

End of life

Headlines

The number of people reaching their end of life is set to increase over the next 20 years, as is the proportion that are dying due to frailty caused by multiple conditions including dementia.

Most people die in hospital and only 1 in 5 die at home, whilst most would prefer to be cared for at home for as long as possible.

More people die in the winter months; this is most noticeable in those with respiratory disease – more than 50% more deaths happen in the winter.

Many people are not included in the “end of life” registers that ensure they receive the most appropriate care, particularly those with non-cancer diagnosis.

Why is this issue important?

Between 2008-2010 there was an average of 3,696 deaths a year in Kirklees. Of those 2 out of 3 (64%) were aged 75 to 85 and 1 in 3 (33%) were aged 85 or over. The remaining 3% were aged under 75. After falling slightly over recent years the number of deaths is predicted to rise to over 4,000 by 2033¹.

The majority of deaths occur following a period of chronic illness related to conditions such as cancer, heart disease, diabetes, stroke, chronic respiratory disease, liver disease, renal disease, neurological diseases or dementia².

People approaching the end of life often have complex care needs requiring support from different agencies at different times and in different places – their homes or nursing homes, hospitals, and hospices. Caring for someone who is dying can be physically and mentally demanding.

What significant factors are affecting this issue?

The most common underlying causes of death and most commonly mentioned contributory causes that are demanding of end of life care in Kirklees are:

- Cardiovascular disease – the underlying cause of 1 in 3 deaths (31%).
- Cancer – the underlying cause of 1 in 4 deaths (25%).
- Respiratory disease – the underlying cause of 1 in 8 deaths (14%) and mentioned in 1 in 3 deaths (32%).
- Alzheimer’s, dementia and senility – mentioned in 1 in 6 deaths (17%).
- Liver or renal disease – mentioned in 1 in 10 deaths (10%).

The typical profile and trajectory of illness leading to death amongst those aged 18 and over in England is³:

Category	Trajectory	% of deaths
Frailty	Multiple co-morbidities accumulating with increasing age leading to a gradual decline and regular exacerbations before last days. (Dementia, Alzheimer's and senility plus a proportion of other causes of death increasing with age.)	42%
Cancers	Gradual decline and then rapid end stages but without previous exacerbations or sudden changes in need.	21%
Organ failure	One predominant chronic condition with regular or fairly frequent exacerbations and with end of life typically being the result of a crisis and therefore more rapid deterioration in functions. (Includes IHD, COPD etc.)	19%
Sudden death	Any deaths where there was no obvious prognosis until last days. (Includes acute myocardial infarction, stroke, pneumonia, accidents.)	14%
Other terminal	Gradual decline with some exacerbations in initial phase then rapid end stage. (Includes Parkinson's, MND, MS, diabetes and other diseases of the nervous system.)	4%

The proportion of people whose needs reflect the frailty trajectory will increase over time due to improved treatments for other potentially life-threatening conditions and the projected rise in the number of people with dementia (see dementia section).

On average between 2008-2010 more than half of those who died in Kirklees (55%) died in hospital, 1 in 5 (21%) at home and 1 in 5 (19%) in a care home, with the remaining 6% in a hospice. Although over this period the annual rate of people dying in hospital has been falling, and the rate of those dying at home has been increasing. All these reflect the national and regional pictures, but the lowest rate of people dying in hospital nationally is 42% and the highest rate of dying at home is 27%^{4,5}. Approximately 40% of patients dying in acute hospitals do not have medical needs requiring a hospital stay⁶.

One of the aims of the national end of life strategy is to identify all those people who should be on an end of life register⁷. Inclusion on an end of life register is linked to better co-ordination and quality of care for patients approaching end of life.

Around 0.17% of all Kirklees patients are on a GP practice Quality Outcomes Framework (QOF) “end of life” register, the same as regionally and nationally. There has been a year on year increase during 2008-09, 2009-10 and 2010-11. This should be higher as around 1% of a GP practice population is likely to die on average each year, although not all can be anticipated in advance, i.e. meet the “3 trigger criteria” for inclusion on a register. It is expected that prevalence rates should be higher both regionally and nationally than current data suggests⁸. This suggests that adults nearing the end of life diagnosed with chronic long-term illness are at risk of not gaining access to optimal end of life care. This issue is exacerbated for patients with a non-cancer diagnosis. Traditionally end of life services have been provided to cancer patients and excluded long-term conditions⁹. People, particularly care home residents, are frequently admitted to hospital towards the end of their lives “for often futile and distressing treatment”¹⁰.

The excess winter deaths index (EWD) is the excess deaths in winter compared with non-winter months expressed as a percentage. The excess winter death index of around 15% for Kirklees has not changed over the last 10 years. The index increases with age; in 2004-2011 the index for people aged 65-84 in Kirklees was 15.9% and for those aged 85 and over 20.2%. The EWD index for those whose underlying cause of death was respiratory disease was 54.6%, but for circulatory disease it was 16.5%¹¹.

Which groups are most affected by this issue?

Everyone dies, but those with cardiovascular disease, cancer, respiratory disease, Alzheimer’s, dementia, senility or liver or renal disease are those most likely to require demanding end of life care¹².

The gender profile changes with age as female life expectancy exceeds males – by age 75 6 out of 10 (59%) deaths are women, this rises to 2 out of 3 (67%) at age 85 and over. Those who are bereaved are also affected by the death of a relative or friend (see [bereavement section](#)).

Where is this causing greatest concern?

Most people would prefer to be cared for at home, as long as high quality care can be assured and as long as they do not place too great a burden on their families and carers.

Some people (particularly older people) who live alone wish to live at home for as long as possible, although they wish to die elsewhere where they can be certain not to be on their own.

Some people on the other hand would not wish to be cared for at home, because they do not want family members to have to care for them. Many of these people would prefer to be cared for in a hospice; and most, but not all, people would prefer not to die in a hospital¹³.

What could commissioners and service planners consider?

Raising awareness

To tackle the taboo within society about discussing death and dying.

Patient identification

Proactive pre-end of life identification – linking the palliative care register with other long-term conditions registers to identify patients at risk of being at end of life so that discussions and advance care planning can be anticipated, rather than reactionary. This is particularly relevant for patients with dementia but the system needs to recognise the frail elderly who do not easily fit into a long-term conditions definition.

Care planning and co-ordination

Defined role for care planning – this links to the key worker role and multi-disciplinary team meetings with the development of clear roles and responsibilities.

Co-ordinated care: aim to have a single point of access for hospice at home, day care and bereavement services, rapid discharge from hospital, carer assessments, communication with out of hours and ambulance service to ensure smooth transition between services and effective referral mechanisms.

Collaborative integrated model of care: allows flexible, joint working and shared resources across providers.

Lead provider integrated model: envisages one provider co-ordinating all parties who support the end of life care pathway. This is the long-term aim which can be phased as the market develops.

Education

Formal education: supports the upskilling of generalist staff through dedicated training from specialist staff.

Mentoring and coaching model: creates a “buddy” system for generalist staff to learn directly from specialist staff, for example to obtain confidence and competence for the delivery of Information Plans where discussions regarding death and dying are not as familiar to generalist staff groups.

Patient and carer empowerment: so that patients can understand what services are available to meet their needs and carers have the confidence to care for their loved one in their preferred place of care.

Information

Improve the sharing of data to enable co-ordinated care. It will facilitate a more streamlined service, from identifying patients with end of life needs to communicating a patient’s preferences around resuscitation or place of death.

Improving information and support to front line staff and hard to reach groups to ensure that patients and their carers know what services are available to support them and that they do have a choice in where they can be cared for and where they can choose to die.

Date this section was last reviewed

24/07/2013 (PL)

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