Children's Cancer Clinical and Supportive Care Protocols

7A-141 – Psychosocial Assessment Guidelines

These guidelines are for children up to the age of 16. A separate protocol will also be required for 16-24 year old (Teenage and Young Adults) age group and incorporates the Child Assessment Framework (Department of Children, Schools and Families).

Guidance
The Children’s Cancer Network CCN in consultation with the MDT’s should agree CCN-wide guidelines for psychosocial assessment.

Definition
Psychosocial care comprises the psychological and social supportive care for a child or young person and his/her family during active cancer therapy, long term follow up and palliative care, as well as for families after bereavement, and includes respite care.

Background
These guidelines set out the expected standard required to ensure a high quality and consistent approach to assessing psycho social support needs of children, young people with cancer and their families. Improving outcomes guidance (IOG) (2005) and CCNCG agree that support needs are highly individual and will change at different stages along the patient pathway. The provision of psycho social care is complex and requires multi-professional collaboration to be effective. This care will take place within the Principal Treatment Centre (PTC) and within the Community often via shared care centres (SCC). This policy supports the clinical shared care agreement for Children & Young people with Cancer between the PTC (Alder Hey) and SCC’s.

This policy supports the introduction of a key worker approach (More than my illness 2008). The role of the ‘key worker’ may be carried out by a number of practitioners from different disciplines. To ensure consistency and clarity this role and the associated responsibilities will be clearly articulated and written information available to families to ensure expectations are met.

As a PTC we are also working towards introducing a gold standard approach developing training for children’s practitioners in models of psycho social care. The training programme will be stratified according to the level of psycho-social intervention particular members of the MDT require in their role. This will range from core competencies for working with children and families for all staff, to additional training for identified staff. The latter will include psychological approaches such as CBT and solution-focussed intervention. The training programme will take a systemic and systematic approach and ideally will be overseen by the Clinical Psychologist ‘level 4’ practitioner. The course will include follow up ‘supervision’ with the Consultant Clinical Psychologist in the use of therapeutic interventions to enable the practitioner to develop their skills and competencies.
Pre-diagnosis
Prior to diagnosis clinical assessments will take place at PTC and SCC’s A&E departments, DGH’s or by G.P’s. It is important that this protocol is shared with these stake holders to ensure a consistent approach to psycho social care. Factual information is ascertained at this point i.e. who the child lives with, full names and DOB of parents/carers and family members, who has parental responsibility, are there any legal orders in place for this child? This information is required on the MDT referral notification form, sent to PTC.

Frequency of assessment
IOG (2005) stipulate assessments must be structured and must be carried out at significant points during the care pathway in particular:

- At diagnosis
- During treatment
- At end of treatment
- During long term follow up
- At relapse
- During palliative care
- At bereavement

Assessments should be carried out in partnership with the patient, their family and other relevant carers and experienced by families as building on previous discussions and not repetition of an information gathering exercise. Copies of the assessment should be available upon request to the family.

Post diagnosis
Psychological and psycho-social care continues through rehabilitation to remission taking account of late effects, and also through palliative care to bereavement. A wide range of clinical and non clinical staff carry out assessments within the Oncology Unit at the PTC. Staff will take a greater or lesser role at different points during the pathway. Currently professionals undertake individual assessment. This policy and the introduction of key worker role seeks to change practice, joint assessments and the sharing of assessments will be introduced to reduce multiple assessing of children and families. Currently professionals assess as follows:

Social Workers
When a child or young person is diagnosed with cancer or leukaemia a CLIC Sargent Social Worker will make contact within 5 working days of referral to them. The family have to give consent to support from CLIC Sargent and a signed data protection form is required (Data protection Act 1998) prior to a service. An assessment based on the Common Assessment Framework (DCSF 2004,CWDC 2007) which focuses on psycho social need is completed in partnership with the child, young person and family over a period of 45 working days and a care plan agreed. This is formally reviewed initially after a 3month period in the treatment journey and then at 6 monthly intervals/or points of significant familial change (outlined in ‘frequency of assessment’ in this policy). The assessment is completed in partnership with the child or young person and family and a copy of the assessment is offered to them.
Paediatric Outreach Oncology Nurses
Paediatric Outreach Oncology Nurse Specialist’s should be included in the initial consultation and present when the diagnosis/prognosis and treatment plans are discussed with the child/young person and their family. This ensures the family have a contact who can explain and reiterate information and liaise with key worker. Psychological assessment is commenced at this time and built on throughout the formation of a positive working relationship.
The POONS will identify and liaise with existing services involved and the available services in the community to ensure the child/young person and the family have structured informed support provided in their local area.
The POONS will throughout their contacts holistically support the child/young person and family either personally or sign post to other services as deemed necessary.

ANP’s
Each child or young person is assessed by an advanced nurse practitioner prior to each course of chemotherapy. Psychosocial needs/issues are included within this assessment and updates will be communicated promptly to the MDT members involved with each patient.

TCT Youth Worker
Each young person aged 13 plus will be introduced to the youth worker. The youth worker provides support on an individual or group work basis, based on need. The Youth worker has a vital role to play in identifying and providing direct emotional support to individual young people during their treatment pathway, inpatient stays on the Teenage Unit and on completion of treatment. The youth worker is collaborative in his approach working together with key members of the MDT. Supervision is provided by the Ward manager.

Clinical Psychologists
It is unlikely that the Clinical Psychologist will assume the role of ‘key worker’ and conduct the regular reviews of psychosocial functioning and well being for all families. Ideally, and with sufficient capacity, the clinical psychologist should be centrally involved in developing the screening for psychological vulnerability, and reviewing with the MDT those families whose assessments indicate heightened distress. Furthermore, the clinical psychologist should have a leading role in developing and delivering the training programme and providing follow-up consultation and supervision.

When a child, parent and/or family is experiencing considerable and intense emotional/behavioural distress and is referred to the clinical psychologist, an in depth psychological assessment will be conducted. This will determine the therapeutic intervention required. A cognitive/neuro psychological assessment may also be indicated.

Change in practice
PTC will work together to introduce joint or were not appropriate the sharing of assessments, this will be directly linked with the introduction of the key worker role.
What should be included in the Assessment?

IOG (2005) stipulate that as a minimum assessment must include:

Information needs

Information should be provided from diagnosis throughout the cancer journey. The information must be available in different formats in terms of language, age, understanding, Braille and 'speaking' books. Information must be considered in different formats, for example, teenagers are more likely to access the internet as read a leaflet.

Information should be provided verbally face to face with children and families. In line with IOG guidance band 6 (core MDT staff) must be appropriately professionally qualified and skilled having completed the Advanced Communication Skills course. Information should then be provided in written or internet accessible format for children and families to look at in their own time. A wide range of leaflets both clinical and informational are available to the patient and their families in clinic, day care and on the 2 wards. Leaflets will be ratified by the MDT as suitable, factually correct, age appropriate and up to date.

A Family held record is given to each newly diagnosed child’s family. It contains description of MDT team, Unit information and services. The PTC has an experienced MDT each skilled in specific areas of information giving medical and non medical. Appropriately skilled professional at PTC will provide following information as stipulated in IOG (2005):

- Disease specific.
- Explaining cancer and side effects
- Unit Information
- Benefits
- Information for siblings
- Information for Grandparents
- Information for schools, teachers, friends
- Services available at the unit and in the community
- Help lines Grants Holidays
- Practical information such as insurance and motability

In addition to the IOG (2005) requirements we have flourishing and dynamic parent’s support group CHICS who are very much a part of the PTC and provide information and social support direct to the children and their families. The PTC also organise siblings information and therapeutic days and Family information days.

Coping skills

The coping skills of the child or young person and family should be assessed prior to and during the period when the diagnosis is given. The key worker should be present when diagnosis is given. All core members of the PTC will complete advanced communication skills course. Initial history taking and clinical assessments should gather:

- significant past family experiences
- wider family and friendship support networks
- previous family members diagnosed with cancer
- other current significant issues affecting family.
The training programme will include approaches to history taking, ensuring that issues of consent and confidentiality are addressed in addition to record keeping.

Each child, young person and family are individuals and will cope in different ways and require differing levels and types of support. Research shows that honesty and openness with children even of a young age (CLIC Sargent, 2009) leads to greater trust and resilience. How, when and to what extent to be open and honest requires considerable skill and judgement, working in partnership with parents and taking account of developmental issues and Gillick competence.

The MDT consists of multi-professionals each bringing their specialist training, experience and knowledge to enable the child and their wider family to cope at different parts of the cancer pathway. The introduction of the key worker, shared or joint assessments and the revised weekly Wednesday afternoon communication meetings will enable high risk families to be identified. If an individual or family require Tier 3 or 4 psychological support and intervention a referral will be made to the PTC’s Psychologist. Screening and identifying very vulnerable children, adults and families early and having the clinical psychologist centrally involved in the Wednesday afternoon meetings and training will ensure governance of psychological interventions delivered by ‘level 2 practitioners’ and facilitate appropriate referrals to ‘level 4’ clinical psychology. Working with children (and their families) facing a potentially life limiting condition and an arduous treatment journey can engender profound emotional responses in staff.

**Practical support issues**
Families often face many practical issues during the cancer pathway (NICE, 2005, p.73). Research shows that families face increased costs such as travel and living away from home (York Report 2004, CLIC Sargent 2009). Many families will not ask for support, it is therefore vital that Oncology staff develop excellent professional relationships with the child, young person and family to encourage open communication of non clinical pressures. CLIC Sargent formally assesses practical needs within their assessment and review process and work with the child and families, MDT and CHICS family support worker’s (parent’s support group) to resolve such issues.

**Social and Cultural circumstances**
Assessments are vital in obtaining essential information to improve the patient and family’s cancer journey and ensuring the appropriate support is in place. The assessment must include:
- Language or method of communication – a child should not be used as an interpreter.
- Religion - to ensure child or young person and families cultural and religious beliefs are respected and met throughout the cancer journey.
- Are there safeguarding issues or vulnerable adults issues?
- What is their understanding of the diagnosis and information they have been told to date?
- How did diagnosis occur and what was their individual journey to diagnosis?
- Does the child or other family member have any other health needs?
- Extended family and friendship networks of the child or young person and family. Vital for looking at resilience and coping skills at different points of the cancer journey.
- Siblings needs.


**Educational related issues**

Children, young people and their families tell us that continuing in Education is one of their key needs (CLIC Sargent 2009). Each child diagnosed is entitled to an Individual educational plan.

Children with brain and other CNS tumours can experience cognitive, behavioural, emotional and personality changes. Such changes can also be the iatrogenic consequences of chemotherapy and/or radiotherapy. Cognitive assessments provided by clinical psychologists with expertise in neuropsychology are recommended by government guidelines; (IOG 2005, IOG 2006). Cognitive assessments can guide schooling and help children and families adjust to these changes. Furthermore, neuropsychological testing will become a central part of determining health status in all CCLG CNS tumour trials.

It is vital that an assessment of a child’s level of engagement with school prior to diagnosis and attainment is ascertained at diagnosis from the child, young person, family and school. This should be repeated in subsequent assessments at key points in the care pathway i.e. end of treatment, relapse, and palliative care. This is commonly undertaken by the Macmillan nurse specialist who also liaise and visit individual schools post diagnosis to ensure information is given and support is in place for the child or young person and encourage child’s continued attendance when well enough. This support is ongoing throughout treatment and will include the coordination of home tuition if required and increased when a child relapses or becomes palliative. Macmillan CNS, and CLIC Sargent Social Workers will attend school meetings when required if a child is under the care of Social Services or if there are specific diagnosis related issues that have an impact on school attendance. Children diagnosed with brain tumours may have significant practical and supportive care needs to enable them to re-integrate and fulfil their educational potential. An educational psychology assessment in such circumstances may be required as an adjunct to the assessments described above.

The Oncology unit has its own Teacher and school room available during term time. The Teacher will liaise with a child/young person’s school and acquire curriculum work, if they are an inpatient for a significant period of time, to ensure continuity of a child’s education, this can include negotiation of examinations being completed in the hospital setting. The Teacher in partnership with the MDT facilitate a school liaison day twice a year in which teacher’s are invited to the PTC for information, advice and support.
**Employment related issues**

A parent/s or carer/s and if applicable a young persons employment status should be established during initial assessments and at key points during the cancer pathway i.e. change in circumstance such as relapse, end of treatment, palliative care, end of life and bereavement. Although not stipulated in the IOG (2005) guidance, research (SPRU 2004, CLIC Sargent 2009) evidence the importance of financial support to be provided to families from diagnosis throughout the care pathway. Therefore this guidance includes this within its requirements:

- One parent may become the main carer for the child which may affect or change their employment situation and financial capacity.
- A review to identify financial need should be completed in partnership with the family at key points in the cancer journey. CLIC Sargent Social worker undertakes such assessments and applies for grants to support families.
- If a parent/carer is self employed this is likely to place a greater financial burden on the family.
- Flexible working policies have been introduced for parents/carers of children under 5 or parents of children with disabilities.
- Employer support letters as Employers are more likely to be supportive with a greater understanding of the carers needs.
- Welfare Benefits - Are the family in receipt of benefits? Support applying for the initial DLA for the child and Carers allowance is provided by CLIC Sargent Social Worker. In more complex welfare rights matters families can be referred onto CLIC Sargent’s Welfare Advice Line (Freephone number) and/or local welfare rights services.

**Level 4 Psychological support**

Currently there is limited capacity available from Clinical Psychology. Based on government recommendations an additional 1.5 wte is required to fully achieve the aspirations described above and reach minimum standards. The identified clinical psychologist for our patients and families is a consultant with many years experience; additional junior staff would ensure a comprehensive psychosocial service.

Children, parents or guardians are referred to the PTC psychologist having been identified as having pre-diagnosis vulnerability and/or by the key worker. Given the proposed role of the clinical psychologist in developing the training programme, providing follow-up consultation/supervision and involvement in Wednesday afternoon meetings for early identification of children and families requiring level 4 specialist psychological intervention will be readily identified.

In addition to the weekly communication meeting, there is a monthly psychosocial meeting. This is attended by those members of the MDT who provide level 2 or 3 psychosocial care and chaired by the Consultant Clinical Psychologist. This is a point of reference to discuss children and families on a need to know basis, plan multi-disciplinary care to avoid duplication, set up consultation/supervision meetings and consider referrals.
It is proposed that certain care pathways will always trigger a clinical psychology referral. These include: potential amputation, and bone marrow transplant. Other presentations which could trigger a referral could include: food refusal with a significant psychological element; non-adherence to treatment; unexplained intensity of symptoms; anticipatory anxiety/vomiting; self harm; depression/withdrawal.

As clinical psychologists are trained to work across the life span (and with learning disabilities) parental mental health issues relating to cancer can also be addressed.

References
