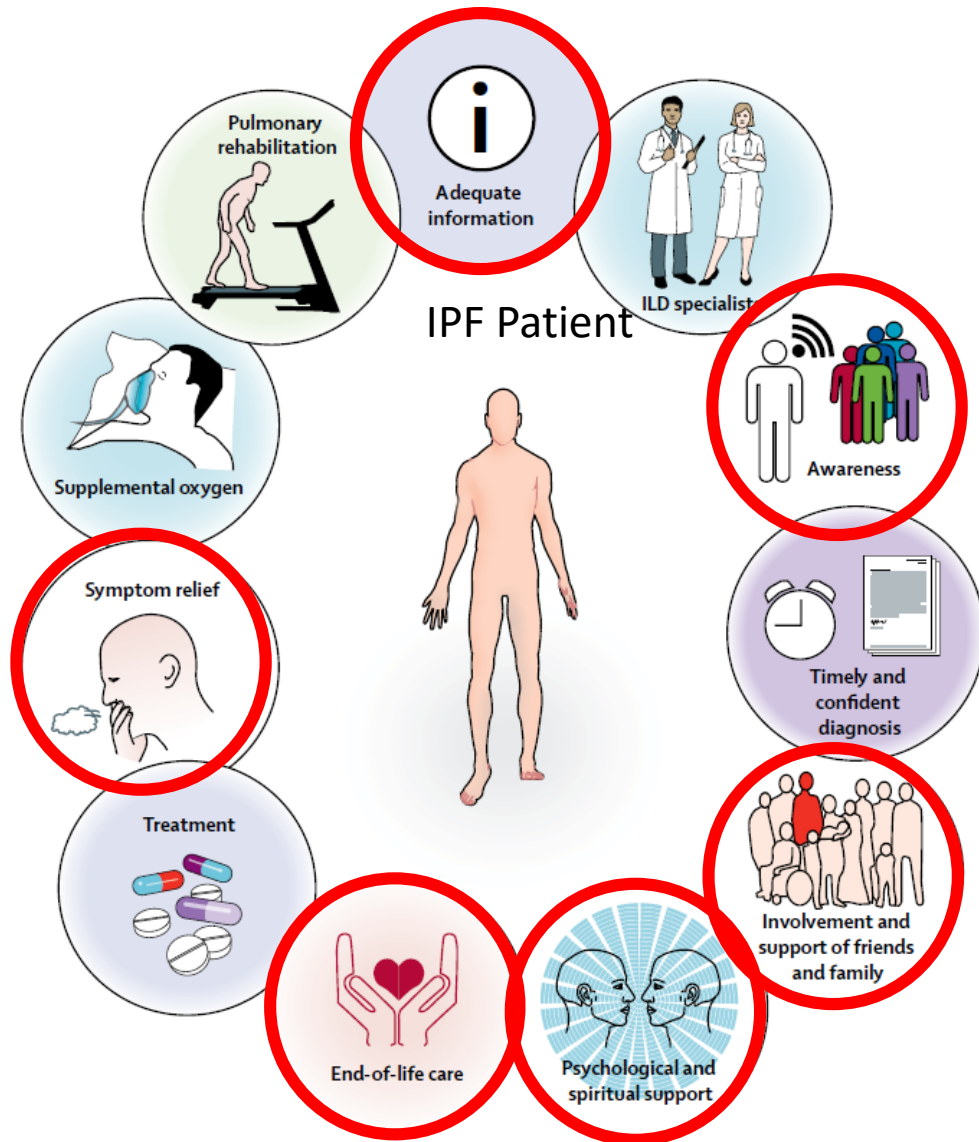


Optimizing Multidisciplinary Care for Patients with ILD

How to Meet Care Needs?



Proposed components of IPF care model

- How to assess needs and when to start therapy?
- What is the best approach to dyspnea management in IPF?
- What is the best model of ACP discussion to improve communication?
- How to coordinate care, engage and support the family better?

Newly Diagnosed Patient with IPF

- 62-year-old golf pro, lives in Scottsdale AZ
- Incidental finding of UIP on CT imaging
- Relatively preserved lung function (FVC 85%)
- Persistent cough and exertional dyspnea MRC 3/5 over the last five-six months
 - Not exercising as much at the gym, but really not affecting work or personal life



Dyspnea Assessment- MRC is not enough

Activity	Rest	Eating	Talking	Light exertion	Stairs	Exercise	Bath/shower	BM	Crisis
Dyspnea 0-10	0	0	0	1	2	2	0	0	NA

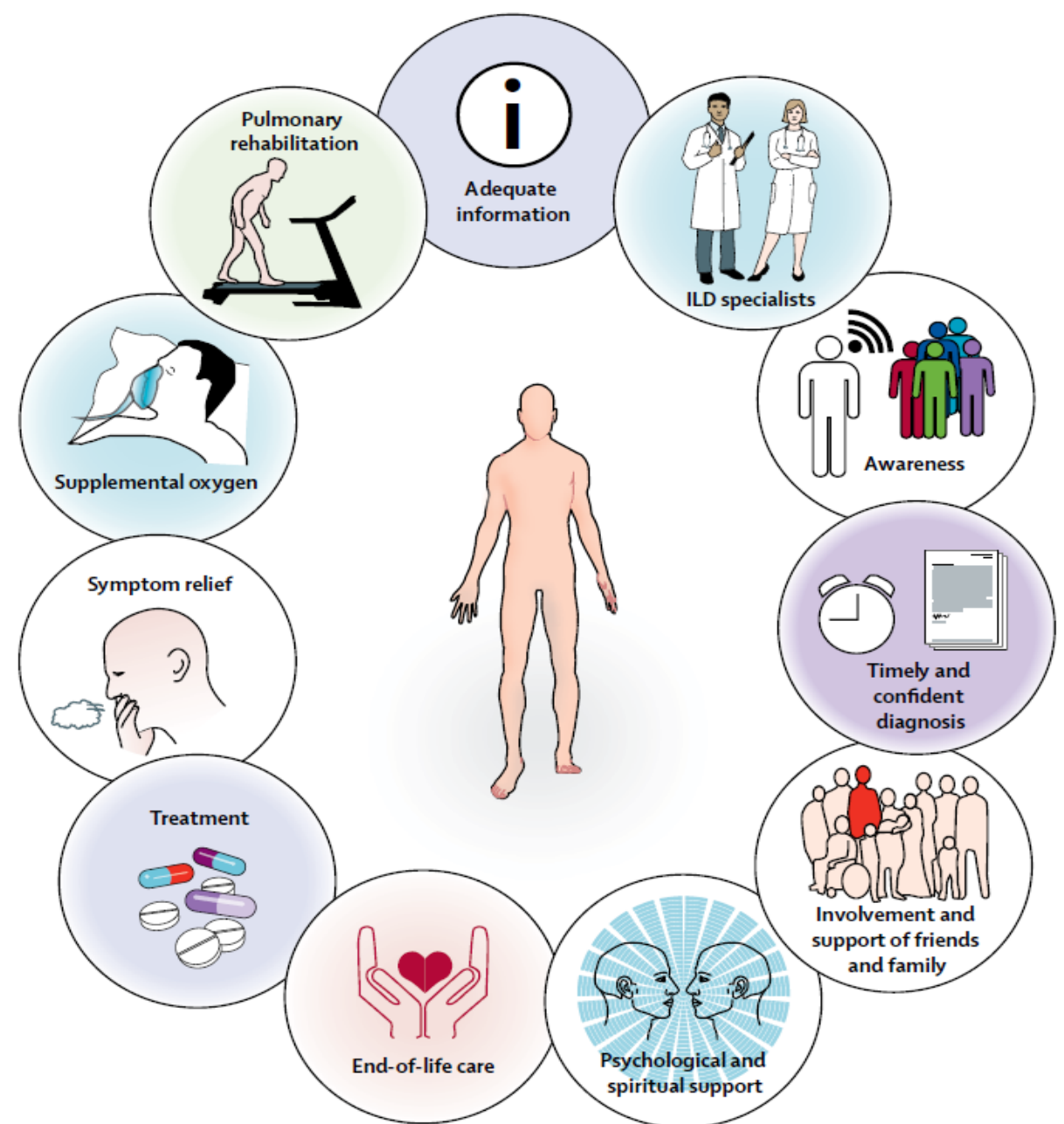


**Systematic dyspnea management using MDT approach:
Should you have a plan in place?**

Questions

- What are the important needs for this patient?
 - Education
 - Support, connections, resources
 - Treatment options including clinical trials, transplant, symptoms etc.
 - Who are the key individuals involved in meeting his needs; how will you coordinate his care?
- Potential for acute exacerbations?
- Should you have an advance care planning discussion?
- Should you evaluate his dyspnea—baseline/exertional/crisis and develop an action plan?

How will you meet the patient's needs?



Patient Care Needs Assessment

Patient concerns	Caregiver concerns	Symptoms and function

Early Advance Care Planning

Goals and Wishes

- Fill in

Fear

- Fill in

Self-Management

- Fill in

Engage Caregiver

- Fill in

Documentation

- Goals of care, preferred place of care and death
- Encourage EOL planning: POA, advanced directives, personal affairs, bucket list



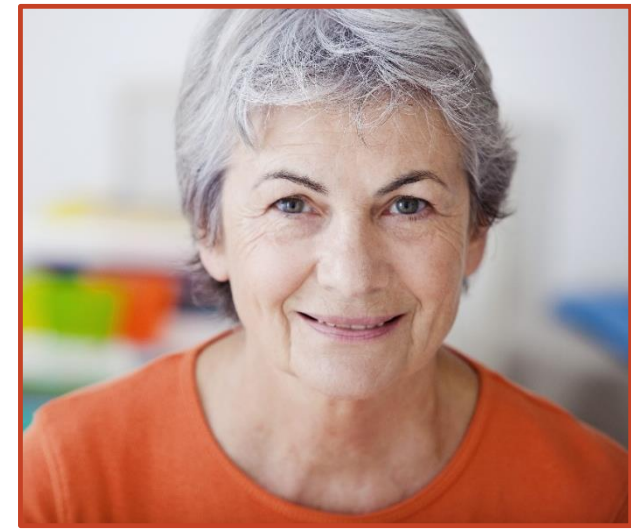
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Patient with IPF Listed for Transplant

- 65-year-old retired university professor, lives in Boulder CO
- Declined over the last year; dramatic change in 6MWT
- FVC is now 72%; MRC 3/5
- She has been evaluated by transplant and would like to be listed



Dyspnea Assessment- MRC is not enough

Activity	Rest	Eating	Talking	Light exertion	Stairs	Exercise	Bath/shower	BM	Crisis
Dyspnea 0-10	1	2	3	4	4	6	2	1	7 Walk/Hike at altitude
1 Very slight	2 Slight	3 Moderate	4	5 Severe	6	7 Very severe	8	9 Extremely severe	10 Maximal

Systematic dyspnea management using MDT approach:

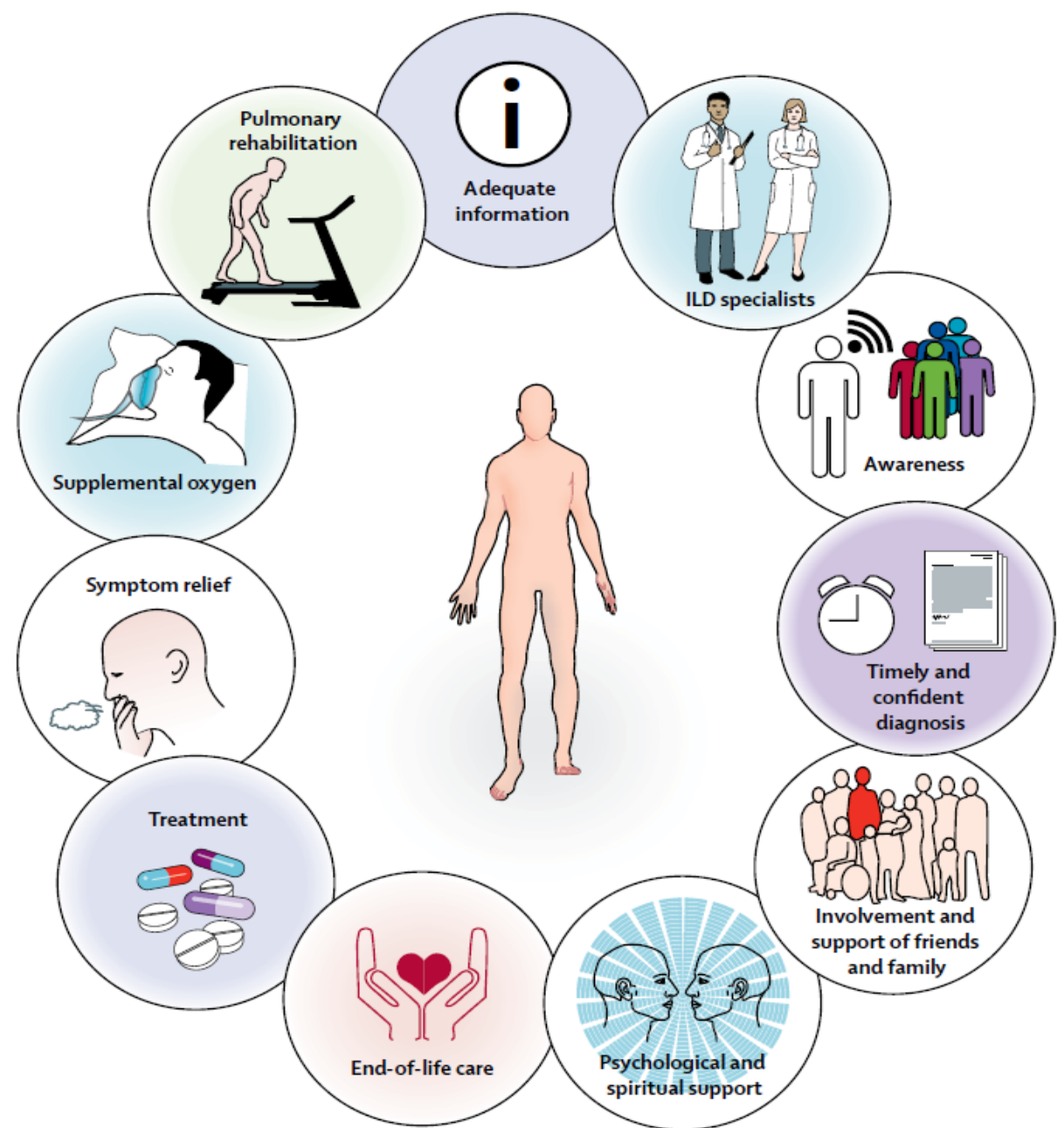
What is the plan, and who is involved in supporting the patient and how?

MD? RN? PT/RT? RD?

Questions

- What are the important needs for this patient?
 - Who is involved in meeting her needs, and how will this be coordinated?
- Should you have an advance care planning discussion?
- Are these issues relevant if she is a transplant candidate?
 - What are the patient's wishes if lungs are not available, and there is further decline?
- If she is listed for transplant, is palliation out of the question?
- Can she be treated with opiates for dyspnea and not impact her transplant outcome?

How will you meet the patient's needs?



Patient Care Needs Assessment

Patient concerns	Caregiver concerns	Symptoms and function

Early Advance Care Planning

Goals and Wishes

- Fill in

Fear

- Fill in

Self-Management

- Fill in

Engage Caregiver

- Fill in

Documentation

- Goals of care, preferred place of care and death
- Encourage EOL planning: POA, advanced directives, personal affairs, bucket list



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Patient with IPF Diagnosed Three Years Ago



- 73-year-old retired high school band director, lives in Boston, MA
- FVC 68%
- Last clinic visit reveals disease progression on HRCT
- Worsening dyspnea (MRC 4/5)
- Tolerating antifibrotic therapy well for one year
- During pulmonary rehab found to have exertional hypoxemia, started 2 L supplemental oxygen two months ago and has been compliant after attending an educational session on oxygen therapy

CMS: Hospice

- To be eligible to elect hospice care under Medicare, an individual must be entitled to Part A of Medicare and be certified as being terminally ill. An individual is considered to be terminally ill if the medical prognosis is that the individual's life expectancy is six months or less if the illness runs its normal course.
- An individual (or his/her authorized representative) must elect hospice care to receive it. The first election is for a 90-day period. An individual may elect to receive Medicare coverage for two 90-day periods and an unlimited number of 60-day periods.

<https://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/downloads/bp102c09.pdf>

Dyspnea Assessment- MRC is not enough

Activity	Rest	Eating	Talking	Light exertion	Stairs	Exercise	Bath/shower	BM	Crisis
Dyspnea 0-10	4	5	5	7	-	8	7	4	8/9 Showering



Systematic dyspnea management using MDT approach:

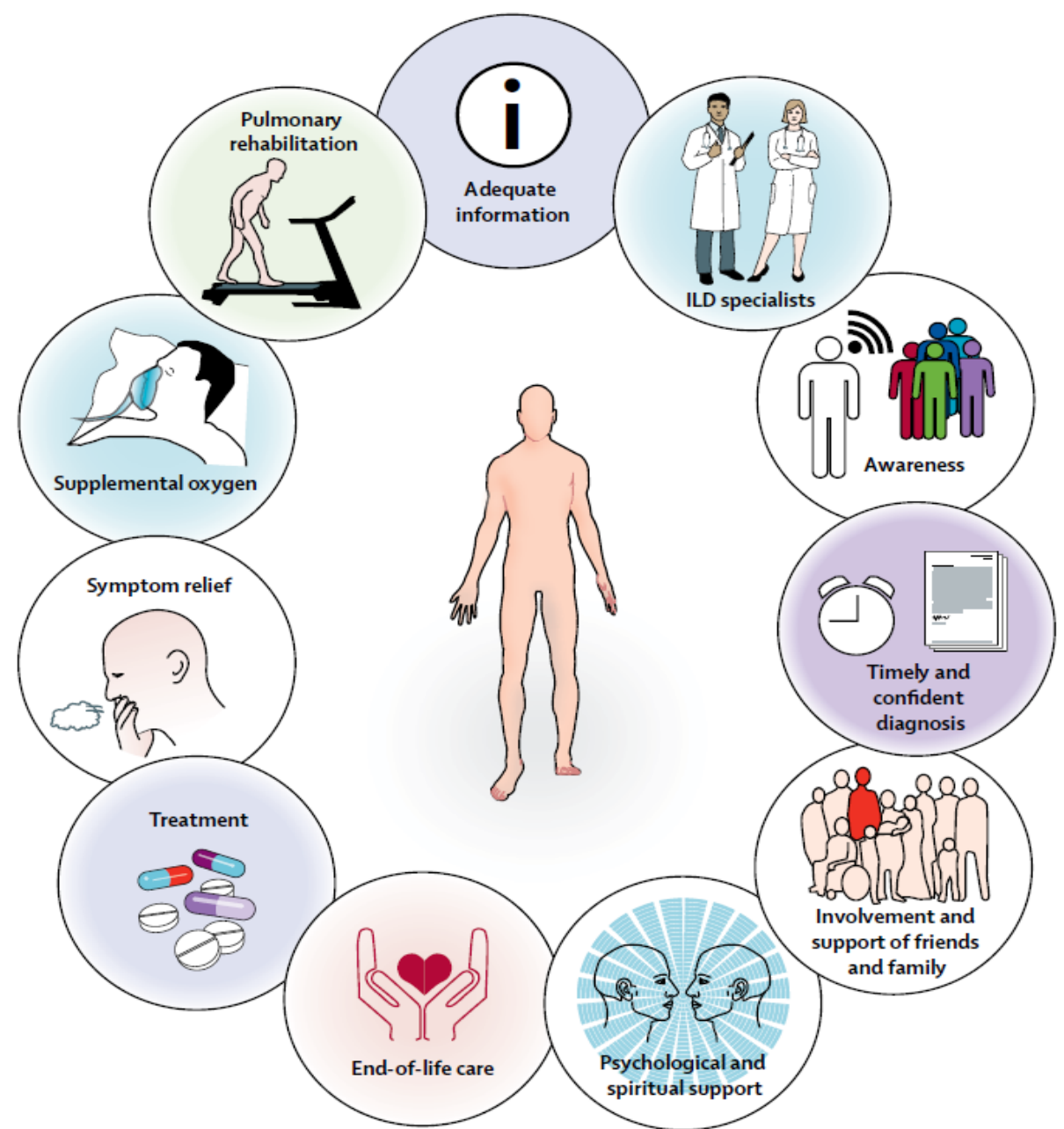
What is the plan, and who is involved in supporting the patient and how?

MD? RN? PT/RT? RD?

Questions

- What are the important needs for this patient?
 - Who is involved in meeting his needs, and how will this be coordinated?
- What are the elements of advance care planning discussion with this patient?
- While he would like to have a home death, he does not have support at home and will need to access local hospice
 - How can this be facilitated?
 - What are the rules in terms of eligibility (life expectancy) for hospice?

How will you meet the patient's needs?



Patient Care Needs Assessment

Patient concerns	Caregiver concerns	Symptoms and function

Early Advance Care Planning

Goals and Wishes

- Fill in

Fear

- Fill in

Self-Management

- Fill in

Engage Caregiver

- Fill in

Documentation

- Goals of care, preferred place of care and death
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Barriers to Effective Palliative Care for ILD

ILD-Related Factors

- Diagnostic uncertainty in some cases obscuring the pathway of care
- Little awareness of ILD in the general population
- Scarcity of evidence for palliative care in ILD
- Only a few established tools to identify the need for palliative care in patients with ILD
- Few established patient-related outcomes for palliative care in ILD

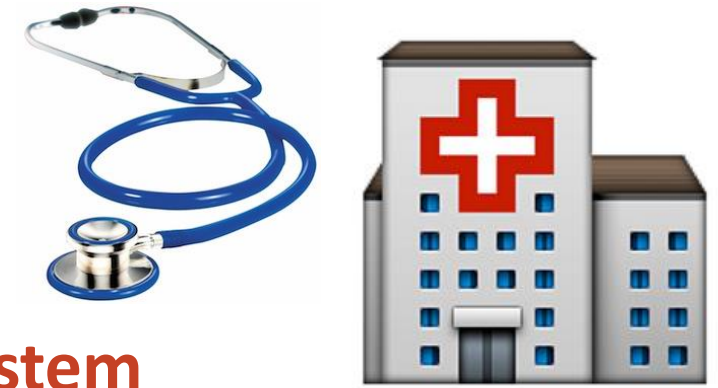


Misconceptions About Palliative Care in the General Population

- Misinterpretation of palliative care as hospice care and end-of-life care by patients and health care professionals
- Do not understand that the objective is to improve QOL
- Little knowledge of scope of palliative care
- Do not appreciate impact as discussions to establish patient health beliefs and preferences left too late in the disease course
- Cultural and religious restraints to palliative care



Health Care Provider and Health System Barriers



Providers

- Little knowledge and lack of awareness of knowledge deficits relating to ILD and palliative care
- Insufficient time to initiate a potentially emotive conversation
- Personal barriers to raising the topic of palliative care in consultations with patients
- Absence of guidelines for palliative care in ILD
- Insufficient awareness of patient's culture, religion or spirituality
- Denial of the patient as the expert of their own disease

Health Care System

- Insufficient palliative care resources
- Insufficient ambulatory care resources
- Limited access to symptom-based therapies (eg, lack of electricity in rural areas for oxygen concentrator for long-term oxygen therapy)
- Insufficient reimbursement for palliative care services
- Deficient collaboration between primary treatment team and palliative care team
- Overloaded and impractical hospital services

Patient-Related Barriers

- Little understanding of the serious nature of the disease, thus affecting acknowledgment of disease by patient and caregiver
- Misinformation regarding palliative care
- Personal beliefs, spirituality, ethnic and cultural identity and traditions
- Communication impairments among patients, caregivers and health care providers
- Denial and desire to protect family and loved ones
- Fear of confronting mortality



Team-Based Models of Care

- Hospital, direct contact
- Home, direct contact
- Home, indirect contact
- Comprehensive, indirect contact
- Comprehensive, direct contact
- Comprehensive, direct and early contact

Direct contact is when team members see the patient; indirect contact is when they advise another health care practitioner (eg, a family doctor) who sees the patient.

A “comprehensive” model is one that provides continuity of service across inpatient and outpatient settings (eg, in hospital and then at home).



Systematic Review

Team Membership and Services

- Team membership includes, at minimum, a physician and nurse. One must be specialized or experienced in end-of-life health care.
- Team services include:
 - Symptom management
 - Psychosocial care
 - Development of patient care plans
 - End-of-life care planning
 - Coordination of care

Team-Based Models of Care

Systematic Review

- Comprehensive team-based care with direct patient contact*
 - Improves QOL, symptom management, and patient and informal caregiver satisfaction
 - Increases the patient's likelihood of dying at home
 - Decreases the patient's likelihood of dying in a nursing home
 - Has no impact on hospital admissions or hospital length of stay

Best outcomes were when end-of-life services were offered earlier
(when a person had up to 24 months to live)

[Moderate-quality evidence]

Health Quality Ontario. *Ont Health Technol Assess Ser.* 2014 December;14(20):1–49.



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Team-Based Models of Care

Systematic Review

- Home team-based model with direct patient contact
 - Increases patient satisfaction and the patient's likelihood of dying at home
 - Decreases emergency department visits and hospital admissions.

[Low-quality evidence]

What Do the PAH and COPD Guidelines Say About Palliative Care?

Guideline Recommendations for Palliative Care PAH

- Incorporation of palliative care services in the management of patients with PAH is recommended
 - The addition of palliative care interventions to assist in management of disease burden and symptoms can often be beneficial to improving patient quality of life.

Review of the literature for the current guidelines did not identify eligible studies that directly evaluated the effectiveness of palliative care therapies in conjunction with standard interventions for PAH; this lack of evidence does not negate the potential benefits with regard to disease burden, pain and symptoms of chronic or acute needs.

Guideline Recommendations for Palliative Care COPD

- Goal of palliative care is to relieve suffering of patients and their families by comprehensive assessment and treatment of physical, psychosocial and spiritual symptoms experienced by patients
- Clinicians should develop and implement methods to help patients and their families make informed choices consistent with patients' values
- Use simple, structured approaches to facilitate these conversations



Guideline Recommendations for Palliative Care COPD

➤ PALLIATIVE CARE, END-OF-LIFE AND HOSPICE CARE IN COPD

- Opiates, neuromuscular electrical stimulation (NMES), oxygen and fans blowing air on to the face can relieve breathlessness (Evidence C).
- In malnourished patients, nutritional supplementation may improve respiratory muscle strength and overall health status (Evidence B).
- Fatigue can be improved by self-management education, pulmonary rehabilitation, nutritional support and mind-body interventions (Evidence B).

Other Assessment Tools: ESAS

Revised Edmonton symptom assessment scale: Numeric scale

Patient name:													
Date:													
Time:													
Please circle the number that best describes how you feel NOW:													
No pain	0	1	2	3	4	5	6	7	8	9	10	Worst possible pain	
No tiredness (Tiredness = lack of energy)	0	1	2	3	4	5	6	7	8	9	10	Worst possible tiredness	
No drowsiness (Drowsiness = feeling sleepy)	0	1	2	3	4	5	6	7	8	9	10	Worst possible drowsiness	
No nausea	0	1	2	3	4	5	6	7	8	9	10	Worst possible nausea	
No lack of appetite	0	1	2	3	4	5	6	7	8	9	10	Worst possible lack of appetite	
No shortness of breath	0	1	2	3	4	5	6	7	8	9	10	Worst possible shortness of breath	
No depression (Depression = feeling sad)	0	1	2	3	4	5	6	7	8	9	10	Worst possible depression	
No anxiety (Anxiety = feeling nervous)	0	1	2	3	4	5	6	7	8	9	10	Worst possible anxiety	
Best well-being (Well-being = how you feel overall)	0	1	2	3	4	5	6	7	8	9	10	Worst possible well-being	
No _____ Other problem (for example, constipation)	0	1	2	3	4	5	6	7	8	9	10	Worst possible _____	

Reproduced from: Watanabe SM, Nekolaichuk C, Beaumont C, et al. A multicenter study comparing two numerical versions of the Edmonton Symptom Assessment System in palliative care patients. *J Pain Symptom Manage* 2011; 41:456. Illustration used with the permission of Elsevier Inc. All rights reserved.

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Other Assessment Tools: NAT-ILD

NEEDS ASSESSMENT TOOL: PROGRESSIVE DISEASE – Interstitial Lung Disease (NAT:PD-ILD) - USER GUIDE

- Used in both generalist and specialist settings, the NAT:PD -ILD can assist in matching the types and levels of need experienced by people with or services to address those needs. Interstitial Lung Disease and their caregivers with the most appropriate people
- In specialist settings (e.g. specialist palliative care services), the NAT:PD-ILD can assist in determining when complex needs have been met and act as a discharge planning tool, or to identify the need for ongoing support
- The NAT:PD-ILD is an important tool for facilitating communication between primary and specialist care providers about patient needs and actions taken to address these.

Completing the NAT: PD

The NAT:PD-ILD is a one-page assessment tool that can be completed by health professionals across a range of disciplines. When completing the NAT:PD-ILD, the following steps should be followed:

ASSESS patient/caregiver level of concern FOR EVERY ITEM, using the response options: “none”, “some/potential for” or “significant”.

CONSIDER the range of issues within each domain that apply to a person at this stage of their illness. Prompts are provided on a separate page to help you.

ACT on each need where you identified some concern (“some/potential for” or “significant”). Your actions may include: directly managed by you, managed by another member of your care team, or referral to someone outside your care team. Record your action on the NAT:PD-ILD.

REFER if required by completing the referral section at the bottom of the tool, ensuring that information regarding the type of referral, the priority of the referral and client knowledge of the referral is included.

INFORM other members of the care team of the outcomes of the needs assessment by:

- a. Filing one copy of the NAT:PD-ILD in the patient’s medical file.
- b. Sending a copy to the person’s GP/other specialist.
- c. If a referral is required, forwarding a copy to the referee.

REASSESS needs by completing the NAT:PD-ILD approximately 6 monthly *or* when the patient’s or family’s situation, or functional status changes.

<https://www.hyms.ac.uk/assets/docs/research/needs-assessment-tool-progressive-disease-interstitial-lung-disease.pdf>



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Other Assessment Tools: NAT-ILD

Needs Assessment Tool: Interstitial Lung Disease

Please complete all sections

Guidance for completion on reverse

Date ____/____/____

Name:

(or attach address label)

Section 1a: Red Flags – If present, be alert for unmet palliative care need:	Y	N	Directly Managed	Refer to other team member	Refer SPCS
Red flag symptoms					
Clinical evidence of right heart failure					
Deteriorating Performance Status					
Has the patient or carer had repeated unscheduled contact with hospitals?					
Failure to attend clinic today?					
Section 1b: Priority referral for further assessment:	Y	N	Directly Managed	Refer to other team member	Refer SPCS
No carer?					
Patient or carer request referral to SPCS?					
You require assistance of SPCS?					

Comments:

Section 2: PATIENT WELLBEING ("Does the patient have.....")	Level of Concern			Action Taken		
	None	Some/Potential	Significant	Directly Managed	Refer to other team member	Refer SPCS
Who provided this information? Patient <input type="checkbox"/> Carer <input type="checkbox"/> Both <input type="checkbox"/>						
Unresolved physical symptoms (including SOB/cough/ mucous; leg oedema, heartburn/reflux/poor appetite, fatigue/insomnia/daytime drowsiness, constipation, pain, cognition, voice, sore mouth, mobility, self-image or sex)?						
Unresolved psychological symptoms / loss quality of life?						
Problems with daily living activities?						
Spiritual or existential concerns (issues about the meaning of life and suffering)						
Work, financial or legal concerns?						
Health beliefs, cultural or social factors making care delivery complex?						
Information needs: Prognosis <input type="checkbox"/> Diagnosis <input type="checkbox"/> Treatment options <input type="checkbox"/> Financial/legal issues <input type="checkbox"/> Support services (social/emotional issues) <input type="checkbox"/>						

<https://www.hyms.ac.uk/assets/docs/research/needs-assessment-tool-progressive-disease-interstitial-lung-disease.pdf>