

HEALTH SCRUTINY PANEL

A meeting of the Health Scrutiny Panel was held on 16 September 2010.

PRESENT: Councillor Junier (Vice-Chair) (In the Chair), Councillors Carter, Davison, Purvis and P Rogers.

OFFICERS: J Bennington and J Ord.

**** PRESENT BY INVITATION:** Graham Leggatt-Chidgey, Chief Executive, Butterwick Hospice

Maureen Thompson, Chief Executive, Teesside Hospice Care Foundation

Middlesbrough and Redcar & Cleveland Community Services:

Allana Massingham, Assistant Director,
Fiona Perry, Clinical Leader,
Janet Breckon, Locality Manager

South Tees Hospitals NHS Foundation Trust
Dr Alex Nicholson, Consultant in Palliative Medicine,
Elizabeth Price, Clinical Matron in End of Life Care.

****APOLOGIES FOR ABSENCE** were submitted on behalf of the Chair, Councillor Dryden and Councillors Cole and Lancaster.

**** DECLARATIONS OF INTEREST**

No declarations of interest were made at this point of the meeting.

END OF LIFE CARE – EVIDENCE

The Scrutiny Support Officer submitted a report the purpose of which was to introduce representation from South Tees Hospitals NHS Foundation Trust, Middlesbrough and Redcar & Cleveland Community Services, Teesside Hospice Care Foundation and Butterwick Hospice.

As part of the background information details were provided of each of the organisations all of which had a key role to play in the provision of End of Life Care (EOLC). A copy of the written responses to a series of questions submitted in advance of the meeting received from each of the organisations had also previously been circulated.

Following introductions the Chair welcomed all representatives who gave a brief summary of the key information and points raised in the respective written submissions and participated in the subsequent deliberations.

The briefing paper from the South Tees Hospitals NHS Foundation Trust summarised the context in which EOLC featured in health provision and identified the main themes being addressed by the Trust. The current focus on EOLC by the Trust was in relation to five domains under strategic issues, service development, education, governance and patient/carer involvement as outlined in the report submitted.

It was noted that in the last six years EOLC had achieved a higher profile than at any time previously in the 62 years history of the NHS. The report outlined various Government direction and policy guidance on the EOLC provision across all healthcare settings.

Specific reference was made to the Trust's Service Development in particular the appointment of a Matron for EOLC and Bereavement; implementation of the EOLC pathway on every adult ward in the Trust; a rapid discharge of the patient's preferred place of care for the last days of life;

development of an EOLC pathway specifically for use on the Intensive Care Unit; and the refurbishment of a ward with an architect designed quiet area specifically for the care of patients; It was also noted that EOLC was included in all induction events for new medical staff and in junior medical training programmes and a module on EOLC had been specifically developed by Teesside University for ward nurses at STHFT.

In relation to patient/carer involvement information leaflets had been produced which all wards could provide to support patients/carers with information and examples of best practice had been shared around the Trust such as bereavement support consultations.

In answer to a question about the number of people who died in an acute hospital setting unnecessarily the Panel was advised that whilst the Trust had concurred with this view the reasons were highly complex as outlined in the report. Reference was made to a number of ways to improve the situation such as supporting clinicians to consider a mechanism whereby primary care clinicians were made aware that future care planning needed to commence. There needed to be a change of culture and for such considerations to become commonplace. Not only action by clinicians and training for them to communicate the issues well and empathetically and to be able to negotiate future care plan discussions but also a societal change to consider it was not meant to be morbid but helpful. Work was progressing in this regard and included: -

- development of more community care both professional and lay, possibly even volunteers;
- protect and probably increase community hospital bed provision as an alternative to acute hospital when 24 hour care was unavoidable;
- develop 'super' care homes with high calibre staff rewarded with a higher tariff to provide an option for admission from home in a crisis rather than acute hospital;
- support the Gold Standard Framework;
- support out of hours doctors by greater use of care plans and clear information about escalation of care decision for frail and 'nearing end of life' patients so they have the confidence to arrange symptom relief but not admission when this is the right thing to do;
- provide resources for access to 'out of hours' palliative care professionals at the very least with properly funded advice lines and probably with the potential for a visit to advise on care at weekends/bank holidays.

In response to a question about what role an Acute Trust should play in the provision of EOLC the following key areas were identified: -

- high quality care;
- rapid assessment and symptom review of patients found admitted who might have been kept at home with speedy review of social and health care packages (integrating with community health and social care professionals) and repatriation to home;
- expert advice from secondary clinicians to primary clinicians on those patients who may be approaching end of life as far as it was possible to determine in order to facilitate commencement of future care planning.

In terms of how Middlesbrough as a health and social care system dealt with those at the end of life and their care, it was indicated that whilst there was much good and excellent care and outstanding developments and initiatives for future provision it was considered to be patchy and needed further work to increase the skills of all concerned. It was also felt that there was a need to improve the support services in community to prevent unnecessary admissions.

In response to clarification sought on the extent of training undertaken the Panel was advised that there was considered to be significant training available although owing to multiple competing demands it could be difficult for managers of clinical teams to release staff for training whilst prioritising clinical service provision in the face of real financial constraints.

In relation to the extent of providing 24 hour EOLC it was reported that whilst there were good services available, including 24 hour district nursing and the palliative care out of hours nursing service, the specialist palliative care team provision in the acute (and community) settings was still office hours orientated which needed to change with attendant resource implications.

The Panel was advised that there was still some work to undertake as previously indicated around ensuring that patients who were approaching EOLC and their carers were engaged early enough where clinically possible to allow people to exercise choice over their EOLC to discuss future care plans.

From a Trust perspective the main issues identified were to implement the EOLC strategy fully and to be highly collaborative in the provision of EOLC to ensure that patients' priorities were realised with the support of a skilled and attentive workforce. Across the health and social economy the greatest opportunity for the future rested in an even greater education and research agenda building on the existing excellent School of Health and Social Care at Teesside University.

Members sought clarification in terms of patient/carers involvement within EOLC guidelines, which took into account feedback comments from family and carers.

The Panel focussed on previous discussions around the difficult issue of a significant number of inappropriate admissions to an acute hospital setting of a patient who could have been cared for in an alternative and appropriate environment. Members sought clarification on the procedures involved in determining at what stage does such a process start. In response, Dr Alex Nicholson indicated that it was very much a training and confidence issue in particular from care homes, out of hours and doctors being unfamiliar with patients and fearing litigation from appearing neglectful by not admitting a patient to hospital. It was recognised that it was an evolving system and reference was made to a number of areas as highlighted in the report submitted. One such area included the support to clinicians to consider the 'surprise question' – 'Would I be surprised if this patient died in the next 6 – 12 months?' as advocated by the NHS North East End of Life Group and endorsed in the STHFT End of Life Strategy and thereby give an indication to primary care clinicians that future care planning needed to commence. Reference was also made to the need to support the GSF for care homes programme so they were empowered to keep residents in care homes and not admit them when they deteriorate but stand to gain nothing from acute admission. Reference was made to the need to support out of hours doctors by greater use of care plans and clearer information about escalation of care decisions for 'nearing end of life' patients so they have confidence to arrange symptom relief but not admissions when appropriate.

A briefing paper submitted from Middlesbrough, Redcar and Cleveland Community Services (MRCCS) summarised and provided an overview of the themes being addressed by MRCCS.

The End of Life Care Strategy (2008) focussed on the identification of quality markers and measures for EOLC upon which MRCCS was focusing with the aim to improve EOLC for the local population as outlined in the report.

The Panel was advised of the Service Developments, which included:

- 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;
- 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;
- development of a Macmillan CNS (Care Homes) role to support colleagues provision of EOLC 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 2010-1;
- currently working on the development of the care pathway for the last days of life, which would 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 could be shared with other professionals which outlined considerations and options as an alternative to a secondary care admission which could include rapid response service, emergency respite, and Primary Care Hospital beds;
- 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 had been adopted Teeswide;
- development of community nursing core care plans for palliative care;
- successful implementation of new syringe pumps for symptom control and the delivery 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.

The report also outlined developments on terms of education and training.

In response to a question regarding the extent to which local services were integrated for EOLC it was stated that there were four integrated teams (health and social care) within MRCCS which provided 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 worked within the locality team and specialist palliative care services worked into the team, as required for those patients with the most highly complex needs. Community Nurses, Community Matrons and Macmillan Clinical Nurse Specialists (CNS) attended GSF meetings in general practice along with GP's.

The Community Matrons provided care management for patients with complex non-cancer diagnosis, which included preparation and planning for EOLC on an individualised basis. The Community Matrons worked closely with all services to co-ordinate appropriate care delivery whilst providing direct clinical care for patients within the last year of life. Such care extended into bereavement support for the carer.

The Multidisciplinary Specialist Palliative Care Team provided holistic assessment, advice and care to patients and carers with the most highly complex needs. Locality Teams could access the Marie Curie Service, which provided sitting/support to patients to enable the carer to have some rest from caring.

It was pointed out that there needed 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'. MRCCS was currently 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 followed the patient. JCUH used such a pathway for the rapid discharge of patients from the acute to their place of care. MRCCS was currently developing a pathway for the last year of life, which would highlight what could be expected at every stage in the patient/carer journey.

In response to a question regarding Nursing Homes in people's experience of EOLC, it was indicated that there had for some time been inequality of care provision for patients/residents of Nursing Homes as the skills had been different than those in other care settings. In order to address such an issue a Macmillan Clinical Nurse Specialist role for care homes had been developed. Reference was also made to a new education programme, which had been developed, between MRCCS Specialist Palliative Care Team and Teesside University to improve the standard of care provided to patients/residents. A nursing /care home focus group had been set up by the Specialist Palliative Care team to support staff in their provision of EOLC. Community Nursing had been supporting patients in nursing/care homes who required a syringe pump over the past two years. The PCT had funded syringe pumps and training for nursing home staff to enable them to manage their own patients care.

From the perspective of MRCCS it was considered that there was currently a lack of clarity about a patient's choice of preferred place of death. MRCCS was involved in the implementation of

Advance Care Planning training and in a quarterly audit which examined the offering of a plan to patients in the last year of life. The GSF focussed on future planning for both the patient and carer, good symptom control, communication with out of hours medical and nursing services, so that prognosis and place of care was adequately communicated. MRCCS was also currently reviewing the support services available in order to sustain the patient and carer at home. The Macmillan CNS (Care Homes) was supporting care homes in addressing advance care plans to prevent inappropriate admission to the acute sector which was part of the programme for implementing GSF and also addressed in the educational module. When a patient was admitted to JCUH for active treatment a pack would be issued to inform staff of the patient's individual needs.

In terms of the capacity of Community Services, MRCCS had indicated that 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 such a group required ongoing support, symptom management, advance care planning, anticipation of future needs and provision of care throughout their last year of life. MRCCS was currently working hard to provide care in the last year of life for patients and their carers but it was noted that the implementation of GSF, advance care planning and the EOLC pathway was providing a challenge to staffing resources. As more people chose to die in their own home/community hospital there needed to be a re-direction of funding following the patient from acute to a community setting. It was also considered that there needed to be more open discussions about EOLC so that patients could make plans for the future and informed decisions about their care. Other issues included the need to improve pharmacy dispensing support and availability of drugs when needed on a 24 hour basis; access to equipment needed to be timely to assist patients to be kept at home; and more access to carer support and sitting services in a particular overnight care.

In relation to coping with demands for a 24 hour service it was indicated that Community Nursing was currently able to respond to patients well within the agreed referral criteria but there were challenges in responding to patients across Middlesbrough Redcar/Cleveland especially for the out of hours CNS service because of the distance to travel especially in adverse weather conditions. Such services were under review as MRCCS was committed to the provision of 24-hour care to patients at the end of life but wanted the provision to be better co-ordinated and standardised.

In terms of training of frontline staff it was indicated that although there were examples of excellent care it was felt that gaps had been identified. It was considered that more work needed to be undertaken 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 were training needs for staff in communication skills. It was considered that there was a need for further investment in the provision of community nursing services to cope with the increasing numbers of patients being cared for at home.

In considering future developments reference was made to the Community Matron and the Specialist Palliative Care Team which provided care to patients/carers at the end of life irrespective of diagnosis. It was pointed out, however that there were some inequalities in the provision of care, for example, patients with dementia, COPD, heart failure, elderly frail especially the support provided by means of GSF and the Community Nursing Service. MRCCS was working hard towards inclusion of all patients at end of life receiving equity of care provision.

Members discussed some of the issues around advance care planning and inappropriate admissions of patients from care homes into acute settings. In response, details were provided of the development of the role of a Macmillan Clinical Nurse Specialist for care homes. The specialist nurse had a clinical responsibility for patients with highly complex needs and was also responsible for facilitating the implementation of the GSF in nursing/care homes in Middlesbrough and Redcar and Cleveland. The aim of such a programme was to improve care to patients/residents by empowering staff and encouraging the development of closer and more effective working relationships between private and public providers of care. It was intended that staff planned 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 to hospital inappropriately at the end of life. Although not often it was pointed out that in some cases a patient and/or family/carer may change their mind with regard to a preferred place for end of life.

In discussing the provision of 24 hour care to patients at the end of life it was recognised that there needed to be better co-ordination and standardisation. It was reiterated that out of hours medical providers needed to work more closely with the out of hours community nursing services and primary care hospitals in order to facilitate the patients preferred place of care/death. In commenting on the out of hours provision it was considered that there was scope to improve the information and access to such information on the Palliative Care Register.

The importance of the education programme was stressed which included the Specialist Palliative Care Team working in partnership with Teesside University in the development of a new module aimed at care home staff; working with GPs; delivery of GSF sessions; informal education on a daily basis with GPs, MRCCS staff and nursing/care home staff; and MRCCS staff receiving advance care planning training.

In the briefing paper provided by the Butterwick Hospice Care, a registered Charity, it was stated that it had provided a wide range of end of life care to the population of Teesside for over 26 years. Its mission was to freely deliver end of life and palliative care, of the highest standards, to patients and their families, regardless of diagnosis, in whatever setting was appropriate and desired by a patient.

The briefing paper outlined the services provided and gave an indication of the expansion over the last fifteen years which now comprised the Butterwick Adult Hospice and Butterwick House Children's Hospice at North Tees Hospitals and the Butterwick Hospice at Bishop Auckland. Last year the Charity had delivered care to over 2,300 patients across all sites providing a comprehensive range of holistic support services for patients and their families.

The Charity made no charge for any of its services which were financed by a combination of charitable income (fundraising), trading (charity shops and two weekly lotteries), grant and commissioned income from the local NHS (PCTs) and directly from the Department of Health. The Charity expended some £3.8 million a year of which £1.3 million was funded from statutory sources. The Panel was advised that as approximately 90% of all patients care costs in respect of the adult services in Stockton were clinical salaries, the short term statutory funding essentially inhibited service development. All of the funding streams from the NHS remained at the 2009/2010 levels as a consequence of the public sector budget constraints which had resulted in the Charity needing to finance £60,000 of inflation costs from increased charitable income.

Butterwick Hospice Care provided its services on the criteria of need not diagnosis. In Stockton over 95% of all adult patients had a cancer diagnosis. It was noted, however, that this percentage was slowly decreasing with particular progress being made with patients referred to the Out of Hours Service.

For the last five years the Panel was advised that the Hospice had provided a highly successful Out of Hours Service for adults in Stockton. The service operated between 8.00 p.m. and 8.00 a.m. 365 days a year and was staffed by a small experienced team of Registered Nurses supported by Health Care Assistants.

The key objective of the service was to allow patients to be well managed symptomatically overnight in their own homes as their illness progresses; to facilitate patients remaining in their preferred place of care and in doing so to reduce avoidable hospital admissions. Typically the Service had a caseload of 150 plus patients at any one time and last year over 80% of patients had been supported in achieving their preferred place of care be that at home, residential care home, nursing home or hospice.

As Butterwick Hospice\Care delivered care on a sub-regional basis the Charity worked with a number of PCTs. The report outlined how service development and planning had evolved in recent years particularly in the Tees area and across County Durham. It was considered that in relation to Teesside there was scope for developing a more robust end of life strategy and increased consultation between the local Hospices and the PCTs.

Taking into account the population demographics and increased patient expectations it was considered that the demand for services such as the hospices would continue to increase. It was

also felt that the ageing population coupled with ongoing healthcare improvements would equally increase the complexity of the care which patients referred to the hospices would need.

The report concluded that the desire to improve end of life care in line with national and local strategies would inevitably face major challenges particularly at a time of economic constraint. The development of transparent partnerships and meaningful consultation and co-operation between statutory, voluntary and possibly the private sector was vital to achieving the required progress on end of life care.

In a briefing paper provided by the Teesside Hospice Care Foundation formed in 1982 it was stated that the primary aim of the organisation was to act as a resources to the local community to provide holistic specialist palliative care at any point during a life-limiting illness.

The ten bedded Inpatient Unit provided specialist palliative care to patients for Control Symptoms, Respite Care, End Stage Care and to Rehabilitate. The Edward & Glenis Guy Day Centre offered professional advice and rehabilitation from a multidisciplinary team. The Bereavement Counselling Services provided support to both adults and children and enabled people to work through their grief and accept what had happened helping them move forward in their lives.

In its mission statement it stated that ' Teesside Hospice Care Foundation exists to enhance the quality of life for those suffering from a life-limiting illness. It offers specialist palliative care and support to patients and carers, in the belief that each person is entitled to dignity and choice within the best provision of care.'

Teesside Hospice worked closely with local Acute Hospital Trusts, Primary Care Trusts, Macmillan Nurses, Community Nursing teams and GPs to deliver specialist palliative care services and expertise to patients, families and carers. A skilled multidisciplinary team offered patients holistic care, ensuring that their physical, emotional, social and spiritual needs were cared for.

It was considered crucial to develop an understanding about the term 'end of life care' and to relate such meaning of the established definitions of supportive and palliative care in order to define the client group or their end of life care needs in a way which was complementary to existing well-established definitions. The commencement of such a phase was variable according to a number of factors including the specific conditions, perspective of individual patients and according to clinical/prognostic judgement. Reference was made to the GSF Team, which had recently produced a set of prognostic indicators, which may assist in making decisions about when 'end of life' begins. Such indicators included the Surprise Question, Patient Choice/Need and clinical indicators.

Teesside Hospice helped over 3,000 people every year from Tees Valley and Yorkshire. Running costs were in excess of £2.1 million per year and local PCTs contributed to around a third of such costs, which equated to £635,592. The Hospice had to raise approximately £4,100 per day by means of its Trading Company running charity shops, a weekly subscription lottery and fundraising department. Whilst in previous years the Hospice had benefited from a three year contract in 2010/2011 the PCT commitment was for one year which included a review of hospice services.

It was indicated that the provision of end of life care across the Tees was variable in terms of resources and quality. There appeared to be confusion regarding the clarity of role and function in terms of District/Community Nurse role, Clinical Matrons and Specialist Palliative Care Nurses in relation to delivering palliative and end of life care. It was felt that a more consistent integrated delivery of health and social care could be provided across Teesside.

Reference was made to data from surveys undertaken some years ago, which indicated that substantially more people would prefer to die at home or in a hospice than actually did. It was considered therefore that patient choice was a challenge and in palliative care it was felt that this needed clarifying for patients, carers and professionals.

It was indicated that much end of life care was delivered by families and carers and that there were insufficient resources to provide 24 hour care at home even with the most comprehensive

care packages. The Out of Hours Palliative Care Service was provided for patients in Redcar and Cleveland PCT areas but not in the Middlesbrough PCT area.

Access to specialist palliative care telephone advice out of hours for patients, carers and professionals was currently provided by Teesside Hospice's nurses and doctors and through them occasionally to the Consultants in palliative medicine on call for the Tees locality. It was confirmed that such a service was not funded by the NHS despite requests by NHS Commissioners for business cases to be prepared to support further development and raising awareness of such advice of the benefit of the population.

Teesside Hospice provided the specialist palliative care service for the locality with patients being transferred from the acute hospital palliative care service for complex symptom management and end of life care. In view of this there had been a rising trend over the last five years of an increasing proportion of patients cared for at Teesside Hospice with complex needs which had increased the pressure on other end of life care and respite care given the maximum availability of 10 inpatient beds and ultimate potential of increased admissions in acute settings.

Confirmation was provided that Teesside Hospice cared for any patient requiring specialist palliative care at any stage of a life-limiting illness and the referral criterion did not discriminate against any condition. From ensuing discussion it was recognised that certain conditions were more difficult to identify a trigger point for assessment of end of life care.

Along with the discussions about a 'good death' and end of life care Teesside Hospice believed that some of the myths about hospices and palliative care should be challenged. It was considered that there was scope for the Specialist Palliative Care workforce to provide the required network across local health communities outside of the traditional organisational boundaries. An out of hours palliative care service for Middlesbrough needed to be commissioned in the form of a dedicated home care service and a robust and funded telephone advice service.

AGREED that all representatives be thanked for the information provided which would be incorporated into the overall review.