




THE ONE IN FIVE REPORT

The voices of people affected by chest,
heart and stroke conditions in Scotland



NO LIFE HALF LIVED





“People want help to not just treat their condition but to rebuild their lives”

Today, one in five of Scotland's population is living with the effects of chest, heart or stroke conditions. During the summer of 2018, Chest Heart & Stroke Scotland conducted the most comprehensive survey it has undertaken with people living with chest, heart and stroke conditions in Scotland. We asked them about how their lives have changed, what makes the most difference to them and what additional support they need. The voice of people affected by chest, heart and stroke conditions is critical to person centred health and social care. The 1,164 responses that underpin our report tell us that opportunities are often being missed to help people live life to the full.

People with chest, heart and stroke conditions are at risk of losing their social connections and their self-confidence. They are more likely to experience isolation, stress and anxiety, and often find it hard to rebuild their lives at home and within communities. They are at far greater risk of experiencing poor mental health, and yet the care they receive remains focused on physical symptoms.

People are telling us that they need something more than medical treatment. They need help to not just treat their condition but to rebuild their lives. And in turn, this maximises the outcomes that can be achieved from medical treatment.

Crucially, people sometimes struggle to access support services, with many not knowing how to find what they need, or what is available in their local area. It is clear that many people are missing out on the emotional, social, and rehabilitation support that could provide them with the best possible quality of life.

Those issues are all compounded for people who are living in our poorest communities, who find it harder to access support and services, and who are less likely to have received rehabilitation. There are stark inequalities, with people who can afford to sometimes paying for private treatment such as physiotherapy, which makes an enormous difference to their recovery.

TODAY, 1 IN 5 OF SCOTLAND'S POPULATION IS LIVING WITH THE EFFECTS OF CHEST, HEART AND STROKE CONDITIONS.

Through this report we want the decision-makers and leaders who are responsible for building services for people – health, social care and beyond – to better understand the reality of living with long-term health conditions. We want this to inform the action that they need to take to improve both current care and to plan for the future.

Throughout the report we highlight opportunities to provide better support and improve people's quality of life. A key element to that is developing a 'Right to Rehab'. Rehabilitation hits the outcomes we all want to see – it is evidence based, cost effective, reduces readmission, and where appropriate can be delivered outwith the clinical setting, reducing reliance on other more expensive and complex services. Rehabilitation can mean the difference between getting back to work, or not. It can be delivered in partnership across health, social care and with Chest Heart & Stroke Scotland. Equitable access to rehabilitation is a matter of life and health.

This is not just about health and social care though – it's about all the care and support which people should receive. Your recovery does not finish once the hospital stay or treatment ends – it's only just beginning.

At Chest Heart & Stroke Scotland our ambition is that there is no life half lived. For many of the people who responded to our survey, they can, and want to, achieve more. To make sure this happens we want to support the NHS in the care they provide, and work with partner organisations to help people across Scotland, whatever their personal circumstances, and wherever they live. Throughout this report we also highlight the actions that we'll be taking to make a difference.



Jane-Claire Judson, CEO,
Chest Heart & Stroke Scotland



Heather, stroke survivor

KEY FINDINGS

The life-changing impact of chest, heart and stroke conditions

People are at significant risk of poor mental health, and yet the care they receive is focused on physical symptoms.

Over half of people of working age highlight the impact on their ability to work as before. This can lead to financial worries, stress and anxiety for them and their families.

Two-thirds of people after a stroke experience enormous loss of confidence and independence. Many struggle to leave the house, or to see their family and friends.

For people living with chest conditions such as COPD and asthma, the biggest impact of their health condition is on their ability to be physically active and get out in the community.

For people living with a heart condition, their confidence is most affected, as well as keeping physically active.

People need services to rise to the challenge, especially in areas of deprivation

Almost one in five people are not accessing support or services because they don't know what is available to them in their communities.

People sometimes feel that once they receive a diagnosis or their treatment ends, they are left to 'get on with it'.

At least half of people rely on their family and friends for information, advice and support, and this figure rises for people after a stroke or with multiple health conditions.

People living in the most deprived areas are less likely to access rehabilitation and support, and more likely to experience mental health problems.

RECOMMENDATIONS

The Scottish Government should commit to and invest in a 'Right to Rehab', ensuring there is universal and equal access to rehabilitation programmes for those who could benefit.

The Scottish Government should make a commitment that all people recovering from chest, heart and stroke conditions have access when they need it to specialist nurses, for as long as it takes to reach their recovery goals.

Investment in allied health professionals (such as physiotherapists, occupational therapists and speech and language therapists) needs to match demand, ensuring everyone receives the best possible chance of getting their lives back.

Specialist psychological support must be available to all those with chest, heart and stroke conditions who need it – in line with clinical guidelines.

Health and social care professionals should be aware of the importance of rehabilitation programmes and be able to both signpost and support people to attend.

Integrated Joint Boards (IJBs) should ensure that their health and social care professionals are able to easily signpost people to the support and services available. This should include all forms of community support, in addition to formal services.

Following discharge from hospital, or on diagnosis, information provided to people on their health conditions should include the importance of receiving support for their mental wellbeing, and how they can access that.

IJBs should build on partnership opportunities with the third sector to identify and target support for people at most risk of struggling with chest, heart and stroke conditions.



Robert Baldock, stroke survivor

THE FACTS - CHEST CONDITIONS



488,000

people are living in
Scotland with asthma
and COPD

Source: isdscotland.org



**PEOPLE
WITH COPD**
are up to 10 times
more likely to have
panic attacks

Source: kingsfund.org.uk



COPD

accounts for over
127,000 hospital
bed days annually

Source: isdscotland.org



**ONLY 9,000
OUT OF
69,000**

people can access
pulmonary rehab

Source: chss.org.uk

PULMONARY REHAB

reduces the number
of hospital admissions
and halves the time
spent in hospital

Source: Royal College of Physicians London

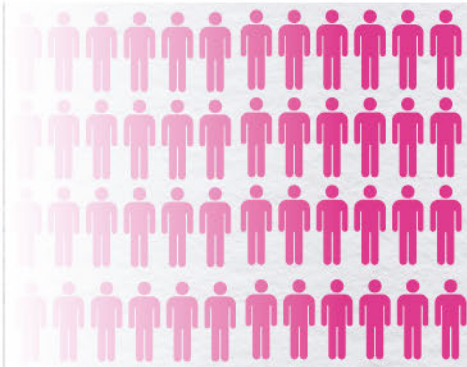


65%

of respondents to
our survey say their
ability to be
physically active is
affected



THE FACTS - HEART CONDITIONS



230,000

people in Scotland are
living with coronary
heart disease

Source: isdscotland.org

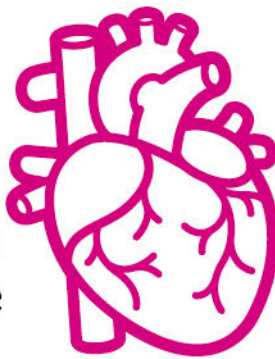


AROUND

48,000

people in Scotland are
living with heart failure

Source: isdscotland.org



People
with a heart
condition are

2-3

TIMES MORE LIKELY

to have depression

Source: kingsfund.org.uk



1/2

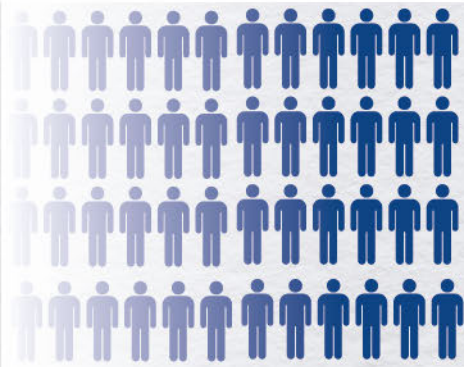
of respondents say their
confidence is affected

54%

of respondents say
their ability to be
physically active is
affected



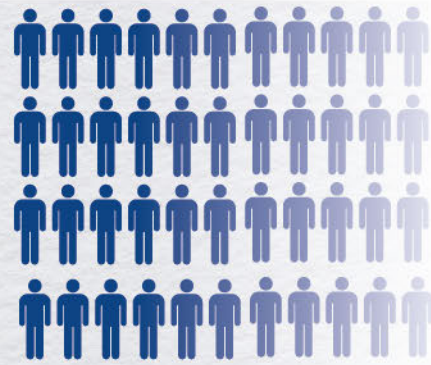
THE FACTS - STROKE



124,000

people in Scotland are
living with the impact
of a stroke

Source: isdscotland.org



£20%

of respondents
have paid for private
treatment after their
stroke

After a stroke,
people are

2-3

TIMES MORE LIKELY

to have depression

Source: kingsfund.org.uk



Access to
**SPECIALIST
STROKE
PSYCHOLOGISTS**
is limited



29%

of people who have had
a stroke want more
access to therapists such
as physiotherapists,
occupational therapists,
or speech & language
therapists





SECTION 1:

THE LIFE-CHANGING IMPACT OF CHEST, HEART AND STROKE CONDITIONS

MENTAL HEALTH AND WELLBEING

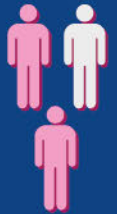
Poor physical health has an enormous impact on people's mental health and wellbeing. Through our survey people told us about the effect that their health conditions have had on their confidence, independence, self-esteem and relationships.

We asked people what aspects of their lives have been affected by their health condition. Two-thirds of people who have had a stroke said they have experienced loss of self-confidence and independence. Half find it difficult to work as before, and many struggle to leave the house, or to see their family and friends.

For people living with chest conditions such as COPD and asthma, keeping physically active and getting out is their biggest difficulty. People with heart conditions reported that their confidence is most affected and their ability to keep physically active.

2/3 PEOPLE

who have had a stroke said they have experienced loss of self confidence.



71%



of people who described their mental health as being very poor reported feeling isolated and lonely, putting them at risk of further ill-health.

May Thomson, from Livingston, had a series of heart attacks five years ago before being diagnosed with heart failure.

“I felt quite down when I came out of hospital and I had to slow down because I was tired all the time. I didn't want to socialise or go to the shops. You feel alone, or isolated, that's the word. You think it's only you it has happened to. You just get it in your head and other people don't know and don't understand. You get to a point where you are fed up with the world. I know I'll never be back to how I was before and that can be frustrating.”



39% of people told us that their mental health was affected by their health condition.



39% of people told us that their mental health was affected by their health condition, and this rose to 46% of people who live in more deprived areas.

Research tells us that people with long-term conditions are at greater risk of experiencing mental health problems. Those with a heart condition or who have had a stroke are two to three times more likely to have depression. People with COPD are up to ten times more likely to have panic attacks.¹

Wellbeing exists on a spectrum which can fluctuate depending on personal circumstances, encompassing both physical and mental health. Where we know that people may be at high risk of mental illness there will be opportunities to recognise that risk and take preventative action. Anecdotally we know that when people visit their GPs or see other health professionals, they highlight their physical symptoms but are reluctant to talk about how they are coping or feeling. Health professionals and people affected both need to know how important it is to highlight mental health as well.

Simple steps can make all the difference. Helping people identify and access support may for example help prevent isolation, improve their physical mobility through rehabilitation and prevent a decline into anxiety or depression. This is not surprising given that only around 25% of people with common mental health problems receive treatment, and that stigma remains a barrier to accessing support.²

Worryingly, people who reported their mental wellbeing was poor were far more likely to say that services weren't available in their local area, that there were long waiting times and that their biggest concern was coping with stress and anxiety. A quarter of those had been unable to access the counselling or psychological support which they need. 32% hadn't been able to access rehabilitation. People living with more than one condition rated their mental wellbeing significantly lower.

Heather is a stroke survivor receiving support from Chest Heart & Stroke Scotland.

“It's not always about the physical or practical things. Sometimes I just wanted someone to be able to cry to and for that to be OK as you don't want to burden your family and friends all the time and make them feel sorry for you. To have someone on your side who is impartial but knows what it's like and can help you is really something special.”



We know that access to specialist psychologists is very limited, with only six Health Boards able to provide a consistent service to stroke patients³ and many don't have any clinical psychologists for cardiac⁴ or respiratory patients⁵. Access to specialist clinical psychological treatment is a component of the Scottish Stroke Improvement Plan⁶ that Health Boards report progress against each year. Clinical guidelines also recommend that appropriate psychological support should be provided to cardiac patients⁷ and to people with COPD as a component of pulmonary rehabilitation⁸.

It's clear that there needs to be a safety net of support and services which means that people can build their confidence and their connections with others, can feel comfortable in raising how they are coping and can access psychological help when they need it. Through supporting people as early as possible we can help prevent mental illness, and when there is a need for clinical support it needs to be fully accessible.

At a strategic level in Scotland there is recognition that by putting people at the heart of the care and treatment they receive, and through the approach to 'realistic medicine', these will help reduce the twin health silos of 'physical' or 'mental' health. The Scottish Government's own mental health strategy highlights the connection between physical and mental health. But at the point of delivery, this person-centred care needs to range from formal rehabilitation to community support and specialist treatment if needed. Closing the gaps which exist in this safety net would make all the difference to the people we support.

RECOMMENDATIONS


Specialist psychological support to be available to all those affected by chest, heart and stroke conditions who need it – in line with clinical guidelines.



Following discharge from hospital, or on diagnosis, information provided to people on their health conditions should include the importance of receiving support for their mental wellbeing, and how they can access that.


Chest Heart & Stroke Scotland will:

Build on our new partnership with See Me to remove stigma, and help ensure that we provide the best possible support for people's mental health.



Identify opportunities to raise awareness and reduce the stigma of the mental health implications of our health conditions – among our people, clinicians, and leaders.

Offer our expertise in designing accessible information to health and social care partners.



Grow our rehabilitation support services to help support more people with their mental wellbeing.

HOW CHEST HEART & STROKE SCOTLAND IS CHANGING LIVES

Rehabilitation Support

Hollie is 22 and has cystic fibrosis. In 2016 Hollie had a stroke, affecting her ability to talk, write or read and she lost the feeling in her right side. Hollie developed severe anxiety and was scared to leave the house. She started to withdraw from the world as it didn't feel safe anymore. That was until she met Wendy, a Rehabilitation Support Coordinator from Chest Heart & Stroke Scotland. Wendy has supported Hollie to re-build her confidence and have the courage to leave the house again. Our Rehabilitation Support Service is there to support people like Hollie and their families so that they can return home and rebuild their lives.

“Wendy was the person who helped me get my life back. I doubt she knows how much she helped me but she did. She really did.”





PHYSICAL ACTIVITY

The benefits of physical activity to people with long-term health conditions are well documented. They range from physical and mental recovery, improved health and wellbeing, and enabling people to better self-manage their conditions and return to work (a key concern for half our respondents).

There was a common thread in the responses to our survey from people across all conditions, with many people reporting that one of the biggest impacts was on their ability to be physically active.

65% of people with chest conditions or after a stroke reported that their ability to be physically active had been affected. 54% of people with a cardiac condition said the same. For some people this might mean that they can't participate in their usual social or sports activities, but for others they may not be even able to leave their house.

This reflects the findings of the Scottish Household Survey which reports that ill health and disability has the biggest impact on participation in physical activity. Only 40% of people with a long term condition are physically active, compared with 89% across the population⁹. However, the Scottish Government's Active Scotland Delivery Plan¹⁰ does not address this core group, despite 45% of adults having a long-term condition¹¹.

Physical activity is a core component of NHS rehabilitation (rehab) programmes for people with heart conditions (cardiac rehab), chest conditions (pulmonary rehab) or after a stroke. These programmes are recommended by clinical guidelines and are designed to maximise people's health, improve their quality of life and help them self-manage their conditions.

Providing rehabilitation programmes offers broader benefits too for the NHS, as people living with long-term conditions are amongst the biggest users of health services in Scotland. For example, over 19,000 hospital admissions a year are due to COPD, with over 127,000 bed days accountable to the disease¹². By helping people stay well and self-manage their conditions¹³, pulmonary rehab reduces the number of hospital admissions, halves the time spent in hospital, and reduces mortality.¹⁴

However, there are challenges for many people in accessing rehabilitation programmes. We estimate that only 9,000 people a year are accessing pulmonary rehab although 69,000 people would benefit¹⁵. Cardiac rehab is usually provided for people after a heart attack – and yet people with other heart conditions should be able to benefit.¹⁶

PULMONARY REHAB

reduces the number of hospital admissions and halves the time spent in hospital.



“Pulmonary rehabilitation has helped me to understand how to cope with my COPD. I didn't know if physical activity was going to be possible with my condition but it is and it really helps.”

Peter living with COPD

Ian Baxter from Angus was diagnosed with COPD in 2004.

“Pulmonary rehabilitation helped to turn my life around. It helped me be much more in control of my COPD and my life. The combination of exercise, education and support was fantastic. I wouldn't be able to do the things I do now, which is quite a lot really, if I hadn't done the rehab course. I believe everyone in Scotland should be entitled to pulmonary rehabilitation. It can be life changing for so many people.”

There are other systemic barriers to being physically active. We often hear from the people we support with our services that there is a significant difference between the therapy they receive whilst they are in hospital and what they can access once they return home. People who have had a stroke for example may have intensive, daily therapy at hospital, but afterwards can face a long wait for just a few short physiotherapy sessions which may not be provided by a stroke specialist. This is borne out by the responses to our survey.



We know that for people to maintain the benefits of their rehabilitation they need to be able to keep active, but many face real challenges such as fluctuating levels of health or fatigue, low confidence or disabilities. Providing supportive and accessible opportunities to be active within local communities can help overcome those barriers.

“I knew that I needed to get my body and heart working but I was struggling because of my heart condition. I tried to access hospital rehabilitation services in my area but I fell through the net because of my age and my heart condition. I wanted to get physically stronger in a safe steady way under proper supervision but I was told I wasn’t able to have cardiac rehabilitation because I had not had a heart attack. In the end I turned to private care and had to pay a lot of money but I was desperate to rebuild my life and it was my only option. I do think though what would have happened if I had been unable to pay?”

Jan, heart failure patient and survey respondent.

HOW CHEST HEART & STROKE SCOTLAND IS CHANGING LIVES

Peer Support Groups: Forfar Airways


Chest Heart & Stroke Scotland has support groups across Scotland offering a range of support including information, exercise, and the chance to meet and talk to others. We know that support groups can make a real difference to people's recovery and quality of life. Forfar Airways is a group supported by Chest Heart & Stroke Scotland for people living with COPD. The group was founded by Ian Baxter. He said "We have about 30 people attending the group each week taking part in physical activity and enjoying the social side. We always do something sociable and often have a sing song too as it's helpful for breathing control. It also helps give us the feel good factor and a sense of belonging. We have a great time together and support each other through good and bad times".



“Life wouldn't be worth living if I didn't have this group. I look forward to coming each week. This is my only afternoon out a week and I really look forward to it. We are like one big family.”


Ann Tyrie, member of Forfar Airways Group

RECOMMENDATIONS



The Scottish Government should commit to and invest in a 'Right to Rehab', ensuring there is universal and equal access to rehabilitation programmes for those who could benefit.

Investment in allied health professionals (such as physiotherapists, occupational therapists, and speech & language therapists) needs to match demand, ensuring everyone receives the best possible chance of getting their lives back.



Health and social care professionals should be aware of the importance of rehabilitation programmes and be able to both signpost and support people to attend.

Chest Heart & Stroke Scotland will:

Launch in 2019 a health defence programme which incorporates physical activity and is delivered in communities across Scotland.



Support and grow our network of peer support groups across communities.

Further develop the support we can provide through our No Life Half Lived Support Service.



SECTION 2:

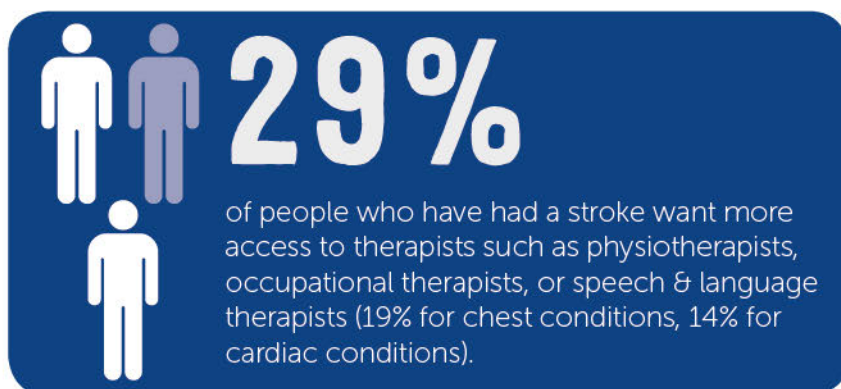
SERVICES MEETING THE CHALLENGE

ACCESSING SERVICES AND SUPPORT

From our experience of working with people living with chest, heart or stroke conditions, we know the importance of creating a pathway of care which incorporates many different services and support. This needs to extend from NHS treatment and rehabilitation right through to community-based support for those who need it. People living with long-term health conditions are twice as likely to be admitted to hospital, accounting for over 60% of bed days used.¹⁷ Joining up all the different aspects of support provides a safety net which gives people the best chance of living well and can reduce the impact on the NHS.

Rehabilitation is not a quick fix – people's recovery and treatment can be a long journey, whether it's someone who has had a life-changing stroke, or a person learning to manage an incurable chest condition like COPD. The package of support needed is different for everyone – some people are able to get their lives back quickly and don't need or want more help. Others though do need long-term support which can help them self-manage their condition.

We asked people about the services that they have received and heard about the wide range of sources of support that people benefit from. Family and friends are important throughout people's journey, with at least half of people relying on them for information, advice and support (more so for people after a stroke or with multiple health conditions). But they are just one part of the picture, and around two thirds of respondents told us they wanted more access to services ranging from specialist nurses, GPs, therapists and social support groups.



Some people feel that after receiving early support and rehabilitation they are then left to find their own way, highlighting that many are on a long journey:

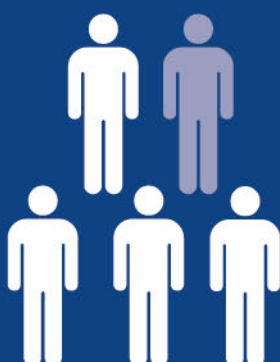
“You get help immediately after your stroke and up to a year afterwards but then nothing.”

quote from survey respondent

The reasons that people gave for why they have difficulties in accessing services are wide-ranging and included the lack of availability of services in their local area, long waiting times, anxiety about attending or disliking being dependent on others to take them.

**AROUND
1 in 5**

people tell us they simply don't know what support is available to them locally, which suggests that they are not currently being signposted to it.

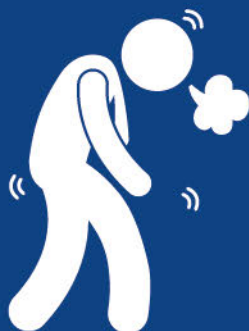


“I wouldn't know where to go for help or who to go to apart from social services... You need to know who and what to ask for and you can't if you don't know.”

quote from survey respondent

36%

of respondents who reported lower levels of overall health had not been able to access rehabilitation.



Some people experience barriers to accessing the services which they want. 36% of respondents who reported lower levels of overall health had not been able to access rehabilitation.

“I found it difficult to mix work with getting to rehab. This meant I had to miss rehabilitation. I was looking for help mentally and physically but didn’t know where to find this.”

quote from survey respondent

24% of people have problems accessing public transport to get to services.

Debbie Matthew from Perthshire is a stroke survivor. She had a stroke aged 40.

“After my stroke, I wasn’t able to drive for nearly a year. I live in a remote part of Scotland without a regular bus service so getting anywhere was really difficult. Transport is only available to the over 65s so, the only options for me were to rely on expensive taxis or the goodwill of family and friends.”

So people not only need to know what support they can receive, and ideally be signposted to that by the health and social care professionals who they see, but also need that support to be flexible and local where possible. Despite the premise of patient-centred care which the integration of health and social care in Scotland is built on, many services still require people to fit around what's available.

We know that the services which are available to people vary hugely across Scotland. Models of stroke care, for example, vary across the Health Boards, despite national improvement being driven forward by the Scottish Stroke Improvement Plan. Chest Heart & Stroke Scotland provides joint funded rehabilitation support in ten Health Boards, and joint-funds stroke nurses in six Health Boards who offer support in people's homes for up to a year after a stroke. Elsewhere, Health Boards provide varying models of stroke nurse services, or none at all.

People with conditions such as heart failure or COPD can similarly benefit from specialist nursing support. However, with ongoing pressures on resources, an ageing workforce, and projected increases in the numbers of people living with long-term conditions, the valuable contribution of those specialists needs to be sustained and inequities in service provision tackled. As well as having a positive impact on people's recovery there are savings to be made. For example, specialist nurses can reduce the likelihood of readmissions with chronic heart failure.¹⁸

Third sector organisations like Chest Heart & Stroke Scotland who deliver services are reliant though on fundraising or on competing for local contracts. We want to work with the NHS and Integrated Joint Boards to ensure we provide these services across the country, working flexibly to meet local need.

Allied health professionals (AHPs) such as physiotherapists, occupational therapists and speech and language therapists are also key to the rehabilitation and recovery of people with our conditions, yet people tell us they struggle to access therapy once they return home from hospital. Community therapy in particular needs greater investment. Audit Scotland's 2017 report on NHS Workforce Planning highlights that only one in four allied health professionals feel there are enough staff to properly do their job. AHPs make up 8% of the NHS workforce, with an increasing vacancy rate.¹⁹

Ruth Ironside from Stonehaven had a stroke age 49. She knows the value of having the support of a Chest Heart & Stroke Scotland stroke nurse.

“My stroke nurse was fabulous. She held my hand through so many ups and downs since my stroke. It has been wonderful to have someone to answer my questions and also the questions that my husband and children had. She definitely helped me rebuild my life after stroke and without her and her team, I certainly wouldn't be where I am today. She has been there for me so many times in the past and I know she'll be there again in the future.”



HOW CHEST HEART & STROKE SCOTLAND IS CHANGING LIVES


Debbie Heaney is a Chest Heart & Stroke
Scotland Stroke Nurse working in Lothian.

“We are here to support stroke survivors and their families as they return home from hospital. We do this by working closely with the NHS to make sure that everyone eligible for the service is able to access it. People referred to our service are visited within three weeks and we support them with whatever they may be struggling with, from helping them to understand what has happened to them, to managing their medication or helping with mobility issues, mood swings, fatigue. All those important issues that have an impact on their day to day lives and their loved ones too.”



RECOMMENDATIONS:


The Scottish Government should make a commitment that all people recovering from chest, heart and stroke conditions have access when they need it to specialist nurses, for as long as it takes to reach their recovery goals.



Integrated Joint Boards should ensure that their health and social care professionals are able to easily signpost people to the support and services available to their patients. This should include all forms of community support, in addition to formal services.

Chest Heart & Stroke Scotland will:

Work with Integrated Joint Boards to identify opportunities to expand our stroke nurse service and double the reach of our No Life Half Lived rehabilitation support services.



Campaign for improved health care to maximise people's chances of recovery including further work on workforce issues.

Ensure that all our services are better embedded within the NHS care pathways in local areas so that health and social care professionals can easily signpost people to our support.

HEALTH INEQUALITIES

The link between income deprivation and poor health is widely recognised – for example in the most deprived areas of Scotland the mortality rate from stroke is 39.5% higher than in the least deprived.²⁰ Through our survey we wanted to give a voice to people living in these areas and learn from their experiences. 15% of respondents to our survey were identified as living in Scotland's poorest communities²¹, and fifteen qualitative interviews were carried out with people from those areas.

For those living in more deprived areas, there is a strong sense of isolation, helplessness and of feeling trapped in their lives. People highlighted to us the lack of support available to them, losing their ability to work or to get out and how all these factors have a serious impact on their quality of life. There was significantly lower access to local support groups too.

Around half (46%) of people in these areas reported that their condition had impacted on their mental health, with contributory factors including being forced to move or feeling physically vulnerable because of their condition. For people living in more affluent areas that figure drops to 37%.

In the most deprived areas of Scotland the mortality rate from stroke is

39.5%

higher than in the least deprived.



15%

of respondents to our survey were identified as living in Scotland's poorest communities.

I don't see my friends... I can't drive anymore... In case I fall, I'm scared to go outside by myself." quote from survey respondent

I was healthy and I had a life... not this big cloud I'm living under now." quote from survey respondent

People responding to our survey highlighted that living with multiple conditions compounded their sense of physical weakness and an inability to get on with their lives. They reported a loss of confidence which was initially due to their poor health but which then developed into more general feelings of fear, disinterest, and introversion.

The ability to pay my bills... it's soul destroying cos there's no way out." quote from survey respondent

We also heard about a lack of knowledge about the support that may be available, and that early access to advice and information is crucial. Once someone's confidence has decreased over time they can feel increasingly overwhelmed by the effort required to make connections and engage with people. Over time, people begin to accept their diminished and shrinking personal world.

Chest Heart & Stroke Scotland has been focusing on working in key communities to pull together the assets and services that people want and need. We now have four Community Hubs in place in Drumchapel, Dumbarton, Hawick and Grangemouth, which combine charity retail spaces with free-to-use community spaces where a range of services are offered.

HOW CHEST HEART & STROKE SCOTLAND IS CHANGING LIVES

Community Hubs


This year in Drumchapel Chest Heart & Stroke Scotland opened its fourth Community Hub. Communities like Drumchapel often have significant health challenges for the people who live there, with lower life expectancy, and higher rates of people with disabilities or long-term conditions. Many of the differences in health in communities like Drumchapel are preventable, and the Hub is a step towards combating these health inequalities. We provide free community space, a drop-in area where people can meet for a coffee and a chat and have been building relationships with a range of local community groups, including Thriving Places which has a free office space in the Hub. Together we are helping improve access to services that will reduce the impact of chest, heart and stroke conditions.

In just a few months our Community Hubs have linked with around 50 different local groups and over 1,800 people have used our rooms for everything from advice on local services to Zumba.




Drumchapel Community Hub opening

RECOMMENDATIONS:



Integrated Joint Boards should build on partnership opportunities with the third sector to identify and target support for people at most risk of struggling with our health conditions.

Chest Heart & Stroke Scotland will:



Build on our network of Community Hubs in areas of deprivation, the local partnerships we are developing and the support services we can offer.

CONCLUSION

This report shows that living with a chest or heart condition or the impact of a stroke is not just about having a medical condition. It can affect every part of people's lives.

We need to see a renewed focus on tackling the social, emotional, and physical issues that are affecting people's lives now. The growing number of people living with these conditions, together with an already ageing population, will continue to have a significant impact on our health services²² unless we can work together to address the unmet needs of the people we are here to help.

There is quite rightly a focus at Scottish Government level on putting people at the centre of the care they receive. But this is not always reflected in the lived experience of the people affected by chest, heart and stroke conditions in Scotland. There is an urgent need to address the impact on people's mental health as well as physical. And there are challenges with accessing the rehabilitation and support that many people need.

We all have a responsibility to listen to the lived experience that this report highlights, working together to make sure that people are supported to live life to the full. We hope that the insight provided by the One in Five report will encourage further progress being made to ensure there is no life half lived in Scotland.

ABOUT THE REPORT

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 2018. Full responses were received from 1,164 people from all regional Health Board areas, and across chest, heart and stroke conditions.

In addition, fifteen qualitative face to face interviews were carried out with people with our conditions living in areas of deprivation.

Analysis of the data was carried out by Scott Porter Research & Marketing Ltd. All responses have been treated in the strictest confidence.

1,164 complete responses were received. 77% of people responding to our survey are living with one health conditions, 20% with two and 3% with three or more.

335 respondents are living with chest conditions, 588 with heart conditions and 538 have had a stroke.

51% of respondents were male, 49% female.

3% were aged 16-39, 21% 40-59, 62% 60-79, and 14% were 80+.

29% of respondents lived alone.

ENDNOTES

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20. [https://www.isdscotland.org/Health-Topics/Stroke/Publications/2018-01-30/2018-01-30-Stroke-Report. pdf](https://www.isdscotland.org/Health-Topics/Stroke/Publications/2018-01-30/2018-01-30-Stroke-Report.pdf)
21. (SIMD 1 and 2 areas) <https://www.gov.scot/Topics/Statistics/SIMD>
22. <https://sctt.org.uk/wp-content/uploads/2017/08/Chronic-Disease-Intelligence-for-Service-Planning-In-Scotland-Final-August-2017.pdf>



WORK WITH US TO CHANGE LIVES

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Chest
Heart &
Stroke
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NO LIFE HALF LIVED

MY PLEDGE TO CHANGE LIVES

I will...



STEP 1
write your pledge



STEP 2
cut along the green
dotted line above



STEP 3
take a selfie with your
pledge



STEP 4
post on social media
#NoLifeHalfLived



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