Health Scrutiny and Performance Panel

DATE: 24th July 2012

End of Life Care Strategy and Pathway development within Walsall

Portfolios: Cllr B. McCracken – Social Care and Health

Report:

This is the second in a series of reports to the Scrutiny and Performance Panel in relation to the overall plan and strategy to improve Palliative and End of Life Care for all Patients and Carers within the Borough of Walsall.

The Report focuses on two key areas:

1. Building on the earlier work around the Liverpool Care Pathway the Panel wish to consider wider issues around death and dying in Walsall.

1. What are the broader plans and strategies around death and dying across the piece? i.e. hospital, community, care home etc.

Recommendations:

That the Panel please note and debate the content.

Contact Officer:

Sue Crabtree – Head of Pallitive and End of Life Care
☏. 01922 602608
✉ sue.crabtree@walsallhealthcare.nhs.uk

Introduction

Background

How we care for the dying is an indicator of how we care for our sick and vulnerable people and is also a litmus test of how well health, social care and other partners work together.

The third national annual report on the End of Life Care Strategy reports that "there is still a large gap between where people say they would prefer to die and where they actually die." Recognition also exists of the national and local challenges in systematically tracking the stated preferences for end of life care and the actual experiences of individual patients and their families.
National End of Life Intelligence Network (2007-2009 data) reveals that Walsall has above the national and regional averages for the proportion of deaths taking place in hospital (regional 58.3%, Walsall comparison 64.2%).

Walsall Healthcare's Vision and Approach to End of Life Care
Vision

The Trust's vision and approach mirrors the national strategy for End of Life Care in aiming to transform care for people approaching end of life, whatever their diagnosis and wherever they are, including enabling more people to be cared for and to die at home should this be their wish. In achieving this vision, our aim is to treat people with the utmost dignity, care and compassion whilst respecting their wishes and in supporting carers.
We acknowledge however that our local approach needs to be underpinned by a cultural shift in attitude towards discussion of death and dying and in encouraging people to feel more comfortable with expressing their wishes and preferences for care at the end of their lives. A priority in moving forward therefore acknowledges and incorporates a large programme of staff education and workforce competency in embedding our Philosophy and standards of high quality, consistent Palliative and End of Life Care across generalist as well as Intermediate and Specialist staff.

Governance Arrangements

Effective partnership working is a fundamental and core component of ensuring that end of life care and treatment, along our care pathway, can be aligned and co-ordinated around the needs of patients and carers. In reflecting this, Walsall Healthcare Trust has established an appropriately constituted steering committee led by an Executive Director. The End of Life Steering Committee reports to the Risk, Assurance and Quality Committee and ultimately to the Trust Board.

End of Life Care has been identified as one of the priorities for the organisation this year and additionally incorporated within both our cluster and local QIPP plans. The increasing focus on quality, innovation and productivity means that our ambitions and envisaged benefits of end of life care need to

2

be effectively captured, recorded and monitored through a plan to track implementation, service improvements and outcomes.

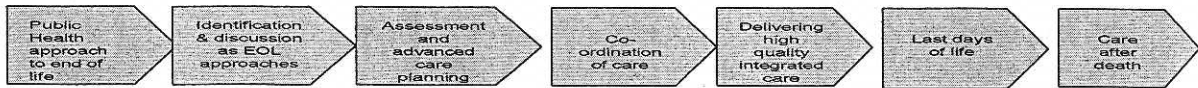**How do we aim to deliver End of Life Care?**

The integrated pathway approach is a widely accepted model in improving standardisation, continuity and collaboration amongst the multi-disciplinary teams and in "getting the basics right every time."

National evidence based tools are well developed that support and formalise standards of care into normal practice. One example of this is the Liverpool Care Pathway (LCP), this was initially developed to take the best of hospice care into other care settings such as hospital, community settings and care homes. Its application as a document supports care of individuals in the last few days of their lives; promoting good communication with the patient and their family/ carers, anticipatory prescribing, good symptom control and assesses spiritual and psychosocial needs.

The Gold Standards Framework (GSF) is a systematic approach to improve and optimise the care of patients in the final year of their life. By identifying patients in need of palliative/ supportive care in the last year of their life, by assessing their care needs and in then communicating and coordinating these care needs within the Multi disciplinary team , improves the quality of palliative care and enables more patients to die in their preferred place of care.

Our local approach to an effective end of life care pathway incorporates the following components:-

Local End of Life Care System

| Public Health approach to end of life | Identification & discussion as EOL approaches | Assessment and advanced care planning | Co-ordination of care | Delivering high quality integrated care | Last days of life | Care after death |

The Implementation Plan for Improving End of Life Care Services within Walsall

The Trust Board of Walsall Healthcare NHS Trust formally endorsed the overall approach to Palliative and End of Life Care in September 2011, and

3

subsequently the overall implementation plan in November 2011. Our approach is based upon the following principles;-

- Services should be developed that enable the numbers of patients able to die in the place of their choice "at the end of their life" to be maximised.
- Service provision incorporates and mobilises a range of specialist palliative and end of life care resource in both the hospital and the community.
- Integrated pathways are developed between hospital and community services in meeting the needs of people at the end of their lives.
- Relevant staff whether in the specialist palliative care team or not, have the competencies and tools to provide good quality end of life care for their patients.

As a result of this endorsement an ongoing action plan of priorities for delivery is maintained and progress reported regularly at all levels of Governance and assurance within the organisation. The second part of the report provides an update of progress against key areas of the End of Life Pathway.

National End of Life Care Modelling Tool

Walsall Healthcare NHS Trust expressed an interest in being an early adopter of the Yorkshire and Humber Commissioner financial modelling tool as part of the Department of Health's (DoH) National End of Life Care Programme in the autumn of 2011. Following selection by the DoH, Walsall has applied the tool as one of only 3 sites nationally.

The model provides a useful basis on which to plan and agree our 'shift of care' assumptions from hospital to Community support at home and in reducing deaths within the hospital, should this be the patient's and families wish. Local application of the tool has provided the following intelligence relating to the number of patient's, types of diagnoses and assumptions as to whether their care could be delivered outside of hospital in the over 75 age group:-

- Approximately 270 people for whom care could have been delivered out of hospital in a year.

- The highest disease prevalence includes respiratory and heart disease.

The data will be utilised to align the associated workforce implications and pathway remodelling to ensure that the 'shift of care' is achieved. Furthermore; we aim to 'rerun' the modelling tool to examine the potential impact in the under 75 year age group.

4

Implementation Plan Progress

Identification & discussion as End of Life approaches
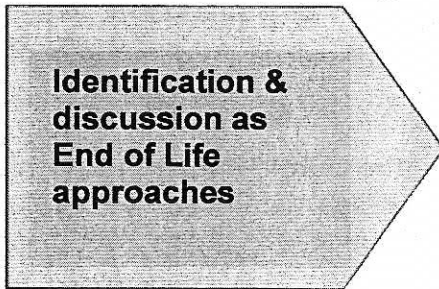
Sharing Information

Findings of both National and Regional audits relating to End of Life Care reveal that there is still a 'large gap' between where people say they would prefer to die and where they actually die. There is broad acknowledgement also that the ability to 'track' and appropriately share preferences for end of life care together with the actual experiences of patient's is an ambition rather than a reality. However; the Department of Health has recently applied to the Information Standards Board (ISB) for Health and Social Care to approve a national information standard that identifies and defines the core content of all locality, End of Life Care Registers (electronic palliative care co-ordination systems) this was released in May 2012. Walsall has already been recognised by the DoH in a post review of Transforming Community Services in demonstrating an "impressive level of I.T integration" Whilst our immediate processes have focused upon effectively sharing information through a paper based system we have now built an electronic solution ,through the utilisation of our IT System, Fusion.

Phase 1 of this development was released beginning of July and will enable a communication system across the Health Economy for the first time so that patients can be identified within the system and enable the provision of an electronic solution to the End of Life Care Register stipulated in the End of Life Care Strategy 2008. This development is crucial to progress the end of life pathway work, there are a number of additional phased developments within the next twelve months that will include an interface and information exchange with a number of other providers such as Badger, Out of Hours Care Providers, West Midland Ambulance Services and Nursing Homes across the Borough. Phase 3 works will include the ability to upload documentation onto the template to share information around patient's wishes, advanced care plans and resuscitation information.

Workforce

The education and workforce sub-group has been formed this reports directly to the End of Life Steering Group. The role of this group is to develop across boundary education programmes for all staff. Progress thus far; there is an existing programme of education for Nursing, Medical, Social and

5

Allied Health Care professional staff that has been formalised across the organisation. As from June 2012 End of Life Training may become mandatory training across the Trust next year this will further expand the learning opportunities. Work is being undertaken to begin reporting on the numbers of both trained and untrained staff with agreed level of knowledge and competence. Alongside this competencies in end of life care for all levels of health care professional have been developed for use. Dr Senthil (nominated lead Consultant) is currently leading the development an End of Life Training programme for all levels of medical staff on a rolling programme. There are also a significant number of e-learning modules available.

Assessment care planning and review
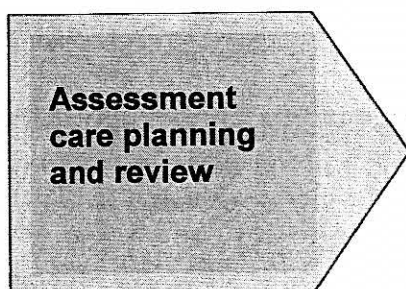
Recording of preferences for End of Life Care remains limited within Specialist Palliative Care Teams and those Primary Health Care Practices and acute wards participating in Gold Standard Framework (GSF) practice. There will be an improvement in this process with the new GSF template within the electronic Fusion system. There will be an ability to report regularly on achievement of Preferred Place of Care (PPC) from the End of Life Care Register. Data presented below are figures for the last two years of achievement of PPC for the Specialist Community Palliative Care Team.

Table 1 Demonstrating achievement of Preferred Place of Care for Specialist Community Palliative Care Team

Was Preferred Place of Care Achieved?	Yes	No	Not Known
2010-2011			
Number of Patients	244	51	121
Percentage	**58.50%**	**12.20%**	**29.00%**
2011-2012			
Number of Patients	321	61	121
Percentage	**63.80%**	**12.12%**	**24.00%**

6

As can be seen from the table above, for patients known to the Specialist Palliative Care Team for those patients where we know there preferences the achievement of PPC is high the national average is approximately 27% currently. But there remains a significant amount of patients for which we do not establish their preferences for a multitude of reasons.

Tables 2 and 3 Demonstrates Actual Place of Death for Patients known to Specialist Community Palliative Care Team

Place of Death 2010-2011				
Home	Nursing Home	Hospice	Hospital	Not Known
190	75	26	122	4
45.50%	17.90%	6.47%	29.20%	0.95%

Place of Death 2011-2012				
Home	Nursing Home	Hospice	Hospital	Not Known
211	73	90	125	4
41.90%	14.50%	14.50%	24.85%	0.79%

Firstly, it is worth noting two points although the figures remain relatively unchanged the cohort of patients for 2011-12 was larger 503 versus 417 patients in the previous year. Also, the number of Hospice deaths has risen from 6.47% in 2010-11 to 14.50% 20111-2012 which clearly demonstrates the impact of the in-patient unit within the new Walsall Palliative Care Centre

Advanced Care Planning Training has continued to be successfully rolled out. Staff from all service areas across the organisation, have attended the two day training, engagement with social care staff has been included in this process. The linked piece of work with the Strategic Health Authority and End of Life programme and has afforded the opportunity to share our learning from the process and exchange knowledge gained from all participants. Progress with training thus far is;

Since commencement of the ACP project (08/11/2011) a total of 76 staff from all sectors have attended either the 2 day programme or tailored programme (CNS & Palliative Care Business Unit Staff) and 33 staff has attended the awareness training. As part of the e-ECLA training, 23 ward champions received educational sessions on the ACP module. Awareness sessions of ACP have been carried out for GP's all clusters, Support groups ICD group; Nursing & care homes – 62 staff so far and BADGER Urgent Care Centre staff have also attended training. Release of the Borough wide Advanced Care planning Document for all Health Care professional to use with their patients is planned for August 2012.

Co-ordination of Care

High Quality Care
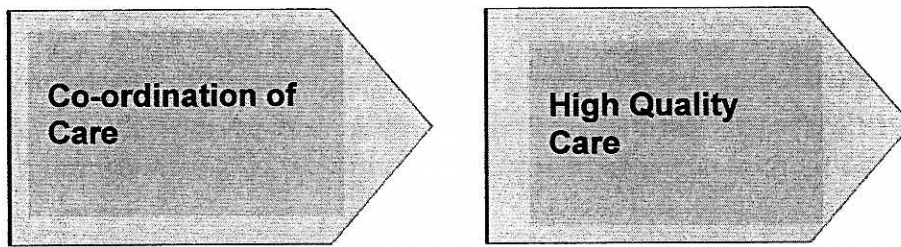
The scope of successfully transforming care for people approaching the end of their lives is both complex and multifaceted; however, progress towards implementation of our plan is moving forward. During the period of the 16th January 2012 to 20th February 2012 an internal review of Palliative & End of Life Care was conducted by the Head of Palliative &End of Life Care. It is acknowledged that some of the impetus for the review was the recent changes that have occurred within the Hospital's Standard Mortality Rate figure (HSMR) but this was not the major focus for the reviewer. To aim to review as many aspects of our organisational care for Palliative and End of Life Care patients and their families, with the aim to improve overall approach and quality of care.

Progress with key Recommendations from the Report

- Access to Specialist Hospital Palliative Care was improved from the 1st March 2012 with the Team providing seven day cover this is being reviewed regularly as part of an on-going process. The recruitment to two new Consultants in Palliative Medicine posts has progressed with the appointment of two medical members for the Team being concluded in September 2012. The two Specialist Teams have begun the process of full integration with changes in single line management as an initial step from April 1st 2012.

- Predominantly the Diversionary End of Life Beds are now being fully utilised the progressive work now is to scope our future potential need. Additionally the first pathway development with Acute Medical Unit is a direct access model for procedures to improve quality of Life for Palliative Care patients but to minimise length of stay, work began in June 2012.

- A discreet piece of work with both Respiratory and Heart Failure Teams to continue to develop and refine those integrated pathways for Palliative End of Life Care phase is ongoing.

- As a result of the organisational review it was suggested that there should be Investment and appointment to several posts within Acute Specialist Palliative Care Team and realignment of existing services into a dedicated resource. Additional resources include the extension of the Specialist Nursing Service to seven days a week and an End of Life

8

Pathway Facilitator. This Business Case has been approved and recruitment to the posts is in process.

Care in last few days of life
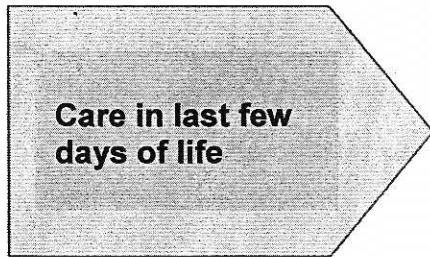
The report from the national Liverpool Care Pathway Team was received into the Trust late December 2011. For the first time acute care settings were benchmarked against organisational and clinical key performance indicators. Listed below is a brief summary of the results, Table 1 which details. This audit is a recommended national audit. Key messages from the audit are listed below:

a. The uptake of LCP was extremely low as there were 292 deaths (April to June 2011) at the time of audit but many more patients were eligible for LCP. The total percentage of deaths supported by LCP in Walsall was 9% compared to the national average of 29%.

b. Walsall only 35% patients on the LCP had a non cancer diagnosis. There have been significant improvements in this however, with the current audit showing that 58% of non cancer patients were on LCP at the time. This compares to a national average of 68% but none the less is an improvement in the use of LCP for non cancer patients.

c. A series of Key performance indicators are a new development in the audit process this year. This provides at a glance picture of relative performance on some key elements in the delivery of care to dying patients and their carers. For the most part all the indicators are green or amber, one KPI was red indicating the need for more work in this area.

For the information below in Table 4 red represents the spread of performance for the bottom 25% of hospitals, amber represents the spread of performance for the middle 50% of hospitals and green represents the spread of performance for the top 25% of hospitals. As you can elicit Walsall was only in the bottom 25% in one area which was ongoing routine assessment of patient relatives or carers. It is note worthy that at a national level the proposal for an End of Life Care Facilitator within every acute hospital setting has been recommended and within the approved Business Case for Palliative Care Developments the organisation will be appointing to this post shortly. The post holder will work within the Specialist Hospital Service and predominantly have responsibility for Palliative Care Practice, education of Acute Staff on LCP and further develop Acute Gold Standard Framework practice as identified within the end of life action plan.

9

Table 4. Walsall Acute Setting Key Performance Indicators (KPI)

		NCDAH ROUND 3 – KEY PERFORMANCE INDICATORS (KPI)	
		National Round 3 (n=131 Hospital Trusts)	Your Site
NCDAH Round 3 Organisational Key Performance Indicators	**KPI 1: Access to Information relating to death and dying: to support care in the last hours or days of life**	Median 71% IQR (57% - 71%)	57%
	KPI 2: Access to specialist support (Specialist Palliative Care Services, LCP Facilitator) for care in the last hours or days of life	Median 63% IQR (50% - 75%)	63%
	KPI 3: Care of the Dying: Continuing Education, Training and Audit	Median 67% IQR (50% - 83%)	75%
	KPI 4: Care of the Dying: Clinical provision/protocols promoting patient privacy, dignity and respect, up to and including after the death of the patient	Median 78% IQR (67% - 89%)	100%
		National Round 3 (n=121 Hospitals)	Your Site (n=26)
NCDAH Round 3 Clinical Key Performance Indicators	**KPI 5: Anticipatory prescribing for the 5 key symptoms that may develop in the last hours or days of life (Pain, Agitation, Respiratory Tract Secretions (RTS), Nausea and Vomiting, Dyspnoea)**	Median 83% IQR (73% - 92%)	73%
	KPI 6: Communication with the relatives or carers regarding the plan of care (LCP), to promote understanding	Median 71% IQR (65% - 80%)	91%
	KPI 7: Ongoing, Routine Assessment of the patient, relatives or carers	Median 76% IQR (69% - 84%) N=120*	49%
	KPI 8: Compliance with completion of LCP (or matched alternative)	Median 67% IQR (59% - 76%)	64%

10

For the past year the LCP education programme has continued. Since commencement of the LCP training within the Acute Trust (05/12/2012) a total of 183 staff have attended the awareness training, of those 183 staff 109 are qualified nurses and Care Support Workers from the key ward areas identified. Within the Community setting since commencement of the LCP training in 2009 a total of 297 have attended the awareness training: 2009=108, 2010=158, 2011=25 & 2012=6.

Care after Death
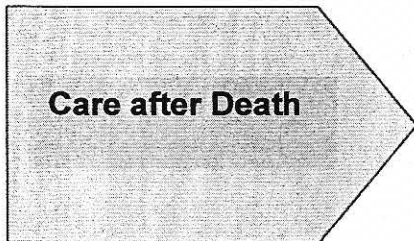
Progress of this work stream is now under development with the group having a formalised planned work programme. The group have reviewed current Bereavement Information across the organisation and a new version will be in place shortly. They have also reviewed the process within the acute care setting of care immediately after death and have made several recommendations for improvement to processes.

The planned engagement with bereaved relatives has remained a difficult challenge for several reasons. The timing of intervention in the post bereavement phase is crucial and type questioning and enquiry is extremely sensitive in its nature. The Group are at present focusing on learning from complaints in this area by adopting a more pro-active approach rather than retrospectively reviewing a complaint of this nature to maximise the learning for all levels of staff.

Additionally a small scale audit within the Bereavement Service has been conducted to scope the usefulness of a Bereavement Support Group with clients who have accessed the service for a period of formal counselling of no less than nine months. The findings from this audit did not provide a clear direction of travel as to whether the formation of such a group would be helpful as an ongoing measure, more investigation is required. All participants referred to their experiences of individual counselling and spoke positively of these experiences. Most referred to the importance of having individual support referring to the 'privacy of feelings.' Sharing difficult and often intimate thoughts, feelings and memories within a group may be inhibiting/intimidating. The two who had experienced group work spoke of feeling 'lost' at times particularly if there was a dominant group member. Anxiety was expressed about being vulnerable with other people who were 'strangers.' Furthermore becoming upset in front of others and witnessing others in states of distress. It was understood that with correct structures groups could be made safe. One participant said that they would join a group if there was no other alternative. Types of groups were also explored within

the audit the Therapeutic Group, given the above uncertainty of being exposed this type of group proved to be the least attractive.

In abstract terms some members of the group were able to see the potential for 'healing' in such groups' this was referred to in a wider context of continuing a relationship with the service. The results of this work will formulate the future way forward for development.

Summary and Conclusion

This is the second paper presented to the Scrutiny and Performance panel at their request this year and is provided to elaborate further on the End of Life action plan in place for the organisation. Development work has been constant and sustained in developing our workforce knowledge and competence and the use of the best practice End of Life Care Tools across the health and social care interface. The priorities for the interval months between reports have focused at all elements of the pathways development Borough wide but particularly on the large I.T development within our Fusion information system. This will enable patients on this pathway to be clearly identified for the first time and information shared with all providers ensuring their wishes and preferences are respected, this is a large step forward in coordination of care for this group. The broader gain from this development is the enhanced partnerships development and continuity of care for patients by the utilisation of electronic solutions; secondly the priority has been to develop a different model of care for the delivery of acute site Specialist Palliative Care to meet the changing demographic population of those patients dying within an acute care setting.

The focus within the next six months will be reviewing progress and effectiveness of the Fusion Gold Standard Framework template and initiation and planning of phase 2 and 3 in the development. This includes sharing this information with Badger out of Hours Provider and West Midland Ambulance Service. Additionally following the investment from the approved Business Case in new Specialist Palliative resource work will continue to further integrate our Specialist Palliative Care Services across the pathway to derive maximum quality of care.

12