

“Like drowning in air”

Lived experience report - Chronic obstructive pulmonary disease (COPD) support in Suffolk

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healthwatch Suffolk

Trusted Insights

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Acknowledgements

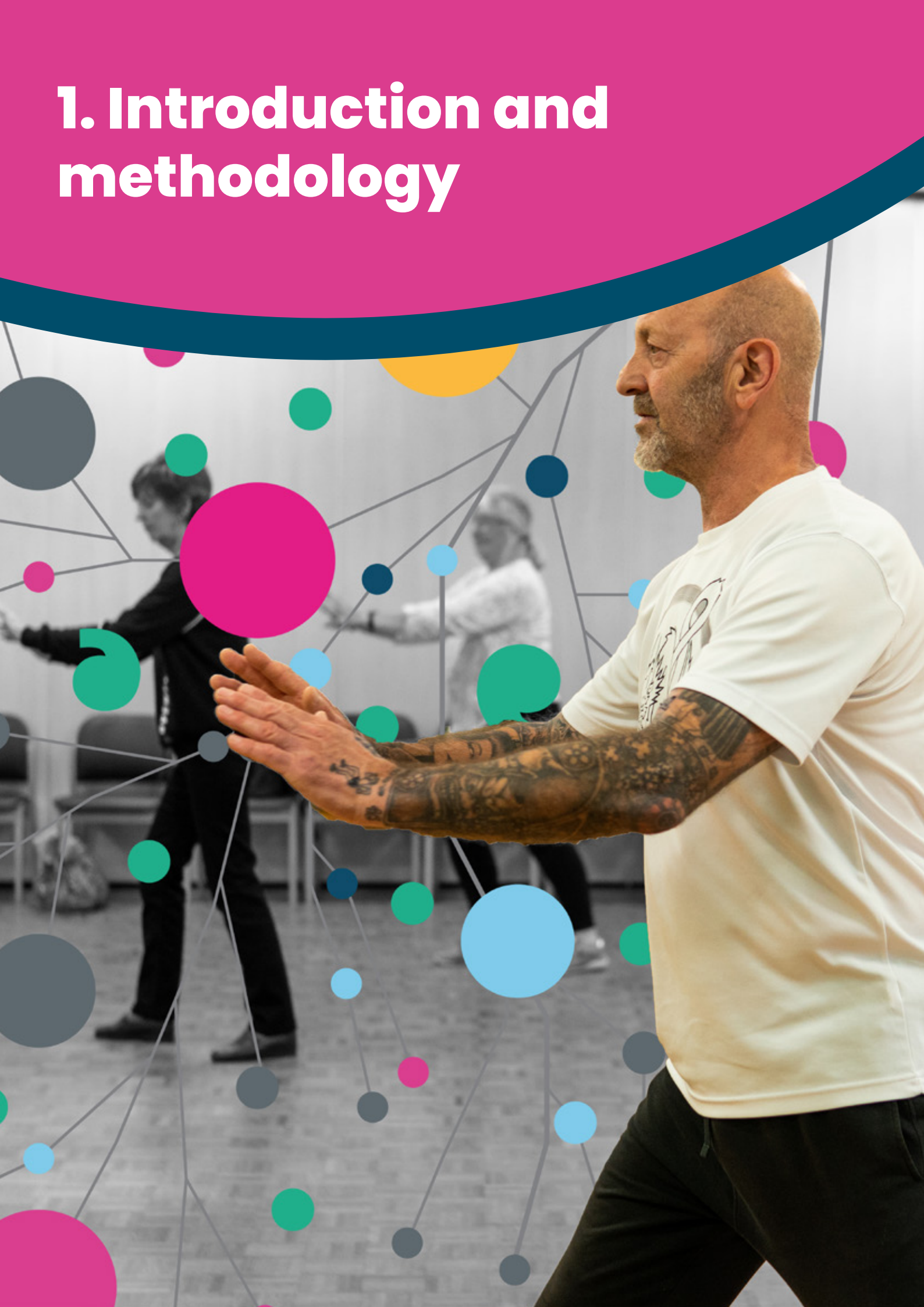
We would like to thank every person that has supported this project and shared their experiences. Particular thanks are due to each of our case study and co-production respondents, who took considerable time to engage in this work and shared their views extensively in the hope it may help to improve local COPD support.

We also thank the Public Health and Communities Team in Suffolk for commissioning this project and enabling people to have their views included in the future shape of local care.

This independent analysis has been compiled by Healthwatch Suffolk CIC. The project was commissioned by Suffolk's Public Health and Communities team to shape and inform the future of COPD support and interventions in Suffolk.

Image credit: Some photos featured in this document have been sourced from the 'Age Positive Image Library from the Centre for Better Ageing. The photos show a more realistic depiction of ageing – to help challenge stereotypes of older people. You can find it at **https://www.agewithoutlimits.org/image-library**.

1. Introduction and methodology



About Healthwatch Suffolk CIC

Healthwatch Suffolk CIC is a social enterprise delivering insight to shape local NHS and social care. We passionately believe that listening and responding to people's lived experiences is vital to create health and care services that work for everyone.

We collect and share lived experience to improve standards of health and social care in Suffolk, regionally and nationally. Our independent role is enshrined in law, supported by trusted data and embedded in local integrated care systems by established relationships with partners.

Our service is founded on long-standing values of transparency, accountability and accessibility. We want everybody to feel equally valued, listened to, seen and heard.



Our core purpose is to...

Collect and share lived experience to influence better standards of health and social care.



We live and breathe...

Co-production in everything possible. We are inclusive, transparent, accessible, and accountable. We believe passionately that listening and responding to lived experience is vital to create health and care services that meet people's needs.

For more information about our role, and how we are inclusive, please visit our website.

Introduction

Working with Suffolk's Public Health and Communities team, Healthwatch Suffolk (HWS) has been exploring people's experiences of living with chronic obstructive pulmonary disease (COPD) in Suffolk.

Why is it important to ask people about their experiences?

NHS Quality and Outcomes Framework (QOF) data recorded in 2022/23, revealed there were 21,346 people living with COPD in the Suffolk and North East Essex Integrated Care Board (ICB) area (2%), and 24,816 within the Norfolk and Waveney ICB area (2.3%).

Respiratory disease affects one in five people and is the third biggest cause of death in England. Yet, outcomes for people with lung conditions have seen little improvement across the last decade. That's why lung health is a clinical priority in the NHS Long Term Plan, and an area that NHS and other decision-makers are seeking to prioritise locally.

To assist Public Health, the NHS, and other local decision-makers in improving and prioritising local COPD support, it is essential to increase understanding of the factors that can influence a person's ability to manage their COPD and maintain their health.

Therefore, this project's primary focus has

been on understanding the opportunities, issues, and challenges people face in managing their COPD effectively at home. While respondents have described their experiences of NHS support, the project has not specifically focused on clinical interventions, but has aimed to explore the factors that influence people's behaviours and how people are able to live well with the condition locally.

The experiences gathered through this project will be used by Public Health, the NHS and local decision-makers to inform local NHS plans and activity for winter pressures 2024-25 and specifically to consider the support people require to avoid unnecessary respiratory-related hospital admissions.

Co-production

At HWS, we strongly believe that listening and responding to people's lived experiences is vital to creating health and social care services that work for everyone. Co-production, therefore, underpins everything we do. We aim to include local people, healthcare professionals and system leaders in the planning and delivery of all our projects, wherever possible.

Within this project, co-production has been achieved through the involvement of people living with COPD, who have contributed by:

- helping to shape and clarify the focus and objectives for the project;
- reviewing and testing data collection tools;
- participating in discussions about emerging themes.

The project has also benefited from the involvement of NHS and Public Health and Communities professionals throughout the life-cycle of the project, including:

- regular monthly update meetings to discuss the progress of the project, but also to respond to issues arising from interviews as they emerge;
- inclusion of members of the Public Health and Communities team in qualitative interviews.
- Engagement of other health professionals/system leaders in the design and communication of the project.

How people's views were gathered

This project has sought to include the experiences of both people living with COPD in the county, and insights from local professionals (those working directly with COPD patients or who may support people in other professional capacities).

People living with COPD

A co-produced online web form for people living with COPD was launched in March 2024. It included a series of closed and open-ended questions, enabling both quantitative and qualitative data to be gathered.

The primary aim of the web form was to recruit and select twelve people to take part in a qualitative interview, where more detail about their experiences could be gathered. The questions on the web form helped to ensure that a diversity of people, with different lived experiences of COPD, were selected for interview.

In total, 82 people responded to the web form and twelve people were interviewed and featured as a case study within this report.

The sample of people who responded to the web form was self-selecting. HWS could, therefore, not guarantee a response from any one population group or demographic. However, with the assistance of our partners and a robust approach to communications, we are confident that news of the project was able to reach a diversity of people and communities.

It should be noted that the responses featured in this research are not representative of all people who live with COPD in the county. However, the depth of qualitative insights gathered is likely to reflect many people's views and experiences.

Healthcare professionals

Due to time constraints for busy healthcare professionals, it was decided that an online, qualitative survey, (hosted on the SmartSurvey platform) would be the best method of gathering views and opinions from staff working with people with COPD.

The survey consisted of four open-ended questions and encouraged professionals to consider non-clinical aspects of COPD support, as well as the clinical care people may need.

Despite continuous communication and direct promotion of the opportunity to participate in the project, response to the professional survey remained low (16). However, responses were received from a wide range of professionals, including representatives from acute and community healthcare, VCFSE, ambulance service, social care, and public health.

Contact us for more information

If you have a question about this report, please contact research@healthwatchsuffolk.co.uk, or call us for free on 0800 448 8234.



Our case studies

Read Carol's story, and find more case studies from page 60.

2. Who took part?



Our respondents

Web form sample

A total of 82 people completed the online web form (between 15th March and 30th June 2024) and shared their experience of living with COPD.

Ethnicity (self-reported)

Over two thirds (56/68%) of the sample were 'White' (either 'White', 'White British' or 'White European').

A further 13% (11 people) described themselves as either 'British' or 'European' and 15 people did not answer the question.

Rates of smoking

Forty-three people answered the question 'do you smoke?', of which only four answered 'yes'.

Diagnosis

Over half of respondents (46/56%) had been living with COPD for more than five years. For some, this meant they were first diagnosed with the condition, when they were in their early 40s.

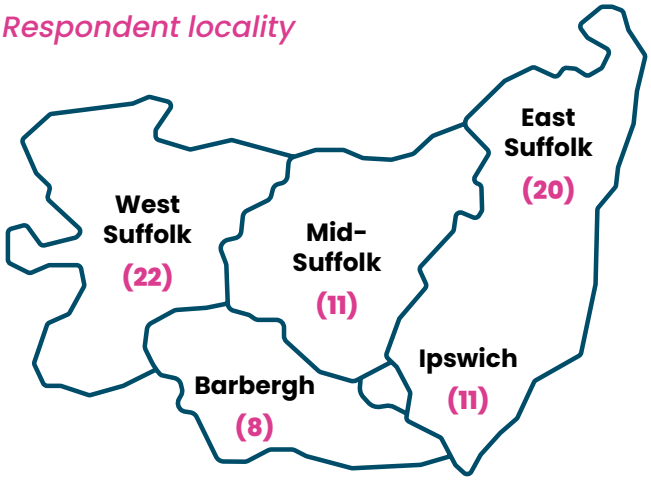
Twelve people (14%) had been diagnosed within the last year, with the oldest being aged 80 at the time of diagnosis.

Confidence to manage condition

Most people (49/60%) reported feeling confident about managing their COPD. However, only 16% felt very confident. Over a third of respondents (31/38%) were not confident about managing their COPD. Respondents who were diagnosed more than 10 years ago were most likely to say they felt confident in managing their COPD (83%), they were also the most likely to say they felt 'very confident'.

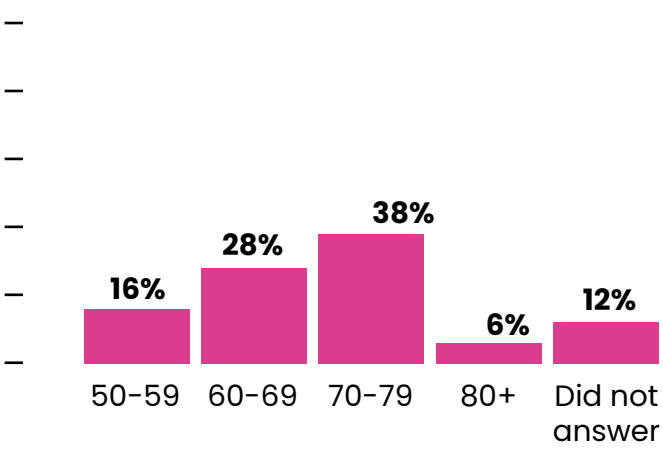
Amongst respondents who had been living with COPD for less than 10 years, there was an even split between those saying they were confident and those who were not. The exception

Respondent locality



In total, **38%** of the web form sample were from East Suffolk (including Ipswich, Suffolk Coastal and Waveney), **27%** were from West Suffolk and **23%** from Central Suffolk (including Mid Suffolk & Babergh). **Ten** people did not answer the question.

Respondent age profile



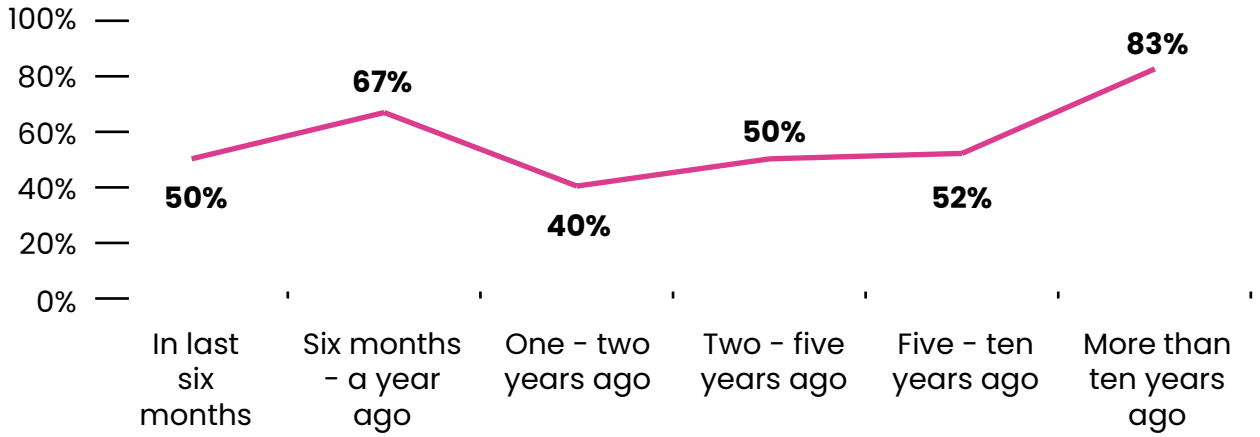
Most respondents (54/66%) were aged between 60 and 79. Ten people chose not to answer this question.

to this, was respondents diagnosed between six months to a year ago, where more people said they felt confident than not. However, care should be taken when interpreting these findings, due to the small sample sizes for some cohorts.



Most people (**49/60%**) reported feeling confident about managing their COPD. However, only 16% felt very confident. Over a third were not confident.

In general, the percentage of those who said they were 'very' or 'quite' confident about managing their condition increased with the length of a person's diagnosis. Those who had lived with COPD the longest were the most likely to report this.



Interview Sample

Sixty-nine people offered to share more information about their experiences with the Healthwatch Suffolk research team. Twelve people were selected for interview to provide a range of different experiences and perspectives on living with COPD.

- Five were male, and seven were female.
- The age range of respondents was 53 to 77. However, the age at which interviewees were diagnosed with COPD ranged from 41 to 71.
- Five people were diagnosed in the last five years, two people had been living with COPD for five to 10 years, and five people were diagnosed over 10 years ago.
- Seven people felt confident about managing their COPD, three of whom were very confident. Five respondents did not feel confident, with one person reporting they were 'not at all confident'.
- Four people had been admitted to hospital within the last 12 months.
- There was a wide variation in the reported impact of COPD on participants' lives, with

two people saying their daily life was not impacted at all by COPD, while four people said it had a significant impact and was affecting over eight aspects of their lives.

- Similarly, there was a wide variation in the steps respondents had taken to manage their COPD, from those who said they had only take one action (four people) to those who had taken five or more steps (four people).
- Respondents were also chosen on the basis of whether they had reported their COPD was affected by financial or housing issues, as these were themes that Suffolk's Public Health and Communities team had asked to be explored in more detail.

"COPD does not affect my everyday life, because I will not let it."

Read Vic's story from page 61.

This report is inclusive of twelve case studies about people living with COPD in Suffolk. In them, we explore how the condition is affecting people's lives as well as things that influence their ability to manage their condition on a day-to-day basis.

Read all of our case studies from page 60.



Professionals sample

Although only 16 people responded to the online survey, there was a good representation of professionals from across the health, care, and public sectors, including:

- Five people working for the NHS in a hospital (clinical role)
- Two people working for the NHS in community services
- One person who was a volunteer in a community group
- One person who was an ambulance paramedic
- One person who worked in social care (occupational therapy)
- One person worked for Public Health and Communities in Suffolk
- One person who was a respiratory specialist nurse in the community and hospital COPD team
- Four people did not answer the question

“[I look stuff up online], just basic stuff. But you don’t know what you’re looking for half the time, and if you search for COPD, you just get an explanation of what it is. You don’t get an explanation of what they can do to help you or any exercises or whatever.”

3. Qualitative themes

People with COPD



This section of the report summarises the key themes that emerged from the twelve qualitative interviews. It also includes data highlights and free text responses from the online web form.

Understanding and awareness of COPD

It was clear from the feedback received, that levels of understanding and awareness of COPD varied considerably amongst respondents.

While some interview participants were aware of the condition through family members having COPD, most reported that at the point of diagnosis they had little or no knowledge of the condition, what caused it or how it could affect them.

Examples of quotes about lack of information included:

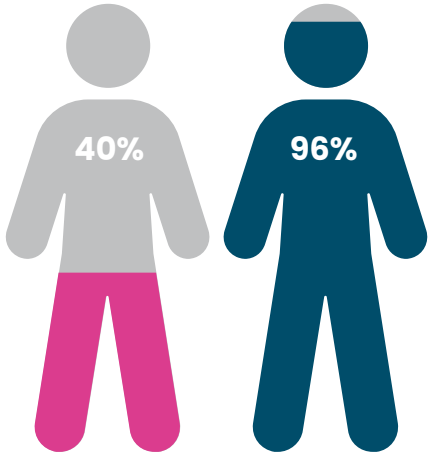
> *"I hadn't really known much about it at all. I'd heard of it. I've never really been told that much."*

> *"No, they didn't explain it at all... So, I've found out what I know myself really by looking it up online."*

> *"They could have sat down with me and explained how to help myself and give me a leaflet. But there was nothing. I came out of there thinking, well, I've done this spirometry and they've told me that my lung capacity is a lot better using this inhaler. They've showed me how to use the inhaler, then the rest is up to me."*

> *"I think there is nothing around for people. You've got no literature on it or anything."*

In the feedback form, respondents indicated their understanding of their condition is likely to develop over time. For example, the percentage of respondents who agreed with the statement 'I feel I have a good understanding of COPD, what causes it, how it is treated, and how it is likely to affect me in the future' was higher amongst respondents who were diagnosed more than ten years ago (96%), compared to those diagnosed between one and two years ago (40%). See table overleaf for more information about responses to this statement.



Responses showed a marked increase in the percentage of ***those who agreed to any extent that they had a good understanding of COPD*** as length of diagnosis increased.

Several of the interview participants reflected on how they had accumulated experience of their condition over several years. This meant they had naturally become 'knowledgeable' about the condition and how COPD affected their day-to-day lives.

Respondents reported that they had:

- Learnt to recognise the early signs of exacerbations;
- Gained an understanding of their physical capabilities;
- Discovered coping strategies and adapted their lives to COPD.

Table: Agreement with the statement 'I have a good understanding of COPD' and length of diagnosis.

	Total	Total %	Last 6 months	6mnth - a year	1-2 years	2-5 years	5-10 years	10 years +
Sample size	82	82	6	6	5	18	23	23
Agree strongly	44	55%	33%	50%	40%	47%	59%	70%
Agree slightly	21	26%	33%	50%	0%	29%	23%	26%
Disagree slightly	9	11%	33%	0%	0%	18%	18%	0%
Disagree strongly	6	8%	0%	0%	60%	6%	0%	4%

Examples of comments about how people had developed their knowledge of COPD include:

"I've been living with this for so many years now. I know within five minutes of getting up in the morning, what my lungs are doing and what my coughing is, and if I'm bringing up stuff that I shouldn't. I know what I'm looking for. I know exactly what I need to do and if I need to start antibiotics or steroids."

"I know my limit. I do get breathless and I do get exhausted, but then I stop what I'm doing. It's a case of just learning to live with it, really."

"You can normally tell when you first get up in the morning. I mean, I've got inhalers. I've got nebulisers. If that tightness doesn't go, like today, I'm quite tight chested, but I'm not using my nebulisers because that's not going to help. You get to know the difference. It's not a tightness because there's an infection or a flare up. It's a tightness because it's just damp and it's just horrible."

"I never go out two days on the trot. Never. Even if it's going to the local shop. I would do that one day, then stay in. I can't do two days on it. I need that recovery time, which I never used to, but now I do."

Some interview participants had enhanced their knowledge of COPD by searching for information online. Typically, respondents who took a more 'active' role in the management of their COPD (see later section on attitudes to health management) were more likely to have searched for information online.

The remaining respondents gave several reasons for not accessing additional information about COPD, including:

- Confidence/skills in using the internet;
- Trust in the information provided on the internet;
- Knowledge about where and how to search for information about COPD.

"Someone's never explained it to me, [what I should do to manage my COPD]. But it's just a matter of learning by experience.

"If I'm cleaning the windows and I get out of breath, I stop. I can push myself so far, but I know actually when to stop. And also, I've got a husband to tell me when to stop."

Examples of quotes about looking for information online included:

> *"I had a little bit of knowledge, but I'd never actually heard of COPD until I went to the doctors, and I was tested and that's when they said: 'Oh, you've got COPD'. And then it's like: 'Oh, what does that mean'", And they explain to you what it is and how it affects you and then 'cause I'm sort of quite an inquisitive sort of person, I thought: 'Well I'll look all this up and find out what it was all about'."*

> *"I wasn't given an awful lot of information really. I mean, thank goodness for Mr. Google, really. I found out an awful lot on there."*

> *"I go on the NHS website because I trust it. I don't do any others. I just look on the NHS website and get all the information I need from there."*

> *"I hate going on the computer... I tend not to try things because I muck up the computer, because I keep losing things on it."*

> *"[I look stuff up online], just basic stuff. But if you don't know what you're looking for half the time, and if you search for COPD, you just get an explanation of what it is. You don't get an explanation of what they can do to help you or any exercises or whatever."*

Pulmonary rehabilitation was recognised by several participants as a key source of information and education about COPD. Those who had attended pulmonary rehabilitation generally saw it as a valuable experience that had enhanced their knowledge about the condition.

However, not all respondents understood what pulmonary rehabilitation entailed, what it offered, or how to access it. This consequently affected their motivation to engage with the service and therefore meant they missed out on the valuable educational elements that the service offers. This is discussed in more detail in the next section (COPD clinical and support pathway).

> **"I'm one of these people, I don't look up on the Internet because I think it gives you more problems knowing this than not knowing."**

Example of quotes about pulmonary rehabilitation as a source of knowledge and information include:

> *"I didn't know anything about [COPD]. They sent me to these exercise classes because of my breathing and because I kept getting these chest infections, and that's actually when I learned about COPD."*

> *"Each session, half of it is exercise and the other half is education. So, education will involve how to use your puffers properly, what it does with your lungs, showing you how your lungs work, even showing you how to bring up your phlegm. It's all very valuable stuff, and then at the end of it, they send you away with a folder of exercises in it, and some of the things that they have covered."*

> *"If anyone hasn't done it, it is very useful because they go through all the medication side, the technical stuff, as well as the bits that will keep you healthy and keep you well, you know, so it is appealing."*

“At first, it wasn’t explained to me really [what COPD is].

“ That’s why the pulmonary rehabilitation does so well because they explain exactly how things work and exactly what isn’t working. And so, I think you know that is something that if someone hasn’t done it. I would really recommend they do because it does, give you a better understanding of what is happening.”

COPD clinical support pathway

Just as people's general understanding of COPD varied, so did their experience and knowledge of the clinical support available to help manage their condition.

The interviews covered support from across the COPD pathway, including pulmonary rehabilitation, rescue packs, annual reviews, smoking cessation services and annual vaccinations. However, the conversations highlighted inconsistency in people's understanding of the support available to them, and how and when to access that support.

Feedback from participants also suggested a lack of clarity about COPD support amongst healthcare professionals. A number of participants reported discrepancies in the messages they had received from their healthcare teams.

Experiences of each of the different elements of the COPD clinical support available are explored in more detail below.

Pulmonary rehabilitation (PR)

While most interview participants had some awareness of pulmonary rehabilitation, this was not necessarily a term they were all familiar with.

Some respondents described having attended a 'course', whilst one person said they had been invited to a 'meeting', though they were unclear what it was about.

Of the seven respondents who had attended PR, most were positive in their feedback. Furthermore, three people had attended PR more than once, which is a positive indication that attendees found the course beneficial. In particular, respondents valued:

- One-to-one time with a physiotherapist;
- Opportunities to undertake exercise in a safe environment, with assistance if they felt unwell;
- Education and information, including the physiological impact of COPD and medications;
- Practical skills like bringing up phlegm and remaining calm when experiencing breathlessness;
- The social aspect of the course and building connections with other people with COPD;
- Signposting to other services (e.g., wellbeing services).

"I think people should do it earlier in their COPD, not later, because it does help to cope with things as it progresses.

"What I've found is it'll go for years being OK, then all of a sudden it's like a cliff edge. You go from being OK to not being OK, and there's no sort of intermediate bit. You wanna learn your techniques and everything when it's not so bad, so it becomes second nature so that when it is bad, you know exactly what you're doing."

> **"I've heard of things called pulmonary rehabilitation, but no one's ever mentioned it to me.**
>
> [Interviewer: How did you find out about pulmonary rehabilitation?] Just Googling."

Although they were generally positive about the content of the PR course, four respondents felt they did not need to repeat the experience again. Two respondents felt they did not 'fit in' with the other members of their pulmonary rehabilitation group, whilst the other two participants simply felt they had learnt all they needed from the course.

Examples of comments about pulmonary rehabilitation include:

"I did find that quite helpful. I mean that they teach you how to breathe properly and pace yourself, which is what you have to do... And it was also good to meet with other people that were actually worse than myself. Which is quite a learning curve."

"There are physios there, and they tell you to just do to your limitations, which is good, but it also spurs you on to want to try and do a little bit more than your limitations, if you know what I mean?"

"Going back [to pulmonary rehabilitation] has boosted me up a bit... It's the same stuff [exercises], but you're with people, and it motivates you."

"I think [six weeks] was plenty long enough. I'm sure they taught us all there is to know."

"This is the second time I've been. The first time I went we got quite friendly. We talked, and this time, it's not so close-knit. You don't talk a lot. There's a bit of banter, but not a lot of chit-chat afterwards."

"The physiotherapist went round and showed you exactly how to breathe from the diaphragm. Where to put your hands to feel that you're breathing properly. I mean, you can read up about it all you like, but when someone actually shows you how to do it, that really does help."

Of the five respondents who had not attended pulmonary rehabilitation:

- Three had never heard of it;
- One respondent knew about pulmonary rehabilitation from internet searches, however, nobody had suggested that he could access the service himself;
- The final respondent had been told about pulmonary rehabilitation by the nurse practitioner at her surgery, but she had been discouraged from accessing the service because the nurse did not feel her COPD was severe enough.

"They gave me a card but the asthma nurse she said to me, I don't know if you're bad enough for that. So when she sort of said it that way and I thought, well, I don't want to take up the place if there's a lot more worse people with COPD than me, so I've sort of hung back."

"Until you've just said about this [pulmonary rehabilitation], I didn't know it existed."

Two interview participants felt that, having worked hard to improve their fitness through pulmonary rehabilitation, they did not want to lose the benefits they had gained once the classes finished. Both had subsequently gone on to help establish focussed 'Breathe Fit'

classes in their local area.

"I think that you know, after you've been on these courses, there should be somewhere for you to go to. And so that's why I decided that I was going to push myself and get one up and running."

"I feel pulmonary rehabilitation is so valuable. There was a group of us that had done the course and we all felt that we'd worked so hard over those six weeks, and I mean it is hard work, that we started our own little group up. Another guy and myself, we said we're going to try and get this together. I kept asking about classes around and there wasn't anything, and then it came up that ActivLives were operating something in Stowmarket and the trainer there used to work for the rehabilitation people, and he had gone over to ActivLives, and he was running the class in Stowmarket. And he's now running one in Leiston on a weekly basis, which is absolutely brilliant."

Other respondents highlighted the difficulties of trying to exercise and maintain fitness at home on their own. They felt it was important that focussed COPD exercise classes should be more readily available in their local community.

"Trying to exercise on your own is just so hard to do to that level. You can go for a walk, but you don't actually do like the exercises they do at pulmonary rehabilitation. It's like home training and weight lifting and it's just a good workout. And to actually do it in your own home, for some people, they just didn't have the space to do it. And if it is cold that is difficult. But to actually go somewhere and meet other people and do similar group activity is brilliant."

"Living on your own, motivation is a real issue. It's easy to say I can't be bothered. It has been two weeks since I last went out on my bike."



"There should be more exercise classes to help. It's alright saying 'But you've got the sports centre', but I don't know whether they do things for COPD. And I think we need specific classes for COPD. If you go to an exercise class, they think you're all the same and then you can't do it all."

Read Carol's story, and find more case studies from page 60.

"They gave us a booklet. We all got the same booklet with the exercises in but trying to make yourself do it at home is very different, isn't it... Because I get tired, and I think I need to save my energy to do the things that I need to do, whereas when I used to get in the car and go up there [for pulmonary rehabilitation], for that hour and do those exercises, it's all about, making yourself, do it really."

Rescue Packs

A rescue pack is a standby pack of medication (usually consisting of antibiotics and steroids) for people with COPD to start using in the event of a flare-up in their breathing.

Nine of the twelve interview respondents had heard of, and used, a 'rescue pack'. However, feedback revealed variations in the way people had accessed emergency medication.

- Some respondents had been provided with a pack to store at home, which meant they were able to respond as quickly as possible to any signs of a flare-up.
- Others had to request a pack from their GP when issues with their breathing arose. Although medication was usually provided swiftly, it did mean a slight delay in starting medication.
- One respondent had received a rescue pack through the NHS 111 service, after experiencing issues with his breathing over a weekend.
- One respondent felt that her GP did not trust her to use her rescue pack appropriately and had therefore made it unnecessarily difficult for her to access emergency medication when she required it.
- Two respondents had never heard of 'rescue packs' and were therefore unaware of how they would access emergency medication in the event of a chest infection or significant flare up in their condition.

"I get mixed messages depending on what GP I see. I did used to have a rescue pack. Then when I asked for another one, another GP said 'Oh no, we don't do them no more'. And then another GP tells me that they do.

"I am a member of a COPD group on Facebook and they all seem to have rescue packs. So it's a bit of an odd one, I don't know."

Examples of comments about rescue packs included:

"I had [a rescue pack] a little while ago. I don't like taking medication if I can help it. I knew I was wheezing and everything else, and I was thinking, 'There's something not right'. And I just kept leaving things and then it got really bad, so I phoned 111. And this lovely doctor came on, and she said, 'I know what you're going through. You need to get some antibiotics.'"

"My husband's retired. We've got a caravan. We wanna go away when we can. But I do not wanna go away without my standby medication because I realise how important it is. And they are saying to me, 'Well, we don't want you to have too many steroids', but if you look at my records, you will see when I used to have standby tablets 20 odd years ago, I wouldn't take them willy-nilly. I would always phone up to say, 'Could I see somebody? This is my peak flow. Should I be taking them?' I never took them. I didn't want to take them as like sweets, but they made you feel as if you were."

Finally, a couple of respondents were concerned about the adverse health risks

of taking too many standby medicines. One respondent chose not to use the 'blanket' antibiotics provided in her rescue pack, because of concerns about how it might impact her health. Instead, she chose to have a sputum sample tested to make sure she received the correct medication for the infection that she had.

Another respondent was advised against using steroids unnecessarily by his nurse practitioner. He was therefore reluctant to use the steroids provided in his rescue pack.

> *"The COPD nurse that I saw, she said to me, 'I don't want to give you steroids', she said, 'because there are lots of good things about steroids, but there are also lots of bad things about steroids'... [When I had a chest infection] the GP sent me a course of antibiotics, and they also gave me some steroid tablets to take and I didn't take them. I thought, I don't think I'll need to, and my partner said to me you should take them but I didn't take them. I just took the antibiotics."*

> *"I have had a long conversation with my doctor about this because I was taking so many antibiotics. I now take a sputum sample to my doctors and have that analysed before I start taking an antibiotic. Otherwise, I'm maybe taking antibiotics for the wrong reason and maybe the wrong antibiotic for that infection. The blanket antibiotic they give you may not be the one that's right for that infection. So by the time you've taken them for a week and then worked out after 10 days that they haven't worked and then they give you another one, your guts are up the creek for six months. I'm not sure whether it was the patches from the smoking or the fact that I'd had so many antibiotics but I got frozen shoulders which took me nine months to get back working again and that was as debilitating, if not more debilitating than COPD."*

Annual reviews

The NICE guidance on 'Diagnosis and Management of COPD in Over 16s' recommends that all people with COPD should receive a review at least once per year. However, feedback from participants revealed a very mixed picture.

- Most respondents simply said they had been for regular reviews at their GP practice, without offering much further comment.



"My last four COPD reviews have been on the phone. I said to them how are you gonna check my lung function on the phone. Oh, we only do that if you're getting more breathless. Well, I AM getting more breathless."

Read Darren's story, and find more case studies from page 60.

- A couple of respondents felt the annual review was simply a 'tick box exercise' that enabled them to access their prescription medication for the next year, and did not really offer them much else of value. However, one respondent did highlight that the practice nurses are not specialists in COPD and, therefore, their knowledge and advice are not as in-depth as the COPD community nurses are able to offer.
- One respondent said her annual reviews seemed to have changed to bi-annual, while another said his last four annual reviews had been conducted over the phone.
- One respondent, who was only diagnosed with COPD nine months ago, was unaware that she should receive an annual review. However, she said that now she was aware, she would make a point of following this up with her local practice.

Examples of comments about annual reviews included:

"I do have an annual COPD check and as I say, the nurses are brilliant but they aren't specialist nurses and so they don't really know. They just check your inhalers and check your using them properly. I'm lucky to have the nurses come in which are much specialised and I get much more information, much more help, more things that I can do to help myself, from them."

"I'm only having them every 2 years I think it was done a couple of years ago, but nothing since."

"A lot of the time, I'd leave the review appointment and think well at least I know I will get my prescription because they always say if you don't go, your prescription might stop."

Annual vaccinations

Most interview respondents had received their annual flu and pneumonia vaccinations and were also up to date with their COVID boosters. There was, however, some scepticism and hesitancy amongst a couple of participants, particularly in relation to the COVID jab.

"I haven't responded to the new COVID jab. This is the first time, but because I've had four already, there's a part of me that says you might as well just carry on with it now, but there's another side of me that's… I'm not convinced. Right from the very word go, I was very, very concerned and anxious about that., At the time I was bamboozled, I was pressured almost, I suppose. I had letters and I had texts and stuff from my surgery. So, I had the first one reluctantly. But I have seen and heard so many people that have had bad reactions from having the injections that it has put me off having any more."

"I used to have my flu one. I didn't have it this year. I had my first two COVID shots, but that's [the COVID jab] what killed my father-in-law, so that has put me off that one. It also made me look into the flu shot and that's just guesswork about what variant it might be, so it's not going to stop me getting the flu."

Younger respondents were surprised to find they were unable to access the latest COVID booster (eligibility being based on age alone and not vulnerability). Given the impact COVID has on lung function, they were disappointed that all people with COPD would not be seen as a priority group to receive the vaccination.

"The fact that they haven't given us another vaccine. I find that really odd. My husband had it because he's over 75, but when I enquired, I was told, 'No, you're not eligible'. It's utterly ridiculous with something that's a lung condition. One of the things that COVID attacks worst of all is lungs and coughing."

"I tried to go down and get the COVID booster and they've said no, you're not in the age range, even though I've got COPD, they say that I don't need to have it any earlier than anybody else."

COPD action plan

The NICE guidelines for 'Diagnosing and Managing COPD in people aged over 16' recommends that patients should have an individualised self-management plan developed in collaboration between health care professionals, patients and their families/carers.

Yet, only one interview respondent mentioned having a personalised action plan. This had been developed in discussion with his local community COPD team. It provided information that enabled him and his partner to monitor changes to his lung function, alerted them to early signs of potential issues. He also felt it was important to receive advice about what actions they should take and when to take them. He and his partner found this document to be an invaluable resource in helping to manage his COPD.

"This is my red alert, green alert and amber alert, for anything that's going wrong in my chest, in my lungs. So you know and if you've got any doubts, just have a little look, and think: 'Is that happening to me now? Yes. I'm gonna have to keep an eye on that now'. And then if that sort of moves on a little bit further onto that stage, there we go... [Interviewer: And do you refer to that then, to check things?] Oh Christ alive absolutely. Oh yeah."

Several other respondents felt that having a plan or some form or 'aide memoir' would be beneficial to help them manage their COPD more effectively at home.

"How would I like to have been given information? That's a good question, because even if they wrote it in a book, I don't know whether or not I would take it on board. I think there's gotta be something that someone's gonna sit you down and say to you and tell you. But then, I think it's something that it would be nice to have - something there to give you a briefing as to 'Don't forget, you still need to do that, and keep an eye on that'."

"Even if it's just a simple aid memoir that says: 'Thank you for coming today. We've identified you've got an issue with COPD. This is what we can do to help'. And then itemise it and just an A4 piece of paper, and give it to your customer. And then they take it home, then look on the Internet. I don't think it would be that difficult to do."



Mervin was the only interview respondent who reported having a COPD self-management plan in place and he had found it very useful.

Read more about Mervin's story from page 76.

Support to quit smoking

Most interview participants had been a smoker at some point in their past. Most had since quit, using a variety of methods including hypnotherapy, medication (Champix), nicotine patches and vaping.

Respondents' experiences of quitting smoking were similar to those shared in the recent Healthwatch Suffolk report on 'Smoking, Vaping and using Tobacco in Suffolk'. The findings from this project, which was also commissioned by the Public Health and Communities team, can be read in more detail on https://healthwatchsuffolk.co.uk/smokingreport/.

Across both reports, the experiences illustrated that people's decisions regarding smoking and when to quit are influenced by a variety of factors and motivations, from social circumstances and networks to family influence, health status, mental wellness, and many others.

Examples of comments about quitting smoking included:

> *"I thought many a time over the years, I really should pack up smoking because I'll end up with a problem. I've actually, given up four times in the past, and this time I've given up and it's four and a half years since I last had one."*

> *"There were a couple of contributing factors, obviously, and I mean probably the main ones were I've got two grandchildren, and I wanted to see them grow up. I was also in a relationship at the time, and the person who I was in a relationship with, her husband, had died from a smoking-related and I thought, again, I want to, you know, I want to live as long as I can with her. But yeah, I mean, the main factors were, well, obviously my children and my grandchildren."*

Some respondents highlighted that once a person had made the decision to quit, it was important they were offered support in a timely manner.

One respondent described her experience of quitting smoking whilst she was in hospital with type two respiratory failure. Having made the decision to stop smoking, following a 'frank' discussion with her lung consultant, she found the lack of support within the hospital 'disappointing'.

> *"It was an absolute battle. It wasn't handled in the hospital very well at all, which is a great shame. I was very surprised that the hospital didn't help more, especially as I was on specialised lung unit and there wasn't support there. I just didn't get it.... I had to ask for patches when I was in hospital, it wasn't offered to me, I had to ask... I mean in the hospital, I was given 15-hour or 16-hour patches, but they used to take them off after 12 hours because they went to a different shift of nurses."*

> *"As I was being discharged, I had a real heart-to-heart with the lung consultant, and he said, 'Support is there to help you stop smoking'. And I said, 'well, I've been asking for three days for somebody to come and see me."*

"[The doctor] told me to give up smoking... Easier said than done.

I gave up a few months ago for six weeks and then my brother died. I started smoking again. But I know I've gotta give up. But it's so bloody hard doing it."



Explore experiences and case studies about smoking, vaping and using tobacco in Suffolk on: www.healthwatchsuffolk.co.uk/smokingreport/.

> "I was very disappointed in the hospital support from the beginning. **If they are to encourage you to quit smoking and not to take it up again as soon as you get out of the hospital grounds, then they really ought to be far more proactive when you're in hospital and make sure everything's in place."**

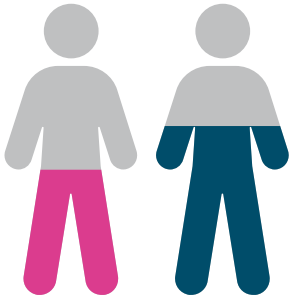
Feeling supported by health professionals

The feedback form asked respondents to indicate to what extent they agreed with the statement 'I feel supported by health professionals involved in my care, to manage my COPD'. Overall, less than two thirds of respondents (64%) agreed, and only a third (33%) agreed strongly.

An analysis of the data by how confident people felt in managing their COPD, revealed (More data is shown in the table below):

- Respondents who said they were very or quite confident in managing their COPD were more likely to say they felt well supported by health professionals;
- Less than half (43%) of people who were not very confident about managing their COPD felt supported by their healthcare teams;
- Three of the four people who were not at all confident about their COPD did not feel supported to manage their condition by their health services.

Those who were 'not very confident' to manage COPD were more likely to indicate they **did not feel supported** by healthcare professionals to some extent.



100% of 13 respondents who were 'very confident' to manage their condition indicated that they felt supported by healthcare professionals and teams to manage their COPD.

	Total			Confidence			
	Count	%		Very confident	Quite confident	Not very confident	Not at all confident
Sample size	81	81		13	36	24	4
Agree strongly	27	33%		92%	33%	12%	0%
Agree slightly	25	31%		8%	39%	31%	25%
Disagree slightly	15	19%		0%	14%	31%	25%
Disagree strongly	14	17%		0%	14%	27%	50%

Table: Agreement with the statement 'I feel supported by health professionals involved in my care, to manage my COPD' and respondent's confidence to manage their condition.

Examples of comments from people living with COPD about the support they received from health professionals included:

"I had a COPD review sometime last year, I think it was and the nurse said to me: "Don't leave [a chest infection] until it gets that bad that you're ill". She said, "If you think or you know, then give us a call, we'll always prescribe antibiotics for you. It will never be a problem."

"[My GP], he is an excellent doctor and he sort of took charge of me. He tells me: 'You need to go here. You need to do this.'"

"But God, that's been such a fight to get what I need. And it just seem like you're just recognised as a cranky old woman who's maybe given up her job in COVID, bit menopausal, so it's gone to her head a bit, mentally-wise and that's how you feel perceived by them. So then you just sort of shut up a bit and think, well, I don't want antidepressants for it. I just want you to see my chest for what it is."

"The doctors, I don't even bother with them anymore because they're useless. Phone them up. You speak to somebody that's not a doctor. They don't read through your records or anything. And you don't get anywhere. And you put in a complaint, you don't hear back from them. And to be quite honest, the way they treat you. It's just disgusting really."

"Doctors overlooking physical symptoms because you have mental health issues. I've found that a lot."



"I'm very well looked after. I have the local COPD team who come out to me and they're brilliant, they are so good. I mean, they keep me out of hospital so many times a year because they come out either every day, or every other day. They monitor and they do the tests at home, and I recover better at home."

Read Michelle's story, and find more case studies from page 60.

"My husband is a keen cyclist. He got me a bike in my 40s, but I could never keep up with him. And he realised then, the level of what I could do... Because of the [spirometry] testing.



"So, we have a tandem now, and I do what I can, and he does the rest. It's a good compromise as I've got older."

Importance of social networks

Several interview participants described how their family and friends had played a critical role in supporting them to live with and manage their COPD, by:

- providing motivation to engage in exercise and remain committed to healthy behaviours (e.g., through specific exercise routines, regular walking together, or the setting up of exercise options at home);
- sharing of daily household tasks such as cooking, cleaning, gardening etc., to help avoid exhaustion;
- spotting signs of increasing or potential risks and encourage people to address them before things escalated;
- helping to reduce anxieties during stressful moments (e.g., hospital admissions, and distressed breathing events);
- supporting mental wellbeing, particularly around self-esteem issues and feeling of 'inadequacy' that can develop when actual physical capabilities do not reflect idealised abilities.

Examples of quotes about support from family and friends included:

"A couple of times, my husband has phoned up my oldest daughter and just said, look, I'd rather not [have the grandchildren]. You've had [a cold], the children have got it. And you know, your Mum will just suffer so much more."

"My husband could see that.... we went for a normal walk, and I couldn't keep up with him. When I got back, apparently, I was very vague.... And I just kept waiting for a doctor to ring me back, but they never rang me back that day. So [my husband] rang 111."

"I've got a lot of people that help me stay well because they take on a lot of the things that I can't do. Not everyone's that lucky. These bits that other people do, without them, things would fall apart quite quickly."

"[The COPD nurses] speak to him all the time and you know they're very open. They say what to do. And they sort of don't listen to me sometimes but listen to him 'cause they know I'll say everything is alright and he'll go: 'No it's not'."

"Someone's never explained it to me, [what I should do to manage my COPD]. But it's just a matter of learning by experience. If I'm cleaning the windows and I get out of breath, I stop. I can push myself so far, but I know actually when to stop. And also, I've got a husband to tell me when to stop."

Where individuals lacked natural support systems, for instance, because their partner

had their own health issues or anxieties to cope with, some respondents had found alternative sources of support.
Online chat forums, WhatsApp groups, and peer support through exercise or social groups were all mentioned by respondents as ways they had supplemented the support they received from their family.

"I must admit with the classes we do, it's really lovely to have the people around because they will push you as well, which is really nice cause people tend to just walk around slowly, but you'll get someone saying, come on, let's just do this and sort of march you off, which I think has really helped. I think it does help a lot to have people around you with COPD."

"[My wife], she worries because I've got quite a list of ailments and so I kind of avoid talking to her a bit about it. I suppose that's why I've got two lady friends who I'm in a Facebook chat with. They have both got debilitating illnesses as well, and we talk about anything."

"[Talking about Breathe Fit] We do support each other. If someone hasn't been for a week or a couple of weeks and they haven't said they're on holiday or anything, then I would generally phone if I had their contact details. And if I hadn't got their details, then I'd say to [the trainer], 'Could you just give them a quick ring?' There was one guy who had an operation recently and he and his wife came in and said it's so uplifting to have the support of the group."

"I'm luckier than most. I've got my husband, and he's absolutely brilliant.

"He does all the cooking, he walks the dogs. I mean, I would not be able to be do as much as I do, without him doing as much as he does."



"I put a lot of my health down to [my partner] because she's always been sort of, well, she is fit and healthy and she's always encouraged me to do that as well. She's been a good influence on me."

Read Vic's story and find more case studies from page 60.

One respondent who lacked any personal support networks reported experiencing depression, anxiety and panic attacks. When distressed breathing events occurred, she felt she had nowhere to turn to for help.

> *"Over the winter time, you don't see anyone. I don't get to see me family. I've got a grandson. I've seen him twice. You know what I mean? So I get really depressed, especially in here. Because that's all my view [into the garden]. I don't hear nothing that goes on out there [to the front of the property]. And like, if it weren't for my mate, I'll phone her up and then I feel I don't want to phone her up all the time. Because I'm going to get on her nerves. My sister phones me once a week. My son phones me once a week, but that's all I've got over the winter. So it's pretty ****. Do you know what I mean? But sometimes you do feel as though, what's the point?"*

> *"I need somebody to talk to, to talk me down, when I'm in that situation [where I can't breathe], but there is no one. I can't phone the Samaritans. So you need somebody there at the end of the line that's gonna help you down. Whether you're having a panic attack or not. But it helps with your breathing if somebody's talking to you. I don't know why, but it just calms you down. The thing is, it always happens late at night. I know my mate goes to bed at nine o'clock. She ain't gonna answer the phone. I need somebody to talk me down."*

“I need somebody to talk to, to talk me down, when I’m in that situation [where I can’t breathe], but there is no one... it helps with your breathing if somebody’s talking to you. I don’t know why, but it just calms you down.”

Attitudes to health management

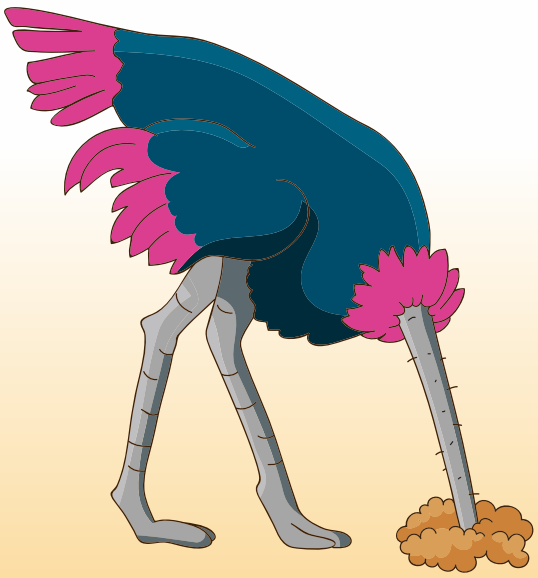
Across the twelve interviews, there was considerable variation in the attitudes of respondents to their personal health management, from those who found it difficult to face the realities of their condition ('I'm a male ostrich'), to those who strongly believed their actions could influence their health outcomes ('I won't allow COPD to rule my life').

There is a growing body of evidence that an individual's knowledge, skills, and confidence in managing their own health is linked to better health outcomes and more positive patient experiences. This is often referred to as 'patient activation'.

The NHS England Guide to Patient Activation[1] states:

> *"Individuals with long term conditions, who are more highly activated, are more likely to engage in positive health behaviours and to manage their health conditions more effectively. On the other hand, people who have low levels of activation are less likely to play an active role in staying healthy. They are less good at seeking help when they need it, at following advice given by healthcare professionals and at managing their health when they are no longer being treated. Their lack of confidence and their experience of failing to manage their health often means that they may prefer not to think about it."*

Moreover, the NHS England guide further highlights that, while people often have a natural ability and inclination to be active in managing their own health, positive attitudes to health management can be developed through person-centred conversations that encourage individuals to reflect on their own goals, strengths, capabilities, and personal resources, e.g., support networks.



People had many different ways of looking at their COPD.

"I have been coughing more phlegm in the last six months. It does keep nagging in the back of my brain... I should really do something about that, but being a man and an ostrich, a male ostrich...."

Read Nick's story from page 66.

[1] Patient Activation Measure implementation guide - click to download PDF from NHS England

> "I think this is where a lot of people fall down. I mean, I don't know, but people say 'Oh, woe is me', you know, instead of saying 'Well, OK, I've got this, but I'll do something about it'. I think even doing a little is better than doing nothing. And there's a lot of people where all they want is 'Oh, poor you'...
>
> **"I don't want 'Poor me'. I don't want people to be sorry. I did this to myself. It was self-inflicted."**

Within the interviews, respondents who expressed a more 'active' attitude to managing their health were more likely to:

- be engaged in exercise and other meaningful pursuits;
- have strong social networks of support;
- feel well supported by their health professionals;
- engage in positive behaviours to managing their COPD (e.g. healthy eating and weight management);
- have accessed clinical support services (e.g., pulmonary rehabilitation or rescue packs);
- have actively searched for information about their condition online.

Examples of comments that illustrated people's attitudes to health management included:

"I think this is where a lot of people fall down. I mean, I don't know, but people say 'Oh, woe is me', you know, instead of saying 'Well, OK, I've got this, but I'll do something about it'. I think even doing a little is better than doing nothing. And there's a lot of people where all they want is 'Oh, poor you' - and I don't want 'Poor me'. I don't want people to be sorry. I did this to myself. It was self-inflicted."

"Taking hold of your life and saying, 'Well, OK, if I have got this, I'll do something about it', which is what I've done with my COPD. And I don't wake up every morning and think 'Oh, I've got COPD. I can't do this and I can't do that'. I wake up every morning and then I get up and I make the breakfast, and I have a wash and brush my teeth and get myself ready, and I get out."

"This nurse said 'You've actually got COPD and 'Do you know what that is?'. And of course, I said 'No'..... Over a period of time, I had to go back and see her again. But I wasn't doing anything about it. I wasn't, to be honest, I didn't think that I needed this blue puffer either and so I didn't use it and I just plodded on."

"I understand that whatever happens is in your own hands. It's your health and you have to do what you feel is right for yourself."

Mental health and wellbeing

Evidence has shown a link between poor mental health and wellbeing and a patient's ability to take an active role in their health management. Addressing these issues is therefore key to enabling people to manage their COPD effectively.

Responses from the online form and interviews highlighted the significant impact that COPD had on people's mental health and wellbeing.

Examples of the ways in which people's wellbeing had been affected by COPD included:

- anxiety and distress caused by an acute breathing event, leading to a loss of confidence;
- self-esteem impact and a feeling of 'inadequacy' that can develop when actual physical capabilities do not match a person's idealised abilities (a concept described within 'self-discrepancy theory');
- loneliness and depression resulting from the need to self-isolate to avoid infection;
- lack of motivation and inactivity as a result of physical exhaustion;
- dissatisfaction with body image, because COPD has caused changes in physical appearance (e.g., weight loss or weight gain);
- regret and guilt over past behaviours (e.g., smoking, and 'bereavement' for lost health).

Examples of comments that highlighted how COPD had affected people's mental health and wellbeing include:

"It does make me feel 'Is it worth it?'"

"Sometimes you think I don't really want to get up and sometimes I feel I'm useless. I think that's the word.

"I can't do things and then I just feel unworthy. I can't fulfil everything you know."

"I get worried about my breathing as well, because when I was hospitalised with a chest infection, I collapsed. So, I get a bit worried that I might do that when I am out because I can't breathe properly. I very rarely do anything on my own now. I do drive but I don't drive very much now. I've lost my confidence a little bit [since being in hospital]."

"I feel so anxious. I get very stressed and anxious. I worry about things quite a lot."

"If I go out, I have to think to myself: 'Is there gonna be somewhere for me to sit' and 'Oh God, that's gonna be embarrassing'. Cause all my mates and everyone know that I was really strong and now I'm this person, who's not half the person. And everyone's standing up. And I've gotta think of somewhere where I can go and sit so, being a very proud person, I've found that to be a challenge that's too stressful for me."

"About four years ago I lost a load of weight through COPD. I lost two and a half stone in a couple of weeks due to COPD. That really brought me down and I was so miserable and I still don't like the way I look. I'm too skinny. And that affects me a lot, because I buy clothes and they just don't seem to fit properly. You know, I'm very conscious of what I wear. I do get a bit depressed with it."

"I'm 53 and been diagnosed with COPD for about 10 years, so was diagnosed quite young, something I hid from my parents, in-laws and children. I was somehow ashamed about it."

"It affects my motivation, my ability to have engaging conversations, going out and relationships."

"Just changing pillows is a challenge, I get so out of breath, the feeling of defeat is so intense I just want to cry."



"I'm a very outgoing bubbly person. I like to be, not necessarily a centre of attention, but I'm a comedian. I like to talk...

"But I've lost the ability to have a conversation. I don't remember things and a lot of that is down to not being out socialising. It's actually quite sad because I was very, very outgoing."

"Every activity causes breathlessness and an instinct to panic as the lack of air may become permanent this time.

"It has left me scared to travel far in case I have an exacerbation and I am constantly watching people around me for coughs, colds, or worse."

"Embarrassment at coughing up mucus regularly."

"I am worried to socialise as I feel different to others, you naturally walk slower as you get out of breath and can't keep up."

"I'm so out of breath showering and getting dressed I hardly bother to leave the house."

"I have anxiety - always worried I will not be able to catch my breath, try not to do anything that may cause breathlessness, this restricts everything, from putting laundry in the washing machine, to hanging it on the line. I worry a lot, don't go out and struggle all day every day."

"I spend most days at home on my own with the dog as my wife and carer works four days a week. This is very isolating for me as I was always out and about amongst other people, I've been a manual self-employed worker so do feel lonely at times."

Support around wider determinants Finance and housing

A key focus of this project was to explore people's experiences of non-clinical issues that impact their COPD. Specifically, the Public Health and Communities team were interested in understanding more about how issues with housing and finance affected people's ability to manage their condition effectively at home. The feedback form asked respondents to indicate, from a list of four answer choices, what made their COPD worse.

Most people (43%/35) said their COPD was not affected by any of the listed factors. Around a third of respondents said they were affected by allergens such as pet hair, dust and pollen (34%), as well as air pollution (33%). A quarter of respondents felt their housing situation (including cold, damp and mould) exacerbated their COPD (24%) and finally only a fifth of respondents (21%) said that finance was an issue for them.

	Count	%
None	35	43%
Allergens (e.g pet hair, dust, pollen etc)	28	34%
Air pollution (e,g traffic fumes from living near a busy road etc.)	27	33%
Your housing situation (e.g, cold, damp, mould etc)	20	24%
Your financial situation (e.g., being able to heat your home)	17	21%
Didn't answer	4	5%

Table: Whole sample responses to a question in the web form about factors influencing people's COPD.

Examples of comments in the feedback form about the factors that had affected respondent's COPD included:

"Exhaust fumes definitely get on my chest causing coughing and increased phlegm. I need the heating on more than I ever used to as I'll often spend hours sitting and not moving around much, so [I] feel the cold more."

"I struggle all the way though the pollen season, it makes my breathing worst. I take antihistamines every day. With the cost-of-living crisis, I don't have the money to heat my home the way I used to."

"I now live alone, I can't afford to heat my house, I use hot water bottles but it's physically draining being cold all the time. My house needs work (i.e. new windows, insulation, but I can't afford to do anything)."

"I believe my home is just another aggravation that impacts on my COPD. Sometimes I can eat, sometimes I can't afford food, but my dog takes priority over me. If I cook, this impacts on my ability to sleep at night due to no way of extracting the cooking smells that rise into my bedroom. The house is open plan with no escape from cooking smells."

Interview participants were also asked about what factors had affected their COPD.

Apart from general comments about exercise, weather and extremes of temperature were the most frequently mentioned factors. This naturally led to discussions about heating and ventilating homes.

Most respondents mentioned the impact of rising costs of energy bills. However, only a couple of respondents said they had been unable to heat or cool their property for financial reasons, while two more respondents said they had needed to use savings to heat their property to a comfortable level.

A couple of respondents had reached out for support with their housing or heating issues. One had applied to his energy supplier to request support with paying bills. However, he struggled to justify putting the heating on when he was the only member of the family at home. Another respondent had applied to Warm Homes Suffolk for support with heating her home, but due to capacity issues they were unable to assist.

Examples of comments about keeping warm or cool included:

"Not only is the cold a problem, but also the heat is too. The thing is, in terms of the property, it got to the point where we had to have an air conditioning unit installed, but we can't afford to run it. When we had the really warm weather last year, I had to sit in here. I didn't go out of this room for two weeks and I just had the air conditioning blowing on me, as cool as I could afford for it to be. It was better than it was outside, but it would have been better and nicer all round if I could have dropped another couple of degrees, but that cost too much money to do that."

"The cost [of heating] has doubled in the last couple of years. We are on oil heating here so we've just filled the oil tank. We fill it in June because it's cheaper to fill in June than it is to fill it in October. We've just used our savings to pay the bills, but you know if it is too cold, I get ill. It's as simple as that. If we didn't have savings, it would have been an issue, but we have been able to put money away over the years, which we now use. If you are living month to month, and you've not got that behind you, well, we wouldn't have been able to afford the last year's heating without help."

"I just turn the heating on when I want it. So my husband dies his death because it's too hot, but he does it. He says 'heating for you is more important than money'."

"I'm on the vulnerability register and so I contacted EDF and I said 'I'm sitting in my bedroom. It's 12° over the winter and I've got COPD. So they agree for me to pay £58 a month. £8 was to go to what I owed them from previous and then £50 a month, so we've been doing that, which was fine. I still didn't put the heating on. Because everyone goes out in the daytime. I can't put the heating on just for myself."

"I just love the fact that I can live in an old cottage, but it's difficult to keep warm. We have a log burner that used to smoke and would give me terrible grief with my COPD. But it's just so expensive and now the government has stopped the heating allowance for pensioners. Our electric heating here is £70 a week. We have storage radiators but I wish I had enough money in the pot to put in the updated version of storage radiators. I did have somebody come out from Warm Homes and they said they wouldn't be able to do anything for this last winter, just gone because they didn't have enough workmen to be able to carry out the work. I need to get back on to them."

Only two interview participants mentioned having mould in their home. Both were living in older, privately rented properties. Both expressed concern that their landlord would raise their rent if they made a big issue of it. Neither participant could directly link the mould in their home to the severity of their COPD.

"If it was council, they would come out and do something, but when it's private like this one, I just have to accept it for what it is. I've done as much as I can to keep it at bay. I use the electric heater in that bedroom now and that seems to keep it clean. But it does cost me a lot of money, but that's how it is. You can't have it either way. You gotta have one or the other. I can't say too much because you know, the rent has been very, very reasonable for the last eight years."

"We have got mould. It's the devil and the deep blue sea because our landlady is very good at only letting out her properties to local people and therefore she always keeps the rent at a lower price. So you don't want to rock that boat too hard because you know at the end of the day she's doing a really good service to the community."

Other issues

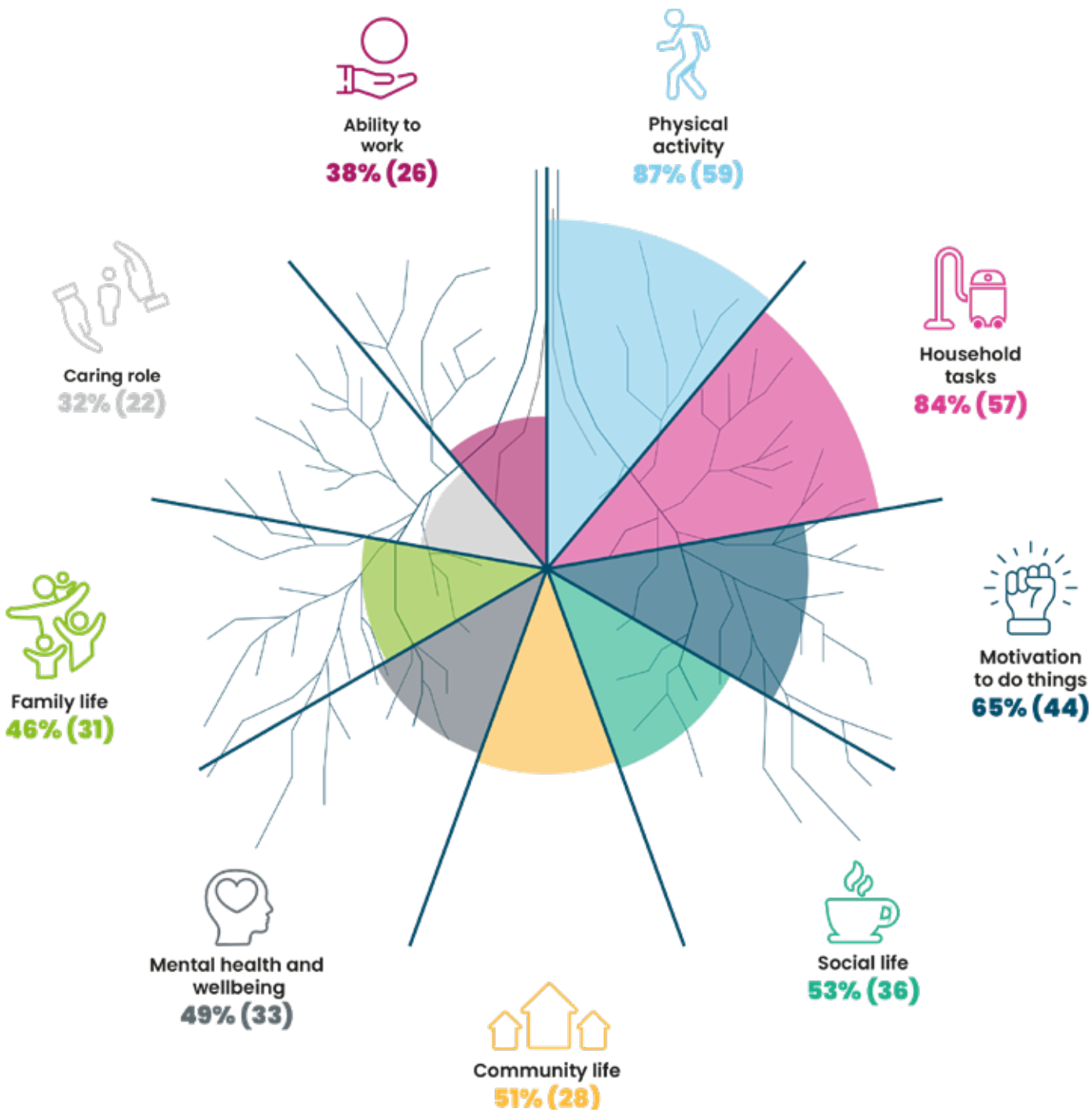
For those who experienced issues with pollen, having access to an effective antihistamine was key to helping them cope. While one respondent received positive support from her GP to access antihistamines on prescription, another had to stop taking her medication due to it causing other health problems.

"[I'm affected by] dust and pollen. Summer's bad, but winter's bad too. They say: 'Oh it's always better in the summer'. Well, it's not because of the dust and everything, and these flats attract a lot of dust. They keep giving me this spray for my nose which I've just found out I shouldn't be using because of my breathing. So I've stopped taking my antihistamines because I started getting really bad nose bleeds but it's like I'm in between a rock and a hard place."

"Around our cottages, there are lots of fields and they used to have animals in them, which used to keep the grass down. But this year it was waist high and I said: 'You just gotta do something about it'……You can't live indoors, you know I love my garden and I love having a bedroom window open, winter or summer. My daughter, told me about a new antihistamine on the market that you can get over the counter which I started to buy for myself and it is amazing. To the point I said to my doctor: 'Can I get it on prescription? Because I'm saving you money because I'm not using any other puffers'. And they said yes."

The feedback form asked respondents which aspects of their daily lives were affected by their COPD. Ability to carry out household tasks was the second most frequently mentioned impact, after physical activity and exercise.

The percentage of respondents who selected each option are shown in the chart below.



Respondents spoke about either having to 'pace' themselves whilst completing tasks (such as hoovering, dusting, cleaning windows and changing beds), or relying on the support of family and friends to help out. For two respondents, this was particularly difficult because they did not have a support network to call upon. One respondent particularly highlighted the need for additional support around household tasks, such as cleaning and dusting, upon discharge from the hospital.

> *"One of the things I found, when I came out of hospital was, because I hadn't been very well for some time, I hadn't cleaned my property properly. I hadn't cleaned my home properly for a long time and when I came out of hospital, I was incapable of doing that, and my husband's older than me and not capable either. I tried to employ somebody to come in and do a deep clean because once it was deep cleaned, I thought I could keep on top of it. But the whole thing as an entity was just like too much to even face when you haven't got any energy whatsoever.*

> *"I think if you're talking about keeping people at home cleaning is one area that could help. And actually, personal hygiene too. I could hardly get in the shower or bend over to wash my hair. And my family's not around, I've got nobody locally that I could call on. So, I think if you're looking at supporting people with COPD in their homes, especially if you've had an exacerbation, you know social care comes into it too. You need support in all sorts of other ways, like being incontinent because you're coughing. Getting yourself well is one thing, getting your environment well with you is also important."*

“If you’re looking at supporting people with COPD in their homes, especially if you’ve had an exacerbation, you know social care comes into it too.

“You need support in all sorts of other ways, like being incontinent because you’re coughing. Getting yourself well is one thing, getting your environment well with you is also important.”

4. Qualitative themes

Professionals



A total of sixteen people responded to the online survey for professionals. Although the sample size is small, there was a good representation of professionals from across the health, care, and public sectors, including:

- Five people working for the NHS in a hospital (clinical role).
- Two people working for the NHS in community services.
- One person who was a volunteer in a community group.
- One person who was an ambulance paramedic.
- One person who worked in social care (occupational therapy).
- One person worked for Public Health and Communities in Suffolk.
- One person who was a respiratory specialist nurse in the community and hospital COPD team.

Professionals were asked four open-ended (free-text) questions:

1. What do you feel are the main things that influence how people are able to manage COPD effectively at home?
2. What do you think could help and support COPD patients to manage their condition more effectively (and prevent hospital admission)?
3. Can you think of examples where non-clinical interventions have led to positive outcomes for COPD patients, or improved their ability to manage their condition?
4. What further support or information do you need to help COPD patients manage their condition more effectively and prevent hospital admission?

The third question was removed in the later weeks of data collection, to reduce the overall length of the survey and improve overall response rates.

Responses to each question were merged into a single overall comment, and then qualitatively coded for key themes.

This analysis does not aim to produce generalisable findings but does provide another perspective on the issues highlighted by those living with COPD.

Understanding of the condition

Most professionals said that a patient's understanding of their condition was key their ability to manage their condition effectively. This not only included knowing how to manage the daily effects of COPD, but also recognising when to seek support, and how to do this.

Some professionals also mentioned the importance of patients being educated about their condition, changes to expect, and their prognosis.

Examples of quotes about understanding COPD included:

> *"Patient motivation and understanding of their condition, especially when and how to seek help appropriately (proactively contacting their GP practice within the week where they recognise they are becoming unwell)."*

> *"Ability to understand what COPD actually is helps to manage it. It needs careful explanation to motivate the patients to comply with the care plan."*

> *"To fully understand their disease and the changes that happen as time goes by, be decisive if they feel an exacerbation coming on."*

Access to medication and confidence taking it

Some professionals highlighted the importance of patients having access to appropriate medication to enable them to

manage any exacerbations of their condition in a timely manner. This could include rescue packs of antibiotics and steroids.

Some stated that patients need to feel confident about using their medication. This included understanding what medications to take, when and how (for example, having good inhaler technique).

Example of quotes about medication included:

"Access to appropriate medication in a timely manner when having an exacerbation of symptoms."

"Confidence in taking medication – technique as well as what to take when."

"Make sure that they all have a rescue pack of antibiotics and steroids and give them freedom to use them."

Professional support

Respondents highlighted the importance of COPD patients having access to professional support. This included having somebody knowledgeable, who patients could easily contact for support and advice. Respondents recommended ways in which professionals support could be improved. These included outreach services, home visiting teams, or virtual wards on discharge.

Examples of these comments included:

"Whether they are routinely seen by a specialist or whether they are only under primary care, and if under primary care, how often do they have a COPD review?"
"Rapid access to targeted professional advice when needed."

"I feel like a service similar to the heart failure nursing service could be really beneficial. A COPD outreach service specialist clinic with home visits who could undertake review of COPD patients but also monitor them, optimise their treatments, but mostly ensure they are well versed in understanding their condition."

Social connection

Many professionals reflected on the benefits of social connection in supporting individuals with COPD. This included support from family and friends, and support networks made up of people with the same experiences.

Two examples of these comments were:

"Having a robust support network particularly in times of crisis. Sometimes people just need reassurance."

"Fitness and networking options in the community – including perhaps community gardening projects, crafting sessions, games afternoons, afternoon tea/dances, fundraising project groups, singing groups… organised day trips to help with social networking and supporting each other."

"Inhaler technique is a very basic thing but very crucial as inhalers helps the medicine to reach the target site which is the lungs.

"When patients have a poor technique there is very little use and they don't benefit from the purpose."

Pulmonary rehabilitation and healthy lifestyles

Some respondents mentioned that patients' willingness to engage with support and actively manage their COPD could be a barrier. This included maintaining a healthy lifestyle (i.e. adjusting diet and exercise) and attending pulmonary rehabilitation.

Respondents mentioned the need for patients to have access to support for maintaining a healthy lifestyle. This included support around exercise, diet, breathing exercises and quitting smoking. Some professionals also suggested greater provision of local exercise clubs or at-home equipment.

> *"Education and support to manage symptoms with reliance on medication (pulmonary rehabilitation). Practicing structured self-help – exercise, support groups, smoking cessation, weight management (community-based programmes and resources)."*

> *"Help to get the patient to understand breathing exercises and techniques, plus help with a good diet."*

> *"Smoking cessation is the first step in the management of patients who still smoke and smoking cessation support is available both in the community and hospital setting."*

> *"Fitness options in the home – equipment provision or help to set up online classes."*

Professionals also emphasised the need for patients to attend pulmonary rehabilitation to tackle breathlessness and improve exercise tolerance. Like interviewees, some professional respondents acknowledged a need for more community-based support groups or networks to support pulmonary rehab courses.

> *"Pulmonary rehabilitation programme enables patients to improve their exercise tolerance. Therefore, the willingness to engage in pulmonary rehabilitation will improve their quality of life."*

> *"If patients can exercise it improves confidence, mood if there were local exercise clubs to continue on with after pulmonary rehabilitation to keep and expand their exercise tolerance."*

> *"More availability for pulmonary rehabilitation or exercise follow on classes – particularly in more local areas."*

Home and environmental influences

A few professionals discussed how the home environment can affect people managing COPD. These comments included issues ranging from exposure to damp and mould, to difficulty with moving around the home. They considered support with home assessments and re-housing as useful offerings for some individuals living with COPD.

> *"I speak to patients who have damp and mould in their properties or have no heating but are waiting to be rehoused which effects their health and mental health."*

> *"Home adaptations at an early point to reduce fatigue and avoid crisis."*

> *"Removing the bath for a wet room for independent washing. Support with re-housing to single level living for those who are no longer able to manage stairs. Home environment in terms of ventilation, humidity and mould."*

Mental health support

Professionals recognised the impact of COPD on wider health, including mental health. It was suggested that mental health support could help improve motivation to engage in COPD management.

"Support with mental health and anxiety."

"With chronic conditions such as COPD they would benefit from a mental health assessment/support. Many patients are depressed or anxious, which leads to them becoming housebound, deconditioning lack of motivation (less likely to attend pulmonary rehabilitation), isolation."

Transport

Some respondents reflected that access to transport could act as a barrier to patients engaging in rehabilitation and social events. They gave suggestions that providing transport would help more people to access these services.

"Transport to appointments and to social events/shops to keep connection with world around them and reduce isolation."

"If we were able to fund transport for patients to go to pulmonary rehab this would greatly improve mood, confidence, physical fitness, etc."

"Transport options to appointments, events, shopping services, family visits – keeping people engaging with their environment and other people."

Finance

Some respondents discussed how financial barriers can impact the management of COPD. They noted that cost could reduce a patient's opportunities to access services or support in the community.

People also discussed housing within the context of this theme. For example, how not being able to afford heating could influence overall health.

"How do we ensure that people don't have financial barriers to managing their COPD, and how do we ensure that money doesn't cause a barrier in maintaining social relationships, whether that be related to specific money-related aspects (e.g. affording to participate in something that keeps a person physically or socially active) or the outcomes of a lack of money (e.g. not wanting to invite friends or family over due to pride or embarrassment)."

"These patients tend to be from lower socio-economic backgrounds, lower educational status, huge overlay with mental health issues: all of which make engaging with services more difficult. There's an element of guilt – 'I've done this to myself'."

"Heating/cost of energy bills in winter is particularly important and highlighted as a concern with patients."

> "Income maximisation for people where they are struggling financially, might be experiencing debt or where they are not claiming all of the benefits and social tariffs they are eligible for. If we have ensured that people have a decent level of financial resilience, then this is likely to impact positively on mental health and their ability to afford a healthier diet and access exercise options of interest to them."

“With chronic conditions, such as COPD, they would benefit from a mental health assessment/ support. Many patients are depressed or anxious, which leads to them becoming housebound, deconditioning lack of motivation (less likely to attend pulmonary rehabilitation), isolation.”

5. Key learning

All respondents



This project has provided evidence of the views of people living with COPD on their condition, management and support available in Suffolk.

The key learning should be viewed as guide to the priorities of people living with COPD in the county. The role of a local Healthwatch is to gather and represent these views as an independent partner in the local Integrated Care System.

How these views are translated into policy interventions, is left here for commissioners and professionals within Public Health and Communities and within health services. Public Health and Communities and health and care services should continue to work in co-production to develop effective and evidence-based systems for people living with COPD.

Overall, the key learning is broken down into six key themes:

1. General understanding and awareness of COPD
2. COPD clinical support pathway
3. Importance of social networks
4. Attitudes to health management
5. Mental health and wellbeing
6. Wider determinants

These are presented in order below, including both a summary of evidence for each theme, and any key recommendations or guidance identified in the feedback gathered.

1. General understanding and awareness of COPD

When people have access to comprehensive information about their condition, they can make better decisions regarding their health. This includes understanding the risks and benefits of medication and adhering to medical advice. It also means they are more likely to engage in preventive measures, such as regular exercise, healthy eating, and routine health vaccinations.

It was evident from the feedback that both patients and professionals felt there was a need for better access to information about COPD. People needed information in different ways, for example written, verbal, face-to-face, or online.

Information provision should be pro-active as opposed to a reactive response to deconditioning. Messaging needs to be consistent, clear and given often (i.e. not just at diagnosis but at different points along the COPD pathway). This could include at annual reviews, GP appointments, pulmonary rehabilitation sessions and any other points of contact with patients in between.

Those who had attended pulmonary rehabilitation had found it an excellent source of information about the condition, but not everyone had engaged with the service. This was either because they did not understand what it was and how it could benefit them, or they were unable to attend for practical reasons such as transport, or personal availability.



Knowledge of COPD can help people to make better decisions about their health. Yet, it was clear people had mixed experiences regarding information they had received about their diagnosis. Some had seemingly been left to learn about their condition through lived experience alone.

Consideration should be given to how the information shared in pulmonary rehabilitation could be made more widely available with those who are unable to attend sessions or classes in person (e.g., online videos). People could also be signposted to support that can help them with accessing information online (e.g., at local libraries and other technical support services).

2. COPD Clinical Support Pathway

People's understanding of the COPD support available to help them manage their COPD was inconsistent. Crucially, some did not know how and when they could access support.

Feedback from participants also suggested there was lack of clarity about COPD support amongst healthcare professionals. For example, participants reported that there were discrepancies between messages they had received, or that professionals had told them they were not suitable for services such as pulmonary rehabilitation.

Mapping COPD Support

A comprehensive review and mapping of the current support pathway for people with COPD would help to identify and clarify what support is available and the eligibility criteria for accessing support.

Patients would benefit from knowing what to expect to receive at each stage and, most importantly, how this will be of benefit to them. Ensuring people have access to the right information about what to expect from services, at the right time in the pathway could increase their confidence and ability to manage their COPD and utilise health care resources effectively.

This information should be shared with both patients and professionals supporting people with COPD to ensure consistency of messaging (see recommendation above about information for patients).

Mapping should take into account any geographical differences between support available to patients living in the Suffolk & North East Essex ICS area, and those living in Norfolk & Waveney.

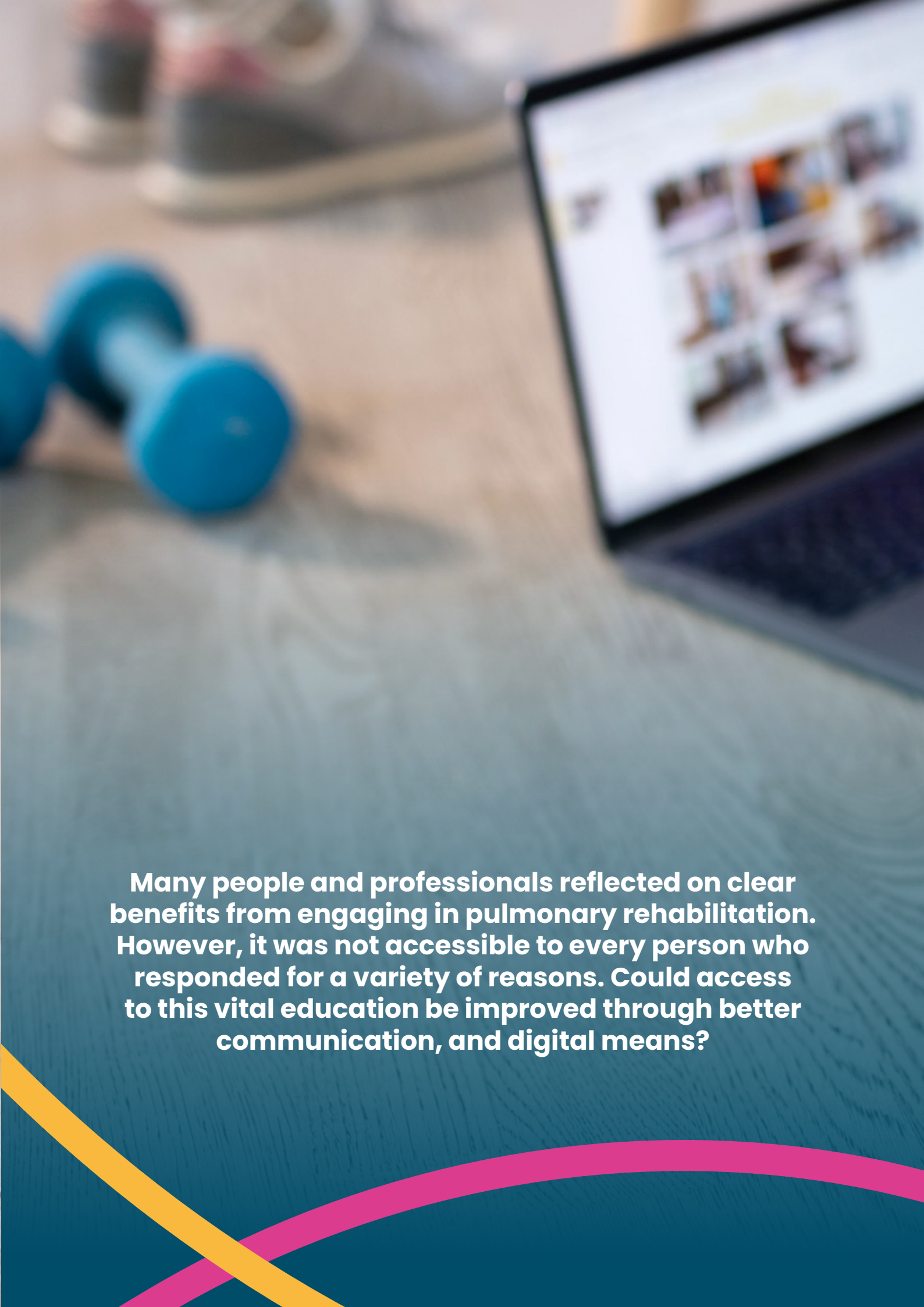
Pulmonary Rehabilitation

It was generally felt that there was a need for more community-based COPD exercise activities or classes to ensure people could continue to build and improve lung function and exercise tolerance, following pulmonary rehabilitation.

This would also be of benefit for those who are unable to attend the main pulmonary rehabilitation sessions.

Feedback also highlighted the important role that friends and/or relatives play in supporting people to manage their COPD. Opportunities to include support networks in training/education activities, such as pulmonary rehabilitation, should be explored (see section on social networks).

Linking social prescribers into the pulmonary rehabilitation offer could also help participants access support around mental health and wellbeing, housing or environmental issues in their home and financial concerns.



Many people and professionals reflected on clear benefits from engaging in pulmonary rehabilitation. However, it was not accessible to every person who responded for a variety of reasons. Could access to this vital education be improved through better communication, and digital means?

Access to Medication (Rescue Packs and Annual Vaccinations)

Most respondents had experienced repeated chest infections and were therefore familiar with rescue packs.

There were no particular issues reported around being able to access emergency medication when it was needed. However, for those who had not experienced a chest infection or flare up, there was a gap in knowledge about standby medication. This could prevent people from accessing timely support when needed.

Feedback from professionals highlighted the need for patients to feel confident about using their medication. This included understanding what to take and when to take it, as well as techniques to ensure effective delivery of medication (e.g., inhaler techniques).

Providing information about different medications would address some of the concerns respondents expressed about adverse effects of antibiotics and steroids.

Most people understood the need to keep up-to-date with their annual vaccinations. However, hesitancy was evident amongst some interviewees, particularly around the COVID jab. This highlighted the need for continued messaging and communication about the safety and benefits of immunisation.

Feedback also reflected confusion around which vaccinations people could have. For example, the different criteria for spring and autumn COVID boosters.

Reviews and Action Plans

Whilst most respondents had received an annual review with their GP practice, they were mixed in their views about how useful these were.

It was recognised that practitioners in primary care did not necessarily have specialist knowledge about COPD, and people felt there had been a lack of consistency in the information they were given by the different health professionals they saw.

Undertaking a mapping exercise (as outlined above) would help bring some clarity for both professionals and patients.

The NICE guidelines for 'Diagnosing and Managing COPD in people aged over 16' recommend that patients should have an individualised self-management plan developed in collaboration between health care professionals, patients and their families or carers.

Yet, only one interview respondent mentioned having a personalised action plan. This had been developed in discussion with his local community COPD team. It provided information that enabled him and his partner to monitor changes in his lung function and alerted them to early signs of potential issues. They had found this document to be an invaluable resource in helping to manage his COPD.

Several others in the sample said they would like some form of aide mémoire that could remind them of signs of concerning issues and what actions they should take. This could be reviewed as part of the annual review process.

Consideration should be given to developing a standard template for a COPD action plan locally. Annual reviews should include a discussion about housing and/or environmental issues, and identification of individuals who would benefit from a housing assessment.



Better local implementation of personalised self-management plans for people with COPD could help people to feel more confident in managing their condition at home, and support planning for winter pressures across the health and care system.

Smoking Cessation

There were a wide range of factors that influenced whether interviewees smoked whether they decide to quit.

Professionals highlighted smoking cessation as a key factor in managing COPD. However, people had a mixed view of whether they had received the support they needed. What was clear from the patient interviews was that once someone had decided to quit smoking, it was important for them receive support in a timely manner, regardless of whether they are accessing help in the community or in a hospital setting.

Support for people to stop smoking also needs to be highly personalised. Some participants felt their motivation to quit had been as a result of considering the impact on their family, while others had done so after critical health episodes. Respondents also reflected on having used diverse methods of having quit or attempted to quit smoking. For more information about people's experiences of smoking and quitting smoking, read Healthwatch Suffolk's report on stories from people in Suffolk.

See https://healthwatchsuffolk.co.uk/smokingreport/.

3. Importance of social networks

The important role of social networks and social support for people living with a long term condition like COPD, should not be understated. Feedback from both professionals and those living with the condition highlighted the crucial role family and friends play in supporting people with COPD.

There were several examples of practical support offered by friends and relatives, for example with cooking, cleaning and gardening. However, respondents also emphasised the psychological support and comfort in helping them to manage their COPD. These included examples such as providing motivation around healthy behaviours, help to manage anxiety, spotting potential risks and providing support around issues affecting mental health and wellbeing.

Consideration should therefore be given to how social networks of support can be enhanced and better supported to help people manage their COPD. This could be achieved through the development of training and resources that helps friends and relatives to know how they can best support their loved one. This might be delivered through information provided by GP practices, the provision of a short online course, video or web page, or adapting the local pulmonary rehabilitation offer to include partners or relatives (for example in one focused session).

For those who lack support networks, or who may be socially isolated, it is important for systems to consider how the positive influence of others may be replicated or encouraged.

This might include:

- Proactive signposting to sources of emotional wellbeing support and grass-roots support networks.
- Ensuring people can meet others with COPD by encouraging them to engage in existing groups (such as Breathe Easy), or to access other local groups and networks who can offer support (e.g., local singing groups or coffee mornings).
- Supporting people develop an emergency plan if they are on their own during a distressed breathing event.

Finally, it should be noted that social skills and confidence can also be a barrier to engagement in some types of support. Not every respondent said they wanted to attend a class in person, and some felt that they would struggle with the social aspect of group support.

To address this, services could provide a choice of ways to obtain key information and support, with multiple offers to meet people's communication needs and preferences.

4. Attitudes to Health Management

Feedback highlighted the importance that people's attitudes to their personal health management has on their ability to manage their condition.

Respondents who expressed a more 'active' attitude (i.e. they believed their actions could influence their health outcomes) were more likely to:

- be engaged in exercise and other meaningful pursuits;
- have strong social networks of support.
- feel well supported by their health professionals;
- engage in positive behaviours to managing their COPD (e.g., healthy eating and weight management);
- have accessed clinical support services, such as pulmonary rehabilitation or rescue packs;
- have actively searched for information about their condition online.

Evidence has shown that positive attitudes to health management can be developed through person-centred conversations (such as health coaching), which encourage individuals to reflect on their own goals, strengths, capabilities and personal resources (e.g., support networks).

Health staff involved in supporting people with COPD (e.g., GP's, Nurse practitioners, staff delivering pulmonary rehabilitation, social prescribers etc) should be provided with access to resources and opportunities to develop the skills necessary to having behavioural change conversations with patients. Identification of patients who could benefit from one-to-one coaching style sessions should also be considered.

For more insights regarding the health coaching approach, please see https://healthwatchsuffolk.co.uk/news/healthcoaching/.

5. Mental Health and Wellbeing

Responses from participants highlighted the significant and wide-ranging impact that COPD had on people's mental health and wellbeing. Examples of the ways in which people's wellbeing had been affected by COPD included:

- anxiety and distress caused by an acute breathing event, leading to a loss of confidence;
- self-esteem issues and feeling of 'inadequacy' that develop when actual physical capabilities do not match idealised abilities;
- loneliness and depression resulting from the need to self isolate to avoid infection;
- lack of motivation and inactivity as a result of physical exhaustion;
- dissatisfaction with body image, because COPD has caused changes in physical appearance (e.g., weight loss or weight gain);
- Rregret and guilt over past behaviours (e.g., smoking and 'bereavement' for lost health).

Professionals also highlighted the link between poor mental health and a patient's ability to take an active role in their health management.

Addressing these issues is therefore key to enabling people to manage their COPD more effectively, particularly in the winter time. Discussions about mental health and wellbeing should also be included within GP appointments, annual reviews and as part of the pulmonary rehabilitation offer to promote

better patient engagement and levels of activation.

Training and resources should be provided to help people with COPD identify and manage any wellbeing issues. Any information about COPD shared with patients should include signposting to wellbeing services. This should also be available to family and friends who support people with COPD.

6. Wider Determinants

Overall, less than a quarter of respondents reported that issues with housing or finance was affecting their ability to manage their COPD effectively. However, for those who were experiencing issues, this was an area of considerable stress and concern.

There is clearly a need to identify people who could benefit from specific support with these issues and to signpost them to services that are able to help. The need for housing or environmental assessments should be considered as part of any annual review discussion, as well as for patients being discharged from hospital.

Raising awareness of the impact of housing and environmental issues on COPD should be explored within the pulmonary rehabilitation sessions, and should be supported by the inclusion of social prescribers to help people access the support they need.

This could be included as part of the annual review at their GP practice or by linking through the pulmonary rehabilitation course.

“I think, as a therapist, it’s really difficult because I always want to be the one that solves the problems. But that accountability, and them taking responsibility as well, works really well – because then they own it, and then they feel a sense of achievement and pride… it’s not just a therapy process happening to them.”

Explore more insights from our work exploring the experience of professionals using health coaching in Suffolk…

https://healthwatchsuffolk.co.uk/news/healthcoaching/

6. Case studies

Our interviews



Vic's story

'COPD does not affect my everyday life, because I will not let it.'

Background

Vic is a 73-year-old man. It was clear throughout his interview that he has a very positive outlook on life, and this has helped him to manage his COPD diagnosed ten years ago.

> *"I don't wake up every morning and think, 'Oh, I've got COPD, I can't do this and I can't do that'. I wake up every morning and I get up. I make breakfast, I wash and brush my teeth. I get myself ready, and I get out!"*

He loved his previous career as a butcher and was also positive about his living arrangements. Commenting about his Housing Association flat in west Suffolk, which he had lived in for 12 years, Vic said:

> *"I don't think anyone could get a nicer flat than this."*

Vic had been in a long-term relationship for seven years. He did not live with his partner, but he saw them every day. He attributed much of his current good health to his relationship and its positive influence on his life.

> *"She's sort of given me what I've been missing for quite a while... you know, love and understanding. A lot of psoriasis is based on stress. I think I put a lot of it down to her and I put a lot of my health down to her as well because she's always been sort of, well, she is fit and healthy and she's always encouraged me to do that as well. So yeah, you know, she's been a good influence on me. I'm lucky I've got somebody that cares about me as well, which I think is important."*

Reflecting on the impact of COPD on his life, Vic was resolute and unwavering.

> *"COPD does not affect my everyday life because I will not let it."*



"I don't wake up every morning and think, 'Oh, I've got COPD, I can't do this and I can't do that'. I wake up every morning and I get up. I make breakfast, I wash and brush my teeth. I get myself ready, and I get out!"



> ***"...maybe one of the reasons why I decided to do something about smoking and getting some help was because [my father] died when he was 56.***
>
> *"So he was quite young and he'd been ill for a good number of years. He'd been in out of hospital."*

Whilst he did experience the symptoms of COPD (e.g., shortness of breath), he was determined not to let the condition limit his daily life. He said he felt no need to inform others about his condition. Examples of his comments included:

> *"I do get out of breath sometimes. I'm not going to say I don't, but it's never stopped me from doing anything."*

> *"I've never told anybody that I've got COPD. I don't really think I need to... I have never told anybody at the gym that I've got COPD."*

Vic was previously a smoker and had managed to quit before he was diagnosed with COPD. He had experienced repeated chest infections and decided to stop.

> *"I decided enough was enough. So I took steps to stop myself, you know, to quit smoking ."*

But it was not just the physical consequences of his smoking that had motivated Vic to quit. He wanted to make sure he could spend time with his children and grandchildren and see them grow up. He also reflected on the loss of his father (and others he knew), who had passed away from respiratory issues or concerns.

He had tried hypnotherapy to quit, which did not work. In the end, he visited a clinic in London, which successfully helped him to stop. Examples of comments about his reasons for stopping smoking included:

> *"There were a couple of contributing factors, obviously. I mean probably the main ones were I've got two grandchildren, and I wanted to see them grow up. I was also in a relationship at the time, and the person who I was in a relationship with, her husband, had died from a smoking-related condition - and I thought, again, I want to live as long as I can with her. But yeah, I mean, the main factors were my children and my grandchildren."*

> *"Not really, no. I mean, I probably should have [known about COPD] because my father died from it. They called it blockage of the airway passage, but I would imagine these days they would probably call it COPD. I mean, perhaps maybe one of the reasons why I decided to do something about smoking and getting some help was because he died when he was 56. So he was quite young and he'd been ill for a good number of years. He'd been in out of hospital."*

Diagnosis and managing COPD

After a further chest infection, Vic consulted his GP and was subsequently diagnosed with COPD. He was prescribed a 'new' inhaler (DUAKLIR GENUAIR) and a five-to-six-week exercise class at a local library, which he said had been 'fine'.

> *"I've been using this inhaler for 10-11 years. Whether it does me any good or not, I don't know, because I've never stopped using it to find out. But it's never done me any harm."*

At the time of diagnosis, V had little knowledge about COPD (although he recognised that this was a relatively new term at the time). He had since taken the time to learn more about his condition.

> *"So, I had a little bit of knowledge, but it's sort of something that I haven't really thought about, and I'd never heard of COPD. I'd heard of emphysema. It was emphysema, and now it's COPD. But yeah, I'd never actually heard of COPD until I went to the doctors, and I was tested, and that's when they said, 'Oh, you've got COPD'. And then it's like, 'Oh, what does that mean?' And they explain it to you, what it is and how it affects you, and then, because I'm quite an inquisitive sort of person, I thought, 'Well, I'll look all this up and find out what it was all about'."*

Vic appeared to be confident with the clinical management of his COPD. He took his inhaler twice a day and rarely required the use of his reliever inhaler. He avoided steroids because of a comment that was made by his COPD nurse when he was first diagnosed. He recalled:

> *"When I was first diagnosed and I went on this course and the nurse, the COPD nurse that I saw, she said to me, 'Would you like to try this [inhaler]?' And I think then it was fairly new on the market, she said, 'I don't want to give you steroids', because there are lots of good things about steroids, but there are also lots of bad things about steroids."*

Overall, Vic felt he understood his COPD well and could recognise signs of chest infections early. He had been able to access rescue packs from his GP practice promptly in the past, which had prevented issues from escalating. He had never been admitted to the hospital for an issue related to his COPD or breathing difficulties.

> *"I know when I'm going to get a chest infection, you know, you can feel it. It's not that I lose breath or anything like that, but I'll start coughing and normally don't cough. And I rang [my GP] because you can ask for a rescue pack, which they did. And they sent me a course of antibiotics, and they also gave me some steroid tablets to take, and I didn't take them. I thought, I don't think I'll need to, and my partner said to me, you should take them. I didn't take them. I just took the antibiotics. I thought, maybe because I caught it quite early, it wouldn't have that much of an effect on me. Thankfully, it didn't."*

> ***"Last year, we had gone up to Lancashire, and I got a chest infection there and I phoned the GP. They sent a prescription to a local pharmacy, and we picked it up. And again, I think it didn't get too bad because I got it early. So yeah, I think I know when I'm not going to be well."***

He reflected on some helpful advice he had received from a nurse at his COPD review in the last year. He said that this had helped him to take a proactive approach to managing early symptoms of respiratory distress.

> *"I had a COPD review sometime last year, I think it was, and the nurse said to me, 'Don't leave It until it gets so bad that you're ill'. She said, 'Give us a call, we'll always prescribe antibiotics for you; it will never be a problem.'"*

> *"Last year, we had gone up to Lancashire, and I got a chest infection there and I phoned the GP. They sent a prescription to a local pharmacy, and we picked it up. And again, I think it didn't get too bad because I got it early. So yeah, I think I know when I'm not going to be well."*

Attitude to managing health

Vic now had a very 'proactive' attitude when managing his health. He took personal responsibility, for both causing his health issues and maintaining his current health. He also reflected on the important influence of his partner, and how they helped him to remain motivated.

> *"I think this is where a lot of people fall down. I mean, people say, 'Oh yeah, that all worries me', you know, instead of saying, 'Well, OK, I've got this, but I'll do something about it'. I think even doing a little is better than doing nothing.*

> *"And there's a lot of people, you know, all they want is 'Oh, poor you', and I don't want, 'Poor me'. I don't want people to be sorry. I did this to myself. It was self-inflicted. So why do I want somebody saying, 'Oh, poor you, what can I do for you?'. I want someone like my partner who says to me, 'Come on, you know you can do that. You can walk up there; you did it last week'."*

Although Vic was determined not to let his COPD diagnosis limit his life, he also acknowledged that it had prevented him from being able to engage in activities he loved.

> *"I can't blame anybody else. I did it to myself when I was 15 years old. If I've got one regret in life, it's that. If I could turn the clock back to that point in my life, I'd love to, because it has stopped me from doing things that I love to do, like climbing a mountain. You know, things like that. But it is what it is, and you just have to live and get on with it."*

He was annoyed by people who did not take the same level of personal responsibility for their health. For example, he reflected on the attitude of others with COPD involved in a course he attended.

> *"But [they were] like, 'Oh, woe is me'. And [they've] been in and out of hospital. I don't know whether it's psychological or whether it's just [they] feel sorry for [themselves, but] everybody sort of pampers to [them]. My partner said to her, 'You know, you've got to want to be able to do this,' but for whatever reason, [they] didn't want to do it."*

Weight management and active lifestyle

Vic had taken steps to improve his diet and to lose some weight. Initially he had done this through an organised group (Weight Watchers), but gave it up. Nevertheless, he has managed to maintain his weight loss and is enjoying the feeling of being able to wear clothes he has not fitted into for years.

He has two dogs that live with his partner, and they help him to remain active.

"And there's a lot of people, you know, all they want is 'Oh, poor you', and I don't want, 'Poor me'. I don't want people to be sorry. I did this to myself. It was self-inflicted. So why do I want somebody saying, 'Oh, poor you, what can I do for you?'.

"I want someone like my partner who says to me, 'Come on, you know you can do that. You can walk up there; you did it last week'."



Vic had a network of people close to him who encouraged him to stay healthy and active. Like others, key people in his life had been an important motivation to proactively manage his health and COPD.

> "...swimming, I thought, 'Oh, I don't know'. I wouldn't go on my own, but we started going together. Now I go on my own.
>
> **"[My sister] may text me tonight and say, 'Oh, I'm sorry, can't make it tomorrow, I'm doing this', but I'll still go."**

"I think keeping yourself fit and healthy is important. I try to eat as healthy as I can. I've lost a bit of weight... I did enjoy Slimming World... I gave it up, but I think I lost about 18 lbs. I'm wearing trousers that I couldn't wear for ages or even a jacket."

In addition to walking the dogs, Vic exercises four times a week. He previously went to the gym. However, he said this had been hard on some of his joints, so he had replaced the gym with swimming because it was 'low impact'.

"I used to go to the gym. I've stopped going to the gym because I just wasn't feeling that it was doing me a lot of good, if you know what I mean, whereas swimming you're using your lungs. I mean, my heart rate goes up to about 140 when I'm swimming... it's expanding your lungs, and I enjoy doing it, so there's no reason not to."

Vic has a network of very 'active' people around him who have encouraged and supported him in keeping fit, including his sister, partner (who also had a gym membership) and others. They clearly helped him feel confident and remain engaged, even when they were unable to exercise together. He said that he also enjoyed the social opportunities he got from swimming. Examples of his comments included:

"[Getting into swimming] was OK because I started off with my sister. And it was just before the pandemic. She'd said to me for a while, 'should we go swimming?' And she was a member of the gym. She goes to Keep Active and does Zumba and things like that. I was at the gym, and that was fine. It didn't worry me, but swimming, I thought, 'Oh, I don't know'. I wouldn't go on my own, but we started going together. Now I go on my own. She may text me tonight and say, 'Oh, I'm sorry, can't make it tomorrow, I'm doing this', but I'll still go."

"I chat to most people as we swim along. There are some people who don't want to know or are not interested, but it's sort of pretty easy, and you'll get two people that swim side by side, and they'll have a little chat. That could be about the weather or what they were doing yesterday. We talk about the football and things like that, but the social aspect is as important as the swimming."

Nick's story

"It's horrible. It's like drowning in air, that's the best way I can described it. To me, nothings happening when I breathe."

Background

Nick is a 69-year-old man. He lives with his partner in Mildenhall and works as a company director for a local industrial door company.

He is also a family carer for his adult stepson, who had a massive brain bleed ten years ago. Although his stepson now has a live-in carer, Nick and his partner continue to provide him with support.

At the time of interview, Nick was also taking time off work to help nurse his wife through some health issues.

Health and wellbeing

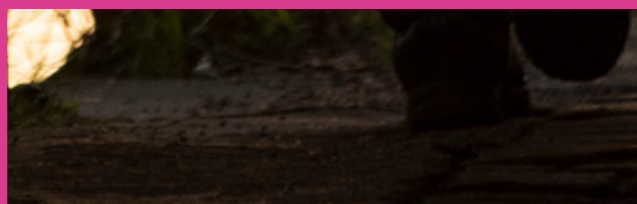
Nick started smoking at the age of 12, but gave up 10 years ago, (using Champix - a medicine that can be prescribed to help people stop smoking) after experiencing shortness of breath. Nick says he had been unaware, when he started smoking, of the risks that it posed for his health.

> *"When I started smoking I certainly wasn't aware of the risks. I don't think anyone was."*
>
> *"I was short of breath. I used to smoke an awful lot. I used to smoke an ounce of tobacco a day and so I was slightly short of breath."*
>
> *"I just finally decided enough was enough. I'd had enough of smoking. I was on this Champix, which is a drug that attaches itself to receptors in your brain, and after a week it is as if you never smoked, and that's exactly what it was like. Absolutely fantastic.*
>
> *"I've never had one since."*

Despite giving up smoking Nick continued to experience breathing difficulties and eventually consulted his GP who diagnosed him with COPD and prescribed a Braltus inhaler.



> **"About four or five years ago, I went to the doctors, and saw the nurse. I did the whatever it was when you exhale as much as you can and I ended up on the floor. The nurse couldn't believe I'd scored so low."**



Nick says that he has had no further contact with health professionals regarding his COPD in the last four years.

> *"About four or five years ago, I went to the doctors, and saw the nurse. I did the whatever it was when you exhale as much as you can and I ended up on the floor. The nurse couldn't believe I'd scored so low. It turned out I've got COPD quite badly. I don't get anywhere near the amount of oxygen in me that I should do.*
>
> *"Then I saw the Doctor and she prescribed the Braltus inhaler and she showed me how to do it and how to inhale it. And that was it, I've never seen anyone since, and that was four years ago."*

Impact of COPD on daily life

In contrast to other interviewees, who described how their COPD impacted their ability to do specific 'activities' like gardening, housework or cooking, Nick described how his COPD was affected by particular types of movement. Specifically, he said twisting or turning actions caused him to feel dizzy and 'as if I am about to flake out'.

> *"Twisting is the killer. Like if you sit in your car and you turn to put the seat belt on or grab the seat belt, that actually really takes my breath away. If I poke about too much in the garden I'll get out of breath and yet I can still occasionally climb ladders. It doesn't affect me at all."*

Overall, Nick described his COPD as:

> *"It's horrible. It's like drowning in air, that's the best way I can described it. To me, nothings happening when I breathe."*

Head in the sand?



Interview respondents demonstrated many different attitudes to their condition and health. Nick had found it difficult to face the realities of his condition and considered himself a part of a generation that 'just put up with it'.

"I have been coughing more phlegm in the last six months. It does keep nagging in the back of my brain... I should really do something about that. But, being a man and an ostrich, a male ostrich...

"It can't be that bad because I am still here.'

Nick reflected on how past trauma's in his life may be affecting his ability to proactively manage his COPD.

> "I'm very tech literate. However, when our boy had a massive brain aneurysm, I refused to look up medical things. I just don't. Because he didn't die, when everyone said he might…. he was that one in a million and he didn't die. So I don't look up information. If it is something technical I'll look at that all day long.
>
> **"It's the ostrich approach, isn't it?"**

Knowledge & Awareness of COPD

Nick described himself as a 'male ostrich' when it comes to facing the realities of his condition. However, he also felt he was part of a generation of people who 'just put up with it' and, at times, this led him to play down the severity of his condition.

> *"I have been coughing more phlegm in the last six months. It does keep nagging in the back of my brain… I should really do something about that. But, being a man and an ostrich, a male ostrich…"*
>
> *"I don't feel any worse now than three to four years ago. Well, at times, I lose a bit more breath…. It can't be that bad because I'm still here."*

The trauma of seeing his stepson critically ill, had made Nick anxious about researching medical information on the internet.

> *"I'm very tech literate. However, when our boy had a massive brain aneurysm, I refused to look up medical things. I just don't. Because he didn't die, when everyone said he might…. he was that one in a million and he didn't die. So I don't look up information. If it is something technical I'll look at that all day long. It's the ostrich approach, isn't it?"*

The recent deaths of three of his friends, due to COPD, however had been a wake-up call for Nick to reflect on his own situation and health more. Although he had not spoken with these friends much in the last few years, he recalls 'two of them were going around the village with a gas bottle and mobility scooter.'

> *"Three of my mates have died, and that's all been COPD. Which to be blunt, has made me think "Oh sh**". Even though I don't feel any worse now than I did 3-4 years ago."*

> "I don't feel confident because I don't know what is involved in managing it. It goes back, again, to the fact that I haven't seen anyone about it…
>
> **"I just haven't got a clue."**

Overall Nick felt that he lacked the knowledge, (and therefore the confidence) to know what he could do to help manage his COPD or maintain his lung health.

> *"I haven't got a clue, and nobody has ever said one thing or another, no… I mean, I've not seen anyone to talk to about this, for at least - with the pandemic - I would think it*

was four years ago."

"I don't feel confident because I don't know what is involved in managing it. It goes back, again, to the fact that I haven't seen anyone about it... I just haven't got a clue."

Steps to manage COPD

Although Nick had received his pneumonia vaccine, ('I thought it would be wise'), he had not received his flu or COVID vaccines because he was on holiday at the time.

"I did insist on the pneumonia jab though because, having COPD and presuming that COVID would be a lung-threatening complaint or disease, I thought that might be wise to have a pneumonia injection. My doctor, who I knew fairly well at the time, gave it to me.

"The last time I was invited [for my flu and COVID vaccines], I couldn't do it because I was in Arizona. So that would be 18 months ago. But when that comes around again, I shall get it."

Nick felt that, due to the manual nature of his job, he did enough exercise to maintain a good level of fitness, without having to do further exercise in his leisure time.

"A lot of our work is quite heavy. Those industrial doors, I mean some of them, are 20 foot wide and 20 foot tall and weigh over a tonne. So yeah, they take some manhandling."

Nick had not heard of pulmonary rehabilitation, although he mentioned having been asked to attend a 'meeting'. Unfortunately, because he was caring for his wife at the time, he was unable to attend the group.

When asked if he would be interested in pulmonary rehabilitation, Nick reflected 'I'd be a fool not to be interested'.

'Until you've just said about this [pulmonary rehabilitation], I didn't know it existed."

'I did get a phone call funnily enough in March, asking if I'd like to go to a meeting of some sort. but my wife had just had a new hip and I hadn't got the time to do it."

Similarly, Nick said that he had never heard of a COPD rescue pack, what it was or how to get one. He did however say that he rarely got chest infections.

"I've never heard of it. It's like you are speaking Klingon."

> **"Until you've just said about this [pulmonary rehabilitation], I didn't know it existed."**

Ashley's story

"You have to push yourself. You have to, because otherwise you would just sit back and you wouldn't do nothing. To be perfectly honest, most days I'll feel a bit like that, and I think 'Just get on with it. Come on, you've got to go; let's do this'..."

Background

Ashley is a 62-year-old man. He is married and has three sons and grandchildren. He worked for a civil engineering company, which required some manual labour (mainly strength-based activity), although he was trying to switch to using machinery more often.

> *"I work on the machines and do manual work. I'm trying to get onto the diggers. I'm trying to get more onto machines. So obviously, as you get older, you don't need all that. Most of my body's worn up now."*

However, at the time of his interview, he was having time off work following an accident in which he came off his electric bike and broke his ribs.

Ashley suffered from general aches and pains in his joints, which he attributed to years of manual labour in his career. Although he was on the list for a replacement knee, he was not in any pain or discomfort and, therefore, felt happy to leave it alone. He said he understood that he would have to have the operation at some point, but he was hoping that it could wait until he retired from work, when the recovery may be less of a financial burden.

> *"[I don't get pain with it] any more. That's why I'm leaving it alone. I've been offered to have a knee replacement twice, and I said no, not while it is like it is. I'm leaving it. I'm happy walking on it. I will have to have [a knee replacement eventually]. If I can get through my work age without having one, brilliant. I don't really*



> **"A bit of a stoic... like the old farmer boys, I'm a bit too hard for me own good."**



want that time off. You know, financially it isn't good, is it?"

Ashley lived in an old building (c1600s), which he says needed modernisation. Mould had formed on the walls in two of the rooms – the main living area, and in the spare bedroom. He and his wife had cleared up as much of the mould as they could and were taking precautionary measures to stop it from getting worse. He felt unable to judge whether the mould had directly impacted his COPD. His comments about dealing with the mould included:

"We're trying to keep on top of the mould ourselves, you know, try and keep it all clear, and that's all we can do... what I do, I actually use the electric heater in that bedroom now and that seems to keep it clean. But it does cost me a lot of money, but that's how it is.

"If it was Council, they would come out and do something... But you know, when it's private [rented] like this one, I have to accept it for what it is. I've done as much as I can to keep it at bay. And we just keep taking it off, well, because obviously you don't want mould to start growing, that's when you get the spores which damage your lungs. And so, we keep the wall clean and clear with a mould treatment. Unless it actually caused it from all the years I've been here."

Managing COPD

Ashley was diagnosed with COPD around four years ago following a routine medical examination at work. He was advised to consult his GP, who made the formal diagnosis during a phone consultation. He later had a spirometry test, which confirmed the diagnosis. He said about the process of receiving a diagnosis:

"I had a medical at work about a month before I was diagnosed with COPD, and I gave up smoking a month before COPD. He did the, you know the blowing test and that was low. And we tried two or three times, and he said, 'You're going to have to see a doctor about it'.

"And at the time, I think we might have been in COVID, I'm not sure. And that was done at a video link with the doctor from the health centre. And he diagnosed it then on the phone. I don't know how they can tell on the phone, but I gave the symptoms, and he told me what it was, and that was it, basically."

At the time of diagnosis, Ashley said he knew very little about COPD, although he had heard the term before. He had not been told much about the condition since his diagnosis, but he was aware that it was essential to exercise his lungs and that his condition will not improve. Examples of his comments about his knowledge of his condition included:

"I hadn't really known much about it at all. I'd heard of it."

> **"I've never really been told that much. Just to keep doing your exercises with your lungs and fill your lungs up and all that sort of stuff, but that was about as far as that went really.**
>
> **"I do know that they're never going to get better, but that's as far as I know really."**

"I've never really been told that much. Just to keep doing your exercises with your lungs and fill your lungs up and all that sort of stuff, but that was about as far as that went really. I do know that they're never going to get better, but that's as far as I know really."

"I know what I've got. So, I need to just deal with it and so I do try to do the best thing for it. It's all I can do unless somebody comes up with a miracle cure, but I don't think that's going to happen. But I do realise that it's never going to get better. I've just got to try and keep it going."

Experience of quitting smoking

Ashley had given up smoking four years ago. He had started smoking at the age of 15 and had always smoked tobacco, which he says 'may be more in his favour' than if he had smoked cigarettes.

He describes himself as having been 'an idiot' for smoking and recognised its potential impact on his long-term health.

"I just gotta try and make the best of it, it's as simple as that."

"I never sort of got into the packets of cigarettes. I always smoked tobacco, which they said maybe more to your favour than bad, if you know what I mean. I don't know. I don't know much about that side of things. I know it is all bad."

Ashley had given up smoking twice, most recently because of his breathing. Both times he went 'cold turkey'. He could not pinpoint why he started smoking again. He felt that stress may have been a factor. However, he doesn't 'even think about cigarettes anymore'.

"...because of me breathing. That was sort of like coughing and then whatever else, and then I thought, 'That's it. I should stop this'."

"[On why he started again] I could have put it down to loads of things probably. I weren't going through a real good time then. That could have been something to do with it. I don't know. And it's just too easy to blame anything, any one thing. You know what I'm saying?"

Ashley had been advised by a COPD nurse that giving up smoking 'suddenly' might have 'triggered' his COPD.

"Can I just say that when I was having a review of my COPD, the nurse actually said that could have been what struck it off. I don't know what she meant, but she just said because I suddenly stopped, that might have been what actually struck the COPD off. But there we go."

Attitude to medication and support to manage COPD

Ashley described himself as a 'bit of a stoic'.

"... like the old farmer boys, I'm a bit too hard for me own good."

He said that this could sometimes lead to him not recognise his own health limitations, and he could overexert himself.

He also described trying to avoid any form of medication unless it is necessary. For example, he had, at one point, refused an inhaler for his COPD. He had also refused the painkillers he was offered, saying that they were too strong, and instead opted to manage his pain with paracetamol. Examples of comments about his attitude to managing his health included:

"I refused any medication. I could have had an inhaler or whatever then and I said 'no, I'm not struggling'. I could breathe, you know, I could walk. And if I stop, I'll get my breath back quite quickly. So it doesn't matter. If I'm going up a big hill or something, I'll stop at the top and I'll get my breath back within a few puffs and away I go again.

"I had [a rescue pack] a little while ago. Like I said before, I wouldn't say I like taking medication if I can help it. But that got so bad that I had to do something. So I phoned 111. And there's a doctor on the other end who prescribed me some.

"She said, you know, COPD, you need to get some antibiotics because you've obviously got a chest infection."

"I've never been one to take medication, if I can help it. Yeah, I do try to go without. It's the same as these broken ribs. I'm doing most of the time without painkillers because I just don't want to be taking them. If I haven't got pain, then I'll leave it."

He talked about the need to pace himself when he was walking, or physically exerting himself:

"Well, it just depends on what I'm doing. If I have to do something for a long period of time, then obviously, I have to have a break because that just gets too much.

"The only way to describe it is, like, when I walk the dog if I'm doing an uphill or a gradient and I'm walking up the top of the hill, then obviously I am going to have a break halfway up or have to break when we get to the top just for a few minutes just to get my breath back and then on my way again. That's just how it is."

Ashley had recently noticed a change in his breathing, particularly in his recovery time after any physical exertion. He also felt this was impacting his motivation to do things. He had seen his GP and had now started to use an inhaler. Unfortunately, due to his recent accident he felt unable to judge how much benefit he was getting from the inhaler.

"I am now [using an inhaler]. I've started. I'm now starting the first day of my second month on a powder one, which is a really low one... Yeah, I felt I was not struggling... like the breathing was a bit harder, you know like.

"Obviously, I'll walk the dog regularly, trying to keep it, and if I get a hill, I'll just try to stamp through it. And I took a bit longer to get me breath back and stuff, but I'm thinking maybe I should get it, because apparently it opens your airway up a bit, these inhalers."

Ashley has received his annual vaccinations. He had also recently had a chest infection, which led to him accessing a 'rescue pack' for the first time:

"I had [a rescue pack] a little while ago. Like I said before, I wouldn't say I like taking medication if I can help it. But that got so bad that I had to do something. So I phoned 111. And there's a doctor on the other end who prescribed me some. She said, you know, COPD, you need to get some antibiotics because you've obviously got a chest infection.

"I knew I was wheezing and everything else. I was thinking, 'There's something not right'. And as I am, I just kept leaving things and leaving and everything and then it got really bad and I'm thinking 'I need to do something about this quickly, you know, and so I phoned the 111 and this lovely lady come on and she said I know what you're going through. You need to get some antibiotics."

He feels well supported by his GP practice. He has been invited for annual reviews of his COPD, which he finds reassuring.

He has been shown how to use his inhalers, and he feels his GP is willing to listen to him. He felt that he never had any problems accessing his GP surgery, and that they recognised the importance of managing his condition.

> *"They phoned me up a little while ago... I'm not a doctor, so I wouldn't know what stage I'm at. So that makes me feel easier if I go and see them and they say, 'You're OK, you're OK as you were' sort of thing and it makes me feel better."*

> *"The doctor that gave [the inhaler] to me, he showed me how to do it. He got a whole box of inhalers and said this is the one I think you should start with, and he he's pretty good because he just said, 'Look, if you feel that's not good enough, you can tell me I'm a rubbish doctor, and we'll up it'. So, he would more or less go on me knowing what I'm talking about."*

Ashley had not heard of pulmonary rehabilitation. He didn't feel it would be something that he would be interested in because he feels he is already doing as much as he can to exercise his lungs.

He had been shown some exercises by the medical examiner who originally picked up his COPD, and he practices them regularly.

> *"I think I put myself through enough as it is. I try to get my lungs open. I feel I do as much as I can with them already. The guy that actually does our work medicals, he's shown me how... you know, he said, look, take an extra breath to fill your lung right up and breathe in as far as you can and then, maybe swallow a bit more to get some more in, you know and that sort of stuff."*

> *"[I do the exercises] whenever I feel I need to. Whenever I feel, whenever it sort of takes you. I just start doing it, and when walking a lot as well. Just whenever it comes into me head I do it. You know, I just do as much as I can really."*

> *"[The doctor] just said, 'Look, if you feel that's not good enough, you can tell me I'm a rubbish doctor, and we'll up it'.*
>
> ***"So, he would more or less go on me knowing what I'm talking about."***

“They phoned me up a little while ago... I’m not a doctor, so I wouldn’t know what stage I’m at. So that makes me feel easier if I go and see them and they say, ‘You’re OK, you’re OK as you were’ sort of thing.

“It makes me feel better.”

Mervin's story

"It frustrates me when everybody assumes that if you've got COPD that you've been a smoker, that it's caused from smoking. That's the first assumption that people have. And I absolutely did not get my COPD from smoke. It might have aided. That might have aided, but that certain wasn't it."



Background

Mervin is a 65-year-old man. He lives with his wife and dog in a bungalow in Ipswich. He used to work as an engineer in the motor trade, but had to stop working about 10 years ago because of various health issues.

Mervin took pride in his overall fitness. He had been a fitness instructor and had his own weight equipment at home:

> *"I was weight training from the age of 13, and I never stopped. I never stopped and so I was training for over 40 years. As far as the fitness side was concerned, I used to instruct, so I've got my own equipment. I don't think there are many people with the injuries that I've got who can do more physical exercise than what I actually do when I'm able. I push myself to limits that most people wouldn't even think about."*

However, in recent years, the stresses of years of manual labour had taken their toll on his body. In addition to his COPD, Mervin had extensive osteoarthritis. He had various operations on his back and spine and three procedures on his right shoulder.

> *"I've done an awful lot of heavy work. An awful lot. It wasn't my lungs, COPD or anything like that which stopped me from working. Certainly not. No, it was my*

> **"I haemorrhaged internally, and it kept on haemorrhaging. I didn't know... This went on, and eventually, I couldn't breathe anymore, and I was taken to hospital. My chest cavity was full of blood... "**



> "She said 'chronic obstructive pulmonary disease'. And I thought, 'God, I'm not going to remember that. God, have I? What's that?' Over a period of time, I had to go back and see her again. But I wasn't doing anything about it.
>
> **"I wasn't, to be honest, I didn't think that I needed this. I didn't think I needed the blue puffer either, so I didn't use it, and I just plodded on."**

structure, back, legs and all sorts."

Having worked in the motor trade all his life, cars were Mervin's passion. He enjoyed 'tinkering about' with classic cars whenever he felt able, and doing manual activities.

"I've been in the motor trade all my life. I still have a few cars around me that I've had for a long time. I would be lost if I didn't have cars around me. I've had two or three months where I've not been able to do much, but as soon as I'm able, I like to get out there and do something with them."

Mervin had first experienced breathing difficulties 21 years ago when he had an accident, which resulted in him haemorrhaging into his lungs. Over several weeks, his breathing had worsened. He was treated for both a chest infection and pneumonia before eventually being admitted to the hospital, where they discovered blood in his lungs. By this time the blood had thickened, causing the lower lobe in his lung to harden.

"I haemorrhaged internally, and it kept on haemorrhaging. I didn't know... This went on, and eventually, I couldn't breathe anymore, and I was taken to hospital. My chest cavity was full of blood... Because the blood had been in my chest cavity for such a long time, it wasn't something that was in there a day or two, it was very thick with clots. Basically, they said that had made the bottom of my lobe go hard."

COPD diagnosis

Following his accident, Mervin did not notice a difference in his breathing. However, two or three years later, he developed pneumonia and began to notice that his breathing had worsened.

"If I'm honest, I can't say that I really noticed that I was more breathless... Some two or three years had gone by when I got pneumonia. I suppose, because my chest had been compromised or made weaker, when I got this pneumonia, I got it very, very bad. And that was really the turning point, I suppose, when I started to realise that I was more breathless. I was starting to get mucus more."

Following this event, Mervin saw a nurse who undertook a spirometry test and told him he had COPD. He did not really understand what the condition was or what he could do to minimise any deterioration in his breathing.

"I went to see the nurse... She asked me to blow into this spirometer and I did, and she said, 'that's a bit low for a man of your build and your size', because I was quite fit. And she asked me some questions and she said, 'I'm going to prescribe you a blue inhaler', which I have to carry all the time now - Salbutamol. I believe it was at that point that this nurse said, 'You've actually got COPD, and do you know what that is?'. And of course, I said 'no'.

"She said 'chronic obstructive pulmonary disease'. And I thought, 'God, I'm not going to remember that. God, have I? What's that?' Over a period of time, I had to go back and see her again. But I wasn't doing anything about it. I wasn't, to be honest, I didn't think that I needed this. I didn't think I needed the blue puffer either, so I didn't use it, and I just plodded on."

The 'wake up call' for Mervin was when he went to blow out a lit candle and found that he had not got enough breath to do it. At this point, he started to take more of an active interest in how his COPD was progressing. He recalled in his comments:

"This particular morning, I hadn't burned the candle out. So when I woke up in the early hours, I went to blow the candle out, and I couldn't. I hadn't got enough puff to blow the candle out, and that was then that I really realised, because I don't know whether I'd been shallow breathing... and I thought, 'Wow', and then suddenly I thought, 'Jesus Christ alive, my lungs are really bad'."

"At first, I wasn't aware of that sort of thing [the saturation tests, etc] when they were taking them. But, over a period of time, I started to realise that I wasn't as good as I used to be. Then, I started asking questions like, 'Well, where was my saturation then? Oh, so, OK, alright. So it's dropped to there. Oh really? Has it'. And so I started to learn."

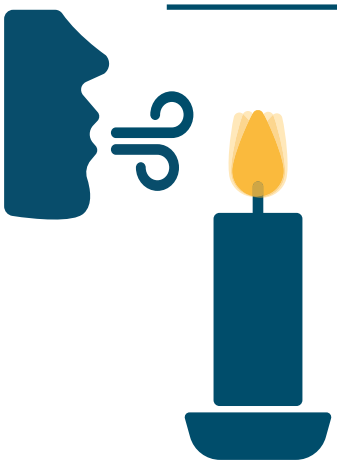
Attitude to COPD and support

Mervin felt frustrated that people assumed a COPD diagnosis is a direct result of a smoking habit. He said that he was only ever an occasional 'weekend' smoker, and while he understands that smoking may have contributed to his COPD, he does not consider it to have been the primary cause of his condition.

"Because obviously one of the things they ask is if you smoke and I said 'yes', but I wasn't a big smoker in the first place... So, I was only an occasional smoker. I say this to you because it frustrates me so much when everybody assumes that, if you've got COPD, you've been a smoker - that it's caused from smoking. That's the first assumption that people have. And I absolutely did not get my COPD from smoke. It might have aided it, but that certainly wasn't it."

Mervin feels quite well supported with his COPD by healthcare professionals. He considered his GP a 'friend as well as my doctor' and received contact from the Community respiratory nurses. However, he also reflected that there had been inconsistencies in the advice he had been given about taking medication, particularly the need to rinse his mouth after using his inhalers. He shared his experience:

"I've been suffering with [a fungal infection



"I went to blow the candle out, and I couldn't. I hadn't got enough puff to blow the candle out, and that was then that I really realised...

'Wow'... my lungs are really bad'."

> "...When I saw the COPD nurse, she said, 'Didn't you know that when you use your Salbutamol, you should always rinse your mouth out, and gargle your throat afterwards?'
>
> **...Because there have been times in the last six or seven years where I've probably used it 30-40 times in a day... And I said, 'Well, nobody's told me this'. I was shocked.**

in my throat] for, I don't know, two or three years... When I saw the COPD nurse, she said, 'Didn't you know that when you use your Salbutamol, you should always rinse your mouth out, and gargle your throat afterwards?'...Because there have been times in the last six or seven years where I've probably used it 30-40 times in a day... And I said, 'Well, nobody's told me this'. I was shocked.

"And then recently, only in the last few months, I was told by a doctor at the hospital, 'No, no, no, Salbutamol, don't make the slightest bit of difference. You don't have to gargle with Salbutamol'... And I'm thinking to myself, well, that makes sense because I've been using it for years, so it's the steroid one that I've been using recently that's causing the problem. And that's quite important because I've been really suffering with that."

In addition to the support from his healthcare team, Mervin clearly relied on the support of his wife. For example, she helped him with using digital technology, took him out to socialise, and prompts him when he cannot easily recall things.

"I have a very bad memory, so that's why [my wife's] still in the room rather than getting on. I asked her to be here in case I needed her to remind me."

Pain and anxiety, resulting from his various health issues, had stopped Mervin from socialising as much as he would like and this conflicted with his ideal self-image and what he thought others might expect from him. He described how this had impacted his pride, and therefore also his confidence and memory.

"I'm a very outgoing bubbly person... I like to talk. But because I've had a lack of socialisation, I've lost the ability to have a conversation... It's actually quite sad because I was very outgoing and I was often out socialising and now I never do.

"I'm 66 next birthday and I know I don't look it.... But if you look so well, people don't get the fact that you really are not good. Because although while I'm sitting here, I look a million dollars, I am very, very limited to what I can do. So, knowing that I have to pace myself, and then when I go out, I got so many issues, you know, going into the loo, not being able to stand up very long, if they want to walk down to the next public house or the restaurant, I can't park there."

Mervin is supposed to be on oxygen therapy for 16 hours a day but says it is rare that he gets this amount. He is conscious of how he looks when wearing all of the tubes and the noise of the machine.:

"I never get 16 hours. I generally get about 12, sometimes 13. I should be sitting on it, quite frankly right now, while I'm talking to you. But I don't. This doesn't look nice. I'm sitting here with the tubes in, and I'm aware of that... They are noisy and an eyesore."

In terms of other steps taken to manage his COPD, Mervin has tried a couple of support

groups but did not find them helpful. He felt that he did not 'identify' with the other members of the group:

> *"I went to a couple of support groups, but I didn't finish them. I found them not helpful. They didn't do anything for me. I didn't find that there was really anyone that was remotely like me there for a start. Everything that I got was so different to most people. Most of the people that I saw there were just, I have to say, were smokers and a lot of them still were. A lot of them were still smoking. Yes, crazy as that sounds."*

He has also attended pulmonary rehabilitation twice, with mixed results. While he has found it helpful as a reminder of what exercises he could be doing, he also felt that it did not align with his own levels of physical fitness or abilities.

> *"As far as the exercises and things that they were teaching... they were, far less than what I would do. And the thing was, some of the exercises... I couldn't do, because of the state of my back... but at the same token, I had got an awful lot more exercises that I do that are as good and probably better. We discussed it; they got that wasn't something that was going to help me... It was very interesting because there's things that you forget, and it's good to have them sort of reconfirmed and put back into your noggle."*

When asked how he would have liked to have received information about COPD, Mervin felt that he had been given all the information he needed at the right time. He felt that it was important that information was offered in person. However, he reflected that having something in writing that can act as a reminder can also be helpful.

> *"I think I got the information at the right time... I don't think there's anything really more that they could have done for me.... I think there's got to be something that someone's going to sit you down and say to you and tell you. But then, I think it would be nice to have something there to give you a briefing as to 'don't forget, you still need to do that, and keep an eye on that'."*

Although Mervin is currently up to date with his annual vaccinations, he is hesitant about having any further COVID jabs. He expressed scepticism about the effectiveness of the vaccinations and worried about the pace at which they had been developed. He believed that the vaccinations had caused him to have other illness. Examples of his comments included:

> *"I haven't responded to the new COVID jab. This is the first time, but because I've had four already, there's a part of me that says you might as well just carry on with it now, but there's another side of me that's not convinced... I was pressured almost, I suppose. I had letters, and I had texts and stuff from my surgery, and then people were saying, 'Christ alive, you can't afford not to get it'.... But I had the first one reluctantly. I have to say, but I did.*

> *"But, do you know, I have seen and heard so many people that have had bad reactions from having the injections.... And, in all my years, I have had the strangest cold on two, if not three, occasions in the last two years that I've never had in over 60 years. I've never had anything so bad, so long lasting, so much mucus. And the amount of people that I've spoken to that have had the same, that have had the injections."*

Managing exacerbations

Mervin shared a copy of his COPD plan, explaining how useful it had been for monitoring any changes to his lungs and breathing and helping him understand what steps he should be taking.

> *"This is my red alert, green alert and amber alert, for anything that's going wrong in my chest or in my lungs. If you've got any doubts, just have a little look and think,*

'Is that happening to me now? Yes. I'm going to have to keep an eye on that now', and then if that sort of moves on a little bit further onto that stage, there we go... [Interviewer: and do you refer to that then, to check things?] Oh, Christ alive, absolutely."

He described how his COPD was affected by extremes of temperature. He also felt that he was affected by pet hair, however, he said that his dogs were his 'babies', and provided a level of security for his property.

"So, I do get more chilled in the colder weather than I ever used to... The temperature makes a massive difference. Anything below 8° for me is a no-no. I mean if it's below 10° and I have to walk up to my workshop... I I'd have to try and hold my breath. And maybe just breathe once before I got to it and got in there."

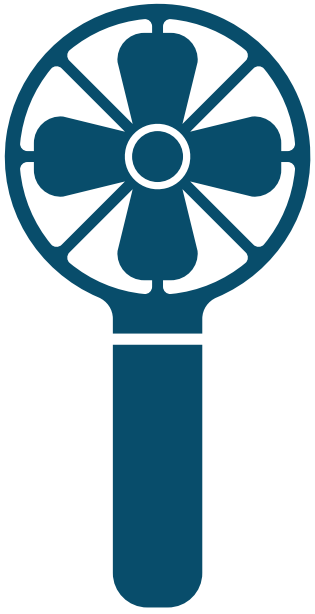
"At the same token, not only is the cold a problem, but also the heat is too... When we had the really warm weather last year, I think it was last year, I had to sit in here. I didn't go out of this room for two weeks... and I just had the air conditioning blowing on us."

"Everyone produces dust, but dogs produce even more. But they are our babies. And we've got a large property, so we need dogs that are going to make sure that, you know, help. We've got cameras too. You know, the dogs, we need them."

The one thing Mervin thought would help people to manage their COPD better was a hand-held fan.

"I've got these everywhere. I have got two hand-held fans in my car. There's one in the kitchen. There's one in my bedroom. See that little hand-held fan?

"When you're getting slightly breathless, or it's warm, you need to have a hand-held fan that you can tilt just to blow into your nose... and that will save you more than anything will. That is the biggest thing that I can give to anybody that suffers from COPD that is breathless. That is absolutely the bible. That is a lifesaver. They're very, very good for people that can't breathe."



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"That is the biggest thing that I can give to anybody that suffers from COPD that is breathless. That is absolutely the bible. That is a lifesaver."

Sheena's story

"I need somebody to talk to, to talk me down, when I'm in that situation, but there is no one."

Background

Sheena is female and aged 62. She lives alone, in a ground floor council flat in Ipswich. She has lived there the last seven and a half years. She moved to Ipswich to be close to her son, but he later moved away.

Sheena has no other family living in Suffolk and she says she only has one friend.

Sheena used to work in a supermarket on customer service desk/kiosk but says 'they got rid of me through medical grounds. I wasn't fit enough for work'. She is now on benefits and receives a Personal Independence Payment. In addition to her COPD she has a number of other health conditions, including arthritis, and uses a walker if she is going out.

Understanding of COPD and diagnosis

Sheena was diagnosed with COPD over 10 years ago. She reported a mixed experience of diagnosis, saying that she did not receive a clear diagnosis of COPD at first. She had a little bit of understanding about the condition, as her mum also had COPD.

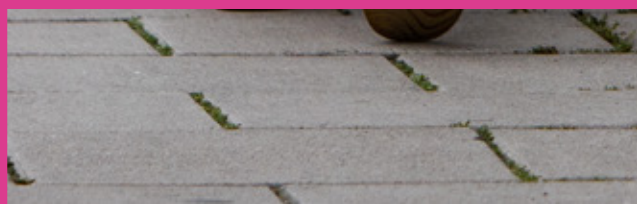
She had also spoken with her practice nurse about COPD, however she said that no one mentioned pulmonary rehabilitation to her at this point.

> *"They didn't say exactly I had COPD. They said I'd pigeon lungs. And the specialist refused to see me because I was smoking. I didn't know, did I? I didn't know. So the young doctor, come over, he said 'he's refusing to see you, but you've got COPD. Your lungs are all blah, blah, blah'. He said 'we'll send the letter to your doctor'. So that was the start of it. And it's just got worse."*

> *"Later on I spoke to this nurse, who'd just done a course on COPD and she was telling me, you know, all about it, but she didn't mention exercising. Nobody mentioned*



> **"The doctors, I don't even bother with them anymore because they're useless. Phone them up. You speak to somebody that's not a doctor. They don't read through your records or anything. And you don't get anywhere."**



exercising until I did the pulmonary rehabilitation."

Experience of accessing care and support

Sheena was currently waiting for a hernia operation however, following an appointment at the hospital the anaesthetist had put this on hold until her breathing was optimised.

Sheena says her GP was asked to refer her to the pulmonary specialist. However, he had decided to send her for pulmonary rehabilitation instead. While Sheena was generally 'fine' about attending pulmonary rehabilitation, she did not understand the reasoning behind this decision. She was not convinced that attending pulmonary rehabilitation would help with getting the hernia operation.

"I'm waiting for an operation on my hernia... They wouldn't do the operation because of my breathing... So they wrote to the doctor to say they had to make an appointment for me at the hospital to see the pulmonary specialist. But my doctor decided no, he's not going to do that.

"He's sending me to the pulmonary rehabilitation, which is what I'm doing. Which is fine because it gets me up, it gets me doing things but I just can't understand why the doctor [has done that]... I can't have an operation unless my breathing's sorted out... so what am I supposed to do? I put in a complaint. They just totally ignored it, not written me back and I've not heard nothing."

Overall, Sheena is not satisfied with the service or support that she has received from her GP practice.

She is reluctant to engage with them about her health, as she says it is 'pointless'. Furthermore, she felt that she had not received the support she needed when she had been to hospital. Based on this experience, she said that she would refuse to go to the hospital.

> "I've sort of become a couch person...
>
> **"That's why going back there [to pulmonary rehabilitation] has boosted me up a bit... It's the same stuff [exercises] but you're with people and it motivates you."**

"The doctors, I don't even bother with them anymore because they're useless. Phone them up. You speak to somebody that's not a doctor. They don't read through your records or anything. And you don't get anywhere. And you put in a complaint, you don't hear back from them. And to be quite honest, the way they treat you. It's just disgusting really."

"I refuse to go to hospital. The people that I've spoken to with COPD they all say the same thing. You go to the hospital, they send you away with a rescue pack. What is the point? Sitting in the hospital for hours on end just to come out with what your doctors can just give you."

This was the second time that Sheena had been on the pulmonary rehabilitation course. She said that while she cannot do some of the exercises, because of her mobility issues, she finds that attending the group was helping to motivate her and get her out and about. However, she also noted that she did not do the exercises given to her at home, as she already had an exercise routine that she followed called 'Lazy Fit'.

"Last year I was doing me exercises, I was doing the 'Lazy Fit'. It's on the computer. And that's all sitting in the chair, yeah. So,

I can do as much or as little as I can. But once my breathing started going and my hips started going, I couldn't do it anymore. So, I've sort of become a couch person. That's why going back there [to pulmonary rehabilitation] has boosted me up a bit.... It's the same stuff [exercises] but you're with people and it motivates you."

Social, mental health support and hospital admissions

Sheena experiences anxiety and depression. She has also had several panic attacks, particularly during acute episodes with her COPD.

She spoke about the importance of having someone to talk to, to help calm her anxieties down. However, she reflected that she could often feel isolated from family and friends. Being on her own, and attacks often coming late at night, meant that Sheena often didn't have any personal support to help her through these episodes and has looked to the ambulance service for help.

"See my problem is I get panic attacks when I can't breathe. The ambulance service is brilliant. The last few times, when I've had these breathing problems, I couldn't even get out of bed. That's how bad I was. And I actually just about made it to the toilet. And I couldn't get off the toilet. I could not. So I sat there and I remembered all my breathing exercises. But the palpitations are still going and then you start going into panic mode because you think 'I'm not going to be able to breathe'.

"I've phoned 111 And I said, 'I'm not going to hospital because all they do is give you a rescue pack and send you home'. And ambulance liaison person phoned me back and she went 'I'm going to send a paramedic out'. He come out and he just talked me through it and he talked me down."

COPD and Lifestyle

Sheena has been advised to give up smoking but has found this difficult.

She has been offered different forms of support in the past but has not really found anything that has helped. She confessed that she did not always tell the truth about her smoking, when talking to health professionals, because she didn't want 'all the earache'.

"[The Doctor] told me to give up smoking..... Easier said than done. I gave up a few months ago for six weeks and then my brother died. I started smoking again. But I know I've gotta give up. But it's so bloody hard doing it."

"I know a lot of people that have got COPD, they say 'I always tell the doctor I don't smoke'. I said 'But you do!'.... Cause I don't want the earache. Do you know what I mean. I know the situation. I know I should give up."

> "I need somebody to talk to, to talk me down, when I'm in that situation, but there is no one. I can't phone the Samaritans. So you need somebody there at the end of the line that's gonna help you down. Whether you're having a panic attack or not.
>
> **"But it helps with your breathing if somebody's talking to you. I don't know why but it just calms you down."**



"[The Doctor] told me to give up smoking... Easier said than done.

"I gave up a few months ago for six weeks and then my brother died. I started smoking again. But I know I've gotta give up. But it's so bloody hard doing it."

Medications, vaccines and management

Sheena's COPD is affected by dust, pollen and the weather.

She has been taking an antihistamine nasal spray but has had to give this up as it was causing her nose bleeds. Sheena has had access to rescue packs in the past, however she was no longer using the steroid medication for emergency purposes only, but when her breathing was bad.

She now has to request an appointment with her GP every time she needs a rescue pack. Sheena has had all her annual vaccines but said that she had not been offered a shingles jab, despite having had shingles more than once. She has received annual check-up from her practice nurse.

> *"They keep giving me this spray for my nose which I've just found out I shouldn't be using because of me breathing. So, I've stopped taking me antihistamines because I started getting really bad nose bleeds but it's like I'm in between a rock and a hard place."*

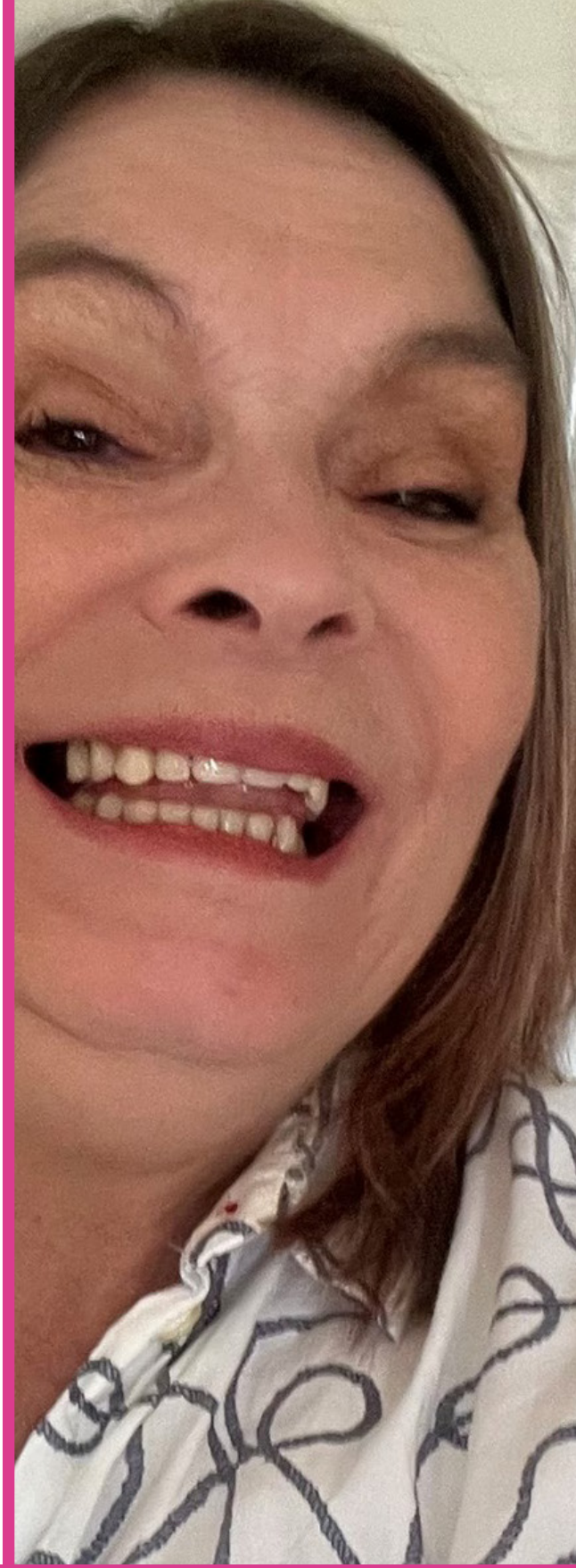
> *"They won't renew them [the rescue pack] automatically. Especially now I'm using them not for rescue. I'm using them because my breathing is bad... I've got a rescue pack and I've got the antibiotics but I've used up the steroids, so I've got to phone that bloody doctors... The doctors are a waste of time and I keep asking for steroids. 'Oh well we can't just keep giving out steroids'. And I said, 'well, what are you gonna do?'"*

When asked what one thing would help people with COPD to manage their condition more effectively Sheena said:

> *"I think if there was someone like that paramedic who could talk to you either by phone or come round to help. Maybe suggest things and, you know, just check you over... Just reassure. Because that's when it hits people. It's the reassurance that they need. Instead of going to hospital because, let's face it, no one wants to go to hospital."*

Michelle's story

"I'm luckier than most I've got my husband and he's absolutely brilliant. He does all the cooking, he walks the dogs. I mean, I would not be able to do as much as I do, without him doing as much as he does."



Background

Michelle is a 58-year-old woman. She is retired and lives with her husband in east Suffolk.

Roughly 16 years ago, Michelle visited her doctor (in Essex) because she had a chest infection. When the infection cleared, she was still experiencing difficulties with her breathing and was diagnosed with asthma. However, another doctor later changed her diagnosis to COPD.

She felt COPD had not affected her much for the first five or six years following the diagnosis. She was very confident in her knowledge of her own condition and felt she could recognise actions she needed to take to avoid her COPD getting worse. Examples of her comments about managing her COPD included:

> *"It's all come on quite slowly. It wasn't really affecting my life. I was still working in London. I was still doing all what I was doing. It didn't really affect my life for a good five-six years so."*

> *"I've been living with this for so many years now. I know within five minutes of getting up in the morning what my lungs are doing and what my coughing is, and if I'm bringing up stuff that I shouldn't. I know what I'm looking for. I know exactly what I need to do and if I need to start antibiotics or steroids."*

> **"I have the local COPD team who come out to me and they're brilliant, they are so good. I mean they keep me out of hospital so many times a year because they come out either every day, or every other day, whatever is needed."**

Support for COPD

Michelle did not often suffer from chest infections but did experience flare ups of her COPD. She managed these with the assistance of the local COPD team, who she credited

"If anyone hasn't done it (pulmonary rehabilitation), it is very useful because they go through all the medication side, the technical stuff, as well as the bits that will keep you healthy and keep you well. So it is appealing.

"I don't know if I'd want to repeat it, I don't see the point. There's only so much they can tell you, and I do exercise."

with keeping her out of hospital and avoiding unnecessary and lengthy hospital stays. She also reflected on how her recovery from flare ups was quicker out of hospital settings. Her reflections on her treatment from the COPD team included:

> *"I have the local COPD team who come out to me and they're brilliant, they are so good. I mean they keep me out of hospital so many times a year because they come out either every day, or every other day, whatever is needed.*
>
> *"They monitor and they do the tests at home and I recover better at home… And I am a very light sleeper anyway, and in a hospital I just don't sleep. There is just too much going on. So, if I go into hospital, I tend to be kept in for a long while because things don't get better. But when they come out to me here, I'm always signed off within a week so.*
>
> *"I find it more helpful that I can call them if I need them…. Then they get me through that flare up, and then they sign me off… I don't know if every health authority has teams like that, but I'm grateful that Suffolk has. The nurses stopped me going into hospital about three or four times a year."*

Michelle had attended pulmonary rehabilitation twice, once in Essex and again when she moved to Suffolk. At the time, she found it to be very beneficial. However, as she had lived with the condition for so long, she felt there was no benefit from additional sessions. She emphasised that she took steps to stay healthy, including keeping fit and prioritising sleep. Examples of her comments included:

> *"If anyone hasn't done it, it is very useful because they go through all the medication side, the technical stuff, as well as the bits that will keep you healthy and keep you well. So it is appealing.*
>
> *"I don't know if I'd want to repeat it, I don't see the point. There's only so much they can tell you, and I do exercise. I do try to keep fit, I do eat well, I exercise. I try to sleep well, you know, I try to look after every other part of my health. And I know the technical side of it too. You sort of live and learn, don't you?"*

She felt that one of the benefits of pulmonary rehabilitation was the one-to-one time participants had with the physiotherapist. She felt face-to-face sessions were probably more beneficial than simply reading the information online or in a leaflet.

> *"The physiotherapist went around and showed you exactly how to breathe from the diaphragm and where to put your hands to feel that you're breathing properly. I mean, you can read up about it all you like, but when someone actually shows you how to do it, that really does help."*

Michelle had an annual COPD review at her GP practice, but she felt the nurses can lack

a depth of knowledge about COPD. She had found the advice and support provided by the COPD Community Team nurses to have been more useful in helping her manage her condition.

> *"I do have an annual COPD check. The nurses are brilliant, but they aren't specialist nurses and so they don't really know. They just check your inhalers and check that you're using them properly. I'm lucky to have the nurses come in, which are much specialised and I get much more information, much more help, more things that I can do to help myself. But I live in a tiny village. We've got a surgery that's open on a Monday and a Friday. My husband is diabetic, and he doesn't see a diabetic nurse here."*

MH also highlighted that annual checks only happen when the patient is feeling well enough to attend the surgery. Therefore, the nurses do not see people at their 'worst'.

> *"Chances are you're not going to have a check when you're having a bad flare-up because you'll cancel the appointment. There's no way you're going out to do breathing tests when you're having a hard enough time stringing a sentence together."*

Managing COPD

Michelle reflected on how exhausting it was to live with COPD, and how it affected her energy levels. She noted that her COPD was affected by the weather, particularly damp conditions.

> *"I don't think people quite realise how exhausting it is to continuously cough. You know it wears you out. So, by 8:00 o'clock in the evening, you're exhausted from coughing, your ribs hurt, your back hurts all the rest of you. Everything feels that little bit worse, doesn't it? You know, if then if you have another night where you can't sleep, because you're coughing, and then it just snowballs, and that causes a lot of my flare ups. It is where I've not been able to rest properly."*

Michelle said that she was fortunate to have savings that she could use to heat her home and buy fresh food. However, she recognised that money worries could be a huge source of stress and anxiety for many people with COPD. Examples of her comments about the impact of living with COPD on managing her finances included:

> *"The cost [of heating] has doubled in the last couple of years... We've just used our savings to pay the bills, but you know if it is too cold, I get ill. It's as simple as that.*

> *"We've got a bit behind us, so we've got the resources to make sure we eat well, to make sure the heatings on, to pay someone to come in and do my garden if I can't get to do it. Stress is something that really triggers COPD, so if you're worrying about how you going to feed yourself for the week or how's the housework's going to get done or who is going to walk the dogs,*

"I do have an annual COPD check. The nurses are brilliant, but they aren't specialist nurses and so they don't really know. They just check your inhalers and check that you're using them properly.

"I'm lucky to have the nurses come in, which are much specialised and I get much more information, much more help, more things that I can do to help myself.



"These bits that other people do; without them, things would fall apart quite quickly."

these things they can really exacerbate your COPD."

In terms of managing the physical symptoms of her COPD, Michelle said she used the breathing techniques she learnt in pulmonary rehabilitation. She also said that she avoided temperature extremes by heating her property to a constant temperature night and day.

"I use the envelope technique when breathing. In the winter, I keep my heating at a constant level because going from one extreme of temperature to another can be difficult. So my heating stays on 21, night and day, every day."

She had learnt the importance of pacing herself, listening to her body and adjusting her activities. However, she said that on days when she felt good, it was easy to overdo things and push herself too far.

She built recovery time into her daily routines, but also felt that sometimes she had little choice, and simply had to keep pushing herself to keep going. This could be particularly difficult when supporting someone else, for example when her mum was in hospital.

"I never go out two days on a trot. Never. Even if it's going to the local shop. I would do that one day, then stay in. I can't do two days on it. I need that recovery time. I never used to, but now I do.

"[Mum] was in hospital for two weeks and trying to get to the hospital every day for 5-6 hours. I just couldn't do it. I had to call my sister because I'd done five days on the trot, and then I just couldn't do it anymore. Which is horrible, because it's my mum. You know you want to be there. Sometimes you've got to push yourself because sometimes you haven't got a choice, you have to do it."

Michelle felt grateful for the network of support her family and friends provided for her. She said that her husband supported her by cooking and walking the dogs. Her neighbours helped by mowing her lawn, and she paid for help with her garden. She said that she would not want to manage on her own.

"I've got a lot of people that help me stay well because they take on a lot of the things that I can't do. Not everyone's that lucky... These bits that other people do; without them, things would fall apart quite quickly."

J's story

"I just got used to being very chesty, I just thought that was normal for me."

Background

J is a 64-year-old woman. She lives in a house on a small estate in Ipswich. She is married with two grown-up daughters (both in their 30s). She also has grandchildren, who she looks after once a week.

J recognised family life can present a unique challenge for people living with COPD.

> *"I have my grandkids, and unfortunately, they pick up so many things... with the best will in the world, you pick up things from them. Mine don't just happen to be a cold. It'll either go to sinusitis or the cough, which then I know if the cough doesn't stop, I need to phone up. I haven't necessarily got an infection, but they will treat it as infected because of the cough, which just gets so big."*

Health and fitness

J led an active life. She was a gym member before she gave up full-time work. Since retirement, she had set up a gym in her garden and regularly used weightlifting and cycling equipment. She walked every day and attended pilates and yoga classes at a local gym.

> *"I'd always gone to the gym. I like to work out... I do like to lift weights and try and go walking every day and cycling. And yes, I do keep active... I've now since joined another gym. I go once, twice a week for that one, just to use gym equipment and to get out really. You know. I've always done something since I was 16."*

> *"I do [an online] class called body pump and a class that helps to keep the muscle mass up because you really do lose so much as you go on with age and having osteoporosis. And due to wastage in my leg, I do try, and so I've always done weights for my health as well as my mental health. I've always done a lot of exercise. You know as much as I can."*



"I have my grandkids, and unfortunately, they pick up so many things... with the best will in the world, you pick up things from them.

> "My husband said 'what are you trying to prove?' and I thought 'you're right, listen to your body more' but part of me thinks, 'you don't want to give up because if you give up, if you pull back, are you going to lose what you got?
>
> **"But you're fighting a losing battle anyway because your age is increasing. It's finding a happy medium, isn't it."**

Overall, fitness was very important to J and she was proactive in maintaining her fitness regularly. But she was also worried about the future and how reducing her activity levels may affect her wellbeing with age. She said that she also found exercise benefited her mental health.

> *"In the summer, I find all of this so much harder on my body. So I've cut the gym down to once a week instead of twice. I get so tired with it. My husband said 'what are you trying to prove?' and I thought 'you're right, listen to your body more' but part of me thinks, 'you don't want to give up because if you give up, if you pull back, are you going to lose what you got? But you're fighting a losing battle anyway because your age is increasing. It's finding a happy medium, isn't it."*

> *"If I can walk every day or and do a little bit of exercise. I'm happy with myself within myself. I'm quite a happy person. I'm retired anyway, so I don't have the stress and strain of the job that I used to have. So, I do try and keep my cup is half full' and do the best I can."*

J felt that her level of fitness and determination has meant that she has often been able to push herself beyond what most other people in a similar situation could manage.

> *"I walked in [to the hospital] and they got me a wheelchair. They said for my levels I should never have been able to walk in, but because I keep a reasonable amount of fitness... They said that 80% of people don't normally walk in with that [type 2 respiratory failure]. I mean I felt absolutely dreadful, but I could still walk."*

Knowledge and understanding of COPD

Having been diagnosed with asthma in her twenties, J has often accepted that being 'chesty' is simply a part of her norm, whilst others around her have noted fluctuations in her condition. Examples of her comments about her breathing issues through her life were:

> *"I just got used to being very chesty so many times, I suppose. And you get to think, 'That's normal for me'. And then when you're admitted to hospital, you realise when the doctor comes to you and says you shouldn't be living like this, you know you should see this for what it is, and you can't be admitted too often with this, without having serious consequences."*

> "...they said that 80% of people don't normally walk in with that [type 2 respiratory failure].
>
> **"I mean I felt absolutely dreadful, but I could still walk."**

"I was getting very tired. And I've never realised just how much… I think all my friends have since said to me, we've always known just how ill you've been over the years. Well, I've got a chest problem, and sometimes I can be about, but a lot of the time, if I get like cold, I might not be around for the next two or three weeks because that's how it gets me."

J's father had also had COPD. Despite having some knowledge and awareness of the condition, J had always thought that it was only people who smoked who got COPD. She was unaware of any possibility that her asthma could develop into COPD.

"I don't know how long I've had COPD. When I look back, quite a few years, I should imagine. But I didn't even open myself to thinking that I would have it.

"My father had it, but he smoked… I've always had chest problems. I never thought for one minute that I would go from asthma to COPD because I didn't smoke, and I always thought people who smoke got COPD, but apparently not."

Having completed some research online, J now feels that there were warning signs about her changing health (e.g., issues with sinusitis and hernias) that could have been picked up on earlier, but were missed by services.

"I go online a lot to look at a COPD site in America, and I've learned a lot… It's quite surprising about the correlation between sinusitis and COPD, you know that threw that up, and I thought 'Oh, that's another red flag'. You know, I've had a hernia repair, because of my cough, before I was diagnosed with COPD. I've had asthma since my early 20s. Yeah. And the cough has been hell all my life, really. And you just think, why didn't somebody say a few years ago 'Look, this medication isn't working. You ought to go up on something else'."

A 'wake up' call came three years ago when J was admitted to the hospital with type two respiratory failure.

"It'll be three years, just over two Decembers ago, that I was admitted to hospital… We went for a normal walk and I couldn't keep up with [my husband]. When I got back, apparently, I was very vague… And I just kept waiting for a doctor to ring me back, but they never rang me back that day. So [my husband] rang 111. And before I knew it, I was over the hospital and I was in there for 5 ½ days under ITU and had Type two respiratory failure. So, that was quite a wake-up call… it was quite scary at one time for my husband, I think. Well, for myself too, but more I think for people looking on, you know."

Support from services

At times, J has felt 'let down' by her health services. She does not feel she has always been listened to or trusted to use or access medication (rescue packs) appropriately. She has also felt that there has been a lack of 'join up' between her hospital team and primary care.

"It took me a long time to get diagnosed. You're just fighting a losing battle against



I never thought for one minute that I would go from asthma to COPD because I didn't smoke.

"I always thought people who smoke got COPD, but apparently not."



> ***"You are just recognised as a cranky old woman who's maybe given up her job in COVID, bit menopausal - so it's gone to her head a bit, mentally wise - and that's how you feel perceived. So, then you just sort of shut up a bit and think, well, I don't want antidepressants for it. I just want you to see my chest for what it is."***

trying to get things done for yourself without them beginning to see you... you've got mental health issues because you're menopausal and you're in your 60s. You've just retired, and you're taken badly to this... But God, that's been such a fight to get what you need.

"You are just recognised as a cranky old woman who's maybe given up her job in COVID, bit menopausal - so it's gone to her head a bit, mentally wise - and that's how you feel perceived. So, then you just sort of shut up a bit and think, well, I don't want antidepressants for it. I just want you to see my chest for what it is."

"Please, can I have what the doctors at the hospital said I need'. They were so good at telling me what I needed, but I wish they could have relayed that to the doctors. "

"We've got a caravan. We want to go away when we can. But I do not want to go away without my standby medication because I realise how important it is. [They say], 'Well, we don't want you to have too many steroids', but if you look at my records you will see when I used to have standby tablets 20 odd years ago, I wouldn't take them willy-nilly."

J attends her GP practice for a COPD review every year, but her experience has been inconsistent. Whilst sometimes this had simply felt like a 'tick box' exercise to get access to prescription medication for the year, her most recent review had been very useful, particularly as she felt the nurse had listened to, and acted upon, her concerns.

"I told her that when I went to Madeira last year, I found it very hard to cope with the weather, and I said my chest felt like it was just pressing down all the time. And when I explained to her how I felt. She said, 'I think you need to move up on your medication'. So, she's given me a higher-strength inhaler and gave me an extra one, too. That's made me feel so much better. She was really good, but then if you try and get them for the following year it doesn't always seem like you can. You just get the one who's there today. So yes, sometimes it can be good. Like last year. I was very impressed, other years I come away thinking 'well, at least it's cleared me for another year, so I can get my prescriptions,' and that's about all I can think of it really."

"Couple of times I've gone [for my annual review] and because I've had steroids within three months of going, they can't take my peak flow because if you've had steroids that would help peak flow to be increased - but they don't tell you that... they don't check your record to see if you've had them."

Although J had heard of pulmonary rehabilitation, she had been 'put off' referring herself because a nurse had led her to believe that her COPD was not bad enough. She did not want to take up a place from someone who may need it more. Having benefited from breathing classes in the past, however, J felt that pulmonary rehabilitation would be something she would like to try.

"A few years ago, when the sinusitis really got a hold, before I had a second op and I went to a Physiotherapist up at the hospital for a course of breathing treatment… That was exceptionally good, and I so wish I held on to it. And she did say at the time, 'You've got enormous trouble with it'…"

"They give me a card [about pulmonary rehabilitation]. But one asthma nurse said, 'But I don't know if you're bad enough for that. So, when she said it that way, I thought that I don't want to take up the place if there's a lot of people more ill with COPD than me, so I've sort of hung back.

"And, last winter, my hubby said you keep looking at this card and going on, and why don't you phone up. Surely you could use it as much as the next person. But no, I haven't done it yet, because I do wonder. I think am I ill enough?"

Managing COPD

J is increasingly aware of the things that might impact her breathing and has learnt to pace herself and adjust activities to suit her energy levels. She has become adept at proactively monitoring her condition and practices self-care when she feels it can help.

"I'm not very good in the heat. I just haven't got the same power I used to have in the heat. I get extremely tired in the heat. Now I do recognise that. So yeah, I take my peak flow. I take a blood oxygen reading. I've learned how to do that now.

"The blood pressure thing comes with me because if you can self-help yourself, you know if you're going downhill. And if you could, you've got the measures to take stuff. Surely, that's for the better for you."

"Sometimes I want to go out and exercise. I get out, set everything up, start, and I think 'this isn't going to happen', you know, or you try and go for a walk and you think, 'Well, I can't do the hills today'. So you just walk slower, and you go on the pavement, you know that type of thing."

J has a very supportive husband. Not only has he encouraged her to maintain her fitness (e.g., by converting their summer houses into a gym, and cycling with her), but he also helps her to monitor her health, prompts her to 'listen to her body' and supports her to avoid situations that may impact her breathing.

"My husband is a keen cyclist. He got me a bike in my 40s, but I could never keep up with him. And he realised then, the level of what I could … So we have a tandem now, and I do what I can, and he does the rest. It's a good compromise as I've got older."

"A couple of times, my husband has phoned up my oldest daughter and just said, look, I'd rather not [have the grandchildren]. You've had [a cold], the children have got it. And you know, your Mum will just suffer so much more… We just said no for a few weeks and she understood that."

J felt that there needed to be better support for people with chronic asthma to understand the risks and signs of developing COPD. She also felt people needed more information at the point of diagnosis to understand things they could do to manage their condition effectively.

"Just better education, I suppose, and maybe them saying that you've had asthma since you're 20s, you're now 60s. Nobody ever says… maybe you have gone from asthma to COPD. Why don't they mention that in these once-a-year things?"

"If they could just give you more tips on how to do things, so you're not so alone, that would be good… I've found out what I know myself by looking it up online."

“Just better education, I suppose, and maybe them saying that you’ve had asthma since your 20s, you’re now 60s.

“Nobody ever says... maybe you have gone from asthma to COPD. Why don’t they mention that in these once-a-year things?“

H's story

"Give me the information when I'm first diagnosed so I can take it forward."

Background

H is a 72-year-old woman, and lives alone in a bungalow on the outskirts of Lowestoft. She moved to Lowestoft three years ago to be closer to her daughter.

H has two daughters – one lives in Norwich. Her other daughter lives just three minutes down the road. She has two granddaughters

H used to work for the civil service, in a customer facing role. Her job has given her a love of talking to, and connecting with, other people.

H's health and COPD

H had a major health issue three years ago where 'I ended up in A&E three times in two weeks and since then my health seems to have gone to pot.'

She has high blood pressure and high cholesterol and is type two diabetic. She also has back problems from a car accident she had 1981. She was diagnosed with COPD nine months ago.

H's father had COPD – he was a coal miner and had bronchitis, emphysema and pneumoconiosis. He also contracted a super-bug when he was in hospital which affected his lungs.

H was a smoker. Over her life, she has given up smoking on four separate occasions. The first time she tried hypnotherapy and gave up for six years. The second and third time she gave up through 'Smoke Free' using Champix, but neither attempts lasted long because she did not get on with the medication.

On her last attempt, H used patches provided through the 'Smoke Free' service and has not had a cigarette for the last four and a half years. She said that she 'will not smoke again'.



> **"I know doctor's surgeries are so busy, but they could have sat down with me and explained how to help myself and give me a leaflet. But there was nothing... They've showed me how to use the inhaler, then the rest is up to me."**



Managing COPD

Day to day, H says her COPD affects her ability to do household chores and walking up or down gradients. She tries to manage without using her Ventolin inhaler, if possible. She was up-to-date with all of her vaccinations.

> *"I get out of breath. Usually, if I'm hoovering, polishing, walking, climbing steps.*
>
> *"When I go down to the beach, come off the beach, there's either a slope or steps, and I have to take my time and I'm puffing and panting like a little engine by the time I've done it. That's really how it affects me. I try not to use my Ventolin inhaler."*

Although H felt confident about managing her COPD, it was apparent that she was not aware of some of the things she could do, or the support available, to help maintain her COPD effectively at home. She felt that it would have been helpful for someone to explain her options to her.

> *"I mean, I'm still confident [about managing my COPD], but there's quite a few things you've told me that I had no clue about. So you know it's that thing, where you don't know, what you don't know, until you find out, but you should know it."*
>
> *"It would have been very handy, for somebody to actually sit down... I know doctor's surgeries are so busy but they could have sat down with me and explained how to help myself and give me a leaflet. But there was nothing.*
>
> *"I came out of there thinking well I've done this reverse spirometry and they've told me that my lung capacity is a lot better using this inhaler. They've showed me how to use the inhaler, then the rest is up to me."*

Access to support for COPD

H had never heard of pulmonary rehabilitation. She was interested to find out more about it, as she thought it sounded like it would be beneficial for her. However, she said that she was limited by her ability to drive long distances. She also mentioned the cost of travel and parking would be a barrier for her.

> *"I could benefit from [pulmonary rehabilitation] but it depends where it is.*
>
> ***"I mean, I'm a pensioner. Yes, I do drive, but I try not to do a large journey and I try not to pay parking fees because pensioners are short of money."***

> *"I think that I could benefit from that but it depends where it is.*
>
> *"I mean, I'm a pensioner. Yes, I do drive, but I try not to do a large journey and I try not to pay parking fees because pensioners are short of money. If it's within easy distance, that's not a problem, but if it's like Norfolk and Norwich Hospital or Ipswich Hospital, I'm not prepared to go that far. I could do it online or via zoom and that sort of thing. But logistics, that's the issue with that. But if I can get there, I would certainly go."*

H has not experienced any chest infections or other acute episodes affecting her breathing since being diagnosed with COPD. She was therefore unfamiliar with rescue packs, what they contained or how to access them.

H was also not aware that it was recommended she should have a yearly review of her COPD (although she does attend her practice regularly for diabetes check ups).

> ***"It seems I was told I had COPD, and dropped. So I've not had any follow up of any kind."***

She was somewhat sceptical that, given how busy her GP practice was, this would happen anyway.

> *"It seems I was told I had COPD, and dropped. So I've not had any follow up of any kind."*

> *"I've got that with the diabetes because I have regular appointments and blood tests and such like. But nobody's mentioned [a yearly review] for COPD. I've just written it in my diary to check. So when it reaches a year, if [the practice] hasn't contacted me, I'll contact them."*

> *"[When you contact the surgery] you now have to tell the receptionist why you want an appointment so they can put you with the right person, and if I ring up and say I'd like to come in and have an annual review with my COPD, chances are they'll say, 'well, you don't need an annual review' or 'we don't do them' or 'we'll contact you when it's time'. So you know in theory, it's a brilliant idea [to have a review], but in practice, I honestly don't know if that's what they do."*

Information about COPD

Whilst H has tried to look up information about COPD online, she said that it is difficult to find things when you don't really know what it is you are looking for. She considered that she was responsible for managing her own health, but felt that this needed to be balanced with having the right information available to her.

> *"[I look stuff up online], just basic stuff. But if you don't know what you're looking for half the time, and if you search for COPD, you just get an explanation of what it is. You don't get an explanation of what they can do to help you or any exercises or whatever."*

> *"I understand that whatever happens is in your own hands. It's your health and you have to do what you feel is right for yourself. But if you haven't been given the information, how do I know what I'm doing is right for me? And I now know what I'm doing isn't right for me, because there's other things that I could be doing."*

H had a number of suggestions about how services could communicate to patients with information about their COPD. She felt that patients should be offered information at the earliest possible opportunity and at any follow up appointments.

She said that she would find leaflets, flyers and text messages with information about managing COPD helpful. She also felt that this could be a starting point to prompt patients to start gathering their own information online.

> *"There's several different ways that it could be done. It could be done with a leaflet to be given to a person when they first diagnosed, and the nurse or whoever it is just says I'm giving you this information about this course that might help you. You can self refer if you want, take it home and read it then if you want any help come back. It's simple isn't it?"*

> *"Text messages. They work a treat. It pings and you look at it straight away, don't you?"*

> *"Even if it's just a simple aid memoir that says: 'Thank you for coming today. We've*

identified you've got an issue with COPD. This is what we can do to help.' And then itemise it and just an A4 piece of paper, and give it to your customer. And then they take it home, then look on the Internet. I don't think it would be that difficult to do."

H felt there was also a place for providing simple information for family members to refer to if they are concerned about a relative with COPD.

"I would like to be able to give [my daughters] a piece of paper and say 'look, I've been told I've got COPD. I've got a piece of paper and an appointment to go for pulmonary rehabilitation. Can I give you this that says these are the signs to look out for and what to do if I have an episode... You don't want to give them all the information, but you want to give them as much information to say these are the signs to look out for. If it gets bad, this is what you do."

Exercise and making friends

H is restricted in how much exercise she can do because of her back issues, but she enjoys walking and has recently joined the 'wellbeing walks' organised through her GP practice. She particularly enjoys the social opportunities this offers and is hoping to develop new friendships.

"[I don't do much exercise] other than cleaning, but I don't do much because of my back. I can walk. I mean, I used to do long distance walking in my younger days and I could walk twenty mile in a day and not think about it. But now if I walk for an hour, I've had it, and that's usually about three miles. I'm thinking my back's killing, but my breathing isn't too bad, unless it's up and down slopes and steps and things. "

"I've started doing the well-being walk that's arranged by the surgery. There's four walks a month, I think it is, of varying lengths. I'm doing those as well now. Since I've started the well-being walks I started seeing some people that I've never met before and we're getting on like, a house on fire, so I feel like those acquaintances could well become friends."

"I would like to be able to give [my daughters] a piece of paper and say 'look, I've been told I've got COPD. I've got a piece of paper and an appointment to go for pulmonary rehabilitation. Can I give you this that says these are the signs to look out for and what to do if I have an episode...

"You don't want to give them all the information, but you want to give them as much information to say these are the signs to look out for. If it gets bad, this is what you do."

Carol's story

"There should be more exercise classes to help. It's alright saying but you've got the Sports Centre, but I don't know whether they do things for COPD. And I think we need specific classes for COPD."

Background

Carol is a 74-year-old woman, and is retired. She used to work with people with dementia but had to leave her job due to ill health (cancer) in 2011.

> *"I worked with people with dementia and I loved it. I was so upset when I had to leave."*

She lived in London, but moved to Mid Suffolk 12 years ago following a diagnosis of both lung cancer and breast cancer. C is in remission from her lung cancer, however she is undergoing investigations to see if she has skin cancer.

> *"I've got lung cancer and then not long after that I was diagnosed with breast cancer as well. I just, said life's too short, let's move and that's what we did. They're doing investigations because they think I might have skin cancer now. Yeah, just another thing to add to the list. I just take it in my stride now."*

Carol only became aware she had COPD five years ago after attending a pulmonary rehabilitation class. Until she had queried it with her consultant, she said that nobody had actually told her that she had COPD.

> *"I kept getting this chest infection and it was causing me breathing problems. I kept going to my doctors because the emergency pack of steroids weren't working. And so, they suggested this six week course which I went on. I never even knew I had COPD, and it was only because they said about the COPD at this class and then I asked my consultant and she says: 'Yes, you've got COPD'."*



"I've got lung cancer and then not long after that I was diagnosed with breast cancer... They're doing investigations because they think I might have skin cancer now... I just take it in my stride now."



"Someone's never explained it to me, [what I should do to manage my COPD].

"But it's just a matter of learning by experience. If I'm cleaning the windows and I get out of breath, I stop. I can push myself so far, but I know actually when to stop. And also I've got a husband to tell me when to stop."

Managing COPD

Carol said all of the information she had received about COPD and how to manage the condition had come from that one course.

> *"I didn't know anything about [COPD]. When they sent me to these exercise classes because of my breathing and because I kept getting these chest infections, that's actually when I learned about COPD. But I wouldn't say I'm on top of it. I wouldn't be able to just go out and explain to someone what it all meant and what it all involves."*

Day to day, Carol's COPD affects her ability to do many everyday tasks, from cooking, to cleaning and getting dressed. She has learnt over the years to pace herself and set herself achievable targets. Examples of her comments about managing her physical symptoms included:

> *"I'm not too bad but there are certain things I cannot do... I can do a bit of housework, but not much. Like, I can only mop a certain amount and then my husband takes over... Getting dressed can take me a while, but I manage, unless it's a really bad day and then my husband helps me. I go walking. But I'm careful of where I walk."*

> *"Someone's never explained it to me, [what I should do to manage my COPD] But it's just a matter of learning by experience. If I'm cleaning the windows and I get out of breath, I stop. I can push myself so far, but I know actually when to stop. And also I've got a husband to tell me when to stop."*

Carol was grateful for the support she received from her husband. However, she said she finds that he worries too much about her, and that she would sometimes like the opportunity to try and do more for herself. Carol felt that it would be helpful for relatives of people with COPD to attend pulmonary rehabilitation classes so they could learn about the condition together. She felt this would give her husband more of an insight into what she is capable of doing for herself.

> *"He worries too much, which is lovely but the trouble is, sometimes it [is] just overpower, and sometimes I think: 'Just let me try it on my own'. I think that's the hardest part, they try and do things for you where you know you want to try and do it yourself, but they worry for you."*

Support for COPD

Carol has had all her annual vaccinations. She has not however had an annual review of her COPD for at least two years. She had meant to chase up with her GP practice, but said she had a lot on at the time of her interview.

Carol's GP practice had suggested she might like to repeat the pulmonary rehabilitation course. She was keen to do so to check that she was doing everything right. However, since she put in her self-referral form, she had not heard anything back.

"I must admit with the [Breathe Fit] classes we do it's really lovely to have the people around because they will push you as well which is really nice.

"[We] tend to just walk around slowly, but you'll get someone saying, come on, let's just do this and sort of march you off, which I think has really helped."

"I just wanted to go, to check up that I'm doing everything right really, but I haven't heard. I must get in touch and see what's going on."

Last September, Carol was admitted to the hospital because of a chest infection, which had not responded to the emergency medication. She was discharged home as a 'virtual ward' patient. She described this experience as 'brilliant' because she felt more at ease at home, but still felt very well supported by her healthcare team.

"I had a chest infection, and you get your emergency stuff and it didn't seem to work. After a couple of days the steroids usually kick in but I wasn't feeling any better, so I went around the doctor's and next thing I'm in an ambulance, off to hospital. Apparently my breathing was really low, so oxygen levels really low. So yeah, so they whipped me into hospital."

Wellbeing and lifestyle

Carol felt there was a gap in provision of specialist exercise classes for people with COPD following the six-week pulmonary rehabilitation course.

She said that there should be specific classes for people with respiratory conditions, where exercises could be tailored to individuals needs and abilities.

Carol has worked hard to establish a Breathe Fit class in her local area, which is provided through ActivLives. She had approached a local gym, spoken to her local councillor, and had built up a group of people who would be interested in the class before she finally managed to get things off the ground with ActivLives.

"There should be more exercise classes to help. It's alright saying but you've got the Sports Centre, but I don't know whether they do things for COPD. And I think we need specific classes for COPD. If you go to an exercise class they think you're all the same and then you can't do it all.

Carol felt that one of the key benefits to having specialist Breathe Fit classes was getting out and exercising with other people with COPD.

While she found that her husband was sometimes reluctant to let her do things by herself, for fear of over-stretching herself, the members of her exercise group helped to motivate her to push herself a bit harder:

"I must admit with the classes we do it's really lovely to have the people around because they will push you as well which is really nice. [We] tend to just walk around slowly, but you'll get someone saying, come on, let's just do this and sort of march you off, which I think has really helped. And I mean, I know in the COPD class if someone sort of taking it easy, I'll say come on, you can do faster than they can do better than that. And I think it does help a lot to have people around you with COPD."

At times, Carol has struggled with her mental health and wellbeing. She said that being unable to do all of the things she would like to, makes her feel 'useless' . Furthermore, Carol had lost a significant amount of weight because of her COPD, which has made her feel dissatisfied with her appearance.

> "Sometimes I feel, and I'm trying to get the words out, I'm useless. I think that's the word. And I can't do things and then I just feel unworthy. I can't fulfil everything you know. And it does make me feel, 'Is it worth it?'"

However, Carol did say that establishing the Breathe Fit class has given her a real sense of achievement and has helped to boost her confidence, especially when she sees how grateful the other members are.

> *"Getting that exercise class up, it actually made me feel good. I'm doing it and proud. And also, that people in the class are really grateful for what we've done and they will, if they're not coming one week, they will actually come and pay the money because they don't want the class to finish."*

Darren's story

"I always expected them [mental health services] to fix me when actually, I realise that the answers lie within myself."

Background

Darren is a 53-year-old man. He lives in Thetford with his wife and two teenage sons. He also has a daughter who doesn't live with them.

Darren was diagnosed with hypopnea four years ago, he also experiences black outs which may be linked to hypoxia. He said that this disrupted his sleep:

> *"I done a sleep clinic about four years ago when they diagnosed hypopnea, which basically means I take about five breaths a minute when I'm asleep. So I go into really shallow breathing, but nothings come of that. But I'm literally running on three to four hours sleep a night at the moment, and that's been for about six months."*

Darren lives with mental health difficulties. He said he has been 'diagnosed with borderline personality disorder with mixed personality disorders, but predominantly depressive and anxiety disorder'. He said he had been in contact with mental health services from the age of 18 up until two years ago.

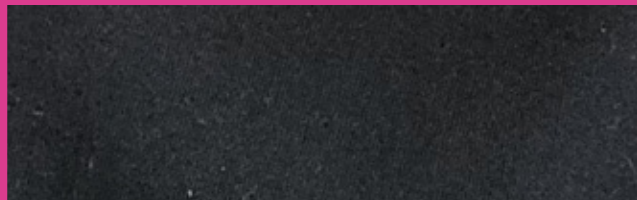
While Darren is not currently working, he gives his time to supporting other people experiencing mental health difficulties. He had set up a support group for Rethink Mental Illness, and had raised over £1,200 for Samaritans, as well as participating in their lived experience panel. He said that this was 'just my way of giving back'.

> *"I find helping others is my way out of the darkness. It's been really rewarding for me. I suffered from like suicidal ideation. And the kids are older now and it's given me something to live for."*

Darren had previously been a smoker, but had given up two years ago.



> **"My last four COPD reviews have been on the phone. I said to them how are you gonna, check my lung function on the phone. 'Oh. We only do that if you're getting more breathless.' Well, I AM getting more breathless."**



"Nobody has ever mentioned rehabilitation or anything I can do.

"I bought some yoga bands the other day. I haven't got round to opening them yet. I just wanted some general exercise that will help my back and things like that, you know. It's all things I've done off my own back. Like I've not been encouraged to do anything really."

Darren's COPD diagnosis

Darren was diagnosed with COPD when he was 40. He says he had little knowledge about the condition at the time and feels that even now, 13 years later, he has not been given much information or advice about what he could do to manage the condition himself. Examples of these comments included:

> *"I can't remember what led up to it. Breathlessness, I suppose. And all I can remember is that I was told 'you've got COPD'. It's an umbrella term now, isn't it? And they said it's probably partly chronic bronchitis and partly emphysema."*

> *"Nobody has ever mentioned rehabilitation or anything I can do. I bought some yoga bands the other day. I haven't got round to opening them yet. I just wanted some general exercise that will help my back and things like that, you know. It's all things I've done off my own back. Like I've not been encouraged to do anything really."*

Inhaler use

Darren was prescribed inhalers for his COPD. These were a blue salbutamol inhaler and a Trelegy Ellipta powder steroid, which he describes as 'horrible'. He says he rarely uses the blue inhaler as he finds it doesn't work for him.

Darren has been offered a new powder form of salbutamol but is reluctant to switch because of the inconvenience of using it without access to water. He finds the steroid inhaler has caused oral thrush because 'It's really hard to rinse away'.

> *"[The GP] said, 'you use your blue inhaler don't you?'. And I said 'no. I've been telling you for 10 years that has never worked.'"*

> *"They did say to me 'we've got a new blue inhaler. It's the same salbutamol but it's in a powder form'. I thought, 'when I'm walking up that hill, when I'm out of breath, if I haven't got a drink, the last thing I wanna do is start spraying that into my mouth.'"*

Accessing information online

Darren said that he liked to research and read up about COPD. Everything he knows about COPD he has learnt from the internet.

He had a pulsometer and had used information on the internet to monitor his own health and ask for help. In addition to looking up information, Darren is also a member of a number of Facebook groups where he is able to connect with others who share similar experiences to himself.

> *"I've got a pulsometer at home and I noticed that as I was getting tired, my breathing was shallowing and it dropped to 88 and I looked it up on Google and it says you need emergency medical attention now. So I phoned 111 the next day, had a chat with them."*
> *"I am a member of a COPD group on*

Facebook {Interviewer: How did you find out about that group?]. Oh I searched it, but unfortunately most of them are in America."

Darren also talked about how he thought a drop in oxygen levels might affect his mental health:

"And when you read about [a drop in oxygen levels], you realise it can start affecting all your organs and it affects the frontal cortex as well, which is for your emotions and your reasoning and things. So as someone who's got a disorder of emotions, that probably plays into it."

Finance, lifestyle and wellbeing

Darren had his driving licence revoked due to his blackouts. The loss of his driving license, in addition to grieving the loss of a close family member two years ago, has affected Darren's activity levels. He has only recently got back into some form of exercise, but he has already started to notice some improvements in his health.

"I've got three dogs and my father-in-law also had a couple of dogs, so he used to pick me up every morning and we'd go to the forest. He was really good and we were best friends as well. He was like a confidant for me, and I walked him through cancer as well and basically, he passed away two years [ago]. So for a while I was pretty sedentary, and, I had my driving licence revoked because I get blackouts. If I cough once or twice. I get dizzy if I cough three or four times, I faint."

"I actually got active again in about May. I did the 'Walk 70 miles in May' for the Samaritans. I thought I'll do this. And since then I've been walking him (the dog). I found it really hard because I was having back problems and all sorts just due to muscle weakness I suppose, and lack of doing stuff. But today we walked for an hour and a half and I'm starting to walk quicker."

Darren has been recommended a local gym which has specially designed equipment to help people with disabilities and long term conditions begin doing more exercise. Darren is considering pursuing this through the Wellbeing service.

"One of my friends, she's got really bad



"...for a while I was pretty sedentary, and, I had my driving licence revoked because I get blackouts. If I cough once or twice. I get dizzy if I cough three or four times, I faint.

"I actually got active again... I did the 'Walk 70 miles in May' for the Samaritans. I thought I'll do this. And since then I've been walking him (the dog). I found it really hard... But today we walked for an hour and a half and I'm starting to walk quicker."

rheumatoid arthritis. And she goes to a special gym where they're really light machines.

"She said to me the other day they can refer you to that... Both my boys are gym mad, which is good for them, but I can't go to that sort of gym, but she said this is a really quiet thing with easy exercising. So that was probably what I was hoping to speak to [the Wellbeing service] about."

Darren's COPD is affected by extremes of temperature. He and his family have found it difficult to afford to heat their property to an adequate level. However, he said that he also finds it hard to justify heating the house when he is the only person there.

He accessed grants for support through EDF. He had also received support from a charity called Turn2Us in the past. He said about his situation with heating and energy bills:

"I'm on the vulnerability register and so I contacted EDF and I said 'I'm sitting in my bedroom. It's 12° over the winter and I've got COPD'. So they agreed for me to pay £58 a month. £8 was to go to what I owed them from previous, and then £50 a month, so we've been doing that, which was fine.

"I still didn't put the heating on. And then we just got a recent bill which said we we're £850 in debt. So I've applied to EDF support fund, which they've approved it, but they want to see us pay three months at £180 to prove we can pay for ongoing and not get behind again. Last week we migrated from tax credits to universal credits, so we're not gonna get any money for six weeks. Which I'm panicking about."

Support to manage COPD

Darren said that his last four COPD reviews had been conducted over the phone. He noted that it was not possible to monitor his lung function remotely, and that he had been getting more breathless. He had received a recent visit from the Community COPD team, however, he felt he already knew the information he was given. His comments included:

"My last four COPD reviews have been on the phone. I said to them how are you gonna, check my lung function on the phone. 'Oh. We only do that if you're getting more breathless.' Well, I AM getting more breathless."

"I see the respiratory team, which was a few weeks ago and they actually give me a handout about 'What is COPD?' I thought. OK. Well, like 12 years later and now, look, I'm gonna actually have it explained to me. But there's nothing in the leaflet I didn't know."

Having had chest infections, Darren is aware of the signs of any issues and has accessed rescue packs from his GP in the past. However, he says he has received conflicting messages from his practice about the availability of rescue medication. He said:

"I get mixed messages depending on what GP I see. I did used to have a rescue pack. Then when I asked for another one, another GP said: 'Oh no, we don't do them no more'. And then another GP tells me that they do, and then I am a member of a COPD group on Facebook, and they all seem to have rescue packs. So, it's a bit of an odd one, I don't know."

While Darren received his Flu, COVID and pneumonia vaccines in the past, he is reluctant to have them this year. He said That the COVID vaccine was responsible for the death of his father in law. This experience had made him question whether he should take up other vaccines such as the flu vaccine. Examples of his comments about vaccines included:

"I used to have my flu one. I didn't have it this year. I had my first two COVID shots, but that's [the COVID jab] what killed my father-in-law, so."
"So that put me off that one. It also made

me look into the flu shot. And that's just guesswork about what variant it might be, so it's not going to stop me getting the flu. Plus because of my antisocial side, I'm not going out much."

In addition to the support, he gets from his wife and sons, Darren has also built a social network through his voluntary work and through online support and chat groups. He said that the support he received here could be very different than from other friends or relatives. Having these connections allowed him to speak to other people who understood his issues.

"[My wife] She's very much 'don't think about it and it'll go away', if you know what I mean? She worries like because I've got quite a list of ailments and so I kind of avoid talking to her a bit about it. I suppose that's why I've got two lady friends who I'm in a Facebook chat with. They've both got debilitating illnesses as well. And we talk about anything.

"[One of my friends said the other day] what's the difference between me telling you something and someone else. I said because I feel heard. I know, you're listening to me."

Darren's story



"I'm gonna die at some point from the COPD and that is through smoking, you know...

Darren also shared his story of smoking, vaping and using tobacco with us.

Find out what he told us, and read other case studies in Suffolk, by visiting:

https://healthwatchsuffolk.co.uk/smokingreport/

Janet's story

"I get worried about my breathing, because when I was hospitalised with a chest infection, I collapsed. So I get a bit worried that I might do that when I am out because I can't breathe properly."

Background

Janet is a 77-year-old woman, and lives in east Suffolk with her husband.

Janet had been retired for 20 years at the time of her interview. She had a son who lived in this country and a daughter who was in America.

Janet lives with arthritis and osteoporosis and has experienced the symptoms of COPD for at least 15-16 years. She was diagnosed with the condition between five and ten years ago. She has problems with mobility following a knee replacement, which she says causes her considerable pain.

Janet had double pneumonia as a child, which she said meant she had 'always been a bit wheezy'. She used to smoke but managed to give up 30 years ago, describing it as 'the most foolish thing I ever did'. She felt 'in my generation [if you didn't smoke], you were the odd one out':

"It is one thing in my life that I regret that I did but that was how it was. You can't take it back. It breaks my heart, when I see young people smoking. I feel like I want to go up to them and say listen to me about what it does to you. But we all think we're not going to get any harm from it, don't we? We think it's not going to hurt you."

She felt giving up smoking had been a case of 'mind over matter'.

> *"I was really coughing one morning, and I got a cigarette out, and I thought, you stupid woman, what are you doing? And I put it back in the packet and threw them away and never had another one. It's mind over matter."*



"It breaks my heart, when I see young people smoking. I feel like I want to go up to them and say listen to me about what it does to you. But we all think we're not going to get any harm from it, don't we? We think it's not going to hurt you."



Receiving a diagnosis and knowledge of COPD

When she first received her diagnosis, Janet had felt disheartened:

> *"Fairly depressed to be honest. Because you don't realise that you've got something that's not necessarily life-threatening, but it's not going to go away. I can distinctly remember the doctor saying, 'Oh, you've got COPD', and I was really taken aback."*

At the time of diagnosis, she knew very little about the condition, even though she had always lived with respiratory issues. She had not been given a lot of information about COPD and felt she needed to rely on the internet for information, (mainly the NHS website), as a trusted source. Examples of comments about her knowledge of COPD included:

> *"I've always been wheezy. I've had a bit of a lung condition. I had double pneumonia when I was a very young child. And so, I've always had not very good lungs really. But then it got worse and worse, and then obviously I went to the doctors and that was when it was diagnosed because I was so breathless.*

> *"I wasn't given an awful lot of information really. I mean, thank goodness for Mr. Google, really. I found out an awful lot on there. I go on the NHS website. I don't do any others. I just look on the NHS website and get all the information I need from there."*

Managing COPD

Janet lived in a bungalow and did not identify any housing issues impacting her COPD. She felt her inhalers helped her to keep her COPD 'quite well controlled' and has tried many different inhalers over the year:

> *"I think the one I'm on now is the strongest one that I can probably have. But that seems to be keeping things under control... I wouldn't want to be without them."*

Day-to-day, Janet's COPD makes her feel exhausted most of the time, but she knows her limits and tries to pace herself throughout the day. Examples of her comments about living with COPD included:

> *"I do wake up sometimes feeling quite breathless during the day. When I get up in the morning and shower, I'm exhausted for a couple of hours by the time I've showered and dried myself and had my breakfast. I do get very tired.*

> *"I know my limit. I do get breathless, and I do get exhausted, but then I stop what I'm doing. It's a case of just learning to live with it, really."*

Janet has received all of her annual vaccinations (flu, COVID, and pneumonia) and has had a recent review of her COPD at her GP practice. Janet attended pulmonary rehabilitation sessions a few years ago, but the course had been cut short because of the COVID pandemic. She had recently been to pulmonary rehabilitation again, and completed the full six-week programme, after a nurse had suggested it during a COPD review.

She had found the course helpful and liked being able to meet up with other people. She had also found it helpful to meet people with more severe symptoms of COPD. She has kept in touch with one of the other ladies attending the course.

> *"I did find that quite helpful. I mean that they teach you how to breathe properly and pace yourself... And it was also good to meet with other people that were actually worse than myself, which is quite a learning curve.*

> *"There are physios there, and they tell you to just do to your limitations, which is good, but it also spurs you on to want to try and*

"I didn't [get any warning that it was going to happen]. We were just going through the hall. I just said 'Oh I don't feel very well', and my husband was ever so good. He tried to grab a chair, but I just flopped down. And then he called an ambulance.

"I get a bit worried that I might do that when I am out because I can't breathe properly. I very rarely do anything on my own now."

do a little bit more than your limitations, if you know what I mean? It's all about advice and giving you confidence, really, isn't it?"

After the course, Janet had found it challenging to maintain the exercises at home. But she had found it easier once she had structured the exercises into her daily routine.

"They gave us a booklet. We all got the same booklet with the exercises in but trying to make yourself do it at home is very different, isn't it?... Because I get tired, and I think I need to save my energy to do the things that I need to do, whereas when I used to get in the car and go up there [for pulmonary rehab], for that hour and do those exercises, it's all about, making yourself, do it really. I do the deep breathing. I do that when I'm sitting watching television."

Reflecting on other influences on her condition, Janet described how the weather can affect her COPD and other long-term conditions.

"If it's foggy or anything like that, I don't go out. And, also if it's very, very hot. If it's hot and humid, I can't go out, and the same goes if it's really cold. I can't deal with it if it's too hot because of the breathing and it makes me just feel like there's no air to breathe."

Hospital admission

Last October, following a chest infection, Janet experienced difficulties with her breathing and collapsed. Fortunately, her husband was there, and he called an ambulance. She was in hospital for five days. While she was in hospital, they also discovered that she had a pulmonary embolism.

This experience has not only affected her physical health, but it has made her feel anxious about collapsing again. She had lost her confidence to do things alone.

"I was already on antibiotics [for a chest infection]. I have a rescue pack of antibiotics that I was taking, and I actually had almost finished them, but it hadn't really gone away, so I was still on the steroids.

"I didn't [get any warning that it was going to happen]. We were just going through the hall. I just said 'Oh I don't feel very well', and my husband was ever so good. He tried to grab a chair, but I just flopped down. And then he called an ambulance.

"I get a bit worried that I might do that when I am out because I can't breathe properly. I very rarely do anything on my own now. Fortunately, I've got my husband to come with me. I do drive but I don't drive very much now. I've lost my confidence a little bit [since being in hospital], but I do drive a little."

Talking about her recovery, Janet explained how she had found it difficult to get back into her exercise routine after her admission.

> *"It was much harder [to get back into exercising], and I couldn't walk as far. It's only recently that I've managed to go a little bit further. Yeah, one of the reasons is because it's not just my COPD, it's because of my arthritis... It's mind over matter."*

Lifestyle and activity

In addition to doing her breathing exercises at home, Janet had the goal of trying to walk a mile every day. She did this with the support and encouragement of her husband and little dog, although the pain in her knee could sometimes restrict the amount of exercise she felt able to do.

> *"I've also been trying to get out for a walk. I try to walk almost a mile a day, and when I come back from that, I have to stop for a little while and take a few breaths. I do manage it, but when I come home, I'm quite exhausted. But I do try to make myself do it.*

The combination of her health conditions is a particular issue for Janet, limiting both her motivation and ability to attend to daily tasks and manage her COPD through exercise. Examples of her comments about how her COPD and arthritis impacted on her motivation to exercise included:

> *"I can't really hoover. I do have a cleaner come in and do my cleaning and hoovering for me. I mean I can dust and do things like that, but as far as doing anything physical, I just can't do it because of my arthritis as well... It's very painful, so I can't do a lot really."*

> *"There are times I think I can't be bothered to do anything because I know I will be exhausted. So, we don't do it. Yes, it does affect my motivation very much, yeah. I don't know what I would do to be honest, if I was on my own."*

Overall, however, Janet felt she was doing as much as she possibly could to manage her COPD.

> *"I do try and keep myself mobile because I know it'll get worse if I don't, but I don't think I could do any more than what I already do."*

"There are times I think I can't be bothered to do anything because I know I will be exhausted. So, we don't do it. Yes, it does affect my motivation very much, yeah.

"I don't know what I would do to be honest, if I was on my own."

Lesley's story

"Getting yourself well is one thing, getting your environment well with you is also important."

Background

Lesley is a 66-year-old woman. She lives in Suffolk and is married with a grown-up daughter.

Lesley's breathing and lung function was first picked up in a pre-operation assessment for an operation on a cyst on her spine. She was provided with inhalers, but nothing more was explained to her about COPD.

> *"I was diagnosed when I had to come in for an operation. You know how they do all the pre-op tests and it was picked up then. They picked it up for the anaesthetic, for the operation...*
>
> *"[Interviewer: Did someone explain to you about COPD and how it could affect you?) Not at that point. It really wasn't raised. I think it was probably because they were managing my spine problem more. I was just given puffers and as the years went on, I kept having chest infections and things like that, it got more complex. It was then that it sort of came out as COPD."*

Lesley had been a smoker since she was barely a teenager and gave up about 18 months prior to her interview. At the time, she had been admitted to hospital with type two respiratory failure. A frank discussion with her hospital consultant made her aware of the realities of her condition:

> *"The consultant was forthright and fair, you know, next time I see you, you're going to be in a wheelchair with oxygen."*

Lesley described how she felt she needed more support on discharge from hospital to help her get back on her feet. This included support to get her property in a fit state, but also social support to help with washing, dressing and personal hygiene.

> *"I think if you're talking about keeping people at home cleaning is one area that*



> ***"Being ill for some time, my home had deteriorated in cleanliness, and in recovery you are still physically unable to regain that. Dust exacerbates COPD... I am too embarrassed to ask a friend or neighbour for personal hygiene." "***



> *"I don't go to very trafficky places. I avoid them. And I do wear a mask a lot of the time and still in public. I elect not to be in heavily populated places, I just don't want to catch anything. So, I went to a funeral last month, and I sat in the porch.*
>
> ***"If I'm uncertain about who's around me, I just take myself out of that situation."***

would help. Being ill for some time, my home had deteriorated in cleanliness, and in recovery you are still physically unable to regain that. Dust exacerbates COPD. And actually, personal hygiene too. I could hardly get in the shower or bend over to wash my hair. And my family's not around, I am too embarrassed to ask a friend or neighbour for personal hygiene."

Lesley's husband is much older than her and has his own health issues. This meant that she felt that she was unable to rely on her him to help her out much.

"My husband's is quite a bit older than me, and some of it's generational, he just wouldn't even think about doing certain things. He's not a very well man. He's only just out of hospital himself."

Support for quitting smoking

Having made the decision to quit smoking, Lesley felt that the response from the hospital had been quite poor, and that she had to battle to get the support she needed.

She also felt that the support she had received from the smoking cessation service once she was back home was quite sporadic, and needed to go on longer than the 12 weeks.

She said that, even 18 months after quitting, she is still using nicotine replacements which she said is 'as expensive as smoking'.

*"I was very surprised that the hospital didn't help more, especially as I was on * a specialized lung unit and there wasn't support there. I just didn't get it…even getting patches was a battle.*

"I had to beg to see somebody from [the smoking cessation service], as I was discharged. Then they only sort of support you for three months or 12 weeks."

Lesley said she had seen a real improvement in her health and overall wellbeing since giving up smoking, and that this, plus the support of her family was what stopped her from taking up smoking again.

"I must say I didn't realise how ill it was making me as a person. Not just my breathing and my COPD, but how ill I was as a person. And how much better I feel as a whole now. I can do so much more than I used to."

Managing COPD

Lesley's COPD is exacerbated by grass pollen. Unfortunately living in a rural location, this had caused her issues in the past, however, she had recently discovered a particularly effective antihistamine which her GP agreed to prescribe for her. She also said she wore a mask in public, and tried to avoid places with lots of traffic, or lots of people around.

"Round our cottages there are lots of fields and they used to have animals in them, which used to keep the grass down but this year it was waist high… My daughter,

told me about a new antihistamine on the market that you can get over the counter which I started to buy for myself and it is amazing. To the point I said to my doctor, 'can I get it on prescription because I'm saving you money because I'm not using any other puffers' and they said 'yes'.

"I don't go to very trafficky places. I avoid them. And I do wear a mask a lot of the time and still in public. I elect not to be in heavily populated places, I just don't want to catch anything. So, I went to a funeral last month, and I sat in the porch. If I'm uncertain about who's around me, I just take myself out of that situation."

Lesley lives in an old property. When asked, she mentioned that they did have issues with mould, however she was reluctant to make a big issue of it because of the low rent on the property.

"We have got mould. It's the devil and the deep blue sea because our landlady is very good at only letting out her properties to local people and therefore, she always keeps the rent at a lower price. So, you don't want to rock that boat too hard because you know at the end of the day she's doing a really good service to the community."

Lesley mentioned that she also had difficulties heating her property. She found running her storage heaters to be expensive, but her log burner exacerbated her COPD.

"I just love the fact that I can live in an old cottage, but it's difficult to keep warm.

"We have a log burner that used to smoke and would give me terrible grief with my COPD. But it's just so expensive and now the government has stopped the heating allowance for pensioners. Our electric heating here is £70 a week. We have storage radiators but I wish I had enough money in the pot to put in the updated version of storage radiators."

Accessing support for COPD

Lesley has had a number of chest infections in the past and was familiar with Rescue Packs. She reported that she had always been able to access a rescue pack from her GP practice when needed. However, she was reluctant to use the 'blanket' antibiotic which was usually provided in a rescue pack, preferring instead to send a sputum sample to her GP.

She felt that this was important ensure that she gets the most appropriate medicine for the infection that she has.

"I have had a long conversation with my doctor about this because I was taking so many antibiotics. I now take a sputum sample into my doctors and have that analysed before I start taking a designated antibiotic course. Otherwise I may be taking the wrong antibiotic for that particular infection, which won't work anyway!"

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"So, you don't want to rock that boat too hard because you know at the end of the day she's doing a really good service to the community."

Lesley had attended pulmonary rehab three times, twice before COVID and one since. She had always attended after a serious chest infection. She said that pulmonary rehab has been the keystone to helping her back on her feet after serious illness:

> *"The classes that they run from the pulmonary rehab classes are absolutely excellent... Every time I've gone it's been after I have had a real bad chest infection, which strikes me down so low. And it really does what it says in the title, it rehabs you. It puts you on your feet again, it gets you fit, which after such an illness, is really excellent. A non-judgemental course which improves your fitness and ability to cope, with education about the disease too."*

Lesley also said that the pulmonary rehabilitation sessions were only held near her once a year. However, she didn't want to lose the benefits she had gained over the six-week course. So, together with another attendee, she had looked for opportunities to keep the class running.

Eventually, she was put in touch with Active Lives, who now offer a BreatheFit class locally every week. Lesley felt that the BreatheFit sessions were so important and valuable, that she is now a volunteer, supporting the sessions by setting up the room and making teas and coffees.

> *"The fact that you're going there, that you've got somewhere to go to, properly run, with support. It also acts as a social group, supporting each other, so, also has mental health advantages. I would certainly think that it's saving the NHS a lot of money by having that group, so it's just a shame it's not funded, as it is a local charity ActivLives. An invaluable resource."*

In addition to the BreatheFit classes, L also does Tai Chi once a week (also run by the local charity - ActivLives). She said she found that the Tai Chi, really helped improve her posture and her overall lung capacity and contributed to her overall sense of wellbeing.



"[Pulmonary rehabilitation] really does what it says in the title, it rehabs you.

"It puts you on your feet again, it gets you fit, which after such an illness, is really excellent. A non-judgemental course which improves your fitness and ability to cope, with education about the disease too."

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