

COPD **LIFE**
IS CALLING™

**Insights into living
with COPD**

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This report is based on real patients' personal stories and should not be taken as medical advice. COPD patients should discuss their condition with a healthcare provider before making treatment decisions or health-related changes.

A new global programme for people with COPD

Imagine gasping for breath after taking just a few steps. Or not being able to play with your grandchildren for fear you could pass out. Think what it must be like going to the cinema and spending the whole film consumed with embarrassment because you have a persistent cough. This is the daily reality for thousands of people with chronic obstructive pulmonary disease (COPD), a chronic and life-threatening respiratory condition.

The disease has a devastating impact on patients by damaging the tubes that carry air in and out of the lungs. This leads to conditions which make it hard for sufferers to breathe such as chronic bronchitis, emphysema and chronic obstructive airways disease. By 2030, COPD is set to become the third leading cause of death globally, exceeded only by stroke and heart disease¹. Although smoking is one of the major risk factors for COPD, the reality is that only one in five smokers will develop the condition. Although considered an 'old person's' disease, COPD also affects younger people, such as those in their 40's^{2,3}.

COPD is already a serious global health epidemic⁴ with a significant impact on health services and

the economy. Many people are diagnosed late leading to worsening symptoms – sometimes even hospitalisation – which places a strain on health services, and the taxpayer due to the loss of working days⁵. The association with smoking means that patients often feel a sense of guilt, and they also experience stigma because of the link with cigarettes.

Without appropriate management, COPD negatively affects not only quality of life, but also has a significant impact on the lives of carers, friends and families^{6,7}. Many people remain symptomatic despite available treatments⁸. A new approach is needed to support people with COPD and others affected by this devastating condition.

The right support and motivational support can bring huge benefits for patients. Take for example Dee Schofield, a mother-of-six who avoided going upstairs for fear of ending up breathless. Today, Dee is enjoying life again and recently completed an eight-mile walk for charity thanks to the support of her consultant. Says Dee: 'It's (COPD) not my identity. I'm still me, I just happen to have COPD.'

'It's (COPD) not my identity...I just happen to have COPD'

Dee Schofield, living with COPD

Better understanding leading to a new approach

Novartis is committed to improving the lives of people living with and affected by COPD. In order to develop a programme that would address the difficulties and barriers faced by this community, Novartis undertook a series of interviews with people with COPD, family members, healthcare

professionals, COPD patient organisations and the media. From these insights, desk research and a long heritage in this disease area, the **COPD: Life is Calling™** initiative was developed and made available for patients wanting more from their lives.

'Hope is one of the most important things that we must hold on to... you can live without wishes but it's another thing entirely to live without hope.'

Ian Venamore, living with COPD

People living with COPD

Washing, getting dressed, walking up stairs - these are daily activities most people take for granted. Yet such activities often pose a great challenge for people with COPD. The breathing difficulties they experience when physically exerting themselves can lead to panic and embarrassment and can mean they avoid altogether activities that trigger feelings of breathlessness. This avoidance can lead to a downward spiral, making physical activity increasingly difficult and frightening. By limiting their horizons, people with COPD can become socially isolated, which in turn can lead to depression.

Friends may fall by the wayside, believing that their once active friend no longer wants to spend time with them – especially if he or she fails to confide in them about the condition (which is common).

There's an emotional burden too – some people with COPD don't want to tell their boss or their wider family for fear of being judged.

The growth of the digital environment and the availability of social media groups and forums offer another avenue of support for people with COPD. However whilst some people with COPD find online communities helpful and supportive, others find them a 'turn-off'. Our interviews with patients reveal that people who share their experiences on such sites can appear 'needy' or 'like victims' on occasion.

'I just thought 'I've got a smoker's cough...There's no point going to the doctor...because it's my own fault.'

Dee Schofield

'Humans have to achieve. If we don't have goals...you will spiral downwards into depression which is as much a killer as your COPD will be.'

Pamela Sutherland

'Stairs are a really, really good way of getting the kind of activity that you need...you can shout at The Archers (BBC radio program) while you're walking up and down.'

Paul Towning

'I find it very difficult to slow down....and that, in turn, leads to breathlessness.'

Ian Venamore

'I'm a Ferrari with no wheels. My mind works as a Ferrari but with bicycle wheels.'

Luisa Branco

'The better informed he (the patient) is, the better he can manage his disease.'

Jose Albino

THE EMOTIONAL IMPACT OF COPD

Guilt and denial are other significant emotional barriers to overcome for people with COPD. Smokers may feel they are 'to blame' for their symptoms so don't feel compelled to see their doctor – or their doctor simply doesn't recognise these symptoms to be indicative of COPD and their diagnosis is delayed. In these interviews, people with COPD revealed that they had limited understanding or knowledge about 'COPD' before their diagnosis. Coming to terms with the diagnosis can leave some in denial whilst others experience feelings of anger or hopelessness. Some continue to smoke because they are unable to overcome their addiction.

With the right support though, people with COPD can be better informed so they become more active thereby improving their lung function and breathing. Many of the people we spoke to had benefited from setting and reaching achievable goals through pulmonary rehabilitation (PR), a scheme offered in hospitals or the community to help achieve optimum breathing. Those who enjoy fulfilling lives have had to accept their limitations – they know they can no longer scuba dive or climb Machu Picchu, but are still able to travel and enjoy hobbies and interests that they had before diagnosis. The message that came across strongly through the interviews was that goals are important, but must be realistic with the person with COPD always taking the lead.

CASE STUDY: John Walsh, co-founder and president of the COPD Foundation says 'Don't be afraid to ask for somebody to listen'. In his experience, people find it hard to share their COPD stories. John is both advocate and patient – he has an inherited disease that causes genetic COPD in adults. His mother died of onset emphysema aged 46; his twin brother Freddy has COPD as does one of his sisters. For five years, doctors believed John had asthma until he was correctly diagnosed with COPD.

John travels regularly because of his job and daily activities such as carrying a suitcase can leave him short of breath if he is in a rush. At times, the reaction from others – the desire to help – can make him feel 'disabled'.

However, by managing his condition well with daily activity and planning enough time to get from A to B, he travels 252 days a year and only needs to use oxygen whilst in flight.

Ten years ago, it was a different story – John dreaded walking from the gate through passport control at Heathrow airport because he'd be 'completely out of breath!' Today, he can complete the task without stopping. His message to others with COPD is to get up and move, 'do more tomorrow than you did today', 'take action today, breathe better tomorrow!'

GOAL: John takes 10,000 steps before even starting his day and challenges himself to take 25,000 steps a day in total.

CASE STUDY: Fifty-three-year-old Pamela Sutherland's breathing is also affected by the fact she has a rare form of Multiple Sclerosis (MS). The fact she has MS too means she cannot challenge herself to do more physically, in contrast with a person who only has COPD. However, Pamela is determined not to let her ill health overshadow her life despite suffering from more than one debilitating illness.

Pamela wasn't surprised by her COPD diagnosis as she'd been a lifelong smoker, often getting through 80 cigarettes a day. In her case, the doctor said giving up smoking would have a limited effect on her breathing. Nonetheless, Pamela set herself the goal of hugely reducing her cigarette consumption, a goal she has achieved. Her approach has been to take control of her own health - she only contacts her consultant when necessary which she finds 'empowering.' It's a pragmatic decision given it can take her a week to recover from the effort of going to hospital, from getting dressed to being carried out of her flat and down several flights of stairs.

The transition from being active (Pamela was operations manager for a distance learning company and a DJ) to housebound has been a challenge - 'Handing it (housework) all over to my husband bit by bit has been painful, but you learn to not say "there's

dust on that"'. Embroidery and dressmaking, which Pamela once enjoyed, are no longer possible because she can't thread a needle. However, Pamela has found new goals to keep her focused and motivated. Three years ago she started using social media and this has now become her 'world,' inspiring her to get up every day and share her experiences online through blog posts and Twitter. Her Twitter following is now more than 74,000 and she says the feedback from followers 'lifts' her. In fact, the impact has been so great that Pamela believes the NHS should provide laptops to people with COPD.

Working out how to 'manage' her limited energy is crucial so she sets herself priorities for the day. Her day starts at 7.30am and ends at 8pm - she has a bed elevator to help her get up and wears pyjamas to save energy on getting dressed. Many people with COPD and other chronic conditions she speaks with online have experienced the loss of friends - 'anyone with a chronic condition finds that friends vanish' - but Pamela doesn't dwell on her old life instead choosing to embrace the new and adjust to what she *can* do.

GOAL: Reducing her smoking from 80 to between six to ten cigarettes a day as well as being active on social media including Twitter. She writes at least 500 words a day on her blog.

CASE STUDY: Climbing mountains and hill walking have always been passions for 58-year-old Paul Towning who lives in Ayrshire, Scotland. A COPD diagnosis six years ago though has meant Paul cannot walk 70 miles a week as he used to.

However, Paul remains focused on being as active as possible - more so than many people without COPD. 'Unless it's hosing down with rain...I'm not going to take the car, I'm going to walk...We still enjoy walking, I'll occasionally do peaks but I've got to plan them.' For him it's about activity, not exercise which he associates with gyms and 'I hate that (gym) environment.'

The fact he played an 'obscene' amount of sport when he was young and sang in a choir means that his lung function is

'much better than it ought to be...I built up a reservoir of lung capacity that not everyone's going to have.' For Paul, the keys to remaining well are to stay as active as possible and taking his medication. Although Paul has not needed pulmonary rehab, he regards it as the 'single most cost-effective intervention' because it removes the fear of breathlessness that comes with increased activity.

He's determined that Alison, his partner of 36 years, will remain his partner and not his carer and remains upbeat despite his diagnosis. He says: 'It's not a sentence to a dismal future...I'd like to die with this condition, not of this condition.'

GOAL: Cycle up to 12 miles five times a week and remain as active as possible.

CASE STUDY: Teacher and mother-of-six Dee Scofield couldn't understand why she was getting chest infections and feeling breathless. She thought she was just unfit or had smokers cough (she smoked between 20 to 40 cigarettes a day) and doctors dismissed her symptoms as a cough or wheezing. COPD was a term she had never heard until she was diagnosed in 2011 after a lung function test. This was after ending up in casualty with breathing problems: 'Every time I started coughing, I couldn't get my breath back. My daughter said I turned grey.'

When she Googled COPD, Dee got 'the shock of my life.' She says: 'I was devastated, just devastated – it was talking about prognosis in terms of years, not decades.' The fact she smoked left Dee with a tremendous sense of guilt, 'what I've done to my body, I've caused myself... There are a lot of people who have problems in life and they've done nothing to their body.'

When she was first diagnosed, Dee had begun to avoid walking, going upstairs and walking her dogs Tess and Fudge because she'd get out of breath. If she visited the theatre, Dee would sit close to the exit in

case she experienced a coughing fit. Even walking down the street was a challenge, 'I'd take my phone out and pretend I was reading a text because I'd have to stop and get my breath. I was embarrassed.' However, breathing exercises have been instrumental in her improved fitness thanks to the support of her consultant at the London Chest Hospital. He told her not to be frightened about getting out of breath. This year she also started pulmonary rehabilitation. Hills are still a challenge and she can't carry shopping but she can go upstairs and, again, planning ahead makes her life more manageable – for example she makes sure to get to the station with time to spare rather than trying to run for a train. Dee finds COPD chat rooms 'depressing' because people often come across as victims or they use these forums to moralise. Instead, her approach is to focus on researching the 'hard facts' about COPD on reputable websites.

GOAL: In September 2013, Dee completed an eight-mile walk with her family in aid of Macmillan, the cancer charity.

CASE STUDY: Married for 48 years, Ian and Judy Venamore say working as a team and taking a 'glass half full' approach to life helps them cope with their respective health issues. Engineer Ian retired in 2011 around ten years after the 'shock' of a COPD/emphysema diagnosis and Judy suffers from a chronic spinal condition.

Says Ian: 'She (Judy) has been my right hand all along. Now she is also my right and left leg, left arm...and is always there to try to do the things I now find difficult to sustain.' Judy's approach is to let Ian make his own decisions about what he's capable of - even when he is out of breath. 'He knows his own body so well...If he says 'Jude, I have to sit' then he has to sit.'

Despite their health issues, the couple who have six grandchildren travel extensively- they have recently cruised the Caribbean and the Mediterranean- and remain determined to live full lives. When Ian suffered an exacerbation on holiday, he dealt with it calmly by sitting on the ground for twenty

minutes until his breathing was under control. Says Ian: 'If you lose confidence in how to handle these situations then that will finish you.' Patience and planning ahead are also essential such as ringing ahead for a wheelchair at the airport or working out how many trips something will take to achieve.

Exercising twice a week at the YMCA is an important part of Ian's routine since his COPD diagnosis. He says: 'If you don't maintain your level of fitness you're only going to fall back to where you were before.' Walking up a hill, taking out the couple's 20ft boat or lifting heavy things are no longer possible. Yet Ian considers himself lucky in many ways- 'You can cry about what you don't have, but while you're doing that, you miss out on what you could have.'

GOAL: helping to prevent future cases of COPD and improve quality of life for fellow patients through his advocacy work with the Lung Foundation Australia.

CASE STUDY: 'It's like being underwater diving and someone pulls off the oxygen bottle,' is how 63-year-old Luisa Branco describes a COPD exacerbation. Diagnosed with COPD in 2001, she has been hospitalised twice so knows first-hand how limiting COPD can be but, as she says, 'life goes on.'

Her doctor has been instrumental in helping her learn how to conserve energy when doing everyday tasks. She's happy if it takes an hour to get up, shower and make her bed at her home in Lisbon, in Portugal, although some days this can take much longer which can leave her frustrated. Luisa, who worked as a psychologist in an institution for people with disabilities, says: 'It's like The Tortoise and Hare fable - I'll make it but at a slower pace.'

When Luisa was first diagnosed, pulmonary rehab wasn't available at the hospital where she received treatment but one has opened subsequently so there is more support for people with COPD. For Luisa, her condition

is a learning process, 'a constant fight to keep my mind sane when the body does not want to obey.' One of the biggest challenges for her has been using oxygen and she has been involved in writing a book about what it's like to travel in Europe with oxygen such as the charges made by airlines.

Luisa did smoke before her diagnosis, a habit she says was 'socially accepted' when she started. Her aim is to prevent children using tobacco and is a member of a patient support group which goes into schools to talk about the health risks of smoking. They use a device which children put in their noses to restrict their breathing and this gives a first-hand experience of what COPD is like. Her advice to patients with COPD is 'It's hard but not desperately hard and... the associations are there exactly to help people succeed together in overcoming the day-to-day difficulties.'

GOAL: Learning to use oxygen, and increasing muscular strength through pulmonary rehab.

CASE STUDY: Unlike many COPD patients, Jose Albino already knew about the disease when he was diagnosed. The 64-year-old was a pharmaceutical sales representative so knew what the impact on his life would be when he was diagnosed 14 years ago. The fact he was better informed was and still is 'incredibly important' says Jose.

Despite his diagnosis, he continues to work thanks to his treatment which includes medication. He says: 'There are things that I can't do, but fortunately, there's still a lot that I can do.' His passion is football and he still watches soccer at the Estadio da Luz in Lisbon- it just means he climbs up more slowly to the third ring than he used to. He believes vaccinations including 'flu jabs are the reason he's not had an exacerbation for 13 years. His daily treatment for COPD is also 'very simple...just one treatment.'

Jose says he has felt completely supported, from the outset, by doctors and family

especially with his successful bid to quit smoking which he did with the help of hospital cessation services. What has been important too for Jose has been setting his own goals such as going for walks- he gained about eight kilos in a short amount of time after his diagnosis and realised he needed to shift the extra weight. He says: 'I started feeling like I needed to exercise more.' Going out and dancing is what he misses most but he still slow dances so that he doesn't 'run out of breath.' 'I mostly can't do things with sudden movements,' he explains.

His view is that people with COPD should have the same rights as people with disabilities such as designated parking spaces. He also believes there should be incentives for people to use non-motorised transport such as electric cars- this would help curb the high pollution levels in cities which can trigger COPD.

GOAL: Going for regular walks

The carers – supporting people with COPD

'If we can get Australians to recognise what COPD is, that would be a huge step forward.'

Megan Rushton, retired legal secretary, Sydney, Australia

It's the carers who provide much-needed support to people with COPD, taking them to hospital appointments, offering love and understanding and supporting them during tough times. Often though, carers feel powerless to influence the lives of those

they look after for the better. People with COPD can be fiercely independent and refuse to heed healthy living messages from healthcare professionals, including quitting smoking.

CASE STUDY: Megan Rushton helped care for her friend Phyl who was diagnosed with COPD in 2010 and had been a smoker for 60 years. They first met when Megan was 18 and working in her first job as a legal secretary. Before COPD, the friends had travelled extensively together but towards the end of Phyl's life she was forced to take a taxi just to travel a few blocks from her home in Sydney, Australia, and eventually became bedridden.

'I knew nothing about COPD until Phyl went to see a specialist,' explains Megan, a retired legal secretary who herself suffers from a chronic health condition (pulmonary fibrosis). 'Her doctor told Phyl she really needed to stop smoking and she did try nicotine patches but she liked smoking too much. Phyl was always a lady who never said a bad word about anyone and she was also very determined – you couldn't tell her what to do. By smoking, she was slowly burning her life away.'

Phyl died in 2010 a few months short of her eighty-third birthday. Towards the end, Megan accompanied her to all medical appointments and saw first-hand how even walking was a struggle. 'She had a female doctor who lived two blocks from her place, so it was difficult to get a taxi because no-one wanted to drive her there,' recalls Megan. 'So I used to walk with her and we'd have to stop along the way, which I totally understand now because she'd get very breathless.'

Doctors didn't offer Phyl pulmonary rehabilitation. However, Megan believes passionately in the importance of pulmonary rehabilitation which she herself has undertaken for her own health condition. 'Get yourself to pulmonary rehab and get exercise, that's what I say to everybody...I loved it, and it was really good and you feel so much better.'

Caring for Phyl and seeing her deteriorate has left Megan determined to increase understanding of COPD. She says: '(If we can) raise the profile of what COPD is...a huge percentage of hospital admissions due to COPD could be avoided. Australians, they don't know what COPD is...But if you said emphysema or bronchitis they would know exactly what you're talking about.' Also, Megan would like see television ads which raise awareness of COPD, similar to those for lung cancer and stroke. However, in Megan's opinion, any awareness campaigns should be targeted at older people because she believes most COPD patients are over 40.

GOAL: Her mission in life is to increase understanding of what COPD is, to encourage people to exercise/be more active and to set up a register of high profile people with COPD who can draw public attention to the disease

Healthcare professionals – treating and Managing COPD

‘What works for one person might not work for another’

Associate Professor Sue Jenkins, Curtin University, Australia

‘They...start to confine their life within the constraints of what breathlessness and fatigue levels they’ll tolerate.’

Prof Sue Jenkins

‘If you get it wrong at the beginning...then you’re on the highway to the wrong regime.’

Prof David Price, University of Aberdeen, UK

‘The person lives with the disease but doesn’t need to be limited by the disease.’

Dr Nelson Marcal, CUF Descobertas Hospital, Lisbon, Portugal

‘We have to help these people know how to manage their illness, the treatment, to attribute new meaning to the changes.’

José Miguel Padilha, Escola Superior de Enfermagem do Porto (Nursing School of Porto)

Motivating anyone with a chronic and debilitating condition like COPD can be a challenge for healthcare professionals. Physiotherapist Sue Jenkins, an Associate Professor in the faculty of health sciences at Curtin University in Australia, sees people who are ‘passive’ towards their disease because of underlying guilt related to smoking. This ‘self-blaming’ mean some people keep their diagnosis hidden and may fail to engage with activity programmes on the grounds that their condition is ‘incurable’ and ‘self-inflicted.’ ‘I still think a fair number still feel guilt,’ says Professor Jenkins. ‘The symptoms and breathlessness...only really impact when they have probably lost about half of their lung function and they think ‘Well, I’m middle-aged...I’m a bit unfit and do a bit less.’

Diagnosis can also be delayed because many people avoid seeing their primary care physician – it’s estimated that up to 85 per cent of those with COPD are undiagnosed⁹. ‘Most people with COPD don’t even realise they have COPD,’ points out to respiratory expert Dr David Worsnop. ‘What that (epidemiological study called BOLD) has found is that most people with COPD don’t even have the diagnosis...it happens for a number of reasons. One is that the cough they just put it down to being a smoker’s cough and they don’t really think it’s an illness. They don’t want to be told that they have an illness so they avoid going along to see someone about it.’

BARRIERS TO DIAGNOSIS

COPD is diagnosed with a spirometry test which measures how much air is exhaled and how quickly. Some doctors such as David Price, Professor of Primary Care at the University of Aberdeen, believe spirometry testing needs to more widely available. He says: ‘It’s trying to make the diagnostic services readily available for people. That’s probably the most important thing we can do globally. I’m a great

believer in what I call micro spirometry to rule out COPD, these are handheld cheap spirometers... they are adequate for ruling out high blood pressure (COPD can lead to high blood pressure in the arteries)’. Some doctors will prescribe antibiotics instead of conducting these tests which can delay diagnoses. ‘Friday afternoon, five o’clock: ‘Can I have some antibiotics? My chest is a bit bad’. It’s so easy

for doctors to say 'Here's some antibiotics, come back if you're not better' rather than actually stopping and thinking 'Does this person have COPD?'" says Professor Price.

Unlike asthma, COPD symptoms build up gradually with people only experiencing breathlessness when they've lost around half of their lung function. At this point, many start to impose restrictions on their activities in order to avoid becoming breathless which can create panic and fear. Unless they break through this pain barrier says Prof Jenkins, people face a

'downward spiral' of being less and less active. One of Professor Jenkins' patients was involved in karaoke and couldn't carry the machine but felt 'inadequate' letting a woman do this. Another wouldn't get for a drink with his friends for fear of becoming breathless. And in another example, a patient couldn't keep up with her friend's walking pace so stopped going to the cinema. 'She's been avoiding going rather than saying to her friend: 'You go ahead and join the queue and I'll see you.' explains Professor Jenkins.

ACCESSING SUPPORT AND INFORMATION

The stereotype of COPD is a person wearing an oxygen mask yet many people appear 'normal'. This in itself is a challenge because the public and those around them don't know or believe they have a health problem. It can mean they don't get the right support – one well-meaning carer would buy large cartons of milk to save money for the person she looked after – but they didn't have the energy to pour them.

Again, these interviews highlighted concerns about misinformation. Information is widely available from a variety of sources however not all sources are reliable. Healthcare professionals say that some people obtain inaccurate information about COPD. Ideally, information should be sought from patient-led organisations dedicated to COPD awareness

although incorrect information can even be proliferated between people with COPD themselves.

GPs only have a few minutes allocated for each patient appointment. But this is not long enough to address the needs of people with COPD. For example, a GP appointment only lasts ten minutes. The term 'COPD' can also be a stumbling block to awareness. People simply don't know what it means and they do not realise the importance of being active, according to some healthcare professionals. 'I don't think GPs have the time to spend with them (COPD patients)', says Professor Jenkins. 'Practitioners might spend longer but it needs reinforcing (goal setting).'

SMOKING CESSATION: THE RIGHT APPROACHES

Smoking is responsible for accelerating the progression of the disease and for ongoing experience of symptoms according to Dr Worsnop. 'If they don't give up smoking, their lungs just keep declining.' For this reason, smoking cessation programmes are crucial in both preventing COPD and improving the quality of life of those who have already been diagnosed. Cessation programmes appear to be widely available in countries such as the UK and Australia. However people with COPD who have been smoking for many years find it incredibly difficult to give up. Working with patients, rather than dictating to them, and providing a supportive environment is key in helping them to stop according to Professor Price. This involves making patients 'feel better' through medication, he says. Professor Price said he had a 'patient 'many years ago' who had been told by another doctor she was not allowed treatment until

she stopped. 'The doctor gave her a week to stop smoking...(I said) 'Obviously we need you to stop smoking but I also want you to feel better'...she came back to see me (after treatment) and was substantially better. It was interesting that she said to me 'Doctor. Can I talk to you about stopping smoking?'

There may be no 'cure' for COPD but people need to remain hopeful that they can improve their quality of life. Professor Price says this is why it is important that doctors and nurses take a positive approach towards people with COPD and not write them off. Following someone through their journey from inactivity and breathlessness to an improvement in their health is hugely rewarding, he says. 'Some doctors don't know what to do for them (COPD patients). Doctors want to save people, they want to walk on water- it's about going on that journey with the patient and seeing them improve,' says Prof Price.

THE PATIENT/DOCTOR RELATIONSHIP

Given the age profile of many people with COPD, some are not receptive to advice from healthcare professionals several decades younger than them. They may even find the man in the corner shop or the woman in their support group more credible. Cultural and language barriers also exist for people from immigrant and refugee communities, according to Prof Jenkins. 'We've got people now who are... fairly recent refugees, who have been referred who have very poor English and going to a healthcare professional is probably very, very different.' Continuity of care goes some way towards tackling these issues. If someone is seen by the same doctor each time they visit the clinic or hospital, they are more likely to build a relationship with them. Professor Jenkins recalls one example where a patient, a professor of chemistry at Cambridge University who had worked in Australia and who had never exercised in their life, signed up for pulmonary rehabilitation because his doctor 'believed' in him. She says: 'There's some evidence that when a doctor endorses a person going to pulmonary rehab they're more likely to actually turn up...he (the professor of chemistry) would never have got here had he not had a lot of faith in his particular doctor.'

Patients fall into two categories, according to nurse José Miguel Padilha from Escola Superior de Enfermagem do Porto (Nursing School of Porto). There are those who make positive changes to their behaviour so they can manage their symptoms better.

And others who present with advanced symptoms such as breathlessness, he says, because they haven't adapted their lives. In his view, it is essential for nurses to help patients realise what the illness is in the initial stages 'and this goes beyond the matter of knowledge and awareness'- they have to be helped to make positive changes. Miguel says that if these changes are not made then patients whose symptoms are identified later can end up 'bedridden, totally dependent on others and inevitably their quality of life is very low.' This has a knock-on effect on family as well as on society. In his view, a multi-disciplinary approach which includes occupational therapists and other healthcare professionals is 'essential' to reduce the impact on Emergency departments for example. Better co-ordination would also reduce work absences for patients with COPD.

A supportive doctor/patient relationship involves the healthcare professional understanding what it's like living with COPD on a daily basis. Dr Nelson Marcal, from the CUF Descobertas Hospital, Lisbon, Portugal, says it is the simple tasks which patients find such a challenge such as taking a bath. He says: 'The steam that stays in the bathroom becomes something almost suffocating, and so they (the patient) have to take a bath with the door open.' One way doctors can support patients, he says, is teaching them 'energy-minimising' strategies so they can carry out everyday tasks.

BARRIERS TO PULMONARY REHABILITATION ENGAGEMENT

Research shows that activity such as pulmonary rehabilitation can reduce flare-ups (exacerbations). Those people with an exercise 'history' are more open to pulmonary rehabilitation. Yet it is estimated that only one per cent of people in Australia for example take part in these programmes and around half of current smokers quit before completing a pulmonary rehab programme, according to Professor Jenkins. Possible reasons for this may be that people avoid activities which leave them breathless, the high transport costs of getting to and from the centre, a lack of transport and that people who still work may find it difficult to take time off. Dr Worsnop comments: 'If you go out into the country in rural areas it's (pulmonary

rehab) is much less common- they just don't have the facilities. The other thing...even though it might be available here (in cities) it's not necessarily suitable for everybody because they might have difficulty getting to the hospital if they don't drive, if they can't use public transport.'

Where pulmonary rehab is offered, healthcare professionals stress the importance of participants first learning exercise techniques in a group setting which is reinforcing and ensures that they will be able to perform them at home. 'They learn that pushing yourself, getting breathless is not going to kill you' says Dr Worsnop and people can also

come back and repeat the programme a year or two later. 'So it's not just a one-off eight weeks, 'you've done the programme, see you later.'" Participants must also realise that these techniques are for life, not for just a couple of months. Initiatives such as texting reminders about exercise can be effective in motivating people. Programmes must be flexible, accessible, self-managing and targeted at individual

interests such as gardening, singing or playing with the grandchildren. Says Professor Price: 'I try really hard to find out what they want to do. So if they want to play bowls, they want to go dancing, do the garden or play with grandchildren then I always try and mix it in with what they want to do. It's motivational work if you like.'

REALISTIC GOAL SETTING

The terms fitness and exercise can scare people – encouraging people 'to move' or 'be more active' can be more effective. Goals set as part of these programmes and by healthcare professionals must be realistic and developed in collaboration with the person with COPD. If people can't see the benefit or have a setback getting them back on course can be difficult. Professor Jenkins believes that an effective approach is motivation interviewing, a type of goal-setting centred on the individual which grew out of talking to people about smoking cessation. 'We say (to patients): 'What do you want to achieve out of this? What were your goals coming here? What do you want to get out of it? And then we say: 'Well, what can we do to help you do that? What can you do to help yourself?' This empowers people to set their own

goals. First, they identify what they personally want to achieve and the healthcare professional then asks them what they've achieved later on.

As for treatment, the cost of drugs can limit access for some. In countries such as Australia and Canada people under the age of 65 have to pay a proportion of the cost of medication. Furthermore, not everyone gets good symptomatic relief from their medication and will stop taking their medication if it doesn't make them better. Non-adherence to treatment can trigger a downward spiral. Dr Worsnop says doctors have a responsibility 'not to just write out prescriptions and hand over inhalers.' They must ensure they monitor people with COPD properly.

Patient associations – supporting people with COPD

'The mind is set up to avoid pain... people subconsciously avoid doing things that they know will give them symptoms.'

Vicky Barber

'They're carrying quite a lot of guilt and...think they're going to be victims in a public arena because people blame the smoking.'

Monica Fletcher, chair of European Lung Foundation and chief executive of Education for Health

'It's like having a piece of string which is a mile long and you can be anywhere on that piece of string,' says Vicky Barber. As a nurse who runs a helpline for COPD patients, Vicky gets to see first-hand the suffering and anxiety experienced by people with the condition. And she also knows that no one patient is the same- every person has different needs and each one is at a different stage in their disease progression.

Receiving a COPD diagnosis can be a harrowing experience. Vicky, who works for the British Lung Foundation, often receives calls from people believing they're going to die after looking up COPD symptoms online. She says: 'The common thing that leads to a nurse hotline call is 'I've just been diagnosed with COPD and I looked it up online and I'm going to be dead in two years' time.' She says it's important people take time to go away and come

to terms with the fact they have a chronic condition: 'Everybody takes time to process things, but very often it will lead to maybe four or five calls because people want that initial reinforcing and reassurance that they're going to be ok...emotionally people need time to process that information.'

COPD is a complex condition that affects people with different degrees of severity. That means people require individualised care plans and interventions. There's no 'one size fits all' solution. Quitting smoking is the single most important intervention for COPD patients, according to Monica Fletcher, chair of the European Lung Foundation and Chief Executive of Education for Health, who says these interventions need to be 'far more aggressive' with more support. She highlights the Barcelona FC campaign Quit Smoking with Barca which had huge appeal because people relate to sportspeople. Quit smoking and sign up for pulmonary rehab or get active is Henry's advice- 'If you live basically a

healthy...lifestyle, get lots of rest, you're more able to lead a more or less normal life.'

Pulmonary rehabilitation is generally available but not always accessible as already highlighted in this report. These exercise and education programmes are sometimes provided in hospitals, not in the community, and that means there may be costs for parking or people have to travel long distances. Some cities do offer transport schemes. Henry Roberts, from patient association COPD Canada which has 3,000 members, highlights Sprint, a service run in downtown Toronto where volunteer services take people to pulmonary rehabilitation sessions for a nominal fee. However, Henry revealed that outside major cities, the nearest programme could be as far as 400 miles away. 'There's a lot of those things (like Sprint) available in major urban centres...but once you start getting out into the hinterlands which is most of the country (Canada), you don't have those services,' he points out.

PATIENTS: DEALING WITH A COPD DIAGNOSIS

The interviews with patient associations showed that most people with COPD have not heard of the condition before diagnosis, and that they often dismiss their symptoms simply as 'smokers cough'. Once diagnosed, there's little understanding of how the condition will affect them and people's reactions vary. Some feel relieved they don't have cancer, others blame themselves for smoking and there are those who become angry that no one warned them about the dangers of tobacco.

People obtain general information about COPD from a variety of sources including websites. On the one hand, the web can provide a valuable resource and help people to reach out to organisations for support. But on the other, online information can be inaccurate. To address this, Monica Fletcher has helped create information cards. These cards are printed with advice on how to check that the online information sources they are using are reputable. She says: 'Is it a good website or a poor website? And we ignore that...at

our peril if we don't actually start to think: 'We've got a third person in this consulting room.'

Women are more likely than men to reach out for help from patient associations, as well as non-smokers who are less likely to feel guilty about their condition. Retired people are also more likely to be involved with patient associations as they have more time than the working population. Overall however, the more determined a person is to improve their life and the less advanced their condition, the more likely they are to seek solutions from these organisations.

This is the experience of the British Lung Foundation (BLF). Over many years, the BLF has encouraged people with COPD to be more active through Breathe Easy groups, local support charities and online resources that give guidance on how to become more involved in media and research. Vicky says: 'The best effect is actually to exercise and keeping their daily... breathing exercises.'

THE IMPORTANCE OF APPROPRIATE SUPPORT

Emotional support from loved ones is essential, although they can also unwittingly hinder the progress of loved ones with COPD. Relatives may reinforce limiting

behaviour by fetching the remote control for their husband/wife instead of encouraging them to get up from the sofa. Says Monica: 'You've got a relative,

maybe your husband, sitting on the sofa out of breath. What do you do? You give them the remote control for the television. The best thing for him is to get up and be able to turn that knob! They may find it difficult that their partner can no longer do as many activities or even simple housework chores, and this can then breed 'resistance' from the person with COPD who feels put-upon. The debilitating nature of COPD can place a strain on relationships with some couples splitting up which in turn can lead to social isolation and depression. Some of the issues couples face when one partner has COPD are 'hugely intimate,' according to Monica. 'We've got a cottage (on holiday) and we want to lie by the fire together and I can't, I get out of breath.'

Emotional support from patient associations is also important to people with COPD. This is illustrated by the following inspiring examples:

- A woman who is back singing again after giving up choir - Vicky helped a patient who gave up the chair

because singing made her feel breathless. What Vicky did was provide her with breathing exercises to help overcome the fear and anxiety this woman felt. Says Vicky: 'She actually just dropped me an email to say that she's gone to Church on Sunday and sung in the choir.'

- A man who took up painting after diagnosis- Henry says painting has now become a great 'passion' for a COPD patient he knows. Says Henry: 'The patient has to be their own greatest advocate. You're in charge of your own health care...but knowing you're not alone is invaluable.'
- A gardener with COPD who helps at the allotment- Monica worked with a man, a professional gardener, who set himself the goal of supporting others at the allotment. This enabled him to enjoy a social life and give something back to the community, thus creating a sense of self-worth and value.

THE COPD COMMUNITY AND ITS PROFILE

Patient associations are generally proactive in using social media to provide information and a sense of community for people with COPD. However, Henry says the older age of the COPD population is a factor in them not being as vocal as, for example, the HIV/AIDS community. 'The conclusion I've come to is age...it's a very old population and when you're 65

and unwell you don't have the kind of energy you used to have. The AIDS community tends to be younger,' he adds. Patient organisations also expressed concern during the interviews about respecting confidentiality and privacy. Vicky points out that 'it's quite difficult as a nurse using social media because...it could be quite easy to be in breach of some confidentiality issues.'

COPD GUIDELINES: ANOTHER CHALLENGE

Another challenge for people with COPD and those working with them is that guidelines on respiratory care can be difficult to understand. This can be confusing for less experienced healthcare professionals, according to Vicky. 'We have national guidelines (in the UK) but we also have local guidelines and often people are working to a local guideline which is (written) by a person who has no respiratory qualifications whatsoever.' Some doctors and nurses, adds Vicky, who are less familiar with COPD go as far as to tell people with COPD that there's not much they can do for them.

The biggest challenge for people with COPD is breathlessness. They actively avoid doing exercise that makes them feel out of breath because it can be a frightening experience. This avoidance 'mind-set' can lead them into a cycle of decline and depression

unless healthcare professionals help them set realistic goals. Simple techniques can help them overcome feelings of anxiety and take up exercise. Research suggests that singing can help relieve breathlessness and improve mood. Vicky sometimes advises people to use weights to keep thigh muscles strong and enable them to carry shopping to the car without feeling breathless. She motivates people with COPD by inviting them to put the past behind them and focus on improving their diet and activity levels for their good health in the future.

Says Vicky: 'You have to focus on health, you have to focus on drinking enough water, having a great diet, and dealing with any anxiety that comes up. Because people are going to have symptoms every day which trigger anxiety.'

The media – raising the profile of COPD

‘You have to find a new way of seeing an old issue.’

Belen Diego Serrano

‘Stories about old people tend to blend together with all of the chronic conditions...it all goes into this big basket.’

Belen Diego Serrano

Coverage of COPD remains limited in the mainstream press. It's not that journalists are unaware of the condition. Rather, that there are no

medical ‘breakthroughs’ considered to be of interest to their editors or readers.

BARRIERS TO MEDIA COVERAGE

Journalists feel that the term ‘COPD’ can be confusing and a barrier to understanding, which was a view also expressed by patients and patient associations. According to journalist Belen Diego Serrano, editors don't know what this acronym stands for and it doesn't tell the reader anything about the disease itself - the term ‘emphysema’ conveys a greater meaning. ‘The fact that it's an acronym...doesn't help at all. I'd rather call it emphysema...it would be a lot easier to go with a word, no matter how ugly a word or how unfamiliar,’ she states. This contrasts for example with the term ‘cancer’ which everyone understands.

The fact that COPD affects older people results in it being lumped together with other health issues related to ageing rather than receiving dedicated coverage. She says: ‘Stories about old people tend to blend

together with all of the chronic conditions...it's like ‘Oh yes, old people with this and we have to pay for their medicines’...it all goes into this big basket.’ Belen feels that although the public do view COPD as a serious disease ‘it's not a condition that people associate with death or at least not imminent death’ unlike cancer which is seen as more life-threatening. However, she doesn't believe that the association between COPD and smoking is a factor in the limited news coverage. Her view is that the public is sympathetic to a generation of smokers who were not aware of the negative health effects related to smoking: ‘People don't judge people with COPD - not like say HIV...people smoked and they didn't really know what they were doing.’

SOCIAL MEDIA AND ONLINE COMMUNITIES

There is a sense that COPD patient associations are not as active online as in other disease areas. In her interview, Belen says she has had limited exposure to these groups. They generally have few interactions with the media to promote their ‘cause’ or raise awareness. This contrasts with conditions such as MS or cancer where online communities are very active and patient organisations have sophisticated media teams who have well-developed relationships with journalists. This is unfortunate as social media channels provide a source of stories for journalists. The internet is also a powerful tool

for journalists to make contacts with healthcare professionals and people with COPD directly. There can be a downside as activists can easily target journalists with negative comments about treatment, organisations or experiences, Belen highlighted a personal example where a story she published about vaccines elicited hundreds of responses from mothers opposed to their use.

There are opportunities to increase coverage of COPD through awareness campaigns and new or novel approaches to the disease. New facts and figures on COPD are important for generating

interest in stories. Belen says that a new study or data that gives a regional breakdown of how many people are affected by COPD, especially in large countries like Spain, would have considerable appeal. She says: 'For national media, data on how many people affected in different regions or nationally, prevalence.' Research linking COPD to environmental factors such as 'the connection with increasing air pollution' would be very topical according to Belen, and a forward-thinking patient association may be able to launch a broader public-facing initiative off the back of this. For example, Belen suggests a cycling initiative to improve lung function or a traffic reduction scheme to reduce air pollution. In her opinion, COPD could be a 'big political issue'. Politics is always a draw for editors who also give more attention to stories they can personally relate to. That COPD is associated with a high mortality rate is also of 'attention grabbing' interest to editors.

There is no doubt that COPD has an effect on the economy and is a burden on health services. Figures demonstrating how much money could be saved through more effective treatment programmes would raise the profile of COPD and be of interest to journalists. Diseases such as diabetes have achieved widespread coverage using this strategy. 'Because the sustainability of the healthcare system is in jeopardy and we have to find a way to make it work, the cost of COPD to society...would be a great story,' Belen says.

There are of course cultural differences that influence how the media reports news in different environments. What 'makes' a story also differs from publication to publication. For Belen, case studies are not a draw. In the UK however, these often provide a 'peg' for a feature or can lead to a story receiving greater prominence on the page.

FINDING A VOICE FOR COPD

For Belen the opportunity to spend time 'in the shoes' of a person with COPD was both eye-opening and compelling. She was invited to take part in the 'straw test', an experiment where she breathed through a straw whilst walking upstairs – thus recreating the lung capacity and breathlessness that a person with COPD might feel on a daily basis. 'It showed you how it felt to be a patient and that was a great approach to the media.'

Conditions which have been considered taboo in the past such as HIV now enjoy greater media profile and improved awareness amongst the public. How can the COPD community replicate this success? Again, the age profile of someone with COPD and the term 'COPD' along with the lack of a recognisable public 'face' are barriers. To overcome these barriers requires people with COPD to become more vocal, to share their stories and to talk more openly about the condition with those around them and with the media.

COPD IN THE MEDIA: A DOCTOR'S VIEW

Doctors believe media coverage of COPD is limited because there haven't been any major treatment advances for some time. 'Journalists don't see it as a 'sexy' subject,' says Professor Price. The language used to describe the condition can be over-medicalised, such as 'exacerbation' for a flare-up, and therefore a barrier to public understanding. Even the term 'rehabilitation' has associations with drug addiction. And Dr Worsnop says that other patient

groups have 'just been better organised at attracting media attention...I think that by the nature of the disease it's more difficult because it's in older patients who may not be so savvy in working with the media.' The message that needs to come across in the media is that whilst COPD is a progressive disease, with the right treatment and management, people with COPD can get on with the things that they enjoy.

Conclusion

This report highlights the impact this condition has on the lives of people with COPD. Many feel a sense of guilt and that they are to blame in some way for their condition. COPD robs many of the ability to socialise, to work and to carry out daily tasks which others take for granted. The overwhelming finding of the interviews is that these are incredibly brave people determined to make the best of their lives. With the right support, people with COPD should be able to take control of their condition to live a life that is, whilst different perhaps to before, still worthwhile and full of activities that they enjoy.

The key messages include:

Goal-setting

People with COPD must take the lead in setting themselves realistic challenges that increase their activity levels e.g. spending time playing with their grandchildren or doing the grocery shopping. This will reduce social isolation and depression as well as improving quality of life. Box-ticking by doctors won't achieve the same results.

Pulmonary rehabilitation

This is a vital tool in enabling people with COPD to overcome the panic they feel when they have difficulties breathing. All programmes must include follow up support and ensure that participants understand this condition is for life, not just the short-term. Access to programmes must be improved.

Terminology

The acronym 'COPD' is a barrier to understanding for the diagnosed, the public and the media.

Public awareness

The public does not realise that COPD is a global health concern. The association with smoking limits interest and empathy from the public. However, older people with COPD were not told of the dangers of tobacco when they started smoking, and highlighting this fact could help overcome stigma towards smoking-related illness. More education is needed to increase public knowledge and awareness of the disease and its impact.

COPD community

Our interviews highlighted that the COPD community is not vocal enough. Some people with COPD feel that the online community come across as 'victims' which is off-putting. People with COPD need to be encouraged to share their stories in a way that is both real and positive.

COPD: Life is Calling™

Taking into account all of the above, and in particular the importance of goal-setting and the need for positive stories, Novartis has launched a new global online community, **COPD: Life is Calling**. Via a website (www.copdlifeiscalling.com) and Facebook page, **COPD: Life is Calling** brings together people living with COPD from around the world, and provides a platform where they can challenge themselves to take positive steps towards overcoming personal limitations imposed by their condition.

By seeing what is possible it is hoped people with COPD will be inspired to not accept their own current limitations, but to find new ways to share and express the things they enjoy (with the support of their healthcare providers).

Please visit our website to find out more www.copdlifeiscalling.com.

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