



Supporting someone
with breathlessness

Accessing care and support - COPD

Knowing how to get the right kind of support for you and the patient is important. Particularly if the patient's illness starts to get more difficult to manage and you need more medical help, sometimes urgently. There can be many different people involved in the patient's care, and it can be difficult to know who to ask for help and when.

The importance of being a 'carer'

Other carers have told us that taking on the label of 'carer' can help get access the right support. Make sure the healthcare team know that you are the person supporting the patient and the key role you have in this. This can help you get the support and information you *both* need.

If you are not keen on the word 'carer', try and think of it as a 'magic word' to help you and the patient get support.

It can help to think of the label of 'carer' as the key that opens doors to help and support for you and the patient.

Who might be on the healthcare team?

It can be difficult to know what each healthcare professional does and how they can help. Below is a list of people that may be providing care for the patient, and what they do. If you are ever unsure about what a healthcare professional does or (what their role is) they will be happy to tell you if you ask. Knowing how your care team works will help you and the patient understand who can help and when.

In COPD care it is common to have several different specialists as part of the healthcare team – some common types of healthcare professionals who might be involved include:

- GP / family doctor
- Respiratory consultant – a doctor who specialises in diagnosing and treating people with lung diseases
- Physiotherapists
- Specialist respiratory nurses
- Lung function technicians – specialist technicians who run tests to diagnose lung diseases



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- Palliative care team – doctors, nurses, pharmacists, and other healthcare professionals who work together to manage symptoms, such as breathlessness, pain, or fatigue

Visit <https://copd.net/basics/healthcare-team/> to read more about **what COPD healthcare professionals do.**

Levels of care in the UK

It can be tricky to understand how healthcare is provided in the UK. If you are ever unsure about what someone means when they use any terms to explain the patient's care, just ask and they will be happy to explain what they mean to you.

- 'Primary care' is a term used to describe the first point of contact for people in need of healthcare – this can include the GP surgery, dentists and pharmacists
- 'Secondary care' is usually hospital care – either planned care (like outpatient appointments) or urgent medical care (like going to Accident and Emergency)
- 'Tertiary care' is highly specialised, consultative treatment usually for inpatients (hospital or hospice) or on referral
- 'Acute care' usually means hospital care such as Accident and Emergency, inpatient, outpatient medicine, surgery and specialist medical care – most inpatient stays under 'acute care' are for a short time
- 'Long-term care' is usually given to people who have serious, ongoing health problems – it usually involves a variety of different services often delivered in the home or in a care home

What is palliative care?

Palliative care is not just for people close to death.

Some people might get palliative care for weeks, months or even years before the end of life. Palliative care helps make sure patients are as comfortable as possible, by managing the symptoms of illnesses that can't be cured. It is an approach in which the whole person is cared for, not just their symptoms.

Some carers and patients misunderstand what palliative care is and can feel shocked when their healthcare team suggest a referral to a palliative service, thinking the patient is about to die. Talking to a palliative care team early on can help guide you both in later treatment decisions.



Helpful tip

During emergencies, you may be asked to repeat details of the patient's medical story (their medical and care history) to each healthcare team that you meet e.g. ambulance services, emergency department teams. This can cause you and the patient additional stress.

It can be helpful (if the patient agrees) to have key notes about the patient's medical story already written down to share with the healthcare teams.

You may find using the 'Medical story' template below helpful for this. There are two versions – a Word version in case you want to download and type in the story, and a PDF version in case you want to print it off and write in the story by hand. You don't have to use them – they are just there for you in case they are useful. The Supporting Someone with Breathlessness website will not be able to see or keep any information you put on these templates.

You may find using our template helpful for this.

[Medical story \(Word, 59KB\)](#)

[Medical story \(PDF, 458KB\)](#)

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