East Midlands Cancer Alliance

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Key Worker Policy to support people living with cancer

Definition of the Key Worker; *"A person who, with the patient's consent and agreement, takes a key role in co-ordinating the patients care and promoting continuity, ensuring the patient knows who to access for information and advice"* NICE (2004)[1]

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East Midlands Cancer Alliance

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0.2	28/04/20	Sally Picken	Draft	Updated with comments received from lead cancer Nurses - Jane Pickard, Liz Summers & Atiya Chaudry-Green, EMCA lead primary care
0.3	30/04/20	Sally Picken	Draft	Updated following review with Jane Pickard & Liz Summers re roles and remits
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0.5	02/06/20	Sally Picken	Draft	Incorporated feedback from lead cancer nurses and primary care transformation group. Specifically: • HNA assessment moved from CNS section to Keyworker section. • Psychology level 2 trained moved from CSW to CNS section. • Note the role of voluntary sector, people as passive recipients or active participants in their care.
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Approved by

EMCA Living with Cancer / Personalised Care Steering Group		17th June 2020

Contents

1. Introduction and Purpose of this Policy

This policy is intended to assist Providers and Commissioners to define the role and responsibilities of the Key Worker and suggests appropriate Health Care Professionals to undertake the role during different stages of the cancer pathway.

This Key Worker policy provides a framework for "Key Worker" roles, utilising best practice and a consistent approach across East Midlands Cancer Alliance (EMCA) to provide a seamless service to those affected by cancer.

The Key Worker role has been pivotal to the cancer patient pathway since its inception in 1995 (Calman Hine)[1] and has continued to evolve with the ambition to enhance and deliver a first class service to people affected by cancer and their families

Definition of the Key Worker; *"A person who, with the patient's consent and agreement, takes a key role in co-ordinating the patients care and promoting continuity, ensuring the patient knows who to access for information and advice"* NICE (2004)[2]

Care for people with cancer or when cancer is suspected is often complex and may involve input from different health professionals working in primary care, secondary care and specialist centres as well as the voluntary and third sectors. Effective communication and co-ordination of care is essential to provide high quality patient centred care and a seamless service to those affected by cancer. It is suggested that people find times of their cancer experience challenging, for example:

- When cancer is suspected
- At diagnosis
- The period immediately following completion of treatment
- During relapse of disease
- When end of life is approaching

Ensuring that individualised person-centred care is well co-ordinated at both strategic and operational levels will lead to improved quality of life for those affected by cancer and higher satisfaction with services. Co-ordination is required to ensure that services work together with no loss of continuity. This co-ordinating role is central to the persons cancer pathway by providing specialist information, support and guidance.

EMCA National Cancer Patient Experience (CPES) results demonstrated that the number of people who reporting having a main contact person who supported them through treatment was higher than the England average – 92.1% vs. 91.5%. This main contact person within acute hospital is often a member of the CNS team who undertakes the role of Keyworker.

2. Context

In most cases the CNS is the Key Worker for people affected by cancer across the whole of their treatment pathway. However, due to increasing demand, other key worker models have been developed due to the increasing pressure on the CNS workforce.

- An increasing incidence of cancer
    - The number of new all cancers combined cases on average each year in the UK is projected to rise from around 420,000 cases in 2023-2025 to around 506,000 cases in 2038-2040 [2]
- Improved survival rates[3]
    - The number of people living with and beyond a cancer diagnosis in England is currently 3 million, rising to 3.5 million by 2025,4 million by 2030, and 5.3 million by 2040
- Ageing population – 70% of those with cancer are likely to have another long-term condition
- Ageing CNS workforce and vacancies - 38% of CNSs are aged 50 and over in 2017 compared to 33% in 2014[3]
- It's estimated that around 20-30% of CNS time is used on administrative tasks and specialist skills are not being optimised [3]

The growing demands means that roles such as cancer support workers and other allied health professionals are also known to provide support to people affected by cancer.

CPES results show there is however, an inequity in provision of CNSs, as people with rare and less common cancers are less likely to have access to a CNS, therefore less likely to feel supported and empowered to make informed decisions about their treatment and care as they move through the pathway, consequently they are more likely to report a significantly worse experience of care.

The NHS Long Term Plan 2019 references the importance of the previously named key worker role and recognises the importance for all people diagnosed with cancer to have access to a Cancer Nurse Specialist (CNS).[5]

By 2021, where appropriate every person diagnosed with cancer will have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support. This will be delivered in line with the NHS Comprehensive Model for Personalised Care. This will empower people to manage their care and the impact of their cancer and maximise the potential of digital and community-based support. Over the next three years every patient with cancer will get a full assessment of their needs, an individual care plan and information and support for their wider health and wellbeing. All patients, including those with secondary cancers, will have access to the right expertise and support, including a Clinical Nurse Specialist or other support worker.

3. Policy Objectives

- To define the role of the Key Worker
- To define who/which Health Care Professions would be appropriate to be a Key Worker
- To outline the responsibilities of the Key Worker
- To ensure the specialist multi-disciplinary teams incorporate the Key Worker role into operational policies and clinical practice where applicable
- To provide a model for use across the East Midlands Cancer Alliance

4. Who can be a Key Worker?

This is usually the Site-Specific CNS at the point of diagnosis but may change depending on the individual needs of the person and where they are in the cancer pathway. For instance, the GP is the Key Worker when someone initially consults them and the GP suspects cancer.

The most appropriate people to be a Key Worker at points of the cancer pathway includes:

- General Practitioners or additional Primary Care Network staff roles to be defined
- Cancer Nurse Specialists/Advanced Nurse Practitioner/Consultant Nurses
- Allied Health Professionals E.g.: Therapeutic Radiographers
- District Nurses/Advanced Care Practitioners/Community Matrons
- Practice Nurses
- A member of the Specialist Palliative Care Team

Cancer Support Workers may, under the direction and supervision of a CNS, undertake less complex keyworker activity for people with cancer. See Section 8 Core keyworker responsibilities for more details.

5. Allocation of the Key Worker

- The allocation of a Key Worker occurs at the point of diagnosis though in some instances this may be during the diagnostic stage
- The Key Worker is introduced to the person at or as soon after diagnosis as possible
- Within Secondary Care the Key Worker will usually be the Site-Specific Clinical Nurse Specialist (CNS) (this includes Advanced Nurse Practitioner/ Consultant Nurses). Alternatively, the role may be undertaken by a Healthcare Professional (HCP) appropriately equipped to meet the person affected by cancer/carers individual needs
- Within Primary Care the Key Worker should be a Health Care Professional with the appropriate knowledge and skills to meet the individual needs of the person affected by cancer. This maybe their GP or an appropriately trained Practice Nurse/District Nurse or associated PCN clinical roles
- People with cancer must have an allocated Key Worker throughout their cancer pathway irrespective of the care setting. The name of the Key Worker MUST be identified and communicated to the person and their family/carers' as well as documented in the relevant clinical record.

6. Changes to the allocated Key Worker

The Key Worker may change during the cancer pathway depending on the individual needs of the person. When handover of the Key Worker role is indicated, it must be done in full consultation with the person and their family /carer where appropriate.

A clear handover from one Key Worker to another is essential to ensure continuity of care and a seamless service for patients/carers. This should include their personalised care and support plan (PCSP).

In the absence of the identified Key Worker an appropriate Health Care Professional will ideally provide appropriate "cover" to ensure continuity of care. To maintain continuity of care and a seamless service across the pathway for persons affected by cancer, it is essential that there is a formal handover of the persons personalised care and support plan.

7. Documentation and Record Keeping

- The name and contact details of the Health Care Professional must be recorded and evidenced in persons' records with reference to the term **Key Worker**.
- It is imperative that Key Worker details are recorded in the persons clinical records.
- The person and their family/carer (where appropriate) will be informed of the name of the Key Worker verbally and will be provided with the name and contact details of the Key Worker in writing.
- The effectiveness of the Key Worker role (when undertaken by a CNS) is audited by the National Cancer Patient Experience survey. Survey results will be used to inform service improvements.

8. Key Worker Core Responsibilities

The Key Worker core responsibilities can be carried out by a number of roles as referred to in section 4 and may include the following:

- Introducing themselves to the person and ensure that the person and family/carer have their contact details
- To coordinate the person's care and act as their first point of contact for the person when specialist advice and support is needed
- Advising the person how to contact their Key Worker – such as virtually (e-mail, video conferencing), telephone support, clinic visits or visits to the clinical area
- Act as an ongoing point of contact for the person and their family/carers
  To offer Holistic Needs Assessments (HNA) to the person to complete at defined points in the pathway. A completed HNA will highlight the most important concerns to the person at that time that need to be addressed in a written care plan
- Ensure people are offered personalised care and support along their cancer pathway whether they are passive recipients or active participants in their care
- Support people in the development of self-management strategies
- Support the person affected by cancer in making informed decisions

- Refer the person on to other agencies/services where appropriate to meet their individual needs
- Act as an advocate for the person affected by cancer and where relevant offer insight into the concerns and wishes of the person
- Promote continuity of care and manage transitions of care throughout the persons cancer pathway and across organisational boundaries
- Provide verbal and written information to meet peoples /carers individual needs
- Access one hours clinical supervision monthly if trained to Level 2 (NICE 2004) to ensure that any change of Key Worker is done in full consultation with the person and family/carer and that the person is provided with revised contact details.
- To ensure that the next Key Worker has the appropriate information about the person to fulfil the role.
- To encourage the person affected by cancer to live actively and well following the end of their cancer treatment

Roles unique to a CNS in a Key Worker capacity also include:

- Be a recognised Level 2 practitioner on completion of relevant training, providing psychological support and identifying and referring people with complex needs, to the Clinical Psychologist/ Psychiatrist
- The CNS will use information from the HNA to develop and agree a personalised care and support plan in consultation with the person affected by cancer.
- Ensure people are offered health and wellbeing and support information (HWBSI)
- Contribute as a core member to MDT discussions and patient assessment/care planning decisions of the team including ensuring the person's most recent HNA results are considered appropriately in MDT decision making
- Support people in discussions where eligible for clinical trials
- Contribute to the management and leadership of the service -
- Lead/participate in research and audit to enhance patient care
- Act as a resource, providing specialist advice related to the tumour type

8.1 The Role of a Cancer Support Worker / Cancer Navigator in supporting a Key Worker

The term Cancer Support Workers (CSW) is used in this document however it also includes the roles of Cancer Navigators. CSW's often work as part of the cancer care team alongside qualified nurses, usually a Clinical Nurse Specialist (CNS). They can support with delegated non-complex tasks to enable the CNS to focus their expertise on managing the complex care needs of people affected by cancer at different points of the pathway:

- being investigated for a cancer diagnosis
- receiving treatment for their cancer
- living with and beyond cancer following treatment

Support Worker activities may include:

- Coordinating care or provide a single point of access for people affected by cancer to easily re-enter the system when they need to.
- The role, which is focused on a partnership with the person affected by cancer, allows the support worker to empower the person to self-manage

- They can provide appropriate advice and escalate any issues to a specialist where necessary
- Direct liaison with patients on optimal pathways to facilitate planned diagnosis (e.g. ordering wheelchairs/equipment; coordinating appointments with patients; organising referrals)
- Supporting people to undertake a holistic needs assessment
- Providing advice and support within outpatient clinics to free up consultant/nurse led clinic time.
- Triage telephone calls that come into the CNS service
- Provide general information, help and support
- Support the development, implementation and evaluation of dedicated Health & Wellbeing events

There may be locally agreed variation to these activities.

9. Personalised Care

The Key Worker will actively promote personalised care to the person affected by cancer.

There are four elements to the personalised care:

a) Personalised Care and Support Plan (PCSP) based on a Holistic Needs Assessment (HNA)

The Key Worker will offer a Holistic Needs Assessment to the person affected by cancer / their carers at key stages of the patient pathway. These are often:

- Around the time of diagnosis
- Commencement of treatment (if appropriate)
- Completion of treatment
- Disease Recurrence
- End of Life Care
- At the persons request without any explanation

The other elements of the personalised care package which may involve the Key Worker are:

b) Health and Wellbeing Support and Information (HWBSI)
c) End of treatment Summary (TS)
d) Cancer Care Review (CCR)

Further details are in **Appendix A**

10. Training Requirements

MDTs are responsible for ensuring competence within their own teams, the Lead Cancer Nurse is responsible for ensuring MDTs are kept informed of any changes to the key worker policy.

References

1 Calman-Hine Report: A Policy Framework for Commissioning Cancer Services: A Report by the Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales (1995).

2 Cancer Research UK [accessed 14th July 2023] https://www.cancerresearchuk.org/health-professional/cancer-statistics/incidence/all-cancers-combined#ref-6

3 Leary, A. and Oliver, S. Clinical nurse specialists: adding value to care. *Royal College of Nursing*. 2010. (ref 30% admin)

4 Macmillan Cancer Support 2022 https://www.macmillan.org.uk/dfsmedia/1a6f23537f7f4519bb0cf14c45b2a629/9468-10061/2022-cancer-statistics-factsheet#:~:text=Last%20updated%3A%20October%202022.,5.3%20million%20by%202040%20i.Macmillan Cancer Workforce in England - A census of cancer, palliative and chemotherapy speciality nurses and support workers in England in 2017 https://www.macmillan.org.uk/_images/cancer-workforce-in-england-census-of-cancer-palliative-and-chemotheraphy-speciality-nurses-and-support-workers-2017_tcm9-325727.pdf

5 National Institute for Clinical Excellence (2004). Guidance on cancer services: improving supportive and palliative care for adults with cancer. The manual. London: National Institute for Clinical Excellence.

6 NHS (2019) The NHS Long Term Plan. NHS, Available at https://www.longtermplan.nhs.uk/online-version/

Bibliography

Calman-Hine Report: A Policy Framework for Commissioning Cancer Services: A Report by the Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales (1995).

CSW Impact brief https://www.macmillan.org.uk/_images/Support-Workers_tcm9-283189.pdf

Independent Cancer Taskforce (2015) *Achieving World-Class Cancer Outcomes: A strategy for England 2015-2020.* Available at https://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf

Leary, A. and Oliver, S. Clinical nurse specialists: adding value to care. *Royal College of Nursing*. 2010. (ref 30% admin)

Macmillan Cancer Workforce in England - A census of cancer, palliative and chemotherapy speciality nurses and support workers in England in 2017 https://www.macmillan.org.uk/_images/cancer-workforce-in-england-census-of-cancer-palliative-and-chemotheraphy-speciality-nurses-and-support-workers-2017_tcm9-325727.pdf

Macmillan Competency Framework for Nurses supporting people living with and affected by cancer (2020) https://www.macmillan.org.uk/_images/competency-framework-for-nurses_tcm9-297835.pdf

Maddams J et al. 'projections of cancer prevalence in the United Kingdom, 201-2040. Br. J. Cancer 107:1195-1202 (2012) https://www.ncbi.nlm.nih.gov/pubmed/22892390

National Institute for Clinical Excellence (2004). Guidance on cancer services: improving supportive and palliative care for adults with cancer. The manual. London: National Institute for Clinical Excellence.

NHS (2019) The NHS Long Term Plan. NHS, Available at https://www.longtermplan.nhs.uk/online-version/

APPENDIX A

PERSONALISED CARE AND SUPPORT PLAN PACKAGE

1. Personalised Care and Support Plan informed by a Holistic Needs Assessment

The Health Needs Assessment (HNA) informs the development of a Personalised Care and Support Plan (PCSP) for the individual following discussions with their CNS or key worker. It assesses the physical, practical, emotional, spiritual and social needs of the person and highlights the most important issues at that time that need to be addressed during or after treatment.

PCSPs should be completed and agreed by the CNS and the individual.

The Key Worker will offer a Holistic Needs Assessment of the patients/carers needs at key stages of the patient pathway. These are often:

- Around the time of diagnosis
- Commencement of treatment (if appropriate for patient care)
- Completion of treatment
- Disease Recurrence
- End of Life Care
- At the persons request without any explanation

2. Health and Wellbeing Support and Information (HWBSI)

All individuals will have access to health and wellbeing support and information. This support may be in the form of an event where there is education and support sessions aimed to provide individuals with the information and reassurance to build the confidence they require to enable them to lead as normal and active life as possible after their cancer treatment.

These sessions may also aim to increase awareness of the local facilities, supportive care and opportunities that are available to them and their families and to promote collaboration between service providers to ensure sustainability of this essential element of supported self-care.

In summary, health and wellbeing information and support **may** be delivered as: 1:1 appointments, rolling programmes or group events

Signposting and access to local services for cancer as a long-term condition health and wellbeing management - On line tools and support – examples include: https://www.cancercaremap.org/ and https://www.macmillan.org.uk/

3. Treatment Summary (TS)

A treatment Summary (TS) is a document produced by a healthcare professional after a significant phase of an individual's cancer treatment. It is designed to be shared with the person living with cancer and their primary care team, to enable them to manage their health and wellbeing. The TS and PCSP can inform and support effective Cancer Care Reviews.

4. Cancer Care Review (CCR)

An individual's GP practice offers a Cancer Care Review (CCR) to them approximately six months after diagnosis. The CCR is a holistic conversation between the individual and their healthcare professional in their GP practice. It is aided by the HNAs, PCPS and TS. It allows an opportunity for the individual to raise any concerns that may be affecting their quality of life, taking into account their existing conditions and medication and enables individuals to discuss

their cancer experience and supports them to manage their own health and wellbeing. The GP Practice can support individuals expressing concerns during their review and signpost them to services such as social prescribing.

Abbreviations

ANP	Advanced Nurse Practitioner
CCR	Cancer Care Review
CNS	Clinical Nurse Specialist
CPES	National Cancer Patient Experience Survey
EMCA	East Midlands Cancer Alliance
HCP	Healthcare Professional
HNA	Holistic Needs Assessment
HWBSI	Health and Wellbeing and Support Information
MDT	Multidisciplinary Team
PCSP	Personalised Care and Support Plan
TS	Treatment Summary