

Chest
Heart &
Stroke
Scotland



NO LIFE HALVED

1 IN 5 HEART REPORT



No Life Half Lived

Executive Summary

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 of what we do. We will work to develop the partnerships that will enable this to be available across Scotland – for everyone, no matter where they live.



Hundreds of thousands of people live with heart disease, Scotland's leading cause of death.

We spoke to 586 people with a heart condition to see how it affected their lives:

- 3 in 5 (**59%**) told us it affected their ability to be **physically active**.
- Fewer than half (**44%**) had accessed **rehab**.
- Nearly half (**46%**) said it had affected their **self-confidence**.
- 2 in 5 (**40%**) said it affected their **mental health**.

More action is need to ensure people with heart conditions can live life to the full:

- Scottish Government must ensure that everyone who needs it must get access to rehabilitation, including cardiac rehab
- Scottish Government and the NHS must resource and support physical activity projects, and make sure that everyone with a heart condition can access support to stay active
- Scottish Government and the NHS must develop a Once for Scotland referral scheme for third sector support, including physical activity and peer support.

"A better future is possible for people living with heart disease – but we need to take action."

Jane Claire Judson, CEO, Chest Heart and Stroke Scotland



Introduction

Five years ago, we conducted the most comprehensive survey we had ever undertaken with people living with chest, heart or stroke conditions in Scotland. Now, five years later, we conducted an even larger survey through an independent research company to find out how people’s experiences have changed. The 1886 responses to the survey, of which 586 were people living with heart conditions, tell us that people 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 heart condition is life-changing for the person affected and for their family and friends. Coronary heart disease remains one of Scotland’s biggest killers. And while heart disease rates declined over the decade as a whole, the increase over the last four years indicates a worrying reversal of this trend.

It is clear many people are not getting the support – and more specifically, the rehabilitation – that they want and need. Too many people in Scotland are missing out on the emotional, social, and rehabilitative support that could provide them with the best possible recovery and quality of life for their futures.

In this report, we put a spotlight on the issues people living with a heart condition are struggling with the most and the actions that are needed to change this. By highlighting what matters most to people with our conditions, we want decision-makers responsible

for creating, developing, and delivering services to more fully understand the reality of living with a heart condition. A better future is possible for people living with heart disease – but we need our decision makers to take action.

We remain committed to our ambition that there should be no life half lived for anyone in Scotland affected by a heart condition. Chest Heart and Stroke Scotland have been supporting people with heart conditions in Scotland for many years, and have developed a range of services through our Community Healthcare Support Services model alongside resources focused on community support, self management, and prevention of cardiovascular disease and events. We will continue to work with the Scottish Government, NHS Scotland, and key partners to help people access the support they need from the very beginning of an acute health event or diagnosis throughout their recovery journey.

This report is a call to action. We must ensure that support for heart disease doesn’t end when people leave hospital, but continues for as long as people need it. Rehabilitation, community support, and cardiac services need to be increased and accessible at all stages of recovery, so everyone living with a heart condition gets the help they need. Scottish Government and the NHS can help us make sure that everyone gets access to the support they need.



CHSS Support

Supported self management and community recovery is increasingly recognised to help people affected by heart conditions, providing support and tools for individuals to manage their condition. Of those we spoke to, two in five (40%) had accessed our support. This 40% rated their health and wellbeing better than those who hadn't used our services.

People living with long-term health conditions, such as heart conditions, have told us they want and need practical advice, information, and support throughout their recovery. They want to know how to manage their condition day to day at home, at work, and when enjoying leisure time and hobbies.

- Nearly 4 in 5 (78%) of people living with heart conditions said they see themselves as having a key role in managing their condition with support from health professionals.

"I found CHSS excellent in the days after the heart attack. Thank you so much."



"Emotionally, the only support I have received has been from CHSS at the time of my diagnosis."

Our Community Healthcare Support Service model is a quality, supported self management and community recovery model informed by expertise, the latest research, and by people affected by our conditions. Our Community Healthcare Support Service can be accessed at any time from acute health event or diagnosis and throughout recovery to long-term management of a health condition.

Our Advice Line is a free and confidential helpline staffed by qualified healthcare practitioners, helping people living with a heart condition to learn more about their condition, how to manage their symptoms, and how to access further CHSS services, as well as external support.

"I am grateful for the professional helpline support provided by CHSS. In the community, the NHS could be greatly improved by investing in the helpline model."



"Once I left hospital, I felt cut adrift. I was so grateful for your helpline to just ask 'is this normal or is it something to worry about?'"

Across Scotland, CHSS partner with peer support groups to enable people living with heart conditions to connect through shared experiences and to access supported self management.

Our Health Defence service, based in Glasgow and Dundee, provides tailored health checks including blood pressure checks, cholesterol checks, and nutrition advice in the local community, alongside physical activity sessions. This empowers people to take charge of their health and understand risk factors for cardiovascular disease. With increasing funding pressures on primary care leading, in many cases, to reactive rather than preventative heart care in General Practice, our Health Defence model can provide crucial community-based support to patients and in turn support the NHS.

Our wider physical activity programme, Movement Matters, which is primarily delivered through virtual classes and by specialist instructors, has enhanced our reach further in supporting people back into safe and effective activity. In addition to this, CHSS are now investing in partnerships to improve our reach in all communities across Scotland. Our partnership with the Scottish Football Association aims to get 25,000 women playing football in their community by the end of 2028, reducing their risk of developing heart disease.

Our Out of Home Cardiac Arrest Bystander Aftercare Project (OHCA), delivered in partnership with the Scottish Ambulance Service and funded by the Scottish Government, provides access to support for anyone participating in CPR or witnessing CPR outwith a hospital setting. This kind of support can offer a better chance of survival - but it can also be upsetting for those who step up to provide help. We provide a dedicated and listening ear to anyone who needs support after providing CPR.

Our Heart-E Module on women's heart health is an education resource for both healthcare professionals and members of the public. With too many misconceptions about womens' risks of heart disease, this kind of education is essential to make sure women can access the treatment they need for heart disease.



Context



300,000 people are living with **coronary heart disease**, a leading cause of death which is responsible for over **1 in 10 deaths** in Scotland



Nearly **50,000** people are believed to be living with **atrial fibrillation**



Almost **1 in 3** have **hypertension** (high blood pressure), a leading cause of heart disease



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

Key Findings

3 in 5 (59%) of people with a heart condition said it **affected their ability to be physically active**



Fewer than **HALF** (44%) of people with a heart condition had **accessed NHS rehab**

Nearly **(46%) HALF** of people with a heart condition said it **affected their self-confidence**



2 in 5 (40%) of people with a heart condition said it **affected their mental health**

What Matters to You?

We spoke to people living with the effects of a heart condition about what matters to them – specifically, which parts of daily life they were most concerned about. Many were concerned about having another heart attack, maintaining their independence, and managing stress and anxiety.

Nearly half (46%) of people living with a heart condition said their biggest concern was the fear of another heart attack or other health complications.

“What’s missing is support from like-minded people that are in the same position, some will have bounced back better than others. It’s getting those people together to help people in a similar position to reduce the fears of the others. After a heart attack, the fear is ‘when is the next one?’”



- Over 1 in 5 (21%) were concerned about **losing independence**.
- 1 in 5 (20%) were concerned about **managing their condition**.
- 1 in 5 (20%) were concerned about **coping with stress and anxiety**, and 19% were concerned about **coping with depression** or feeling down.
- Nearly 1 in 5 (18%) were concerned about **dealing with pain and discomfort**.
- 1 in 6 (16%) were concerned about **rebuilding confidence**.

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



Impact

The consequences of a heart condition can be extremely varied and impact on lots of different areas of people's lives.

The most common impact is on people's ability to be physically active. Physical activity can play a key role in recovery, help reduce risks of future cardiac events, and enable people living with heart conditions to maintain independence. It is crucial that all people living with a long-term heart condition can access the community recovery and self management services they need to maintain safe levels of physical activity and live life to the full.

3 in 5 (59%) said their heart condition affected their ability to be physically active.

"I am physically very weak and feel the need to get help to build up my fitness and stamina but have no idea how or where to access help."



"Probably the most important unmet need I have is physical exercise. I don't know how good various classes are, and I have often overdone it, i.e. aqua aerobics. I was so excited I could do it that I used weights which were too heavy (as it turned out)."

- More than half (52%) said their heart condition caused issues with their **sleep and fatigue**.
- More than 2 in 5 (42%) said it affected their ability to enjoy **personal independence**.
- 2 in 5 (40%) said it affected their ability to enjoy **hobbies and interests**.
- Nearly 2 in 5 (39%) said it affected their **ability to get out**.

"I cannot do my former outdoor natural history interests and would need assistance. I need new friends and new hobbies to give a let up for struggling at home and give me something to look forward to."



Mental Wellbeing

A serious medical event like a heart attack or a diagnosis of a heart condition can significantly impact our wellbeing and mental health. Sadly, many people said their mental wellbeing was impacted by their heart condition.

- Nearly half (46%) said their heart condition affected their **confidence**.
- 2 in 5 (40%) said it affected their **mental health**.
- More than a third (36%) said it affected their **happiness**.
- Over a quarter (29%) said it affected their **self-esteem**.

"I found going home on my own after a myocardial infarction terrifying. I had dreadful anxiety symptoms including non-cardiac chest pain."



"I worry a lot and do not sleep well. I feel I need maybe regular help with anxiety and a group for people with heart-related problems where your concerns could be raised and fears put to bed."

Loneliness

A long-term heart condition can impact on people's ability to get out, communicate, and socialise, leading to isolation and loneliness.

Over a third (34%) said they experienced loneliness or isolation as a result of their condition.



Stigma

Attitudes towards heart conditions can also have a significant impact on people's lives. Nearly 1 in 5 (18%) said they had been judged or treated negatively because of their condition.

Those who were treated differently told us these experiences of being judged had a significant impact on their lives:

- Nearly 3 in 5 (58%) said stigma made them feel **overlooked and unsupported** because people didn't understand or recognise their condition.
- Half (51%) said it limited their **social life and relationships**.
- Half (50%) said it negatively affected their **mental health**.
- Nearly half (47%) said it lowered their sense of **self-esteem**.
- Nearly half (46%) said it made them **feel embarrassed**.
- More than 2 in 5 (43%) said it made them feel **reluctant to ask for help** and support.



Access to Services : Rehabilitation

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

Rehab can improve quality of life and reduce the risk of future heart problems for people with heart conditions (NHS), yet fewer than half (44%) said they had accessed NHS rehab. Of those who accessed rehab services through NHS referral:

- Less than 2 in 5 (38%) of people with a heart condition accessed **cardiac rehabilitation**.
- Only (6%) of people with a heart condition accessed **physiotherapy**.
- Less than a quarter (22%) of people with a heart condition accessed **occupational therapy**.
- Nearly 3 in 10 (28%) of people with a heart condition reported they were **not referred to NHS rehab** at all.



"I would have liked the rehabilitation I read I would get in the booklet on leaving hospital."

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"I have been awaiting cardiac rehabilitation for months, and I am worried about weight gain. I need to know my exercise limitations and need some help with some routine which I can do at home and which is safe."

Access to Services & Support

Many people living with a heart condition are still not getting the support they need to live life to the full.

- 3 in 5 (60%) experienced some kind of **difficulty in accessing services**.
- Half (49%) said there was **support they needed but weren't able to access**.
- 1 in 5 (20%) of people living with a heart condition **did not know what support was available** in their area.
- More than 1 in 7 (15%) said that having **no central place for information** was a barrier to them accessing support.
- More than 1 in 7 (15%) said that **waiting lists were an issue**.
- More than 1 in 7 (14%) said their doctor or health professional **was not able to offer guidance** on available support.

"I was recently diagnosed with a heart condition and the time taken to see specialists was so long. There was no support offered by GP while waiting for referral. Now I would like more information on how to help myself, what the long-term prognosis is, to know if there is support out there."

"I have not had the support and management of my heart condition from the NHS that I would wish for. I don't know who to ask about new symptoms or if my lifestyle choices are healthy or harmful, such as exercise. How will I know if my heart condition deteriorates to the point where I should seek help?"

Of those who had difficulties accessing the services they needed:

- More than 1 in 7 **(14%)** said they needed **access to cardiac rehabilitation**.
- Over 1 in 10 **(11%)** said they needed **access to mental health therapy** or emotional support.
- Over 1 in 10 **(10%)** said they needed **access to physiotherapy**.

"I feel the emotional impact of having a myocardial infarction (MI) has not been well supported. I have been made aware that I missed out on post-MI support both in hospital and on discharge by the Cardiac Specialist Nurse I eventually saw 8 weeks afterwards. I have attended the first cardiac rehab exercise class at my local hospital but was disappointed that there was no dietary or lifestyle info or emotional support – purely circuit training which has sadly exacerbated other physical problems."



Many people said that they would benefit from peer support to build friendships, learn more about their condition, and support their recovery and self management through sharing experiences of living with a heart condition.

"I would find it helpful being part of a peer support group understanding and dealing with my Atrial Fibrillation condition. This would help me understand how others deal with concerns/anxieties."



Access to Services & Support

From our survey, we heard about the value that peer support groups can provide for those who are able to access them.

“Peer support groups are good to be in but hard to find. Often, they provide a lot of info that professionals don’t have time to tell you about, plus handy tips on managing your own conditions, social contact and friendship.”



However, there was clear geographical variation in the availability of peer support groups across Scotland, and many told us they were not given information on peer support that was available in their area.

“Perhaps a peer support group would help, but I wasn’t given any information about one.”



Employment & Cost of Living

People with a disability and those with long-term health conditions are more likely to experience financial hardship. Nearly half of all people in the UK who live in poverty are living with a disability or live with a person with a disability (Disability Rights UK).

- More than 3 in 10 (31%) of people we spoke to said that they were impacted by the rise in the **cost of living** and had cut back on essentials, including heating.

It is particularly concerning that people living with heart conditions have cut back on heating given that cold homes can increase the risk of heart disease and cardiac events (House of Commons).

Many people who responded to our survey said that the cost of living and employment was a concern:

- More than 1 in 5 (21%) of people living with a heart condition said their health impacted their **ability to work as before**.
- Over 1 in 6 (17%) said it impacted their **ability to work at all**.

"It has been difficult to get speciality referrals and work have not been supportive ending in a change of career."

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"I live alone so I fear becoming more ill and needing extra help both physically and financially but don't know how to prepare for this. I would find it helpful to have a regular meeting with a health professional, maybe every 3 months, so I have a place to voice my concerns and get some advice about managing my health and planning for the future."



Caring

Being an unpaid carer impacts on people's mental and physical wellbeing and is recognised as a social determinant of health.

3 in 5 (60%) of people with a heart condition told us they received care, the majority of which was unpaid care from family.

However, just over a quarter (27%) of people with a heart condition told us they were carers themselves.

Nearly 3 in 5 59% of people with heart conditions were living with more than one health condition. People living with these conditions need person-centred support that responds to their needs and considers the whole person, not just one health condition.

"I am a carer and have a health condition. I get tired and frustrated and sometimes feel I have no one to talk to. My work has suffered, and it has caused problems. My employer talks about support, but when push comes to shove, they are really not supportive at all."



Case Study

Margo Gibson, 61, lives in Kilmarnock. Formerly a childminder, she was born with a congenital heart condition and had a valve replaced in open-heart surgery at the Golden Jubilee Hospital in July 2023. Margo said:

"It has taken me a long time to get over the operation. I'm probably still trying to get over it. But I still think I've got a lot of living to do."

What has helped Margo in her recovery is the solid support of her family – husband Tam and sons Ross and Mark – and a tightknit group of friends. She sings the praises of the staff of the Golden Jubilee Hospital in Clydebank where that lifesaving operation to replace the aortic valve in her heart took place.

Now, added to that list is the Killie Heartmates, a Chest Heart & Stroke Scotland affiliated peer support group for cardiac patients in her hometown of Kilmarnock in Ayrshire. Margo joined the group in January this year after undergoing an eight-week cardiac rehab course at nearby Crosshouse Hospital.

The twice-weekly classes have become her lifeline, she says, adding:

"I love the exercises we do, but I love the cup of coffee and the chat afterwards just as much. The group treats me like the 'wean' – I'm one of the youngest and I'm 61! But they are all so welcoming and friendly."

"I had severe anxiety after the operation. Recovery is tough. I'd put on weight, and I needed to do something, but I was terrified even to go for a walk."

"Going to the Heartmates has given me a bit of confidence again. I wouldn't have even come to the group except they said I could bring someone along, so my best pal Jac comes with me. Before I would never have needed someone to come with me to anything. I just got on with things. But everything changed after the operation, and I'm still adjusting to the new me."

"I'd say to anyone who doesn't go to a class like this that they are missing out. And if my experience can help another person, I'll be happy. Recovery isn't a bed of roses, but you don't have to face it alone."



Margo benefits from CHSS services, and did not take part in the research survey.

Recommendations

REHAB SERVICES

- Scottish Government must ensure that everyone who needs it has access to quality, accessible rehabilitation, including cardiac rehabilitation, physiotherapy, and occupational therapy. Access to services should be universal and equitable, and available whenever it is needed.
- Scottish Government and NHS Scotland must work together to improve the availability of, and access to, cardiac rehabilitation programmes.
- 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 Professionals to support rehabilitation delivery, including investment in the future physiotherapy workforce by increasing the number of training places for Scottish domiciled undergraduates and opening new apprenticeship routes to qualifying, as called for by the Chartered Society of Physiotherapists (CSP).
- Everyone with a heart condition should be able to access support to stay physically active in a way that is accessible to them, including through CHSS local physical activity groups and prevention services. Health and social care services should be able to refer directly to local third sector services who offer support.

SERVICES AND SUPPORT

- Every person with a heart condition should have access to self management support to help them live life to the full.
- Scottish Government and NHS Scotland should work together to develop a Once for Scotland referrals scheme to third sector support, such as our Community Healthcare Support Services and CHSS Partnered Peer Support Groups.
- Primary and secondary care, as well as community health and social care, should be able to refer to local third sector support.
- Scottish Government and NHS Scotland should resource and support community physical activity projects such as Walking Football Scotland, which can both prevent heart disease and enable people living with a heart condition to live life to the full.
- Scottish Government and NHS Scotland should resource and support the development and expansion of community-based prevention services, such as CHSS' Health Defence services, which provide tailored health checks including blood pressure and atrial fibrillation monitoring, cholesterol checks, and nutritional advice in community hubs in areas of deprivation.

Recommendations

MENTAL HEALTH AND WELLBEING

- Everyone with a long-term heart condition must be able to access appropriate psychological and emotional support at the time they need it.
- Emotional and psychological support needs to be easy to access, and people should be shown at discharge how they can access this support in the future.
- Local health and social care services must be able to signpost to peer support groups as part of a whole system approach to psychological support and mental wellbeing.
- Specialist psychological support for people who have received a cardiac diagnosis or who have had a cardiac event must be available when they need it.
- Scottish Government and local authorities must ensure that psychological support is resourced adequately to meet demand.
- Support to address loneliness and isolation must include specific action to support people with long-term health conditions, including long-term heart conditions.

COST OF LIVING

- Scottish Government must consider greater financial support for people with heart conditions, including support to cover the cost of heating.
- More support needs to be available to help people with heart conditions who want to return to employment, including where they need adjustments or support to retrain.

CARING

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

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 survey responses were received.** This report is based on the responses of **586 people living with the consequences of a heart condition**, which was **31%** of the total sample.
- **59%** of respondents who had a heart condition were **living with more than one health condition**. **39%** were **living with two**, and **20%** are **living with three or more**.
- **44%** of respondents had been diagnosed with their heart condition **5 or more years ago**, **29%** of respondents had been diagnosed between **1 and 5 years ago**, and **12%** had been diagnosed in the last **6 months**.
- **51%** of respondents living with a heart condition were male, **47%** were female. The number of non-binary respondents was too small to declare.
- 1% of respondents living with a heart condition were aged 20 to 39, 15% were aged 40 to 59, 68% were aged 60 to 79, and 15% were aged over 80.
- 97% of the sample were white, 1% were Asian, and other ethnicities were too small to declare.



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