



COPD Self-Management: A Patient–Physician Perspective

Michael Coakley · Michael Drohan · Elaine Bruce · Sylvia Hughes · Neil Jackson · Steve Holmes

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ABSTRACT

This article is co-authored by five patients living with chronic obstructive pulmonary disease (COPD), and a primary care physician who has over 30 years of clinical experience and is involved in educating healthcare professionals. The first section of this article is authored by the patients, who describe their experiences of living with COPD. The section that follows is authored by the physician, who discusses the management of COPD in the context of the patients' experiences.

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M. Coakley
Patient Author, Dublin, Ireland

M. Drohan
Patient Author, Waterford, Ireland

E. Bruce
Patient Author, Carrigbyrne, Ireland

S. Hughes
Patient Author, Limerick, Ireland

N. Jackson (✉)
Patient Author, Bath, UK
e-mail: bigjacko@bigjacko.com

S. Holmes
The Park Medical Practice, Shepton Mallet, UK

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SECTION 1: PATIENT EXPERIENCES

COPD Diagnosis

The trigger for our initial medical investigations tended to be chest infections, breathing problems, coughing and bronchitis. Other triggers included the need for an explanation for a persistently sore chest or our changing behaviour—a way to explain to people that we were not just sleepy or lazy, a bit overweight or out of shape.

A COPD diagnosis can have a big impact on your mental health. It can be difficult to accept a disease, especially when you know the physical limitations that lung deterioration will bring. Reactions to the diagnosis included tears, fear, shock and depression. All sorts of questions came into our mind, such as “what about the kids?” and “what about work?”. The diagnosis seemed like a death sentence—“stage 3” sounded like cancer... does this mean that I don't have long to live? Other reactions included panic and not really taking things in properly. We felt shell-shocked and doomed. Having seen friends and relatives with COPD become very sedentary, moving from couch to bed (or toilet) and not a

lot more, younger family members were heart-broken. Certainly, researching on Google was very scary, to the point of inducing very negative thoughts. Thoughts of death were even on the mind—"is it time to get our affairs in order if time is short?"

Information at diagnosis tended to be general—improve your diet and exercise—without a proper explanation of COPD or how to use the inhalers we were prescribed. We all wish we knew then what we know now. The key is to understand the importance of lifestyle changes—you can't do as much as other people, but you can live a long, happy and fulfilled life. You just need new skills: new ways to breathe, advice on how to get the phlegm up more easily, and how to be physically active while giving yourself time to catch your breath. Planning ahead, so you can do things at your own pace, is important too. That, and realising you have the power to manage your COPD, helps to keep away the depression.

Self-Management

A self-management plan can feel like you are on your own at first, that there is not much which can be done for you. That mindset soon evolves into finding daily coping strategies to help manage your COPD, which prepares you for what you can do if things get worse. By consistently working on the day-to-day challenges, you can do a lot to reduce the risk of infections and exacerbations.

Ultimately, you are in the best position to judge what's going on in your body. Understanding that you can be in control of your COPD, rather than it being in control of you, is key to shifting your mindset. Even though COPD is a progressive, incurable disease, the feeling of being in control makes a real difference. By learning to spot certain signs, you become your own warning alarm. For instance, a symptom like green phlegm can indicate an infection, and may therefore require medical advice regarding antibiotics. Taking control also means making sure you get the best out of your inhaler, by using it regularly and with the correct technique. Knowing that it is possible to

stabilise your decline in lung function gives you a lot more confidence in your ability to control your symptoms. Spirometry is also a key tool for monitoring your progress. In the same way that mechanics provide you with detailed information about your car after a roadworthiness check, doctors should trust their patients with similar information about their health, providing regular and detailed information about lung function (spirometry), symptoms and other aspects of COPD.

For many of us, pulmonary rehabilitation was the catalyst for self-management. There are huge benefits to pulmonary rehabilitation: some people report feeling 10 years younger; for others, it helps them deal with loneliness by connecting with other people. Once you begin exercising, it quickly has a positive effect on your body and your breathing. It also highlights the need to learn more about your medications and why you need to take them regularly alongside physical exercise. Doing this takes away a lot of the fear and reduces the stress. While medication is useful, it is not the only answer: a combination of pulmonary rehabilitation, exercise and a support network is really what makes the difference. Nutrition is also important, and virtual conferences such as World COPD Day and World Health Day provide healthy recipes and help to explain why a good diet is needed.

In terms of daily routine, you wake up to your alarm, get out of bed (eventually) and go to the bathroom. It's only after a few minutes of "normal life" that you remember that you have COPD, and then it dawns on you: you're functioning with only half your lungs working and everything requires extra effort. During the day, you may forget about your condition again until you go to climb some stairs and have to stop to regain your breath before you can continue. This can be disappointing, and also embarrassing if people see you pausing for breath on the stairs. There are many situations that someone with COPD will find awkward, difficult, hard, impossible, or an absolute nightmare to contemplate, but often you don't know until they happen. Some days, showering is simple; other days, you can push yourself that bit too much, and the combination of water temperature, tiredness, room temperature difference, and even level of

steam or pungency of the shampoo are enough to set you off. Obviously, there's the realisation that running for a bus is an absolute impossibility, but as a car driver, that's not normally an issue. But if someone has parked too close to your door, and you have to squeeze yourself in, the feeling of breathlessness that follows can feel like a "near-death experience", even when you've experienced the same situation many times before.

You tend to plan things in your day to avoid entering that "grey area" of risk. This means leaving more time for things, not rushing, going out when the crowds won't be as large, or researching the layout of anywhere new you are visiting, for example, locating any stairs or tight spaces. Having a carer on hand to lean on, hold a hand, or just "talk you down at a moment of crisis" is a real benefit, but it's not always possible. Remaining positive—especially in public—is so important, and you can always cry later at home when no one's looking. You have to remind yourself that nobody's perfect, and if you make it on your own, the feeling of empowerment is a real endorphin boost and makes it worth the extra effort.

COVID-19

The effects of coronavirus disease 2019 (COVID-19) were far-reaching. Isolation from your family, even while living in the same house, had major effects on your mental health. For many of us, the loneliness and depression made us withdraw from society, and we lost motivation to wash or dress ourselves. Over time, this even led to thoughts of not wanting to live. All of this combined with the physical discomfort of struggling to breathe with a mask on! You became a hermit, suffering from the effects of severe boredom due to sitting at home all day. Frequent coughing caused people nearby to worry that you have COVID-19 and keep their distance. Even your own family felt they had to withdraw due to fear of infecting you, which was very difficult to bear. There was a general sense that you are not safe. You live in fear—fear of crowds and fear of getting COVID-19, which could amount to a death sentence. You start to drop out of

exercise, of singing courses, slowly becoming more inactive. You put on weight and became more lethargic. It felt like being in a war. You try to stay strong, putting on your tin helmet and somehow pushing through, just hoping you'll come out alive on the other side. Although it was hard, you just had to keep faith that your exercises and day-to-day routine would help you survive this period.

All of us experienced major disruptions to our routine medical care. It was not possible to see a respiratory doctor, with little or no spirometry and no medication reviews for three years—just a lot of time spent on lengthy waiting lists. You felt totally abandoned, without the backup of your normal healthcare professionals (HCPs), the only silver lining being that GP practices were now able to email pharmacies for repeat prescriptions, making access to our medications easier. Because of the lack of face-to-face care, there was no choice but to persist with day-to-day self-management strategies, like going out walking early in the morning and late at night.

Support Groups and Online Tools

Online tools were invaluable during the COVID-19 pandemic, with many support groups moving online. WhatsApp was used for group singing in the morning, helping to lift spirits. Some of us also took part in an initiative called "Sing Strong", established by the charity COPD Support Ireland, which taught us useful singing and breathing techniques. Exercise classes were also held online, with many people sharing messages and jokes on WhatsApp to motivate each other and stay positive. Importantly, online channels made it easier for us to check in on each other and connect to our family through platforms such as FaceTime. However, even with everyone being so connected, we all felt the impact of the lack of human contact.

Effective self-management includes knowing who you can talk to when things get tough, be it a family member or friend on the internet... even someone you can talk to at 3 am when you need to. Being able to join support groups that have expert patients and guest HCP speakers was very beneficial. It really helped to

talk with other people who knew what you were facing, and who were fighting the same battle, although it was still difficult when you saw people at the end of their journey.

We have all benefited from several fantastic tools and resources, and we hope that other patients will too. These include World COPD Day (<https://goldcopd.org/world-copd-day-2023/>) and World Health Day (<https://www.who.int/campaigns/world-health-day/>) websites. National COPD support organisations, such as COPD Ireland (<https://copd.ie/>), also provide valuable information, for example, the COPD and Me information booklet (<https://copd.ie/wp-content/uploads/2021/10/COPD-Me-Booklet-2021.pdf>).

Conclusion

COPD is a condition that you can live with for many years and manage in many different ways. It is something that you can control to a large extent, rather than you being controlled by it.

Once the initial shock from the diagnosis passes, and you realise that COPD is not a death sentence, it is clear that with the appropriate knowledge and support, patients are able to live a fulfilling life. For this to happen, a good relationship with your doctor is vital, as is active engagement with external support networks. Living with COPD means having to adjust your way of life and plan better to overcome the challenges you may face. Nevertheless, it is possible to live a full life and not be defined by your disease. You begin to understand that COPD is simply something you have, but it will never be something you are.

SECTION 2: PHYSICIAN'S RESPONSE

Introduction

I thank the patients for sharing their collective experience of living with COPD. HCPs can learn much from listening to their patients to better understand their lived experience, including their needs and feelings [1].

COPD Diagnosis

As described by the patients, reactions to a diagnosis of COPD can include tears, fear and shock, and it's important that HCPs are aware of these reactions and able to respond to them—indeed, they should anticipate and prepare for this situation.

HCPs working in palliative care typically receive training on how and when to break bad news [2, 3]. For significant diagnoses, patients are often offered the option of taking someone they know to their initial appointment for moral support. Unfortunately, this isn't always the case with COPD. Some clinicians don't consider how the diagnosis might affect patients in terms of non-health-related issues, such as work, family, friends and hobbies. A well-established care model that promotes consideration of not only the physical aspects of a disease but also the social and psychological aspects is the triaxial model, in which the HCP, patient and caregiver all share input on care [4]. Within this, clinical input can be enhanced if the clinician breaking the bad news understands the patient's history and current situation, and where any explanation is based on the patient's ideas, concerns and expectations of their health and treatments [5]. Understanding the patient is key to this, and asking questions such as "What do you understand about X, Y or Z?" or "Which areas are you most concerned about?" is a very useful approach.

Language can also play a big part in how a diagnosis is received. Although COPD is a serious condition, global COPD guidance (e.g. the Global Initiative for Chronic Obstructive Lung Disease [GOLD] report) acknowledges that there are effective interventions to improve overall quality of life and reduce exacerbation rates and other symptoms. Many people with stable, well-controlled COPD will adapt to their condition and minimise its impact in a similar way to people with types of arthritis, colitis and many other long-term conditions. So, it's important to mention the positives and describe COPD and its impact carefully. It is also important to carefully consider the language we use, and training and continued

professional development regarding communication skills should be considered for all clinicians. A simple example of how language can lead to confusion is a “negative” test result; this may sound like good news to an HCP, but may sound like bad news to a patient, who may associate the word “negative” with a bad result. Similarly, a “positive” result may sound like good news to a patient, but it may be used to diagnose a particular condition.

HCPs should also bear in mind that people respond differently to being diagnosed with COPD (or any significant condition). Their reactions will depend on what they know about the condition, what they have read and what their friends have told them. Some patients will be in shock at the time of diagnosis and find it hard to take in information, so it’s important that HCPs direct them to reliable sources of information that they can browse at their own pace (e.g. materials produced by national healthcare bodies, professional societies or patient charities [6, 7]). HCPs should also consider recording their consultations so the patient can relisten to their appointments [8], providing digestible amounts of information (often termed “chunked” information) verbally [1, 6, 7, 9], and directing new patients to expert patients (who have lived experience and are happy to talk to others with the condition) [10, 11].

The diagnosis process is further improved when the clinician involved is expert enough to confidently answer and address a wide range of possible questions from the patient; however, this is becoming increasingly challenging, as many patients now have easy access to expert information online, which can result in complex, specialised questioning. Fortunately, many clinicians have developed strategies to manage this, including highlighting incorrect information and weaknesses in information, providing education on the limits of online information and encouraging the use of reliable sources [12, 13].

In summary, interactions between clinicians and patients at and following diagnosis are of critical importance for establishing an effective partnership for care management. Clinicians need to understand the patient, use careful language, provide people with chunked

information about their condition, give them some time to process it and ask them to come back in a few weeks to discuss their questions. Hence, planned diagnosis appointments (where patients are offered support) and follow-up appointments (where patients can ask questions) should be a part of routine good practice. Unfortunately, appointment availability and time constraints within many healthcare systems can make delivering this kind of care challenging.

Self-Management

The notion of self-management of diseases has been around since the 1950s, and there are plenty of written plans out there for people with COPD [14]. However, an effective self-management plan requires an understanding of an individual’s ideas, concerns and expectations. It needs to be personalised for the patient, not written for the professional—it’s not about simply handing out a plan and ticking a box. Ultimately, self-management plans require us to move towards a care model where clinicians and patients make decisions together (often referred to as “shared decision-making”) [15], rather than a paternalistic model in which HCPs make decisions based on what they believe to be in the patient’s best interests, and effectively tell the patient what they think the patient should do [16]. After all, patients may spend only a few hours of the year with their physician, so for the remainder of the year they are going to have to self-manage.

Typically, each patient receives (or should receive) 1–2 routine reviews with their physician each year (according to guidelines) [17, 18]. They should also have a consultation whenever they have an exacerbation (on average, once per year), plus a follow-up appointment after each exacerbation. Other consultations may focus mainly on other problems, so with the limited time allocated to each consultation, the time spent discussing COPD with their HCP each year may be as little as 30–40 minutes spread over 4–5 consultations. For the remaining 360+ days, patients have to manage themselves.

Another major barrier to this type of care is the lack of continuity in patient care across

the healthcare sector. I have spent lots of time in rural communities, which has given me the opportunity to see the same patients repeatedly, often over many years. This continuity enables you to develop a deeper understanding of each patient's needs and to deliver personalised treatment and care [19]. However, this is an exception, not the norm. Unfortunately, in general, continuity of care is worsening because of the systems we've developed to manage high healthcare demands. The number of doctors has dropped, particularly in primary care. The intensity of work has also risen, and many clinicians have reduced their hours [20]. This has been partly alleviated by other HCPs, e.g. specialist respiratory nurses, carrying out work (often excellently) that was previously done by primary care physicians [21]. However, this does not appear to have reduced pressure on the system, which has been further aggravated by the recent COVID-19 pandemic [20, 22].

The lack of continuity in patient care is exacerbated by poor communication within the healthcare system. In addition to the slow communication of non-digital patient records, the use of templates has limited the data captured in digital notes. Although templates promote the collection of standardised, relevant data, they do not allow the physician to capture data on some of the more individualised aspects of problems that affect patients [23]. This is unfortunate because addressing patient preferences is essential to providing personalised care plans. Otherwise, it is very difficult to personalise recommendations around exercise, nutrition, smoking cessation, medication use and emergency treatment. Therefore, many good clinicians record not only medical information, like the number of exacerbations a patient has had, but also personal information (for example, their hobbies and things that motivate them to want to change). Patients will often tell you their ideas, concerns and expectations about COPD and the care they receive, which helps you to understand what motivates them. It's about working with people to help them stay positive and manage their disease as effectively as possible.

For some people, social prescribing [24] can be fundamental to forming effective self-management strategies. For instance, local walking

and singing groups can improve breathlessness and exercise capacity in patients with COPD [25–28]. Global COPD guidance advises assessment and monitoring of symptoms and exacerbation history as part of ongoing review, together with regular (annual) spirometry tests for monitoring lung function [17, 29]. Indeed, it can be very useful to show a patient stable (i.e. non-progressive) lung function test results, and such tests can also be used to help patients who have undertaken pulmonary rehabilitation or an exercise programme recognise that being fitter allows them to get a lot more out of life. However, it is important to remember that at an individual level, smoking status, symptoms, exercise capacity, exacerbations and lung function (FEV_1) do not predict whether COPD will progress; it is only when considered together that they can predict progression [30].

COVID-19

It is well documented that many patients experienced limited or no access to regular healthcare during the COVID-19 pandemic [31]. Patients were told to stay at home to protect themselves and save the National Health Service [32, 33]. Consequently, many people with COPD limited their physical and social activity during lockdowns, which had three negative outcomes: (1) isolation and loneliness increased depression rates [34, 35], (2) fears and anxiety concerning infection rose [36, 37], and (3) many patients experienced physical deconditioning as a result of reduced physical activity [33].

Despite this, the pandemic accelerated the use of remote healthcare services, with some clear benefits. Phone consultations, emails and the digitalisation of prescriptions and test results proved to be extremely valuable. Many of these approaches are now here to stay; however, as previously suggested, remote services should complement, not replace, face-to-face healthcare services [38], even during a pandemic. It is vital that we learn from this and prepare for ways in which to maintain face-to-face services within future shielding programs.

Support Groups and Online Tools

As highlighted by the patients, patient support groups, such as Breathe Easy in the UK [39] and peer-to-peer support groups and exercise classes set up by COPD Support Ireland [40], are incredibly beneficial. It is crucial that physicians are aware of such groups and can recommend them to their patients if they are available—and we should be encouraging patient charities and local community groups to support and develop these. Throughout the pandemic, many support groups adapted very well from being face-to-face to being online [14]. However, in the UK, funding appears to have declined for these services over the last 5 or 6 years. Some organisations that switched to remote services have not resumed face-to-face interactions, with many of these groups having closed entirely. For patients who prefer face-to-face groups, this is a huge loss of support. In Ireland, by contrast, post-COVID funding is driving nationwide expansion of the network of peer support and exercise groups [41].

Although patient-to-patient support and advice is extremely valuable, there is also a role for HCPs in support groups, including remote groups. However, COPD can change over time, so patients must be wary of comparing their health to that of others in their group. HCPs who regularly see patients with the same conditions are likely to be aware of relevant changes and can guide patients through them. Additionally, online resources can be extremely useful, and emerging technologies are available that can enable patients to self-monitor their disease and establish the likely cause of acute exacerbations [42], thereby helping patients to feel supported in managing their condition and improving their day-to-day quality of life. However, there is a lot of misinformation out there. Moreover, some information, such as adverts for medical products, may not necessarily have a patient's best interest at heart. It's therefore essential that HCPs direct their patients towards local support groups, which typically have some HCP involvement, as well as reliable sources of online information.

It is crucial to remember that the growing role of digital health has the potential to increase inequality in healthcare [43]. The pandemic led to a huge increase in the number of people who were willing and/or able to access online services; however, this isn't possible for everyone. Vulnerable populations (including the elderly and homeless), individuals living in deprived areas, and immigrants may not have the technology and/or language skills required to access online services. Additionally, those who do have access may not be offered online services as a result of unconscious bias on the part of HCPs.

Conclusion

Moving forward, we need to improve communication around the time of diagnosis. We need to promote early engagement between patients and appropriate support groups, and provide them with links to useful, reliable sources of information. We also need to remove negative language and focus on how people can manage their condition and live well, including people who lack access to online tools. Ultimately, we need to move towards a healthcare model where patients and HCPs are partners in learning and decision-making.

After all, the Canadian physician William Osler famously said, "listen to your patient, he is telling you the diagnosis" and "the good physician treats the disease; the great physician treats the patient who has the disease". Together, these phrases highlight the need for physicians to not only listen to their patients but to understand their story—that is, to understand their individual ideas, concerns and expectations regarding their health and treatment [44, 45].

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Declarations

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