End of Life Care for the Pulmonary Patient Balancing Compassion with Evidence Based Medicine in the Era of COVID-19

Jennica Johns, MD
Pulmonary Critical Care Fellow
The Ohio State University Wexner Medical Center

Case

Patient is a 77 yr old F that presents for follow-up in clinic

- COPD requiring 2LPM continuous
- Independent
- Progressive dyspnea over last 3 yrs
- 4 admissions in the last 1 year
- Triple inhaler therapy, roflumilast
- CT chest with diffuse emphysematous changes

Doctor what can I do to improve my quality of life?

- Pulmonary Rehab?
- More supplemental O2?
- Inhaler teaching?
- LVRS?
- Transplant?

What would you do next?

Objectives

- Understand mortality and morbidity related to advanced lung disease (ALD)
- Appreciate how end of life (EOL) discussions are currently taking place and utilize key clinical clues to help facilitate these discussions
- Recognize common symptoms in ALD and be able to apply basic treatment strategies
- Identify when patients may benefit from hospice services
- Correlate learning points to current COVID-19 pandemic and be able to implement skills with broader population

Background

Background

- 65 million people have moderate to severe COPD worldwide
- 3 million people died of COPD worldwide in 2005
- United States Data from 2017:

Cause of Death	No.	% Total Deaths	% Change from 2016-2017
1. Heart Disease	647,457	23	-.3
2. Malignant Neoplasms	599,108	21	-2.1
3. Accidents (unintentional injuries)	169,936	6	4.2
4. Chronic Lower Respiratory Diseases	160,201	5.5	0.7
5. Cerebrovascular Diseases	146,383	5	0.8

World Health Organization (WHO) https://www.who.int/respiratory/copd/burden/en/
CDC FastStats Deaths ad Mortality https://www.cdc.gov/nchs/fastats/deaths.htm
CDC FastStats Deaths ad Mortality https://www.cdc.gov/nchs/data/nvsr/nvsr68/nvsr68_09-508.pdf

Background

- Dyspnea is responsible for 50% of tertiary care admissions [14]
- $50 billion in direct and indirect health care costs related to COPD alone [10]
- Significant symptom burden and disproportionately reduced QOL at end of life [1]
- COPD Pts are less likely to be referred to palliative care [1]
- People with COPD are more likely than people with lung cancer to die in a hospital[1]

End of Life Discussions in Patients with Advanced Lung Disease

End of Life Discussions

- 68-99% of patients with COPD and advanced chronic lung diseases were interested in discussing end of life care preferences [11]
- All of pulmonologists surveyed in a study agreed that "knowing the patient" is very important to discussing goals [3]
- Pts infrequently discussed end-of-life issues in routine outpatient clinical care [11]
- Only 2 physicians out of every 10 self-reported discussing of EOL for their patients with chronic lung disease in outpatient setting [11, 16]
- Approximately 10% of patients recall having end of life discussions in the outpatient setting [16]

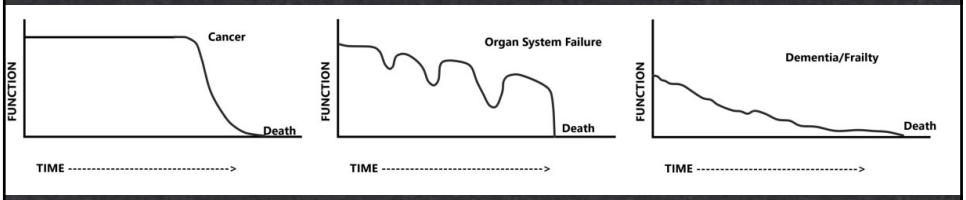
Why Do We Have These Discussions So Infrequently?

Perceived Barriers to Advance Care Planning in Outpatient Clinic

Patients Perspective	Physician Perspective	System Related
Insufficient knowledge regarding their own disease	Unpredictable disease course/ Difficult prognostication	Lack of organizational support
Insufficient knowledge of meaning of palliative med	Worry of “taking away hope”	Lack of formal training
Unawareness that palliative medicine is an option	Perceived hesitance of Pt to want to have these discussions	Time constraints
	Time restraints	
	Uncertainty on whose responsibility it is to initiate discussion	

Adapted from: Jabbarian, L. J., et al (2017). Advance care planning for patients with chronic respiratory diseases: a systematic review of preferences and practices. *Thorax*

Predicting Prognosis is Difficult



Adapted from: Lynn J. Perspectives on care at the close of life. Serving patients who may die soon and their families: the role of hospice and other services. JAMA 2001. ;285:925 -32

Predicting Prognosis is DIFFICULT

- Very few chronic lung diseases follow a predictable course
  - IPF vs. Fibrosing NSIP
  - COPD
  - CF vs Non-CF Bronchiectasis
- COPD has predictive models but they are quite limited
  - FEV1
  - BODE index
  - Progression is very "heterogeneous"

BODE Index

	0	1	2	3
BMI	≥ 21	< 21		
Obstruction	≥ 65	50-64	36-49	≤ 35
Dyspnea (MMRC)	Going up hill	Walking on level ground	Stop after 100 yards	Getting dressed
Exercise (6MWT)	>1148	820-1149	492-819	<492

Approximate 4 year survival based on score

0-2 → 80%

3-4 → 70% (67%)

5-6 → 60% (57%)

7-10 → 20% (18%)

End of Life Discussions

- "Prognostic paralysis"
  - Leads to less referrals to palliative medicine (1)
  - Pts with advanced often have limited understanding of their disease (11)
- Perfect timing of discussions is unclear- but markers include:
  - Declining functional status
  - Declining perceived QOL by patient
  - Recurrent admissions to the hospital
  - BODE and absolute FEV1 not as helpful

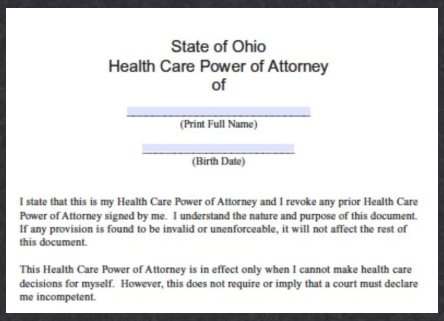
What should Advance Care Planning (ACP) look like?

Core Elements of ACP studied in Chronic Respiratory Disease
1. Discuss End of Life
2. Clarify Values and Goals
3. Involve a Personal Representative
4. Document Patients Wishes

Jabbarian, L. J., et al (2017). Advance care planning for patients with chronic respiratory diseases: a systematic review of preferences and practices. *Thorax*

Advance Directives

- Health Care Power of Attorney
  - Document that legally designates your surrogate decision maker
  - Activated when Pt lacks capacity for decision making
  - Can list 1st and 2nd agent
  - Can list multiple people for agent



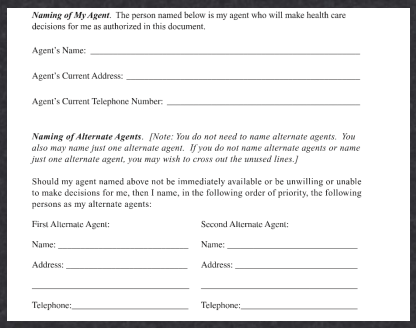
State of Ohio
Health Care Power of Attorney
of

_____
(Print Full Name)

_____
(Birth Date)

I state that this is my Health Care Power of Attorney and I revoke any prior Health Care Power of Attorney signed by me. I understand the nature and purpose of this document. If any provision is found to be invalid or unenforceable, it will not affect the rest of this document.

This Health Care Power of Attorney is in effect only when I cannot make health care decisions for myself. However, this does not require or imply that a court must declare me incompetent.



Naming of My Agent. The person named below is my agent who will make health care decisions for me as authorized in this document.

Agent's Name: _____

Agent's Current Address: _____

Agent's Current Telephone Number: _____

Naming of Alternate Agents. *[Note: You do not need to name alternate agents. You also may name just one alternate agent. If you do not name alternate agents or name just one alternate agent, you may wish to cross out the unused lines.]*

Should my agent named above not be immediately available or be unwilling or unable to make decisions for me, then I name, in the following order of priority, the following persons as my alternate agents:

First Alternate Agent:

Name: _____

Address: _____

_____

Telephone: _____

Second Alternate Agent:

Name: _____

Address: _____

_____

Telephone: _____

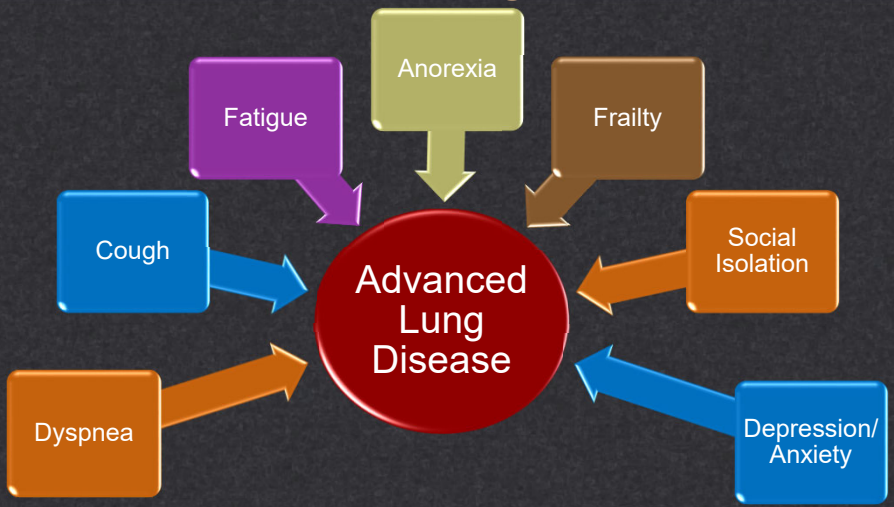
This is HARD!

- Uncertainty
- EMBRACE
- Build prognostic awareness
- Allow patients to plan

Symptomatic Treatment of patients with Advanced Lung Disease

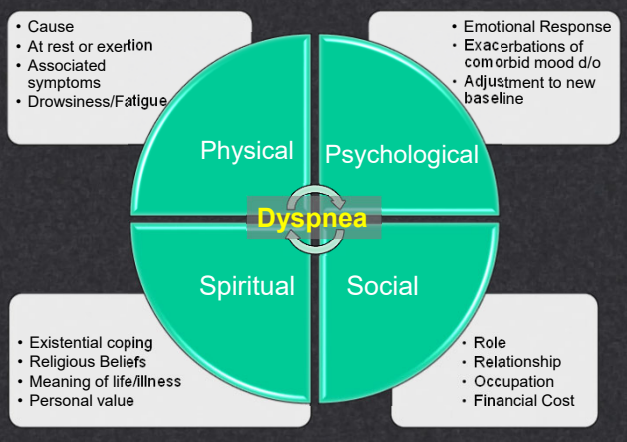
- Even when medical treatment is optimized, a large proportion of people with COPD have significant symptom burden [1]
- Insidious onset
- Normalization of symptoms
- Often require multidimensional approach to treatment

Symptom burden of those with advanced lung disease



Dyspnea

- **Difficult to treat**
- **Multifactorial in nature**
- **Hypoxia ≠dyspnea**



Total Dyspnea, Current Opinion in Supportive and Palliative Care. 2008; 2(2):110-3

Dyspnea

Non-Pharmacologic Interventions

Intervention	Sample Size	Outcome
Handheld Fan	Multiple Trials RCT N= 40	↓ Dyspnea Score
Breathing Techniques	2 Trials N = 74	↑ 6min Walk Distance
Cognitive Behavioral Therapy	1 Trial N = 222	Large improvement in CRQ score
Pulmonary Rehabilitation	Multiple Trials N >1,000	Improved CRQ score
Tai Chi	2 Trials N = 48	Improved CRQ score

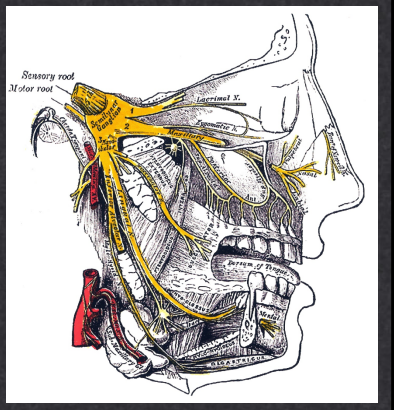
Maddocks, M., et al. (2017). Palliative care and management of troublesome symptoms for people with chronic obstructive pulmonary disease. *The Lancet, 390*(10098), 988-1002.

Dyspnea

Fooling the Brain with a Fan

- **Concept first demonstrated in 1950s**
  - **Forced apnea testing**
- **Use of fan has been studied since 1980s**
  - **Randomized controlled trial**
    - **N = 40; Applied to face vs leg (control)**
    - **Outcome: change in dyspnea score**

The Trigeminal Nerve



Qian, Y., Wu, Y., Moraes, A. R. D., Yi, X., Geng, Y., Dibaj, S., … Bruera, E. (2019). Fan Therapy for the Treatment of Dyspnea in Adults: A Systematic Review. *Journal of Pain and Symptom Management*. doi: 10.1016/j.jpainsymman.2019.04.011

Dyspnea

Pharmacologic Interventions

- Oxygen
  - There is no evidence that oxygen palliates the sensation of breathlessness in patients *without* hypoxia
- Opioids
  - Most well studied
- Benzodiazepines
  - No evidence to support use
- Antidepressants
  - Use has been suggested, but not well studied
- Prednisone
  - No evidence for use of low dose daily prednisone

Opioids for Dyspnea

- MOA: Bind to three main receptors (mu, delta, and kappa)
- Endogenous opioids are thought to be a natural mechanism in relieving dyspnea
- Study [5]:
  - N: 17 patients with COPD
  - Intervention: treadmill exercise with randomization to 10mg naloxone or saline
  - Measured patients self reported dyspnea scores and β–endorphins
    - 3 fold increase in β–endorphins
    - Mean breathlessness higher in the naloxone group

Mahler, D. A., Murray, J. A., Waterman, L. A., Ward, J., Kraemer, W. J., Zhang, X., & Baird, J. C. (2009). Endogenous opioids modify dyspnoea during treadmill exercise in patients with COPD. *European Respiratory Journal*, *33*(4), 771–777. doi: 10.1183/09031936.00145208

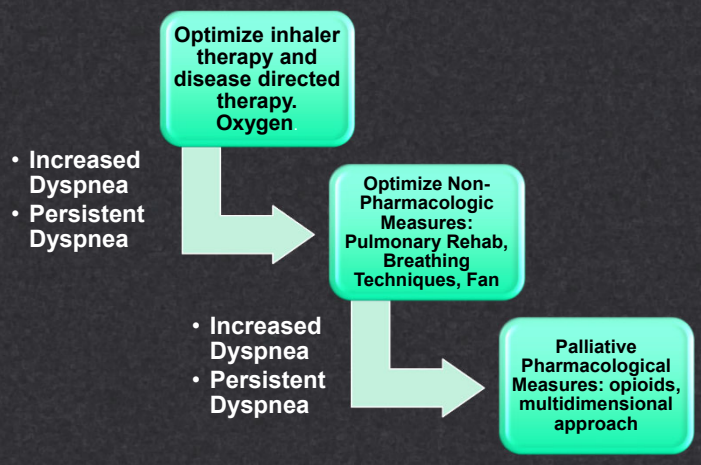
Opioids for Dyspnea

"Randomised, double blind, placebo controlled crossover trial of sustained release morphine for the management of refractory dyspnea"

- **N = 48**
- **88% were patients with advanced COPD**
- **Randomized to 20mg sustained release PO morphine in the morning for 4 days, followed by placebo for 4 days**
- **No previous opioid use**
- **Measurements: quality of sleep, dyspnea, wellbeing, performance on physical exertion**
- **Participants reported significantly improved dyspnea scores when treated with morphine**

Abernethy AP, Currow DC, Frith P, Fazekas BS, McHugh A, Bui C. Randomised, double blind, placebo controlled crossover trial of sustained release morphine for the management of refractory dyspnoea. BMJ 2003. ;327:523 -8

Dyspnea in Patients with Advanced Lung Disease



Adapted version: Palliation of chronic obstructive pulmonary disease. Lal, A., Case, A. (2014). Annals of Palliative Medicine. 3(4).

Dyspnea in Patients with Advanced Lung Disease

Benzodiazepine use

- Cochrane systematic review, published in 2016
- There were 8 studies included
- Population
  - Total of 214 patients
  - All patients had advanced cancer or COPD
- Results:
  - There was NO beneficial effect of BZDs for relief of breathlessness compared to placebo
  - BZD use was associated with statistically significant increase in drowsiness and somnolence

Simon, S. T., Higginson, I. J., Booth, S., Harding, R., Weingärtner, V., & Bausewein, C. (2016). Benzodiazepines for the relief of breathlessness in advanced malignant and non-malignant diseases in adults. *The Cochrane database of systematic reviews*, *10*(10)

Symptomatic Treatment of Patients with Advanced Lung Disease

Other Common Symptoms

- Cough
  - Difficult to treat (make sure easy reasons treated, ex: GERD, PND)
  - Gabapentin/Lyrica
  - Complex physiotherapy and speech and language intervention
- Fatigue
  - Pulmonary Rehab
  - Evaluate for NIPPV
  - Optimization of supplemental O2 requirements
- Depression/Anxiety
  - Don't forget about depression
  - Ensure anxiety not just due to dyspnea (which is treated with opioids)

Patients with ALD have significant symptom burden

Opioids are first line for refractory dyspnea

No evidence to support use of Benzodiazepines

Hospice referral

- Goals of Hospice
  - Reduce suffering, Improve QOL
  - Physical symptom burden, emotional needs, and spiritual needs
  - Multidisciplinary approach
- When to make referral
  - Appropriate Timing
  - Patients goals
  - Poorly controlled symptoms despite initial management
- Limitations
  - High-cost medications
  - When the Pt is not ready- It's okay! Evaluate prognostic awareness

Let's Come Back to Our Case

Case

Patient is a 77 yr old F that presents for follow-up in clinic

- **COPD requiring 2LPM continuous**
- **Independent**
- **Progressive dyspnea over last 3 yrs**
- **4 admissions in the last 1 year**
- **Triple inhaler therapy, roflumilast**
- **CT chest with diffuse emphysematous changes**

How does this relate to COVID-19?

COVID-19 & Comorbidities

"Clinical Characteristics, Comorbidities, and Outcomes Among Patients With COVID-19 Hospitalized in the NYC Area"

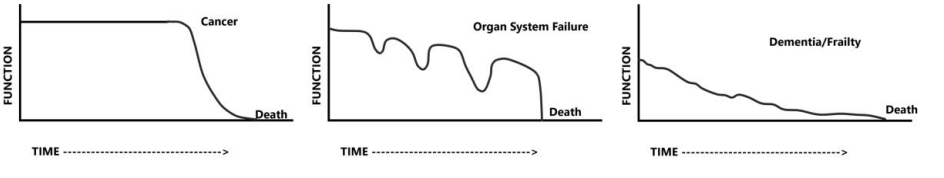
N= 5,700

Publish date: 4/22/2020

Comorbidities	No. (%)
Chronic Respiratory Disease -Asthma -COPD	 479 (9%) 287 (5.4%)
Cardiovascular Disease -HTN -CAD	 3026 (56.6%) 595 (11.1%)
Obesity (BMI>30)	1737 (41.7%)
Diabetes	1808 (33.8%)

Predicting Prognosis is DIFFICULT

- Mortality data surrounding COVID is evolving
- How do we predict those that will have poorer outcomes?
- "Prognostic Paralysis"



Advanced Care Planning still Needs to Happen EARLY

- This was the case prior to COVID and is even more imperative now
- Ideally with provider that patients is familiar and comfortable with
  - Primary care office setting
  - Specialty clinic
- If not done prior to admission to hospital, should be done early in presentation
  - Non-emergently, when Pt can do thoughtfully and be active participant
  - Our institution has made a strong recommendation that all admitted with COVID-19 should have undergone ACP within 1 hour

Tools for ACP in Era of COVID

"COVID Ready Communication Playbook" by VitalTalk		
C	Check-In	"How are you doing with all of this?"
A	Ask about COVID	"What have you been thinking about COVID and your current situation?"
L	Lay Out Issues	"Is there anything you want us to know if you got COVID?/If your COVID gets really bad"
M	Motivate them to choose a Proxy & Talk about what Matters	"If things took a turn for the worse, what you say now can help you family/loved ones" Make a recommendation –if they are able to hear it
E	Expect Emotion	Watch for this-acknowledge at any point
R	Record the Discussion	Any documentation-even brief- will help your colleagues and your patient

Advanced Care Planning

Billing

- **These ACP discussions do take time, but hopefully will allow you to better care for your patients in the future**
- **You can bill for this time**
  - **Time-based billing code in increments of 30 minutes with at least 16 minutes or more spent on ACP**
  - **99497: the first 30 minutes face to face with patient, family members, and/or surrogate (1.5 RVU)**
  - **99478: additional 30 minutes (with at least 16 min beyond the first 30 min), as many times as needed to cover time spent (1.4 RVU)**

Symptom Management

Treatment of Acute Dyspnea and Acute on Chronic

- **Treatment of acute dyspnea ≠ treatment chronic dyspnea**
- **Treat underlying cause**
- **Non-pharmacologic options including fans can be great options for patients**

Summary

Prognostication is difficult

More early ACP needs to occur with our Pts

Pts with ALD have significant symptom burden

Opioids are the only supported *pharmacological* treatment for chronic refractory dyspnea (this differs from acute dyspnea)

Fans are a great non-pharmacological option to treat acute or chronic dyspnea

Acknowledgements

Philip Diaz, MD

Jillian Gustin, MD

Sarah Tapyrik, MD

Todd Barrett, MD

Lauren Goodman, MD

James Allen, MD

Hospice Qualification for Advanced Lung Disease

1. Disabling dyspnea at rest or with minimal exertion and little or no response to bronchodilators, resulting in decreased functional capacity, fatigue and cough
2. Progression of end stage pulmonary disease, as evidenced by prior increasing visits to the emergency department or prior hospitalizations for pulmonary infections and/or respiratory failure
3. Room air findings of hypoxemia or hypercapnia
   - $pO_2 < 55$ mmHg and oxygen saturation < 88%
   - $pCO_2 > 50$ mmHg

Hospice Qualification for Advanced Lung Disease (continued)

4. Cor pulmonale and right heart failure (RHF) secondary to pulmonary disease
5. Unintentional progressive weight loss greater than 10% of body weight over the preceding six months
6. Resting tachycardia > 100/mm.

Dyspnea in Patients with Advanced Lung Disease

- Opioids as a class reduce dyspnea, however most of studies conducted use morphine
- Starting doses of morphine for opiate naïve patients
  - Extended release
    - Starting dose: 15mg PO daily (based on trial)
    - Usual dosing interval q8-12 hours
  - Immediate release
    - Starting dose: 15mg PO q4 hours as needed
    - Preparations with solutions can allow for lower starting doses
  - Contraindication: renal dysfunction

References

1. Maddocks, M., Lovell, N., Booth, S., Man, W. D., & Higginson, I. J. (2017). Palliative care and management of troublesome symptoms for people with chronic obstructive pulmonary disease. *The Lancet, 390*(10098), 988-1002. doi:10.1016/s0140-6736(17)32127
2. Higginson, I. J., Reilly, C. C., Bajwah, S., Maddocks, M., Costantini, M., Gao, W., & GUIDE_Care project (2017). Which patients with advanced respiratory disease die in hospital? A 14-year population-based study of trends and associated factors. *BMC medicine, 15*(1), 19. doi:10.1186/s12916-016-0776-2
3. Sullivan, K. E., Hébert, P. C., Logan, J., Oconnor, A. M., & Mcneely, P. D. (1996). What Do Physicians Tell Patients With End-Stage COPD About Intubation and Mechanical Ventilation? *Chest, 109*(1), 258–264. doi: 10.1378/chest.109.1.258
4. Dalgliesh, V., & Pinnock, H. (2017). Pharmacological Management of People Living with End-Stage Chronic Obstructive Pulmonary Disease. *Drugs & Aging, 34*(4), 241–253. doi: 10.1007/s40266-017-0440-3
5. Mahler, D. A., Murray, J. A., Waterman, L. A., Ward, J., Kraemer, W. J., Zhang, X., & Baird, J. C. (2009). Endogenous opioids modify dyspnoea during treadmill exercise in patients with COPD. *European Respiratory Journal, 33*(4), 771–777. doi: 10.1183/09031936.00145208
6. Abernethy, A. P. (2003). Randomised, double blind, placebo controlled crossover trial of sustained release morphine for the management of refractory dyspnoea. *Bmj, 327*(7414), 523–528. doi: 10.1136/bmj.327.7414.523
7. World Health Organization (WHO) https://www.who.int/respiratory/copd/burden/en/
8. CDC FastStats Deaths ad Mortality https://www.cdc.gov/nchs/fastats/deaths.htm; https://www.cdc.gov/nchs/data/nvsr/nvsr68/nvsr68_09-508.pdf
9. Stapleton, R. D., & Curtis, J. R. (2007). End-of-Life Considerations in Older Patients Who Have Lung Disease. *Clinics in Chest Medicine, 28*(4), 801–811. doi: 10.1016/j.ccm.2007.08.002
10. Ray, S., Guarascio, Finch, & Self, T. (2013). The clinical and economic burden of chronic obstructive pulmonary disease in the USA. *ClinicoEconomics and Outcomes Research*, 235. doi: 10.2147/ceor.s34321

References

11. Jabbarian, L. J., Zwakman, M., Heide, A. V. D., Kars, M. C., Janssen, D. J. A., Delden, J. J. V., … Korfage, I. J. (2017). Advance care planning for patients with chronic respiratory diseases: a systematic review of preferences and practices. *Thorax, 73*(3), 222–230. doi: 10.1136/thoraxjnl-2016-209806

12. Qian, Y., Wu, Y., Moraes, A. R. D., Yi, X., Geng, Y., Dibaj, S., … Bruera, E. (2019). Fan Therapy for the Treatment of Dyspnea in Adults: A Systematic Review. *Journal of Pain and Symptom Management.* doi: 10.1016/j.jpainsymman.2019.04.011

13. Selecky, P. A., Eliasson, C. A. H., Hall, R. I., Schneider, R. F., Varkey, B., & Mccaffree, D. R. (2005). Palliative and End-of-Life Care for Patients With Cardiopulmonary Diseases. *Chest, 128*(5), 3599–3610. doi: 10.1378/chest.128.5.3599

14. Parshall, M. B., Schwartzstein, R. M., Adams, L., Banzett, R. B., Manning, H. L., Bourbeau, J., … Odonnell, D. E. (2012). An Official American Thoracic Society Statement: Update on the Mechanisms, Assessment, and Management of Dyspnea. *American Journal of Respiratory and Critical Care Medicine, 185*(4), 435–452. doi: 10.1164/rccm.201111-2042st

15. Lanken, P. N., Terry, P. B., Delisser, H. M., Fahy, B. F., Hansen-Flaschen, J., Heffner, J. E., … Yankaskas, J. R. (2008). An Official American Thoracic Society Clinical Policy Statement: Palliative Care for Patients with Respiratory Diseases and Critical Illnesses. *American Journal of Respiratory and Critical Care Medicine, 177*(8), 912–927. doi: 10.1164/rccm.200605-587st

16. Janssen, D. J., Spruit, M. A., Schols, J. M., & Wouters, E. F. (2011). A Call for High-Quality Advance Care Planning in Outpatients With Severe COPD or Chronic Heart Failure. *Chest, 139*(5), 1081–1088. doi: 10.1378/chest.10-1753

17. Lynn J. (2001). Serving Patients Who May Die Soon and Their Families: The Role of Hospice and Other Services. *JAMA,* 285(7):925–932. doi:10.1001/jama.285.7.925

References

18. Maurer, J. (2012). The Progression of Chronic Obstructive Pulmonary Disease Is Heterogeneous: The Experience of the BODE Cohort. *Yearbook of Pulmonary Disease*, *2012*, 38–40. doi: 10.1016/j.ypdi.2012.01.028

19. Celli, B. R., Cote, C. G., Marin, J. M., Casanova, C., Oca, M. M. D., Mendez, R. A., … Cabral, H. J. (2004). The Body-Mass Index, Airflow Obstruction, Dyspnea, and Exercise Capacity Index in Chronic Obstructive Pulmonary Disease. *New England Journal of Medicine*, *350*(10), 1005–1012. doi: 10.1056/nejmoa021322

20. Abernethy, A. P., & Wheeler, J. L. (2008). Total dyspnoea. *Current Opinion in Supportive and Palliative Care*, *2*(2), 110–113. doi: 10.1097/spc.0b013e328300cad0

21. Simon, S. T., Higginson, I. J., Booth, S., Harding, R., Weingärtner, V., & Bausewein, C. (2016). Benzodiazepines for the relief of breathlessness in advanced malignant and non-malignant diseases in adults. *The Cochrane database of systematic reviews*, *10*(10)

22. Trigeminal Nerve photo https://commons.wikimedia.org/wiki/File:Gray778_Trigeminal.png