



Introducing Health Sciences: COPD
Living with COPD

Presenter

It can be difficult to imagine just how much the breathlessness and fatigue that result from COPD can affect normal life.

Doctor

I remember one patient in particular er – she used to teach medical students and tell them about what it was like to be breathless and she in particular said about how it's difficult brushing her teeth; that she had to brush one side of her teeth and then stop and have a rest and then brush the other side of her teeth and then stop and have a rest. And she used to do that with the loo seat down, sitting on the loo so she didn't get breathless. So even a really, ordinary, everyday things, can become very, very difficult.

“Because I've always been on the go haven't I and now it's I – I can't seem to slow down but then I have to because I'm I'm breathless all time. I'm leaning on things to you know I can't sit down for long –

.....

“You could pretend to be looking at something – and you're not –

“And I never go without a trolley even if I only want two things –

“Have the trolley to lean on

“I can't knit. No -I used to knit a lot. “

“And gardening.”

Embroidery and I can't do that

“All things that I used to do you know like decorating and –

“I used to love decorating.”

"I love decorating but it's impossible now but I used to do it for everybody round about. You know I'd go out hanging wallpaper and things but I just can't do it now and I'd love to be able to do it again. You can't go socialising really because I mean like going in to a concert room or something like that – if you cough or you look as though you're out of breath they think well she hadn't done nowt. What's up with her?"

"Always get a seat near a door."

"Yeah you do don't you? I mean I used to go to theatres a lot but I never visit theatres now because if I start coughing it's going to disturb everybody else."

"And that's not because it's smoky is it?"

"No it's because it's dry you see – it gets overheated you know – you start coughing and then I'd get thrown out wouldn't I?"

I know

"That's one of the things I miss – going to theatres and that but er and then I used to go dancing a lot but that's out isn't it?"

Doctor

Patients also get exacerbations where they get a period where the breathlessness even gets worse than usual and they need extra treatment and if you're already struggling to manage at home then it's going to mean in the end coming in to hospital.

"And how do you feel Jim when you start with an exacerbation?"

"I just don't want to do anything. I just sort of collapse and put the television on and that's it."

"And do you find that frustrating?"

"Yes very frustrating because there are things that I want to do and I can't you know I've set to do certain things and all of a sudden I can't and it's upsetting."

"When I'm starting on one I just say to Jean – Jean I'm off. I've got to go and lay down. That's all I do. I feel so tired. So weak. You know I can't even lift my arms up and the only way out is go and have a lay down."

"Just don't do anything at all?"

"Yeah just lay down because I just can't do anything. I can't find the strength in me."

"Got no energy."

Presenter

As well as the physical restrictions, embarrassment about their symptoms prevents many people with COPD from leading active social lives.

"What embarrasses you Betty when you're out?"

"Coughing – because once you start it takes some you know I mean for example I was walking round a market one day and started coughing and one of stall holder's shouts watch your smoking love! You know and that's one of the things –"

"When you have stopped smoking –"

"Yeah because it's er and I think well it's just one of them things. I mean he didn't mean nowt you know but it did –"

"My difficulty is coughing – coughing – I feel embarrassed when I go anywhere. Every time I – every time they start talking I start coughing"

"You just can't enjoy yourself like you used to. And you can't walk –"

"Do you get embarrassed because you're breathless?"

"Yeah – erm – people look at you sometimes and think oh what's up mate you know and you see well I've never smoked and I don't know why I should be like this. And unfortunately there's no cure. They can help you but they can't cure you."

Doctor

Patients often do get problems with their mental health as well that they get anxious and depressed and it's easy to understand because they can't do their normal day to day things and they often become confined to their house and socially isolated so there is often an element of depression and anxiety – anxiety about their breathing and what it's going to mean for them in the end.

"When I used to look after Jim, Jim used to twiddle his thumbs like this and have an on running joke with is wife because he used to get stressed and he used to wind his thumbs round in circles and we used to talk about thumb speed didn't we – just to check the level of how he was feeling that day because if his thumbs were going full tilt."

'You knew –'

'You knew what he were like –'

'I find that while I'm breathless all the time if anything else in my other life other than that upsets me I get even more breathless. I can't stand stress and strain and aggravation you know. That brings it – brings it on worse.'

'Any stress brings on exacerbation.'

'And I've been a bit stressed over the last few months.'

'Yeah, yeah,'

'What about you Bill? You've been a bit down haven't you with your disease?'

'I've been down yeah because I mean I were always active and never had a builder in me house. I've done absolutely everything myself and it's coming to terms with –'

'I know you like your pond in your garden and you've been a bit restricted with that haven't you? '

'It's even hard work trying to get a bit of blanket weed out and stuff and not only that I don't like people to see me when I get one of these ... breathing things.'

'When you're breathless.'

'I mean me sister called other night and I said Jean – because I were having a bit of a turn and I more or less kicked her out of room like and said – Jean's in front room getting me – I want to help you. I said you can't. I said just – you know I just like to be on my own when I'm like that.'

Doctor

It's very easy for patients to get very depressed about their condition when they're socially isolated, very anxious. They worry that they're going to get so breathless one day that it's going to really harm them, maybe even going to keel over and die. And it's really important to try and enable people to make the best use of the lung power that they've got and to try and break that cycle of decline and try and er break that cycle of building up more and more

anxiety er about the disease and getting more and more focused in it – er on it. If they do try and break the cycle then they can do more and they can feel better for it.

Presenter

Coping with COPD requires many lifestyle changes. Access to a support group like Breezes can play a vital part.

'Coming here made my depression better because I realised I were just being mardy because when you think about it I looked round and saw everybody else I thought well you misery. I know it sounds awful but it cheered me up.'

'In between times I've been very glad of specialist nurses and people like you in particular, who we can go to for advice if we need it.'

'I'm scared to go down garden in case I had an attack. Now that I've learned with this groups and COPD that if you have an attack it's not going to be death of you.'