHS and offered an online course but I would appreciate talking face to face with a speech therapist and going through exercises with them."*
>
> *"My daughter has had to fight for me to get a referral to a speech therapist. If she hadn't helped and kept on I wouldn't have got one."*

Support

Many people with our conditions are still not getting the support they need to live life to the full.

Two thirds of people with aphasia **(67%)** experienced some kind of **difficulty in accessing services.**

31% said **communication difficulties were a barrier** to them accessing services.

> *"If I was able to communicate better, this would help a lot, but it restricts me in a lot of ways. I don't know what help is available to know what to ask for."*

25% didn't know what was available in their area.

22% said they **didn't know where to get information.**

People with aphasia were also more likely than other stroke survivors to say their condition made it hard for them to find information.

> *"I would like to continue attending an aphasia communication group locally, face to face but most are only available for a limited time."*
>
> *"There's no help for someone under 65 years old after a stroke in this health area."*
>
> *"I have found a Stroke Support Group. If only I had found them 8 years ago."*

Many people said they would benefit from befriending services, helping them to feel more connected or to support them to enjoy their hobbies and interests.

> *"I would like to meet more people and go out more."*
>
> *"I would like access to a befriender who has similar interests so I could go to the football, go fishing, etc."*
>
> *"I would like a befriender but there are no volunteers in my area currently."*

Access to Work

Aphasia can significantly impact on someone's ability to work, and therefore their financial wellbeing.

43% of people with aphasia said the condition impacted on their ability to work as before – more than stroke survivors without communication difficulties **(28%)**.

They were also more likely to say that their health had an impact on their finances – more than stroke survivors without communication difficulties **(32%)** compared to **(19%)**.

More than half of people with aphasia **(54%)** said they were on benefits.

> *"I had very severe aphasia after a stroke and I have not been working since then. Although my language is much better I still feel that I need some ongoing support with my aphasia so I could think about working again."*
>
> *"I would have liked to have someone (professional or a very able volunteer) who could support me to find resources, technology and people which could help me back into work."*
>
> *"I would like employment and pension advice. Although I have been referred to Citizens Advice, I find this type of interaction very difficult "*

Increases in the cost of living have made this financial pressure even more acute.

A third **(32%)** of people with aphasia said their families had cut back on essentials such as heating.

Caring

Many people with aphasia rely on support from unpaid carers. 81% of people with aphasia said they were cared for by a family member or friend. It's essential to consider this need for support.

It's important to recognise that being an unpaid carer impacts on people's mental and physical wellbeing, and is recognised as a social determinant of health. Carers must be able to access the support they need for their own health and wellbeing.

> *"I receive personal care daily, but there should be respite for my wife if she needs it, when she is ill. What happens when my wife goes into hospital for a short time? Who looks after me?"*
>
> *"I rely on my mum to cook and clean the house, but mum is 76 and has her own mental health and illnesses to deal with, which makes it difficult for her to cope with managing me on my own."*
>
> *"My wife is my main carer and advocate for me, but can't get enough cover as no carers around and not paid enough to stay. This causes my wife very bad mental stress, physical exhaustion and frustration. It makes our life far harder than it needs to be."*

Finally, 38% were living with another condition in addition to aphasia and having had a stroke. People with aphasia need person-centred support that responds to their needs and considers the whole person, not just one health condition.

Case Study

Martin McKelvie, 57, lives in Barrhead, Renfrewshire. A former area manager with Glasgow City Council, Martin had a stroke in March 2022 that has left him with aphasia.

Once used to negotiating his way through spreadsheets and financial reports, after his stroke Martin found himself struggling to find everyday words or even say his own name.

> *"Since my stroke my physical recovery has been slow but it has been helped by intensive physiotherapy and occupational therapy. However, my speech did not return and I'm now living with aphasia. Before my stroke, I hadn't heard about this condition or realised what it might mean for me or my family, friends and my work."*

After his stroke, Martin was determined to return to work and worked hard with the various therapists, including a speech and language specialist and a stroke psychologist. While his speech has gradually improved, he has been unable to return to work.

> *"I was so sure I could go back to work. But the therapist was so honest with me. She told me I was miles off going back to doing what I'd done, like working with spreadsheets. In my job, I'd have to speak to maybe 100 men at a time – how could I do that when I couldn't even remember the months of the year? That has meant I've had to take medical retirement just short of marking 40 years of service to Glasgow City Council.*

Martin talks of his recovery as two steps forward – literally – and one step back at this time, admitting he felt depressed and isolated by the effects of the stroke. He has been supported in his recovery through a Chest Heart & Stroke Scotland communication support group despite originally being reluctant to join.

> *"I've never been one for joining clubs. I couldn't see what good this could do for me. But I eventually went to the first meeting and it was really helpful to share my experience with others and hear from other people like me. That's what has been so good about the group. Everyone understands what the others are going through. I'm so glad I got over thinking this was a club I wouldn't want to join.*

> *"It's taken a while for me to get there, but the CHSS advice is for me to say to people 'I've got aphasia, I need a bit of time'. Now I do that, and the reaction is positive. No one is annoyed, and I get a bit of time to do what I need to do."*

Despite the way stroke has upended his life, Martin remains positive and thankful for all the support he has been able to get but he knows there are lots of other people less fortunate than him that don't get the support they truly need.

Recommendations

REHAB SERVICES

- Scottish Government must ensure that everyone with aphasia has access to quality, accessible speech and language therapy, as well as other forms of rehab. Access to services should be universal and equitable.
- NHS Scotland should increase the availability of speech and language therapy after a stroke, ensuring that this is available for as long as it's helpful and at whatever point it is needed.
- NHS health boards should ensure that it is easy for people with aphasia to access services again in the future.
- The Right to Rehab should be recognised as an essential component of the Right to Health, and incorporated into future human rights frameworks.
- Scottish Government must ensure proper resourcing of Allied Health Professional staffing to support rehab delivery.
- Scottish Government should ensure that Health Boards are adequately resourced to provide Augmentative and Alternative Communication (AAC) for people with aphasia who cannot speak, ensuring they have a Right to Speak.
- Scottish Government and NHS Scotland must incorporate data on provision and uptake of speech and language therapy and other aphasia services into datasets on stroke rehab

Recommendations

SERVICES AND SUPPORT

- Everyone living with aphasia should have access to self management support to help them live life to the full.
- Primary and secondary care should be able to refer to Chest Heart & Stroke Scotland and other local third sector support, including necessary community healthcare and peer support, and befriending services.
- Scottish Government and NHS Scotland should work together to develop a Once for Scotland referrals scheme to third sector support, making referrals easier for clinicians.
- NHS Scotland and local authorities must ensure that staff are aware of the symptoms of aphasia and how best to provide inclusive support, ensuring that people do not experience stigma or judgement when accessing services.
- Everyone with aphasia should be able to access support to stay physically active in a way that is accessible to them. Health and social care services should be able to refer directly to local third sector services who offer support.

CARING

- Scottish Government must identify strategies to protect the health and wellbeing of carers.
- Health and social care services must ensure that adequate support is available to allow carers to access treatment, rehab, respite or other support.

LONELINESS AND MENTAL HEALTH

- NHS health boards should ensure that people with aphasia are referred to community support groups and befriending services from discharge, ensuring support is available throughout their recovery.
- NHS health boards must ensure that people with aphasia are be able to access appropriate psychological and emotional support at the time they need it .
- Scottish Government and NHS health Boards must ensure that specialist psychological support is resourced adequately to meet demand.
- Targeted community support groups need to be available for younger people and those of working age.

COST OF LIVING AND EMPLOYMENT

- Scottish Government and NHS Scotland must ensure that vocational rehabilitation is available to people with aphasia who want to, and are able to, return to work.
- Scottish Government must consider greater financial support for people with long-term health conditions such as aphasia to cover cost of living increases.

Methodology

The survey (offered both in paper form and online) was publicised and distributed by Chest Heart & Stroke Scotland, and made available to complete over a five week period during summer 2023. Full responses were received from 1886 people from all health boards and across all conditions. Analysis of the data was carried out by Scott Porter Research & Marketing Ltd. All responses have been treated in the strictest of confidence.

- **1886 complete responses were received.** Of these, **250** responses were from **people living with aphasia**. These responses form the basis of this report.
- **45%** of the sample were women, while **53%** of the sample were men. The number of non-binary respondents is too small to declare.
- **38%** were **living with another condition** in addition to aphasia and the effects of stroke.
- **73%** had **received some kind of support from CHSS.**
- 2% of respondents were aged 20-39 years, 24% were aged 40-59 years. Over half (56%) were aged 60-79 years. The remainder (16%) were aged 80 or older.
- 96% of the sample were white, 1 % were Asian, and the number of participants from other ethnicities was too small to declare.

Some of the quotes included in this report may have been written by a family member, friend or CHSS member of staff on behalf of a person with aphasia.

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NO LIFE HALF LIVED

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