



Systematic assessment of palliative care needs: Efficacy, time, resource implications & future directions

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Overview of Palliative Care Program (2003-2009)



COMPLETED WORK (2003-2008)

- Phase 1: National qualitative study - perceptions of palliative care, issues surrounding referral in the Australian health care system.
- Phase 2: National survey of doctors - current referral practices, predictors of referral, prevalence of triggers precipitating referral for SPC.
- Phase 3: Development of national Palliative Care Needs Assessment Guidelines and a Needs Assessment Tool, to facilitate needs-based care and enhance SPC resource utilisation.
- Phase 4: Evaluation of the impact of the guidelines and tool on patient & caregiver outcomes.

WORK UNDERWAY IN 2009

- Phase 5: Development of national dissemination plan and training packages for referrers and palliative care services.
- Phase 6: Generalising the resources to non-cancer palliative populations.

Overview of the Needs Assessment Tool: Progressive Disease - Cancer (NAT: PD-C)

NAT: PD-C



- Aims to facilitate care based on types and complexity of needs:
 - no problems and no need for services;
 - minor problems (ie, low need), which may be met by their primary health professional;
 - medium to high needs and potentially require a referral for full assessment by specialist services
- Designed for ongoing use in both *generalist* and *specialist* care settings

NEEDS ASSESSMENT TOOL : PROGRESSIVE DISEASE CANCER (NAT: PD-C)

COMPLETE ALL SECTIONS

PATIENT NAME: _____

DATE: _____ DIAGNOSIS: _____

PATIENT/ADDRESS LABEL

SECTION 1: PRIORITY REFERRAL FOR FURTHER ASSESSMENT

| | Yes | No | If yellow boxes are ticked, consider assessment by SPCS | |
|--|-----|----|---|--|
| 1. Does the patient have a caregiver readily available if required? | | | | |
| 2. Has the patient or caregiver requested a referral to a specialist palliative care service (SPCS)? | | | | |
| 3. Do you require assistance in managing the care of this patient and/or family? | | | | |

SECTION 2: PATIENT WELLBEING (Refer to the back page for assistance)

| | Level of Concern | | | Action Taken | | |
|--|------------------|----------------|-------------|------------------|-----------------------------------|-------------------|
| | None | Some/Potential | Significant | Directly managed | Managed by other care team member | Referral required |
| 1. Is the patient experiencing unresolved physical symptoms (including problems with pain, sleeping, appetite, nausea, bowel, breathing or fatigue)? | | | | | | |
| 2. Does the patient have problems with daily living activities? | | | | | | |
| 3. Are the patient's psychological symptoms interfering with wellbeing or relationships? | | | | | | |
| 4. Does the patient have concerns about spiritual or existential issues? | | | | | | |
| 5. Does the patient have financial or legal concerns that are causing distress or require assistance? | | | | | | |
| 6. From the health delivery point of view, are there health beliefs, cultural or social factors involving the patient or family that are making care more complex? | | | | | | |
| 7. Does the patient require information about (tick any options that are relevant): <input type="checkbox"/> The prognosis <input type="checkbox"/> The cancer <input type="checkbox"/> Treatment options <input type="checkbox"/> Financial/legal issues <input type="checkbox"/> Medical/health/support services <input type="checkbox"/> Social/emotional issues | | | | | | |

COMMENTS: _____

SECTION 3: ABILITY OF CAREGIVER OR FAMILY TO CARE FOR PATIENT (Refer to the back page for assistance)

| Who provided this information? (please tick one) <input type="checkbox"/> Patient <input type="checkbox"/> Caregiver <input type="checkbox"/> Both | Level of Concern | | | Action Taken | | |
|--|------------------|----------------|-------------|------------------|-----------------------------------|-------------------|
| | None | Some/Potential | Significant | Directly managed | Managed by other care team member | Referral required |
| 1. Is the caregiver or family distressed about the patient's physical symptoms? | | | | | | |
| 2. Is the caregiver or family having difficulty providing physical care? | | | | | | |
| 3. Is the caregiver or family having difficulty coping? | | | | | | |
| 4. Does the caregiver or family have financial or legal concerns that are causing distress or require assistance? | | | | | | |
| 5. Is the family currently experiencing problems that are interfering with their functioning or inter-personal relationships, or is there a history of such problems? | | | | | | |
| 6. Does the caregiver or family require information about (tick any options that are relevant): <input type="checkbox"/> The prognosis <input type="checkbox"/> The cancer <input type="checkbox"/> Treatment options <input type="checkbox"/> Financial/legal issues <input type="checkbox"/> Medical/health/support services <input type="checkbox"/> Social/emotional issues | | | | | | |

COMMENTS: _____

SECTION 4: CAREGIVER WELLBEING (Refer to the back page for assistance)

| Who provided this information? (please tick one) <input type="checkbox"/> Patient <input type="checkbox"/> Caregiver <input type="checkbox"/> Both | Level of Concern | | | Action Taken | | |
|--|------------------|----------------|-------------|------------------|-----------------------------------|-------------------|
| | None | Some/Potential | Significant | Directly managed | Managed by other care team member | Referral required |
| 1. Is the caregiver or family experiencing physical, practical, spiritual, existential or psychological problems that are interfering with their wellbeing or functioning? | | | | | | |
| 2. Is the caregiver or family experiencing grief over the impending or recent death of the patient that is interfering with their wellbeing or functioning? | | | | | | |

COMMENTS: _____

IF REFERRAL REQUIRED FOR FURTHER ASSESSMENT OR CARE, PLEASE COMPLETE THIS SECTION

1. Referral to: (Name) _____

2. Referral to: (Specialty) General practitioner Social worker Psychologist Specialist palliative care service
 Medical oncologist Radiation oncologist Haematologist Other _____

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

4. Discussed the referral with the client. Yes No

5. Client consented to the referral. Yes No

6. Referral from: Name: _____ Position: _____ Signature: _____

ISSUES TO CONSIDER WHEN RATING THE LEVEL OF CONCERN

PATIENT WELLBEING

- Physical symptoms**
- Does the patient present with unresolved physical symptoms such as drowsiness, fatigue, dyspnoea, vomiting/nausea, pain, constipation, sleep problems, diarrhoea, or loss appetite?
- Activities of daily living**
- Is the patient having difficulty with toileting, showering, bathing, or food preparation?
 - Is there a caregiver to assist the patient?
- Psychological**
- Is the patient experiencing sustained lowering of mood, tearfulness, guilt or irritability, loss of pleasure or interest in usual activities?
 - Is the patient experiencing feelings of apprehension, tension, anger, fearfulness or nervousness, hopelessness or a sense of isolation?
 - Is the patient requesting a hastened death?
- Spiritual/Existential**
- Is the patient feeling isolated or hopeless?
 - Does the patient feel that life has no meaning or that his/her life has been wasted?
 - Does the patient require assistance in finding appropriate spiritual resources or services?
- Financial/Legal**
- Are there financial concerns relating to loss of income or costs of treatment, travel expenses, or equipment?
 - Is the family socio-economically disadvantaged?
 - Are there conflicting opinions between patient and family relating to legal issues such as end-of-life care options and advance care plans?
 - Is the patient or family aware of the various financial schemes available and do they need assistance in accessing these?
- Health Beliefs, Social and Cultural**
- Does the patient or family have beliefs or attitudes that make health care provision difficult?
 - Are there any language difficulties? Does the patient or family require a translator?
 - Is the family preventing information about prognosis from being disclosed to the patient?
 - Does the information have to be passed on to a particular member of the family or cultural group?
 - Is the patient or family feeling socially isolated?
 - Does the family live more than 50km from the primary service provider?
 - Is the patient of Aboriginal or Torres Strait Islander descent?
 - Is the patient over 75 years of age? (NB: older patients are under-represented in SPCSs.)
- Information**
- Does the patient want more information about the course and prognosis of the disease and treatment options?
 - Is the patient aware of the various care services available to assist them and do they need assistance in accessing these? (eg financial and legal assistance, psychological services, support groups, pastoral care.)

ABILITY OF CAREGIVER OR FAMILY TO CARE FOR PATIENT

- Physical symptoms**
- Are the patient's physical symptoms causing the caregiver and family distress?
- Providing physical care**
- Is the caregiver having difficulty coping with activities of daily living, medical regimes or practical issues such as equipment and transport?
- Psychological**
- Is the caregiver having difficulty coping with the patient's psychological symptoms?
 - Is the caregiver requesting a hastened death for the patient?
- Family and Relationships**
- Is there any communication breakdown or conflict between patient and family over prognosis, treatment options or care giving roles?
 - Is the patient particularly concerned about the impact of the illness on the caregiver or family?
- Information**
- Does the caregiver or family want more information about the course and prognosis of the disease and treatment?
 - Is the caregiver or family aware of the care services available to assist them and do they need assistance in accessing these? (eg respite, financial and legal services, psychological services, support groups, pastoral care.)

CAREGIVER WELLBEING

- Physical and psychosocial**
- Is the caregiver experiencing physical symptoms eg fatigue, physical strain, blood pressure/heart problems, stress related illness, or sleep disturbances?
 - Is the caregiver feeling depressed, hopeless, fearful, nervous, tense, angry, irritable or critical of others, or overwhelmed?
 - Does the caregiver have spiritual/existential issues that are of concern?
- Bereavement Grief (pre and post death)**
- Is the caregiver or family experiencing intrusive images, severe pangs of emotion, denial of implications of loss to self and neglect of necessary adaptive activities at home or work?

Cancer Helpline 13 11 20 Multicultural Cancer Information Service Support and Information
 pack Patient survivor link up Telephone counsellors Understanding Cancer Programs
 Cancer Helpline 13 11 20 www.cancer.gov.au Living with Cancer Programs
 Cancer Helpline 13 11 20 Multicultural Cancer Information Service Support and Information

SECTION 1: PRIORITY REFERRAL FOR FURTHER ASSESSMENT

| | Yes | No | If yellow boxes are ticked, consider assessment by SPCS |
|--|-----|----|---|
| 1. Does the patient have a caregiver readily available if required? | | | |
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| 3. Do you require assistance in managing the care of this patient and/or family? | | | |

SECTION 2: PATIENT WELLBEING (Refer to the back page for assistance)

| | Level of Concern | | | Action Taken | | |
|---|------------------|----------------|-------------|------------------|-----------------------------------|-------------------|
| | None | Some/Potential | Significant | Directly managed | Managed by other care team member | Referral required |
| 1. Is the patient experiencing unresolved physical symptoms (including problems with pain, sleeping, appetite, nausea, bowel, breathing or fatigue)? | | | | | | |
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| 7. Does the patient require information about (tick any options that are relevant): | | | | | | |
| <input type="checkbox"/> The prognosis <input type="checkbox"/> The cancer <input type="checkbox"/> Treatment options <input type="checkbox"/> Financial/legal issues <input type="checkbox"/> Medical/health/support services <input type="checkbox"/> Social/emotional issues | | | | | | |

COMMENTS: