Dudley
Metropolitan Borough Council

Agenda Item No. 10

Select Committee on Health and Adult Social Care - 15th January,2009

Report of the Director of Partnerships and Service Improvement

Palliative Care

Purpose of Report

1. This report provides an update on end of life care for people in Dudley.

2 Background

The National End of Life Care programme (2004) was established to help health and social care professionals throughout England to improve end of life care for their patients, regardless of their diagnosis, age, gender, level of ability or care setting. Around half a million people in England die each year, and the care provided to these people, and their families and carers, forms a significant proportion of the workload for many health, social care, and voluntary sector staff. However, very often care for this vulnerable/important group is not coordinated effectively across the different service providers, and is not designed around people's expressed wishes and preferences about their care.

In response to these challenges, the government put in place a number of initiatives to improve care for people at the end of life. These include

- NHS National Service Frameworks: CHD, Renal, Older persons, Long Term Conditions, Diabetes.
- Building on the Best (DH, 2003);
- NHS Cancer Plan (2000)
- Emergency Care Policy
- NICE Guidance Improving Supportive and Palliative care for adults with cancer (2004)
- Mental Capacity Act (2005)
- Our Health, Our Care, Our Say' (DH 2006)
- 'Our NHS, Our future' (DH 2007).
- NHS Next Stage Review (2008)
- End of Life Care Strategy (2008)

The principal aims of these initiatives are to bring about a step change in access to high quality care for all adults approaching the end of life, irrespective of age, gender, ethnicity, religious belief, diagnosis or care setting, and which respects each individual's needs and preferences.

Within Dudley we are committed to implementing the National End of Life Care agenda and have been involved in the development of the regional End of Life Clinical Pathway Group (CPG) as part of Our NHS Our Future (2007).

In 2007 every PCT was tasked with reviewing their end of life care service provision as part of their Operating Framework. The aim of this was to identify existing services, to highlight where the gaps in service provision are and to then to develop an action plan and long term strategy based on local needs and identified gaps

Priorities for development

Nationally, regionally and locally, end of life care groups recognize that palliative care services are not always equitable or fair, that patients do not die where they would choose to and experience unnecessary symptoms. The End of life Care Programme and more recently the End of Life Care Strategy (2008) advocates the use of a whole systems approach which involves:

- Earlier identification of people entering the end of life stage
- Care planning and assessment
- Coordination of care
- Delivery of high quality services in all locations
- Management of the last days of life
- Care after death
- Support for carers throughout the persons pathway and after their death.

To help deliver this whole systems approach the national programme and strategy supports the use of tools to support clinicians and enhance patient and carer experience. The three possible models of care which follow the patient through their pathway of care with a terminal illness are:

- The Gold Standards Framework (GSF)
- The Liverpool Care Pathway (LCP)
- Advanced Care Planning (The Preferred Priorities of Care (PPC) is an example of advanced care planning)

<u>The Gold Standards Framework (GSF)</u>

The GSF is a systematic approach to improve and optimise the care of patients in the final year of their life within the community. It builds on the good work that is already established but formalises best standards of care into normal practice. By ***identifying*** patients in need of palliative/supportive care in the last year of their life, by ***assessing*** their care needs and then ***communicating*** and ***coordinating*** these care needs within the team, improves the quality of palliative care and enables more patients to die in their preferred place of choice.

<u>Advanced Care Planning (ACP)</u>

Advanced care planning is a process of discussion between an individual and their care provider and might include the person's concerns, what is important to them, their understanding of their illness and their preferences for types of treatment or where they wish to be cared for. This discussion should be documented, regularly reviewed and communicated to other key persons involved with the patient.

The Liverpool Care Pathway (LCP)

The LCP was initially developed to take the best of hospice care into other care settings such as hospital, community and care homes. It is a document that replaces all other documents for patients in the last few days of their life. The LCP promotes good communication with the patient and their family/carers, anticipatory prescribing, good symptom control and assesses spiritual and psychosocial needs.

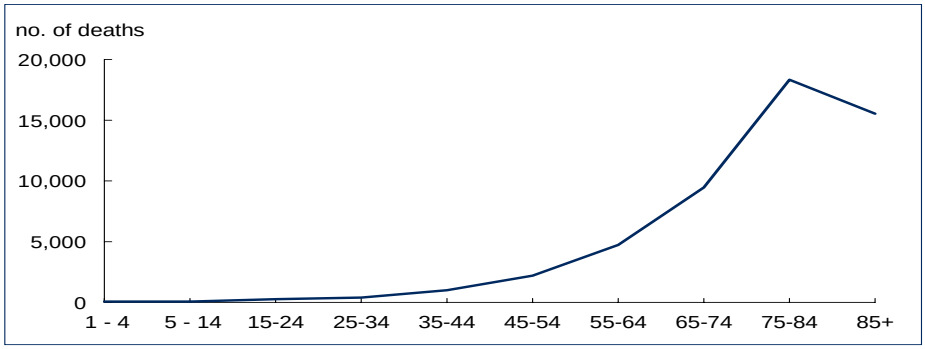
These recommended tools are being rolled out within the Dudley Health Economy and are at different levels of implementation. These tools and guidelines were originally developed around palliative care services for patients with cancer. Although more recently these have been adapted and developed so that they can be used as tools for all clinicians, in any care setting and for all patients whatever their diagnosis, it is widely acknowledged that there remain significant differences in the palliative care needs of those with cancer compared with those who have palliative care needs and have a non malignant disease (National Council for Hospice and Specialist Palliative Care Services 2000).

Epidemiology

We know that on average 1% of the population dies each year. However, with our increasing rise in the number of older people across the West Midlands this % will continue to increase for at least the next 20 years.

End of life care is a relevant topic for all age groups, even though half of all deaths occur amongst the over-75s

Age at death, West Midlands residents, 2004

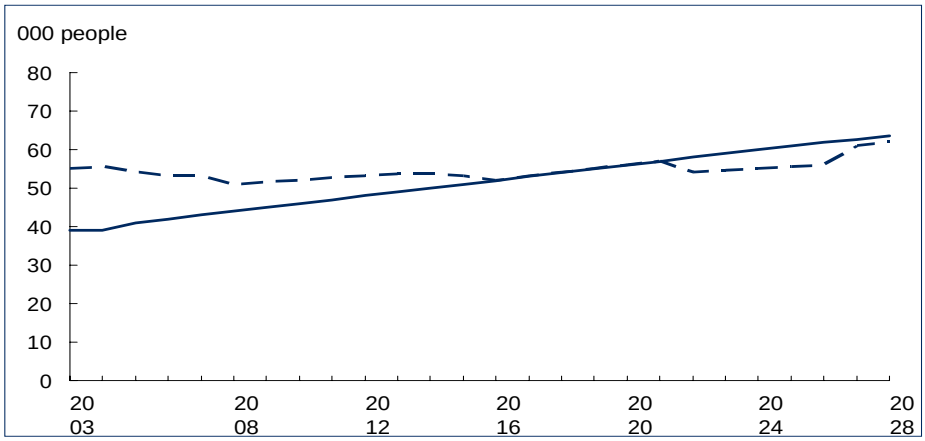


Note: Deaths aged under 1 year excluded from chart (415 deaths)

Source: Mortality statistics, National Statistics

End of life care will therefore become an increasing issue as the elderly population rises

Elderly population in former Birmingham and the Black Country



Source: *Population projections and their effect on end of life care for BBCHA PCTs*, Dr Khesh Sidhu, 2005

Rise in % increase of the population dying until 2028

With increasing age, comes increasing levels of morbidity in particular related to dementia. Patterns of disease in the last years of life are also changing and more people are dying from chronic disease such as heart failure, airways disease and renal failure. It is also difficult to diagnose a particular disease as the main cause of death, as many older people suffer from several conditions together that might all contribute to death (WHO 2004). Dementia is an example of one condition that is regularly under diagnosed.

The other change in the demographics of the elderly population is going to be the increase in the numbers living alone and also the number living in care homes. This is because of widowhood, the fracturing of families and children moving away from localities where their parents live. This ultimately will lead to a reduction in the availability of 'intimate' and unpaid carers who currently provide the majority of the caring in support of those dying, particularly in their home setting (WMCPG 2008). Between 2% and 5% of people aged 65 or older live in care homes. These are older people who are frail and or have chronic physical or mental disability such as stroke, heart failure, Parkinson's disease or dementia (Hockley 2002). These people will clearly have palliative care needs.

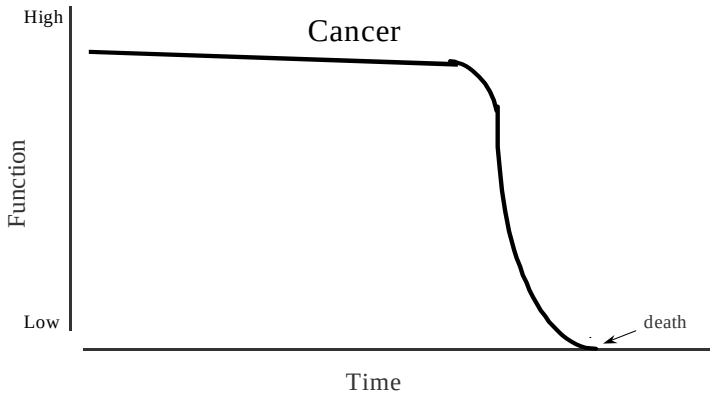
Making the case for palliative care need at population level

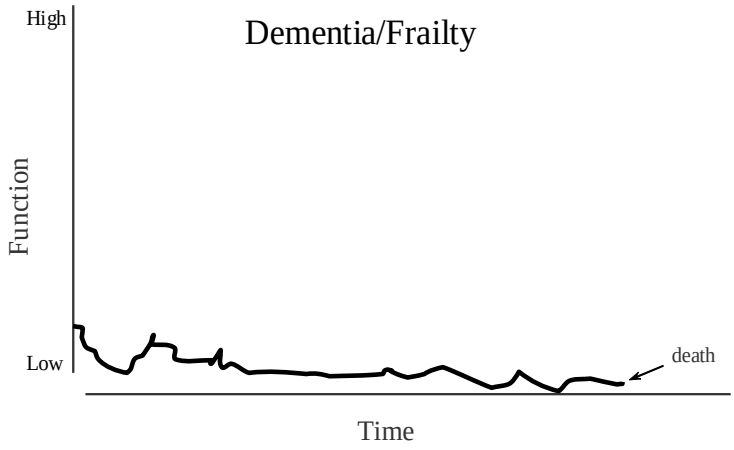
Age bands	**65-74**	**75-84**	**85+**
Cancer			
Number of deaths	33305	43330	20474
Number with dementia	977	3800	20474
% with dementia	2.90%	8.80%	29.10%
Circulatory			

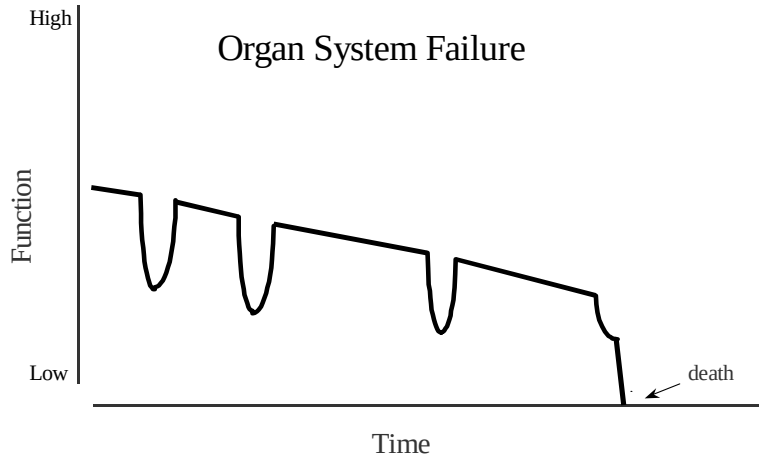
Number of deaths	31548	71469	67962
Number with dementia	941	6319	19992
% with dementia	3.00%	8.80%	29.40%
Respiratory			
Number of deaths	9615	21019	18239
Number with dementia	283	1817	5224
% with dementia	2.90%	8.60%	28.60%

National Council for Palliative Care (NCPC)

It is very difficult to predict the course of many chronic diseases affecting older people which mean that forward planning, crisis avoidance, end of life care discussions and support for relatives and carers is not delivered in a proactive manner. The following examples illustrate this:







The challenge therefore is to ensure that all patients who are at the end of their life have access to a range of services to suit their individual needs and will not be dependent on their disease, the care setting, age, gender, sexuality or level of ability.

Progress to date

For many years Dudley has had a Palliative Care Steering Group with membership covering agencies from the acute sector, primary care, social services and voluntary and charity organisations. Generalists and specialist who provide and commission palliative care within Dudley have met within this structure to drive and sustain good practice in palliative care benchmarked against national and regional frameworks. This group now incorporates the aims of the national end of life care programme and strategy and is in the final process of developing their own local end of life strategy.

In January 2008 Dudley launched the Joint Agency Palliative Care Support Team. This is a group of health and social care assistants who provide palliative/end of life care to patients who have expressed their wish to die at home. The only criterion for this service is that the patients is registered with a Dudley GP and has a life expectancy of 4-6 weeks. The group of health and social carers provide comfort care and support to the patient and their family/carer, they are managed by a facilitator from health and social care and work closely with district nurses, GPs, Macmillan nurses and allied health care professionals to provide quality palliative care. To date over 95% of patients referred to this team have achieved their preferred place of care.

Within Dudley Primary Care over 90% of GP practices have a supportive and palliative care register which includes all patients who have end of life care needs. Within this framework are guidelines and clinical indicators which help practitioners identify patients with malignant, non malignant disease, the elderly frail and specifically dementia.

The Liverpool Care Pathway has been adapted for local use to reflect local and regional guidelines concerning symptom control in cancer and non

malignant disease, and adapted to consider patients with communication difficulties. The training programme aimed at generalists working in the community has focused on this approach to end of life care to improve access and equity for all our patients. This training programme will continue to develop and reflect any local or national changes or recommendations.

Advanced Care Planning is in the early stages of implementation within Dudley and a training programme is being delivered in conjunction with the local hospice to give clinicians the knowledge and skills to have the complex end of life care discussions that patients may have. This training will be all inclusive for any clinician who has patients with end of life care needs. Guidelines to support practice have been developed and ratified and a local document is being piloted.

Dudley is also working closely with the SHA and has secured 12 month funding for 2 posts in the community and 1 post in the acute sector to enhance end of life care for patients in a care home setting through the development of the Supportive Care Pathway (SCP). Pan Birmingham Palliative Care Network developed the SCP which encompasses the key elements of the above recommendations. The Trust has adopted this tool and the facilitators are rolling out a training programme for care homes so that they may implement it where appropriate to ensure that any service user in our care, coming to the end of their life, can die with dignity.

Ensuring access to end of life care is equitable and fair is an important part of the national programme and within Dudley we have worked towards reducing this gap for clients with learning disabilities who have end of life care needs. A group of committed professionals have developed a training programme to help support the carers of clients with learning disabilities with end of life needs to keep them in their preferred place of care by providing them with the knowledge and skills around end of life.

Raising awareness of end of life issues is also a priority for development in Dudley. A leaflet has been designed and distributed across the borough which outlines services that are available to all patients who have a life limiting illness and more recently a Palliative and End of Life Care website has been launched which gives much more information about the services that are available across the borough. This website is available across all agencies and also to the general public.

Embedding the previously mentioned systems and tools so that they become a part of normal practice will clearly improve coordination of services. However as outlined in the national End of Life Care Strategy there are still major improvements that are necessary and the audit of end of life care services undertaken in 2007 has highlighted our areas for development.

Future developments

Area of Need	Action required
Training for generalists and	Continuation of Advance Care Planning training

specialists in end of life care	Establish use of the LCP as standard practice for care in the last few days of life. Training for all frontline staff in earlier identification of patients approaching the end of life (NB. This must include non malignant diseases)
Care Homes: improve access to specialist palliative care, increase awareness of the end of life care agenda, education & training for care home staff, reduce inappropriate admissions to hospital	Baseline audit of current situation Identify specific areas of need Development of an education package Post review audit
Raising awareness of end of life with the local community	Long term plan in line with the CPG/ SHA and the national strategy. Will involve working with local communities in new ways
Out of hours access to Specialist Palliative Care Services	Two areas needed to extend service provision to offer 24/7 1. Extend the existing community Macmillan service to 7 days a week 9-5pm 2. Provide access to medical/nursing advice 5pm-8.30am 7 days a week. This would need to be available to all patients within Dudley who are end of life (not disease specific or other entry criteria)
Better **respite care** for patients and carers	1. Look at what we have at present that meets the specific needs of client and carer group. 2. Easier access to emergency/ crisis respite that will support the patient and their carer in their own home. i.e. not respite beds day sitting service such as crossroads or the Alzheimer's Society.
Support **Care Closer to Home**	Continued support for the growth and development of the joint agency palliative care support team
Sharing **good practice**	Open Day
Development of **Psychology and Bereavement** services	1. Mapping exercise of what we already have 2. Analysis of where the gaps are. 3. Submit proposal of development plans to commissioners.

Conclusion

Traditionally, high quality care at the end of life has mainly been provided for cancer patients in inpatient hospices, but this kind of care now needs to be provided for all patients with end of life care needs whatever their diagnosis and whatever their care setting. Dudley is committed to embed and improve the good practice that already exists and acknowledges that there is still much work to be done and will incorporate the regional and national guidelines and recommendations to help deliver this.

Finane/Law

No implications

Equality impact

An impact assessment has been undertaken.

Recommendation
This report is for information.

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