

# El Enfoque Paliativo desde el diagnóstico hasta el final de vida en las personas con EPOC

*Sesión intermensual Paliativos  
15 de junio 2022  
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REUNITE | EVALUATE  
ADVANCE.

11<sup>th</sup> IPCRG WORLD  
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Desktop Helper No. 3

# Improving the life of people with COPD by integrating a supportive and palliative approach from diagnosis to end of life

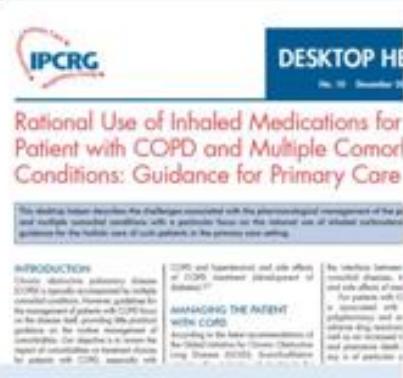
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With special thanks to Anna Spathis (contributor) and  
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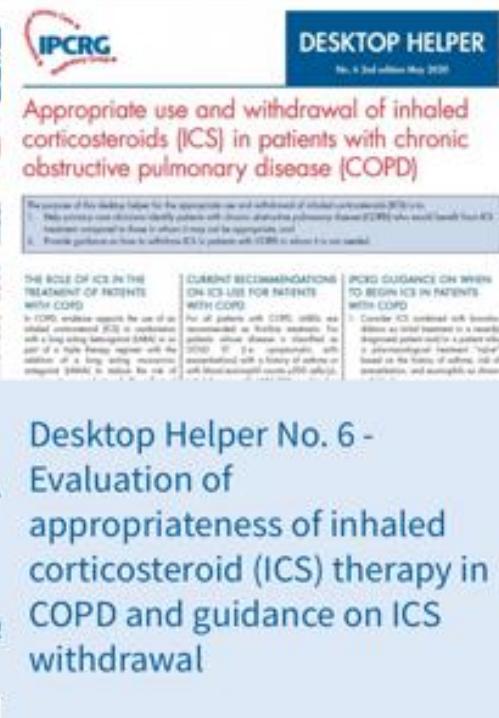
*Breathing and feeling well through universal access to right care*



# Los Helper de IPCRG



**Desktop Helper No. 10 - Rational use of inhaled medications for the patient with COPD and multiple comorbid conditions: Guidance for primary care**



**Desktop Helper No. 6 - Evaluation of appropriateness of inhaled corticosteroid (ICS) therapy in COPD and guidance on ICS withdrawal**



**Desktop Helper No. 7 - Pulmonary rehabilitation in the community**

## DESKTOP HELPER

No. 3 April 2022

# Improving the life of people with COPD by integrating a supportive and palliative approach from diagnosis to end of life

This desktop helper supports a long-term, holistic approach to chronic obstructive pulmonary disease (COPD) management. The course and prognosis of COPD can be difficult to predict. Care is directed towards enhancing the quality of life of the individual and their family, slowing progression, reducing symptoms and preventing exacerbations, which is why palliative approaches are useful from the time the COPD diagnosis is communicated. It is important to remember that 'palliative' is a broad term for approaches that address individual needs across the spectrum of COPD.<sup>1</sup>

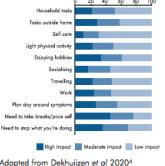
## INTRODUCTION

People live with COPD from years to decades, experiencing a lower quality of life (QoL), and greater functional limitations, anxiety and depression than others who are the same age without COPD. These potential significant changes in QoL and expectations from life may be improved with enhanced care, highlighting the need for a long-term and holistic approach to support people with COPD and their carers.<sup>2</sup> Care selection is based on repeated discussions during the evolving prognosis and symptom trajectory, identifying and minimising distressing symptoms and ensuring medical, physical, social and spiritual support. This may include support to access a supportive and financial core package from social care and other non-medical services.<sup>3</sup> From beginning to end, COPD must be treated using a stepped approach, including for COPD and its common co-morbidities such as cardiovascular disease (CVD), depression or anxiety, diabetes, renal disease, lung cancer and osteoporosis. Treatment must be based on appropriate pharmacological and non-pharmacological interventions and knowledge of the person's functional status and goals of each stage of COPD stabilisation and progression (e.g. evaluated at least annually). Variations will depend on the local availability of healthcare and therapies, cultural norms and the individual's beliefs and goals.

## IMPACT OF COPD

COPD is a chronic disease that impacts every aspect of life and is often diagnosed after months or years of people reducing or eliminating activities to lessen breathlessness or feelings of exertion or fatigue. For people living with COPD, the challenges may be due to a combination of factors including common comorbidities such as heart disease or anxiety.<sup>2,3</sup> COPD lowers overall QoL, including social interactions, mood, energy, family life and self-care (Figure 1).<sup>4</sup>

**Figure 1: The high burden of COPD. International survey of people with COPD receiving maintenance therapy**



## INCLUDING THE PREFERENCES OF THE PERSON WITH COPD IN THEIR LONG-TERM CARE

A crucial step in long-term care that includes care planning is understanding the individual's current state by assessing symptoms burden (perhaps using the COPD Assessment Test available at <https://www.ipcrg.org/capt/>), functional ability (e.g. ability to do what matters most) and social support (family and social interactions, self-care), the frequency and severity of exacerbations (e.g. may be labelled as episodes of 'bad colds' or 'cough flus'), and ideas, concerns and fears about the future (e.g. as being independence, ability for self-care and the need to live in a 'nursing care facility'). The individual with COPD and their family may share feelings, frustrations and concerns about the future of their health and care team and we can also use this information and these team members, help

to open important discussions. People living with COPD respond us — 'If you ask us questions then LISTEN to our answers'<sup>5</sup> (Table 1).

Table 2 provides questions to guide discussion on long-term care to help you explore the broader aspects of care and identify those areas of greatest importance to each individual.

An important advantage of care continued over months and years is that the conversations are built upon our previous discussions — our knowledge is cumulative and evolves. Understanding and documenting how the individual can best benefit from planned goals, future plans and end of life care/living/wills, can ensure their preferences are recorded and available when care needs change, particularly if hospitalisation. These questions can be set in the Open questions, Affirmation, Reflective listening, Summarising (OARS) framework (see the IPCRG Desktop Helper COPD and more at <https://www.ipcrg.org/dh121/>) that helps establish and maintain a holistic and attending to each and all of the person's needs, irrespective of life expectancy.

**Non-drug treatments**  
Evidence-based smoking cessation is the most effective treatment to slow progression of COPD in people who are tobacco dependent (see the IPCRG Desktop Helper patients quit tobacco)<sup>6</sup> and employ the Ask, Advise, Act approach of every consultation. Success will be improved if tobacco dependence management and support services such as 'quit lines' are also used.<sup>7</sup>

**Drug treatments to be used in conjunction with non-pharmacological interventions**  
Related breathlessness are the first line COPD pharmacotherapy.<sup>8,9</sup> Whenever possible, use long-acting single or dual bronchodilators which can improve breathlessness and oxygen saturation while reducing symptoms and ease people also risk the risk of future complications.

**Learning about community resources**  
To make plans, people need to know what is available to them. Information on local and regional resources needs to be gathered and shared with the person, in their home, home visits and telephone video visits may show you where and how the person with COPD lives to facilitate better understanding of opportunities to support their interests and needs for care with COPD and any associated comorbidities.

See how Seneeth Samanayake, a GP in Sri Lanka uses a palliative approach using the resources available in his community in our online Supplementary material S2.

**Table 1: The perspectives of people with COPD—what my healthcare team needs to know**

1. My healthcare team needs to know who I am and what my functional status is and what my goals are. Without this baseline, many of the conservations take too long or are irrelevant.
2. Ask me 'What is a usual day's activity like for you? What have you had to give up or modify over the last few years? What do you not want? e.g. I never want to go to a nursing home.'
3. Ask me 'What are your thoughts about your life over the next year or if your COPD gets worse? This is something that is often done during in-person visits where the clinician can read body language and have more success.'
4. Ask me 'What do you and your family want us to know and put in your medical record about your goals and future plans?'
5. Many of us don't know what we don't know or what to ask. Let us know what our options are by sharing information, a website link or someone to talk to.
6. Finally, if you do then LISTEN to our answers.'

Thanks to the people with COPD who allowed Barbara Town to interview them.

**Table 2: Questions to ask to guide broader care and to record in the medical record**

- Essential questions to ask of each visit:
- What brings you here/today this visit?
  - Any special concerns from you, your family or your carer?
- Questions to be asked subsequent visits to help to develop an understanding of:
- What is your understanding of where you are with your COPD at this time?
  - What are your fears and worries for the future?
  - What are your hopes for the future?
  - What outcomes/consequences/results would be unacceptable to you?

See our online Supplementary material S3 for additional questions to help with your conversations with individuals and their families. Listen to author and surgeon Alia Gwadra discuss the importance of these 4 questions to understand people's priorities of care (<https://www.ipcrg.org/dh044.pdf>).

## ACTIVELY MANAGING SYMPTOMS INCLUDING BREATHLESSNESS

People with COPD may have many symptoms including fatigue, cough, depression, anxiety and sleep disturbance that each require 'relieving' (symptom relief) treatment. These can be offered by evidence-based care clinicians holistically and attending to each and all of life care/living/wills, can ensure their preferences are recorded and available when care needs change, particularly if hospitalisation. These questions can be set in the Open questions, Affirmation, Reflective listening, Summarising (OARS) framework (see the IPCRG Desktop Helper COPD and more at <https://www.ipcrg.org/dh121/>) that helps establish and maintain a holistic and attending to each and all of the person's needs, irrespective of life expectancy.

We have identified data to present different levels to evaluate unmet patient and carer needs for breathlessness and other interventions for breathlessness such as positive psychology, singing therapy, self-hypnosis and laughter therapy, but they are not yet well supported by evidence. Preferences and risk assessment. When available and feasible to use, non-invasive ventilation may also reduce daytime breathlessness in people with advanced breathlessness.<sup>10</sup>

See our online Supplementary material for a full list of supporting references at <https://www.ipcrg.org/dh033.pdf>.

To know the evidence as well as have an awareness of local practice and beliefs which may vary from one place to another, local programmes of COPD in people who are tobacco dependent (see the IPCRG Desktop Helper patients quit tobacco)<sup>6</sup> and employ the Ask, Advise, Act approach of every consultation. Success will be improved if tobacco dependence management and support services such as 'quit lines' are also used.<sup>7</sup>

**Drug treatments to be used in conjunction with non-pharmacological interventions**  
Related breathlessness are the first line COPD pharmacotherapy.<sup>8,9</sup> Whenever possible, use long-acting single or dual bronchodilators which can improve breathlessness and oxygen saturation while reducing symptoms and ease people also risk the risk of future complications.

**Managing malnutrition**  
Fatigue, muscle weakness and overall health decline are often associated with nutritional support.<sup>11</sup> About 1 in 3 people with COPD are at risk of malnutrition, particularly underweight, causing poor outcomes and increased risk of death.<sup>12</sup> Malnutrition is the loss of skeletal muscle (sarcopenia) and lean tissue mass (cachexia). Malnutrition can result from inadequate food access, to food or drink refusal, or from cognitive impairment. (Figure 2).<sup>13</sup> Even where there is no cognitive impairment, there is a backdrop of long-term decline. Even where hospitals are available, patients with COPD are often admitted to acute care facilities for long periods of time. Some events can highlight the need to discuss palliative and end of life care. For example, if a patient with COPD acute respiratory failure will likely die in the next 2 years. This could be a key moment to involve the care team in discussing advance care planning, including registering or updating or completing a living will, if these are available. The palliative care team can support the patient and family with current status, available resources, involving the person and family decides and coordinate care with other services to meet the full range of needs. Since it is often not possible to predict when a patient with COPD will die, especially as they near end of life, having discussions earlier to supplement discussions

exacerbations.<sup>13</sup> Add corticosteroids when these exacerbations cannot be prevented with beta-agonists, inhaled ipratropium or, if available, PR.<sup>8</sup> Inhaled inhaled or oral corticosteroids are considered therapy for breathlessness.<sup>8</sup> Additional drug options

**Table 3: Non-pharmacological interventions to address breathlessness and exercise capacity**

- Intervention Purpose/aim
- Pulmonary rehabilitation Can relieve breathlessness and fatigue, improves emotional state and enhances person's sense of control over their condition – moderately large and clinically significant improvements
- Facial breathing with a fan or cool fan Can relieve breathlessness and fatigue, enhances physical activity. Movement of air over a person's face is thought to stimulate a vagal response
- Facial breathing with a fan or cool fan A cool fan is an alternative
- Mindfulness/meditation 20–50 minutes of breathing reduces breathlessness in lung disease, and anxiety/depression in chronic disease; enhances non-evaluative breathing, reduces breathlessness by active breathing
- Relaxation techniques Some evidence can help anxiety, breathlessness and fatigue in COPD. Guided imagery ('thinking of a nice place'), progressive muscular relaxation and counting are most acceptable
- Pacing May help breathlessness as a component of an evidence-based complex intervention
- Walking aids Can improve exercise capacity
- Cognitive behavioural therapy Problem-solving approach that challenges unhelpful thoughts/behaviours; reduces anxiety in COPD in short term; increases pulmonary rehabilitation attendance
- Breathing techniques Most studies do not find this intervention improves breathlessness, although it may be helpful for those with mild COPD, and pursed lip breathing may be helpful for those with moderate COPD. However, these are key component of evidence-based complex interventions for breathlessness
- Acupuncture/presure Improves breathlessness in advanced disease and may reduce anxiety
- Inspiratory training Conflicting evidence for impact on breathlessness; people need to be carefully selected

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See <https://bbc.in/2PfjgPh>; <http://cambridgebreathlessness.com/>

available health and social services, faith organisations and online self-help resources. Tools such as question in Table 1 can guide discussions around advance care planning and a register of people for whom discussions around advance care planning would be appropriate. Such discussions should then be recorded in the patient's notes and regular reviews. The Breathing Thinking Functioning model<sup>10</sup> has been found by primary care clinicians in the UK to be a very helpful and practical way discussions to linked video cast non-disruptive teaching, e.g. recording a video of people discussing their wishes are known to be helpful to facilitate communication with the person's carers to ensure that the person's wishes are known to be feasible to communicate.



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See <https://bbc.in/2PfjgPh>; <http://cambridgebreathlessness.com/>

care may be shared or transferred to other groups of health professionals. Policies and preferences should not be static and must be reviewed regularly. This may be influenced by the family's circumstances. For example, if this preference may change to a hospice. For this reason, advance care planning should be reviewed over time and re-assessed according to our online Supplementary material S5 for examples of formulating for end-of-life prescribing.

**Figure 3: Possible deadly trajectories in people with COPD**  
Diagnosis → 1st exacerbation → 2nd exacerbation → Death

There are multiple trajectories for people with COPD. Some are predictable and others unpredictable. For example, if a person with COPD has a stroke, they may never walk again. If they have a heart attack, they may never walk again. If they have a fall, they may never walk again. If they have a fracture, they may never walk again.

**Figure 4: Possible deadly trajectories in people with COPD**  
Diagnosis → 1st exacerbation → Death

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**Figure 5: Possible deadly trajectories in people with COPD**  
Diagnosis → 1st exacerbation → Death

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**Figure 7: Possible deadly trajectories in people with COPD**  
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to identify solutions which may include better food access, setting goals to increase body weight and muscle mass, exploring dietary advice and dietitian led meal support systems.<sup>14</sup>

**A useful pathway for guidance on managing malnutrition in COPD is available [www.nutritionpathway.co.uk/copd/](http://www.nutritionpathway.co.uk/copd/). Quality assurance may help to improve patient choice to support choices to support best use of limited resource.**

**Role of primary care team**  
People with COPD attend primary care throughout their life, and therefore primary care must respond to their changing need for symptom relief which is independent of disease severity and duration.<sup>15</sup> Managing malnutrition can result from inadequate food access, to food or drink refusal, or from cognitive impairment. (Figure 2).<sup>13</sup> Even where there is no cognitive impairment, there is a backdrop of long-term decline. Even where hospitals are available, patients with COPD are often admitted to acute care facilities for long periods of time. Some events can highlight the need to discuss palliative and end of life care. For example, if a patient with COPD acute respiratory failure will likely die in the next 2 years. This could be a key moment to involve the care team in discussing advance care planning, including registering or updating or completing a living will, if these are available. The palliative care team can support the patient and family with current status, available resources, involving the person and family decides and coordinate care with other services to meet the full range of needs. Since it is often not possible to predict when a patient with COPD will die, especially as they near end of life, having discussions earlier to supplement discussions

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# Puntos claves del desarrollo

- Objetivos y lenguaje
- Preguntas clave y cómo sentirse cómodo con ellas
- Priorizar las intervenciones según literatura
- Valor de las intervenciones farmacológicas

# Objetivos

- Apoyar un enfoque holístico a largo plazo para el control del EPOC
- Identificar las necesidades de cada individuo al momento del diagnóstico
- Empoderar los profesionales de Atención Primaria al enfrentamiento de la planificación de decisiones y los cuidados del final de vida

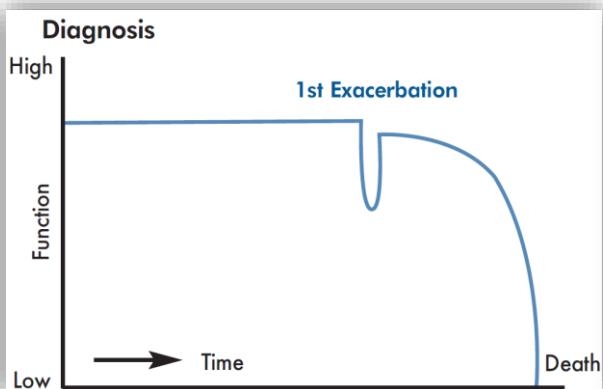
# Contenidos

- Impacto del EPOC
- Preguntas al paciente
- Conocer los recursos locales
- Tratamiento activo de los síntomas (*Disnea in primis*):
  - No farmacológico
  - Farmacológico

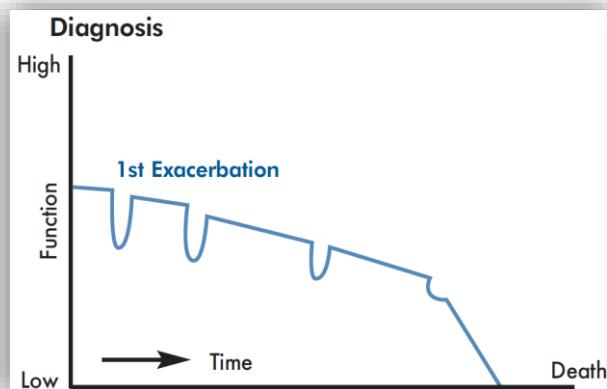
- Desnutrición
- Rol del EAP y de los cuidadores
- Breathing-Thinking-Functioning model
- Planificación anticipada y final de vida
- Trayectorias
- Final de vida

# Trayectorias

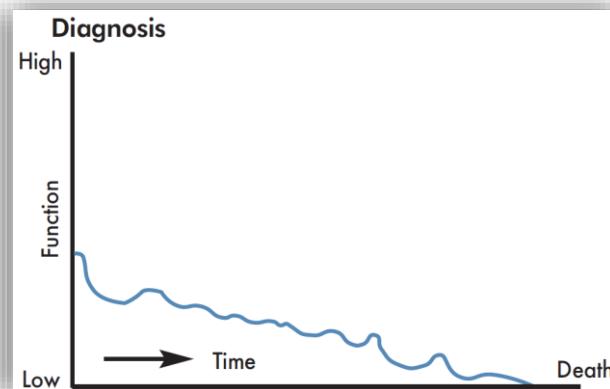
Lives without exacerbation for a long time, then declines



Long-term limitations with intermittent exacerbations/serious episodes

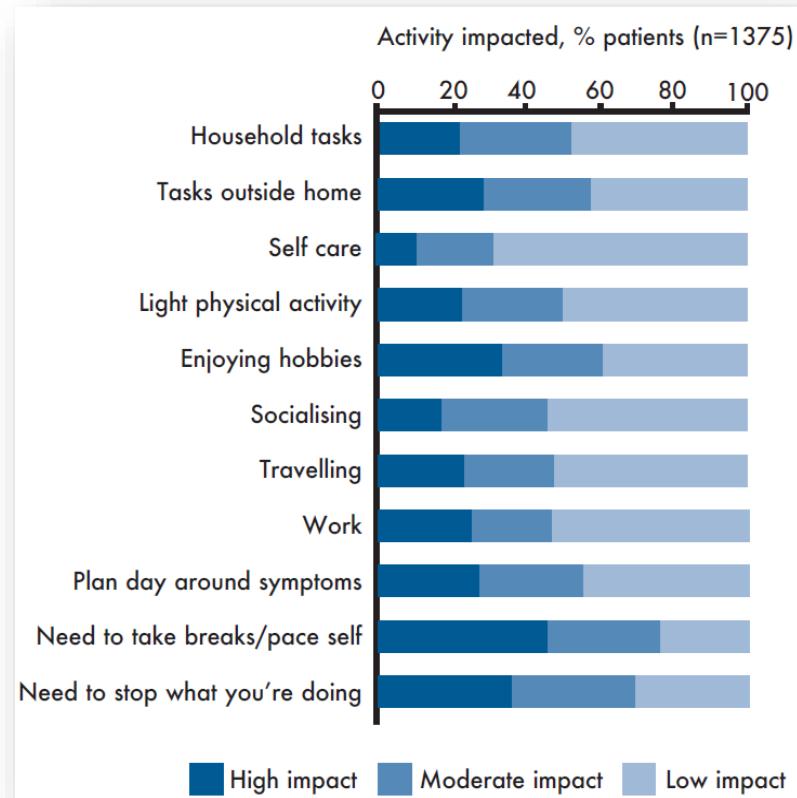


Prolonged dwindling, frailty, multiple mental and physical morbidities



# Impacto del EPOC

- Cada aspecto de la vida influyendo en la QoL incluyendo interacciones sociales, estado de ánimo, trabajo, familia y autocuidado.
- Las personas con EPOC eliminan o reducen actividades debido a la disnea (*“air hunger”*).



# Objetivos terapéuticos con el paciente

## Preguntas esenciales en cada entrevista

- Como te puedo ayudar?
- Alguna preocupación por tu parte o por parte de tu familiar/cuidador

## Preguntas para entrevistas sucesivas

- En qué momento de la enfermedad crees que estamos?
- Que preocupación tienes respecto a lo que vendrá?
- Que objetivos te pondrias, en un momento avanzado y con poco tiempo por delante?
- Que eventos considerarías inaceptables?

**Recordar hacer hincapié sobre las preferencias respecto a Seguimiento hospitalario, hospitalización o final de vida.**

# Sugerencias

What is a usual day's activity like for you?  
What have you had to give up or modify over the last few years?  
What do you not want?"

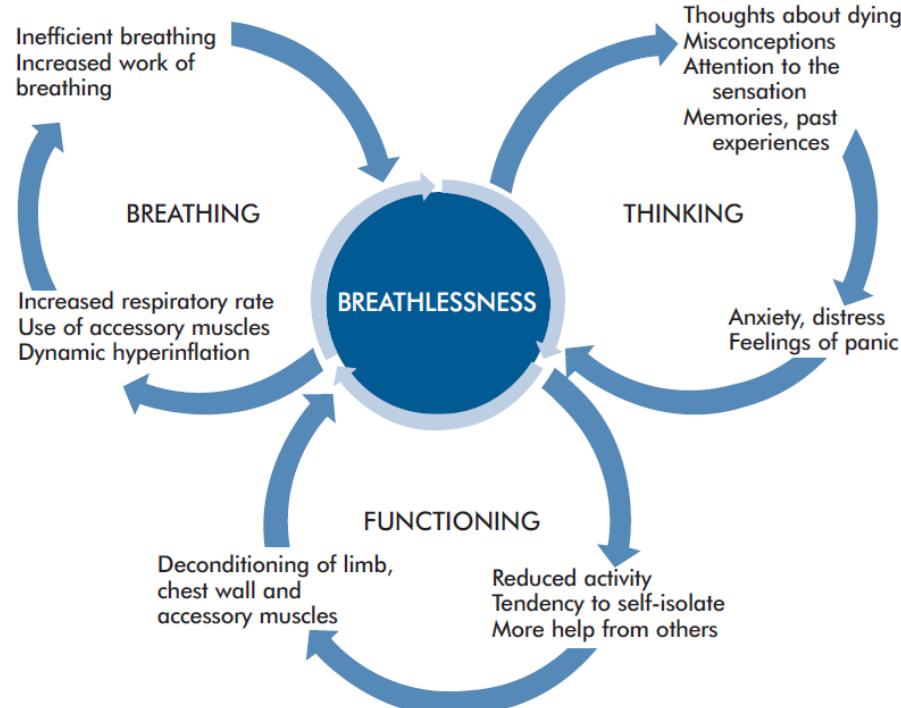
What are your thoughts about your life over the next year or if your COPD gets worse?

What do you & your family want us to know and put in your medical record about your goals & future plans?

# Tratamiento activo de la disnea

## The Breathing-Thinking-Functioning model<sup>2</sup>

- El síntoma más común y desafiante
- Puede no ser relacionado con la severidad del EPOC
- Lo más efectivo:
  - Dejar adicción tabáquica
  - Rehabilitación pulmonar<sup>1</sup>



1. IPCRG Desktop Helper No. 4 - Helping patients quit tobacco - 3rd edition. <https://www.ipcrg.org/desktophelpers/desktop-helper-no-4-helping-patients-quit-tobacco-3rd-edition>; 2. Spathis A, et al. npj Prim Care Respir Med 2017;27:27. Image with permission of the Cambridge Breathlessness Intervention Service (<https://www.btf.phpc.cam.ac.uk/>)

# Intervenciones no farmacológicas

Intervención	Beneficios
“Aire en la cara”	Alivio a corto plazo y reducción de tiempo de recuperación tras crisis
Mindfulness/meditación	Pueden ayudar la disnea ya que mejoran control de ansiedad
Técnicas de relajación	Pueden ayudar la disnea ya que mejoran control de ansiedad
Paseo	Puede reducir la disnea asociado con las otras actividades
Instrum. para caminar	Pueden incrementar la capacidad física
Tratamiento cognitivo conductual	Útil con pensamientos circulares y reduce ansiedad
Técnicas de respiración	Puede reducir la disnea asociado con las otras actividades
Acupuntura	Mejora disnea en enfermedad avanzada, puede reducir ansiedad
Entrenamiento musculatura inspiratoria	No clara evidencia

# Tratamiento farmacológico

- Los broncodilatadores inhalados son la opción de primera línea aunque no se consideran como terapia para la disnea<sup>1,2</sup>

## Morfina

- Dosis bajas regulares de liberación sostenida por vía oral para la disnea crónica incapacitante<sup>3,4</sup>
- Morfina de liberación inmediata en dosis bajas para la EPOC muy avanzada<sup>1,5-7</sup>

## Benzodiazepinas

- Utilizadas en algunos países
- No hay pruebas a favor o en contra de su eficacia para aliviar la disnea<sup>8</sup>

## Oxígeno

- Considerar para los hipóxicos en reposo<sup>1</sup>
- No hay evidencia de beneficio para los que tienen falta de aire pero no hipoxia

1. GOLD 2022 Report. Available at <https://goldcopd.org/2022-gold-reports-2/>; 2. O'Donnell DE, et al. Adv Ther 2020;37:41–60; 3. Verberkt C, et al. JAMA Intern Med 2020;180:1306–14; 4. Wiseman R, et al. Australian Fam Phys 2013;42:137–40; 5. Ekstrom M, et al. Ann Am Thorac Soc 2015;12:1079–92; 6. Barnes H, et al. Cochrane Database Syst Rev 2016;CD011008; 7. Currow DC, et al. ERJ Open Res 2020;6:00299-2019; 8. Simon ST, et al. Cochrane Database Syst Rev 2016;10:CD007354.

# Planificación anticipada

- Incluir la discusión de la ventilación no invasiva, el lugar preferido para la muerte, las decisiones/órdenes de no reanimación y las directivas/testamentos anticipados.<sup>1</sup>
- Registrar estos planes en la historia clínica y asegurarse de que se comparten con los cuidadores y otros profesionales sanitarios pertinentes
- Revisar y actualizar periódicamente los planes de atención anticipada mediante preguntas como:
  - **"Antes, pensabas que te gustaría... ¿Sigue siendo eso lo que te gustaría?"**
- Considerar la posibilidad de establecer un registro para seguir y anotar estas discusiones
- El lugar de fallecimiento preferido puede cambiar

1. Patel K, et al. Respirology 2012;17:72–8.

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