Middlesbrough Scrutiny Committee

- How many deaths were there in the Middlesbrough population in 2009? Public health profile data available is up to 2007 The number of deaths occurring each year has fallen from 1,439 deaths in 2005 to 1,362 deaths in 2007 The annual average number of deaths for this period was 1,389
- What were the main causes of those deaths and, what were the percentages of the main causes of death?

Circulatory disease was the major cause of death in 2007. The two prime causes of death, cancer and circulatory disease accounted for 60% of all deaths

Circulatory 31.1% Cancer 29.1% Respiratory 15.2% Other 24.7%

What is the percentage split for place of death? i.e. between home, Hospital, hospice, nursing home?

Place of death between males and females 2004-2007 More than half of all male and female deaths occurred in hospital Male (M) female (F)

Hospital 62.1 %(M) 57.3 (F) At home 22.8 %(M) 19.7 %(F) Resident home 4 %(M) 8.7 %(F) Hospice 3.8 %(F) 3.2 %(M) Nursing Home 3.7 %(M) 8.1 %(F) Elsewhere 2.5 %(M) 1.2% Psychiatric Hospital 1.2 %(M) 1.8 %(F)

What is the (2010/11 financial year) budgetary provision for End of Life Care (EOLC) in Middlesbrough?

Please note in the response that it's not possible to identify what is spent on treating EOL patients across all settings, particularly hospitals, as there are no designated procedure codes to capture EOL care. However, we do have some specific categories of spend that can be identified as follows:-

Hospices £410k STHT £54k Prescribing £91k

Total £555k (2010/11)

In addition to this, further non recurrent resources may be available in 2010/11, however plans are yet to be finalised.

- To which service providers does that money go and in what proportion? As above
- What does the current EOLC service provision in Middlesbrough look like? End of life care is delivered across a variety of areas of service provision. The type of provision available within the community are community hospital beds, the Macmillan nursing team including a Macmillan nurse for care homes, community matrons, district nurses, care home provision. The continuing care team ensure there is a robust process in place to facilitate rapid discharge from the Acute provider. Services are also delivered by Teesside Hospice and the Marie Curie Service. EOLC is also delivered in the Acute Trust and supported by the Macmillan team/ palliative care team including palliative care consultant and the clinical matron for end of life and bereavement services. There is also a pilot project over the next two yrs. The project involves the appointment of a Macmillan nurse post to facilitate palliative discharge. There has also been the development of end of life care beds within the Acute Hospital.
- > Where are the EOLC facilities and what are numbers of WTE staff,

As described above End of life care can be delivered in the persons own home, community hospital, care home, hospice or the acute sector. However, where possible the NHS are trying to facilitate an individuals preferred priorities of care, and where this has been identified as home all effort is made to achieve this.

Whose principal focus is EOLC?

As a Commissioner NHS Tees has developed a strategic plan, within which are 8 clinical themes, each theme has key initiatives. The key initiatives for EOLC relate to provision of information and advice, training and awareness, and community provision. The strategic delivery group (SDG) is responsible for overseeing the development of the initiatives. All Wilson is the Load Director for the Tees

development of the initiatives. All Wilson is the Lead Director for the Tees SDG and Anne Greenley is the lead representative South of Tees. The focus areas for the group are:

Single point of contact

Increased access to bereavement support

Expand sitting service and carers support

Expand community nursing (24hr support)

Support for Hospice care

Expand community Specialist team

Mandatory training (e learning) for care home staff

GSF training for Nursing and care homes

Implementation of Advanced care Plans Communication skills training For the provider the principle focus would be with all services involved in the delivery of palliative/ end of life care for example district nursing, Macmillan nursing service, palliative care services and the Hospice.

The research for 'A Good Death' highlights that around 15% of people would wish to die in a hospice and around 60% would like to die at home. How does Middlesbrough's current capacity for specialised EOLC service provision look against that demand?

In order to facilitate the 60% wishing to die at home there is a significant amount of education and training required for generalist services. The training requirements are advanced care planning, gold standards framework, Liverpool care pathway (last days of life), syringe driver training, palliative care guidelines, communication skills. These areas are all identified in the regional charter, under a time to plan and care and support. All of which have been identified as part of the work programme for 2010/2014.

Currently there is a Macmillan nursing service that covers South of Tees which includes access to occupational therapy and a community consultant and also includes a Macmillan Nurse for care homes. There is the Marie Curie service and the rapid response service that is accessible in the community.

There is also Teesside Hospice which has a 10 bedded in patient unit and the availability of community nursing beds at Carter Bequest Hospital.

In the Acute trust there is the acute palliative care consultant and palliative care team which includes Macmillan nurses, Macmillan palliative discharge nurse and a clinical matron for end of life care and bereavement support.

However, EOLC does not always require specialist provision, it is about equipping generalist services with the knowledge and skill to deliver good quality end of life care.

Does Middlesbrough have a well publicised and accessible information source for those seeking advice or information about EOLC? Information booklets have recently been developed as information had

previously been identified as a gap. The booklets developed include:

- When someone is dying,
- What to do when someone is dying,
- The process of grief and loss,
- What to tell the children

• A bereavement information leaflet for children

The booklets have gone out to the patient and carer focus group and a range of professionals for proof reading and comment prior to printing.

There is also support and advice available from the district nursing service and the hospice. The patients who are known to the district nursing service will be given contact numbers for in and out of hours as well as the hospice helpline. However, this service is not widely publicised but is targeted in that it is promoted to patients and carers who are identified as end of life rather than the general public.

There has been a lot of activity regarding raising public awareness on the subject of death and dying through the consultation process and the development of the Regional Charter and the development of the Compassionate Communities Project led by Teesside University and NHS Tees Public Health. The University are also part of the national pilot researching communication skills locally for end of life care. The evaluation will be presented to the SDG in September 2010 with recommendations.

- What does NHS Middlesbrough expect commissioned providers to do, to ensure that sufficient time and notice is given to people that they are approaching the End of Life, to ensure that their wishes can be put into practice?
 - NHS Middlesbrough expects all patients who are on the end of life pathway to have a "preferred priorities of care" document completed. The "preferred priorities of care" document is the patients document not a professional document and remains with the patient. Training has been provided to professionals across health and social care [including the independent sector] to enable this.
 - All patients who are at the end of life (6-12 months of life) to be identified on a palliative care register in general practice and the carers have their needs identified and assessed as required .
 - Commissioners expect that all patients who are at the end of life are identified on a palliative register in general practice. The practice should have the knowledge and understanding of end of life care and access to provision. This should include GSF, Preferred Priorities of Care, EOLC pathway (last days of life), prescribing flow charts and syringe drivers, access to medication, pharmacy, local support services and out of hours services.
- How much progress has been made so far in Middlesbrough, in your view, As to the implementation of 'A Good death'?

The North East regional Charter identifies the principles of a good death some of which are ;

<u>Respect</u>: to have clear honest and tailored information and good communication throughout illness or frailty

<u>Time to plan</u>; if appropriate to be told clearly and compassionately the reality that death is coming

<u>Care:</u> Access to end of life care in the location we choose, and have clear information on who to contact 24/7, to be given the opportunity to take part in decisions which affect care

<u>Support:</u> To have support with the practicalities of dying, death and matters after death

The developments identified below support these statements; There has been investment in training and education for the independent providers in GSF 8 care homes from Middlesbrough 09/10 and a further 8 care homes 10/11 have joined the programme. The first wave will be going through the accreditation process in July and November 2010.

Teesside University has also developed a certificate level course for end of life care and care homes [all those who attended the course passed]. The homes that took part included residential care, care homes with nursing, learning disabilities, and elderly mentally frail

Tees Valley Alliance are providing end of life care training for domiciliary providers, and care homes at the Further Education colleges across Tees. All courses have been fully booked and there has been genuine interest in accessing the NVQ units;

HSC 226 to support individuals, who are distressed,

HSC 384 to support individuals through bereavement

HSC 385 to support individuals through the process of dying

There has been Advance Care planning training for Tees to equip the workforce to deliver good quality end of life care and facilitate preferred priorities of care.

Teesside University are also undertaking a pilot project funded by the SHA for the development of compassionate communities

There has also been the development of information booklets to support the patient, carer and professional this development was supported by the end of life focus group.

Teesside University have just completed an audit on use of the palliative care register in general practice across Tees. Recommendations supported the development of the information booklets and standardisation and consistency within practices regarding the equity of access and the frequency of the GSF meetings. This work will be further developed over 2010/2011

All practices and care homes with nursing received literature and prescribing formularies for palliative care, including the elderly mentally frail liaison team, and the CHC team

All developments have progressed due to partnership working across the patch. There is no doubt that there is still further work to be done.

Is EOLC service provision seamless, between organisations, in Middlesbrough?

An end of life questionnaire has recently gone out to all practices across Tees which will help inform commissioners and providers of the current process and identify areas of good practice and areas where there is need for greater collaborative working. These results will be collated and will identify where key actions need to be addressed

Is NHS Middlesbrough satisfied that EOLC skills are viewed as core Skills for frontline health services workforce?

EOLC skills are required for all frontline practitioners whether they are in health, social care or the independent sector. The key to success would be the standardisation of training and education to ensure that a moving workforce has transferable skills, and that the skills acquired are recognised by all organisations involved in the delivery of end of life care. The SDG are promoting the National End of Life Care e- learning training programme for all providers to supplement learning.

Where should EOLC develop from here?

The SDG will monitor and review progress on developments The focus areas for this year are;-

- The development of a 24 hour advice line
- Bereavement information packs
- o GSF for care homes
- o GSF in general practice
- Access to medication
- Preferred priorities of care
- End of life care training for care homes and domiciliary providers
- E learning for end of life care
- o Communication skills
- Review core services, community nurses, sitting service, hospice, and specialist end of life care.