End of life care in Barnsley: Health & Wellbeing Board, April 2013

Introduction

This short report suggests that:

- the demand for quality end of life care in Barnsley is greater than currently provided for;
- too many expected deaths occur in a hospital setting, which is not the choice of most people;
- more should be done to improve choice of place of death and to facilitate a good death, including the setting of a target to reduce expected deaths in hospital.

The report has used a range of sources that are detailed in the appendix, mainly using national data. However, it should be noted that there is a significant lack of detailed local analysis about end of life care demand. The report is concerned with adult care only.

What do we mean by end of life care

In the context of this report, 'end of life' refers to people that a healthcare practitioner would say no to the question 'would you be surprised if this patient died in the next 12 months?' Such patients are likely to include people with advanced, progressive and incurable conditions, such as cancer or Parkinson's Disease and people in frail health, with a number of co-existing conditions.

Within the context of 'end of life' the person is more likely to benefit from a palliative approach to care that concentrates on the relief of the symptoms manifesting from the condition, such pain control and emotional support, as opposed to a curative approach that aims to completely remove the symptoms, such as curing the cancer that is causing the pain.

Such palliative care can be delivered by a 'generalist' team, such as a General Practitioner and District Nurse, or by a 'specialist' team, which is usually led by a Consultant in Palliative Medicine and would include a wider range of practitioners, such as Social Workers, Dieticians, Nurse Specialists and Physiotherapists. Specialist Palliative Care practitioners work closely with the patient, their family and friends, dealing with not just the physical symptoms, but also the psychological support and will often be involved in providing bereavement care.

Therefore, this report describes the demand for end of life care in people expected to die (the 'surprise' question) and does not cover the end of life care needs of people not expected to die, such as those from the result of trauma, cardiac arrest or suicide. However, it should be noted that the skills of palliative care practitioners, in particular bereavement support, can be applicable when dealing with unexpected deaths.

How many local people need end of life care

One percent of the Barnsley population is expected to die each year, a figure that has been consistent for some time, is similar to many other boroughs in England and likely to remain so for many years to come, although the numbers dying will increase as the population ages (the numbers of people aged 85 and over is expected to increase by 146% by 2033). In 2010 there were 2,349 deaths in Barnsley.

Not all deaths require palliative care and as described above, this report is concerned with expected deaths. It is estimated that 25% of all deaths are unexpected due to accidents, suicide, homicide, etc, and that a further 15% of deaths caused by chronic disease are also unexpected. Therefore, an estimated 60% of deaths would be expected, which for Barnsley is approximately 1,500 deaths each year.

There are very few studies exploring the numbers of people who may require palliative care, although the current estimates are that 0.8% (1,800 people) of the Barnsley population would be in such need.

Where are local people dying

Although the number of deaths do not reflect the full activity of palliative care services, the proportion of deaths relating to a provider does give a useful indication of the scope of activity. As can be seen from the list below, the biggest proportion of Barnsley deaths take place in a hospital setting at 55%.

Place of death for Barnsley people

- Hospital: 55% (1,290)
- Own home: 20% (470)
- Nursing or care home: 19% (446)
- Hospice: 5% (95)
- Other: 1% (48)

It is very likely that the vast majority of deaths in care and nursing homes, family homes and the hospice are expected, whereas a high proportion of hospital deaths are likely to be unexpected. Using the same proportion of unexpected (40%) and expected (60%) deaths as described above[1], the numbers of expected deaths in Barnsley Hospital may be circa 770 each year (60% of 1,290), most of which are likely to have some degree of palliative care need. A recent study of two acute hospitals has indicated that one third of all hospital admissions would meet the criteria for palliative care. There is anecdotal evidence to suggest that end of life care in hospital could be improved by promoting a palliative approach

[1] A logical assumption, but one that needs further analysis.

and involving specialist teams, especially for patients admitted as an emergency.

Where would people prefer to die

Numerous surveys suggest that for most people their first choice of place of death is at home, followed closely by a hospice setting. Increasingly there is evidence that most people would prefer not to die in a hospital. However, as described above, most Barnsley deaths occur in a hospital.

Barnsley Hospice believes that too many Barnsley deaths occur in hospital. It suggests that the Health and Wellbeing Board adopts a strategic target to reduce the number of expected deaths in hospital settings.

How could a reduction of expected deaths in hospital be achieved

The experience of Barnsley Hospice is that all health and social care services in Barnsley provide good quality care. In many end of life care cases, practitioners have good skills and experience to facilitate a pain free and dignified death, that not only benefits the patients, but also their family and friends. However, such provision is spread unevenly across the borough. Analysis of referral data from Primary Care practices to specialist palliative care services ranges from 4.8 per 1,000 of practice list size to zero and that patients in the least economically developed areas of Barnsley are less likely to be referred.

There is anecdotal evidence to suggest that in too many end of life care situations, practitioners are ill equipped to facilitate a good death, often focusing on curative care, due to a lack of palliative care training and experience, as well as their own fears of dealing with death, which results in a less than good death in a place not of the patient's choice.

Barnsley Hospice believes that a reduction in expected deaths in hospital could be achieved via the following key developments:

- improving the understanding about the demand for end of life care[2];
- improving the training and education of health and social care practitioners about end of life care, especially in primary and secondary care;
- the development of a shared register of people expected to die within a 12 month period;
- improving the integration of specialist palliative care provision;
- improving the practical support around end of life care to Primary Care;
- improving community engagement with the people of Barnsley in order to have a meaningful discussion about dying and death.

Conclusion

Barnsley Hospice suggests that the demand for end of life care is greater than currently provided for and that far too many people who are expected to die are doing so in a hospital, which is not their preferred place of death. The adoption of a strategic target to reduce expected deaths in hospital would stimulate better care and patient choice, which can be achieved by a variety of developments, such as improving end of life care training; greater integration of specialist palliative care services and a shared register of people requiring end of life care.

Barnsley Hospice is already committed to working with Public Health on the reworking of the Joint Strategic Needs Assessment and would welcome the opportunity to work with the Health and Wellbeing Board to improve end of life care in Barnsley in the development of the Joint Health and Wellbeing Strategy.

Ian Carey, Chief Executive Officer, Barnsley Hospice, April 2013

Appendix

The following sources of information have been used to inform this report:

- Marie Curie end of life data atlas (www.mariecurie.org.uk/)
- Help the Hospices Commission on the future of Hospice Care (www.helpthehospices.org.uk/)
- Association of Palliative Medicine guide to commission palliative care (www.apmonline.org)
- National Council for Palliative Care 10 question guide to ensure good end of life care in your area (www.ncpc.org.uk/sites)
- Dying for Change, Leadbeather & Garber, DEMOS
- National end of life care intelligence network (www.endoflifecare-intelligence.org.uk/home)

[2] Barnsley Hospice is already committed to work with Public Health on a more detailed analysis of the demand for end of life care as a contribution the the Joint Strategic Needs Assessment.