Chest
Heart &
Stroke
Scotland

# NO LIFE HALF LIVED

## STRATEGY 23/28

# 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 YOU CAN SHAPE YOUR FUTURE AND LIVE THE LIFE YOU 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 of everything we do. We will work to develop the partnerships that will enable this to be available across Scotland.

*WHOEVER YOU ARE, WHEREVER YOU ARE*


# Reasons Why? Our Families, Friends, & Communities

**1 in 5**
**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**

**477,000**
people in Scotland are living with **asthma or COPD**

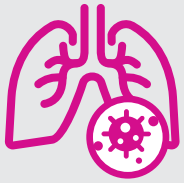
**300,000**
are living with **coronary heart disease**

**136,000**
people are living with the impact of **a stroke**

**46,000**
are living with **heart failure**

**55,000**
people are living with undiagnosed **atrial fibrillation,** a leading cause of stroke and one of the most common forms of abnormal heart rhythm

**180,000**
people are living with **Long Covid**



**2 in 3**
people living with **COPD** are undiagnosed or have an incorrect diagnosis

Almost
**1 in 3**
have hypertension – **high blood pressure** – increasing their risk of heart attack, stroke and heart failure

# No Life Half Lived in Scotland

**People with our conditions need and want to know how to manage their condition day to day and live as well as they can. Experiencing a life changing event like a heart attack or stroke or being diagnosed with a chest or heart condition or Long Covid can mean that people are scared and alone. Many people don't know where to turn.**

Nobody in Scotland should have to face their health journey on their own. We will deliver a community where people with our conditions can support each other, secure the expert help they need, and advocate for the care that matters to them.

*WELCOME TO THE CHARITY THAT NEVER UNDERESTIMATES THE POWER OF A CUP OF TEA – AND ALWAYS AIMS TO DELIVER* ***NO LIFE HALF LIVED***

**WE'RE HERE FOR PEOPLE LIKE JOHN.**

**Lifesaving is not a word John bandies about easily. But when he speaks of the support he received from our Advice Line after having a heart attack, it's the one that comes readily to mind.**

*"What CHSS has done for me has been absolutely massive. It's been incredible. Lifesaving is the word coming into my head, and it sounds over-dramatic, but CHSS has been so vital to my recovery.*

*"I was so desperate for help. I was really weak and in constant pain, and everyday tasks were beyond me. When Tracey first phoned me, it was perfect timing and a trigger just to open up and share my feelings. I was so desperate for support, and some of the things she gave me – coping mechanisms and therapy guides – I still use today."*

# One in Five Report

**More than half of people in Scotland with our conditions do not get referred for the rehabilitation they should receive as set out in national standards and guidelines. This means that over half a million people are not getting the right support and are not accessing the first step in supported self management.**

**1886**
people from across Scotland living with our conditions **told us what matters to them**

Only **45%** of people with our conditions **get referred to rehab**

More than **2 in 5** people with our conditions say their condition **impacts their mental wellbeing**

**47%** of people with our conditions say there was **support** that they needed **but they couldn't access it**

**1 in 5** people said their health condition affects their **financial position**

**1 in 3** people are living with **more than one** of our conditions

**PEOPLE SUPPORTED BY CHSS RATED THEIR HEALTH AND WELLBEING GREATER THAN THOSE WHO DIDN'T GET CHSS SUPPORT**

# One in Five Report

## WHAT THE SURVEY TOLD US

**One in five (1.1million) people in Scotland have or are affected by chest, heart and stroke conditions and Long Covid.**

In 2023 we engaged with 1886 people in what is Scotland's largest ever survey of people living with our conditions. The One in Five report includes feedback on the impact of the Covid 19 pandemic, the cost of living crisis, and the experience of those living with a new long-term condition – Long Covid. The feedback on access to rehabilitation echoes the official NHS and Scottish Government published data – fewer than half of people with our conditions report receiving the rehabilitation they should have access to as set out in national standards and guidelines.

**The key thing people told us was that they felt lonely and scared after diagnosis.**

People are also really worried that the right care isn't available to them, and they may not get the right care if they have a future health emergency. Their top concern since diagnosis was the fear of having another significant health event.

Here at Chest Heart & Stroke Scotland, we have listened and developed a response rooted in the lived experience of people with our conditions.

## WHAT PEOPLE TOLD US

***"I feel concerned, worried about the future, and as if life is on hold."***

*"No ongoing support available. Only able to access rehab/support when health declines."*

***"Not being able to breathe is scary. It makes you anxious, and that makes breathing worse."***

*"People like me, of a certain age, tend to plod on ourselves, and we shouldn't. We should ask for help. I wish I'd contacted Chest Heart & Stroke Scotland at the time because I think it would have been very helpful to me. Get support if you need it – do what I didn't do, which is to ask for help. Be brave. And don't stop doing things that you want to."*

***"People who have had a stroke need more information about what it means. No one should be left alone like I was after they leave hospital."***

# The Challenge

**Everyone with our conditions should have access to a quality supported self management and community recovery service. In Scotland, we know supported self management and community recovery are critical to living well with our conditions. But the gap between this consensus and what happens in reality is much wider than it should be.**

Our One in Five survey tells us this is what people with our conditions want and need and that when they can access it, they rate their health more highly than those who don't. And we know it has a positive impact for our healthcare colleagues, preventing readmission and enabling our healthcare services to focus on what they do best.

Our stakeholders – service users, volunteers, NHS colleagues, health and social care decision makers, fellow essential sector colleagues, and our research community, have fed back that they want us to have a clear focus and to lead in this area.

Supported self management and community recovery is not available to all and where it is, it differs in quality and impact. The number of people who should get the rehabilitation set out in national standards and guidelines and don't is around half a million. This means that those who should have access to quality supported self management and community recovery is likely to be more. There is currently no identifiable national approach to measuring this – a further issue to address.

The challenge to close this gap is significant. One of our values is to be courageous – and so we will be. Another is to be innovative and collaborative. We can't do this alone, and the partnerships we have built, and will build, are critical to this mission. Challenge accepted.

### HERE FOR PEOPLE LIKE MARGARET

Margaret, 60, has had three mini strokes or TIAs since September 2021. No longer able to do a demanding job in education, she felt left in limbo, caught in the gap between NHS care and what would come next.

*"When I was discharged from hospital, I was so scared. There was no one to ask what would happen next. I was scared to sleep – would I waken up in the morning? It was a very scary time not just for me but for my family too.*

*"Things changed from the moment Chest Heart & Stroke Scotland stepped into my life at the time when the NHS had stepped back.*

*"I would not have recovered as well or looked forward to what life has in store for me if they hadn't been there to encourage, help and support me."*

# We Are Here For You


**WE'RE HERE FOR PEOPLE LIKE DOUGLAS AT EVERY STAGE OF THEIR JOURNEY.**

**Our incredible supporter, fundraising hero and volunteer Douglas is the embodiment of No Life Half Lived.**

Douglas had two strokes, seven years apart. The second stroke was much more severe than the first and left Douglas struggling to walk and speak.

Then he met one of our stroke nurses who supported him to get back to doing the things he loves and living his life to the full. He began walking again and found physical activity an extremely important part of his recovery journey.

Since his strokes, in 2003 and 2010, Douglas has become deeply involved with our work and devotes his time to helping other stroke survivors with their recovery.

He is one of our dedicated trustees, he volunteers with our Community Support Service, serves on several of our working groups, and has raised vital funds by taking on multiple epic fundraising challenges over the years.

Douglas is an amazing part of Clan CHSS and it's thanks to incredible input from survivors like Douglas that we're able to help people across Scotland live life to the full.

# Community Healthcare Support Service

**Our One in Five report tells us that people who received our services rate their health higher than those who have not.**

People with our conditions have told us they want and need practical advice, information and support throughout their recovery journey. They want to know how to manage their condition day to day: at work, at home, or when enjoying hobbies and leisure time.

That journey might start with knowing they have a family history of heart disease, through understanding common early symptoms such as breathlessness, tiredness and chest pain. It might start more suddenly – with an unexpected heart attack or stroke.
We will be there.

It might continue with a hospital admission and stay, with rehabilitation in a clinical setting, and discharge back to home.
We will be there.

The journey will continue with the challenges and achievements living with a long-term health condition brings: recovery, relearning, managing their health, managing their life. People with our conditions need support whether that's learning to walk or talk again, returning to work, conquering the anxiety that breathlessness brings, thinking about what to eat, how to exercise, managing finances or being able to spend time doing what they love with their loved ones.
We will be there.

Life with one of our conditions has ups and downs.
We will be there.

Most of the time, people with our conditions manage their lives and health by themselves, without formal healthcare support. It can be tough, it can be lonely, and at times it can feel like the hardest of tasks. It can also be life affirming and an experience that shows how resilient and wonderful they are.
We will be there.

When someone is ready, and wants to become part of the amazing chain of support built by people with our conditions, they can become a volunteer, a fundraiser, a sharer of stories and friendship.
We will be there.

**HOW WILL WE DO THIS?**

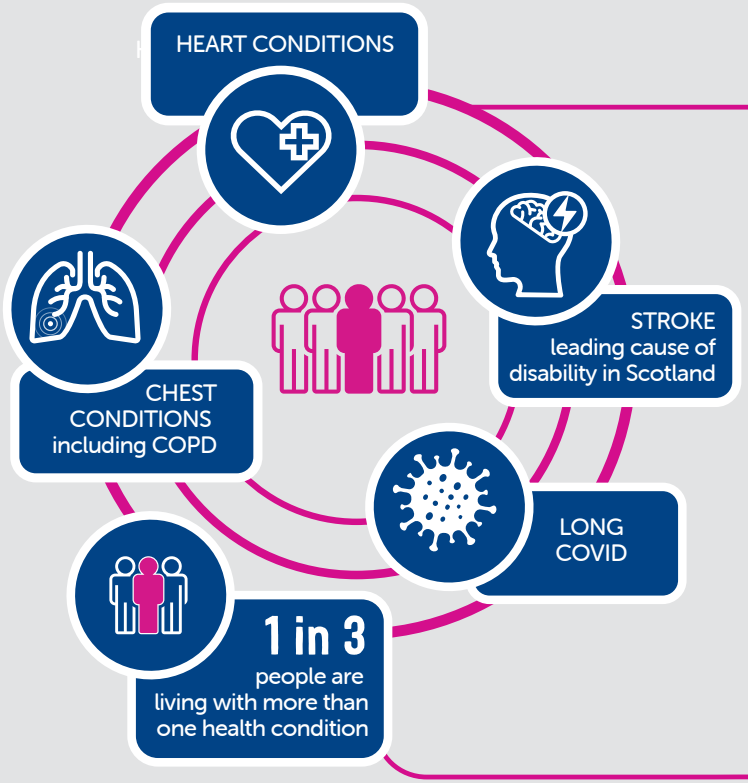
**We will deliver our Community Healthcare Support Service.**

The Community Healthcare Support Service model is a quality supported self management and community recovery model informed by expertise and the latest research – and most importantly, by people with our conditions.
We believe it should be available to all.

*OUR COMMUNITY HEALTHCARE SUPPORT SERVICE WILL PROVIDE ALL OF THIS AND WE WILL BE WITH EVERYONE WHO NEEDS IT, EVERY STEP OF THE WAY*

# Community Healthcare Support Service

**One in five people in Scotland are affected by chest, heart and stroke conditions and Long Covid.**




Our Community Healthcare Support Service is there to:

### PREHAB / PREVENTION

- Improve knowledge of risk factors, identify early signs and symptoms, and tackle health inequalities to help individuals and communities in Scotland live healthier lives.

### ACUTE EVENT/ DIAGNOSIS

- Provide immediate support and advice at point of acute event or early diagnosis.
- Understand what matters to you and your recovery.
- Access to education for healthcare teams and people with our conditions.

### AT HOME & IN YOUR COMMUNITY

- Provide access to an evidence based self management program originally developed at Stanford University so no one has to feel isolated and alone.
  - 6 week supported self management course.
  - Module on managing your condition with optional activities.
  - A tailored, personalised approach to support recovery including peer and volunteer led support.

Everyone develops the ability to live well and with confidence.

### GROW THE CHAIN OF SUPPORT

- People can support each other by providing social, emotional and practical support.
- Working with our volunteers to help extend awareness of our conditions and our reach.
- Work with research partners to close the implementation gap.

Over the next 5 years, we will work to:

**measure**

Develop a robust measure of who can access quality supported self management and recovery. Close the gap.

**campaign**

Campaign to ensure the right to rehab so that the first step in the self management journey is in place.

**reach**

Increase our reach and support so that 150,000 people a year have access to our Community Healthcare Support Service.

**tailor**

Co-produce our services so they are people-led. Enable personalisation so each person has control over their recovery journey.

**connect**

Build stronger connections with our partners and stakeholders to help inform and deliver our work.

**Our Community Healthcare Support Service model is summarised to the left, setting out the key stages of the supported self management and community recovery journey. It is important to note that the model recognises and supports:**

- self management in each key stage – we know that people with our conditions spend more than 90% of their time managing their condition outwith formal healthcare services
- individuals can move between phases as needed
- volunteers can contribute to all phases of the pathway
- carers can access each phase of the model, as well as those living with our conditions.

**People affected by these conditions need and want practical advice, information and support throughout their recovery journey.**

**Our framework of support can be accessed at any time from acute health event or diagnosis of long-term health condition throughout recovery to long-term management of their condition. Some people might come in and out of the services when they need them.**

# Our Services in Action

### HOW WILL WE DO THIS?

**We will work to deliver our Community Healthcare Support Service across Scotland. Our service is based on a framework of supported self management and community recovery led by people with our conditions and informed by expertise and published research.**

At CHSS we have a strong track record of working in partnership with third, public and private sector partners. We can't achieve closing the supported self management and community recovery gap alone and so we will build on this partnership work and increase it.

We will work to increase our engagement with health and social care in every area of Scotland to close the gap. We will put in place the relationship management resource and expertise we need to achieve this.

We also have a track record in engaging and working directly with people with our conditions. We will work to improve and increase our participation and engagement work across all we do.

In doing all of this, we recognise and value the relationships we have today, and those we will build. We never underestimate the power of a cup of tea – the start of any positive change begins with trust, confidence, and the ability to exchange, change and learn from the views of others.

### PARTNERSHIP WITH NHS LOTHIAN AND POGO DIGITAL HEALTHCARE

In June 2022, we launched an innovative Digital Support Pathway in partnership with NHS Lothian and Pogo Digital Healthcare to transform care for Long Covid patients in Lothian.

With invaluable input from people living with Long Covid, we developed the pathway, comprising the digital platform MyTailoredTalks and 12 weeks of support from our Advice Line. The pathway allows GPs and other clinicians to refer patients automatically into our Long Covid Support Service and provides tailored self management information to people living with Long Covid.

> *"The support from Chest Heart & Stroke Scotland is the only help that's out there. My GP referred me on to CHSS, and that has been such a help. MyTailoredTalks have been really good. In a lot of ways, the talks are refreshing what I already knew because I've had chronic fatigue for years, but it's great to be reassured and try and follow what I know are the methods to undertake."*
> *Mike is living with Long Covid and his GP referred him to our Long Covid Support Service.*

## PARTNERSHIP WITH NHS GRAMPIAN

**Over the past two decades, we've been working in partnership with NHS Grampian to provide care to stroke survivors and their families.**

Our renewed Service Level Agreement of 2020 outlines our commitment to delivering our Stroke Nurse Service, including clinics, Community Stroke Services, and a stroke educator. This collaboration enables us to support people to manage their conditions and live well in the community once they return home from hospital.

In addition, we work closely with NHS Grampian to provide respiratory care to people living with chest conditions in the region. The respiratory teams can directly refer patients with respiratory conditions to our Advice Line. In line with this, we have invested £150,000 in the creation of a Community Respiratory Team which provides wraparound care at all stages of lung disease.

This kind of partnership, where we all bring our best to the table to create change, is critical to our past and future success. Over the next five years we will work to spread this approach and achieve even more for people with our conditions.

**Dr Kris McLaughlin, GP and Clinical Lead for Respiratory at NHS Grampian, said:**

*"We are excited to have a new community-based service for patients with lung conditions. This will be a great benefit to patients with long-term respiratory conditions who will be able to receive additional care and support close to their own home.*

*"The team will support patients at all stages of illness from newly diagnosed with a condition through to support after a hospital admission. We believe that both patients and their families and carers will all feel more confident in managing their respiratory illness long term with the input from the team."*

# What Impact Do We Want to See?

**Everyone with our conditions should have access to a quality supported self management and community recovery service. The number of people who do not currently have access to this is estimated to have a starting baseline of over half a million people. Over the next five years, we will work to:**

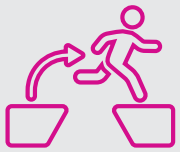
- develop a robust measure of who can access quality supported self management and community recovery
- campaign to ensure the Right to Rehab is in place so that the first step in the self management journey is established
- secure the funding required, taking our income from £10m to £15m a year by 2028
- narrow the supported self management and community recovery gap across the next five years by 35%
  - We will work to deliver 10% [50,000] through our own service delivery of our supported self management and community recovery model.
  - We will work to deliver 20% [100k] through our supported self management and community recovery portal, where individuals can self direct their journey of self management.
  - We will work to ensure that people with our conditions have access to a supported self management and community recovery offer in every health board area. This may be adoption of the model, delivery in partnership, or through building on the service level agreements we have currently.

**We estimate this would mean at least an additional 175,000 people per year will be reached and supported by 2028.**

A key test for impact will be people with our conditions reporting that they can live their life well and can access all parts of the pathway for their condition to the agreed standard. To do this, we will create a feedback loop from the One in Five 2023 report and through our participation and engagement work. We engaged with over 1850 people through our One in Five work – we will increase this to 3000 by 2028.

# Our Values

**Five years ago we published our new values. They steered us through some challenging times, and provided a framework through which to see our behaviours and take decisions about the next right step. They hold true now more than ever:**



**AGILE**
We will adapt to the needs of our people and the environment we work in.

**INNOVATIVE**
We will look for improvement in what we do and be creative in developing new services.

**INCLUSIVE**
We will adopt a human rights-based approach to our work and be accessible.

**ACCOUNTABLE**
We will take ownership for our work and hold decision makers to their responsibilities.

**COLLECTIVE**
We can only achieve our goals by working together and learning from each other.

**COURAGEOUS**
We will say what needs to be said and do what needs to be done to meet our goals.

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