

## HEALTH SCRUTINY PANEL

A meeting of the Health Scrutiny Panel was held on 3 June 2010.

**PRESENT:** Councillor Dryden (Chair); Councillors Junier, Lancaster and P Rogers.

**OFFICERS:** J Bennington, P Clark, R Hicks, J Ord and I Parker.

**\*\* COUNCILLORS PRESENT BY INVITATION:** Councillors Brunton, Budd, McIntyre, Porley, Rooney, J A Walker, Whatley and Williams.

**\*\* ALSO IN ATTENDANCE:** Professor Edwin Pugh, Regional Clinical Lead for End of Life Care, and Consultant in Palliative Medicine, North Tees and Hartlepool NHS Foundation Trust  
Keith Aungiers, Head of Projects and Intelligence, Public Health North East (GONE).

**\*\* APOLOGIES FOR ABSENCE** were submitted on behalf of Councillors Carter, Cole, Davison, Mrs H Pearson and Purvis.

### **\*\* DECLARATIONS OF INTEREST**

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

## **END OF LIFE CARE REVIEW – INTRODUCTION**

A report of the Scrutiny Support Officer had previously been circulated the purpose of which was to introduce local NHS representatives to provide an initial briefing around the topic of End of Life Care, the Panel's next scrutiny topic for review.

The Chair welcomed Professor Edwin Pugh, a Consultant in Palliative Medicine, North Tees and Hartlepool NHS Foundation Trust and regional clinical lead for End of Life Care and the Regional Public Health Group for 'A Good Death' and also Keith Aungiers, Head of Projects and Intelligence, Public Health North East, GONE. An invitation had been extended to all Members of the Council and the Chair thanked those in attendance.

Members were advised that the Panel had agreed that prior to determining the terms of the reference of the review it would be beneficial to have an initial briefing on recent developments in End of Life Care including regional developments around the End of Life Care Strategy.

Professor Pugh thanked Members for the invitation to attend the meeting and gave a brief overview on the subject of End of Life Care. In his initial introduction he stressed the importance of the involvement of the community and not just the NHS as to how end of life was managed. A copy of the updated North East Regional Charter, 'Compassion at End of Life', which had been produced in partnership across health, social care and other organisations in the North East and with the involvement of patients, carers and their representatives was circulated at the meeting. Copies of the NHS Public Health North East document, Better Health, Fairer Health, a strategy for 21<sup>st</sup> Century Health and Well-Being in the North East was also distributed at the meeting.

By way of introduction an indication was given of the key drivers for change and action taken over the last two years which included Professor Lord D'Arzi's review; Strategic Health Authority in terms of its End of Life Strategy; National End of Life Strategy; National Audit Office End of Life Care; and Quality Markers.

As part of the background data details were provided of comparative information between 1900 and 2000 in particular the age at death and the top three causes of death. The average age at death in 1900 was reported as 46 years compared to 78 years in 2000. The top three causes of death in 1900 were reported as infectious disease, accident and childbirth in comparison with 2000, which showed that cancer, organ failure and frailty/dementia were the top three causes of death.

Reference was made to a regional survey of over 4,000 people, in particular the information which related to Middlesbrough in terms of the place where people had died and individual's preferred location as follows:-

Place		Preference
Hospital	61%	15%
Home	21%	60%
Care Home	13%	0%
Hospice	3%	15%

Statistical information was provided from the Office of National Statistics 2006, which demonstrated the causes of death, and in what location as follows:-

Category	Hospital	Hospice	Home	Nursing/ Care Home
Neoplasm	52%	12%	28%	8%
Circulatory system	62%	0.1%	23%	13%
Respiratory system	70%	0.2%	16%	14%
Nervous system	48%	0%	11%	40%

Statistical information was provided from the perspective of the North Tees and Hartlepool Hospital in terms of the following:-

- 1600 deaths a year;
- 97% of people who died were admitted as an emergency;
- around one quarter of hospital deaths were people aged under 70 and almost a half were 80 or over;
- around one quarter of hospital deaths occurred within the first three days of a stay;
- admissions where people had died equated to 21248 (9.8%) bed days;
- there was a national projected increase in deaths of 20%.

It was noted that a similar pattern was likely to be reflected in relation to James Cook University Hospital.

From a Care Home perspective the following statistical information was given:-

- 1 in 5 people over 65 will die in a care home;
- on average 50% of residents died within two years of admission;
- increasing frailty of residents;
- 27% of residents were likely to be confused, incontinent and immobile;
- evidence showed that there was less staffing in care homes than in hospitals and hospices and an isolation to training and lack of palliative care knowledge.

The Care Home scenario showed that:-

- one quarter of residents died in hospital;
- there were wide variations between care homes;
- 595 of those admitted could have remained in care home with extra support.

It was noted that there were wide variations between care homes and that 59% of those admitted to hospital could have remained in a care home with extra support.

Reference was made to the publication by the NHS Public Health North East of Better Health, Fairer Health a Strategy for 21<sup>st</sup> Century Health and Well-Being with particular regard to the last chapter entitled Towards a Good Death. Their vision was reported as the following:-

'The North East will have the highest quality services to support individuals (along with their families and carers) in their choices as they approach death.

By a good death we mean one which is free of pain, with family and friends nearby, with dignity and in the place of one's choosing.'

From a Society perspective it was considered that death and dying should be seen as:-

- a normal part of life;
- more than a medical responsibility;
- a Public Health and Societal Issue;
- a responsibility of a 'compassionate community' to be more aware and responsive to the needs of people.

It was acknowledged that were very different socio-economic circumstances some 60 years ago in Middlesbrough which had a close community at that time which had gradually eroded away as such circumstances have changed over the years. Inevitably it would take considerable time to retrieve a greater sense of community.

The roles to play in a 'compassionate community' were seen as follows:-

- acknowledgement that end of life care was the responsibility of the wider community and organisations;
- involved end of life care in local government policy and planning;
- offered people a wide variety of supportive experiences, interactions and communication;
- had a strong commitment to social and cultural difference;
- provided easy access to grief and palliative care services.

Reference was made to one of the intentions under the chapter of 'A Good Death' of the Better Health, Fairer Health document of 'We will create a charter for end of life care, with a statement of the rights and entitlements that should be honoured both for the individual preparing for death, and their carers and families. This should relate not only to medical and nursing care but also to the behaviours of all agencies and sectors who deal with these issues.'

An indication was given of some of the current perceptions of death and dying in the North East which included:-

- death was becoming medicalised;
- there was an over-use of expensive hospital facilities;
- death was a taboo subject;
- there was a wide role and responsibilities of non-NHS organisations and society at large not addressed.

In terms of the action taken so far, a multi-agency regional advisory group had produced a draft charter to which there been 2,500 responses to the associated public and organisational consultation exercise. Other work involved raising public awareness and social marketing campaign; research into societal attitudes and behaviours; joint working with the new national Dying Matters Coalition; and national and regional launches.

For the Charter to be successful it needed:-

- support by the public;
- support by NHS, local authorities and the voluntary community sector;
- ownership and backing by all agencies;
- fit with NHS Constitution.

On a personal note Professor Pugh gave an indication of some of the challenges for agencies and Society, which included major shifts in expectations and culture in society and organisations.

Inevitably it would take considerable time to evolve and develop a 'Compassionate Community' approach. A challenge for statutory agencies and local organisations was to adopt the Charter.

Some of the questions to be asked of services and Society included:-

- is social and health care provision seamless?;
- do we provide 24 hour support?;
- do we have compassionate human resource policies for people with illness and carers?;
- are we planning to enable choice of place of living, dying and death?;
- is end of life care a core skill of staff?;
- are we creating compassionate communities?.

Although reference was made to the availability of counselling and paid leave in certain circumstances for Middlesbrough Council staff, in general terms it was considered that there was more scope for employment policies to assist with End of Life Care issues.

Professor Pugh referred to Keith Aungiers, Head of Projects and Intelligence, Public Health North East (GONE), and provided information about changing public attitudes and the Dying Matter Coalition. The National Council for Palliative Care had set up the Coalition as a broad based, inclusive national Coalition, working in partnership with almost 7,000 members across a range of sectors.

The Mission statement of the Coalition is 'Support changing knowledge, attitudes and behaviours towards death, dying and bereavement, and through this to make 'living and dying well' the norm.'

The Panel was advised of the main conclusions including the following:-

- consensus amongst the public, across cultures, on factors contributing to good EoLC;
- most people had not talked about dying, death or bereavement;
- little qualitative research, which showed that views and experiences were tightly linked which could shift when people considered factors at play;
- assumptions about individualism and autonomy did not fit well with needs and daily experiences of those affected by dying, death and bereavement;
- cultural, historical themes, role of faiths, beliefs were critical too;
- the 'it's a long way off' perception was key;
- people were more likely to talk to trusted family members and GPs;
- need to make it easier for more people to talk about it;
- may need different strategies for men and women; and regional strategies;
- need to use different approaches for different groups, segment audience and approach/materials.

In terms of the progress made reference was made to the following:-

- key target groups had been identified and key performance indicators to measure progress developed;
- a range of leaflets, posters, audio material and a Website had been developed;
- an Awareness Week had been organised with events across the country and media interest;
- reference was made to a GP pilot project to improve confidence of end of life conversations with patients and building community projects with DM members to raise awareness locally.

Members of the Health Scrutiny Panel indicated that the Dying Matters Coalition would be given further consideration by the Panel.

Taking into account personal experiences and comments of constituents Members indicated that there appeared to be a need to raise awareness of what services were available to individuals and their families and carers. In response, it was indicated that in considering the needs of individuals in providing appropriate support there was a need to develop a culture shift in providing 24-hour services and that the commissioning arrangements should reflect such requirements.

Whilst it was acknowledged that there was a myriad of voluntary organisations which provided support in a variety of ways it was considered that such activities should be more co-ordinated. The overall perceptions of many people was that End of Life Care was predominantly the role of the NHS and don't recognise that there were important roles to play by others. As previously indicated it was difficult to get the message across that End of Life was a normal part of life and that a massive change in culture was required in order for this to be changed. It was acknowledged that there was a current perception of a strong emphasis on medical need and therefore there was a need to develop more confidence amongst the community to identify and establish ways of providing a network of support in the community. Extending current training opportunities and assisting staff in the community to develop appropriate skills was an important consideration. The work of community development workers was seen, as an important area to establish what structures existed which would assist in subsequently developing appropriate models.

It was acknowledged that an important consideration of any future discussion was what local authorities could do as community leaders in influencing and assisting access to and location of End of Life Care.

It was considered that there was a need for more of an overall focus on getting the most out of life. As previously indicated one of the crucial areas to be developed was that of providing 24-hour services and to train people to gain the necessary skills in pursuance of the Charter and providing the most appropriate information and care for individuals, families and carers.

**AGREED** as follows:-

1. That all representatives and Members be thanked for the information and contribution to the deliberations details of which would be included in the overall review.
2. That the Health Scrutiny Panel gives further consideration to the establishment of the terms of reference for its scrutiny review into End of Life Care.

## **OVERVIEW AND SCRUTINY UPDATE**

In a report of the Chair of the Health Scrutiny Panel, Members were advised of the key matters considered and action taken arising from the meeting of the Overview and Scrutiny Board held on 4 May 2010.

NOTED