

Chest  
Heart &  
Stroke  
Scotland



# OUR VOICE OUR VOTES OUR ASKS

CHEST HEART & STROKE SCOTLAND'S  
2026 SCOTTISH PARLIAMENT MANIFESTO

**NO LIFE HALF LIVED**





### **My name is Alastair.**

I've experienced an Aortic Valve Replacement (AVR) a total of 3 bypasses and a Heart Attack.

I live with the physical and mental effects of these conditions every day, but I am glad to be here!

Being a passionate human being, Scot and an active voter, it matters hugely to me what the next Scottish Government does to help and support people who are having to live with long-term health conditions.

With active help and support, we can live as full a life as possible whilst contributing to daily life, why, because we matter and we deserve to be heard.

Most importantly, we need a government that will listen to our voices – voices you can strongly hear throughout this important manifesto from Chest Heart & Stroke Scotland.

We all need Awareness, Recognition and Co-operation (ARC) from all who are in a position to provide this support and be part of a strong team regardless of political party allegiance

Thus giving all voters the ability to contribute, educate and inspire.

A government for all and serving all!

Thank you for listening.

ALASTAIR MAIR



# SCOTLAND'S HEALTH TODAY .....

**SCOTLAND IS ALREADY IN THE MIDST OF A POPULATION HEALTH CRISIS, WHICH IS PREDICTED TO WORSEN OVER THE COURSE OF THE NEXT PARLIAMENT AND BEYOND.**

- Scotland's population is aging and growing, expected to **raise the increased burden of disease by 21% by 2043<sup>1</sup>**.
- **Health inequalities continue to grow**, with the gap between life expectancy and healthy life expectancy continuing to grow between the most and least deprived communities<sup>2</sup>.
- Our **NHS services are failing to cope with this demand**, with record waiting lists and A&E waiting times<sup>3</sup>.

## ON ELECTION DAY IN SCOTLAND...

**31** will people have a **stroke**



**16** people will be diagnosed with **heart failure**

**32** people will have a **heart attack**



**16** people will be diagnosed with **coronary heart disease**

**41** people will be admitted to hospital because of **chronic obstructive pulmonary disease (COPD)**



At Chest Heart & Stroke Scotland we believe something simple - no life should be half lived. People in Scotland affected by chest, heart and stroke conditions and Long Covid must be heard and supported.

The next government will need to make significant changes to our healthcare system if we are going to give everyone the chance at the healthy life they deserve. If the following asks are adopted by all parties we can make real, tangible differences to the health of our country.



1. Acting now to add life to years, and years to life for Scotland's future - Our blog - Public Health Scotland  
2. Scotland's life and healthy life expectancy: Key facts and figures - SPICe Spotlight | Solas air SPICe  
3. British Medical Association [www.bma.org.uk/advice-and-support/nhs-delivery-and-workforce/pressures/nhs-under-pressure-scotland](http://www.bma.org.uk/advice-and-support/nhs-delivery-and-workforce/pressures/nhs-under-pressure-scotland)

# INTRODUCTION.....

**At Chest Heart & Stroke Scotland, we're standing with the 1 in 5 people across Scotland living with chest, heart, and stroke conditions, and Long Covid.**

We are Scotland's largest organisation dedicated to providing support to people living with our conditions. Our life-changing services are built on supported self management, backed by evidence and fuelled by the belief that everyone deserves the opportunity to live life to the full.

But people in our communities need more than we alone can give. That's why, as we head toward the 2026 Scottish Parliament election, our message is clear: the voices of those living with chest, heart and stroke conditions, and Long Covid, cannot be sidelined. Because behind every condition, there is a person, a family, a future and a life that matters. And every voice deserves to be heard. With more than a million votes behind them, they must be heard.

We need rehabilitation and supported self management to be front and centre in our NHS. We need improvements across primary and urgent care. We need decisive action on prevention so fewer families face the life-changing impact that a stroke, a heart attack or a major diagnosis can bring, and so unjustifiable inequalities in life quality and expectancy start to shrink.

As we go into this election we offer practical solutions. We know the third sector is essential in improving Scotland's health, and we want to lead and be part of that change. The next government needs to recognise everything the third sector has to offer as strategic partners if it is going to make the changes our country needs.

Our manifesto is not a list of demands – it's a call to build a fairer, healthier Scotland. No matter who forms the next government, they must act. Because people with long-term conditions don't need more promises. They need change.

Jane Claire Judson  
Chief Executive  
CHSS



"We know the third sector is essential in improving Scotland's health, and we want to lead and be part of that change."

## OUR ASKS.....



### PREVENTION & COMMUNITY DETECTION

Everyone gets the best chance to reduce their risk of long-term conditions

**KEY ASK - Create a network of NHS, third sector and community services to detect cardiovascular risk factors,** such as cholesterol, blood pressure, blood sugar and atrial fibrillation



### ACUTE & SECONDARY CARE

Everyone can access the high-quality specialist care they need for their condition

**KEY ASK - Deliver an equitable 24/7 national thrombectomy service** ensuring everyone can benefit from this essential service regardless of where or when they have their stroke

**KEY ASK - Support clinicians to develop and implement national care standards for COPD** so people with respiratory conditions get the care they deserve



### REHAB & SELF MANAGEMENT

Everyone with a long-term health condition gets the support they need to live well

**KEY ASK - A Rehab guarantee -** Ensure everyone is assessed for support and rehabilitation needs upon diagnosis or discharge from hospital, including a rolling patient-centred review



### HEALTH BEYOND HEALTH CARE

No one lives in poverty because of poor health, and no one has a long-term health condition because of poverty.

**KEY ASK - Review Carer Support Payment** to ensure no one is pushed into poverty by their caring role

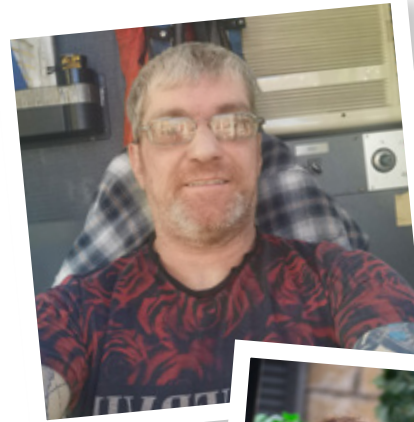
# OUR VOICE .....

**People with our conditions are at the heart of everything we do – including our asks of government. They know better than anyone that things need to change, and our manifesto is their voice.**

We surveyed the people we support, meeting them in person to find out what mattered most to them. Their priorities formed the basis of our proposals. Our peer-group partners and advisory groups helped us to develop these into the manifesto asks that you see here. This reflects their concerns, their priorities and, importantly, their solutions.

We know healthcare matters to everyone, with half of voters saying it's one of their top priorities<sup>4</sup> ahead of the 2026 election. For voters with one of our conditions, it matters even more.

"85% of our service users rated the NHS as the most important issue to them ahead of the 2026 election. This is compared to half of voters from the general populations who say healthcare is one of their top priorities."



4. Source: Mark Diffley, Diffley Partnership Ltd. Immigration ranked as a top concern for Scots, newreport reveals | The Herald



# WHAT MATTERS.....

## COMMUNITY REHABILITATION

60% of our service users said access to **community rehabilitation services**, such as physiotherapy, speech and language therapy, and occupational therapy was of highest importance. That's why NHS services and rehab services feature so prominently in this manifesto.

Rehabilitation services are essential to help people live life to the full after a diagnosis or hospitalisation. They also prevent readmissions and save the NHS money, making them a net benefit for the NHS. The numbers of people living with long-term conditions is forecast to increase, so support to help people live well is absolutely essential.

People with our conditions also told us they wanted **better access to GPs** and to **community healthcare**. Getting access to primary and community healthcare when you need it is something voters with our conditions value highly.

## ECONOMIC IMPACT OF MANAGING A LONG-TERM CONDITION

People with our conditions are also affected by the same economic factors as other voters. In fact, disabled people are more likely to live in poverty. Not all of those living with chest, heart and stroke, stroke and Long Covid conditions will live with a disability, but many do, and it's an important factor to consider. Our service users said the economy was the single biggest issue for them outside of healthcare, with many raising the need for help with rising costs.

## PREVENTION AND HEALTH INEQUALITY

As a charity, we start even before people are affected, by working in communities to help people live well and reduce their risk of disease. It is essential that government does more to help people live healthier, longer lives – so we've also included some asks on preventing major health problems.

## SUPPORT FOR CARERS

Finally, people with our conditions wanted support for the people who care for them – their spouses, partners, children and siblings who provide essential unpaid support. But they also wanted more independence, for more support to be provided for them so their families didn't have to pick up these responsibilities. Support that helps people live life to the full also helps their families to live healthier, happier lives and to be more economically active.

People with our conditions understandably focused on the need to support people already affected by chest, heart and stroke conditions, and Long Covid.

*"Carers are often left completely unsupported in the present structure."*



**85%**  
of our service  
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**60%**  
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# 1. PREVENTION AND COMMUNITY DETECTION.....

## OUR ASKS

- **KEY ASK - Create a network of NHS, third sector and community services to detect cardiovascular risk factors**, such as cholesterol, blood pressure and blood sugar
- **Develop enhanced support pathways for women with cardiovascular risk factors** such as PCOS and pre-eclampsia, including through third-sector support
- **Introduce a duty for all public bodies to consider health**, viewing all work through a lens of health creation as well as disease prevention
- **Work with supermarkets to expand existing schemes on access to fresh fruit and vegetables**, supporting everyone to have a more nutritious diet
- **Increase access to third-sector physical activity schemes** for those with long-term health conditions and in low-income communities
- **Introduce restrictions on alcohol marketing** to reduce the impact of health harming products
- **Expand investment in community CPR training** and growing the amount of support to those who witness out-of-home cardiac arrest to give everyone the best chance to survive out-of-home cardiac arrest

## EVERYONE GETS THE BEST CHANCE TO REDUCE THEIR RISK OF LONG-TERM CONDITIONS

**Not every stroke, respiratory condition or heart attack is preventable. But the next government can prevent more people from developing these kinds of long-term health conditions.**

Over the next 20 years significantly more people are predicted to be living with stroke and respiratory conditions<sup>5</sup>. An additional 37,000 people will be living with stroke in 2044, and 87,000 more people will be living with chronic obstructive pulmonary disease (COPD), an incurable and progressive disease that makes it hard to breathe. We also know that Scotland's poorest communities have higher rates of disease and are four times more likely to die from heart disease before 75 and seven times more likely to be hospitalised with COPD<sup>6</sup>.

It is essential that we prioritise prevention and give everyone the chance of a longer, healthier life. That means putting more resources into community healthcare, taking action on the things we know make people sick and making sure everyone can benefit from the things they need to stay healthy. The systemic changes this requires will also make our NHS more sustainable in the long term. Cardiovascular disease alone costs the NHS around £950million every year, with a wider cost to the economy of a staggering £2.5bn<sup>7</sup>.

No one part of society can address disease prevention in isolation. The NHS needs to support much greater partnership working, allowing community organisations, primary care and providers such as pharmacies and housing organisations to work together.

We need urgent action to detect factors that put people at increased risk of chest, heart and stroke conditions, so people can get the support they need before they become sick. We need system changes that make it easier for people to stay well and that target resources to communities who are most affected.

5. Scottish Burden of Disease study Forecasting the future burden of disease: Incorporating the impact of demographic transition over the next 20 years November 2022

6. Scottish Health Survey (dashboard) 2023

7. British Heart Foundation – Scotland Factsheet, Jan 2025.  
[www.bhf.org.uk/-/media/files/for-professionals/research/heart-statistics/bhf-cvd-statistics-scotland-factsheet.pdf](https://www.bhf.org.uk/-/media/files/for-professionals/research/heart-statistics/bhf-cvd-statistics-scotland-factsheet.pdf)



## EARLY DETECTION MATTERS

Many of the long-term conditions Scotland's population faces could be prevented, or better managed, through early detection and management of risk factors. Undiagnosed high blood pressure, obesity or atrial fibrillation are just some examples of health challenges that, left untreated, can lead to conditions such as a heart attack or stroke. Through targeted intervention to work with individuals to mitigate these risk factors, we can turn things around not only for individuals but for Scotland's healthcare system.

Cardiovascular disease is a key example of how we can make change through cost-effective interventions. CVD causes more than a quarter of all deaths in Scotland, second only to cancer<sup>8</sup>. With the rising burden of disease, and the impact of obesity on our health, this number is expected to continue to rise. However, CVD risk can also be mitigated by finding individuals with risk factors and working with them to manage the condition.

Through our Health Defence and Advice Line offerings, Chest, Heart & Stroke Scotland has been working with GPs to support individuals to navigate the diagnosis of a risk factor condition and make changes to support their health. This programme could be expanded and adapted to include other risk factors for wider long-term conditions – saving lives and our NHS.



## OUR VOICE - JOE

**'Being part of support groups can make a massive difference'**

Joe was in his 50s when he had two heart attacks three weeks apart and knew he had to change his lifestyle if he was to recover fully.

Now 78, Joe still diligently does his heart rehabilitation exercises and helps others dealing with living with a heart condition as part of two Chest Heart & Stroke Scotland affiliated peer support groups.

He says: "I knew my lifestyle had to change, and it did. I stopped smoking after my first heart attack. I'd previously tried to stop without any success. But cardiac rehab helped rebuild my confidence and strength.

"I am still doing my rehab exercises today. You have to keep going at rehab because you can improve your health and fitness. The groups I'm in are also about prevention and raising awareness of heart disease and heart health.

"Being part of support groups like this can make a massive difference to your recovery."

8. National cardiovascular disease (CVD) prevention and risk factors toolkit | Right Decisions

## 2. ACUTE AND SECONDARY CARE.....

### OUR ASKS

- **KEY ASK - Deliver an equitable 24/7 national thrombectomy service** ensuring everyone can benefit from this essential service, regardless of where or when they have their stroke
- **KEY ASK - Support clinicians to develop and implement national care standards for COPD** so people with respiratory conditions get the care they deserve
- **Invest in reducing waiting times for cardiology**, especially for echocardiograms and other diagnostics
- Fund a pilot scheme to **increase the use of Group Consultations/Shared Medical Appointments** to increase primary care access for people with similar long-term conditions<sup>9</sup>
- **Include gender and sex data** in all care bundles and audits to identify where women’s treatment experiences lag behind men’s
- **Address gender and sex inequity in clinical trials** and through research funded through the Chief Scientist’s Office
- **Prioritise improving compliance with care standards** with Healthcare Improvement Scotland being brought in to support boards that consistently fail to meet standards
- **Create and implement a national doctor led long covid pathway**, ensuring equitable access to support across Scotland

### EVERYONE CAN ACCESS THE HIGH-QUALITY SPECIALIST CARE THEY NEED FOR THEIR CONDITION

**Scotland’s clinicians are world leading. Our cardiologists, stroke nurses and radiologists work round the clock to provide life-saving care. But a lack of strategic investment in urgent and life-saving treatment has jeopardised services, with clinicians struggling to provide the levels of care needed.**

Scotland’s stroke services have been unable to meet our own standards of care since before the pandemic, with just over half of patients in 2024 getting the treatment they needed. There is also significant inequality in support. According to CHSS-funded research from the University of Aberdeen, people living in Scotland’s most deprived areas are more likely to die in the year following a stroke than those in other areas. Thrombectomy, an essential stroke treatment, is only available during weekdays across large parts of the country. This variation exacerbates regional health inequalities, meaning rural and island communities simply do not get parity of care.

Too many people with respiratory diseases such as COPD or interstitial disease are waiting long times for diagnosis or testing, with significant variation across the country. Waiting times for cardiology remain high, with thousands of people remaining to be seen by a specialist for testing or treatment.

People can recover and live full and happy lives after major health events – but they need access to the best acute treatment and specialist testing. A lack of investment and regional inequalities are holding many too people behind.

**We need the next government to fight for our specialist services – to stand up for our clinicians and prioritise the essential services that patients need. Stroke clinicians have been very clear about what they need – so our asks on stroke have been formulated jointly by them, the Stroke Association and CHSS.**

9. Effectiveness of shared medical appointments delivered in primary care for improving health outcomes in patients with long-term conditions: a systematic review of randomised controlled trials - Mei Yee Tang <https://pubmed.ncbi.nlm.nih.gov/38453205/>



## THROMBECTOMY

Thrombectomy is a life-changing procedure that can dramatically improve recovery outcomes for stroke survivors. Simply, thrombectomy is a removal of a clot from the brain mechanically. But the impact is immense, making it three times more likely that a stroke survivor can live independently.

Thrombectomy changes lives. Analysis in 2017 found thrombectomy could save the health and care system £47,000 per patient over a five-year period<sup>4</sup>, £61,000 in 2024<sup>10</sup>, by reducing the cost needed on rehab and further support. Yet access in Scotland remains limited and inconsistent. Every year, hundreds of people could benefit from this treatment, but too many miss out because of when and where their stroke occurs. Thrombectomy is a standard medical procedure in many countries and should no longer be a postcode lottery in Scotland.

**CHEST HEART & STROKE SCOTLAND HAVE BEEN LEADING THE CAMPAIGN ON THROMBECTOMY SINCE 2017. WE CANNOT AFFORD TO REACH TO A 10-YEAR ANNIVERSARY OF THIS CAMPAIGN DURING THIS PARLIAMENTARY TERM. THE NEXT GOVERNMENT MUST ACT.**



## OUR VOICE - MICHAEL

Michael, 33, had the first of two strokes in March 2023 and had a thrombectomy to remove a blood clot. An aneurysm caused a second stroke that also required surgery. The first stroke was the result of a bacterial infection that damaged his heart, and he needed valve replacement surgery.

"I was given a thrombectomy after my first stroke. I didn't realise this procedure is only available 9-5, Monday to Friday. I got to hospital at 4.30 in the afternoon, and I was lucky the stroke team decided I needed to be treated right away, and they all stayed to do that.

"Now knowing the difference thrombectomy can make in recovery, I think it's essential that this procedure is available to everyone, no matter where you live or what time you are admitted to hospital. It's a game-changer where stroke recovery is concerned.

"In hospital, I'd been the youngest person on the stroke ward by years. Everyone there had their own goals, but theirs were getting home or being able to look after themselves. I was only 31. I was desperate to get back to work and I needed to know that was possible. The stakes felt much higher for me.

"Recovery is tough, and it's a lifelong journey, but it's possible. I want other young stroke survivors to know they can recover, they can get back to work or back to doing the things they love most."

10. <https://www.iomcworld.org/proceedings/budget-implications-for-the-uk-nhs-of-implementing-mechanical-thrombectomy-for-the-treatment-of-acute-ischemic-stroke-pa-49204.html>

### 3. LIVING LIFE TO THE FULL .....

#### OUR ASKS

- **KEY ASK - A Rehab guarantee** - Ensure everyone is assessed for support and rehabilitation needs upon diagnosis or discharge from hospital, including a rolling patient-centred review
- Expand provision of **technologically enabled rehab gyms, significantly increasing access to rehab services**
- **Adapt the Diagnosis Connect Model for use in Scotland**, allowing NHS Services to refer directly to trusted third-sector service providers at point of diagnosis or discharge
- **Help people with lung conditions breathe easier by developing, funding and implementing a nationwide expansion of pulmonary rehabilitation**
- **Develop tailored psychological services for people with communication difficulties such as aphasia**
- Set an ambitious target to **cut chronic loneliness in half by 2036**, recognising loneliness as a public health emergency

#### EVERYONE WITH A LONG-TERM HEALTH CONDITION GETS THE SUPPORT THEY NEED TO LIVE WELL

**We know leaving hospital after a major event or diagnosis is only the start of a long journey. Sadly, this is often where support drops away. Too many people feel isolated and afraid as they adjust to living with a long-term condition. Their day-to-day life can look very different, and the future seems uncertain.**

Everyone with a long-term condition should get the opportunity to live a full and happy life to the absolute fullest – and that means they need support to help them do that. But too many people tell us they struggle to get access to the support services they need. Our 1 in 5 Report showed that fewer than half of people with our conditions were able to access NHS rehab, with more saying they couldn't access the support they needed<sup>11</sup>. That includes peer support, counselling, and domestic support.

With more people predicted to live with long-term health conditions, we need to change the way we think about healthcare. We're calling for long-term condition management to be a core part of the next government's vision for health. Health is about more than living longer – it's about living well and getting the support you need to do that.

The NHS can't do this alone. Supporting people to live well requires partnership – not just between the NHS and social care but between the public and third sector. Chest Heart and Stroke Scotland is one of more than 2,000 health charities in Scotland, many of whom provide specialist support to help people manage their health. With a workforce of more than 12,000 people, Scotland's voluntary health sector is bigger than some NHS health boards. We have the time, the capacity and the expertise to support people to manage their health – and it's time to make us part of the solution.

*"With a workforce of more than 12,000 people, Scotland's voluntary health sector is bigger than some NHS health boards"*

11. CHSS 1 in 5 Report, 2023

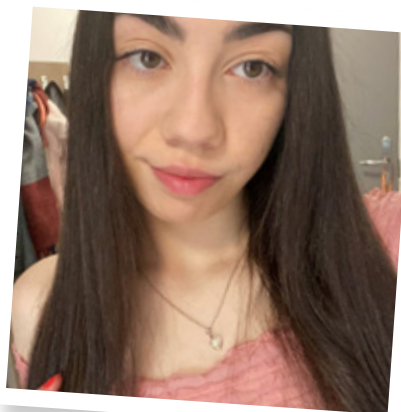


## SUPPORTED SELF MANAGEMENT

Most people living with any kind of long-term health condition already self manage their health. CHSS estimates people living with a long-term condition spend 95% of their time outside of formalised health and social care services, meaning they are always the person left to adapt their life to better reflect their needs, energy and mobility. But doing this alone is hard and means missing out on valuable support. Supported self management is about partnership working between professionals and people living with long-term conditions, helping people to develop skills, learn from tips and build support networks so they can really thrive.

Supported Self Management is at the heart of all of CHSS services. We build our support around this approach, so people can learn skills that help them live well with long-term health conditions. Our Supported Self Management Programme is the only evidence-based programme of its kind in Scotland, originating from Stanford University in the USA. Of the people who have taken part in the programme so far, 98% would recommend it, with many seeing an improvement in managing fatigue, pain and emotions.

Only a small proportion of people who live with a long-term condition are offered support to self manage, with the rest left to fend for themselves. We know the NHS cannot provide this kind of support – but it absolutely must refer people to where they can get this essential support, including from third-sector services.



### OUR VOICE - HANNAH

**"It's so important for anyone living with a chronic condition to know where to get help."**

Hannah Fleming, 23, was diagnosed with Long Covid while a student. With support from a Chest Heart & Stroke Scotland Advice Line practitioner, Hannah was able to finish her studies and graduate as a nurse last year.

"Speaking to Sharon was the best thing to happen to me. She had so much understanding and so much advice for me. I don't think I could have got through those months without her.

"It was difficult to study and work, I was so unwell. But information and advice from Sharon helped me go on and finish my degree. I still use the techniques she gave me today.

"The other great thing was that my mum was always with me when I was speaking to Sharon, so the family were part of this support, too.

"The advice Sharon gave me was so important and I still use those techniques today. The key was on pacing, being able to decide what I could and couldn't do at times. Sharon explained about planning my week out, giving myself time to recover, and helped me share that with friends and family so they understood why I might not be able to take part in something.

"I know how much of a difference getting support and the right information made to me. It's so important for anyone living with a chronic condition to know where to get help."

## 4. HEALTH BEYOND HEALTHCARE .....

### OUR ASKS

- **KEY ASK - Review Carer Support Payment** to ensure no one is pushed into poverty by their caring role
- **Simplify Adult Disability Payment** to make applications easier, ensuring no one who could benefit is missing out
- **Commit to increasing ADP** above inflation by the end of the parliament to lift more disabled people out of poverty
- **Increase availability of vocational rehab** so everyone who wants to work can do so
- **Develop a scheme to help organisations provide employment that benefits people's wellbeing**, so they can be health creators, not just job creators
- **Recognise and address the volunteering crisis in Scotland, and commit to increasing investment to tackle it**

### NO ONE LIVES IN POVERTY BECAUSE OF POOR HEALTH, AND NO ONE HAS A LONG-TERM HEALTH CONDITION BECAUSE OF POVERTY.

**Persistent declines in living standards have hit people hard. Incomes are stagnating, costs are rising, and people living with long-term conditions are some of the hardest hit.**

Life with a long-term condition or a disability is already expensive. Research by Scope found that disabled households face an extra £975 per month in costs, including on assistive technology, living adaptations and transport<sup>12</sup>. This contributes to an unacceptably high rate of poverty for disabled people of around 30%, 10% higher than non-disabled people<sup>13</sup>.

We also know poverty is a significant contributor to poor health, putting more than a million people in Scotland at higher risk of significant disease and a shorter life. People with long-term health conditions face a vicious circle of poverty and ill health – as disabled people and those with long-term health conditions becoming poorer, they become more at risk of poor health outcomes.

Many people with our conditions are supported by unpaid carers, often spouses or children who may give up work to support their family member. Being out of work is a key predictor of poverty for unpaid carers, putting their own health at risk<sup>14</sup>. People we spoke to in developing this manifesto impressed on us that it was essential for carers to get more support. With women more likely than men to become carers, and half of women taking on caring responsibilities by 46, it is essential to view the gendered nature of this support<sup>15</sup>.

Unpaid carers in Scotland provide a staggering £15.9bn worth of care every year<sup>16</sup>. However, someone caring full time would only receive £4,300 a year in Carers Support Payment every year, for providing 35 hours of unpaid care a week (Social Security Scotland)<sup>17</sup>.

The uncomfortable but undeniable truth is that if we want people to live better for longer, the next Scottish government needs to take urgent action on poverty. Poverty shortens lives, creates health inequalities and targets disabled people. This is without a doubt the greatest challenge in this manifesto – but we need our government to step up to the plate if we want to finally make a change.

12. <https://www.scope.org.uk/campaigns/extra-costs>

13. <https://www.jrf.org.uk/uk-poverty-2025-the-essential-guide-to-understanding-poverty-in-the-uk>

14. Poverty and Financial Hardship of Unpaid Carers in the UK - [www.carersuk.org/media/dnxerxqv/poverty\\_financial\\_hardship\\_uk\\_web.pdf](http://www.carersuk.org/media/dnxerxqv/poverty_financial_hardship_uk_web.pdf)

15. Will I Care? The Likelihood of being a carer in adult life. Carers UK. [www.carersuk.org/media/warllcph/carersrightsdaynov19final-2.pdf](http://www.carersuk.org/media/warllcph/carersrightsdaynov19final-2.pdf)

16. Valuing Carers 2022: Scotland, Dr Jingwen Zhang, Dr Maria Petrillo and Prof Matt Bennett (2024).

17. <https://www.mygov.scot/carers-support-payment>





## OUR VOICE - ALICE

### **"I had to give up the job I loved"**

Alice is 52 and a mum of five and stepmother of two. Diagnosed with Long Covid in 2023, she lives with symptoms such as chronic fatigue and mobility issues and can no longer work.

"You don't really hear much about Covid now, it's like it never happened. But it happened, and it changed everything for me. People think Long Covid is just fatigue. But there's so much more to it.

"I had to give up the job I loved in a care home and adjust to a life where I only have limited energy and rely so much on other people in a way I never did before.

"Long Covid affects everyone in different way, but it's especially tough for women. We need better understanding about women's health and the different pressures we feel. As mums, we women carry a lot of guilt. We feel guilty for saying no to things, for not always being able to do things for the family.

"But you simply can't do what you used to when you live with a chronic condition. I'm getting better at saying no when I don't have the energy for something, but it's taken a long time for me to get to this point.

"Every time I do something, I know there will be consequences. It's taken time for me to understand this, but it's important others know it, too."



## OUR VOICE - HAZEL

### **"I want to go back to work. I want to be able to do all the things I used to."**

Hazel is 58. She lives with epilepsy and also suffers from osteoarthritis and osteoporosis. In 2021, she underwent thrombolysis to dissolve a blood clot in her heart.

"When I collapsed with the blood clot, it was a complete shock because I was very healthy. I worked as a healthcare assistant and would do between 15,000 and 20,000 steps every day. I had no idea there was something wrong.

"I spent four days in hospital, then I was off work for six months. I was referred to the Chest Heart & Stroke Scotland Advice Line, and they were so helpful in giving me direction on things like nutrition and exercise. Thankfully everything now seems fine with my heart, but I'm dealing with other health problems.

"My bones are very sore because of the osteoarthritis and osteoporosis. Last year I needed ankle fusion surgery, so now I have screws holding me together. I spent three months in bed not doing anything, and it's only recently that I have been able to walk again.

"I am trying to get my fitness back and to return to where I was. I know I need to exercise to keep my heart healthy. I had a check-up recently and all is well with my heart.

"But I want to go back to work. I want to be able to do all the things I used to. The support I got from CHSS made such a difference to me, and that's the kind of support I still need now."

# SHARED ASKS FROM SCOTLAND'S STROKE COMMUNITY .....

As part of our drive for NHS recovery, prevention of avoidable illness, and to improve outcomes across health and social care, we will implement the 'Delivering stroke as a priority' actions developed by the stroke community in Scotland.



- Deliver an equitable 24/7 national thrombectomy service. Thrombectomy saves lives and money. It is a standard medical procedure in many countries and should no longer be a postcode lottery in Scotland.
- Increase inpatient and outpatient rehabilitation capacity. Front-loading spending on inpatient and outpatient rehabilitation will save money and promote recovery from stroke by reducing the need for ongoing support.
- Acute stroke care will be given the same hospital status as other specialist units. Stroke is designated a clinical priority and needs the same protection for beds, staff and other resources that is afforded to coronary care or trauma units.
- Develop an innovative long-term stroke-specific workforce recruitment and retention plan. Measures to address the shortfall in stroke staff will include a bigger profile for stroke in education syllabuses and increased opportunities for career progression.
- Ongoing failure to meet stroke standards to be escalated to Health Improvement Scotland. This will make the auditing process more robust and ensure NHS boards place greater emphasis on meeting the needs of stroke patients.

## ENDORSED BY

British & Irish Association  
of Stroke Physician

Chest Heart & Stroke Scotland

The Stroke Association

Royal College of Physicians  
and Surgeons of Glasgow

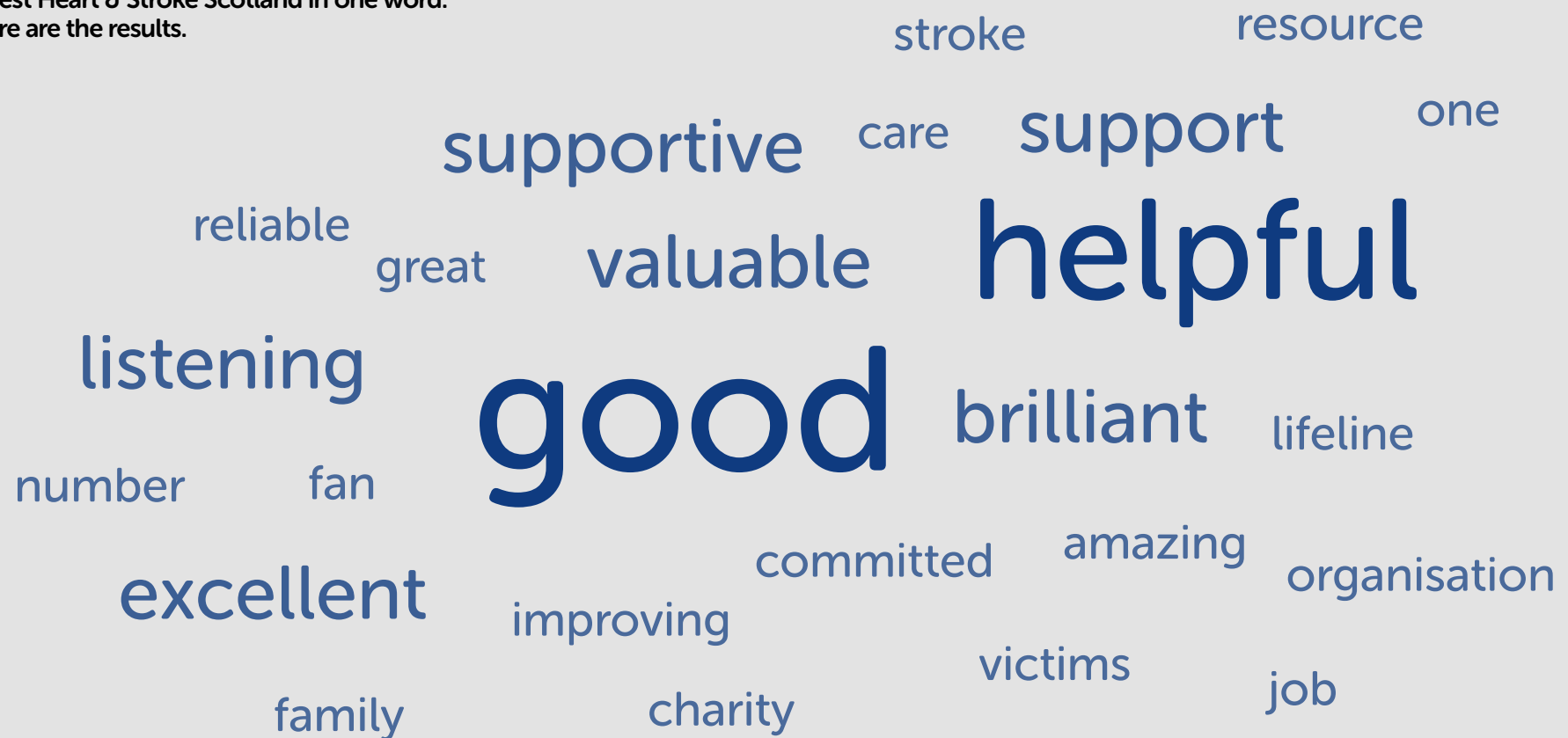
Royal College of Physician  
of Edinburgh

The Scottish Stroke Nurses Forum



## OUR VOICE .....

In our focused discussions at local peer group assemblies and at our focus groups across Scotland, we asked people living with our conditions to tell us what they think about Chest Heart & Stroke Scotland in one word. Here are the results.



## METHODOLOGY.....

**This manifesto has been developed through consultation with CHSS service users, advisory groups and peer group partners. We are extremely grateful to everyone who took the time to give us their feedback and participate in this process.**

We distributed a survey to our service users and amongst a small number of peer group partners to determine what mattered most to them.

We received 239 responses, almost all of which were digital.

Out of those who identified their condition, 19 had aphasia, 57 had a cardiac condition, 37 had a respiratory condition, 20 had Long Covid, 139 had had a stroke and 49 had had a Transient Ischaemic Attack (TIA).

Survey respondents identified the NHS as their single largest priority, with

- 85.6% rating this as 'highest importance'.
- 61% rated community rehabilitation as highest importance, with
- 36% rating this as high importance.
- 47 % rated the economy as highest importance, and
- 42% rated the cost of bills as highest importance.

When asked to identify five key areas for the Scottish Government to prioritise, the most popular were 'better access to GP appointments' (17%), 'better access to rehabilitation' (13%), 'bringing down the cost of bills' (12%), 'a social security system which meets our needs' (11%) and better support for carers (13%).

We also spoke to the CHSS Aphasia Reference Group and the CHSS National Advisory Panel and held a number of focus groups through our Peer Group Partners. We spoke to 55 people across eight groups, which allowed us to explore survey questions more thoroughly, including drawing out more detail and giving us space to discuss potential policy solutions.





## My name is Su

I was diagnosed with the lung condition bronchiectasis in my early 60s. But I found no information or support available when I was discharged from hospital. Now in my 70s, I found a positive way forward when I was referred for pulmonary rehabilitation.



Pulmonary rehabilitation was the making of me. It gave me my life back and gave me the confidence to start exercising again. I'd had no idea how much or how little exercise I could safely do, so I didn't do any.

Rehab is so important for people living with a lifelong medical condition. We need to know what exercise is right for us and

how much we can do. If nothing else, exercise can simply lift your mood, which is so important.

Pulmonary rehab didn't just help my lung health, it helped with my general health and made me less of a problem for the NHS.

Thank You

SU



Chest  
Heart &  
Stroke  
Scotland



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**NO LIFE  
HALF LIVED**