



Supporting someone
with breathlessness



As the patient becomes more unwell - COPD

Symptoms can change for people living with breathlessness – they can become more difficult to manage. Some carers have found it helpful to know what to expect, so that they can feel more prepared.

What to expect

It is likely that the patients' symptoms will get more intense at some stage. They may need more medical appointments, hospital visits or treatments, as well as support from others with daily living.

*'Expect more trips to the hospital and know that you are certainly not failing'
– 'Phil', former carer*

It isn't possible to put a timeframe on how someone's symptoms may change in the later stages of living with COPD. For some, symptoms may gradually get worse over a number of weeks, months or even years until the patient dies. For others, they may go through several ups and downs where their symptoms suddenly get worse (often requiring urgent medical help), then become a little better again. This can be a particularly upsetting time for these patients and their carers, particularly if the COPD has been under control for a while. For some people, these ups and downs with symptoms can become a pattern until the patient doesn't improve and dies. Carers can also find it difficult to adjust to times when things are much calmer, and there is less for them to do.

*'We couldn't believe it when the phone rang and they told us he'd died. You know, it was like "this can't be true". You know, "he's been like this so long"
– 'Lisa', former carer*

Sudden changes can sometimes happen in COPD patients' symptoms. It may be that at some point the patient will not be able to say for themselves what they want to happen, so it's important to have talked together, ahead of time, about what to do about future treatment decisions. For example, it might help to talk about whether they would like to have an **Advance Directive or an Advance Decision to Refuse Treatment**. The Macmillan website has more information about what these are – although the Macmillan website refers to cancer, this information is relevant to COPD too. Visit <https://www.macmillan.org.uk/cancer-information-and->



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support/treatment/if-you-have-an-advanced-cancer/advance-care-planning/advance-directive

Common symptom changes

When caring for someone with breathlessness due to COPD, there are some general changes in symptoms to look out for as the illness progresses. This is not a complete list, and how each patient's symptoms change will be unique to them. You will be better able to judge whether the patient's symptoms are changing if you have a clear idea of what is a normal baseline level for them. If you have any concerns or questions talk to your health care team – they are best placed to give you advice about the person you care for.

You might notice:

- more breathlessness
- wheezing – usually a higher pitched noisy breathing
- chest tightness
- a need to clear the lungs of mucus everyday
- a lack of energy
- a loss of appetite and weight loss
- more infections and flare ups – you can learn more about this on the [Managing infections](#) page of the website.

What you can do to help the patient

Talk to your health care team (e.g. district nurse, specialist nurse or GP) if you find it difficult to manage any symptoms the patient has. They may recommend the patient has a respite stay.

Look at the Macmillan website for helpful advice on **how you can manage some of the difficult symptoms** patients can have towards the end of their illness at home. Visit <https://www.macmillan.org.uk/cancer-information-and-support/treatment/if-you-have-an-advanced-cancer/end-of-life/the-last-few-weeks-of-life#46699>

Please keep reading onto the next page



The impact on emotional health

It's common for carers to feel drained, both physically and emotionally, as the patient's symptoms start to worsen and they rely on you for even more support. You may feel you have very little time for yourself. At times like these it's especially important to try and **look after your own health** and well-being even though you may feel reluctant or unsure about doing so. You can learn more about this on the [Looking after your own health](#) page on the website.

*'A lot of people said (to me), "Cor, you've lost weight". But, of course, you do, you know – anxiety and stress and everything'
– 'Cathy', former carer*

What you can do to help the patient

More often than not, the patient will also be struggling with difficult emotions as symptoms change. Some patients may start to withdraw from their normal daily life. Encouraging the patient to talk honestly about their feelings can help. This could be talking with you, with other family or friends, or with a trained professional such as a nurse or counsellor.

'I don't think my mum had ever really told me how she was struggling. She would always try and put a brave face on it' – 'Greg', former carer

Have a look at our videos

There are two videos about this topic on the website that you may find useful:

- **'Advance decision to refuse treatment orders'** where you can learn what 'Advance decision to refuse treatment orders' are and why it's important that carers and patients make arrangements to have one
- **'As the patient becomes more unwell'** where you can learn what symptoms to expect as a patient with COPD becomes more unwell and ideas for how to manage them

Last reviewed: 08/05/2020