


Coversheet for Network Site Specific Group Agreed Documentation

Document Title	Guidelines for Implementing Psychosocial Needs Assessments for Children and Adolescents with Cancer
Document Date	July 2010
Document Purpose	This document provides local guidance for the implementation of national policy relating to psychosocial assessments of children & young people with cancer and their families
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References	<ul style="list-style-type: none"> ▪ NICE (2005) Guidance on Cancer Services: Improving Outcomes in Children and Young People with cancer – The Manual ▪ DH (2009) Quality Measures for Children’s Cancer Services ▪ CLIC Sargent (2009) “More than my illness: Delivering Quality Care for Children with Cancer” ▪ Goldenring & Cohen (1988) Getting into Adolescent HEADS ▪ Pan Birmingham Cancer Network (2008) Guidelines for the implementation of Holistic Needs Assessment for Adults with cancer

Consultation Process	Consultation with; <ul style="list-style-type: none"> ▪ Birmingham Children's Hospital NHS Foundation Trust MDTs (Oncology, Leukaemia, Neuro-oncology, Retinoblastoma, Stem Cell Transplant, Teenage & Young Adult Psychosocial, Palliative Care, Long Term Follow-up & Late effects) ▪ Psychosocial Needs Assessment Workshop 19.11.09 ▪ West Midlands Paediatric Oncology Shared Care Units ▪ Paul Nash – Birmingham Children's Hospital NHS Foundation Trust Chaplaincy Dept. ▪ Janette Vyse & Caron Eyre – Birmingham Children's Hospital NHS Foundation Trust Bereavement Services
Review Date (must be within three years)	July 2013
Approval Signatures: Network Site Specific Group Clinical Chair	
Date Approved by Network Governance Committee 26 / 07 / 2010	

Guidelines for Implementing Psychosocial Needs Assessments for Children and Adolescents with Cancer

Version History

Version	Date	Summary of change/ process
0.1	19.11.09	First Draft by Jeanette Hawkins (Birmingham Children's Hospital NHS Foundation Trust lead cancer Nurse) – circulated to Children's Young Persons Holistic / Psychosocial Needs Assessment Workshop delegates (multi-professional group)
0.2	15.12.09	Amended Following Workshop and re-circulated for comment to Birmingham Children's Hospital NHS Foundation Trust & Paediatric Oncology Shared Care Unit (POSCU) MDTs (hosted by PBCN), West Midlands Paediatric Oncology Supra Network Group, BCH Chaplaincy, BCH Bereavement Services. For consideration by the Guidelines subgroup
0.3	02.06.10	Amendments following Guidelines Sub Group

1. Scope of the Guideline

- 1.1 This document provides guidance for the implementation of psychosocial needs assessments for children and adolescents with cancer and their families / carers.
- 1.2 This document is also designed to support the peer review measures 09-7A-141 (Psychosocial Assessment Guidelines), 09-7B-325 (PTC Psychosocial assessment Guideline) & 09-7B-421 (POSCU MDT Psychosocial assessment Guideline) [DH Manual for Cancer Services (2008): Children's Cancer Measures (2009)]

2. Guideline Background

- 2.1 The NICE Improving Outcomes Guidance for Children & Young People with Cancer (2005) psychosocial care section recommends that:
 - a. All families should be offered the advice and support of a social worker.
 - b. All families should have access to expert psychological support.
 - c. There should be a structured psychosocial assessment at significant points throughout care pathway.
 - d. Assessment of information needs should be included.
 - e. There should be access to neuropsychological services for cognitive assessment particularly for those with CNS tumours.
 - f. Sibling and family support groups should be encouraged (limited in West Midlands by psychology capacity).
 - g. Commissioners should consider needs of CYP with cancer when developing psychological support services.
 - h. All families should be offered benefits advice.
 - i. Cancer Networks have a pivotal role to play in service provision for CYP with cancer.

- 2.2 Children & Young People's Cancer Services (up to sixteen years) in the West Midlands are organised around a designated Principal Treatment Centre (PTC) at Birmingham Children's Hospital (BCH) and seven Paediatric Oncology Shared Care Units (POSCUs) across the West Midlands.
- 2.3 The PTC and POSCUs work closely with tertiary services at the Royal Orthopaedic Hospital, and radiotherapy and teenage & young adult services at the Queen Elizabeth Hospital. Co-ordinated services for young adults 16 to 24 years are in development pending further guidance from the National Cancer Action Team for this age group.

This guideline is intended to be utilised across the West Midlands Paediatric Supra Network Group (up to sixteen years). Services providing care for sixteen to twenty four year olds should utilise either this guideline or the "Guidelines for the Implementation of Holistic Needs Assessment for Adults with Cancer". (Pan Birmingham Cancer Network (2008)

3 Guideline Statements

The approach to psychosocial assessments for children and young adults with Cancer should be informed by the guidance offered in the CLIC Sargent (2009) "More than My Illness" report, and the Cancer Action Team (2007) Holistic Common Assessment of Supportive and Palliative Care Needs for Adults with Cancer: Assessment Guidance.

- 3.1 Shared Care Units have agreed to use these guidelines
- 3.2 A multi-professional approach should be taken for the assessment of children & young people with cancer to ensure that each of the domains are assessed by those with the most appropriate skills, and that repetition for families is avoided. A summary of specific additional needs identified in these assessments (e.g. those requiring referral on) is presented at the MDT meeting.
- 3.3 The MDT is responsible for agreeing an action plan for supporting the additional psychosocial needs of the patient and the family / carer. Actions, referrals and outcomes will be recorded at the MDT meeting.
- 3.4 All patients with a diagnosis of cancer will have a family centred care holistic assessment undertaken by nursing staff. This is a routine part of all in-patient admissions. This will be extended to newly diagnosed patients who do not require an in-patient admission, and be undertaken by oncology out-patient / day care nurses. Care plans are developed with the child / young person and family to manage needs in partnership.
- 3.5 Patients from "out of region" who access the national retinoblastoma (RB) service will have an initial assessment done at diagnosis and the RB CNSs will liaise with local paediatric oncology centres and shared care units for assessments further in the pathway.

- 3.6 At the following time points along the patient pathway the family centred care holistic assessment will be checked and supplemented by the key worker:
- a) Around the time of diagnosis.
 - b) During treatment (between 3 and 6 months recommended, although patients on 3 years of Leukaemia treatment may benefit from assessment during the 2nd year which is recognised as a time of struggle due to prolonged duration of treatment).
 - c) Around time of relapse.
 - d) Prior to stem cell transplant.
 - e) At the end of treatment assessment may be modified and could include use of “Wellbeing Thermometer” for Parents / Carers
 - f) At the start of palliative care.
 - g) At any point where there is significant change and families or health / social professionals feel it would be helpful, e.g. after amputation, severe neurological deficit or post surgery.
- 3.7 Family needs at a time of bereavement require a different approach from the above assessment. The Bereavement Needs Assessment Tool in the Help the Hospices Guideline is recommended. (Relf, Machin & Archer (2008))
- 3.8 The BCH family centred care holistic assessment assesses developmental status, abilities, personality / characteristics and usual state of health in 12 domains reflecting both physiological systems, psychological and emotional needs, play & education and spiritual / cultural / identity needs. These domains are assessed to establish what the child / young person can do for themselves, what family / carers or other health professionals do to support the needs and what needs are currently outside the family’s capacity to manage. Additional needs that cannot be managed by the nursing team will be shared with the patients Key Worker and the MDT, and appropriate referrals and action plans agreed.
- 3.9 Patients (particularly adolescents) and carers must be informed that health professionals share information with others who support their care. They should be fully informed that they can request certain information is kept confidential, and be informed under what circumstances and by what process we would breach confidentiality. Their understanding of this should be checked. Trusts should refer to local policies on confidentiality & informed consent.
- 3.10 Patient assessments may differ in POSCU settings and other models of assessment are acceptable providing they are holistic in nature and include the patient’s interaction with and support from the family. The BCH Family Centres Care Holistic Assessment can be used in POSCUs if required. Similar advice is offered to Children & Young People’s Services in ROH and UHB TYA Unit.
- 3.11 Coinciding with the time points identified above the patient / family / carers will also be offered an enhanced psychosocial assessment and additional psychosocial support from the CLIC Sargent Social Work Team which provides a region wide service. Their assessment is based on the “Common Assessment Framework (CAF)” as recommended in the “More than My Illness” report. A broad summary of enhanced needs identified in this assessment will be shared with the patient’s Key Worker and the MDT although the detail of the assessment may be kept confidential / or shared according the patient / family

wishes and any safeguarding issues identified. Care plans are developed with the child / young person and family.

- 3.12 Some patients, particularly those with Brain Tumours, may require a full CAF Assessment due to the complexity of their needs. The process for CAF Assessments is not covered by this guideline, but the actions recommended in this guideline should assist identifying those patients who require a full CAF assessment. Trusts should refer to their local Safeguarding & Child Protection Policies.
- 3.13 The CLIC Sargent assessment includes family coping strategies, parenting capacity, housing, finance, employment. Families will be given informed choice about referral to CLIC Sargent Social Workers that identifies their psychosocial support role, and differences from Statutory Social Work roles that they may have more common understanding of.
- 3.14 The CLIC Sargent Team re-assess needs every 3 months for as long as the family need support. Cases are closed in consultation with the family when they family are maintaining their own needs. Repeat referral can be made at any point thereafter if new needs arise, e.g. relapse, palliative care, change in family circumstances.
- 3.16 Where additional needs are identified in either of the above assessments children, young people or their families should be referred on to other services according to the needs of the situation and in consultation with the MDT when required. Examples include referral on to psychology, local social services, chaplaincy / spiritual leaders, education, local disability services, GP for family members, bereavement counsellors, rehabilitation services, or educational psychologists.
- 3.17 If referral is deemed necessary but there is no service or inadequate service to refer to this should be recorded by the MDT and relevant service managers informed. This is particularly important for psychology, counselling, CAMHS and bereavement service gaps.
- 3.18 Information needs are met through the provision of a "Parent Held Record" that has core information inserts and individually tailored inserts according to the diagnosis & treatment plan. Patient / parent information prescriptions should be developed to support this process.
- 3.19 At the time of providing the Parent Held Record or patient information prescription the child / young person / family's individual information needs should be assessed and re-assessed at the specified time points along the treatment pathway by the key workers. This is an aspirational recommendation dependant on sufficient resources being obtained for the key worker role.
- 3.20 The West Midlands Paediatric Supra Network Group should link with the PBCN adult holistic needs assessment steering group and explore the possibility of using the Somerset cancer registry to record when assessments have been completed.
- 3.21 Children / young people and close family / carers should be asked how they will let healthcare workers know if they are feeling stressed / distressed or have new spiritual, emotional or psychosocial needs. They should be informed that all

health professionals are open to these feelings being raised, but may refer them to other people who have more skills in a particular area.

- 3.22 Information on how to access financial and benefits advice should be included in the Parent Held Record. Patients can be directed to CLIC Sargent Social Workers, the PBCN Macmillan benefits advice service, Citizens Advice Bureau, & expert Benefits and Welfare Officers.
- 3.23 Psychosocial needs assessments, using a family centred holistic approach, can be undertaken by children's / young people's trained nurses at the PTC, in any of the designated POSCUs units, or linked services for children / Y.P. at ROH and UHB. Assessments can be undertaken in both in-patient and out-patient settings.
- 3.24 Key workers who review assessments at the specified time points should be clinical nurse specialists, advanced practitioners, paediatric oncology outreach nurses, or shared care paediatric oncology lead nurses.
- 3.25 Key workers should be working towards advanced communication skills training and level 2 psychology through provision within the PBCN.
- 3.26 The important role of allied health professionals & medical staff in helping inform patient assessments is acknowledged. Staff such as hospital school teachers, play specialists, youth workers, clinical support workers, spiritual leaders and many other health care workers involved in care are often in an ideal position to contribute to the assessments of both patients and carers. They should be encouraged to inform nursing staff or MDT meetings of information that contributes to the overall assessment.
- 3.27 Where patients receive care at both the PTC or POSCU and / or other tertiary service the MDTs should agree local plans for sharing assessment information within boundaries of confidentiality and data protection, but to aim for enabling a smooth pathway of care for patients.
- 3.28 Information on family centred holistic & focused psychosocial assessments should be made available to families. Patients and families should be made aware that the purpose of such assessments is to help ensure that they are receiving all the support that is available to them in their area, and that health professionals show respect and understanding for their lives beyond the cancer diagnosis. They should however, be informed that it may not be possible for us to solve or resolve all of their problems and needs, but will do our best to refer them on to other services that may be able to help where such services exist.
- 3.29 The implementation of the psychosocial assessments should be carried out in conjunction with Key Worker Guidance (PBCN, 2008).

4 Monitoring of the Guideline

- 4.1.1 Implementation of the NICE Improving Outcomes Guidance for Children and Young People with Cancer is required nationally by the end of 2010. DH Quality Measures for Children's Cancer Services 2009 and self assessment peer review will commence in August 2010 with planned peer review visits in 2011. DH

Quality Measures for Young People's Services are not expected until 2011.

- 4.1.2 Each year every Trust should have audited the implementation of psychosocial assessments along the patient journey for each MDT annually until it can be demonstrated that assessments are a fully established part of practice.

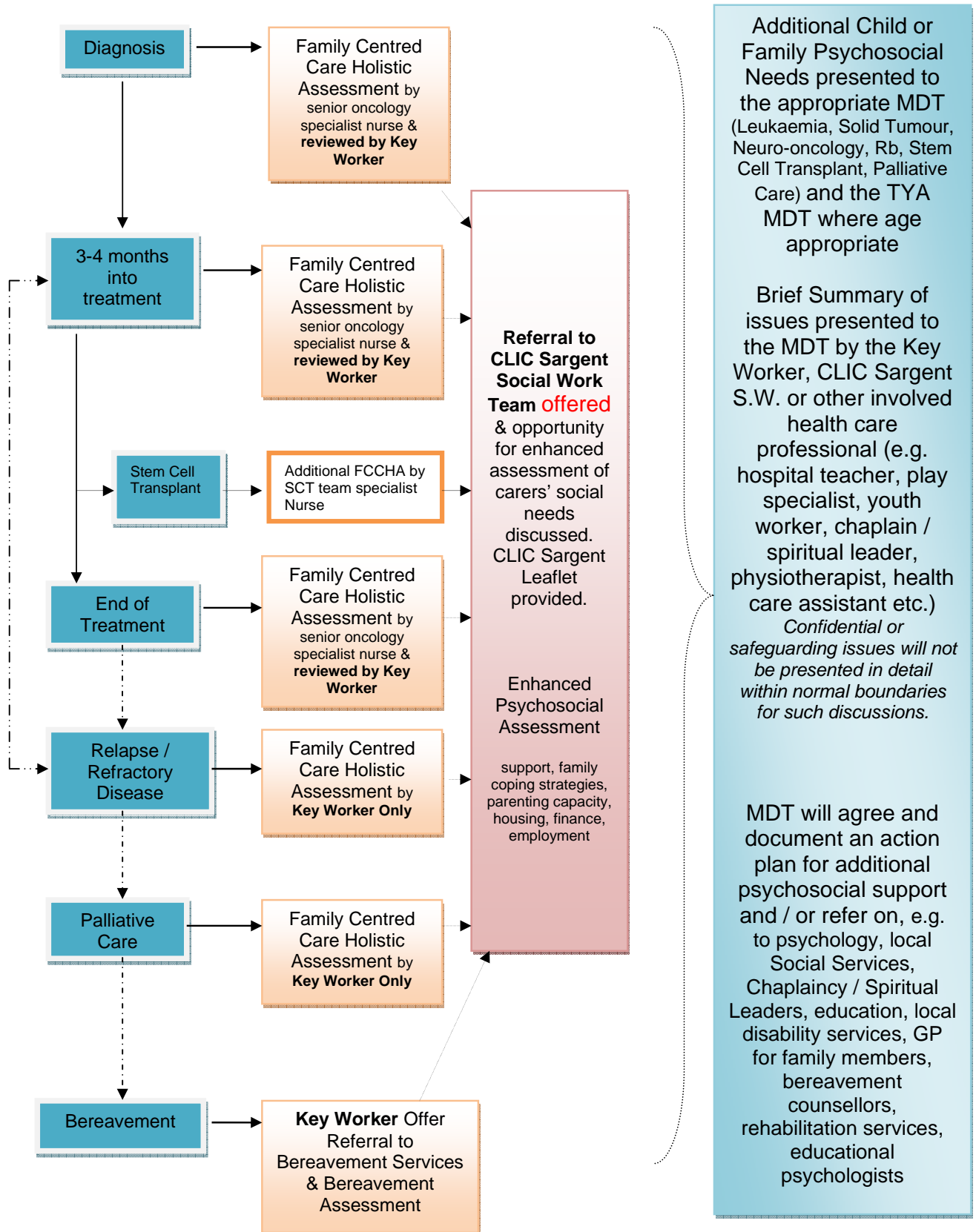
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1. Cancer Action Team (2007) Holistic Common Assessment of Supportive and Palliative Care Needs for Adults
<http://www.kcl.ac.uk/content/1/c6/02/41/17/finalprintedreportGuidancerevisedholisticcommonassessmentFINAL.pdf>
2. CLIC Sargent (2009) "More than my illness: Delivering quality care for children with cancer"
3. Goldenring & Cohen (1988) Getting into Adolescent HEADS
4. NICE (2005) Guidance on Cancer Services: Improving Outcomes in Children and Young People with cancer – The Manual DH Manual for Cancer Services (2008): Children's Cancer Measures (2009)
5. Palliative Care Needs for Adults with Cancer: Assessment Guidance. London, Cancer Action Team.
6. Pan Birmingham Cancer Network (2008) "Guidelines for the implementation of holistic needs in cancer care V1" <http://www.birminghamcancer.nhs.uk> (Important Documents – Network Guidelines – Lead Nurses) *last accessed 18.05.2010*
7. Pan Birmingham Cancer Network (2008) "Guidelines for the role of the Key Worker in Cancer Care V1" <http://www.birminghamcancer.nhs.uk> (Important Documents – Network Guidelines – Lead Nurses) *last accessed 18.05.2010*
8. Reif, Machin & Archer (2008) "Guidance for bereavement needs assessment in palliative care" Help the Hospices <http://www.helpthehospices.org.uk/our-services/developing-practice/bereavement/assessing-bereavement-needs/> *last accessed 18.05.2010*

Appendix 1
Holistic Needs Assessment of Child / Young Person within the context of their Family



Approval Date of Network Site Specific Group

Date: July 2010

Approval Date of the Governance Committee

Date: July 2010

Approval Signatures

Pan Birmingham Cancer Network Governance Committee Chair

Name: Doug Wulff



Signature:

Date: July 2010

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Date: July 2010

Network Site Specific Group Clinical Chair

Name: Deepak Kalra



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Date: July 2010