

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.

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 | | |
|--|------------------|--------------------|-------------|---------------------|-------------------------------|---------------|
| Who provided this information? Patient <input type="checkbox"/> Carer <input type="checkbox"/> Both <input type="checkbox"/> | 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 <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"/> | | | | | | |

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 <input type="checkbox"/> Carer <input type="checkbox"/> Both <input type="checkbox"/> | 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 <input type="checkbox"/> The diagnosis <input type="checkbox"/> Treatment options <input type="checkbox"/> Financial/legal issues <input type="checkbox"/> Support services (social/emotional issues) <input type="checkbox"/> | | | | | | |

Comments: _____

| Section 4: CARER/FAMILY WELLBEING “Carer or family experiencing.....” | Level of Concern | | | Action Taken | | |
|---|------------------|--------------------|-------------|---------------------|-------------------------------|---------------|
| Who provided this information? Patient <input type="checkbox"/> Carer <input type="checkbox"/> Both <input type="checkbox"/> | 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 <input type="checkbox"/> Spiritual Care <input type="checkbox"/> Psychology <input type="checkbox"/> OT PT <input type="checkbox"/> | Copy to GP Y N |
| Social Services <input type="checkbox"/> Specialist Palliative Care <input type="checkbox"/> Local/specialist ILD Clinic <input type="checkbox"/> Other <input type="checkbox"/> | |
| Priority of assessment needed: Urgent (within 24 hours) Semi-urgent (2-7 days) Non-urgent (next available) <input type="checkbox"/> | |
| 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?)