**Standard Guideline**

**KEY WORKER DESIGNATION FOR PATIENTS RECEIVING CARE WITHIN PAEDIATRIC HAEMATOLOGY AND ONCOLOGY SERVICES**

**SETTING**
Bristol Royal Hospital for Children, South West Region – Paediatric Oncology Shared Care Units (POSCU)

**FOR STAFF**
All staff involved in care within Paediatric Haematology and Oncology

All areas that are designated to the care of children with cancer. These areas include inpatient, outpatient and supportive care throughout the South West (SW) regional POSCU’s.

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**GUIDANCE**

**ISSUE**
All children with cancer will move between hospital and home throughout their cancer treatment. They will receive supportive care as inpatients, outpatients and with their local shared care hospital and community teams. NICE Improving Outcomes Guidance for Children and Young People with Cancer (2005) requires that cancer services have processes in place to ensure effective communication and co-ordination between all professionals involved in the care of the child.

These guidelines set out the agreed approach to care co-ordination / Key Worker designation within the Haematology / Oncology Department at Bristol Royal Hospital for Children and across the teams delivering care throughout the SW regional POSCU’s. They specify the process for designation of a Key Worker and standard of care co-ordination that should be achieved when delivering care to the child with cancer and the role of the ‘key worker’ for a patient on an active treatment pathway.

**PRINCIPLES**
There is a need to ensure integration and co-ordination throughout the child and family’s cancer treatment pathway. This may be within and between primary, secondary and tertiary care settings, and health and social care settings.

Care for children with cancer often needs to be continued over many years, across organisational and professional boundaries. Continuity of care is essential at diagnosis, during treatment, follow-up and palliative care; the allocated key worker will be reviewed at these significant milestones.

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

**DEFINITION**

**What is a Key worker?**
“A person who works with you to plan, coordinate and communicates with the members of your care team”

1. [Extended until February 2021]
SCOPE OF PRACTICE

Care of children with cancer is the responsibility of all health and social care professionals delivering care.

The multidisciplinary team (MDT) consists of staff members from these areas:

- Haematology/Oncology Inpatient wards: Starlight Ward, Apollo Ward, and Bone Marrow Transplant (BMT) Unit
- Haematology/Oncology BMT Outpatient Unit (Ocean unit)
- Paediatric Oncology Outreach Nurse Specialists (POONS)
- Clinical Nurse Specialist (CNS) – CLIC Sargent, Leukaemia, Oncology/Neuro oncology
- Clinical Haematologists and Oncologists
- Aftercare Team
- CLIC Sargent Social Work Team
- Dieticians
- Clinical Psychologists
- Physiotherapy
- Speech And Language Therapist (SALT) /Ophthalmology/Audiology
- Endocrine Team
- Neurology Team
- Shared Care Co-ordinator
- Local Shared care Hospital
- Local Education Teams
- Local Social Services
- Pharmacist

THE ROLE OF THE KEY WORKER

The NICE Improving Outcomes Guidance for children and Young People with Cancer (2005) suggest that the key worker role may include to:

- Provide practical and emotional support to the child and family.
- Co-ordinate the provision of information and ensure that it is timely, tailored to the age of the child and the needs of the family and understood.
- Ensure the provision of a written care / treatment plan and an initial needs assessment of the child and family to inform the care plan.
- Liaise with health and social care agencies and professionals in the community, including the primary care team.
- Liaise with educational institutions and support reintegration for the child wherever possible.
- Ensure that the child and family acquire new skills as needed, for example care of nasogastric tubes, care of central lines.
- Case manage the care needs of the child and family as they move between settings along the patient pathway, for example during radiotherapy.
- Co-ordinate palliative care to provide specialist advice and support to families and healthcare professionals.
- Provide direct clinical care and expertise at certain points throughout the child’s cancer treatment.
### RESPONSIBILITIES OF THE KEY WORKER

**Assessment and Care Planning**

In conjunction with the wider MDT ensure the child and family wider needs including both clinical and non clinical in nature are assessed at initial and ongoing stages during treatment; with appropriate packages of care implemented.

**Coordinating service delivery**

Be a named individual who, where required, acts as the first point of contact for multiple services and alongside the MDT will ensure that needs are met holistically.

- The key worker will co-ordinate and have direct overall awareness of multi-professional / multi-agency input.
- Liaise with agencies and professionals, at both a practice and strategic level, in all sectors and healthcare settings as well as across geographical boundaries.
- Enable a shared understanding of goals and approaches amongst those closely involved in the child and family care.
- Ensure information is shared across agencies and practitioners.

**Enabling the child and family**

Coordinate the provision of information and ensure that it is timely, tailored to age and the needs of the family and is understood.

- Ensure families know about and can access the services to which they are entitled.
- Act as an advocate and help the family develop their own self advocacy skills.
- Empower children and families, where possible, enabling them to take on the coordination of care.

**Providing Specialist Cancer Support**

Ensure the child / young person and family as well as local primary care professionals acquire new skills as required.

- Ensure understanding of cancer treatment and side effects.
- Assess the child and family response to diagnosis and monitor how they are coping. To refer on for specialist psychosocial support where appropriate. To provide opportunities to discuss the progress of their disease and treatment.
- Advise the child and family on pain and symptom management related to cancer and its treatment.
- Support local agencies and professionals more generally in knowing what to expect from a cancer treatment process.
| Coordinating transition to agreed new Key worker | 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 the Principal Treatment Centre to the Shared Care Centre or at key clearly defined transition points (end of treatment, long-term follow up, After Care, palliative care).

Whenever a change of key worker is proposed, the original key worker should seek agreement from the child and their family and the new key worker. Once agreed, the original key worker should notify all professionals involved in the child’s care.

Make the child / family 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. |

| Coordinating Transition to TYA / Adult services | Establish links with a counterpart in Teenage and Young Adult (TYA) / adult services.

Conduct joint transition planning between child and key worker. |

| Delivering palliative and end of life care | Coordinate palliative and end of life care to provide specialist advice and support to families and professionals, with cross cover to provide a 24 hr service if required and achievable.

Provide specialist expertise and advice for symptom management and end of life care.

Ensure that the child and family preferences and choices are elicited, especially in relation to end of life care. To ensure that these preferences and choices are documented through the wishes document / framework; leading to the facilitation of an appropriate sustainable and safe package of care.

At the right time coordinate the communication of care plans and end of life decisions to the child and family and other health care professionals involved in care. |

Maintain ongoing contact |
BRHC KEY WORKER (LEUKAEMIA / SOLID TUMOUR CNS) + LOCAL KEY CONTACT

POSCU KEY WORKER + CNS KEY CONTACT (LEUKAEMIA / SOLID TUMOUR CNS)

CLIC SARGENT CNS KEY WORKER/NEURO-ONCOLOGY CNS

LEUKAEMIA

TRANSITION POINT MAINTENANCE THERAPY

CLIC SARGENT CNS KEY WORKER

LEUKAEMIA

NEURO-ONCOLOGY / SOLID TUMOUR

LOCAL BRISTOL PATIENT

INTEGRATED CARE MEETING

CNS SUPPORT

POINT OF ADMISSION

SW REGIONAL PATIENT

Extended until February 2021
Key Worker Designation – Further detail see Appendix 1

COMMUNICATION

- The name, designation and contact details of the key worker are recorded within the child’s notes and family held records. A label will be affixed inside the front cover of the notes with these details completed.

- The child and family are 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.

- 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 (over 4 weeks) of the key worker, another key worker must be nominated.

QUALITY MEASURES

- Patient and family experience feedback will provide a measure of the quality of care co-ordination and key worker support. All providers should review this feedback given by local patients and families through survey and focus groups addressing any areas of weakness that emerge.

- Patients and/or families reporting that on diagnosis they were given clear information

- Patients and/or families reporting that they received written information about the team providing their care

- Patients and/or families reporting that the people treating and caring for them were working together to provide the best possible care

- Patients and/or families reporting that following treatment they were given clear information about what was going to happen next

- Patients and/or families reporting that they knew how to contact their Specialist Nurse/Key Worker
- Patients and/or families reporting that they saw their Specialist Nurse/Key Worker

- Patients and/or families reporting that when seen by the Specialist Nurse/Key Worker they received enough support from them

- Patients and/or families reporting that they had been given enough emotional support during their treatment

- Patients and/or families reporting that they were given information about sources of support. Monitoring will be undertaken, and reported through the relevant Principal Treatment Centre / Shared Care Unit mechanisms.

**CNS CROSSCOVER – MDT FOCUS**

The CNS team will cross cover each other for the purpose of MDT discussion, ensuring phone queries and core value cover is addressed - not to cover direct workload, when on planned leave.

**ACKNOWLEDGEMENTS.** Great Ormond Street Hospital for Children NHS Trust Haematology Oncology Department - Caring for Children with Cancer Key worker Policy.

**REFERENCE**


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**RELATED DOCUMENTS**

**AUTHORISING BODY**

Children’s Clinical Effectiveness

BMT, Haematology and Oncology Governance Group

**SAFETY**

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**QUERIES**

Contact: CLIC Sargent CNS Ext 28576

Matron - Paediatric Haematology / Oncology Ext. 28190 Bleep 2029
Appendix 1 - KEY WORKER DESIGNATION

- It may not be possible to nominate a key worker at the point of admission, although at the point of diagnosis and following MDT discussion at the weekly Integrated Care meeting a Key Worker will be nominated either from within the team at the Bristol Royal Hospital for Children or a member of the POSCU MDT.
- Should a POSCU Key Worker be nominated then a CNS Key Contact within BRHC MDT will ensure ongoing effective communication with the POSCU key worker should the patient be receiving ongoing care in Bristol.
- For a patient diagnosed with Leukaemia within the wider Bristol geographic area the Paediatric Leukaemia CNS would undertake the role of Key Worker until a point of transition to maintenance therapy, whereby this role would be fulfilled by a CLIC Sargent CNS. The exception to this would be for a patient diagnosed with AML, receiving primarily inpatient-based therapy.
- For a patient diagnosed within the wider Bristol geographic area with a malignancy of solid tumour in origin a CLIC Sargent CNS would undertake the role of Key Worker with CNS support provided by the Neuro Oncology CNS for neuro-oncology patients only.
- The key worker, may be a single individual or a small team of professionals, will provide cross cover, care co-ordination, information and communication with the child and family and be an integral member of the child’s multidisciplinary team. Therefore, the key worker may change at different points in the child’s care trajectory.
- The aim should be to provide continuity of care throughout the child’s pathway of care.

The following roles have been agreed by representatives from the wider South West MDT as being able to facilitate the role of the key worker for a patient on treatment:

- Consultant Haematologist / Oncologist
- Paediatric Clinical Nurse Specialist Team (POONS, CNS)
- TYA Nurse Specialist

The following could be link / specific named contacts / deputies / close associates and delegated to but not act in the primary key worker role:

- Allied Health Professional
- Psychologist
- Ward Nurse

The following shouldn’t undertake the key worker role or undertake associated responsibilities:

- Teachers
- Volunteers / Parents / Peers
- Registrar
- GP
- External Staff to the NHS