

Beyond Drug Treatment: Palliative Care, Oxygen, Pulmonary Rehabilitation, Support Groups

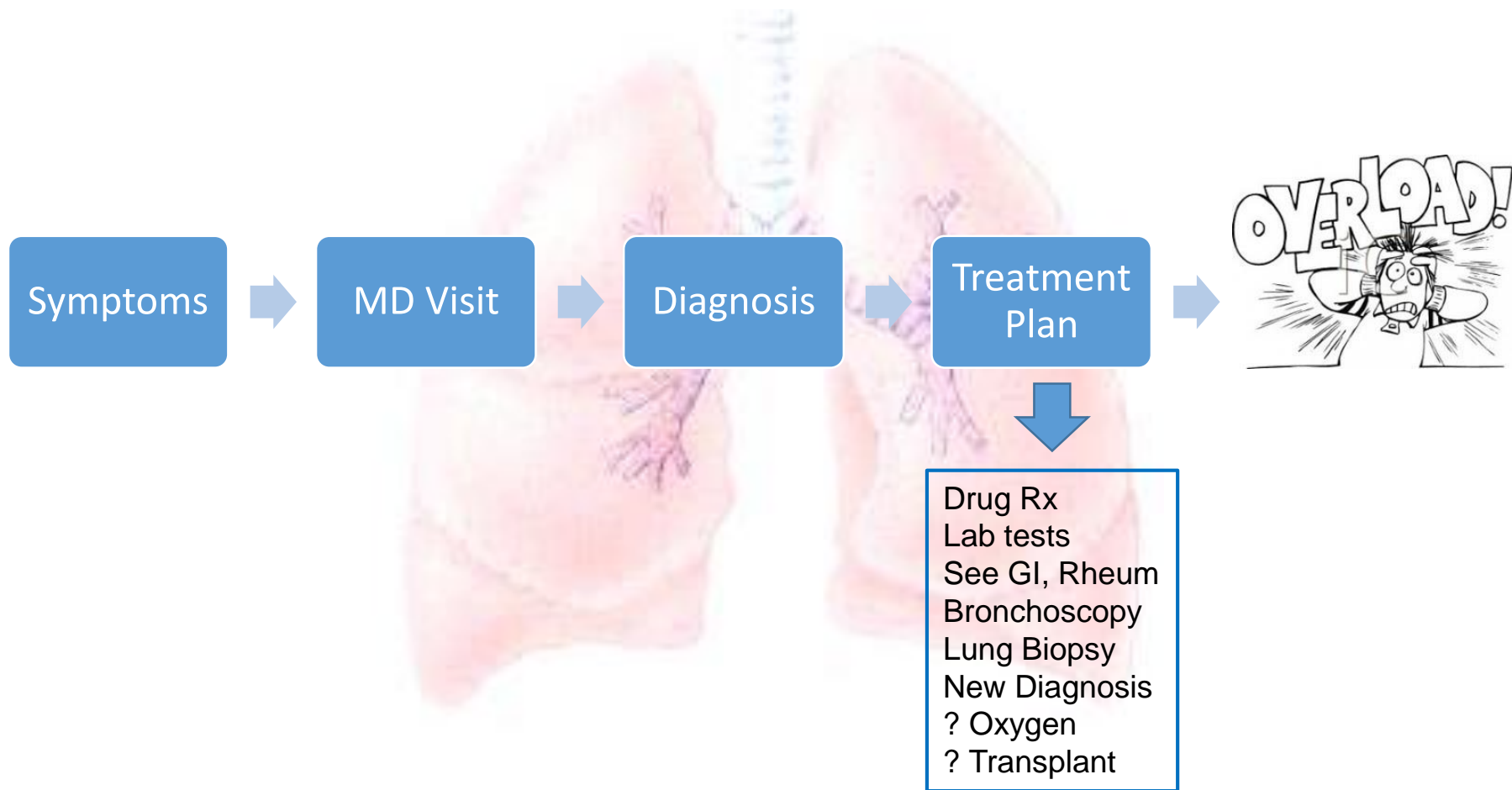


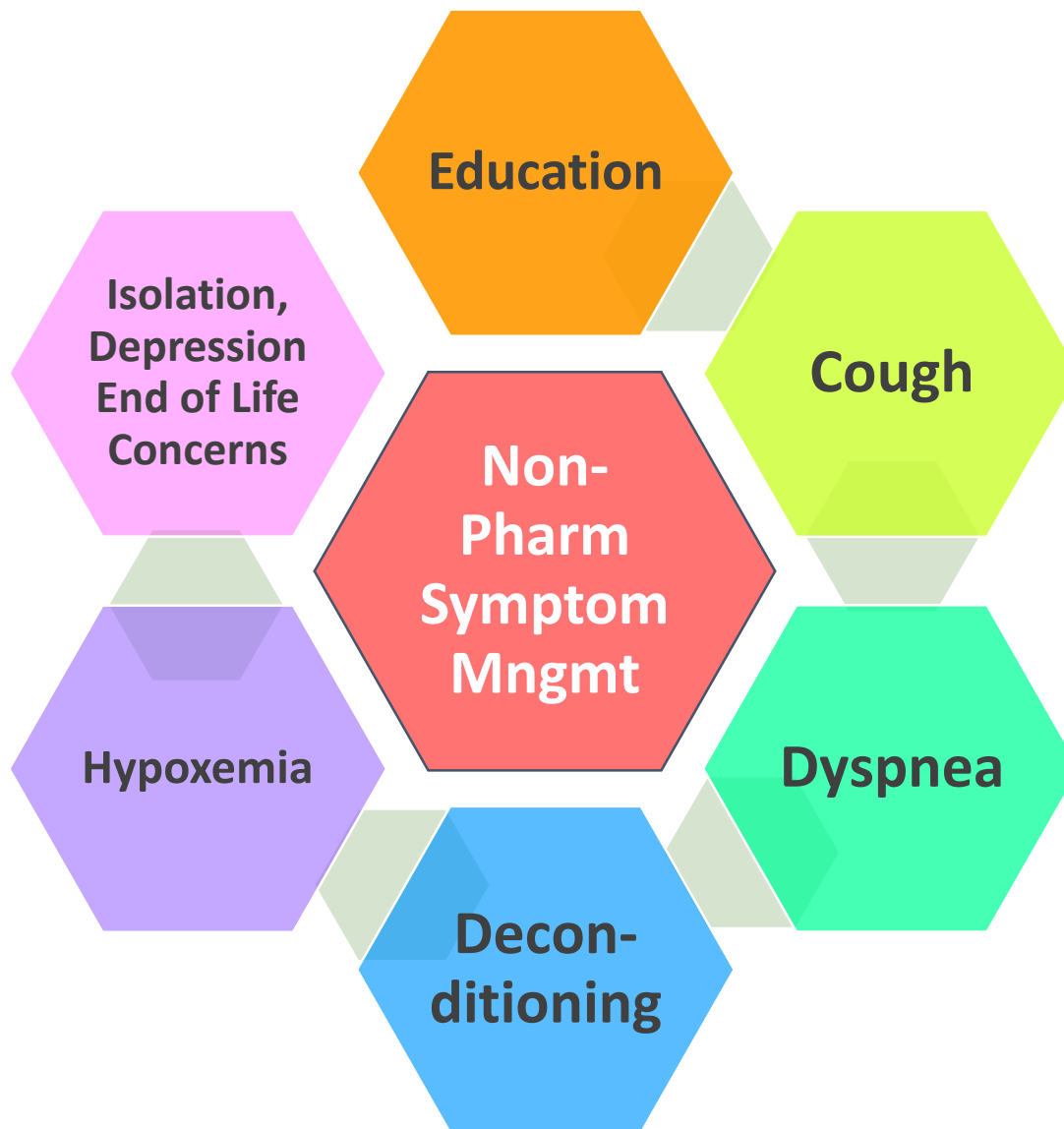
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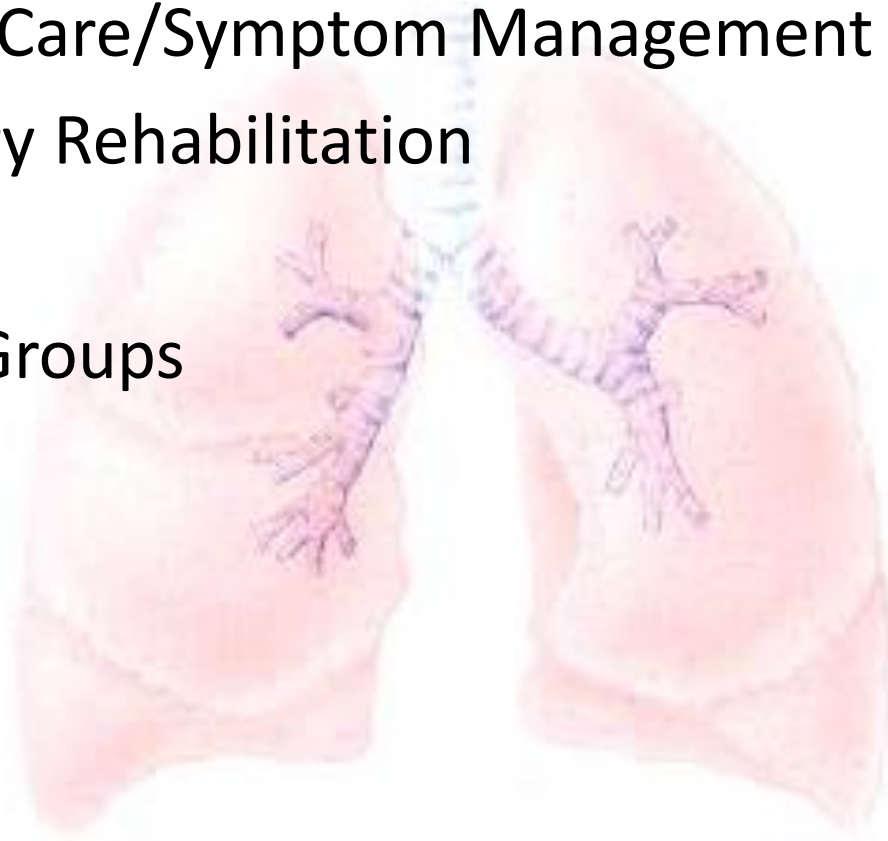
Beyond Drug Treatment



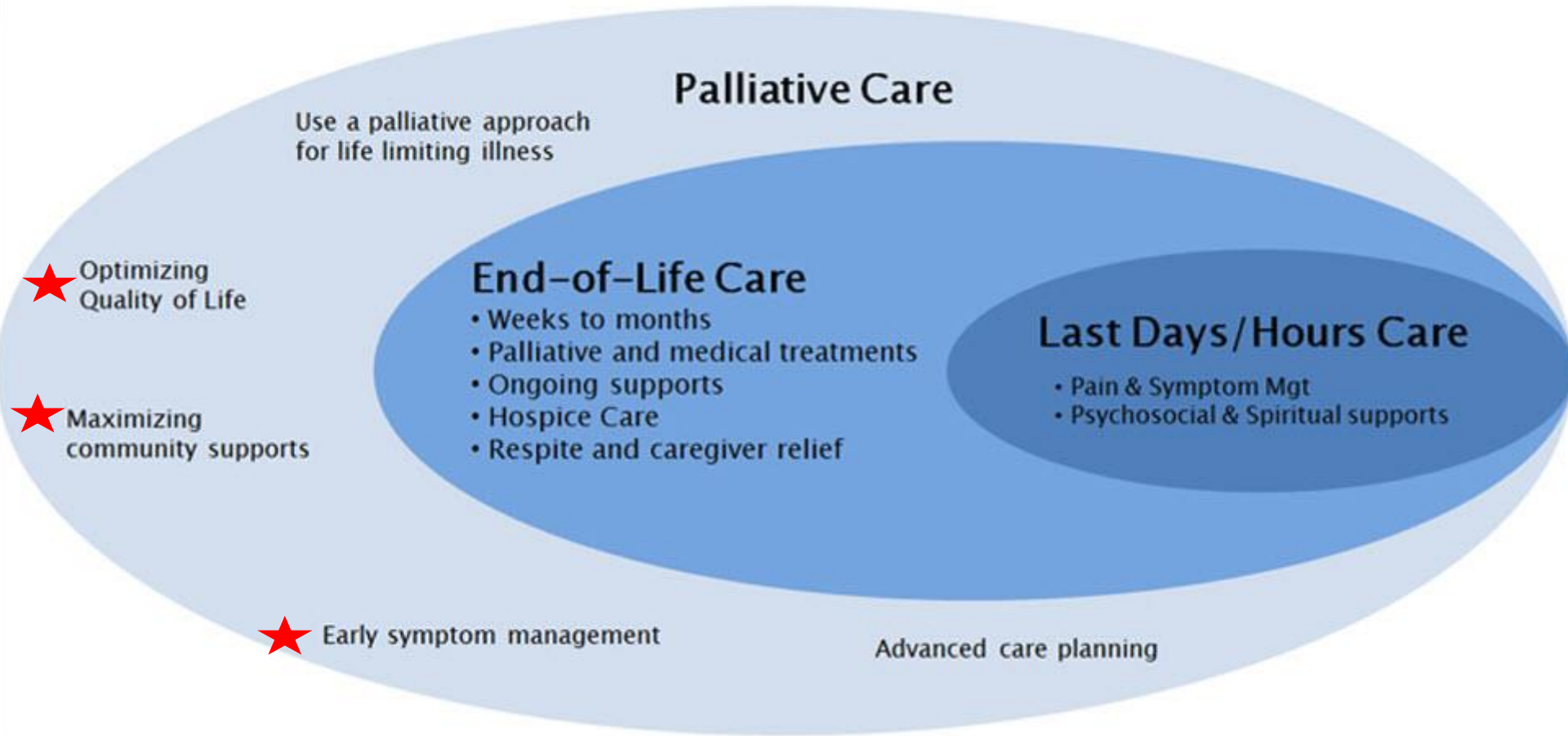


Beyond Drug Treatment

- 1) Palliative Care/Symptom Management
- 2) Pulmonary Rehabilitation
- 3) Oxygen
- 4) Support Groups



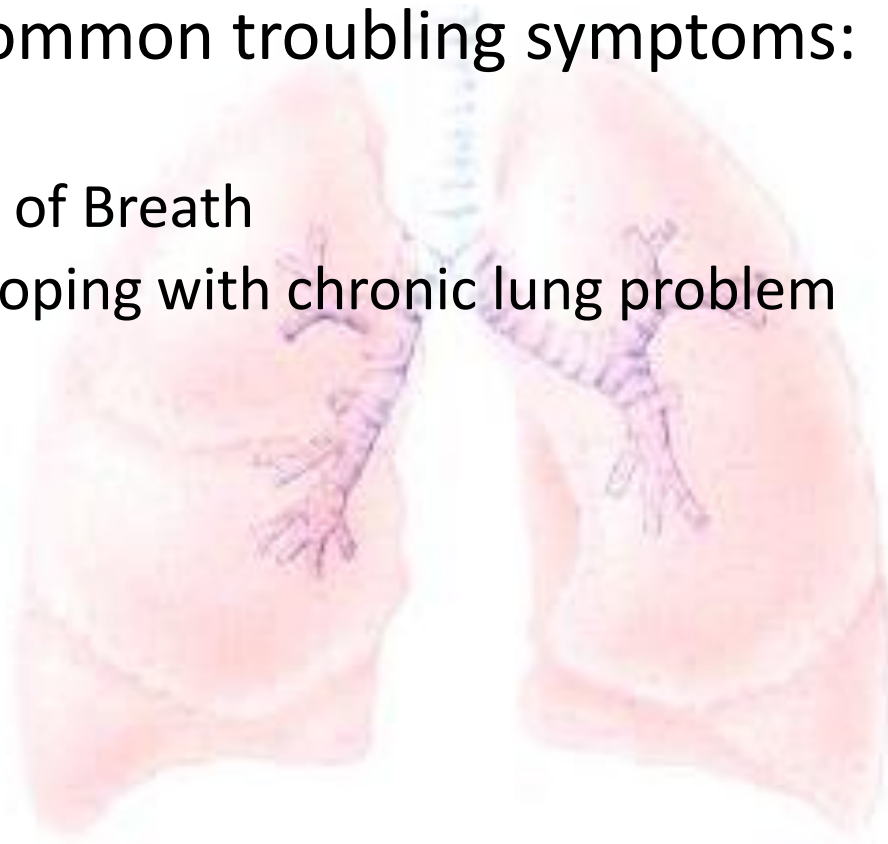
Beyond Drug Treatment: Palliative Care



Palliate: to make a disease or its symptoms less severe or unpleasant

Beyond Drug Treatment: Palliative Care

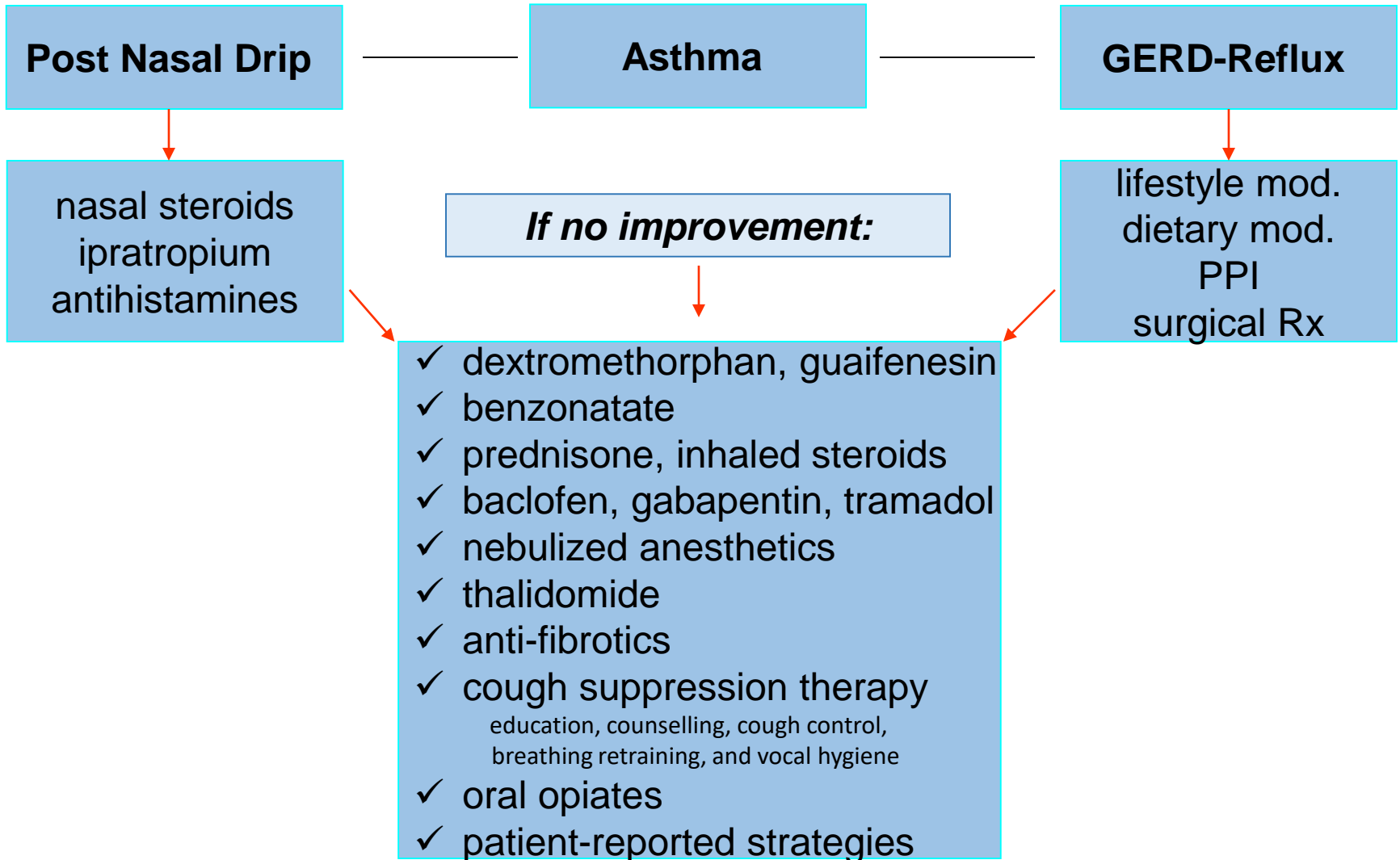
- The most common troubling symptoms:
 - Cough
 - Shortness of Breath
 - Anxiety/Coping with chronic lung problem



Symptom Management: Cough

1. Why do I cough?
 - a) Inflammation in the airways of ILD patients causes “up-regulation” of sensory innervation = cough
 - b) Increased amount of proteins called neurotrophins in IPF sputum affects sensory nerves
 - c) Mechanical ‘pull’ on airways from lung scarring may trigger cough
 - d) MUC5B gene may be associated with cough severity in IPF patients

Symptom Management: Cough



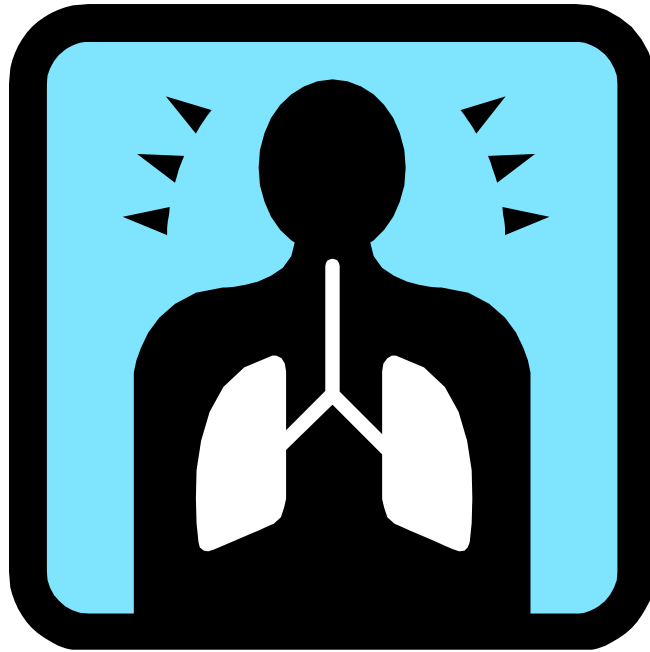
Symptom Management: Cough

•Patient-Reported Strategies to Decrease Cough (N=105):

- Lozenges with cough suppressant/oral anesthetic (especially before making phone call, during 'social times')
- Warm liquids - honey and lemon in hot water
- Ginger tea, turmeric
- Sips of water, ice chips, Biotene spray (moisture)
- Chewing/swallowing carefully, slowly (MCTD pts)
- Avoiding irritants, triggers
- ↑ oxygen during coughing as needed
- Hypnosis
- Yoga/relaxation/slowed breathing techniques
- Nothing (29%)*



Symptom Management: Breathlessness



Symptom Management: Breathlessness

Lung Scarring or Inflammation



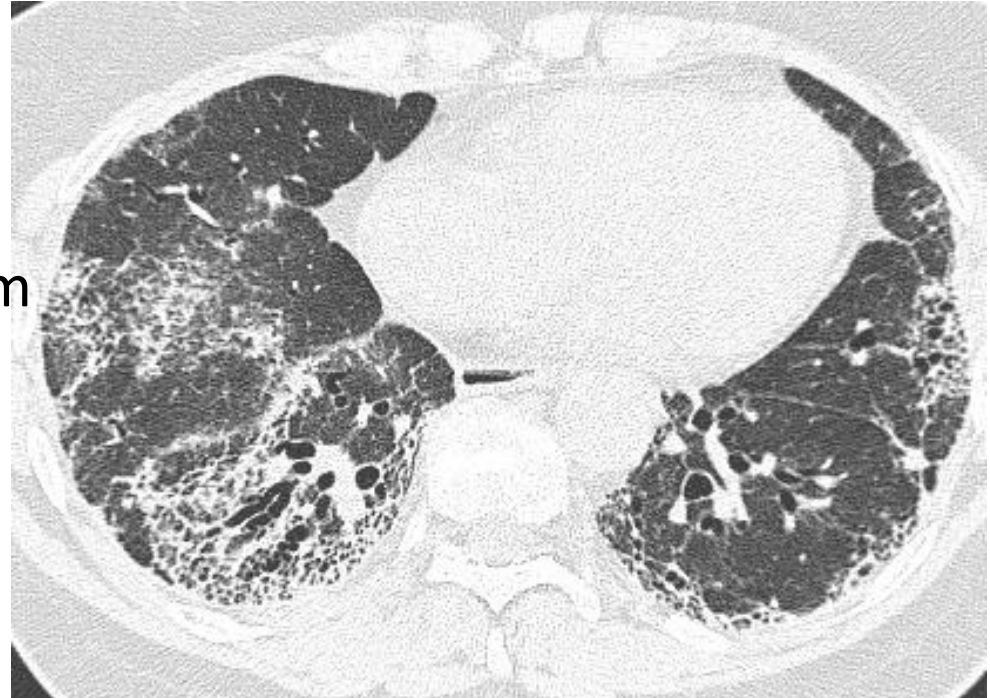
- Increased lung stiffness
- Restriction of lung inflation
- Difficult for oxygen to get from
airsac into blood stream



Increased WOB
Rapid Shallow Breathing
with exertion

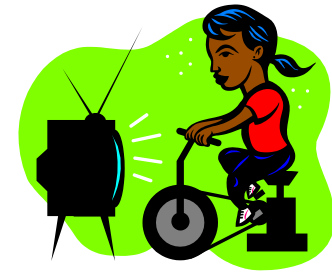


SOB



Lung receptors, hypoxemia, deconditioning,
anxiety and depression

Treating Breathlessness



- Pursed lip breathing/breathing retraining
- Fan/cold air/open windows
- Relaxation/visual imagery/meditation
- Distraction: headphones, social interaction
- Yoga (modified)
- Small meals
- Ideal body weight
- Oxygen if hypoxemic
- Opiates/Narcotics/Anxiolytics



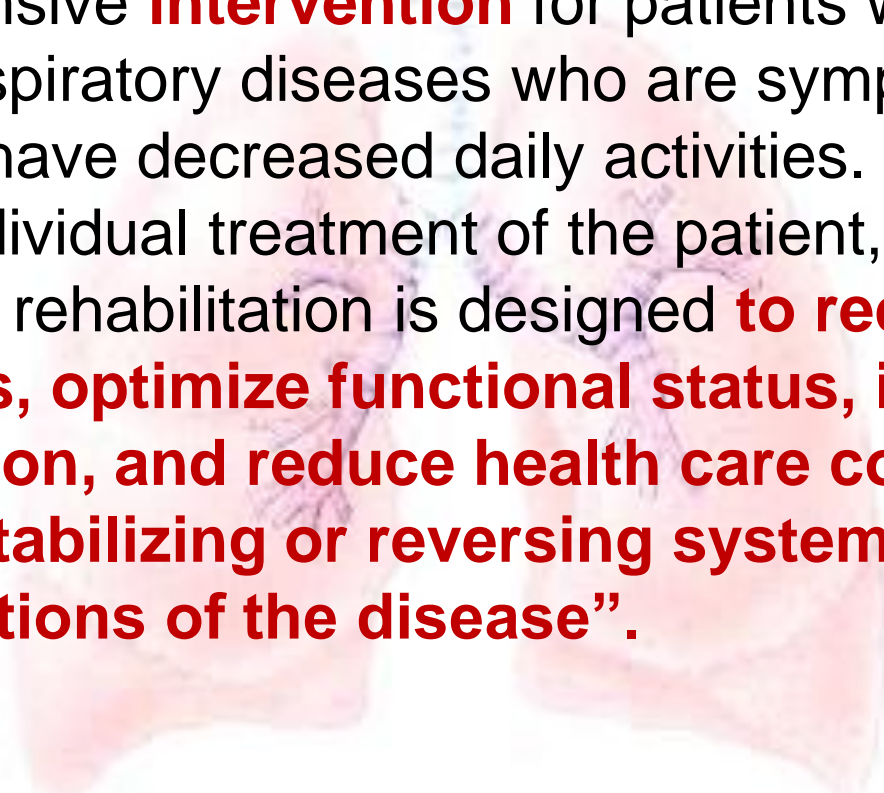
Impact of Exercise on Breathlessness



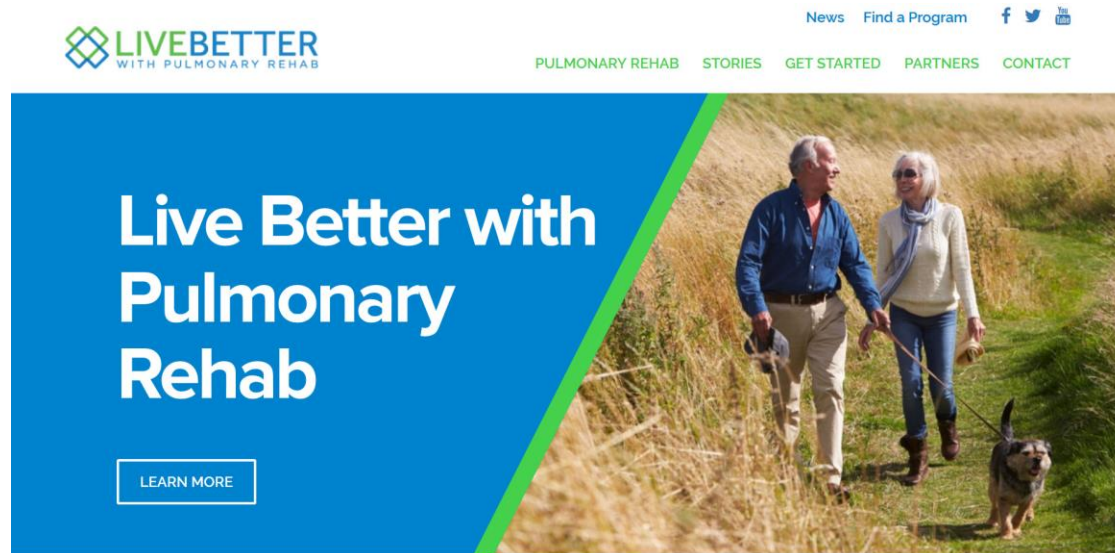
- Builds endurance
- Strengthens muscles
- Desensitization to SOB
- Improves mood
- Facilitates travel, work, and socialization
- Maintains ideal weight
- Decreases anxiety, panic
- Maintenance critical
- *Does not change PFTs*

Beyond Drug Treatment: Pulmonary Rehabilitation

“an evidence-based, multidisciplinary, and comprehensive **intervention** for patients with chronic respiratory diseases who are symptomatic and often have decreased daily activities. Integrated into the individual treatment of the patient, pulmonary rehabilitation is designed **to reduce symptoms, optimize functional status, increase participation, and reduce health care costs through stabilizing or reversing systemic manifestations of the disease**”.



Beyond Drug Treatment: Pulmonary Rehabilitation



The banner features the 'LIVEBETTER WITH PULMONARY REHAB' logo in the top left. To the right, there are links for 'News', 'Find a Program', and social media icons for Facebook, Twitter, and YouTube. Below these are navigation links: 'PULMONARY REHAB', 'STORIES', 'GET STARTED', 'PARTNERS', and 'CONTACT'. The main content area is split: a blue triangle on the left contains the text 'Live Better with Pulmonary Rehab' and a 'LEARN MORE' button. The right side shows a photograph of an elderly couple walking a dog on a grassy path.



WHAT IS PULMONARY REHABILITATION?

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BENEFITS OF PULMONARY REHAB

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Live Better with Pulmonary Rehabilitation is a pilot project of the American Thoracic Society (ATS) and the Gawlicki Family Foundation to increase public awareness of pulmonary rehabilitation. Live Better's mission is to inform and educate individuals with chronic lung disease about the potential benefits to them of pulmonary rehabilitation.

Beyond Drug Treatment: Pulmonary Rehabilitation

- 6-8 Weeks
- 2/wk, 2 hrs
- Education
- Exercise
- Social Support

Health Benefits

Pulmonary Rehabilitation can help you realize some or all of the following health benefits:

- 1 Decrease shortness of breath/breathlessness
- 2 Increase exercise capacity
- 3 Increase energy and stamina
- 4 Improve feeling of well-being
- 5 Decrease feelings of depression and anxiety
- 6 Increase ability to do things in life that you need and want to do
- 7 Communicate more effectively with your healthcare team
- 8 Connect with other people with similar breathing problems
- 9 Increase your ability to manage your own lung problems in collaboration with your healthcare team

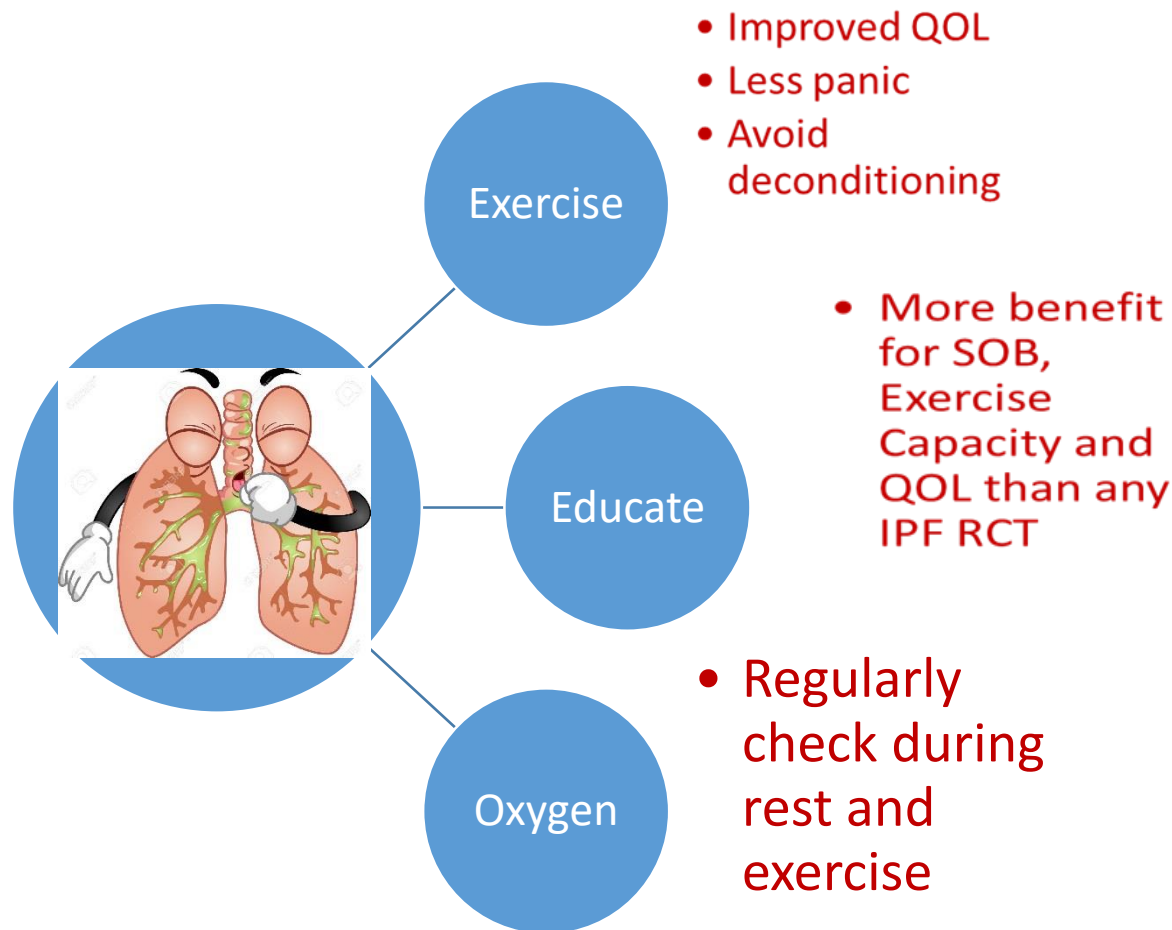


Beyond Drug Treatment: Pulmonary Rehabilitation

Study	Sample	Δ 6MW, m	Dyspnea	QOL
Dowman et al 2017 RCT	142 ILD	25	Improved	Improved
Nakazawa et al 2017 Review	NA	NA	Improved	Improved
Ryerson et al 2014	54 ILD	57	Improved	Improved
Holland et al 2012	44 ILD	21	Improved	NA
Huppman et al 2013	402 ILD inpt.	46	Improved	Improved
Kozu et al 2011	65	31 (MRC 2)	Improved	NA
Swigris et al 2011	21	62	Fatigue improved	SF36 non sig
Garvey 2010 Review	NA	NA	Improved	Improved
Salhi et al 2010	11 RLD	107	Improved	SGRQ non sig
Ferreira et al 2009	99	56	Improved	NA
Holland et al 2008 RCT	57	35	Improved	Improved
Nishiyama et al 2008 RCT	30	42	No Change	Improved
Jastrzebski et al 2006	31	NA	Improved	Improved
Naji et al 2006	26	NA	Improved	Improved

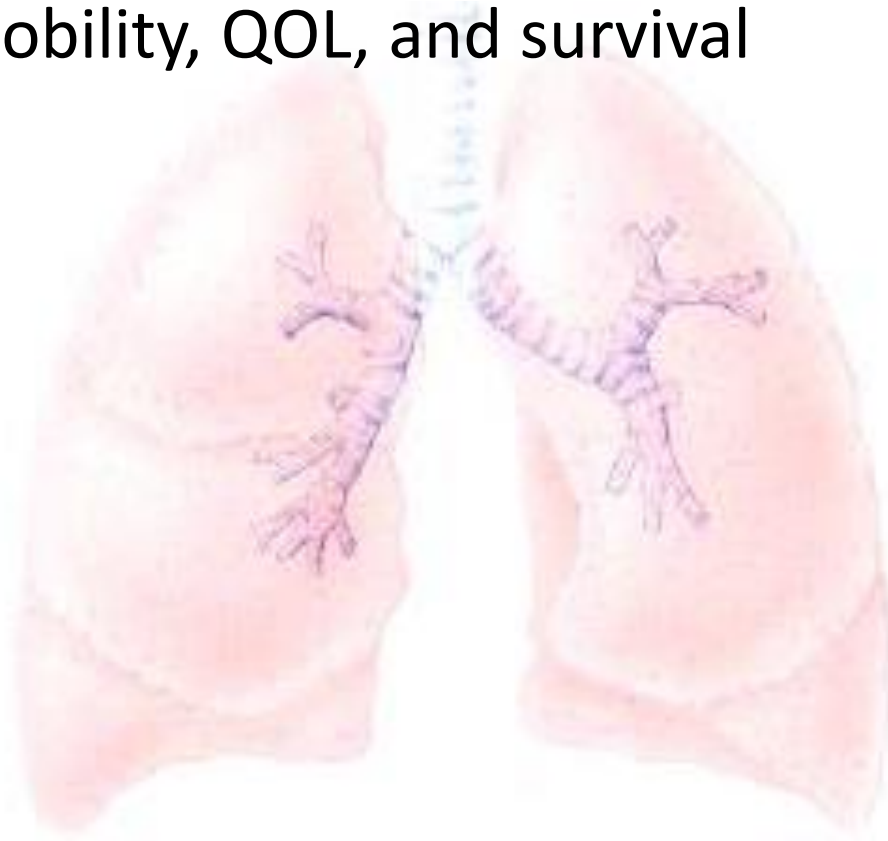
Breathlessness: Key Points

“Complex interplay between mechanical, neurologic and psychological factors” (Garibaldi and Danoff, *Respirology* 2016)



Beyond Drug Treatment: Oxygen

- Prescribed for relief of hypoxemia and breathlessness, improved mobility, QOL, and survival



Beyond Drug Treatment: Oxygen



- Regularly assess oxygen saturations at rest & exercise
 - 6 Minute Walk & Exercise Oximetry
 - High Altitude Simulation Testing
 - Overnight Oximetry
 - The need for oxygen is not based on shortness of breath
- Test oxygen sats in clinic & receive oxygen prescription:
 - At rest
 - With exertion
 - During sleep
 - Goal is to titrate oxygen to keep saturations >90%
 - Medicare covers oxygen if your saturation is ≤88%

Beyond Drug Treatment: Oxygen



- Pros:
 - May decrease breathlessness with activity
 - Improve ability to get out of the house, travel, work
 - Allow for higher levels of exercise to improve stamina and strength
 - Allow travel by plane or to altitude
- Cons:
 - Physically cumbersome treatment
 - Hard for some due to social issues
 - Risks of tripping, fire
 - Smaller, lighter portable oxygen concentrators (POCs) don't go above 3 L/min continuous, or 6 pulse

Oxygen 101: Liquid Oxygen

- Oxygen cooled down to liquid; provides larger amt. oxygen in smaller canister
- Delivers up to 10 L/min. cont. flow (different units for higher flow).
- Uses homefill system
- Higher costs of liquid:
 - More frequent delivery
 - Longer time to service
 - More customer needs
 - Scarce availability



Refill from
reservoir

Liquid
Portable



Oxygen 101: Compressed Gas

E Tank: compressed gas, semi-portable, lasts 3 hrs. on 3L/min continuous or 1.5 hrs on 5 L/min



M6 (B) Tank: compressed gas, portable, lasts with OCD or OCR



Transfill Systems:
Homefill
I Fill
Ultra Fill



Portable Oxygen Concentrators: Size Matters!

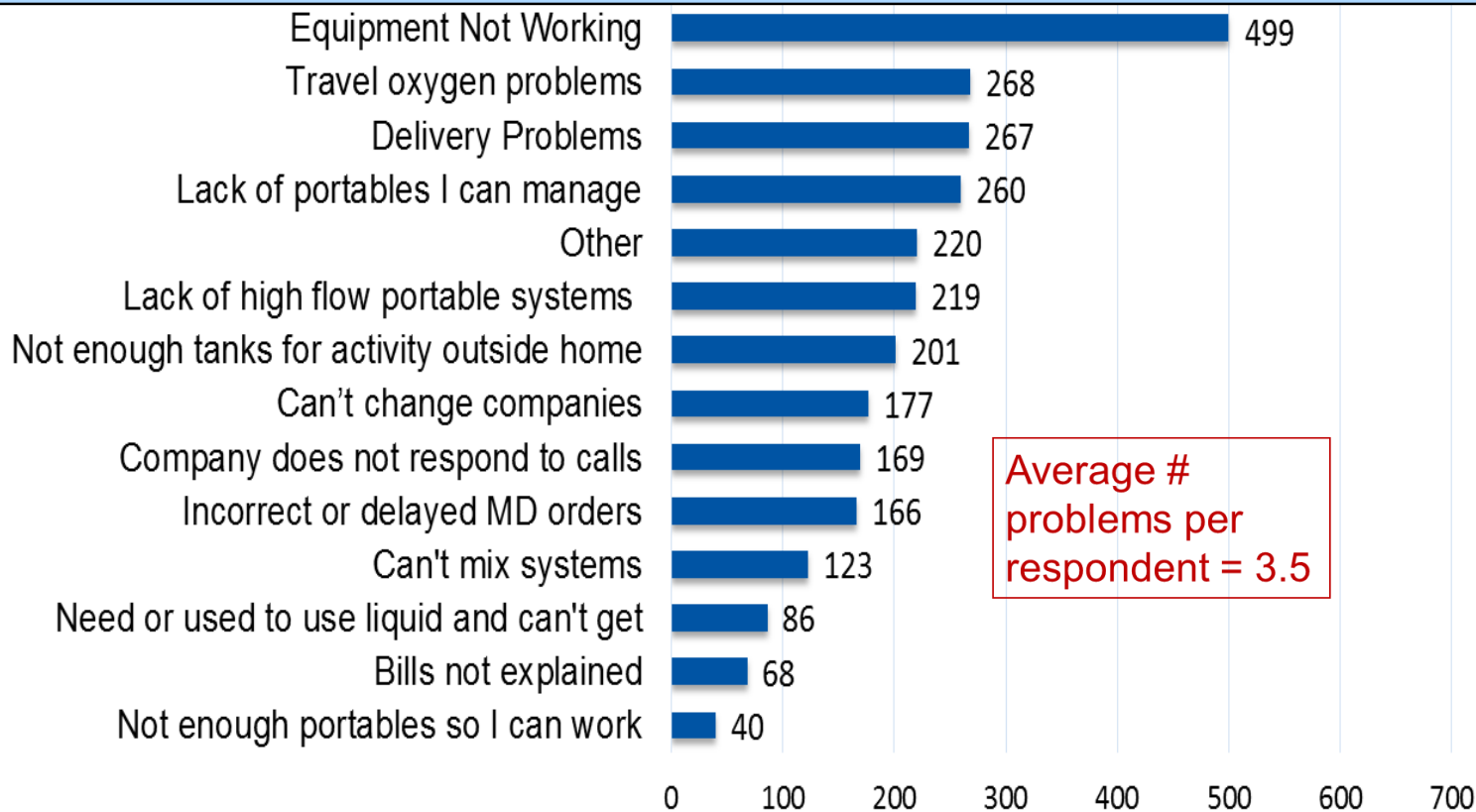


- 3-20 lbs
- Uses battery; concentrates ambient air to 90-96% oxygen
- Can run off DC power
- FAA approved; need battery for 1.5 x hours of flight
- Higher liter flow=shorter battery life
- Very important to get tested on the system BEFORE pt. purchases it
- No *continuous* flow > setting of 3 or *pulse* flow over setting of 6

Oxygen Survey Results (1926 pts): 51% experienced oxygen problems

What types of oxygen problems do you have? (n=899)

(Able to select more than one choice)



Oxygen and Travel



- ALWAYS let your healthcare provider know of your plans to travel on oxygen a MONTH in advance
- ALWAYS check your airlines website and speak to their medical travel department to confirm forms needed
- Some POCs have an FAA stamp on them but older ones will not and for those you will need an MD letter/Rx
- ALWAYS carry a copies of the form/letter/MD order with you when you travel
- You will need 1.5 x the flight length in battery hours for your POC. Always plug in while waiting for your flight and confirm with airlines if your seat will have outlet.

Beyond Drug Management: Support Groups



Beyond Drug Management: Support Groups



Education, Socialization, Caregiver
Support, Networking- all in one

Beyond Drug Management: Support Groups

- Options: (resource manual)
 - In Person
 - Online
 - Phone In



Beyond Drug Management: Support Groups

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300+

Patients and Caregivers

350+

Healthcare Professionals

65+

Global Faculty Members in Government,
Academia, and Industry

75+

Academic and Industry Posters

Beyond Drug Management: Support Groups

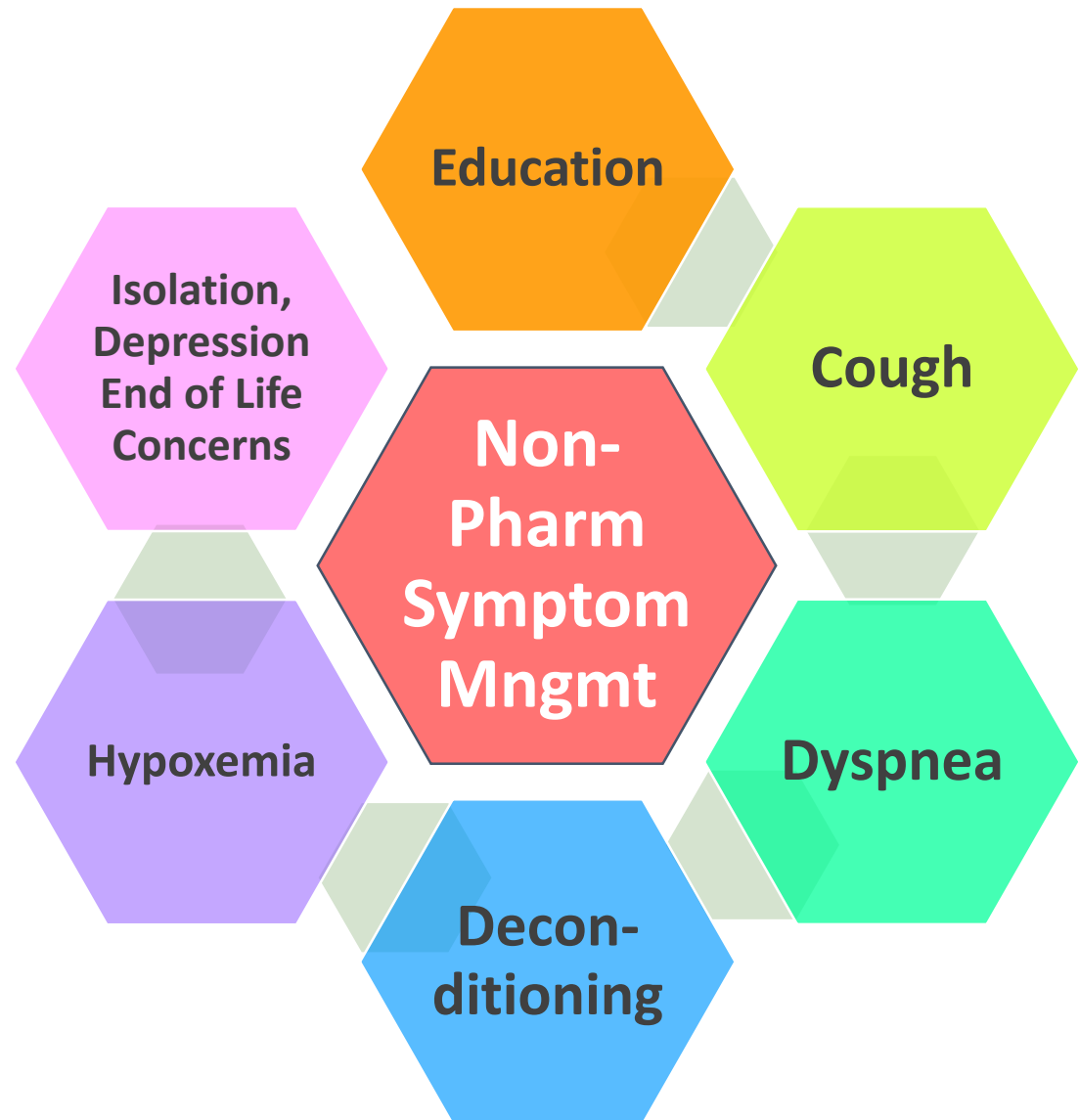


Clinical Trials: An Important Option

- National registries to collect long term data
- Trials coming up testing new anti-fibrotic drugs as 'add-on' therapy
- Close follow-up, support, hope
- More trials coming for non-IPF pts.

Beyond Drug Management: *Summary*

- ✓ Palliative Care
- ✓ Pulmonary Rehabilitation
- ✓ Oxygen
- ✓ Support Groups



Thank you!



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We would like to honor and thank a very special ILD nurse who dedicated many years to improving the quality of life for countless ILD patients at UCSF and beyond

Sally McLaughlin RN, MSN,
ILD Nurse Coordinator UCSF

