Paper for Middlesbrough Health Scrutiny Panel with Regards to End of Life Care

Middlesbrough, Redcar and Cleveland Community Services Perspective: for the Middlesbrough Council Health Scrutiny Panel

This paper summarises and provides an overview of the themes being addressed by Middlesbrough, Redcar and Cleveland Community Services (MRCCS) and answers the questions we were presented by the scrutiny panel. End of life care is currently high on the national agenda and focuses on:

- Implementation of Gold Standards Framework
- Advance care planning and discussions about the patients preferred priorities of care / death
- Implementation of the Care pathway for the last days of life (Liverpool Care Pathway) for all expected deaths

End of life care is one of the 8 high impact actions for nursing and midwifery (NHS Institute for Innovation and Improvement, 2009), linked to Lord Darzi's NHS review.

Current Objectives for MRCCS

The End of Life Care Strategy (2008) focuses on the identification of quality markers and measures for End of Life Care. MRCCS is focusing on these with the aim to improve end of life care for the local population by:

- Focusing on the provision of high quality care in the last year of life for all patients, not dependant upon diagnosis
- More widespread implementation of the care pathway for the last days of life
- Implementation of advance care planning using the preferred priorities of care document – choice of care
- To increase the numbers of people who are able to die in the place of their choice and avoid inappropriate admissions to hospital, as identified in the high impact actions (NHS Institute for Innovation and Improvement, 2009)
- Identification of patients in the last year of life for Gold Standards Framework (GSF) (home, primary care hospital and nursing / care home)
- Identification of a key worker (case manager) for patients / carers
- Implementation of holistic assessment and care planning
- Identification of carers needs- referral for carers assessment
- Delivery of care in all locations (home, primary care hospital or nursing/care home)
- Referral to the fast track team in the last days of life
- Working collaboratively with other care providers
- 24/7 face to face care (1 hours response time)
- Provision of bereavement support to carers
- Link with patient and carer involvement via the Tees End of Life (EOL) focus group

- Increase the number of staff undertaking education in end of life care

MRCCS engages with the Teeswide Strategic Development Group and the North East End of Life Clinical Innovation Team.

Service Developments

- Development of an End of Life Policy
- Development of an End of Life Strategy linked to the national End of Life Strategy for the NHS (DH, 2008)
- Successful implementation of the care pathway for the last days of life for patients at home, primary care hospitals and care homes
- Progressing with the implementation of the care pathway for the last days of life in nursing homes
- Facilitating the implementation of Gold Standards Framework (GSF) in General Practice (new practices in the development phase)
- Community Nurses, Community Matrons and Macmillan CNS attend GSF with aligned GP practice to support the planning of patient care in the last year of life and support for their carer into bereavement – this improves communication and ensures that services are planned for the individual needs
- Development of a Macmillan CNS (Care Homes) role to support our colleagues provision of end of life care in the independent sector through implementation of GSF and education
- Lead on the implementation of GSF in 14 nursing / care homes 2009-10
- Commencing the GSF programme in 16 nursing homes 2010-11
- Currently working on the development of the care pathway for the last days of life, which will follow the patient (acute, community and hospice)
- Community Matrons liaise with the discharge planning team to support and facilitate speedy but appropriate discharge from secondary care for patients on caseload
- Community Matrons develop crisis management plans with patients that can be shared with other professionals which outline considerations and options as an alternative to a secondary care admission. This can include rapid response service, emergency respite, Primary Care Hospital beds etc.
- Macmillan CNS liaise with other providers (Hospice and JCUH MDT) in the provision of seamless care for the most highly complex patients
- Development of a series of local bereavement booklets which have been adopted Teeswide
- Development of community nursing core care plans for palliative care
- Successful implementation of new syringe pumps for symptom control and the deliver of education to support this
- Community Matrons and Specialist Palliative Care Team offer an advance care plan to all patients on caseload and document service users preferences for the last year of life

Education

- Specialist Palliative Care Team worked in partnership with the University of Teesside in the development of a new module aimed at care home staff
- Specialist Palliative Care Team delivery of the new module to nursing / care home staff
- Specialist Palliative Care Team delivery of education at the care home focus group
- Specialist Palliative Care Team delivery of education requested by individual teams within MRCCS and care homes
- Specialist Palliative Care Team work in partnership with the University of Teesside in the planning and delivery of two palliative care modules aimed at certificate, diploma and degree level
- Development and delivery of an induction programme which focuses on end of life care for qualified nurses
- Planning and implementation of educational updates for all MRCCS nursing staff focusing on end of life care (Commencing October 2010)
- Hold an open forum education session 6 times/year for all health and social care professionals within MRCCS
- Delivery of education to General Practitioners during protected time and at request
- Specialist Palliative Care Team attending GSF to deliver 'bite size educational sessions' to the multidisciplinary team
- Specialist Palliative Care Team involved in informal education on a daily basis with 'generalist professionals' (General Practitioners, MRCCS staff and Nursing / Care home staff)
- MRCCS staff involved in receiving advance care planning training currently (Teeswide project)

Response to Specific Questions Submitted in Advance

1. **In the view of MRCCS, to what extent are local services integrated when people are facing the end of life?**

   Four integrated teams (health and social care) within MRCCS provide generalist palliative care to patients in the last year of life, two locality teams in Middlesbrough and two in Redcar and Cleveland.

   Community Nurses and Community Matrons work within the locality team and specialist palliative care services work into the team, as required for those patients with the most highly complex needs. Community Nurses, Community Matrons and Macmillan Clinical Nurse Specialists (CNS) attend Gold Standard Framework meetings in general practice along with General Practitioners (GP's). The aim is to discuss all patients in the last year of life. Each patient is allocated a case manager (key worker) this is usually the community nurse who will provide supportive care to patients on a regular basis.

The provision of palliative care by Community Nurses tends to fall into three distinct areas:

1. Psychological support visits where holistic assessments & care plans are formulated and implemented. These support visits enable the community nursing staff to build and develop relationships with patients and families, this rapport and engagement supports Community Nurses in the management of people and their carers at home in the last year of life.

2. The hands on clinical interventions required in palliative care e.g. care in the last few weeks / days of life, syringe pump management, wound care & catheter care.

3. Community nurses visit the carer in bereavement to provide support. However support for carers could be developed further through the provision of signposting to other bereavement services

The Community Matrons provide care management for patients with complex non cancer diagnoses. This includes preparation and planning for end of life care on an individualised basis. The Community Matrons work closely with all services to co-ordinate appropriate care delivery whilst providing direct clinical care for patients within the last year of life. This care extends into bereavement support for the carer.
The Multidisciplinary Specialist Palliative Care Team provides holistic assessment, advice and care to patients and carers with the most highly complex needs. The team offers support to carers into bereavement and referral onto specialist bereavement services as required. The team also provides advice and support to generalist providers to enable them to manage the patients care, including the provision of education.

Locality teams can access the Marie Curie Service which provides sitting / support to patients to enable the carer to have some rest from caring. This service is provided across MRCCS, however in Redcar and Cleveland there is also the Palliative Care at Home Service. Both services are vital to ensuring patients are cared for in their preferred place of care and in supporting their carers. They provide different levels of service and have different grades of staff available for sitting / support visits. The Community Nursing Service provides all of the nursing interventions for patients receiving the service. The proposed vision for the support sitting service is to have one service across Middlesbrough, Redcar and Cleveland and an options appraisal is currently being undertaken. The aim is to offer the same standard of care to patients but with clear and strong links to the Community Nursing Service, for example referral pathways, training and development, line management and clinical leadership.

Is there an End of Life Care Pathway?

There needs to be a distinction between 'the end of life pathway' (people in the last year of life) and 'the care pathway for the last days of life'. Locally the end of life pathway has been the provision of care in the last days of life, however nationally the end of life pathway more recently refers to the last year of life. For this reason the current end of life care pathway will be referred to as the 'care pathway for the last days of life'. This is currently being implemented across all care settings within MRCCS. An ongoing audit which examines the use of the pathway for all expected deaths is being implemented; this has identified that although it is being successfully implemented, education needs to focus on promoting a greater uptake of its use in non cancer patients. The pathway for the last days of life has been identified as a commissioning for quality and innovation (CQUIN scheme 2010-11) for MRCCS.

Currently MRCCS is working with other care provider services at Teesside Hospice, JCUH and Nursing Homes to adapt the current care pathway for the last days of life so that the pathway follows the patient. JCUH use this pathway for the rapid discharge of patients from the acute to their place of care.

We are currently developing a pathway for the last year of life which will highlight what can be expected at every stage in the patient / carer journey. Professionals will easily be able to identify what services they should be providing. The pathway for the last year of life will be clearly disseminated and roles defined so that MRCCS staff are aware of the care provision they need to provide. Although many patients receive the care they require in the last year of life there are currently inequalities in the provision of care and support especially for non cancer patients. The Specialist Palliative Care Team work closely with the Community Matrons to address this issue by examples of good practice and the delivery of education to their 'generalist colleagues' in all care settings throughout Middlesbrough, Redcar and Cleveland.

2. What are MRCCS views on the role played by Nursing Homes in people's experience of End of Life Care?

There has for sometime been inequality of care provision for patients / residents of Nursing Homes as the skills of staff have been different than those in other care settings. In order to address this issue a Macmillan Clinical Nurse Specialist role for care homes has been developed; the post holder has clinical responsibility for patients with highly complex needs within nursing homes. The post holder also has responsibility for facilitating the implementation of the Gold Standards Framework in nursing / care homes in Middlesbrough, Redcar and Cleveland. The aim is that every nursing home throughout Middlesbrough, Redcar and Cleveland will be part of the programme. This aims to improve care to patients / residents in this setting by empowering staff and encouraging the development of closer and more effective working relationships between private and public providers of care. Staff will plan their patients' care along the pathway and anticipate their patients' needs in advance, rather than waiting for a crisis to occur and the patient being admitted inappropriately at the end of life.

A new education programme has also been developed between MRCCS Specialist Palliative Care Team and Teesside University to improve the standard of care provided to patients / residents. Implementation of advance care planning (ACP) and the care pathway for the last days of life will prevent inappropriate admissions to hospital and facilitate the patient being cared for in their preferred place of care. The first cohort of students achieved a 100% pass rate with the support of the post holder and the Specialist Palliative Care Team.

A nursing / care home focus group has been set up by the Specialist Palliative Care Team to support staff in their provision of end of life care. The Specialist Palliative Care Team have set up a website working in partnership with North Tees and Hartlepool teams to support the educational needs of staff, with links to all appropriate end of life information and support required for the delivery of care.

Community Nursing has been supporting patients in nursing / care homes who require a syringe pump over the past two years. The PCT have funded syringe pumps and training for nursing home staff to enable them to manage their own patients care. Community Nursing will continue to support nursing staff over the coming year until nursing home staff feel competent in the delivery of care. Community Nursing will continue to manage syringe pumps in EMI and Learning Disability Nursing Homes.

3. The panel has already heard that too many people die in hospital unnecessarily, which is expensive and usually not people's preferred place to die. What can MRCCS do about this? What is it doing about this?

Currently there is lack of clarity about a patient's choice of preferred place of death. MRCCS staff are currently undertaking advance care planning training using the preferred priorities of care tool (www.endoflifecareforadults.nhs.uk accessed August 2010). Currently, patients are not consistently asked if they wish to record their wishes. MRCCS is involved in the implementation of Advance Care Planning training and in a quarterly audit which examines the offering of a plan to patients in the last year of life (CQUIN scheme 2010-11). Advance Care Planning is currently in the early stages of implementation within MRCCS, with Specialist Palliative Care Team and Community Matrons leading the way and supporting generalist services.

The aim is that within the Gold Standard Framework meeting the multidisciplinary team discuss the patients preferred option for end of life care, which means all professionals involved in the patients care are then made aware of their choices. Discussions at Gold Standard Framework meetings help to support the patient within their own home and aims to facilitate the patients preferred place of care within either, the patient's home, the hospice, nursing home or primary care hospital. The aim is to prevent inappropriate admission to the acute sector by redirecting those who choose to die in hospital to a primary care hospital bed. GSF focuses on future planning for both the patient and carer, good symptom control, communication with the out of hour's medical and nursing services, so that prognosis and place of care is adequately communicated. Input from

the key worker / care manager is essential for the success of GSF. Currently not all staff have the knowledge or skills to provide appropriate end of life care examples of this are: staff fears of addressing sensitive issues / conversations and their ability to recognise the dying patient. Improvement in this area of practice can be addressed by making end of life care training mandatory. MRCCS have a measure (CQUIN, 2010-11) for a community nursing key worker to hold the same patients on their caseload as the GP has on their GSF register.

Allied health and social care professionals are also important as they provide support and equipment / adaptations which help to maintain the patient at home through the provision of holistic care and support to daily living.

MRCCS are currently reviewing the support services available in order to sustain the patient and carer at home.

Patients' are often admitted in the last week / days of life because of patient or carer fear or fatigue due to increasing health and social care problems. It is therefore vital that the patient and carer have developed a therapeutic relationship with their key worker / case manager over the past year, so that they know the patient and carer well, and they are then able to provide the increasing support and care that is needed, tailored to the individual's preferences. This requires anticipatory planning from the key worker / case manager and any other professionals involved in the patients care. There are examples of excellent care being delivered, but further work is required to develop the competencies and skills in palliative care.

The Macmillan CNS (Care homes) is supporting care homes in addressing advance care plans to prevent inappropriate admission to the acute sector; this is part of the programme for implementing GSF and also addressed in the educational module. The post holder is working with North Tees and Hartlepool and JCUH discharge team in the development of an information pack. The plan is that when a patient is admitted to JCUH for active treatment the pack will inform staff of the patients' individual needs, the tool will be standardised and easily recognisable by acute hospital staff. The tool will also act as a communication tool with Nursing Homes on discharge. Nursing Homes who have completed GSF are ideally placed to provide an alternative to hospital admission for those who require further support.

4. According to research done for the 'A Good Death' around 60% of people want to die at home, whereas around 21 % do. In the view of MRCCS is there sufficient capacity in Community Services to allow more people their wish to die at home?

Locality teams may find it a challenge to cope with increasing numbers of patients being cared for in their own home or a primary care hospital setting as this group of patients require on going support, symptom management, advance care planning, anticipation of future needs and provision of care throughout their last year of life. MRCCS is currently working hard to provide care in the last year of life for patients and their carers. The implementation of GSF, advance care planning and the end of life care pathway is

providing a challenge to staffing resources. As more people choose to die in their own home / community hospital there needs to be a re direction of funding following the patient, from acute to community.

The general public are not always aware of the services that are available to them as they approach the end of life and this needs to be openly communicated. There needs to be more open discussions about end of life care so that patients can make plans for the future and informed decisions about their care. Carers require more support networks to support them in caring for those dying at home.
We need to improve pharmacy dispensing support and availability of drugs when needed on a 24 hour basis. Access to equipment needs to be timely to enable patients to be kept at home. There needs to be more access to carers support and sitting services, in particular overnight care. This ideally would be provided by social care providers. Also improved access to continuing healthcare funding via the fast track route, this potentially would minimise the risk of a crisis occurring and avoidable admissions to the acute sector.

5. Does MRCCS feel that services for EOLC are sufficiently '24 hour' to meet local need?

Patients / carers are given contact details so that they can contact the community nursing service as required on a 24 hour basis. Community Nursing are currently able to respond to patients well within the agreed referral criteria of 4 hours – in most cases this can be within 1-2 hours. However, there are challenges in responding to patients across Middlesbrough Redcar/ Cleveland especially for the out of hours CNS service, and this is due to the geography e.g. travel to the far areas of East Cleveland can take up to 1 hour from the Middlesbrough base, and this does not take into account adverse weather conditions which again delay response times. MRCCS have a CQUIN measure to have 'face to face' contact with patients in the last year of life within 1 hour at request.

The out of hours nursing service / Marie Curie provision is currently under review within MRCCS. MRCCS is committed to the provision of 24 hour care to patients at the end of life but want the provision to be better co-ordinated and standardised. Out of hours medical providers need to work more closely with the out of hour's community nursing services and primary care hospitals in order to facilitate the patients preferred place of care / death.

Out of Hours Specialist Palliative Care provision is currently provided by Teesside Hospice on a 'good will' basis however this should be adequately funded especially if the numbers of patients are to increase. Out of Hours Palliative Medicine Consultant cover is provided (Teeswide) on a telephone advice basis. There is no face to face provision for Specialist Palliative Care 7 days / week; however the provision of community nursing is a priority in order to provide continuity and support for patients.

6. **Is MRCCS satisfied that frontline staff are sufficiently trained to deal with the issues connected to EOLC? Connected to the questions above, does MRCCS feel it is appropriately commissioned to provide effective community services to deliver high quality EOLC, reflective of local need?**

   Education provision in EOLC is available and has been accessed by some staff within MRCCS. Training is provided in house by the Specialist Palliative Care Team within MRCCS and in partnership with Teesside University and can be accessed locally within the community. MRCCS currently does not have the appropriate IT software to provide access to national on line end of life training; however this is being addressed later this year. The Specialist Palliative Care Team has an educational plan with locally available education and is targeting key staff (new staff at induction and key workers / care managers). Education is provided by the team at an open forum session and can also be tailored to individual teams at request.

   Although there are examples of excellent care there are also gaps identified. More work needs to be done to support staff to understand their role in the provision of appropriate care and at least have a general understanding of palliative care and bereavement support. In order to implement advance care planning there are training needs for staff in communication skills so that they can manage difficult conversations appropriately.

   As the numbers of patients being cared for at home there is need for further investment in the provision of community nursing services to cope with the increasing numbers of patients being cared for at home.

7. **Where does EOLC in Middlesbrough need to develop? What is good about EOLC in Middlesbrough now? Does MRCCS feel that EOLC is of an equal standard irrespective of what terminal condition someone has, or are there differences in the patient experience depending upon the condition the patient has?**

   MRCCS needs to have sufficient skilled and competent staff to provide good end of life care (not dependant upon diagnosis). Training in EOLC should be considered as mandatory. Community Matrons and the Specialist Palliative Care Team provide care to patients / carers at the end of life irrespective of diagnosis, however some inequalities in the provision of care remains e.g. patients with Dementia, COPD, Heart Failure, elderly frail especially the support provided via GSF and the Community Nursing Service. Historically palliative care services have focused on cancer patients, in more recent years the experience we have gained has been transferred to focus on all patients in the last year of life irrespective of diagnosis. MRCCS are working toward inclusion of all patients at the end of life receiving equity of care provision i.e. inclusion in GSF, providing regular support, appointment of a key worker / case manager, advance care

planning, end of life care pathway, preventing avoidable admission at the end of life.

8. **In addition to the themes outlined above, if there are any other issues you would like to raise, please feel free to do so within the paper.**

    a. MRCCS are currently working to develop an end of life / bereavement policy
    b. MRCCS are also developing a strategy for EOLC
    c. Questioning the redirection of funding from acute to community
    d. EOLC training to become mandatory for all health and social care professionals, so that staff are skilled and equipped to provide excellent tailored care close to home