

Guideline for the Implementation of Holistic Needs Assessment for Adults with Cancer

Version History

Version/ draft	Date	Comments
1	10.02.09	Discussed at the guidelines sub committee – approved following minor amendments
1.1	Autumn 2010	For review with Psychology measures in mind also the draft SPC measures. Circulated to the Psychology NSSG, the HNA steering group and the Lead Cancer Nurses.
1.2	12.11.10	Following consultation. For submission to the Guidelines Subgroup.
2.0	25.01.11	Minor changes approved by Guidelines subgroup

Date Approved by Network Governance	25 January 2011
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Date for Review	25 January 2014
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1. Scope of Guidance

- 1.1. This document provides guidance for the implementation of Holistic Needs Assessment (HNA) for patients cared for within Pan Birmingham Cancer Network.
- 1.2 This document is also designed to support the implementation of the HNA element of the Supportive and Palliative Care Improving Outcomes Guidance and peer review measure 10-1E-105X (Psychological screening).

2 Background

Key recommendation 2 of the NICE guidance on Improving Supportive and Palliative Care for Adults with Cancer states that Holistic Needs Assessment should be undertaken at key points within the patient pathway. Cancer Networks are responsible for ensuring there is a unified approach to its implementation and that professionals carry out assessments in partnership with patients and carers.

Equally, Key Recommendation 9 states that all patients should undergo systematic psychological assessment at key points and have access to

appropriate psychological support. Patients want and expect to receive emotional support from professionals who are prepared to listen to them and are capable of understanding their concerns (p. 16, IOG, 2004). All staff directly responsible for patient care should offer patients general emotional support based on skilled communication, effective provision of information, courtesy and respect. Patients and carers found to have significant levels of psychological distress should be offered prompt referral to services able to provide specialist psychological care.

Included in these guidelines is the Well Being Assessment (originally the Distress Thermometer or DT), which is one recommended tool that facilitates this process. Other tools are also available and are acceptable as long as they cover all the dimensions described in the Cancer Action Team / King's College London document².

3 Guideline Statements

- 3.1 The assessment guidance produced by Kings College London and the Cancer Action Team² should be used to support the process of local implementation of HNA along the patient pathway[♦].
- 3.2 All patients with a diagnosis of cancer should be offered a HNA at each of the following points along the patient pathway:
- around the time of diagnosis
 - commencement of treatment
 - completion of primary treatment plan
 - each new episode of disease recurrence
 - the point of recognition of incurability
 - the beginning of the end of life
 - the point at which dying is diagnosed
 - at any other time the patient may request it
 - at any other time that a professional carer may judge necessary.

In some cases, some of these points may follow one another quickly in time. In this case unnecessary repeated assessments should be avoided as one assessment may cover more than one part of the pathway.

- 3.3 The assessment should include the 'domains' listed below. Further information on each of these domains is available in the assessment guidance produced by Kings College London and the Cancer Action Team², and the Wellbeing Assessment (see Appendix 1).

[♦] Pages 6 – 16 of the Kings Fund document are not intended as a tool but outline the 'domains' to be covered by the assessment. Other tools can be adapted to include these domains; within PBCN the Patient Concerns Checklist has been adapted to include these domains.

Assessment Domains

- background information and assessment preferences
 - physical needs
 - social and occupational needs
 - psychological wellbeing
 - spiritual well-being
- 3.4 In addition to the above five domains, the following two areas should be considered when carrying out the HNA. These are specified in the peer review measures.
- information needs
 - carers needs
- 3.5 Site specific teams and cross cutting teams at Trust level should meet and agree who will take responsibility for assessments along the patient pathway in order that unnecessary repeated assessments are avoided.
- 3.6 Where patients are cared for across Trust sites the Multidisciplinary Teams should agree local plans for the implementation of HNA. These should include documentation and communication systems that enable a smooth pathway of care for the patients.
- 3.7 Teams should produce local documentation, or alternatively use the adapted Wellbeing Assessment (see pages 13 and 14, Appendix 1).
- 3.8 Teams choosing to use the Wellbeing Assessment should ensure that all those using the tool are familiar with the accompanying guide (see appendix 1 which contains a guide to carrying out Holistic Needs Assessments, and to using the Wellbeing Assessment).
- 3.9 The professional carrying out the HNA should have experience in cancer care and up-to date information on local service providers, referral criteria and support services. Where assessments are taking place during periods of treatment intensity, the assessor should have good knowledge of the patient's disease and likely treatment options.
- 3.10 All professionals carrying out HNA should have access to and be familiar with the guidance document published by Kings College London and the Cancer Action Team².
- 3.11 All professionals carrying out HNA should be working towards Level 2* psychological support. All staff, even at Level 1, should also be able to identify and respond appropriately to distress.

* Level 2 of the four tier psycho-oncology model in the Supportive and Palliative Care IOG¹. In PBCN Level 2 practitioners complete the Advanced Communication Skills Training an additional session that focuses on screening, basic psychological assessment and interventions and attend regular clinical supervision for the psychological support they offer.

- 3.12 Information on HNA should be made available to patients.
- 3.13 The implementation of the HNA should be carried out in conjunction with the Key Worker Guidance.

Monitoring of the Guideline

Implementation of the guidance will be considered as a topic for audit by the NSSG in 2013.

References

- 1 NICE (2004) Improving Supportive and Palliative Care for Adults with Cancer.
- 2 Cancer Action Team (2007) Holistic Common Assessment of Supportive and Palliative Care Needs for Adults with Cancer: Assessment Guidance. London, Cancer Action Team.
- 3 Pan Birmingham Cancer Network (2008) Patient Information on Holistic Needs Assessment.
- 4 Pan Birmingham Cancer Network (2008) Network Key worker guidelines.

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ENDORSED BY THE CLINICAL GOVERNANCE COMMITTEE

Appendix 1 – Using the HNA (page 1 of 11)

This document was written by Helen Guy and is intended to be used by those using the Wellbeing Assessment.

Part One – Holistic Screening and Assessment domain 1 Background information and assessment preferences

1. Please make sure the following information is collected prior to the first Holistic Assessment (information may be collected from the patient's care record). If this is not the first assessment, please check to see if any of the information has changed.

Family name

Forenames

Preferred name

NHS ID

Date of Birth

Gender

Ethnicity

Religion

Occupation

Relationship status

Home address

Telephone number

Next of kin

Carer

Dependents

Preferred language for written communication

Preferred language for spoken communication

Interpreter required?

Relevant clinical history and pre-existing morbidities

Allergies

Treatment plan

Current medication and complementary therapies that have been used or are being used

Diet

Alcohol intake

Exercise

Smoking

Admissions since last assessment

Support/care currently received

Preferred place of care/place of death

Name of GP

Name of GP practice

Hospital consultant

Other professionals involved in care

Information needs and preferences

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Part Two – Introduction to Holistic Assessment

Aim

1. To provide a brief holistic (i.e. biological-psychological-social-spiritual) assessment of patients at any stage through their treatment.
2. To document the patient's
 - Physical state and experience of treatment side-effects (e.g. pain, nausea, fatigue etc)
 - Psychological and emotional well-being or concerns (anxiety, depression, relationship, sexual or family concerns, etc)
 - Social/practical concerns (e.g. housing, finances etc.)
 - Existential/spiritual concerns
3. To identify services and resources that may help to resolve the patient's concerns.

Background

The more concerns people have the more they are likely to be distressed, (Cull et al., 1995) yet rarely are these concerns expressed by patients or identified by healthcare staff (Parle et al.,1996). It seems that, whether their concerns are physical, (Ward et al.,1993) psychosocial, (Maguire, 1999) or spiritual (Heaven & Maguire,1997) many patients are reluctant to complain about them due to commonly held expectations and assumptions:

Common assumptions which deter patients from revealing their physical, spiritual or psychosocial concerns.

- Raising difficulties is seen as the responsibility of doctors, not patients (Detmar et al.,2000).
- Patients and relatives sometimes lack the confidence, social skills or language to ask questions of healthcare professionals, or express their feelings.
- Healthcare professionals are seen as too busy and important to be burdened with the patient's concerns.
- Patients feel constrained by the common social pressure to 'think positively' at all times.
- Patients may feel shame at admitting they have particular difficulties (e.g. sexual, financial, literacy etc).
- Those harbouring guilt about their previous lifestyle (e.g. smoking) may be more reluctant to voice their concerns (Heaven & Maguire, 2003).
- Emotional and even physical distress is often seen as inevitable and untreatable.

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Similarly, healthcare staff are generally poor at detecting even severe levels of distress in their patients, (Sollner et al., 2001; Passik et al.,1998) and oncologists tend to leave it to their patients to raise concerns if they have them (Detmar et al., 2000) or simply block patients' attempts to communicate their concerns. (Maguire,1992) The resulting impasse amounts to a failure of communication with the result that patients' distress goes unattended. The NICE Supportive and Palliative Care Guidance (2004) points to the fact that "individual patients have different needs at different phases of their illness, and services should be responsive to patients' needs" (p.5). This suggests the need for a brief, structured holistic measurement tool that any member of the healthcare team can use to assess their patients' physical, psychological, social and spiritual concerns.

Principles of using this holistic assessment tool

1. Make it clear that this is a normal routine assessment.
2. Move from the general to the specific.
3. Make the process transparent to the patient. Explain the purpose of the meeting and enable them to see what you are writing on the assessment sheet.
4. Emphasise patient's own resources in managing difficulties. Make it solution-focused.
5. Assessment is not therapy, but it is an opportunity for patients to tell something of their experiences and possibly to see that these experiences and their feelings are normal.

Dr James Brennan, Consultant Clinical Psychologist
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Part Three – Holistic Screening and Assessment domains 2-5

The Wellbeing Assessment has been adapted from the Distress Thermometer (DT) and is one promising screening and assessment measure which appositely covers four of the five assessment domains recommended for Holistic Common Assessment (Physical, Social and Occupational, Psychological and Spiritual).

The DT was initially developed by Roth and colleagues (1998) as a 0-10 distress analogue scale. In 2003, the National Comprehensive Cancer Network in the United States produced Clinical Practice Guidelines for Distress Management and added a problem list to the thermometer. This was then evaluated by Jacobsen and colleagues (2005) who conducted the first multicentre evaluation of the Distress Thermometer and found the DT compared favourably with longer screening measures.

In the UK, an extended version of the tool was developed and included a section for prioritising problems and an action plan (Brennan, 2005). In 2007, the DT was validated in the UK against other well established measures such as the HADS and GHQ, and 4 was deemed as a good indicator of distress (Gessler et al., 2007).

In 2008, the DT was adapted by Psychologists working with the Pan-Birmingham Cancer Network to include the assessment areas recommended in the Holistic Common Assessment Guidance (Kings College London and the National Cancer Action Team, 2007). This revised tool is called the Wellbeing Assessment (see page 13). Instructions for administering the Wellbeing Assessment are outlined below.

Helping patients complete side 1 of the

1. Explain to the patient that you would like them to complete the Wellbeing Assessment, as this provides a good way of finding out how they are managing and if they have any particular concerns. It may be helpful to tell them that this is a routine measure used with all patients and can be useful in helping with any difficulties. Please make sure you gain the patient's consent to use the Wellbeing Assessment, please also check to see if the patient would like someone with them throughout the assessment. For example: *You have come here for a follow-up appointment today, and I'd like to find out any concerns you may have and how you are managing. It would be helpful if you could complete this checklist now, so that we can discuss it in more detail later on. It is up to you how much you would like to share with me, but of course if you do have concerns we won't be able to help you with them if we don't know what they are. We use the Wellbeing Assessment with all patients. Are you happy to complete this? Would you like someone with you? The instructions are written on both sides of it; however, if there's anything you don't understand please ask for help.*

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2. The instructions for completing the Wellbeing Assessment are written on the Checklist. However, some patients may need further help and guidance about how to complete it. The instructions provided on the checklist are as follows:
 - a) Using the thermometer, please circle a number that best describes how much distress you have felt in the past week, including today. 0 stands for no distress and 10 stands for very distressed.
 - b) Next, please tick any of the following concerns that has been as cause of distress for you in the past week, including today.
 - c) If you have a concern or difficulty that isn't on the list, please write it in the 'Other problems' box:
 - d) On the second side of the tool, patients are given the following instructions: *Please write down you four greatest concerns below. The professionals supporting you will ask to see this checklist. They will find out more about your difficulties and help you plan how to address your concerns.*

Completing the plan of action with patients

3. Thank the patient for taking the time to complete the checklist. It maybe helpful to ask the patient how they found completing the checklist. Please note some patients may require extra support to complete the checklist.
4. Please ask the patient if you can see the checklist. Quickly scan the front page of the checklist to see how the patient has rated their overall level of distress on the 0-10 thermometer. A score of 4 or above may suggest that the patient is experiencing significant psychological distress. It is important to gain more information about the patients concerns and adopt a problem solving approach which is outlined below. The evaluation and intervention process (see page 15) also provides a useful overview.
5. Please check that the patient has ticked concerns on the list that relate to them.
6. It is important to acknowledge all the concerns the patient may have, but focus on the 4 greatest concerns. For example: *Thank you for taking the time to complete the checklist, I can see you have lots of concerns, I wonder if we can focus on your four greatest concerns today.*

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7. Ask the patient to consider each of their greatest concerns. Go into it in a little more depth; *When did it begin? What does it involve? What does the patient think it means? What may be maintaining it? When is it worse/better? Are there any solutions which have already been tried?*
Add this information to the description box of the checklist.
8. Consider with the patient what might be done to resolve it. Model a problem-solving approach towards resolving the problem (see problem-solving box below).
 - a) It is likely that some concerns may be resolved
 1. immediately (e.g. providing further information,
 2. prescribing an analgesic) or through a further
 3. consultation with a professional at a later date.
 - b) Some concerns may be resolved through the patient
 1. taking action (taking up a new or old interest,
 2. contacting a family member, obtaining further
 3. information, attending a support group, taking more
 4. physical activity etc.)

Problem-solving

1. What is the nature of the problem or concern facing you?
2. Brain-storm a list of possible options without limiting yourself to 'sensible' or logical options
3. Describe the pros and cons of each option by imagining its consequences
4. Decide upon the best solution, all considered
5. Describe the steps needed to implement this plan
6. Implement the plan if possible within an agreed timeframe
7. Evaluate how well the outcome solved the problem and return to the brain-stormed list to consider further options if needed

Brennan (2005)

- c) Some concerns may require a referral to another service (other medical specialist, social worker, benefits advisor, spiritual leader, clinical psychologist, counsellor etc). It is essential that the professional conducting the interview is aware of specialist resources that are locally available as well as their referral criteria. In discussing a possible referral to a 'mental health professional', such as a psychologist or psychiatrist, it is important to reassure the patient that such referrals are commonplace and in no sense a sign of failure or shame.
9. Summarise what you have discussed and what steps *you* will take (e.g. referral), if any, and those that the patient has agreed to take. Record the agreed actions in the 'plan of action' box on side 2 of the checklist.

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In the plan of action, please consider *who* will be reviewing this action plan and when.

10. At this point it is very important that you complete the consent box at the bottom of page 2. Please ask the patient if they are happy to consent to:
 - a. Having a copy of their checklist shared with their GP
 - b. Having a copy of their checklist placed in their medical records
 - c. Having a copy of their checklist shared with all relevant health care professionals.
 - d. Having a copy of their checklist shared with specific professionals only (if this is the case, please specify which/who)

11. Please complete the patient details section at the bottom of page 2. Note the patient's name and NHS number. Note the date of the assessment as well as the date of the last Holistic Assessment. Please record the reason for this Holistic Assessment for example:
 - a. Around the time of diagnosis
 - b. Commencement of treatment
 - c. Completion of the primary treatment plan
 - d. Each new episode of disease recurrence
 - e. The point of recognition of incurability
 - f. The beginning of end of life
 - g. The point at which dying is diagnosed
 - h. At any other time the patient may request
 - i. At any other time that a professional carer may judge necessary

It is important that the reason for the assessment is recorded sensitively on the checklist and you may want to use your own words, rather than the codes above.

Finally, add your name, job title and contact details.

12. Please ask the patient if they would like their own copy of the checklist. If possible photocopy straight away, if not please make arrangements with the patient for posting it on.

13. Finally, ask the patient if they have any remaining questions.

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November 2008

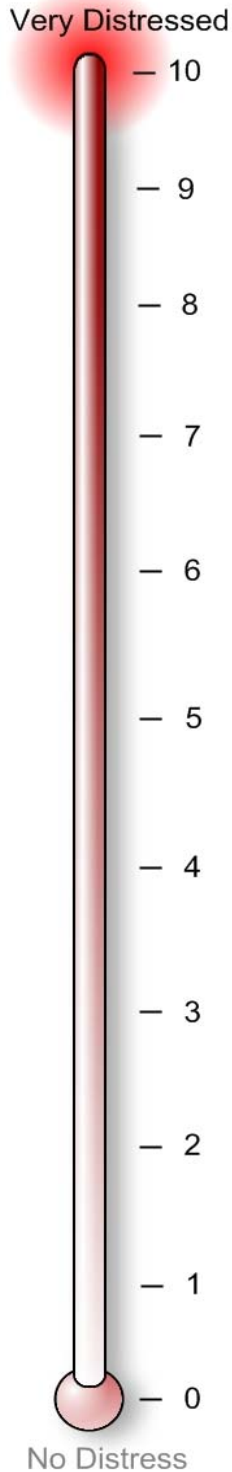
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References

- Cull, A., Stewart, M., Altman, D.G. (1995). Assessment of and intervention for psychosocial problems in routine oncology practice. *British Journal of Cancer*, 72, 229-235.
- Detmar, S.B., Aaronson, N.K., Wever, L.D.V., Muller, M. & Schornagel, J.H. (2000). How are you feeling? Who wants to know? Patients' and oncologists' preferences for discussing health-related quality of life issues. *Journal of Clinical Oncology*, 18, 3295-3301.
- Gessler, S., Low, J., Daniells, E., Williams, R., Brough, V., Tookman, A. & Jones, L. (2007). Screening for distress in cancer patients: Is the distress thermometer a valid measure in the UK and does its measure change over time? A prospective validation study. *Psycho-Oncology*, 17(6), 538-547.
- Heaven, C.M. & Maguire, P. (1997). Disclosure of concerns by hospice patients and their identification by nurses. *Palliative Medicine*, 11, 283-290.
- Heaven, C. & Maguire, P. (2003). Communication issues. In Lloyd-Williams M. (Ed.) *Psychosocial Issues in Palliative Care*. Oxford: Oxford University Press.
- Jacobsen, P., Donovan, K., Trask, P., Fleishman, S.B., Zabora, J., Baker, J. & Holland, J.C. (2005). Screening for psychological distress in cancer patients: A multicenter evaluation of the Distress Thermometer. *Cancer*, 103(7), 1594-1602.
- Kings College London & National Cancer Action Team. (2007). Holistic Common Assessment of Supportive and Palliative Care Needs for Adults with Cancer. Assessment Guidance.
- Maguire, P. (1992). Improving the recognition and treatment of affective disorders in cancer patients. *Recent Advances in Clinical Psychiatry*, 7, 15-30.
- Maguire, P. (1999). Improving communication with cancer patients. *European Journal of Cancer*, 35, 1415-1422.
- Parle, M., Jones, B. & Maguire, P. (1996). Maladaptive coping and affective disorders among cancer patients. *Psychological Medicine* 26, 735-744.
- Passik, S., Dugan, W., McDonald, M.V., Rosenfield, B., Theobald, D.E. & Edgerton, S. (1998). Oncologists' recognition of depression in their patients with cancer. *Journal of Clinical Oncology*, 16, 1594-1600.
- Roth, A.J., Kornblith, A.B., Batel-Copel, L., Peabody, E., Scher, H.I. & Holland, J.C. (1998). Rapid screening for psychological distress in men with prostate carcinoma: A pilot study. *Cancer*, 82, 1904-1908.
- Sollner, W., DeVries, A., Steixner, E., Lukas, P., Sprinzi, G., Rumpold, G. & Maislinger, S. (2001). How successful are oncologists in identifying patient distress, perceived social support, and need for psychosocial counselling? *British Journal of Cancer*, 84, 179-185
- Ward, S.E., Goldberg, N., Miller-McCauley, V., Mueller, C., Nolan, A., Pawlik-Plank, D., Robbins, A., Stormoen, D. & Weissman, D.E. (1993). Patient-related barriers to management of cancer pain. *Pain*, 52, 319-324

Using the thermometer, please circle a number that best describes how much distress you have felt in the past week, including today.

Next, please tick any of the following concerns that has been a cause of distress for you in the past week, including today.



Practical/Social Concerns:

- Child care
- Feeling lonely
- Getting to places
- Housework / Shopping
- Housing
- Money worries / Insurance
- Preparing meals / Drinks
- Washing / Dressing
- Walking / Getting around
- Work / College / School issues

Family/Relationship Concerns:

- Children
- Cultural needs
- Intimacy
- Looking after parents
- Partner
- People close to you
- Sexual functioning

Emotional Concerns:

- Anger
- Contradictory / Confusing information
- Confusion
- Depression
- Fears / Worries
- Lost interest in usual activities
- Nervousness
- Feeling panicky
- Unable to make plans
- Sadness / Grief
- Too much / little information
- Unable to make plans

Physical Concerns:

- Balance / Dizziness
- Breathing difficulties / Coughing
- Body image
- Changes in bowel habit / Constipation or diarrhoea
- Changes in urination / Passing water
- Changes to skin/nails / hair
- Dry nose / Congested
- Eating / Drinking (swallowing)
- Fatigue / Tiredness
- Fertility
- Fevers / Temperature changes
- Genital / Gynaecological
- Hair thinning / Hair loss
- Hearing
- Indigestion
- Memory / Concentration
- Nausea / Vomiting
- Oral health / Sore mouth
- Pain / Changes in sensation
- Poor sleep
- Seeing
- Speech
- Swelling
- Tingling in Hands / Feet
- Weakness
- Weight
- Wound care

Spiritual / Religious Concerns:

- Changes in faith or beliefs
- Uncertainties around purpose / Meaning of life
- Why me

Other problems:

Would you like to talk about any of these issues? Yes No

Well-being Assessment

Please write down your four main concerns below. The professionals supporting you will ask to see this checklist. They will find out more about your difficulties and help you plan how to address your concerns.

Main concerns:	Description	Plan of action
1		
2		
3		
4		

Patient Consent to share this assessment with:				Name of Patient:	
GP	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	NHS Number:
Copy in medical records	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Date of today's assessment:
All relevant health care professionals	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Previous assessment: yes / no
Specific health care professionals	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	Staff name, job title and contact details:
Please state who: _____					

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OVERVIEW OF EVALUATION AND INTERVENTION PROCESS

