

KEY WORKER GUIDELINE

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1.0 Introduction

Supportive care impacts on all services, both specialist and generalist, that may be required to support people with cancer and their carers. It is not a response to a particular stage of disease, but is based on the assumption that people have needs for supportive care from the time that the possibility of cancer is first raised.

NICE Improving Supportive and Palliative Care for Adults with Cancer (2004) requires that cancer services have processes in place to ensure effective co-ordination between all professionals involved in the care of the patient.

The Cancer Reform Strategy (2007) recommends that higher priority should be given to improving the co-ordination and continuity of care, recognising also that the settings in which care is being delivered are changing as new service models are introduced (e.g. community-based 'integrated cancer care' programmes, models to reduce the length of hospital stays). This is further supported by the North West Cancer Plan (2007).

These guidelines set out the agreed approach to care co-ordination within ¹Merseyside & Cheshire Cancer Network. They specify the standard of care co-ordination that should be achieved by any organisation involved in delivering cancer services and the role of the 'key worker'.

The Merseyside & Cheshire Cancer Network was formed in 2000 and links together the organisations that provide care for people with cancer across Merseyside and Cheshire. The Network covers a population of 2.3 million people and encompasses one Strategic Health Authority, seven Primary Care Trusts, twelve Hospital Trusts, ten Hospices and a number of voluntary organisations.

These guidelines apply to the delivery of both supportive and palliative care, and therefore cover the needs of patients who are expected to be discharged from treatment, as well as those requiring end of life care.

The key worker is defined in the NICE guidance as:

"A person who with the patient's consent and agreement takes a key role in co-ordinating the patient's care and promoting continuity, ensuring the patient knows who to access for information and advice."

2.0 Scope of Policy

Supportive care is not a distinct speciality but is the responsibility of all health and social care professionals delivering care.

Care for patients with cancer often needs to be continued over many years, across organisational and professional boundaries. Continuity of care is essential during treatment, follow-up and palliative care.

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There is a need to ensure integration and co-ordination of care, throughout the patient's cancer journey. This may be within and between primary, secondary and tertiary care settings, between statutory and voluntary sector and across health and social care settings.

Such complexity of needs requires a co-ordinated approach to service provision. The key worker role offers the mechanism to promote clinical continuity & ensure such co-ordination.

The purpose of this document is to set out the agreed approach to care co-ordination within Merseyside & Cheshire Cancer Network and therefore applies to all providers. This document should be read in conjunction with the following:

- Manual for Cancer Service Standards 2004
- NICE Improving Supportive and Palliative Care for Adults with Cancer 2004
- Cancer Reform Strategy 2007
- North West Cancer Plan 2008
- MCCN Holistic Needs Assessment Guideline 2009
- Locally produced MDT/key worker leaflets (information for patients)

3.0 The Role of the Key Worker

The NICE Supportive and Palliative Care Guidance for Adults with Cancer (2004) suggests that the key worker role may include:

- Orchestrating assessments to ensure patients' needs are elicited
- Ensuring care plans have been agreed with patients
- Ensuring findings from assessments and care plans are communicated to others involved in patient care (including the GP).
- Ensuring patients know who to contact when help or advice is needed, whether the 'key worker' or other appropriate personnel
- Managing transition of care

There are a number of challenges in meeting the above definition of a key worker. It may not always be possible for a key worker nominated at the time of diagnosis to provide ongoing care co-ordination and continuity as the patient may receive care in a number of different care settings. Therefore the key worker may change at different points in the patient care trajectory.

The single named key worker will provide care co-ordination, information and communication with the patient and be an integral member of the patient's multi-disciplinary team. The aim should be to provide continuity of care throughout the patient pathway.

The national standard is for key workers to be in place for 100% of cancer patients by December 2009. Network wide key worker audits will be undertaken to monitor compliance.

4.0 Responsibilities of the Key Worker

The responsibilities of a key worker within MCCN are as follows:

- *Continuity of care:* to achieve continuity of care, so that the patient knows who to contact for information or support. To introduce themselves proactively to the patient and provide contact details.

- *Breaking bad news:* whenever possible, to be present when the patient is given their diagnosis.
- *Initial assessment:* to ensure that a holistic assessment is carried out of the patient's needs.
- *Ongoing assessment:* to ensure that a holistic assessment is repeated at regular intervals to maintain an up-to-date picture of the patient's needs.
- *Care planning:* to ensure that a care plan is drawn up, in conjunction with the patient and based on information obtained from the initial assessment. To ensure that patients are given the opportunity to participate in decision making. To ensure that the care plan is updated at regular intervals.
- *Preferences and choices:* to ensure that patients' preferences and choices are elicited, especially in relation to end of life care. To ensure that these preferences and choices are documented i.e. PPC document.
- *Care monitoring:* to assess the patient's response to their diagnosis and monitor how they are coping. To refer on for specialist psychosocial support where appropriate. To provide opportunities for the patient to discuss the progress of their disease and treatment.
- *Liaise with primary care:* to establish and maintain contact with the patient's GP so that they are kept informed of key developments in treatment and prognosis.
- *Provide information:* to provide timely information to meet needs expressed by the patient, family members and carers.
- *Provide support:* to provide general emotional and psychological support, both proactively and as requested by the patient, family members and carers.
- *Arrange a new key worker:* to liaise within or between multi-disciplinary teams to identify who is best placed to take on the key worker role from the original person, e.g. when responsibility for care transfers from one MDT to another, from a cancer unit to a cancer centre, or into the community or a hospice. N.B. sometimes the original key worker at a cancer unit may remain responsible for liaising with the patient even though care is now being provided by a cancer centre. When this is agreed it should be clearly documented.
- *Notify a change of key worker:* whenever a change of key worker is proposed, the original key worker should seek agreement from the patient and the new key worker. Once agreed, the original key worker should notify all professionals involved in the patient's care.
- *Respond to patient choice:* to make the patient aware that they can request a change of key worker if they feel the existing arrangement is not working successfully, and to act upon any such request.
- *Discharge patient:* where the patient has come to the end of their active treatment or surveillance, explain how the patient should re-access services in the event of future problems and make the patient aware of ongoing sources of support. To obtain feedback that could help improve services for other patients in future.

5.0 Designating the Key Worker

Providers should ensure that:

- Each patient will have a named key worker who will be identified at the MDT where the initial cancer diagnosis is made and treatment planning decisions discussed. The key worker will ideally be a Clinical Nurse Specialist. In the absence of a specialist nurse, a senior nurse or other health care professional will be nominated as key worker by the MDT lead clinician.

- The nominated Key workers should be reviewed at key points in the patient's cancer journey and these identification points are:
 - Around the time of diagnosis
 - Commencement of treatment
 - Completion of the primary treatment plan
 - Disease recurrence
 - The point of recognition of incurability
 - The point at which dying is diagnosed
 - At any other point requested by the patient
- With the patient's agreement, they will be informed of the name of their key worker verbally and will be provided with written information of the name and contact number. The patient should be aware that they can request a change of key worker if they feel the existing arrangement is not working successfully.
- Re-allocation of a key worker, at the patient's request, should take place within seven working days of the request and is the responsibility of the existing key worker.
- The key worker's name will be recorded in the medical notes in an appropriate place, by the CNS. Other health professionals will be informed of the name of the key worker as appropriate (e.g. patient hand held key worker card, letters to the patient's GP).

During the treatment phase, where chemotherapy and radiotherapy may be part of the treatment plan, it is important to establish who will perform the key worker role. It may be appropriate for this to be a chemotherapy nurse or therapy radiographer, as they will have regular contact with the patient over an extended period. If the patient requires supportive and palliative care, the key worker may be a member of the community nursing team or the specialist palliative care team. Care may be shared between team members, e.g. a CNS and chemotherapy nurse, a CNS and speech therapist.

Patient Pathway	Suggested Key Worker
Diagnosis	Site specific Clinical Nurse Specialist (CNS) General Practitioner (GP) AHP Consultant/medical team if no site specific CNS in post
Commence Treatment/Pre Op	District Nurse/Community Matron Site specific Clinical Nurse Specialist (CNS) AHP Chemotherapy Nurse
Complete Treatment/Post Op	District Nurse/Community Matron

	Site specific Clinical Nurse Specialist (CNS) AHP Chemotherapy Nurse Research Nurse Patient Information Manager
Disease Recurrence	District Nurse/Community Matron Site specific Clinical Nurse Specialist (CNS) GP Chemotherapy Nurse Palliative care CNS AHP
Palliative Phase	District Nurse/Community Matron Site specific Clinical Nurse Specialist (CNS) Palliative Care CNS Palliative Care Consultant Hospice Nurse GP Nursing Home Staff AHP
At any point the patient requests	Assess point in pathway and agree with patient.
Re-allocated by service provider	As appropriate
Transfer to Continuing Care	As appropriate

6.0 Record Keeping

Providers should ensure that:

- The name, designation and contact details of the key worker are recorded within the patient notes. Multi-disciplinary teams must agree a method of documentation, for example, the MDT proforma, which is signed and dated.

- The patient is provided with written information detailing the name of the key worker, designation and contact details. The key worker's details should be included in all correspondence.
- The key worker may change, as patient's needs change, ensuring that the patient is being guided by the most appropriate health care professional. A change of key worker must be documented as above and all the relevant professionals informed.
- A clear handover of key worker needs to be negotiated. Changes must be kept to a minimum as the value of continuity cannot be over-stressed.
- In the short-term absence of the key worker, an appropriately qualified colleague will provide cover. In the event of a lengthy absence of the key worker, another key worker must be nominated.

7.0 Key Worker Competencies

As a minimum standard, the key worker must be a clinical practitioner, i.e. a doctor, nurse or allied health professional. The key worker cannot be a secretary or healthcare assistant, although the key worker can delegate tasks to them whilst retaining overall responsibility.

The minimum required competencies for the key worker role are:

Communication Skills

- Communicate with a range of people on a range of matters in a form that is appropriate to them and the situation.
- Develop and maintain communication with people about difficult and complex matters or situations related to supportive & palliative care.
- Present information in a range of formats, including written and verbal, as appropriate to the circumstances.
- Listen to individuals, their families and friends about their concerns related to supportive & palliative care and provide information and support.
- Work with individuals, their families and friends in a sensitive and flexible manner, demonstrating awareness of the impact of a cancer diagnosis, and recognising that their priorities and ability to communicate may vary over time.

Assessment and Care Planning

- Understand the range of assessment tools, and ways of gathering information, and their advantages and disadvantages.
- Assess pain and other symptoms using assessment tools, pain history, appropriate physical examination and relevant investigation.
- Undertake/contribute to multi-disciplinary assessment and information sharing.
- Ensure that all assessments are holistic, including:
 - Background information
 - Current physical health and prognosis
 - Social/occupational well-being
 - Psychological and emotional well-being
 - Religion and/or spiritual well-being, where appropriate
 - Culture and lifestyle aspirations, goals and priorities
 - Risk and risk management
 - The needs of families and friends, including carer's assessments.
- Regularly review assessments to take account of changing needs, priorities and wishes, and ensure information about changes is properly communicated.

Symptom management, maintaining comfort and well being

- Be aware that symptoms have many causes, including the disease itself, its treatment, a concurrent disorder, including depression or anxiety, or other psychological or practical issues.
- Understand the significance of the individual's own perception of their symptoms to any intervention.
- Understand that the underlying causes of a symptom will have an impact upon how care should be delivered.
- Understand the range of therapeutic options available, including drugs, hormone therapy, physical therapies, counselling or other psychological interventions, complementary therapies, surgery, community or practical support.
- In partnership with others, including the individual, their family and friends, develop a care plan which balances disease-specific treatment with other interventions and support that meet the needs of the individual.
- In partnership with others, implement, monitor and review the care plan.
- Awareness of cultural issues that may impact on symptom management.

Advance Care Planning

- Demonstrate awareness and understanding of Advance Care Planning, and the times at which it would be appropriate.
- Demonstrate awareness and understanding of the legal status and implications of the Advance Care Planning process in accordance with the provisions of the Mental Capacity Act 2005.
- Show understanding of Informed Consent, and demonstrate the ability to give sufficient information in an appropriate manner.
- Use effective communication skills when having Advance Care Planning discussions as part of ongoing assessment and intervention.
- Work sensitively with families and friends to support them as the individual decides upon their preferences and wishes during the Advance Care Planning process.
- Where appropriate, ensure that the wishes of the individual, as described in an Advance Care Planning statement, are shared (with permission) with other workers.

The competencies identified above have been adapted from Department of Health *Core competencies for end of life care* June 2009.

8.0 Key Worker Training

Individuals to identify any training need requirements through their Personal Development Review (PDR), to ensure compliance with competencies for key worker role (7.0).

- The key worker must have post-registration training and education in intermediate/advanced communication and/or counselling skills.
- Basic cancer awareness – impact of diagnosis and treatment. Practical, financial and emotional impacts.
- Network Holistic Needs Assessment training - patients' emotional and psychological experience of cancer.
- The key worker must be either a recognised core-member of the relevant cancer or palliative care local or specialist MDT, or a member of the patient's primary health care team.

- The key worker is responsible for identifying any other personal training needs required in relation to fulfilling this role.

9.0 Quality Measures

The network patient experience survey will provide a measure of the quality of care co-ordination and key worker support. Providers should review the feedback given by local patients through this survey and address any areas of weakness that emerge.

- % patients reporting on diagnosis they were given clear information
- % patients reporting they received written information about the team providing their care
- % patients reporting that the people treating and caring for them were working together to provide the best possible care
- % patients reporting that following treatment they were given clear information about what was going to happen next
- % patients reporting that they knew how to contact their Specialist Nurse / Key Worker
- % patients reporting that they saw their Specialist Nurse / Key Worker
- % patients reporting that when seen by the Specialist Nurse / Key Worker they received enough support from them
- % patients reporting that they had given enough emotional support during their treatment
- % patients reporting that they were given information about sources of support

Monitoring will be undertaken annually by the individual MDT's, and reported through the relevant local cancer hospital/primary care groups.

10.0 Acknowledgements

This policy has been adapted from Kent and Medway Cancer Network 'Care Co-ordination and Key Worker Guidelines', with thanks.

11.0 References

- National Institute for Clinical Excellence (2004) *Guidance on Cancer Services: Improving Supportive and Palliative Care for Adults with Cancer*.
- Department of Health (2004) *Manual Cancer Services Standards Quality Measures*
- Department of Health (2007) *Cancer Reform Strategy*
- NHS North West (2008) *The Cancer Plan for the North West of England to 2012*
- Department of Health (2009) *Core competencies for end of life care*

12.0 Policy Consultation

Draft policy was distributed to the following:

- Acute Trust Cancer Management Teams for circulation to cancer and palliative care MDT's
- Supportive & Palliative Care CNG
- AHP CNG
- EOL & PC CNG
- Lead Nurse CNG
- Cancer Locality Groups
- Cancer Partnership Group
- Local Hospice and Voluntary sectors

13.0 Plan for dissemination

This policy will relate to all cancer & palliative care MDT's and primary care teams across the Network. Distribution will be via the relevant CNG and cancer management teams. On approval implementation will be immediate. A copy of the policy will be available on MCCN internet site for all users.

14.0 Policy Review

This policy will be reviewed annually.

Appendix 1 – Key worker flow chart

