

# Palliative care for patients with COPD

**Vastgesteld op:** 08-03-2021

**Methode:** evidence based

**Regi houder:** LAN

**Gegenereerd op:** 29-04-2026

**Bron:** <https://palliaweb.nl/richtlijnen-palliatieve-zorg/guidelines/palliative-care-for-patients-with-copd>

# Inhoudsopgave

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## Summary

## General

- Start providing palliative care if two or more of the following situations apply:
  - a negative answer to the ‘surprise question’, ‘Would I be surprised if this patient died within the next 12 months?’;
  - physical, psychological, social and/or spiritual symptoms and/or problems which are unacceptable to the patient, in spite of optimal disease-oriented treatment, and which lead to a lower quality of life;
  - poor physical condition (severe limitations in their activities, dependence for everyday activities, Karnofsky performance status  $\leq 50$ );
  - underweight, established based on the following factors:
    - low BMI ( $< 21 \text{ kg/m}^2$ ), **and/or**
    - unwanted weight loss of  $> 5\%$  over the past 6 months or  $> 10\%$  over a longer period ( $> 6$  months), **and/or**
    - low fat-free mass index ( $< 17 \text{ kg/m}^2$  for men, or  $< 15 \text{ kg/m}^2$  for women);
  - severe breathlessness (MRC score of 5: too breathless to leave the house, or breathlessness during dressing/undressing);
  - FEV1  $< 30\%$  of predicted value; - (start of) long-term oxygen therapy or respiratory support at home;
  - one or more hospital admissions for COPD exacerbations per year;
  - serious comorbidity (e.g. pulmonary heart disease, chronic heart failure, renal insufficiency, diabetes mellitus, cancer); - ‘milestones’ such as:
    - statement of incapacity for work;
    - hospital admission involving invasive or non-invasive ventilation;
    - decision that the patient is not eligible for a lung transplant or for bronchoscopic or surgical interventions to reduce lung hyperinflation;
    - overburdened informal carer;
    - necessity of relocation or adjustments to the patient’s home.
- Pay attention to all dimensions of being ill – physical, psychological, social and spiritual – and use an interdisciplinary approach. Provide basic palliative care in all these areas. Ensure early detection of symptoms and problems for which consultation and/or referral is necessary.
- Have regular conversations (at least annually and more often if necessary) with the patient and their loved ones to review the situation, their understanding of it, their health literacy and other skills, and their wishes. During these conversations, address the symptoms and how these affect the patient’s ability to function physically, psychologically, socially and spiritually, while also paying attention to the burden of their disease. Explore the patient’s thoughts and wishes relating to the future and treatment goals. Discuss their prognosis, if possible and if so desired.
- Continue disease-oriented treatment aimed at symptom relief for as long as possible.
- Start symptom-oriented palliative care if the symptoms are unacceptable to the patient and/or if they experience psychological, social or spiritual problems in spite of optimal disease-oriented treatment.
- During palliative care in the terminal phase, it is important to pay particular attention to burdensome symptoms and signals and to focus your actions mainly on making the patient comfortable, alleviating their suffering and improving the end of their life.
- Involve the patient’s informal carer and loved ones actively in the patient’s care. Pay attention to the health literacy and other skills, financial means, workload, values, wishes and needs of the informal carer and loved ones of the patient, both during the disease process and after the patient’s death.
- Consult the other guidelines for palliative care if necessary ([www.pallialine.nl](http://www.pallialine.nl)).
- In case of symptoms which are difficult to treat and/or other complex problems, ask experts or a specialised palliative care team for advice, and/or refer the case to specialised healthcare providers.

## Advance Care Planning (ACP)

- Address the topic of ACP with the patient in a timely manner, and involve their loved ones. Use the criteria listed previously and clues given by the patient to decide on the right moment.
- Topics that may be addressed during such conversations are:
  - an assessment of what the patient knows about their disease, and what their expectations are;
  - their world view / spiritual ideology and cultural background;
  - preferences regarding (life-sustaining) treatments, including (non-)invasive ventilation;
  - fear of suffocation;
  - hospital admissions;
  - preferred place of care and place of death;
  - crisis situations (including refractory symptoms);
  - living will;
  - legal representation in a situation of rapid deterioration and legal incapacity;
  - end-of-life wishes;
  - bereavement care.
- Record agreed ACP preferences and decisions in the patient's file and in their individual care plan.
- Talk to the patient and their loved ones at least annually and more often if needed about their life goals and choices, to see whether these have changed.

## Organisation of care

- Make sure there is communication between healthcare providers involved at home and in the hospital at least once a year, to discuss the way the treatment is going as well as any changes to the patient's medication, treatment arrangements and care.
- After hospital admission, an outpatient consultation or an ACP conversation, inform the other healthcare providers about the treatment arrangements agreed on and the patient's wishes for the end of their life. At least bring their GP up to date, in writing and preferably also by telephone. The GP should in turn inform the hospital clinicians, in writing and preferably also by telephone, about any treatment arrangements agreed on and the patient's end-of-life choices as well.
- Agree with the patient who is their central healthcare provider, and offer to engage a dedicated specialised nurse.
- The central healthcare provider should draw up an individual care plan with the patient.
- Review the individual care plan at least annually, but more often if necessary.
- If patients with advanced COPD are eligible for palliative care they should be registered as such with the out-of-hours GP centre.
- The team of healthcare providers involved will consult with one another, with input from the patient and their loved ones, at set times and if necessary on an ad-hoc basis, to assess the patient's well-being and care requirements. Review the preferences and decisions recorded in the individual care plan at least annually and more often if necessary. In family medicine, consultations will preferably take place in the form of a PaTz group ('palliative home care group') or similar interdisciplinary meetings. In hospital, these consultations will preferably take place in the form of interdisciplinary meetings, for which the patient's GP may also be invited.

## Information provision

- Provide information to the patient and their loved ones about:
  - the nature of COPD as a disease;
  - the possible course of the disease and the uncertain prognosis;
  - the influence of lifestyle;
  - physical symptoms (especially breathlessness, cough, fatigue) and mental symptoms (e.g anxiety and depression) as well as treatment options;
  - position and transfers;
  - financial and practical matters;
  - organisation of care.
- Adapt the information provision to the wishes and health literacy skills of the patient and their loved ones.
- With regard to information provision about breathlessness:

- Recognise the impact and variability of breathlessness.
- Get a clear picture of the expectations, views and concerns around breathlessness.
- Explain that breathlessness can get worse as a result of anxiety, worrying and unconstructive thoughts.
- Proactively ask whether the patient has a fear of suffocation, and explain that suffocation does not happen with COPD. Provide information on options for symptomatic treatment of breathlessness, including palliative sedation in case of refractory breathlessness in the terminal phase.
- Encourage the patient to self-manage their health. Discuss:
  - which measures, lifestyle changes and non-pharmacological options they can use themselves to prevent or relieve symptoms;
  - recommendations on the use of medication;
  - when and how they can ask for help, e.g. in case of an exacerbation;
  - the extent to which physical activity and mobility can be supported;
  - how the patient can maintain a social life;
  - their physical and emotional balance.
- Bring up smoking and stigmas and guilt with regard to smoking addiction (past or present). Discuss giving up smoking.
- Support the information you provide with leaflets, and draw attention to relevant websites.
- Provide information to the patient and/or their loved ones about possible support from the following people:
  - fellow COPD patients;
  - general practice-based nurse specialist;
  - physiotherapist;
  - respiratory nurse specialist;
  - occupational therapist;
  - speech and language therapist;
  - dietician;
  - pharmacist;
  - social worker, psychologist or general practice-based nurse specialist for mental health;
  - people who offer support to informal carers;
  - spiritual counsellor.

## Psychosocial and existential problems

### Anxiety and depression

- For every patient with COPD, check whether they have anxiety or depressive symptoms and discuss these problems with the patient.
- In case of doubt about the presence of anxiety or depressive symptoms, use a screening instrument such as:
  - for anxiety: HADS or BAI;
  - for depression: HADS, BDI, GDS or PHQ-9.
- Educate patients about anxiety or depression to prevent these conditions.
- Refer patients to a general practice-based nurse specialist for mental health, a psychologist or a psychosomatic physiotherapist.
- If there is an indication for pharmacological treatment:
  - In case of anxiety: if the life expectancy is >3 months, preferably an SSRI, and if the life expectancy is <3 months, preferably a short-acting benzodiazepine.
  - In case of depression: SSRI (1st choice) or a tricyclic antidepressant, depending on the presence of (relative) contraindications and comorbidity, and potential side effects, previous experiences, price and patient preference.

### Social

- Together with the patient and their loved ones, discuss what is important to them when it comes to social care needs, and of what support is required.
- Review and assess the nature and severity of the concerns, problems and risks experienced by the patient and their loved ones.
- Discuss with the patient and their loved ones what the options and expectations of the informal carer are.

- Explain the patient's situation to the informal carer and discuss how they can support the patient. Provide information on relevant support options.
- If appropriate, bring up the topics of intimacy and sexuality with the patient and their partner.
- Pay attention to the financial means, workload, values, wishes and needs of the informal carer, and offer support to prevent or reduce possible overburdening.
- Provide bereavement care to the patient's loved ones and/ or informal carer to help them deal with their loss and grief as well as possible.

### **Spirituality and sense of fulfilment**

- Discuss the spiritual dimension with the patient and their loved ones. The questions from the 'diamond model' of the Mount Vernon Cancer Network may be of use here.
- In such discussions, pay attention to:
  - spirituality and sense of fulfilment;
  - the link between disease progression and reduced spiritual well-being
  - existential loneliness;
  - emotional exhaustion;
  - worrying about the future;
  - fear of death;
  - loss of hope;
  - loss of dignity.
- If you feel that you cannot offer the patient and/or their loved ones the spiritual care that they deserve, refer them to a spiritual counsellor or someone who shares their world view, unless particular expertise (e.g. of a psychologist or medical social worker) is indicated, for instance in case of an existential crisis.

### **Breathlessness**

- Refer the patient to:
  - a physiotherapist for breathing exercises and possibly inspiratory muscle training to reduce their breathlessness;
  - a speech and language therapist (in case of problems with the connection between breathing and voice);
  - an occupational therapist for breathing exercises and advice on proper breathing regulation during activities and on posture;
  - a centre for home ventilation in case of chronic hypercapnic respiratory insufficiency;
  - a centre for bronchoscopic lung volume reduction in case of hyperinflation and emphysema (after consultation).
- Recommend the use of a rollator for support.
- Recommend the use of a fan (possibly a handheld fan) aimed at the face.
- With regard to oxygen therapy:
  - In case of an exacerbation, provide short-term oxygen treatment, while waiting for bronchodilators, corticosteroids and/or antibiotics to become effective. Try to end the use of oxygen after treatment of the exacerbation, depending on the patient's symptoms.
  - Consider trying oxygen treatment in case of severe breathlessness in the final weeks or months of the patient's life, if they do not respond to opioids and nonpharmacological interventions. Assess the effect after a number of days and continue the treatment if it appears to be effective.
- In case of an MRC breathlessness score of 4 or 5 in spite of optimal disease-oriented treatment and non-pharmacological symptomatic treatment:
  - Start with:
    - 5 mg IR oral morphine as needed, up to a maximum dose of 30 mg/24 h. In case of predictable breathlessness, 5 mg of oral morphine is given 30–45 minutes before the triggering event; or
    - 10 mg SR oral morphine twice daily, with an extra 5 mg IR oral morphine as needed; in case of insufficient effect, the SR morphine may be increased to 10 mg 3 times daily or 15 mg twice daily.
    - If 30 mg IR or SR morphine per 24 hours does not have an effect, or if the effect is insufficient: discontinue.
    - If subcutaneous administration is opted for: 10 mg subcutaneous morphine per 24 hours, or 2 mg 6 times daily, or 2 mg as needed.

- In case of contraindications or intolerance to morphine:
  - 5 mg SR oxycodone twice daily, or
  - 5 mg IR oxycodone as needed, or
  - 12 mcg/hour transdermal fentanyl. Stop giving oxycodone or fentanyl if there is no effect or if the effect is insufficient after 1 week.
- Consider benzodiazepines in case of breathlessness and anxiety.

## Dry tickling cough

- Discuss giving up smoking with the patient.
- Treat triggers (if present and if possible):
  - bacterial infections (paranasal sinuses, ears, airways, lungs);
  - post-nasal drip;
  - aspiration;
  - reflux;
  - side effects of medication;
  - comorbidity (e.g. heart failure, lung cancer) as a cause of the patient's cough.
- Start symptomatic treatment if their coughing leads to other symptoms or deterioration thereof and/or if it has an impact on their quality of life:
  - Consider referral to a speech and language therapist for cough-suppressing treatment.
  - If the measures mentioned above do not have sufficient effect:
    - Consider treatment with 10 mg SR morphine twice daily and/or IR 5 mg as needed.
    - Consider 5 mg SR oxycodone twice daily and/or 5 mg IR as needed in case of a contraindication to morphine.
    - Consider 12 mcg/hour transdermal fentanyl if oral administration of morphine or oxycodone is not desirable or not possible.
    - If strong opioids do not have sufficient effect, consider using oral gabapentin or pregabalin, nebulized cromoglycate or lidocaine, or an SSRI (paroxetine or sertraline).