



Living with: Long-Term Conditions

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healthwatch
Stoke on Trent

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Background

Healthwatch Stoke-on-Trent is the city's independent health and social care champion. We're here to listen to the experiences of local people using local health and care services and about the issues that matter to the people of Stoke-on-Trent.

The Stoke-on-Trent Joint Strategic Needs Assessment 2022 update, states that the numbers of people suffering from Long-Term Conditions (LTCs) have risen dramatically in recent years, largely because of the increase of an ageing population and lifestyle factors such as smoking, drinking and overeating.

LTCs are more common among older people with 58% of people over 60 suffer from an LTC compared with 14% of people under 40. Research has found that two thirds of people aged 65-84 have two or more LTCs, whilst among people aged 85 and over, this proportion rises to over 80%.

Data from patients registered with general practices in the area covered by Stoke-on-Trent Clinical Commissioning Group in 2020/21 show that:

- 48,064 patients (all ages) were recorded as having hypertension.
- 40,127 patients (aged 18 and over) were suffering from depression.
- 20,033 patients (aged 17 and over) had diabetes.
- Prevalence of eight of the 10 most common LTCs were higher in Stoke-on-Trent compared with England.

Based on the GP Patient Survey for 2020/21, 49.6% of people surveyed in Stoke-on-Trent felt supported to manage their long-term condition, which is similar to the national average (54.0%). (JSNA update 2022)

The Joint Stoke-on-Trent Health and Wellbeing Strategy 2021-2025 sets out a four-year vision for health and wellbeing in Stoke-on-Trent. It acknowledges that whilst there have been improvements across several key health outcomes, the health of local people is worse than the England average. Life expectancy is lower for those living in the most deprived areas of Stoke-on-Trent compared with those living in the most affluent areas of the city.

It is recognised that an increasing number of people have multiple conditions and that people with long-term conditions use a considerable proportion of health care services (50% of all GP appointments and 70% of days spent in hospital beds), and their care absorbs 70% of hospital and primary care budgets in England.

NHS England state that “the NHS should be supporting people to be as independent and healthy as possible if they live with a long-term condition such as heart disease, asthma, or depression, preventing complications and the need to go into hospital. If they do need to be treated in hospital, the NHS should work with social care and other services to ensure that people are supported to leave hospital and recover in the community.”

The purpose of this study is to understand the long-term conditions that people live with in Stoke-on-Trent and the support they receive to manage them. Our study aims to find out the type and number of conditions they live with, the ease of access to diagnosis and ongoing support, and what support patients believe would be helpful to manage their conditions more effectively themselves.

With the results in hand, our objective is to inform the Health and Wellbeing Board, commissioners, and providers, of the support that patients would find helpful to better self-manage their conditions in ways that may reduce visits to the GP and hospital admissions.

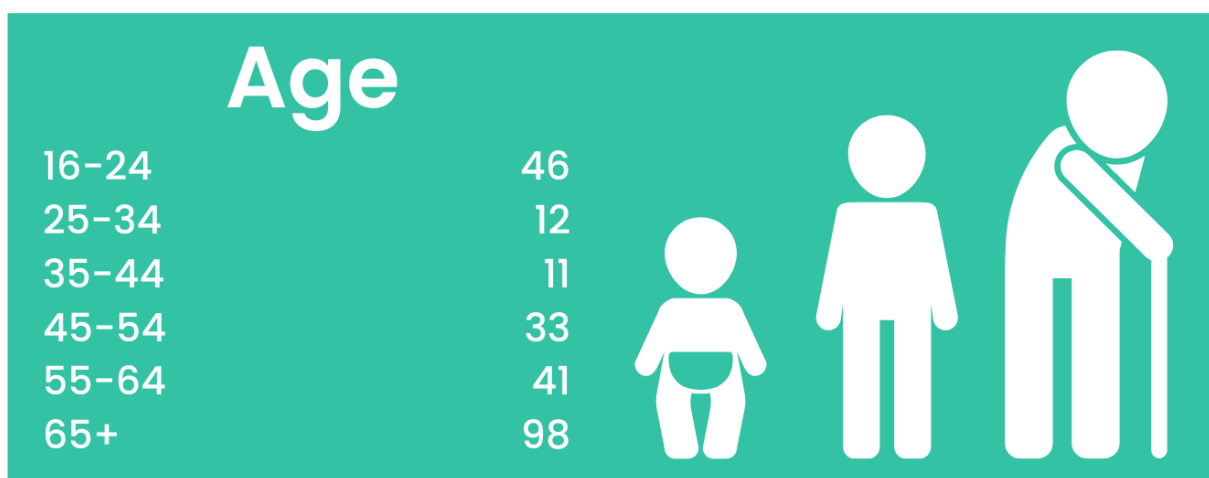
What we did

We undertook this study through 2 surveys. The first survey ran November to January 2023 and elicited 27 responses. Due to a small number of responses, and feedback from respondents about the length of the survey and the dual nature of it we paused this survey on 9th January and developed an amended shorter survey focusing on diagnosis, management, and support for the conditions. The survey was promoted widely through our social media platforms and in person at support groups where people with long-term condition attended and in total over the 2 surveys, we received 197 responses which we combined to produce the following findings.



Who we spoke to

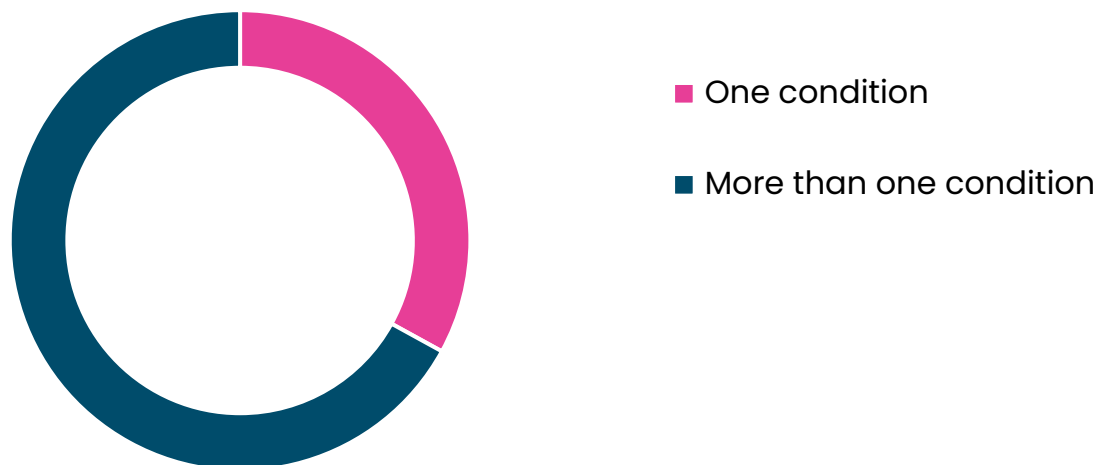
We attended groups and events across Stoke-on-Trent and asked people if they had a long-term health condition to complete our survey. At the end of the survey, we included a set of optional questions for demographic purposes.



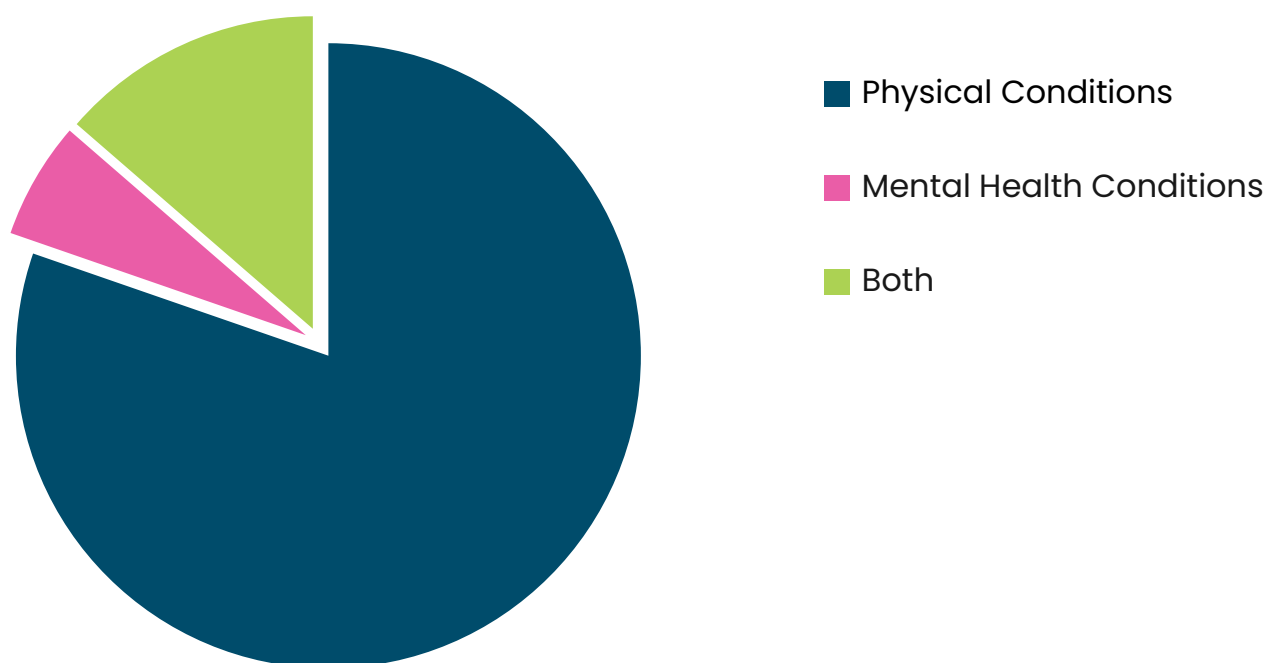
Key Findings

The Survey used a mixture of closed and open text questions, so questions have been analysed according to question type. The open questions have been analysed by theme.

1. What long-term condition(s) do you live with?



In total, from 197 survey responses, 347 conditions were reported. 65 (33%) reported living with one condition and 132 (67%) reporting more than one condition.

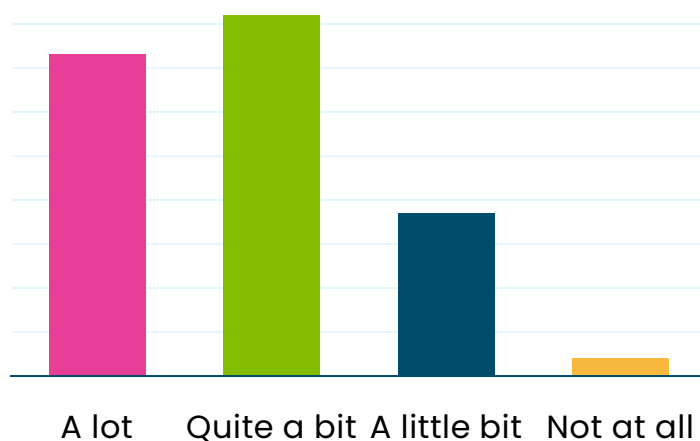


106 reported only having physical health conditions, and 8 had only reported mental health conditions. 18 respondents have both a physical and a mental health condition.

Most conditions that participants reported fell under the main NHS LTCs categories:

Type of long-term condition	Number of people
Cancer	2
Cardiovascular	31
Dermatological	3
Ears	5
Eyes	4
Haematological	1
Inflammatory and immune system	42
Injuries and accidents	5
Mental Health	26
Metabolic and endocrine	34
Musculoskeletal	54
Neurological	15
Oral and gastrointestinal	26
Renal and urogenital	5
Respiratory	51
Stroke	19
Other	10

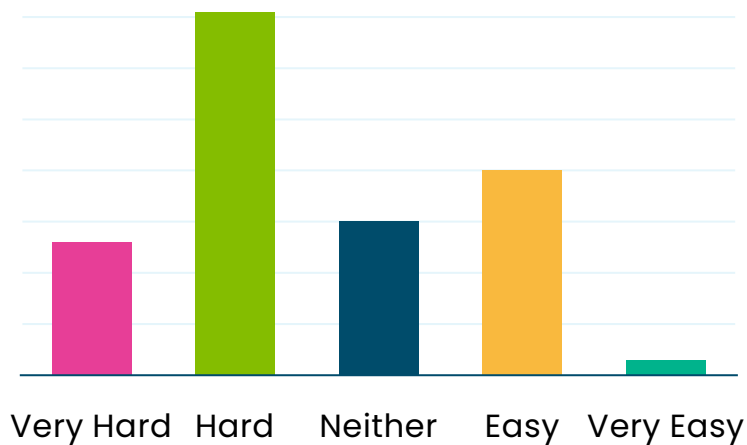
2. To what extent do your health conditions impact on your quality of life?



Most people reported that their condition(s) impacted their quality of life to some degree. However, 4 of our respondents had felt that their condition(s) had not impacted their quality of life at all. Through further investigation on these individual responses, we had found that they all:

- were only living with 1 long-term condition, all of which were physical health conditions.
- felt confident in self-managing their condition through medication (4) and lifestyle changes (2).
- had a very easy or easy diagnosis through either incidental finding through routine check-ups or had a known family history.

3. How did you find getting a diagnosis?



Overall, 57% of people found getting a diagnosis to be hard or very hard, whereas 26% found getting diagnosed to be easy or very easy. The remaining 18% had not considered getting diagnosed to be hard nor easy.

We also gave the opportunity for people to tell us why they considered getting their diagnosis to be easy, hard or somewhere in between.



“I wasn’t ever really seeking any diagnosis. So when I started stage 3 CBT, I was shocked to be instantly diagnosed.

From a young age I’d been to various other therapies and sought other mental health support but wasn’t diagnosed.

So, getting diagnosed was really easy and really hard at the same time.”





"I could only get telephone appointments, so I was prescribed different medications for depression before finally seeing someone face-to-face and getting a diagnosis of Parkinson's disease."



The main difficulties experienced in getting a diagnosis were getting an appointment: firstly, with the GP in lockdown and then with a consultant following referral to the hospital, and having more than one long-term condition.



"So many conditions. The more you have, the harder it is to diagnose, as they are reluctant to refer you for investigation for more than one thing at a time."



Respondents reported that having more than one long-term condition causes more issues with diagnosis due to having a range of symptoms that can often lead to misdiagnosis or other issues going unnoticed.

Some had shared that they felt their doctors or specialists undermined their symptoms for reasons such as: age, mental health, lack of understanding and not having a broader perspective on an individual's health.



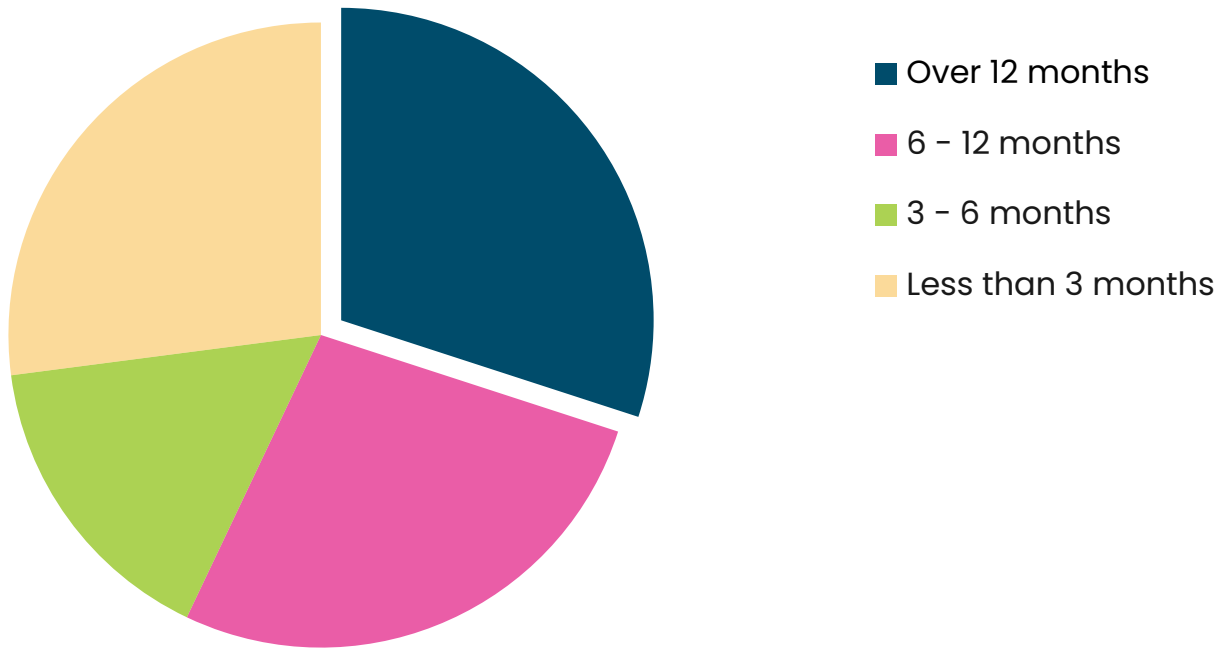
"It took a long time (7 years), to be diagnosed. And a further 5 years with no treatment and being told it was all in my head. It took requiring extensive surgery..."



Of those who did not feel that they had faced any difficulties in getting diagnosed had often been admitted to hospital as an emergency. Other reasons for having an easier diagnosis included:

- receiving a diagnosis through incidental finding
- having a family history of the condition
- quick referrals and test results
- using private healthcare services
- clear and recognisable symptoms

4. How long did it take to get a diagnosis?



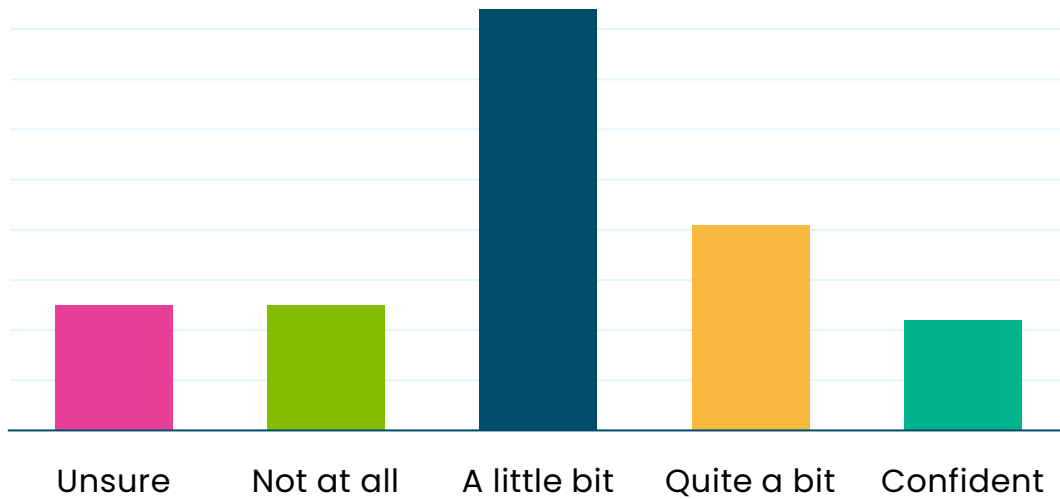
We asked those who had answered 'over 12 months' to specify how long, with this some had even shared their reasoning behind the delay. Most of these had reported their diagnosis having taken between 2 to 3 years. Some had even reported even longer up to 10 years, while others are still awaiting getting their confirmed diagnosis.

Reasons cited for the delay in getting a diagnosis were given as;

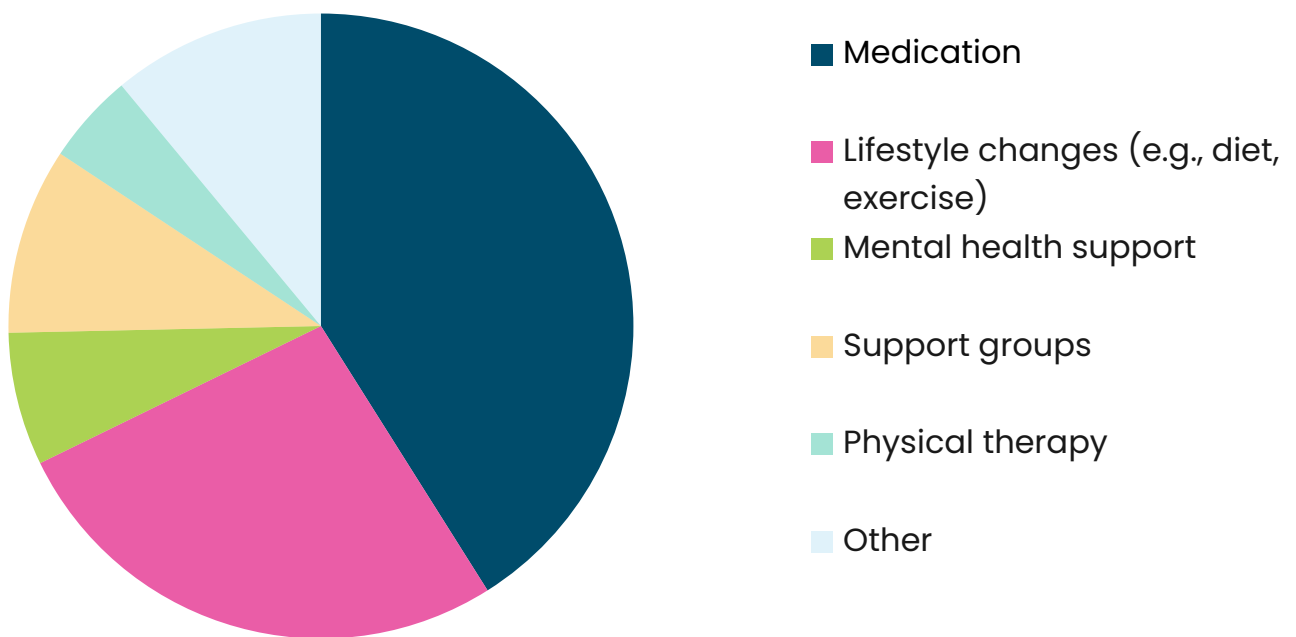
- Delays in getting appointments GP and hospital
- Misdiagnosis
- Additional mental health issues

1. "It took 2 years of going back and forth between various doctors before getting to the right consultant for a diagnosis."
2. "I was waiting for a long time to get a diagnosis as waiting for x-ray's scans and tests.
3. "I waited 7 months to get an appointment and then all the tests took place over another 4 months"

5. How confident do you feel to self-manage your long-term condition(s)?



6. How do you self-manage your long-term condition(s)?

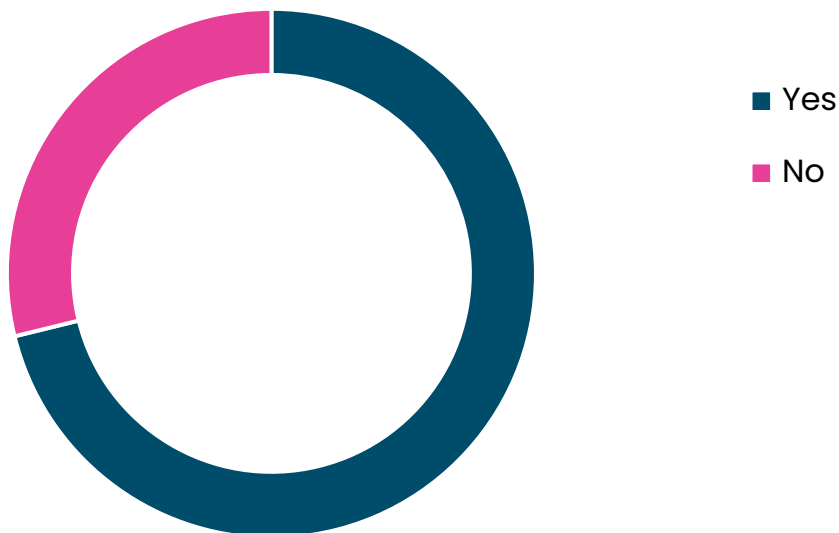


A main theme arising from this question was the use of holistic therapies. Several participants reported that they use therapies such as acupuncture, chiropractor, meditation, yoga, hypnosis, massage, and CBT as a means of managing their conditions, and most reported that access to these often depends upon being able to fund themselves as they are not available through the NHS for many patients.

Other themes that emerged from this question were around self-care, daily routine, and family and friends' support. participants stated:

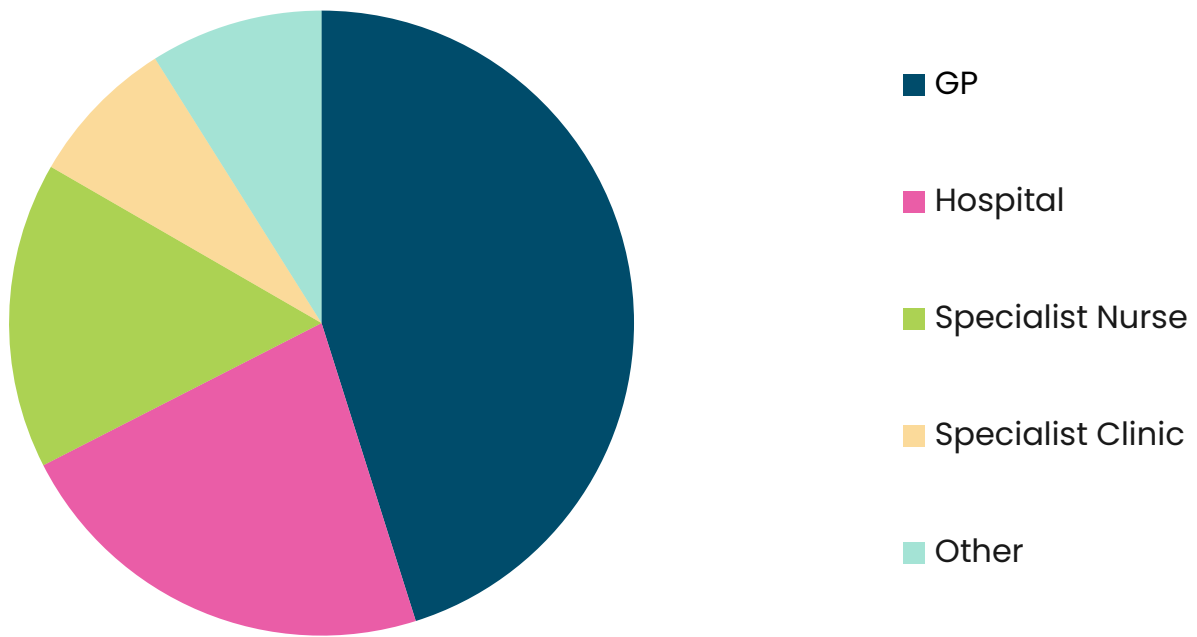
1. "I try to have a daily routine in order to keep me positive when the pain is at its worst."
2. "My husband does a lot for me, and I support him, so we just muddle through that way."
3. "Keeping busy with uni work and utilising my network when I feel I am not coping"
4. "I seek out friends and family who help keep me cheerful and take my mind of it when it is really getting me down"

6. Do you require regular medical support to help manage your condition(s)?

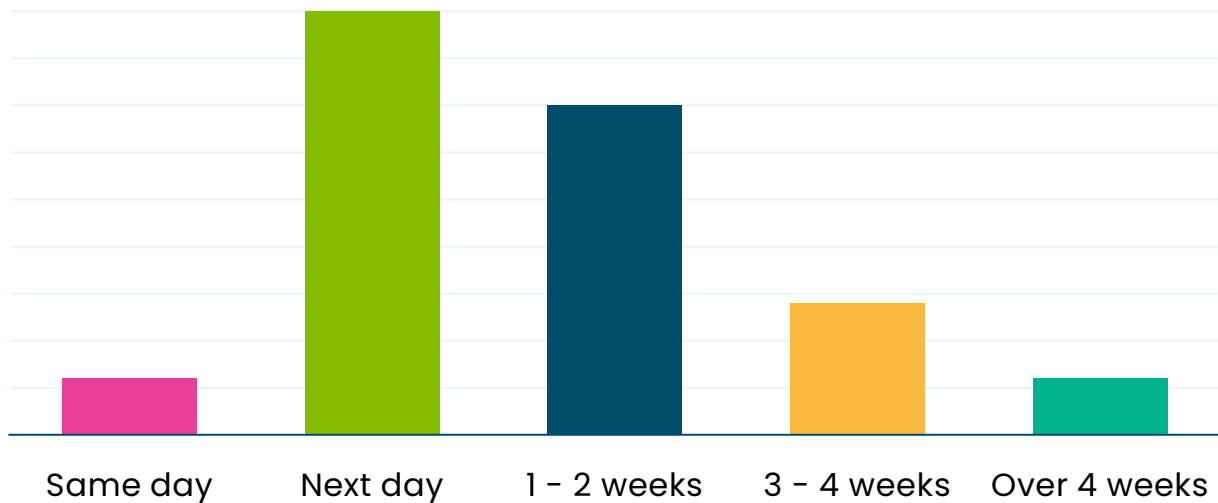


The following questions, 7 through to 9, were given to the 121 people stated that they do require regular medical support.

7. What services do you use?



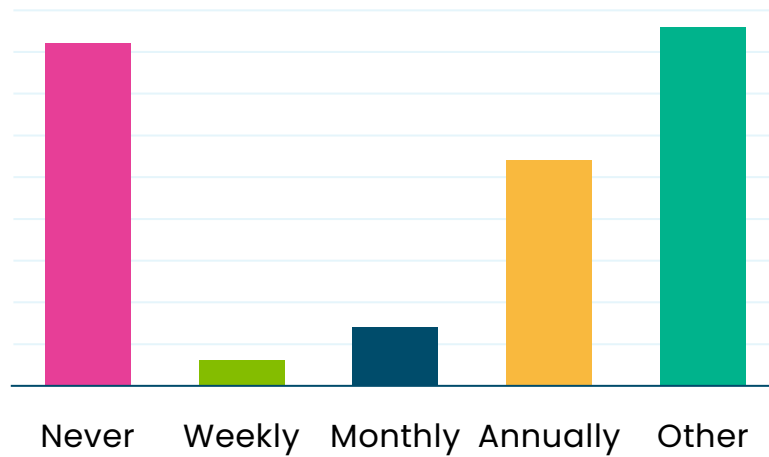
8. How long does it take for you to get an urgent appointment?



The remaining 15 participants reported that they do not need urgent appointments with their long-term condition.

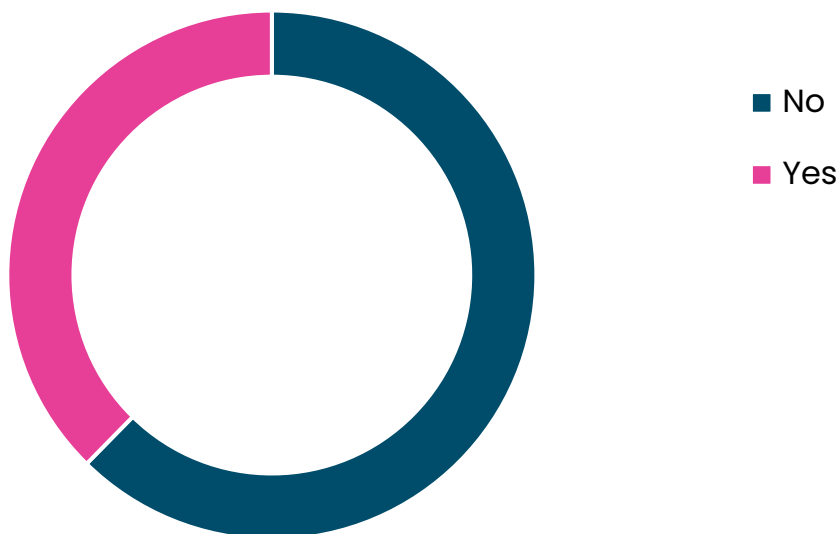
Those who said they could get an appointment in over 4 weeks felt that they are not considered as urgent by the practice and some participants believed that their mental health was a factor negatively influencing whether they got an appointment or not.

9. How often do you see your specialist?



Of the 43 that answered 'other', the majority shared that they would see a specialist every 6 months or that their appointments with a specialist were so random that they couldn't say.

10. Have you been admitted to hospital because of your long-term condition?



64 respondents had at least one admission to hospital due to their long-term condition(s). Of those, 39 received the support they needed at home but 25 did not, with the majority of those not requiring support following discharge, or the support they felt they needed not being available.

Additional Comments

We asked participants if they would like to make any additional comments and to share what changes would make the biggest difference to how they were able to self-manage their long-term condition(s) better. Through these comments we were able to pull-out some common themes.

Information, advice and guidance

The most common comments that that emerged was about the need for more and better information about the condition(s) and how to manage them daily. Some shared that although they had been given information, they would have benefitted more if it had been given to them in a different format.



"I need a better understanding of the conditions and more information on how to manage them"

"I have lots of leaflets and pamphlets but unless someone goes through them with me, they are not much good."



Treatment and support

Support and treatment was the second most commented theme, this included more regular follow up support and on-going oversight by a medical professional following diagnosis.



"I have Parkinson's and haven't seen a consultant for over 2 years. So, I am receiving no treatments other than medication.

I am sure this isn't right. I should be getting more tests and treatment, but I don't.

I'm left to get on with it without any help. That can't be right"





“I have not had any tests for over 2 years and know my condition has deteriorated.

It would be helpful if someone could tell me what I could do to help slow down the process”



Prevention and self-help

Prevention and self-help is another theme that was commented upon by many participants. This referred mostly to the provision of practical help and advice as well as access to a better range of preventative services. Access to services such as physiotherapy was mentioned frequently as something that participants felt had helped in the past but was not available in the long term.



“Physiotherapy did help to improve my mobility before. I don’t have physiotherapy now but I believe it would help”

“I feel I should be doing more with my diet and exercise, but I am not sure what I should do. Advice and help around that would be beneficial at this stage”



Group support

Several participants commented on the impact of their long-term condition(s) and particularly where pain is a feature, and where the condition is one that has a significant impact on quality of life. Conditions that are rare and where there is no access to support was seen as impacting on mental health in several responses. Participants described the feeling of loneliness associated with living with some conditions and the value and benefits of having mental health or group support to help them manage the condition(s) better.



“It would be good to have access to a support group.

It is such a debilitating condition; you feel very lonely trying to deal with it on your own”



Our Conclusions

Healthwatch carried out this study to understand the long-term conditions people in Stoke-on-Trent live with and the support they receive to self-manage those conditions. Our study aimed to find out the type and number of conditions they live with, the ease of access to diagnosis and ongoing support, and what support would be helpful to manage their conditions better.

132/197 people participated in the survey reported having 2 or more long-term conditions, with a small number reporting having multiple conditions. The conditions reported ranged across the whole spectrum that fall under the NHS categories for long-term conditions. 66% of people said it was hard or very hard to get a diagnosis and this was particularly prevalent during the pandemic when appointments were hard to arrange. 77% of participants reported that their health conditions impacted on their quality of life from quite a bit to a lot. The comments made gave insight into these impacts which included: independence, mobility mental health, relationships, and daily activities. Despite this 71% of participants stated that they felt a little bit, to confident to self- manage their LTC's through a range of actions from medication to physiotherapy.

The data highlighted in the comments indicated that the key issues around better self-management related to the availability of good clear information on how to manage the conditions and where to find support and follow-up after diagnosis. It was of note that a considerable number of people took personal responsibility through some positive steps to self-manage their conditions, e.g., lifestyle changes, complementary therapies and support groups and stated that if there was more and easier access to these, this would help them manage their conditions better. Many respondents reported a distinct lack of specialist medical oversight of their LTC's with many participants reporting that this lack of follow-up hindered their self-management through lack of understanding of their progression, and of techniques or actions to manage themselves.

Most people were managed by their GP practice and most people did not report having to wait significant periods of time for an appointment. However, these appointments were for flare ups of the condition and not for routine issues such as information to help them manage better themselves. 35% percent of people reported never seeing a specialist for information, support, or on-going management. What came over strongly from the feedback was a strong willingness and desire to better self-manage if the right information and support is available. This was evidenced by a considerable number of people who made use of a variety of holistic therapies, but these were mainly only available to people who could afford to fund these themselves.

Recommendations

Based on our findings, we have the following recommendations to improve local services for people living with long-term conditions:

- **Information** – Following diagnosis, whether in a primary or secondary care setting, services should ensure that information is available to all patients to inform them about their diagnosis, any treatment planned and what support is available to help them manage their condition effectively.
- **Signposting** – GP practices through the role of Social Prescriber to look at signposting people with long-term health conditions to appropriate support services to look at ways to maintain and improve a patients' quality of life.
- **Additional support** – Health systems across Stoke-on-Trent should consider the role that complementary therapies can play in maintaining a patients' mental and physical well-being to enable them to manage their conditions in the community, removing some of the pressure on primary and secondary care.
- **Mental and social factors** – The health system needs to take a more holistic approach to treating people with long-term conditions particularly taking note of the impact on mental health and thus a patients' ability to self-manage.
- **Communication** – Services should explore ways to improve communication and understanding between patients and professionals. Particularly around the course of the long-term conditions and what patients can do to manage its progression and help themselves to stay well for as long as possible.

Next Steps

This report has been shared with the Staffordshire and Stoke-on-Trent Integrated Care Board and an invitation made for their response to be included, to establish how the services have taken into account the recommendations for improved information, communications and signposting to enable people to self-manage their conditions better.

A response from The Staffordshire and Stoke-on-Trent Integrated Care Board

The Staffordshire and Stoke-on-Trent Integrated Care Board

Our portfolio is committed to high-quality, person-centred care pathways and culture. Our outstanding leadership and clinical governance will drive and improve the delivery of high-quality person-centred care for our end of life, long-term condition, and frailty (ELF) pathways. We aim to drive the prevention agenda forward using a co-produced, multi-agency approach, backed with sound data and future modelling which will enable us to predict demand and meet the needs and aspirations of our population. We will ensure that the right partners at the right times are at the helm of everything we do, and that people are at the heart of the portfolio.

At the heart of our ambition is ensuring that we harness the right expertise. As part of this, we will make sure that everything we do is driven through Clinical Improvement Groups, which will bring the appropriate clinical and professional insight to review and develop clinical pathways.

Long-term Conditions

Our ambition is to enhance person-centred approaches to long-term conditions, including supported self-management, proactive care, and support for families and carers. These approaches are fundamental and essential components for people living with LTCs.

The NHS Long Term Plan published in 2019 identified cardiovascular disease (CVD), stroke and respiratory disease as clinical priorities. Our plans for CVD, diabetes and respiratory disease include the development of Clinical Improvement Groups and a strategy to improve the health outcomes and quality of life for all those living with or at risk of these conditions. CVD and respiratory conditions are also explicitly referenced in the ICP Strategy, with a focus on preventing premature mortality from CVD and respiratory disease.

Why is this important for our population?

Ongoing patient and public involvement has made clear that our population needs access to health and care at the right time, in the right place and through right pathway to ensure their needs and wants are achieved. Our portfolio aims to achieve this through robust pathways and transformation to meet their needs. Many parts of the health and care system fail to sufficiently improve the quality of life of older people and those with a long-term condition.

We know that people at the end of their life and their carers may not always have access to the consistent and personalised care that they require and that there are unacceptable health inequalities among our population. We want our services to be more streamlined to make them more collaborative, integrated and patient centred. It is hoped that such an approach will benefit the population and improve efficiencies and outcomes within the NHS. The newer developments in treatments, service reconfigurations and technology should enable such a strategic change.

Healthwatch Stoke-on-Trent's Long-term Conditions report

The report detailing the views of the public are important to the transformation and pathway development. The report show people are themselves wishing to be more involved with being at the centre of their care and a desire to self-manage as much as possible. We aim to work with Healthwatch to enable people to be involved in the transformation process to inform the work of the Clinical Improvement Groups, that will look at all things including information and communication at all points in peoples care journey.

– Steve Grange

Executive Director of Strategy & Strategic Transformation and
Deputy Chief Executive of Midlands Partnership University NHS
Foundation Trust (MPFT).

Thank You

We're grateful to everyone who helped shape this document by sharing their stories, thoughts, and reflections.

References

1. [Stoke-on-Trent City Council, Joint Strategic Needs Assessment - 2022 update.](#)
2. [Stoke-on-Trent Health and Wellbeing Board, Stoke-on-Trent Joint Health and Wellbeing Strategy 2021 - 2025.](#)

The contract to provide the Healthwatch Stoke-on-Trent service is held by
Engaging Communities Solutions C.I.C.

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