

1 in 5 Aphasia Report

Summary



Our vision:

People with chest heart and stroke conditions **should be able to live full lives**, with the right support, at the right time, and in the right place.

Scotland should be a place where people can shape their future and live the life they want to lead.



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Our mission

Every person with our conditions should have **access to quality, supported self management** and **community recovery**.

We will **work with people with chest heart and stroke conditions** to make this happen.

We will put **what matters to people** with chest, heart and stroke conditions at the **centre of our work**.

We will develop **partnerships** that make this support available for everyone across Scotland.



Introduction

One in five **(1.1 million) people in Scotland** live with a chest, heart or stroke condition or Long Covid.

We need the **voice of people affected by our conditions** to help us to develop and deliver our services.

We have conducted our largest **survey** to find out how people's conditions affect their lives.

The **1886 responses** to the survey tell us that people with our conditions:

- **struggle with loneliness and mental health**
- **cannot get the support they need** to live their lives to the full.

Everyone included in this report described themselves as having aphasia.



Research:

- We wanted to show people **what life with aphasia is like**, and **what needs to change**.
- Nearly **2000 people** with chest, heart and stroke conditions **completed our survey**.
- **250** of the people from the survey **lived with aphasia**.
- This is what they told us about **life with aphasia**.



Key findings



Over **40,000** people in Scotland have aphasia



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



MOST PEOPLE with aphasia (**67%**) experienced some kind of **difficulty accessing services**

Key findings



HALF of people with aphasia (**50%**) said there was **support they needed but could not access**



More than **HALF** of people with aphasia (**52%**) said their condition affects their **mental health**



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



Aphasia

Around **1 in 3 stroke survivors** experience aphasia.

This means there are over **40,000 people with aphasia in Scotland.**

Aphasia can affect **speech production, understanding speech, reading and writing, and using numbers.**

People with aphasia may have **difficulty finding words.**

Aphasia **does not affect intelligence.**

Aphasia is a language disorder, it can **affect every single aspect of our lives.**

Communication is central to how we build **relationships, connect with others** and **live independently.**



What matters to you?

We asked people with aphasia what mattered most to them.

- Almost three quarters (**72%**) of people with aphasia said **communication** was one of their **biggest concerns**.
- 2 in 5 (**40%**) of people with aphasia 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%**) of people with aphasia said they were concerned with **losing independence**.
- A quarter (**26%**) of people with aphasia said they were concerned with **rebuilding confidence**.



What matters to you?

- **83%** of people with aphasia said their **speech was affected**.
- **69%** of people with aphasia said their condition affected their ability to **communicate with others**.
- **61%** of people with aphasia said aphasia impacted their **sleep or fatigue**.
- **60%** of people with aphasia said their health condition affected their ability to be **physically active**.



What matters to you?

- **60%** of people with aphasia said aphasia impacted their **personal independence**.
- **57%** of people with aphasia said aphasia impacted their ability to pursue **hobbies and interests**.
- **52%** of people with aphasia said aphasia impacted their ability to **get out**.

Mental Wellbeing

Aphasia can have a significant impact on wellbeing.

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



Mental Wellbeing

- Some people needed additional support around their **mental health** because of aphasia.
- One in eight (**12%**) people with aphasia had accessed **mental health support or psychological support**.
- Mental health **services** must be more **accessible**.
- One in seven (**14%**) said that they needed specialist mental health support because of aphasia but **had not been able to access it**.

Loneliness

- Difficulties in communicating can have an **impact on our relationships**.
- Nearly half (**48%**) of people with aphasia said they experienced **loneliness as a result of their condition**.
- People with aphasia were **more likely** to say they **experienced loneliness** than other stroke survivors.



Stigma

Sadly, a third of people with aphasia said they felt they had been **treated negatively because of their condition.**

Stigma can make people feel **isolated, embarrassed and impact on their self esteem.**

A third of stroke survivors who experienced stigma **(38%)** said it made them **less likely to seek help.**



Access to Services and Support

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.

Rehab includes **speech and language therapy, physiotherapy** and **occupational therapy**.

Many people with Aphasia **(67%)** accessed **NHS Support**.



Access to Services and 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**.
- Just over a third (**39%**) had accessed **occupational therapy**.
- Only **12%** had accessed **mental health support**.
- Half of people with aphasia (**50%**) say there was support they needed but **weren't able to access**.
- The biggest need was for **speech and language therapy**.



Support

- Many people with our conditions are still **not getting the support they need** to live life to the full.
- Most people with Aphasia (**67%**) experienced some kind of **difficulty accessing services**.
- **31%** said **communication difficulties** were a **barrier** to them accessing services.
- **25% didn't know what was available** in their area.



Support

- **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 to find information.**
- People with aphasia said they would like **support to enjoy hobbies** and interests.
- People with aphasia said they would **benefit from a befriending service.**



Impact of CHSS support

Access to support and advice can hugely benefit people's wellbeing.

People with chest, heart and stroke conditions who had **accessed CHSS support rated both their health and mental wellbeing higher** than those who had not been able to access CHSS support.



Cost of living

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

43% of people with aphasia said the condition **impacted on their ability to work as before.**

People with aphasia were **more likely to be affected financially** than other stroke survivors.

A third of people with aphasia say their health condition **affects them financially.**

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

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

Caring

81% of people with aphasia said they were **cared for by a family member or friend.**

Being a carer impacts on people's mental and physical wellbeing.

Carers must be able to access the support they need.

38% were living with **another condition** in addition to aphasia and stroke.

People with aphasia **need person centred support** that responds to their needs and considers the whole person.



What needs to change?

Scottish Government should:

- Make **Rehab a Right** in Scottish Law.
- **Provide support** for people with aphasia who want to **return to work**.
- **Provide better financial support** for people who cannot work because of aphasia.
- Ensure health boards can **provide Assistive Technology**.
- Provide **better support for people caring for people** with aphasia.

What needs to change?

Health and Social care should:

- Make sure **staff understand aphasia**.
- Make sure that **speech and language therapy is available** for as long as you need it.
- Support people with aphasia to stay **physically active**.
- Refer people with aphasia to **community support** and **peer support groups**.
- Make sure there is appropriate **community support for younger people with aphasia**.
- Make sure that **emotional and psychological support is available and accessible**.
- Provide **specialist psychological support** and **mental health support**.
- Provide support for **carers** to get rest and **look after their own health**.



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NO LIFE HALF LIVED