

COPD with Dr Andrew Whittamore Asthma & Lung UK and Felicity Payne

Speaker 1:

Welcome to the Sunflower Conversations where we explore the Hidden Disabilities Sunflower and its role in supporting people with hidden disabilities.

Chantal Boyle:

Welcome to the Sunflower Conversations with Chantal. I have the pleasure of being joined by Felicity Payne and Dr. Andy Whittamore today, to talk about chronic obstructive pulmonary disease, abbreviated to COPD. It's a name which is for a group of lung conditions that cause breathing difficulties, but what do we know about it? Andy, would you mind, first of all, just explaining what is COPD and some of the lung conditions that come under its description please?

Dr Andrew Whittamore:

I think firstly, you've actually highlighted, it's a bit of a mouthful to say in its full title, so we do abbreviate it to COPD. And absolutely right, it is a group of conditions where there's been damage caused to the lungs, which can't be repaired, and that causes people difficulty with breathing, it can cause regular chest infections, it can cause cough for some people, and it can be really debilitating and quite disabling and distressing for people. There are two main types of COPD that we recognize medically. One's called emphysema, which is where there's damage to the sacs at the end of the lungs, which is where all the oxygen is exchanged for carbon dioxide. And then there's chronic bronchitis, which is where the tubes going down to those sacs, get damaged as well. And that causes more of a narrowing to the lungs.

So there's different versions that affect different people in different ways, but the difficulty we've got is that we know there's people out there who have got COPD that don't know it. And also the fact that the symptoms of COPD overlap with so many other conditions. I'm sure you've had coughing, I'm sure you've had breathlessness at times, but that doesn't necessarily mean you've got COPD and people sometimes overlook that, both in the medical profession and people who are suffering those symptoms, unfortunately.

Chantal Boyle:

You mentioned that it's damage which has been caused to the lungs, so can you explain to me some of the ways in which that might occur? How do you get COPD?

Dr Andrew Whittamore:

So people get COPD when there's been long-term irritation to the lungs and that irritation, in Europe and the western world, is most commonly caused by smoking. Perhaps in more developing countries, it's more by people cooking over on ventilated stoves, so there's actually smoke coming off their cookers and so on. But as I say, in this country, it's mainly people who've been exposed to smoke. Other common reasons that we see people get COPD is where there's been a long term exposure to dusts or fumes or chemicals, at home or at work or even from air pollution as well. So there's lots of other things that feed into that. It takes a long time to develop. It's not something you develop in just a few years, it takes many years to do enough damage for people to be able to measure the damage, which is why it's really important that when people start to get symptoms of breathlessness or chest infections regularly, then they speak to their doctor or team to try and work out why that's happening to them.

Chantal Boyle:

That's good advice. So Felicity, what type of COPD do you have?

Felicity Payne:

I have emphysema. I don't really know how I got it. In theory, because I gave up smoking when I was 30, I was told at that point, "If you give up smoking now you'll be fine," and 30 years later I wasn't fine. So I'm not sure about is just smoking on your own, but what I think is important is that I was always in a smokey atmosphere. My parents smoked, my husband smoked. I started getting symptoms not long after he died and he had been smoking all the time. So all my life I've been with smoke. There's another thing that I find quite interesting is a longitudinal study from Denmark, I think it is, where they've been looking at some children growing up after they've had tonsils taken out. You are more liable to get COPD if you've had your tonsils out when you're very young. It's to do with developing of your... I forgot the words now.

Dr Andrew Whittamore:

Immune system.

Felicity Payne:

Immune system. Not many people have heard of that, but I think that is probably quite important, because people stopped taking tonsils out of children just regularly now, haven't they? It's obviously known that it's not a good idea. There's other things as well that I think that come into it. My mother had COPD, she smoked into her 50s and she got diagnosed officially at the age 87 with emphysema. I get fed up with everybody just saying, "It's your fault, you smoked." And I don't think, on its own, I don't think that was... If everything else wouldn't have been there, I think it might have been a different story.

Dr Andrew Whittamore:

I agree completely because I know people who have smoked very heavily for their entire life and haven't got COPD, but there are some things clear that make people more at risk. So there are genetic reasons, and we know that's not just... For example, from your mum, it's possibly from your grandmother and beyond that as well. And actually, people who smoke now are damaging the genes that they're then passing on to their children in future. There is some sort of protective genetic factors as well, so it's not just smoking. There must be some other things in how we're built that protect people or put them at risk. As I said, there's been around pollution and other things that increase the risk as well. Being born prematurely, so if you've got small underdeveloped lungs, again, that's just another risk factor. Doesn't mean you're going to get it, but it's just another thing that makes it more likely.

And that immune thing is something we're still doing a lot of research about. People who have had very severe illnesses when they're growing up are more like to get damaged their lungs, which later on might make them more susceptible to other things that trigger COPD off. And interesting what you say about your mum. She probably, if we did scans on her, did have COPD when she was 50 or 60, because I said people get used to breathlessness, they live with it. And it might have been that she had to become more frail and more unwell with other things before somebody said, "You've got something wrong with your lungs. Let's have a look." [inaudible 00:06:47] comes too late.

Felicity Payne:

It was a scan, she had chest pain and took her in overnight.

Chantal Boyle:

That's how it was discovered. Well, when I was born, my mum and her sisters were smoking in the room, as me as a newborn baby in the little car in the hospital. It's not like they had a side room and that was okay.

Dr Andrew Whittamore:

Times changed though.

Felicity Payne:

I remember when I was young, the time when I was giving up smoke, wasn't smoking, everybody smoked. So that's also, when you look at our generation, that most of us did smoke to some extent. In the hospital, the nurses and the doctors, they were all smoking.

Dr Andrew Whittamore:

We used to prescribe cigarettes, apparently, many, many years ago.

Felicity Payne:

A friend of mine was a nurse and she said, down in where the nurses and the doctors go when they're not being doctors and nurses said it was always really smoky down there.

Chantal Boyle:

Felicity, would you mind explaining how does your COPD or emphysema, how does it affect you? How does it feel? Could you explain to me, what does it feel like?

Felicity Payne:

Well, it's constantly like you can feel your lungs. I don't know if you've got nerves on your lungs, but you can feel them the whole time. And you're slightly breathless all the time. When I first was diagnosed, I said to my sister, "I can't live like this." Because it was sudden. It was literally very, very quickly that I got from no symptoms to quite a bit, lot of symptoms. Obviously, you have to learn to live with it, I am living a normal life now, and my brain's got used to the whole idea of this. You have to push yourself. I believe exercise is the most important thing, and I've always have exercise. I used to do marathons and all sorts, and I still exercise now, but I know that it's going to hurt my lungs. When I'm going up hills particularly, and I warn people now that actually, don't worry, that I will probably be breathing really loud. That is what I do. I'm not going to fall over. I'm not going to just die. It's the way it is.

Chantal Boyle:

That's interesting. So what kind of support can people give to you when you are experiencing the breathlessness and the pain?

Felicity Payne:

Well, nothing really. They just have to ignore it, really, but there's other things as well that come with it. There's all sorts of things that come with it. Things like, at the moment, they think I might have sleep apnea, I don't sleep very well. I'm on four to six hours sleep at night. Acid reflux, I've got that as well, which is not very pleasant. I don't cough very much, a cough for me is a sign of I've getting an infection just like everybody else. I get slight confusion when I'm tired. I lose words, which I've already done today. I've lost a word that was quite an easy word. Some days, if I've had good sleep, then I'm a lot better, though it is a sign of sleepiness. I can still beat everybody else at Scrabble, so my brain is still all right inside somewhere.

Chantal Boyle:

And Andy, would you say that the forgetfulness of words, is it because is that the lungs produce oxygen?

Dr Andrew Whittamore:

I think what we're talking about there is probably more the effect of the sleep apnea. So where there's maybe not enough oxygen getting to the brain at nighttime because of Felicity's breathing pattern at night, nothing to do with COPD, not directly anyway. And then, that can just mean that the brain is struggling the next day a bit more.

Chantal Boyle:

Andy, what do you hear from patients with regard to the effect that COPD has on their lives? Felicity has had to make some mental adjustments to live with her condition.

Dr Andrew Whittamore:

I think that the most common time that I come in contact with people with COPD is actually when they're having a flare up, or some people call that an exacerbation. And that can just be that the way the lungs are feeling, that they just not breathing as well as they were for a temporary period of time, which might be a few days or a few weeks. But that can be due to infection as well. That can then make it much worse at the same time. So I see people who are feeling unwell, they're feeling breathless and ultimately they're very scared at that point. They're scared of needing to go to hospital, they're scared of the medication that they might need. They're scared, is this the next step towards the end of their life? Are they going to need oxygen? Things like that, that are quite big steps and get very really scary for people.

The other side of it is, I suppose, when I see people day to day for their routine reviews. And actually, Felicity said something really, really crucial. She's learnt to cope with it, which means trying to be as active as she can and accepting that sometimes she'll be very breathless, but we'll still achieve things. Most of us, when we've got an injury or an illness, we learn to cope with it by not setting it off. So for example, if you had a bad ankle today, you'd learn for the next sort of week or so not to walk in it as often as you would.

The problem we get with lots with breathing conditions like COPD is they learn to adapt by doing less, which means they get more breathless, they're more likely to feel breathless when they do any activity, and then you get this vicious cycle, actually their muscles start to get weaker, which means their muscles demand more oxygen.

Chantal Boyle:

Yes, of course.

Dr Andrew Whittamore:

And that means they get even more breathless when they try and do anything. So you've got this vicious cycle where people maybe who haven't got dreadful... They've got COPD, but it's not too bad, they can't do things like getting out of a chair and walking around the house, because actually they've become detained. So Felicity's approach is actually perfect. You do need to be breathless, you shouldn't be scared of getting breathless, and actually, you need to keep the body and the lungs and the heart and everything else working as well as you can to prevent the breathless is getting worse. I think going back to when one of my first ever clinics of people with COPD, I had two people coming to one after the other. One had very, very slight damage their lungs from COPD and came in a wheelchair.

Because she was doing less and less and then couldn't get around the house, and we dragged her in for an appointments and the family brought her in a wheelchair. The second person, I looked at her lung results and she only had less than a third of her lung working, really severe emphysema. She came in Lycra, she came in on the way to the gym. And actually the impact of that, having a third of her lung, and being active and really pushing herself, she was significantly more active, happier, getting on with life, compared to the person who would let COPD dominate their life. I'm not saying everybody is good at one end or the other, but it's very easy to see how human nature means that we start to do less naturally, which means doing something becomes harder and harder and harder.

Chantal Boyle:

It's like you say, when you are not well, often, whether it's a physical injury or a virus, I guess we have it in our head, we need to rest. Recuperate, and like you're saying, it's not always the right approach, is it?

Dr Andrew Whittamore:

And one of the battles we've got I think generally in the NHS is that we want a magic pill or a magic inhaler or something. And actually there's a lot of hard work that goes into getting the body back to as fit as it can be. Maybe not perfection, maybe not athlete status, but actually just by doing more and being more active, we can get more out of our bodies, which means whatever condition we've got will have less impact.

Chantal Boyle:

That's servicing a car. [inaudible 00:14:38]

Dr Andrew Whittamore:

Exactly right. You've got to keep ticking over.

Chantal Boyle:

So Felicity, in the beginning, in the early stages of your diagnosis, how did it affect your work and your social life? It sounds like, as you said, you found different ways to cope with it now, but initially how did you?

Felicity Payne:

Well, it was an awful time, because recently my husband had died and then my mum had died, and I've been looking after her. So I was of low ebb and I put that down to why I was suddenly picking up nasty infections, which I did. Before the nasty infections I was all right. I couldn't get any help from my doctor surgery, I was sent away because I had a cough and everybody apparently had a cough and I would get better in summer, and I didn't and kept getting infections. And that, I think, it was that did the lung damage a lot more because before that, like I say, that I had no idea that I had anything wrong with my lungs, not at all. It was very depressing, because you are not getting the right support really. The nurse at the doctor said, "Well, you're lucky it's not cancer."

Which was not very great because my husband had died of cancer, my mother had died of cancer and it wasn't really great thing to say. And then she said, "I've got a heart condition." I thought, "Well, so what?" Then she phone me up a few days later and asked me if I was suicidal, which I thought was quite bizarre. The whole thing was bizarre and I was told to rest and I was warned off all sorts of things. I was warned off of doing too much and take little steps and sit down a lot. And I got myself an oximeter and I was told off having one of those cause I couldn't possibly understand it.

Chantal Boyle:

Can you just tell me, what's an oximeter?

Felicity Payne:

It's the thing you put on your finger to measure your oxygen. I'd hardly use it now. I used to use it all the time to monitor, but I know how I feel and I've now got my Fitbit that tells me overnight what my oxygen is roughly. And actually it is sometimes incredibly good. It's not always incredibly good, but it goes up to 97% and sometimes when I've had it checked in the clinic and things I've had, it's 97%, which is somebody with COPD is pretty good, it is. And it does drop down to 92 as the lowest, but that's the lowest I've ever gone down to, so I think that's good.

Dr Andrew Whittamore:

So we wouldn't normally recommend that people get an oximeter because I suppose Felicity is sort hinting it or feeds into the anxiety a little bit sometimes. And actually how you feel is much more important. There are times when actually we do use oximeter, from a medical perspective and when we routinely review people. But actually, people with more severe COPD who map perhaps on the board line of needing oxygen or if they have got oxygen then it's really useful in those cases, but for most people it's not particularly useful.

Felicity Payne:

But I like things like that. I enjoy this.

Dr Andrew Whittamore:

Measuring things.

Felicity Payne:

No, just understanding things. I like to understand things. If I do this, will my oxygen go up and blah blah blah? I bet when you're first diagnosed and you don't get help, which is a really... At this moment in time, a lot of people can't get help, it's hard to even get to see a nurse. Even at our places let alone doctors, you don't see anybody anymore.

Chantal Boyle:

It's an isolating space to be in and quite scary.

Felicity Payne:

And it's always the "why me?" Everybody else around me that they smoke is still fine, they're still smoking, they're still fine. [inaudible 00:18:12]

Dr Andrew Whittamore:

I think that adds to a few things actually. Obviously the NHS is under a lot of strain at the moment and there's not as much staff as we'd all think that we need to be out there. But actually people don't get the information and advice about what their condition is early enough.

Felicity Payne:

Exactly.

Dr Andrew Whittamore:

Because actually, a lot of people want to know why they've got it, what they can do to help control it and look after it, but actually it just improves people's wellbeing generally, if they actually know what they're dealing with.

Felicity Payne:

Exactly. Once you've got a diagnosis, you've got something you can do with it. When you haven't got a diagnosis, it's just scary. And also, if you already got your head against a brick wall, you are not getting help, where they should be giving you help. I'm in my local Breathe Easy group, I'm on the committee and I [inaudible 00:18:56] forgot what you called it. And obviously, it's a drop in the ocean with Breathe Easy groups. But the amount of people that we have had coming through and it has changed them immediately. They've got other people, we've had a few people have died and what their family always said, that they changed immediately when they started coming to Breathe Easy, not just lying at home waiting to die and things.

Dr Andrew Whittamore:

The isolation's really important actually to try and get over. And then there's online communities, there's Breathe Easy groups. And something we do try and refer to, is something called pulmonary rehabilitation.

Felicity Payne:

I know about that.

Dr Andrew Whittamore:

And the benefit of all these things is actually, you see people in with worse conditions, you see people with better conditions and you'd learn from their experiences of how they've dealt with it and what they can do. And even just learning some of the, I suppose, the myths behind it. People with COPD often feel is a death sentence, but actually there's people there who read it 20, 30 years and they're still doing what they're doing and they seem to be doing all right. And that can be very reassuring to somebody when they're newly diagnosed and think they're going to die.

Felicity Payne:

Well firstly the nearly diagnosed is I was given the British Lung Foundation a little magaziney thing and you went from being diagnosed to death within a few pages, that wasn't great. But I was sent to the pulmonary rehab, but they said I was too fit and I wasn't suitable because I was too fit. And since then I've been campaigning for pulmonary rehab for all, because now I work with Asthma and Lung UK. So I have a patient voice there. But we have now, in our review group, we have our own pulmonary rehab along with University of Brighton. They have physiotherapist, so they're trained to be physiotherapists. That is a great thing. They have to pay obviously a little bit towards it because the students have to have people who are actually qualified with this. So we have to pay those. But we've got two groups now going sort, I'd say, twice a week now.

And that's where the people who are really getting the benefit of everything is pulmonary rehab, because they're making friendships as well. Recently, a friend of mine who I worked with, he went to pulmonary rehab, that's again his ex-wife said that he changed immediately when he was so down and miserable. And he was life and soul at the party at the Breathe Easy. I couldn't believe it when he suddenly died, in mid seventies, but he had other things as well. He had heart conditions and things like that. It was good that he had that last year or two where he didn't feel so down.

Chantal Boyle:

And the Breathe Easy groups and the pulmonary-

Dr Andrew Whittamore:

Rehabilitation?

Chantal Boyle:

... rehabilitation. Thank you. We'll put the links to these in the show notes for people.

Dr Andrew Whittamore:

If I can fit in a few of the gaps about pulmonary rehabilitation. Felicity mentioned that they pay for it and I think that the thing to say is, pulmonary rehabilitation is free on the NHS.

Felicity Payne:

Yes, it is.

Dr Andrew Whittamore:

Because it is more effective for people who have got more breathlessness, there is sort of a threshold where we should be referring people when they're breathless doing everyday activities but her Breathe Easy group Asthma and Lung UK are also campaigning for better access for everybody with any breathing problems to be referred early. Because it provides two things. One is... Well, three things. One is education, about what the condition is and what people can do to help look after themselves with it. Secondly, it is a group so actually you can learn from other people and build friendships and even just learn from each other really. And finally, it's about giving people the confidence to be more active.

So it's not necessarily excel's classes, it's about you personally becoming more confident to do more with it. And something I see in my own practice and we hear from around the country is exactly like that breathe easy group that you've described, once people have been through pulmonary rehabilitation, they want more. They know how important it's to them and they will pay for it. In many cases, they'll join gyms, they'll join paid classes, they'll bring into their own Breathe Easy groups. And that's something we see so much, that once people get pulmonary rehabilitation it makes such a massive difference, they just want more.

Chantal Boyle:

And the Breathe Easy group, is that a charity? And they nationwide, are they?

Dr Andrew Whittamore:

The Breathe Easy is sort of a voluntary set of groups, run in combination with Asthma and Lung UK and people tend to go and people make contributions when they're there to sort of tea, coffee and room higher and things like that. They bring in expert speakers. Again, it's a network really. So actually you don't have to go every time, but when you do go, you've got people there who know what they're talking about. They know what they've been through and can help support each other to move forward. But I think Felicity's probably better at talking about that than I am.

Felicity Payne:

I think the most interesting thing is, actually we never talk about our lung conditions. Nobody does. Nobody does. People come and talk to us about lung condition things occasionally and diet, which is really important because that was a lacking thing for me because I don't eat meat. And we had somebody, the British Lung Foundation sent to us and she was saying the importance of having a lot of protein. I'd ignored everybody who said, "Just don't have dairy, because it may give you more sputum in your lungs." Which I don't believe anyway, it might do it for a few people but I don't think everybody. And she said the importance of it was, for me, it was important that I did have cheese and milk and things and eggs. I have got reasonable muscles from swimming so much. And you need the protein for your muscles basically. It's no good-

Dr Andrew Whittamore:

But that comes back to what I was saying about, if the muscles get weaker then you start demanding more oxygen, which means you feel breathless. So you have to use the muscles and keep them well built up by protein, whether that's meat or alternatives.

Chantal Boyle:

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Dr Andrew Whittamore:

Something interesting. We talked about people doing exercise, and Breathe Easy, and support from pulmonary rehabilitation, but actually there's different ways of exercising the lungs. There's been a bit of a spike in recent years of people doing singing for breathing.

Felicity Payne:

I do.

Dr Andrew Whittamore:

Swimming, as you say-

Felicity Payne:

I do.

Dr Andrew Whittamore:

... It's not just a gym or class based things. People playing musical instruments, again, it just trains the lungs and just allows you to use what you have got even more. So like my patient, who's got less than third of her lung working, she was using that third as best as she could.

Felicity Payne:

Because we don't have the tests anymore, we haven't had them since before lockdown. I've got the name of it, it's spirometry.

Dr Andrew Whittamore:

Spirometry.

Felicity Payne:

And the last spirometry I had my lung capacity is 123%. So that was quite amazing.

Chantal Boyle:

What was the lung capacity be of somebody who doesn't have COPD?

Dr Andrew Whittamore:

So spirometry is a breathing test where you blow into the machine as hard and as fast as you can. And it allows us to measure how narrow the airways are. In emphysema, because the airways aren't narrowed in the same way, you're going to get slightly better lung capacity anyway. The results of spirometry compared to averages for people without COPD. So in theory, a hundred percent, or between 80 and a hundred percent. Once it starts dipping below 80% there is a narrowing there that is obviously causing some degree of problems, but that doesn't always correspond to how the person is feeling because I say how people deal with breathlessness, how active they are, however many other conditions they've got. But that's only one get down to those levels then that's when you start thinking of COPD as a diagnosis.

Chantal Boyle:

And I really like the other suggestions of ways to exercise your lungs, the singing, the music, because those are things that you can do socially as well, aren't they? So that lends to-

Dr Andrew Whittamore:

Exactly. And they're hobbies as well as all the other benefits as well. And actually, we can add some links to the notes from the Asthma and Lung UK webpage. We got a network of groups and things that are doing that at the moment.

Chantal Boyle:

That would be brilliant. And I know that, Felicity, you like swimming but you were telling me how perfume and [inaudible 00:27:46].

Felicity Payne:

But just before we go on, everybody seems to think you have to do the special singing for breathing. You don't. I joined a normal choir, I can sing with everybody else. I know it's sort of techniques and things like that, but I probably get all my techniques from swimming, because I swim with my head in the water when I do alternate lengths of one... I do crawl as fast as everybody else still, but I take a rest on every other length by actually doing double arm breasts, but the backstroke, old English backstroke, well not with the legs that looks silly. And so I can actually swim a mile without stopping, but all the time my head in the water, I am actually exercising how I'm breathing out, because I'm breathing it out underwater. And on a good day, I always check myself on a good day when I first start, but I can go all the way out the swimming pool swimming without taking my head out the water. I've never actually managed to touch the side yet, but one day I will.

But so very few people with lung conditions go to swimming pools. One, they're told that chlorine is a problem. Chlorine is not a problem in our swimming pool, unless people get in the pool without showering with perfumes on and things like that, which sets off this sort of gas that you can feel before you smell it and that is a problem. Mostly the swimmers are fine, they all shower and we don't have that problem. When you get the aquafit, which I was socially prescribed to go to, there's people coming along with their makeup on and they're perfume in the pool, they don't shower at all and it's a nightmare. It is absolutely nightmare because you cannot breathe. And I'm not the only one, I was in once when there was three people, three of us, I knew the other two come to Breathe Easy.

So I knew that they had problems. And there was somebody with perfume on and it was really bad. And I asked if they could open the door at least. And it's escalating into this awful thing where I was told that I shouldn't be in the swimming pool more or less, I'm not to go in the deep end cause I said I am breathless. And I just think, it is something that's really not known about perfumes and things like that, but how they cause reactions in our lungs, people with lung conditions, perfume is one of the worst. When I used to do a lot of Zumba, I always used to go at the front because nobody could be in front of me with perfume on. I always used to go to the door and keep it open and people used to try and shut the door and I say, "No, I need that door open." But a lung condition, it's not the same as you are invisible. I can't see it, it's an invisible disability. And they don't actually understand and you get told off and you're not treated in the same way as anybody's got another disability. That you wouldn't dream of sending people, they just got to put up with it. These things are so simple, they could be so simply done. And if people knew even. They don't know.

Chantal Boyle:

That's right.

Felicity Payne:

And people are so embarrassed to say they've got lung conditions. I'm doing the opposite. I tell everybody that I have Emphysema and I'm doing this and I'm doing that. And they don't dare then have that bit back coming back about. And we need people to come out and say, "I'm a normal person, I don't deserve this necessarily and I've got a lung condition and I need some things where they're small things and please can you help."

Chantal Boyle:

Well that brings me on to two things. One, I wanted to ask you about your thoughts about the Hidden Disabilities Sunflower, which is about making the invisible visible. And then also, to your point about the empathy, what is the general... Is there a stigma, do you think, about people having COPD? And I never heard really about it, if I'm being honest, until the pandemic and where people would talk about not being able to potentially wear a mask because they had COPD. So there's two questions there, or three. Take whichever you like first.

Felicity Payne:

Which was the first one?

Chantal Boyle:

So what do you think about the Hidden Disability Sunflower?

Felicity Payne:

Well I've looked at what you are doing. It's really great thing, because we all need to be able to have a normal life as best as we can. I've got a partner who's got something completely different and his is more visible, and people actually overdo it, he doesn't like people to notice that actually has a disability. He's got a thing called ataxia, which means his speech is a bit... And his gait, the way he walks and things. But he doesn't like it to be recognized, but actually he does need to be recognized. And people are always asking me, "What's wrong with him?" And I say, "Well, he'll tell you if he wants to." But anyway, it is a terrible stigma. It is. Every time I go to any health professional is, "So you've got COPD, is it because you smoked?" And I'm thinking, "Well..." And it is on every bit of paper that gets sent to doctors to doctors to doctor, it's there. If somebody has a heart condition. You don't go around saying, "Is that because you've eaten lots of cake?" Don't do it. You don't do it. It's just, you don't.

Chantal Boyle:

Because it's a blame gain type of thing.

Felicity Payne:

Because you've been diagnosed, it's there on your records. You don't need to say it every time. I've turned the other way, instead of trying to hide it, I will tell people and then I'm in charge. I'm in charge. And it's not them, "You are going to ask me questions because I've just shut it down."

Chantal Boyle:

You've taken the power back.

Felicity Payne:

I've shut it down. And I think that the more people who say, "Yes, I've got a lung disease." 20% of the population, I think it is, in their time will have a lung disease. It's a common thing. And my daughter-in-law who's a social worker, when she first started going around, she's going, "Mom, there's loads of people like you who got..." I say, "I know. It's common thing, it's not rare." But it seems like it's rare because nobody ever talks about it.

Chantal Boyle:

When do you think then, when would be sensible, Andy, for an individual to seek a diagnosis? What are the watch outs that we should be aware of?

Dr Andrew Whittamore:

We've just said that 20% of the population have a lung condition at some point or other, I would go even further that say a hundred percent of people got lung symptoms at some point. If I made you run up the stairs two or three times now you'd be breathless, so would I and so would Felicity, just slightly differently and maybe for slightly different reasons in that. So what we, Asthma and Lung UK, have been doing is we've want people to basically consider when they're getting lung symptoms. And we've got something on our website called a breath test.

And it's basically encouraging people to assess how breathless they are, when they're getting breathless and whether that is bad enough for them to go and seek help. Because as we've already said before in this chat, people's lung health deteriorates gradually over time anyway. People with lung conditions generally do less, so they don't notice their more breathless. They're just naturally adapting and doing less things. So what we need people to do is compare themselves to their friends and family and people of a similar age. Are they doing less than what they used to? Are they getting more breathless, doing simple things? Are they actually getting new symptoms like coughing or regular chest infections? And if any of those things is happening, then they need to try and speak to their GP or their practice, about getting some checks into what's going on. One of the biggest difficulties we have is if Felicity came to me with her symptoms today, I wouldn't be able to presume she's got COPD, she might have asthma, she might have a clot on her lung, she might have lung cancer, she might have heart disease.

It might be that she's just very unfit. All of those things contribute to symptoms that mirror what COPD is and has, and actually you can have a lot of those things at the same time. So it's not just a question of somebody coming to me and I say, "Well, you used to smoke a lot, you're now breathless, you must have COPD." Because unfortunately we do do that a lot on the NHS. But we say, "So COPD is one of the things we need to check you for, but we also need to rule out all those other things."

Chantal Boyle:

And the way it's diagnosed is through a scan, is it?

Dr Andrew Whittamore:

No, the main way that we diagnose COPD is through breathing tests as spirometry, but you can pick it up on scans. It's important we do things like x-rays to make sure that people haven't got lung cancer or in infection or something else going on. It's important that we consider their heart health. Have they got heart problems at computing to the symptoms they've got? Cause if we just, again, let's look at smokers, they're more likely to get COPD, but they also can get heart disease and other things. So actually they've got a risk of two diseases causing the same symptoms at the same time. So it's important that we look at the person holistically, so the whole of them, and consider all the different reasons why they might be getting the symptoms they are. And then performing the right test to try and look into that in more detail.

Chantal Boyle:

And there's not a magic pill, you can't take that.

Dr Andrew Whittamore:

So the way we treat COPD is firstly, if we know there's a reason why they've got COPD, or could be making the COPD worse, we try and remove that from their life. So if they are a smoker, helping them to stop or cut down, if they're exposed to lots of dust or things in the workplace, dealing with that. And then it's about reducing the progression, so helping people to not get flareups. And the most common reason for people flaring up is actually viral infections. So flu jab, COVID jab, pneumococcal vaccine as well, they were really important to help stop people getting flareups that can then damage their lungs worse. As Felicity said, she felt she got worse with all the infections she was getting when she was around the time of their diagnosis. It's then helping people to be as active as they can.

So referral to pulmonary rehabilitation to learn about the disease, to be more active, to try and give them confidence to use their lungs as much as they can. So whether they've got 30% or 80%, effective lungs using all of it as well as they can to stay well. And of course that then helps to prevent other diseases creeping in as well. So you're preventing heart disease and depression and things like that. We do use inhalers, and what inhalers do is that they open up the airways just a little bit to allow breathing to become more easy for people. It's not as good as being more active, but actually it can help people to get on that journey and do well. And some cases we use in inhalers to try and prevent people flaring up as often. But in the main, it's all about changing how people view their lungs and how well they can use it and stopping them, getting those flareups.

Chantal Boyle:

Do some people who have got very poor lung capacity, do they have to have an oxygen tank with them? Does that help?

Dr Andrew Whittamore:

There are cases where people's lungs have become so... Or the amount of lung that's effective has reduced so much that actually they need oxygen to help support them to get enough oxygen around the body, to help the brain work and the muscles work and the heart, it's not many people with COPD, it's not the majority, but a sizeable number of people do go onto that sort of level. And there's different ways in which people use oxygen. Some people actually only use it when they're wanting to be active because actually that gives them the boost of oxygen they need to be able to use their muscles and everything well. Some people do need it what we call long term, so they're using it for most hours of the day to help improve their symptoms and keep them well.

Chantal Boyle:

And anything else, Felicity, that you do to manage your symptoms in addition to your exercise and your singing and your instrument playing?

Felicity Payne:

Well, I stopped work six years earlier than I should have done because the one thing that was causing the problem, making me worse, I couldn't do anything else. I was already doing everything I should have been doing, was to leave work because I was working in crowded classrooms and that there's a great place for catching infections. And actually it did work. I had no ever actual financial support other than the money in the bank I had. But I managed to get to my pension age without being absolutely penniless. But health is to me, you haven't got health, you haven't got anything. If you have got something wrong with you, you've got to do the best you can to live with it and get on with it because there's only one other alternative, which is not the good one. I've not had a serious lung infection. I've only had one. And that was last spring.

That was when people were... Was it last spring or the spring... I can't remember. When people kept coming out mixing again and people with COPD were getting infections because we hadn't been mixing our antibodies that great. But I've been okay ever since.

Chantal Boyle:

That's really, really good news. And it's great that you... Obviously, having to leave your work is sad, but that's definitely given you a better quality of life and sense of health wise.

Felicity Payne:

Although I miss my students. I like working with young people. It's very hard at first, just working with people of your own age. I can tell you.

Chantal Boyle:

They keep you young.

Felicity Payne:

[inaudible 00:42:12] Its a different ball game with young people.

Chantal Boyle:

So Andy, what advice and support does Asthma and Lung UK provide?

Dr Andrew Whittamore:

So first thing I'll do is, a lot of people might have heard of Asthma UK and the British Lung Foundation. I know the last couple of years they've merged into one charity called Asthma and Lung UK. So all the great things that you knew which previous organization you might have been aware of have all come together and generally just still providing the same support for people with lung disease but with a bigger voice. So being a bigger charity, we can have more clout and we are campaigning for better lung care for everybody within the NHS. So earlier diagnosis, better diagnosis, better treatments, and better care from the NHS and how that goes forward. We're also campaigning for more research. We've talked today about how common lung conditions are, and yet we get a fraction of the funding that the other disease areas get. And actually we're looking to massively increase amount of funding that we get for research, to actually help understand conditions like COPD more, find the new treatments that can be life changing and even find subtle ways of actually improving people's lives more generally.

So there's lots of things that we can do with that. The website, asthmaandlung.org.uk has lots of great information about what the conditions are, so COPD and other conditions, how they're managed, what people can do to look after themselves. And as we've suggested, it's also links to local Breathe Easy groups, other ways of keeping your lung health going. If you want something a bit more personal than that, we actually have an excellent helpline. So staffed by some excellent expert trained nurses who've been doing this for absolute years. They're experts in their field. And actually, as I say, we can have their phone number on the end of this for people so that there somebody to call and go through what's going on.

And that can be simple things like help getting benefits, what they can do around the workplace, whether they're getting the right care that they need. There's lots of little things like that that can just help people understand whether they're getting all the things to help their condition as well as they can. So there's loads of things out there, but in the background to say we are pushing the government department health, research organizations to make sure that more is done for people with lung conditions.

Chantal Boyle:

That's fantastic. Thank you. And thank you, Felicity as well, for your time and sharing your story. And I think this is going to be really informative for many people. So thank you very much both of you, for your time today.

Speaker 5:

If you are interested in any of the advice, discuss in this podcast, please follow up with your GP or healthcare practitioner.

Speaker 1:

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