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Nonpharmacological therapies for interstitial lung disease

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Abstract

a) Purpose of review: Interstitial lung diseases (ILDs) cause unpredictable degrees of fibrosis and inflammation in the lungs leading to functional decline and varying symptom burden for patients. Some patients may live for years and be responsive to therapy and others disease trajectory may be shorter and similar to patients with lung cancer. This ultimately affects the patient's quality of life as well as their caregiver(s).

b) Recent findings: Nonpharmacological therapies play an important role in treatment of interstitial lung disease. These include symptom management, pulmonary rehabilitation, oxygen therapy, and palliative care. While ILDs are associated with high morbidity and mortality, different models of care exist globally. New tools help clinicians identify and address palliative care needs in daily practice and specialty nurses and ILD centers can optimize care.

c) Summary: This paper provides an overview of nonpharmacological therapies available for patients with interstitial lung disease.

Keywords

Interstitial lung disease; nonpharmacological therapy; symptom management; pulmonary rehabilitation; oxygen therapy; palliative care

Introduction:

Interstitial lung disease

Interstitial lung diseases cause varying degrees of fibrosis and inflammation in the lungs of patients (1), and the disease progression leads the patient to experience functional decline and varying symptom burden, ultimately affecting quality of life. It is critical that the clinician is able to make a confident diagnosis of the specific form of ILD and formulate a patient-centered, personalized management plan to achieve remission or stabilization of the disease process when possible (2).

Compliance with Ethical Standards

Conflict of Interest

Kathleen Lindell declare no conflict of interest.

Human and Animal Rights and Informed Consent

This article does not contain any studies with human or animal subjects performed by any of the authors.

It is important for providers to relay disease information in a timely manner that is easily understood by patients and their caregivers to help them best manage their ILD. The words used to describe the major scarring lung diseases include: Interstitial lung disease, Idiopathic Pulmonary Fibrosis (IPF), Hypersensitivity Pneumonitis (HP), etc.; these terms confuse not only patients but also other medical providers (3).

Patients with Interstitial Lung Disease experience a wide range of diagnoses and can benefit most from early evaluation at a center with ILD expertise, such as the Pulmonary Fibrosis Foundation (PFF) Care Center Network (4). Connecting patients with access to clinical trials and support groups can provide additional benefit to participate in research studies to advance knowledge and treatment of ILD's, provide accurate information about their disease, and help to connect with other patients with similar needs. These measures can help to improve social support and help the patient and caregiver avoid social isolation ultimately improving their quality of life. Early educational programs can help to increase knowledge of the disease so that patients and their caregivers can have a better understanding of the effect and consequences of these relentlessly progressive diseases (3, 5). Participation in support groups offers the patients and their caregiver(s) the opportunity to receive additional education and support outside of the office visit. Support groups offer resources to teach individuals how to cope and adapt to the lifestyle that is often dictated by their illness. The Pulmonary Fibrosis Foundation provides a list of support groups that are local and international, and on-line and telephone based communities (6).

Nonpharmacological therapies play an important role in the treatment plan for patients diagnosed with Interstitial lung disease (ILD).

Symptom Management

Patients with ILD have a wide range of diagnoses and prognoses; some may live many years with a disease that is responsive to treatment, but in those patients with Progressive Idiopathic Fibrotic Interstitial Lung Disease (PIF-ILD), the disease trajectory is shorter and similar to that of lung cancer (7, 8). Despite the varied nature of ILD, patients experience common symptoms related to their chronic lung disease which contribute significantly to their morbidity and impact their quality of life (9). In a quantitative review of patients with PIF-ILD, the overwhelming majority of patients had breathlessness (68.2 – 98%), cough (59 – 94%), heartburn (25–65%), and depression (10–49%) (7). In addition, this review found that patients experience a wide array of constitutional symptoms including sleep disturbances, fatigue and weight loss, and anorexia (7). The psychological stress of having a chronic life-limiting illness can complicate symptom control requiring effective symptom management, best achieved by a multidisciplinary approach that incorporates patient education and self-management to articulate goals of care and treatment plans (9). A number of both pharmacologic and nonpharmacologic therapies are available to reduce symptoms in patients with IPF. These include low-dose narcotics, pulmonary rehabilitation (including pursed lip breathing) for treatment of dyspnea, and supplemental oxygen (10, 11). Dyspnea and cough often improves with supplemental oxygen. Cough is challenging to treat, but distressing to patients and caregivers. Treatment options include a range from hot tea, honey, menthol lozenges to treatment of gastroesophageal reflux, postnasal drip medication,

benzonatate, and opiate-containing medications (12). Early identification of symptoms and referral for palliative care to alleviate symptom burden and improve quality of life are crucially important treatment goals (13). Pulmonary rehabilitation also plays an important role in symptom management (9).

Pulmonary Rehabilitation

Pulmonary rehabilitation (PR) has demonstrated physiological, symptom reducing, psychosocial, and health economic benefits for patients with chronic respiratory disease (14). Patients with ILD experience reduced functional capacity, dyspnea, and exercise-induced hypoxia (15). Referral to PR includes exercise training that has shown improvement in long-term outcomes in ILD including six-minute walk distance (6MWD), dyspnea, health related quality of life, and peak exercise capacity for patients with ILD (16, 17). In a study of 142 participants with different ILD's (IPF, asbestosis, connective tissue disease-related ILD and other causes of ILD), participants were randomized to 8 weeks of supervised exercise training or usual care. Those participants who participated in supervised exercise training significantly increased their 6MWD and health related quality of life, with more lasting effects in those with milder disease (16). In another study done at 3 PR centers in North America, PR improved functional capacity and quality of life in patients with a variety of ILDs, with benefits lasting for at least 6 months (17). This group reported that the "consistency and magnitude of benefit across endpoints is substantial and markedly better than pharmacological interventions that have been studied in these diseases" and suggest that pulmonary rehabilitation should be the first line of therapy for patients with ILD (17). Barriers for participation in PR may include distance from patient's location and reimbursement for attendance. Reimbursement may involve getting authorization from the patient's payor source. Patients may qualify for Cardiac rehabilitation; while the focus may differ between cardiac and pulmonary, the emphasis is on supervised, safe exercise.

In another study of patients with ILD attending pulmonary rehabilitation, patients wanted ILD-specific content and wanted information about end-of-life planning and most were happy to discuss it in a group. In that same study, clinicians supported discussion of advanced care planning but not necessarily in the pulmonary rehabilitation setting (18). Communication with patients about goals of care is crucial and continued research is needed in this area.

Oxygen Therapy

In the 1980's, use of supplemental oxygen therapy increased after the NOTT (Nocturnal Oxygen Therapy Trial) and the MRC (Medical Research Council) trials demonstrated survival benefits of providing long-term oxygen therapy to patients with resting arterial partial pressure of oxygen consistently less than 55 mm Hg (19, 20). Today, more than one million people in the United States use long term oxygen therapy, the majority with chronic obstructive lung disease (COPD) (21). Oxygen therapy is the most frequently used treatment for patients with ILD and IPF to treat hypoxemia and halt progression or prevent development of hypoxia-induced pulmonary hypertension, cardiovascular morbidity, or cognitive dysfunction (22, 23).

Oxygen prescriptions vary greatly for patients with ILD with patients often requiring oxygen with exertion and sleep earlier in the disease process before they require oxygen with rest. In one study, exertional hypoxemia was found to be more severe for patients with fibrotic lung disease than those patients with COPD. This group compared results of a 6-minute walk test (6MW) performed on room air in 134 patients with ILD and 247 patients with COPD. Diffusing capacity (DLco) was the strongest predictor of desaturation in both cohorts with ILD patients experiencing greater oxygen desaturation during the 6MW compared to patients with COPD (24).

Supplemental oxygen has allowed patients who otherwise would be homebound to be more mobile, work, exercise or attend pulmonary rehabilitation, travel, care for family members, and also experience improvement in their symptoms, including dyspnea, ultimately improving their quality of life (25, 26). Patients who require supplemental oxygen, especially those with ILD experience frequent and varied problems with receiving adequate portable systems to meet their dose requirement. Oxygen equipment is bulky and options are limited as oxygen dose increases. In a study of 30 clinically stable ILD patients with varying disease severity, carrying portable oxygen versus using oxygen from a stationary concentrator resulted in significantly greater dyspnea and shorter distances in timed testing (23). Portable systems can deliver continuous flow (CF) and intermittent flow (IF) and, while IF devices are safe and generally effective in correcting hypoxemia, there is variability in delivery and patient response and therefore patients need to be tested on these devices. (26). Use of a pulse oximeter is recommended to allow patients to adjust their oxygen flow to maintain saturations >89% at all times (27).

In a recent ATS survey of 1926 patients with lung disease who used oxygen, individuals with IPF were rarely on oxygen more than 5 years, but frequently used oxygen > 5LPM (28). Patients who received oxygen education had less health care utilization, including emergency visits and hospitalizations (28). Use of “a detailed discussion that includes an educational overview of oxygen, recommendations for how to use oxygen correctly, and disclosure of what hardships and benefits the patient (and their caregiver) might expect from oxygen” is endorsed for patients prescribed oxygen therapy (27). The process of oxygen prescription can be improved by providing patients with clearer expectations and trustworthy educational resources (29).

Palliative Care

ILDs are highly disabling and patients experience a loss of functional ability, resulting in great symptom burden as the disease advances ultimately impacting the patient’s quality of life (11). Patients with ILD often suffer unmet physical and psychological needs as they live with their ILD (30).

Palliative care is the comprehensive treatment of the discomfort, symptoms, and stress of serious illness and should be started as soon as the patient is diagnosed. Symptom management is relevant even in patients with mild to moderate disease. Traditionally, palliative care was seen as replacing the curative care with palliative or end-of-life care, but the paradigm has shifted and palliative care should be offered alongside all other treatments for the disease (9, 31). See Figure 1. In prior studies, patients with advanced lung disease,

including IPF have been found less likely to receive palliative care than malignant diseases and other chronic conditions, including dementia (32, 33). Several reasons for fewer referrals include uncertainty regarding prognosis, lack of provider skill to engage in discussions about PC, fear of using opioids among patients with chronic lung disease, fear of diminishing hope, and perceived and implicit bias against patients with smoking-related lung disease (34).

The main goal of palliative care (PC) for patients with interstitial lung disease (ILD) is to improve and maintain quality of life. Optimal quality of life care includes symptom-centered approaches, best supportive care, caregiver-centred management, disease-stabilizing care, patient-centred management, and end-of-life care (35). PC includes all of the interventions aimed to improve and optimize qualify of life (QoL) in patients affected by progressive disease (36). PC also includes helping the patient and their caregivers with advance care planning through the process for preference of end-of-life care (11). Addressing goals of care early in the disease trajectory is associated with improved patient outcomes and reduced intensity of end-of-life care (37).

Palliative care can be delivered by a member of the clinical care team, referred to as primary palliative care, or an interdisciplinary team, referred to as secondary or specialty palliative care. Optimal PC for patients with chronic lung disease, such as ILD should incorporate both primary and specialty PC (38). Challenges facing specialty palliative care include increased demands on limited resources (39). Supportive care is a term that has been associated with better understanding and more favorable impressions than palliative care (40). Hospice is different from palliative care and should be offered when the patient is not expected to live greater than 6 months (41). Resources are available to find non-hospital based (42) and hospital based palliative care programs (43),

The goals of PC are to prevent and relieve suffering, support the best quality of life for patients facing serious illness and their caregivers, and encourage discussions regarding EOL preferences. Studies have reported that even when patients and their caregivers understand the terminal nature of their disease, they did not appreciate that symptoms could escalate rapidly, resulting in death (30). Because of the unpredictable nature of ILD, especially IPF, early introduction of PC should be considered a standard of care. The mantra “It is wise to hope for the best, but it is also wise to prepare for the worst” can introduce the concept of advance care planning to the patient and their caregiver (44).

Tools to Help Clinicians Identify Palliative Care Needs

Identification and management of patients’ palliative care needs can be challenging for clinicians. The Needs Assessment Tool: Progressive disease in interstitial lung disease (NAT:PD-ILD) is a single page guide to prompt clinicians to assess patients’ well-being, informal carers’ need and information needs prompting referral for specialty palliative care (45) See Table 1.

Role of ILD Clinical Nurse Specialist

Nurses are considered to be central to health care provision and highly valued by patients (46). Symptom management and palliative care are the hallmarks of nursing, especially

within the realm of the ILD Clinical Nurse Specialist (47). The CNS provides expert knowledge and advice to patients and their families throughout all stages of care and is frequently the main clinical contact for healthcare working in concert with clinical care team. The main focus is on managing symptoms and frequently adjusting the plan of care as the disease progresses. Nurse and interdisciplinary-led research makes important contributions to the evidence base of clinical practice, especially in the non-pharmacological approaches to symptom management. These collaborations work to advance the care provided for patients.

Conclusion

ILDs are complex. Education and clarity of communication are essential for the patient and their caregiver(s) to understand and appreciate the magnitude of the disease. Participating in support groups and research studies offer the patient the ability to actively manage their disease. Different ILDs can have similar symptoms and complications, and it is important to address them with symptom specific treatments including pulmonary rehabilitation and supplemental oxygen therapy. Because the disease course is unpredictable, it is important to initiate palliative care early after diagnosis to optimize symptom management and address advance care planning. These nonpharmacologic therapies are crucial in supporting the patient and their caregiver(s) as they live with their interstitial lung disease.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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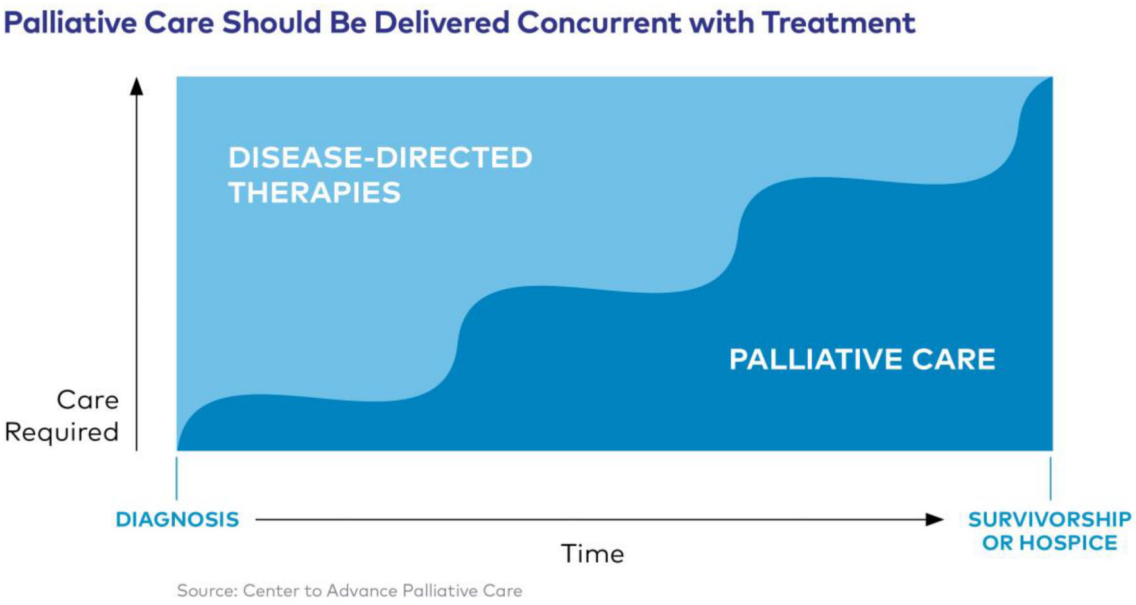

Figure 1.

Palliative Care's Place in Serious Illness

Used with permission from Center to Advance Palliative Care.

Table 1.

The Needs Assessment Tool: Progressive disease in interstitial lung disease (NA:PDILD)

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.

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Needs Assessment Tool: Interstitial Lung Disease

Name:

(or attach address label)

Please complete all sections

Guidance for completion on reverse

Date ___/___/___

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**		
Who provided this information? Patient ☐ Carer ☐ Both ☐	None	Some/ Potential	Significant	Directly Managed	Refer to other team member	Refer SPCS
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 ☐ Diagnosis ☐ Treatment options ☐ Financial/legal issues ☐ Support services (social/emotional issues) ☐						

Comments:

Section 3: ABILITY OF CARER OR FAMILY TO CARE FOR PATIENT (*"Is the Carer / Family……."*)	**Level of Concern**			**Action Taken**		
Who provided this information? Patient ☐ Carer ☐ Both ☐	None	Some/ Potential	Significant	Directly Managed	Refer to other team member	Refer SPCS
Distressed about the patient's symptoms?						
Having difficulty providing physical care?						
Having difficulty coping with the patient's psychological symptoms?						
Concerned about financial or legal issues?						
Experiencing problems that are interfering with inter-personal relationships or functioning, or is there a history of such problems?						
Information needs: Prognosis ☐ The diagnosis ☐ Treatment options ☐ Financial/legal issues ☐ Support services (social/emotional issues) ☐						

Comments:

Section 4: CARER/FAMILY WELLBEING "Carer or family experiencing……."	**Level of Concern**			**Action Taken**		
	None	Some/ Potential	Significant	Directly Managed	Refer to other team member	Refer SPCS
Unresolved psychosocial problems or feelings *(loneliness, depression, anxiety, frustration)* that are interfering with their wellbeing or functioning?						
Grief over the future death of the patient?						

Comments:

IF FURTHER ASSESSMENT REQUIRED, PLEASE COMPLETE THIS SECTION:

Referral to (Name)…… **Patient aware of referrals**: Y N

Speciality: ILD Nurse Specialist ☐ Spiritual Care ☐ Psychology ☐ OT PT ☐ **Copy to GP** Y N

Social Services ☐ Specialist Palliative Care ☐ Local/specialist ILD Clinic ☐ Other ☐

Priority of assessment needed: Urgent (within 24 hours) Semi-urgent (2-7 days) Non-urgent (next available) ☐

Referral from: Name…… Position…… Signature ……

ISSUES TO CONSIDER WHEN RATING LEVEL OF CONCERN

RED FLAGS – If present consider further assessment by own team +/- SPCS if required

Right heart failure- Clinical evidence of right heart failure

Deteriorating Performance Status – functional ability worse since last ILD review

Repeated unscheduled contact- 3 or more contacts from either patient or caregiver since last ILD review

Failure to attend clinic – may indicate physical or social difficulties, change in circumstance or acute admission preventing attendance.

PATIENT WELLBEING – does the patient present with unresolved problems with the following:

Physical symptoms: Does the patient present with unresolved symptoms such as:

- SOB, cough, leg oedema, heartburn/reflux/poor appetite, fatigue, insomnia/daytime drowsiness, constipation, pain or cognition. Or is the patient experiencing problems with self-image/sexual intimacy?

Psychological "Does the patient have…."

- Sustained lowering of mood, tearfulness or guilt? Loss of pleasure in usual activities? Feelings of anxiety, panic attacks, anger or fearfulness?
- Is the patient struggling with the implications of, or emotional response to the diagnosis?
- Is the patient requesting a hastened death?

Activities of daily living

- Is the patient having difficulty with toileting, showering, bathing, or food preparation?
- Do they require more information about the services available to them to maximise their daily function

Spiritual/Existential – "Is the patient expressing concerns about the meaning of life, or suffering…."

- Feeling hopeless? That life has no meaning or that his/her life has been wasted?
- Having difficulty thinking about the future, including the end of life?
- Requiring assistance in finding appropriate spiritual resources or services?

Work/Financial/Legal concerns

- Consider loss of income, costs of treatment, travel expenses, equipment, or future care needs (such as residential care)?
- Is the family socio-economically disadvantaged?
- Is the patient or family aware of the various financial schemes available and do they need assistance in accessing these (e.g. social worker)?

Are there conflicting opinions between patient and family relating to legal issues such as end-of-life care options and advance care plans?

Health Beliefs, Social and Cultural – "Does the patient or family…"

- Have beliefs or attitudes that make health care provision difficult – for example believing that palliative / hospice care is not available to them?
- Have any communication difficulties (due to language/disease/disability)? Does the patient or family require assistance?
- Feel socially isolated?
- Need information passed on to a particular member of the family or cultural group?
- Want information about prognosis to be withheld from the patient, or are they reluctant to discuss prognosis? If so, has this been explored?
- Have logistical difficulties accessing services (distance, transport, cost)?

Information – "Is the patient aware of/that…"

- Available services and do they need assistance accessing these? (e.g. financial /legal assistance, psychological services, support groups, pastoral care.)
- Advance Care Planning (ACP) and have their views / attitudes towards it been explored?
- Does the patient have a perception of their individual disease and prognosis? Do they want more information (including written information)?

ABILITY OF CARER OR FAMILY TO CARE FOR PATIENT

Physical symptoms

- Are the patient's physical symptoms causing the carer and/or family distress?

Providing physical care

- Is the carer having difficulty coping with activities of daily living, medical regimes or practical issues such as equipment and transport?
- Have they received all the practical information they require?

Psychological/ coping- "Is the carer / family…"

- Having difficulty coping with the patient's psychological symptoms (esp. anxiety, panic attacks and depression)?
- Requesting a hastened death for the patient?

Work/Financial/Legal concerns

- Consider loss of income, costs of treatment, travel expenses, equipment, or future care needs (such as residential care)?
- Is the family socio-economically disadvantaged?
- Is the patient or family aware of the various financial schemes available and do they need assistance in accessing these (e.g. social worker)?
- Are there conflicting opinions between patient and family relating to legal issues such as end-of-life care options and advance care plans?

Family and Relationships

- Is there any communication breakdown or conflict between the patient and family over prognosis, treatment options or care giving roles?
- Is the patient particularly concerned about the impact of the illness on the carer or family?
- Is the disease having an adverse effect on the relationship between patient and carer? (consider impact of physical, psychological and personal cares, sexual dysfunction and change to previous roles within relationship.)

Information – "Do/are the carer or family…"

- Require more information (including written information) about the course and prognosis of the disease and treatment?
- Aware of available services/ need assistance accessing these? (e.g. Financial/legal psychological services, support groups, pastoral care.)
- Are the information needs of the patient and family congruous?

CARER AND FAMILY WELLBEING - "Do the carer or family…"

Physical and psychosocial

- Experience physical strain, ill health, fatigue, disturbed sleep? Is there evidence of anxiety, depression or feelings of hopelessness?
- Have spiritual/existential issues that are of concern?
- Currently feel that caring has a net positive or negative affect for them personally and their relationship with the patient?

Grief (pre death)

- Experience intrusive images, severe emotion, denial of implications of loss to self and neglect of necessary adaptive activities at home or work?
- Know of the progressive nature of advanced ILD? Has future care planning been considered?
- Have access to support services (such as ILD Nurse Specialist, SPC, Local support groups, post bereavement support?)