Palliative Care
in partnership

Palliative Care Keyworker

Role & Function
2017

Background

The Living Matters Dying Matters strategy (LMDM, 2010) recommended that ***'each patient identified as having end of life care needs should have a keyworker'*** (Recommendation 9)***.***

NICE and the General Medical Council both define the '*end of life'* as ***'people who are likely to (or may) die in the next year (12 months)'.***

The LMDM strategy also highlighted that '***as complexity and/or decline become apparent, the need for care to be planned, organised and delivered, often across care settings, will require significant co-ordination'***. The role of the palliative care keyworker is therefore crucial.

Around 15,000[i] people die each year in Northern Ireland and around 75% (11,250) of those will be expected deaths who could benefit from a palliative care approach. Research shows that 81%[ii] of people, given the choice, would prefer to be cared for and die in their own home. Therefore it is important to ensure that appropriate support, care and advice is in place locally to enable them to do so.

Purpose

This paper is an update to the original **'Definition and Competencies for Keyworker Function'** paper which was agreed by Living Matters, Dying Matters in 2012. The development of this paper has been led by the Palliative Care Project Management Team and updated in collaboration with Public Health Agency Nursing Leads, Regional District Nursing Leads and the Trust Palliative Care Service Improvement Leads, in line with regional priorities for best practice palliative and end of life care and has been approved by the Regional Palliative Care Programme Board – Palliative Care in Partnership on 8 February 2017.

The following paper sets out the regional definition, responsibilities, function and core competencies of the Palliative Care Keyworker role. It is not an overarching policy for delivery and these principles should be embedded into local policies and procedures to facilitate best practice palliative and end of life care at a local level.

Keyworker Definition

The Palliative Care Keyworker (the keyworker) is an identified individual with responsibility for planning and co-ordinating care for patients who (as a minimum) have been identified as likely to be in their last year of life. This should include co-ordinating care across interfaces (within and between professionals, teams and care settings), promoting continuity of care and ensuring that the patient and those important to them know how to access information and advice. The aim of the keyworker role is to ensure communication and co-ordination to ensure maximal quality of life and support the person to remain in their preferred place of care.

Role and Responsibilities of the keyworker

The role of the keyworker is to:

- Act as a main point of contact for person and those important to them
- Provide practical and emotional support to the person and those important to them
- Provide information, where appropriate, and ensure that it is timely and tailored to the person's needs and understanding
- Ensure the appropriate communication/discussions take place at the person's pace to allow them to have an active and informed role in their advance care planning
- Ensure the person's details are appropriately recorded on the local Trust Palliative Care Register/ co-ordination system
- Co-ordinate assessments, referrals and multidisciplinary team care planning to ensure appropriate interventions take place in a timely fashion
- Ensure that assessment, review and update of care plans takes place so that symptoms are managed and physical, emotional, and spiritual needs are met
- Ensure that systems and processes are in place to ensure handover of information on a 24 hour basis to all relevant services
- Ensure those important to the person and carers are aware of who to contact on a 24/7 basis for advice and support.
- Ensure that the carer/those important to the persons needs have been assessed (e.g. offered a carer's assessment and appropriate reviews)
- Co-ordinate and share information within and between care settings and services
- Act as an advocate for the person as appropriate
- Ensure that those important to the person/ carers are supported as necessary including what symptoms and signs to look out for and how these should be managed.
- Provide information and guidance to other professionals relating to the person and those important to them
- Co-ordinate appropriate care in the last weeks and days of life with the aim of facilitating the person to be cared for in their preferred place, where safe, practical and appropriate to do so
- Co-ordinate bereavement follow up.

Core Competencies

The keyworker should be competent in the following areas[1]:

- Overarching values and knowledge of Palliative and End of life Care
- Effective and appropriate communication

[1] Please refer to **Palliative & End of Life Care Competency Assessment Tool 2012 (Health and Social Care – Living Matters, Dying Matters)**

- Facilitating advance care planning (Advance Care Planning Level 2)[2]
- Awareness of the roles and responsibilities of all related professionals/services
- Co-ordination of systems and processes on a 24 hour basis.
- Holistic assessment[3] and care planning
- Symptom management, maintaining comfort and well being
- Co-ordinating care in the last days of life.

Keyworker Function

The keyworker should be named and recorded when (as a minimum) it is recognised that the person is likely to be in their last year of life, has palliative and end of life care needs and is placed on the GP palliative care register i.e. the green phase on the End of Life Care Operational System (ELCOS) onwards. This decision should be discussed and agreed as part of the multidisciplinary team meetings either in primary care or agreed in another setting and then communicated to primary care, respecting person's preference and considering continuity of care.

In cases where the person has a condition which may lead to a loss of capacity (i.e. such as dementia) is it important to identify the person as early as possible (ELCOS Blue Phase) in order to allow time for advance care planning discussion to take place and be recorded (if that is the person's wish).

The District Nurse will **typically** be the keyworker. However, there may be occasions when it would be appropriate for other specialist nurses or AHP professionals to be the keyworker, for example, where it has been agreed that these professionals are best placed to provide the keyworker function. On these occasions, there must be appropriate local procedures in place to ensure there is 24/7 support available for the person and those important to them.

The four operational elements of the keyworker function are:

1. **Identification:** Attending regular (preferably monthly) meetings with GP practices and the MDT team to proactively identify people who are likely to be in their last year of life. Allocating an appropriate keyworker for each person identified and activating palliative care as per ELCOS.
2. **Contact & Co-ordinating care:** Holistic assessment, referrals to services, co-ordinating care, providing advice and support to the person and those important to them. Recording the person's details on the local Trust Palliative Care Register/co-

[2] Please refer to **NI Wide Advance Care Planning Training/Implementation Guidance (Living Matters, Dying Matters 2015)**

[3] Holistic assessment should include assessment of the person's physical, social, emotional and spiritual needs e.g. using tools such as **eNISAT** or the **Palliative Care Aide Memoire.**

ordination system. Facilitating advance care planning discussions[4]. Ensuring local arrangements are in place and that the person and those important to them know who to contact of advice and support 24/7.

3. **Care in the last weeks/days of life:** ensuring person-centred care delivery and emotional support for the person and those important to them in the last weeks and days of life (ELCOS yellow and red phases). Supporting the person to achieve their preferred place of care, when practical and safe to do so.
4. **Bereavement follow –up:** Providing pre and post bereavement support to those important to the person. Including post bereavement visit, signposting to bereavement services, removal of equipment, notes and medications.

The role of the keyworker in other care settings

In Hospitals: When a person who has been identified as likely to be in their last year of life (as a minimum) is admitted to hospital, the hospital staff should make contact with the person's keyworker in the community (typically the District Nurse) to discuss continuing care and discharge arrangements.[5] During the inpatient stay the person and those important to them should have an identified staff member who will be their named contact for the time the person is in hospital.

If a person is identified as likely to be in the last year of life during a hospital stay then it should be recorded within the Regional Discharge Pro-formas and the GP Discharge Summary. Where immediate action is required the hospital should contact the local District Nurse to discuss keyworker arrangements on discharge.

In Hospices: : When a person who has been identified as likely to be in their last year of life (as a minimum) is admitted to a hospice or referred to hospice services, the hospice staff should make contact with the person's keyworker in the community (typically the District Nurse) to discuss continuing care and discharge arrangements (if appropriate) .[6] During the inpatient stay the person and those important to them should have an identified staff member who will be their named contact for the time the person is in hospice.

In Nursing Homes and other longer stay healthcare facilities[iii]: In terms of the four operational elements of the Keyworker role, the District Nurse will play a key role in the identification of residents in Nursing Homes and other longer stay healthcare facilities as part of the GP practice MDT meetings. Once identified, communication should be made with the registered nurses in the nursing home or other longer stay healthcare facilities and

[4] Please refer to ***'Advance Care Planning Operational Guidance for Health and Social Care Professionals in Northern'***

[5] Please refer to '***Guiding principles to enable effective discharge planning for adults from hospitals and transitional settings.' Section 4.2.3***

[6] Please refer to '***Guiding principles to enable effective discharge planning for adults from hospitals and transitional settings.' Section 4.2.3***

they will normally fulfil the other operational elements of the Keyworker role (Contact & Co-ordinating Care, Care in the last weeks/days of life and Bereavement follow-up).

Following identification, the registered nurse within the nursing home/longer stay healthcare facility will be the keyworker and be responsible for assessing and co-ordinating the on-going care needs of the person along with the GP and other members of the multi-disciplinary team. The registered nurse will liaise with other professionals including the District Nurse as required.

Keyworkers in Nursing Homes and long stay healthcare facilities should ensure there is clear communication from the nursing home to the District Nurse (or other appropriate community professional) to ensure the person is included on the local Trust register/co-ordination system (where local systems allow) once they have been identified (as a minimum) as likely to be in their last year of life.

Specialist Palliative Care Services

Local arrangements should be in place for the keyworker to make appropriate referrals to specialist palliative care services where the person has unresolved complex physical, emotional, social or spiritual symptoms despite previous interventions.[7]

Specialist Palliative Care professionals should not normally be the keyworker, unless there are particular circumstances which make them best suited to the role. In such cases, appropriate local arrangements should be in place to ensure the SPC professional can fulfil the keyworker role and for there to be 24/7 cover and co-ordination for the person and those important to them.

Monitoring and measures

Each person identified as likely to be in their last year of life (as a minimum) should be:

- Placed on the GP Palliative Care Register for QOF
- Registered on the local Trust Palliative Care Register/co-ordination system
- Allocated a keyworker
- Given the opportunity to discuss and record their advance care planning preferences
- Supported to achieve their preferred place of care, where practical and safe to do so.

[i] Approximate average using NISRA Recorded Place of Death Statistics 2012-2015
[ii] Office for National Statistics (UK) 2015
[iii] Other longer stay healthcare facilities for example the Neurology Unit at Musgrave Park Hospital or Thompson House, Lisburn.

[7] Please refer to '***Community and Inpatient Specialist Palliative Care Services Referral Guidance and Services Directory***'