North Yorkshire County Council

Scrutiny of Health Committee

1 July 2016

End of Life Care and "Dying Well"

Purpose of Report

1. The purpose of this report is to provide an initial framework for the Scrutiny of Health Committee to embark on an in-depth project to examine End of life Care Services with a view to informing the "Dying Well" priority in the North Yorkshire Joint Health and Wellbeing Strategy (JHWS).

Background

2. This report marks the first stage of an in-depth project which the Scrutiny of Health Committee is going to undertake into End of Life Care (EoLC) across North Yorkshire.

3. In July last year this Committee was consulted on the 2015 Update of the JHWS 2015-2020. The Committee felt there should be a greater emphasis on improving EoLC and supporting friends and relatives deal with bereavement and, in some cases, the longer term problems around isolation and loneliness. The Committee recommended that EoLC should be given greater prominence in the Strategy and that there should be a specific priority - "Dying Well".

4. These recommendations were accepted by the Health and Wellbeing Board.

5. The Public Health team, working with all key stakeholders locally, has recently completed a "deep dive" review of EoLC as part of a programme of work to refresh the Joint Strategic Needs Assessment (JSNA). The JSNA provides the evidence base for organisations to develop their plans in line with the ambitions set out in the JHWS, describing the local picture, in comparison to national data and policy and potential areas for improvement. The document also outlines variations across North Yorkshire: some of these may be appropriate to meeting the needs of local people, others may indicate opportunities for action.

6. Against a background of its involvement last year and work which is now taking place on the JSNA it is timely for the Committee to carry out further work on this topic. The Committee will be working proactively with all stakeholders to influence policy at an early stage rather than operating in the "traditional scrutiny mode" examining proposals from the NHS.

National review by the Care Quality Commission (CQC) - "*A different ending: Addressing inequalities in end of life care*", (Published: Monday 9 May 2016)

7. A national review by the Care Quality Commission (CQC) has found that people from certain groups in society are experiencing poorer quality care at the end of their lives than others because providers and commissioners do not always understand or fully consider their specific needs.

8. The review reports that only 67% of the 40 clinical commissioning groups (CCGs) it surveyed said that they had assessed the end of life care needs of their local populations – meaning that one in three had not.

9. Also, the CQC found that only 18% of the 40 CCGs had commissioned specific services for at least one of the population groups considered in its review – this includes people whose social circumstances make them vulnerable, older people, people with dementia, a learning disability, a mental health problem, or a chronic progressive illness other than cancer.

10. The impact of this could be that local health and care services are not fully equipped or ready to help these particular groups of people in their areas to get truly personalised care at the end of their lives.

11. This could lead to people's wishes not being met or them not having the full range of options of where they would prefer to be cared for and die available to them.

12. For example, an older person may be admitted to hospital in the last days of their life when they would prefer to die at home. While in some areas commissioners and providers are taking an equality-led approach, the review findings raise concerns that some might not be fulfilling their duties under the Equality Act 2010, which states that all public bodies have a legal duty to consider the needs of a range of equality groups when carrying out their day-to-day work.

13. In its national review, CQC is calling for action to make sure everyone has the same access to high quality, personalised care at the end of their lives, regardless of their diagnosis, age, ethnic background, sexual orientation, gender identity, disability or social circumstances.

14. The CQC's overview report is available at:

    http://www.cqc.org.uk/sites/default/files/20160505%20CQC_EOLC_OVERVIEW_FINAL_3.pdf

Methodology

15. The first stages will be for Committee to strengthen its understanding of EoLC services locally and to understand the needs of people who might be nearing the end of their life, including the impact the situation is having on their families and friends.

16. The project will include desk research in terms of pulling together national and local policy guidance, collating and analysis of statistics, and mapping the involvement of the relevant agencies and organisations – statutory and voluntary. Some of this work be undertaken "behind the scenes" by your Scrutiny Support Officer with support from colleagues in other parts of the County Council and from colleagues in NHS. The JSNA will inform much of that work.

17. Members' role will include exploring key issues with stakeholders. It is also envisaged that groups of Members will hold focus group sessions with recently bereaved friends/relatives.

18. Healthwatch North Yorkshire is also looking at EoLC. Joint work is being planned.

19. The project will be overseen by County Councillor Jim Clark, Chairman, working closely with the group spokespersons.

Joint Health and Wellbeing Strategy 2015 - 2020

20. The current version of the JHWS is available at: http://www.nypartnerships.org.uk/CHttpHandler.ashx?id=21125&p=0

21. An extract from the Strategy relevant to this project are shown in APPENDIX 1.

Saint Michael's Hospice, Harrogate

22. Saint Michaels' exists to improve the lives of people affected by terminal illness, both those living with it and their families and carers.

23. As a start of the Committee's engagement work with other agencies on this project Mr. Tony Collins, Chief Executive, will be attending the meeting to summarise the role of his hospice and that of the other hospices across North Yorkshire.

24. Mr. Collins' briefing will include information on mortality and end of life care statistics for North Yorkshire, activity and funding levels of the four North Yorkshire Hospices and agreed strategic directions of clinical commissioning groups and other commissioners. Mr. Collins will also summarise

examples/case studies of good and bad practice and guide Members though through the sensitive issues around EoLC.

25. Mr. Collins has indicated that he will be able to help with a bereaved relatives focus group as his hospice also run a comprehensive bereavement service for adults, children and young people. The hospice often brings together focus groups of the bereaved to examine strategic and policy matters.

26. Mr. Collins has also indicated that he will be able to help arrange for Members to meet with patients focus group, although this is notoriously difficult to navigate.

27. Information from Saint Michael's web site:

Facts and Figures

The difference Saint Michael's makes:

- Saint Michael's improves the lives of people affected by terminal illness and bereavement.
- 1 in 2 people know someone who has been cared for by a Hospice
- We serve the population of the Harrogate district.
- As this population ages, more people are living longer with serious illness, which means more people need our help.
- We currently care for more than 2000 people each year.

The services Saint Michael's offers:

- We offer physical, emotional, psychological, practical and spiritual care to our patients and their families.
- Our services are available to people living with any terminal illness or bereavement. Although a large number of cancer patients use our services, we also care for people with other illnesses, such as chronic obstructive pulmonary disease, Parkinson's, motor neurone disease and end stage heart and lung disease.
- The team at Saint Michael's makes around 18 home visits every day.
- Each year Saint Michael's Hospice offers around 2,700 day therapy sessions.
- We are currently helping around 500 local people live with lymphoedema
- Last year we offered 3,650 days of inpatient care
- Saint Michael's Just 'B' service currently has a caseload of 80 children, young people and adults living with bereavement caused by murder, suicide, disaster and terminal illness.
- All our services are free to patients and their families

The Saint Michael's team:

- Saint Michael's is supported by a volunteer workforce of around 600 people, giving their time, energy and skills for free
- Volunteers outnumber our staff by 6 to 1.
- Our patient care team include doctors, nurses, occupational therapists, physiotherapists, lymphoedema practitioners, bereavement support workers, psychologists, social workers and chaplains.

28. Additional information is shown in APPENDIX 2.

Recommendations

29. That Members:

a) offer any comment/advice on the methodology and on the issues that need to be take into account as part of this project;
b) consider the existing and potential role of hospices in EoLC;
c) note the additional support which has been offered to help the Committee engage with relatives and patients and consider how best to take that work forward.

Report From:

Bryon Hunter, Scrutiny Team Leader

North Yorkshire County Council, County Hall, NORTHALLERTON

23 June 2016

Background Documents: None

Dying well

Why is it important?

In North Yorkshire, although most people would prefer to die in their own home, around half die in hospital. The proportion dying at home will increase, but because of a rise in the death rate, the actual numbers dying in hospital will also increase unless we do something to change this.

There has been a substantial shift towards patient choice with people increasingly encouraged to be directly involved in shaping treatment plans for themselves and their relatives.

Death and dying is now beginning to be debated more openly. Nevertheless it still seems to be the case that, in practice, the discussion of death as an inevitable and, in some cases, imminent aspect of life is regarded as morbid and thus avoided.

Hospital cannot offer the individual the same comfort and familiarity that they might find if they were able to die in their own home and in their own bed, surrounded by the people that they love.

Encouraging conversations around quality of life, how and where a person might want to be cared for, as well as financial issues, helps to make sure the wishes of the person dying are followed. If family know about the dying person's wishes it can help them if they ever have to make decisions about care and can help to remove some of the stress at a difficult time.

This could include exploring options such as hospice care which can provide care for the dying and support for the family provided in a person's own home or elsewhere.

What have people told us that they want from this strategy?

"To consider how bereavement support is provided to grieving friends and relatives."

"Dying well is very important for all ages and providing support to friends and relatives should have greater prominence from all organisations"

What changes can you expect to see?

By 2020, you can expect to see:

- A greater range of support options for people in their last years of life.
- More people receiving support for themselves and their families at the end of life.
- More people dying at home or in the place that they choose.
- Greater numbers of trained staff and carers with deeper understanding about the range of issues in end of life care.
- Adoption of new and emerging best practice and principles around end of life care (Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020 - www.endoflifecareambitions.org.uk).
- End of life care being planned in an effective and sensitively appropriate way, and for staff to be adequately trained.

APPENDIX 2

North Yorkshire County Council Scrutiny Committee
Background Information

The need in numbers
Nationally

- 500,000 people die each year and this is expected to rise by 17% in the next 15 years[1]
- The all-cause mortality is around 29% Cancer, 28% circulatory and 15% respiratory illness[2].
- The % of deaths in 85+ is expected to rise from 32% to 44%[3]
- It is estimated that ¾ of deaths in England are expected and therefore can be supported by end of life care; this is presently 355,000 people, rising to 440,000 by 2030.[4]
- It is estimated that 47% of these deaths are complex and will need the support of specialist end of life care services[5].
- Hospices
    - More than 220 in the UK[6]
    - 90% of hospice care is delivered through day services or at home[7]
    - Around 50% of people say they are concerned that there won't be enough hospice care available in the future[8]
    - The hospice sector supports at least 120,000 patients per year, rising to 360,000 when you consider the family members who are supported[9]. This is likely to be underrepresented due to unmet need[10].
- Over 60% of people would prefer to die at home[11]. However in a recent survey only 34% ranked this as a priority in care instead the priorities in care are 'having as much information as they wanted' and 'choosing who makes decisions about their care'[12].
- VOICES report key findings[13]
    - 43% of people reported that care in the last three months of life was outstanding or excellent.
    - Pain relief was inadequate for 53% of people who died at home, 32% who died in hospital, 25% in care homes and 13% in hospices.

[1] https://www.england.nhs.uk/wp-content/uploads/2014/11/actions-eolc.pdf
[2] 2014 ONS mortality stats
[3] Ibid
[4] Ibid
[5] Ibid
[6] https://www.hospiceuk.org/media-centre/facts-and-figures
[7] Ibid
[8] Ibid
[9] Ibid
[10] https://www.mariecurie.org.uk/globalassets/media/documents/policy/campaigns/equity-palliative-care-uk-report-full-lse.pdf
[11] http://www.dyingmatters.org/sites/default/files/files/NCPC_Public%20polling%2016_Headline%20findings_1904.pdf
[12] British Social Attitudes Survey: http://bsa- 30.natcen.ac.uk/media/36320/bsa_30_dying.pdf
[13] http://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/england2015

- Almost 16% of people reported that services were not well coordinated at the end of life
- Over 16% reported not receiving adequate support despite asking for it.
- 82% of people reported that their loved one died in the right place.

- It is estimated that there are 111,000 people in the UK who would benefit from end of life care but who are not receiving it.[14]
- There have been recognised gaps in services with only 21% of hospitals offering face to face 7 day a week end of life care services and 73% offer 5 days a week.

North Yorkshire End of Life Care

Tables 1/2.[15]

Area of usual residence	Population Number (thousands) All ages			Deaths (numbers) All ages			Rates Crude death rate (deaths per 1,000 population)	Age-standardised mortality rate[1]		
	Persons	Males	Females	Persons	Males	Females		Persons	Males	Females
UNITED KINGDOM	**64,105.7**	**31,532.9**	**32,572.8**	**576,458**	**279,171**	**297,287**	**9.0**	**1,001.9**	**1,176.3**	**867.4**
ENGLAND	**53,865.8**	**26,534.0**	**27,331.8**	**473,552**	**229,291**	**244,261**	**8.8**	**979.2**	**1,149.7**	**847.2**
North Yorkshire	**602.7**	**297.3**	**305.4**	**6,216**	**3,001**	**3,215**	**10.3**	**921.6**	**1,101.2**	**789.1**
Craven	55.5	26.8	28.8	636	288	348	11.5	879.2	1,029.4	769.5
Hambleton	89.9	44.5	45.4	882	405	477	9.8	862.6	958.6	780.7
Harrogate	158.2	77.4	80.8	1,494	731	763	9.4	833.1	1,055.1	678.4
Richmondshire	53.9	29.2	24.7	430	211	219	8.0	918.7	1,070.1	820.7
Ryedale	52.2	25.6	26.6	622	291	331	11.9	983.8	1,106.1	893.6
Scarborough	108.2	52.3	55.9	1,413	700	713	13.1	1,061.1	1,289.0	888.1
Selby	84.7	41.5	43.2	739	375	364	8.7	964.2	1,179.8	802.3

Area of usual residence	Age group All Ages		15-24		25-34		35-44		45-54		55-64		65-74		75-84		85 and over	
	Males	Females	Males	Females	Males	Females	Males	Females	Males	Females	Males	Females	Males	Females	Males	Females	Males	Females
ENGLAND AND WALES[1]	**245,585**	**261,205**	**1,429**	**625**	**2,675**	**1,395**	**5,485**	**3,252**	**12,045**	**8,057**	**24,401**	**16,424**	**47,787**	**33,982**	**77,357**	**70,740**	**72,246**	**125,058**
North Yorkshire	**3,001**	**3,215**	**18**	**12**	**23**	**5**	**48**	**29**	**127**	**81**	**231**	**156**	**542**	**387**	**956**	**850**	**1,040**	**1,683**
Craven	288	348	2	0	0	0	7	2	6	3	19	16	47	39	95	99	111	189
Hambleton	405	477	3	2	8	0	4	0	19	8	32	25	81	55	124	141	130	244
Harrogate	731	763	3	5	3	1	8	7	27	19	62	28	119	68	239	187	267	444
Richmondshire	211	219	3	0	2	0	4	4	3	7	13	14	35	39	72	52	77	100
Ryedale	291	331	2	1	2	1	2	3	14	12	26	19	47	44	93	93	104	157
Scarborough	700	713	3	3	3	3	17	8	35	14	54	42	133	97	220	184	234	362
Selby	375	364	2	1	5	0	6	5	23	18	25	12	80	45	113	94	117	187

The population is 599,708[16] of which it is estimated from national statistics that we expect around 4800 people to die each year of which 3,600 will be expected and require end of life care services.

Number of deaths by usual residence	Apr-15[3]	May-15[3]	Jun-15[3]	Jul-15[3]	Aug-15[3]	Sep-15[3]	Oct-15[3]	Nov-15[3]	Dec-15[3]	Jan-16[3]	Feb-16[3]	Mar-16[3]	TOTAL	Seen at the hospice IPU (number (%)	Seen at the hospice DTU (number (%)	Seen within the community team (number (%)
North Yorkshire	**499**	**496**	**483**	**499**	**452**	**483**	**512**	**545**	**589**	**567**	**571**	**577**	6,273	-	-	-
Craven	52	58	38	56	40	49	46	45	66	58	68	55	631	-	-	-
Hambleton	54	66	71	82	62	83	81	69	77	76	92	90	903	-	-	-
Harrogate	139	118	133	128	125	113	135	132	154	152	138	141	1,608	170 (10.5%)	135 (8.4%)	611 (38%)
Richmondshire	38	33	36	40	26	34	40	37	42	37	44	36	443	-	-	-
Ryedale	40	55	46	42	38	49	46	51	51	57	37	68	580	-	-	-
Scarborough	102	119	100	95	102	104	111	129	118	112	119	108	1,319	-	-	-
Selby	74	47	59	56	59	51	53	82	81	75	73	79	789	-	-	-

[14] https://www.mariecurie.org.uk/globalassets/media/documents/policy/campaigns/equity-palliative-care-uk-report-full-lse.pdf

[15] http://webarchive.nationalarchives.gov.uk/20160105160709/http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-327606

[16] file:///C:/Users/edobson/Downloads/North_Yorkshire.pdf

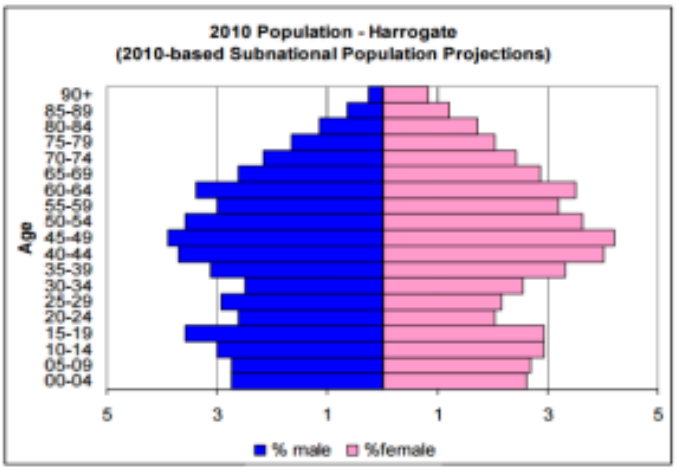
- North Yorkshire has a statistically higher than average[17]:
    - Older population (those above 65, 75 and 85) for males and females
    - Death rate
    - Percentage of deaths
    - Deaths in care homes
    - Deaths from heart disease
- North Yorkshire has a statistically lower than average[18]:
    - Deaths in hospital
    - Residents in urban localities
    - Deaths from respiratory disease
    - Deaths from liver disease
- In North Yorkshire there are 118,617 people over 65, 16,448 over 85. Given the working definition:

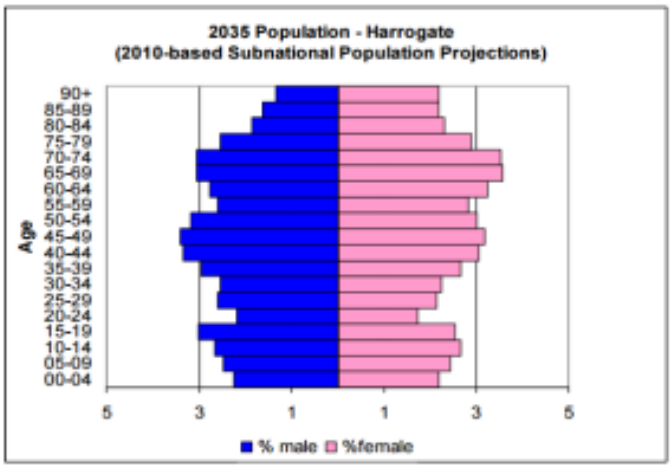
End of life care is care that:
Helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support[19].

We could state that while it has been estimated that 3600 will die within the population each year it is likely that from the 16,448 over 85 some end of life care service will be required and could be required for longer than the last months of life.

Harrogate and District

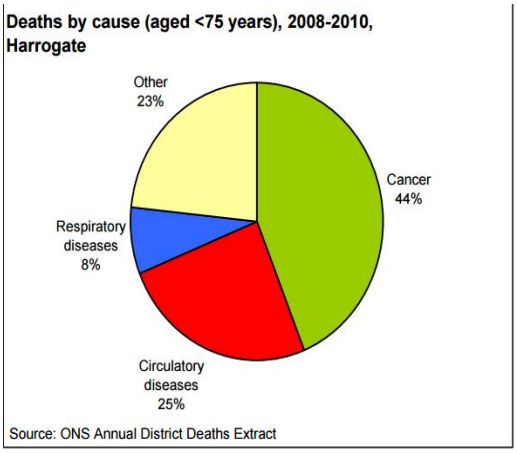
Harrogate has a population of 158,000 with a fairly rural makeup, population density of 121 per km, which is above the North Yorkshire average of 75 but significantly lower than the national average of 401[20]. The age structure of the Harrogate District is detailed below[21].





In the Harrogate District the death by cause is illustrated by the following[22]:

[17] Ibid
[18] Ibid
[19] http://www.ncpc.org.uk/sites/default/files/AandE.pdf
[20] http://www.nypartnerships.org.uk/CHttpHandler.ashx?id=18700&p=0
[21] Ibid
[22] http://webarchive.nationalarchives.gov.uk/20160105160709/http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-327606



The leading cause of death for those dying prematurely (<75 years) in Harrogate is Cancer, accounting for 44% of all deaths.

Hospices are value for money

Hospices provide value for money in two respects firstly the economics:

a) Hospices can support in the reduction of unnecessary admissions[23].
b) Hospices can reduced hospital deaths by 20% each year generating a saving of £80m to the NHS[24]
c) The palliative care funding review for England found:
    a. Extending 'specialist and core' services could result in net savings

Then the outcomes for end of life care provided through hospice care are comparably higher:

a) 88% drs and 85% nurses showed dignity and respect to patients and families in the last three months of life compared with 59% and 53% respectively for hospitals.[25]
b) 85% rated hospice care as good, excellent or outstanding compared to 69% in hospitals[26]

The evidence to note in value for money

a) A review found that home based end of life care services to be inconclusive on cost effectiveness[27].
b) Zimmerman[28] found that in 7 RCT's reviewing cost effectiveness only one study found significant cost savings, this study was based in the USA. The only UK study contained in this report noted that there was no significant difference.
c) SCIE said 'the NHS should have a better evidence based understanding of the relative costs of specialist and generalist care at the end of life, analysed according to place of care deliver'
d) There is a systematic lack of data around cost effectiveness[29]
e) Higginson et al (2009) found that the total costs for providing end of life care were £1789 less expensive than the control group but this was not statistically significant. [30]

[23] https://www.mariecurie.org.uk/globalassets/media/documents/policy/campaigns/equity-palliative-care-uk-report-full-lse.pdf
[24] https://www.hospiceuk.org/media-centre/facts-and-figures
[25] http://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/england2015
[26] Ibid
[27] Cochrane E, Colville E, Conway R (2008) Addressing the needs of patients with advanced non-malignant disease in a hospice day care setting, International Journal of Palliative Nursing, 14, 8, 382–387.
[28] Zimmermann C, Riechelmann R, Krzyzanowska M, Rodin G, Tannock I (2008) Effectiveness of specialized palliative care: a systematic review, JAMA, 299, 14, 1698–709.
[29] https://www.mariecurie.org.uk/globalassets/media/documents/policy/campaigns/equity-palliative-care-uk-report-full-lse.pdf

f) Day care services were inconclusive when examining their cost effectiveness[31]s.

Inequalities in end of life care

The CQC said 'commissioners and providers do not always consider the needs of everyone in their community'[32].

a) Malignant vs Non Malignant
    a. 88% of IPU and 75% of all referrals to hospices are for cancer despite this accounting for only 29% of deaths[33].
    b. There is a trend where non-malignant diagnosis are been referred 12% in 2008 and 20% in 2013. [34]
    c. This trend is translated into generalist end of life care where on average malignant diagnosis had 11.4 GP visits on average compared to 3.9 for non-malignant.[35]
b) Learning disabilities
    a. Less likely to have access to end of life care[36]
    b. Receive inadequate pain control[37]
    c. More likely to have their death described as not being planned for, uncoordinated and poorly managed.[38]
c) LGBTQIA+
    a. 1.6% of the population is thought to be LGBT but estimates have reached up to 6%.[39], this equates to around 800,000 people over the age of 65 who would be LGBT[40], meaning approximately 40,000 would die annually.
    b. LGBT have a higher likelihood of dying due to lifestyle risk factors such as smoking, alcohol and drug abuse which are attributed to stress from marginalisation and discrimination.[41]
d) BME
    a. Evidence to demonstrate that there is a lower uptake of end of life care services within this group.[42] Only 6.2% of BME access palliative care despite 14% population prevalence, this % drops further when you look at the over 65 age range to 4%[43].

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[30] Higginson IJ, McCrone P, Hart SR, Burman R, Silber E, Edmonds PM (2009) Is short-term palliative care cost-effective in multiple sclerosis? A randomized phase II trial, Journal of Pain and Symptom Management, 38, 6, 816–826

[31] Douglas HR, Normand CE, Higginson IJ, Goodwin DM, Myers K (2003) Palliative day care: what does it cost to run a centre and does attendance affect use of other services?, Palliative Medicine, 17, 7, 628–637.

[32] http://www.cqc.org.uk/sites/default/files/20160505%20CQC_EOLC_OVERVIEW_FINAL_3.pdf

[33] https://www.mariecurie.org.uk/globalassets/media/documents/policy/campaigns/equity-palliative-care-uk-report-full-lse.pdf

[34] Ibid

[35] Ibid

[36] Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) (2013). http://www.bristol.ac.uk/cipold/fullfinalreport.pdf

[37] Ibid

[38] Ibid

[39] https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/june-2016/reality-end-of-life-care-lgbt-people.pdf

[40] Ibid

[41] Ibid

[42] Calanzani N, Koffman J and Higginson IJ (2013). Palliative and end of life care for black, Asian and minority ethnic groups in the UK: demographic profile and the current state of palliative and end of life care provision. Public Health England, King's College London and Marie Curie Cancer Care.

[43] https://www.mariecurie.org.uk/globalassets/media/documents/policy/campaigns/equity-palliative-care-uk-report-full-lse.pdf

b. There is evidence that when they do take up end of life care there are poorer outcomes[44]

e) Homeless
   a. They die at 3 times the rate of matched controls in the general population[45]
   b. The average age of death is 40 – 44 years old[46]
   c. Over a third die in hospital[47]
   d. The most common cause of death is multiple organ failure[48]

f) Dementia
   a. 1/3 of people will die from dementia with complex physical and psychological needs[49].

g) Transitioning CYP
   a. There are at least 49,000 under the age of 19 living with life-limiting or life-threatening conditions, this number has doubled in the past decade[50]
   b. Over 2000 16 – 30 year olds die each year[51]

h) Geography
   a. People from deprived socio-economic areas experience poorer qualities of care.[52]

Collaborations to support end of life care

a) Herriot Hospice Homecare
b) Wilfward
c) Dementia Forward

Additional services

- Bereavement
  - Just 'B's caseload is currently 182 including the waiting list
  - Bereavement increases the risk of mortality and poor health which in Scotland was estimated to cost £20 million which when extrapolated to England was between £150 -£190 million[53].
  - The number of bereaved people is likely to increase with the increase in the proportion of elderly people[54].
  - The House of Lords reported that we are 'woefully unprepared' to deal with this[55].
  - Rising funeral poverty will impact where the average shortfall is £1277[56].
  - The National Council on Palliative Care said that just 54% of HWB had considered end of life care and of these very few had considered bereavement as a key driver[57].

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[44] Ibid
[45] Office of the Chief Analyst, Department of Health (2010). Healthcare for single Homeless People. http://www.qni.org.uk/docs/healthcare%20for%20single%20homeless%20people %20NHS.pdf.
[46] Ibid
[47] Ibid
[48] Homelessness and End of Life Care (2013). Report by Marie Curie Cancer Care and St Mungo's
[49] Sampson EL, Burns A and Richards M (2011). Improving end-of-life care for people with dementia. British Journal of Psychiatry; 199(5): 357-9.
[50] http://www.york.ac.uk/inst/spru/news/appgBP.pdf
[51] Ibid
[52]http://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/england2015
[53] http://www.dyingmatters.org/sites/default/files/Life%20After%20Death%20FINAL(1).pdf
[54] Ibid
[55] Select Committee on Public Service and Demographic Change (2013) 'Ready for Ageing?' London: The Stationary Office.
[56] http://www.dyingmatters.org/sites/default/files/Life%20After%20Death%20FINAL(1).pdf

        - This led to Dying Matters to recommend 'Clarity about who is responsible locally for commissioning and providing bereavement support with better coordination and information about services'[58]
- Lymphoedema
    - Saint Michael's current caseload is approximately 480.
    - There is thought to be between 80,000 and 124,000 people living with Lymphoedema nationally which sits it alongside MS and HIV[59].
    - 25% of Lymphoedema is caused due to cancer[60]
    - 97.5% of those in receipt of specialist care stated that their swelling was controlled compared with less than 80% within non-specialist services[61].
    - For every £1 spent on lymphoedema treatments it is estimated that it would save £100 in reduced hospital admissions due to swelling and infection.[62]

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[57] NCPC (2013) Does Dying Matter to England's new Health and Well-being Boards?
[58] http://www.dyingmatters.org/sites/default/files/Life%20After%20Death%20FINAL(1).pdf
[59] Morgan, P.A., Franks, P.J., and Moffatt, C.J. (2005). Health-related quality of life with lymphoedema: a review of the literature. Int Wound J. Mar;2(1):47-62
[60] Lymphoedema: an underestimated health problem. C.J. Moffatt, P.J. Franks, D.C. Doherty, A.F. Williams, C. Badger, E. Jeffs, N. Bosanquet And P.S. Mortimer. J Med 2003; 96:731–738
[61] Lymphoedema: Service Provision and Needs in Scotland. Margaret C Sneddon University of Glasgow, funded by Macmillan Cancer Support. http://eprints.gla.ac.uk/50066/1/50066.pdf
[62] http://www.macmillan.org.uk/documents/aboutus/commissioners/lymphoedemaservicesanevidencereview.pdf

Terms of Reference Table
Board of Trustees

Abbreviation	Meaning
APM	Associate of Palliative Medicine
BME	Black, minority ethnic group
BOT	Board of Trustees
CAF	Charities Aid Foundation
CCG	Clinical Commissioning Group
CNS	Clinical Nurse Specialist
COG	Clinical Operational Group
CQC	Care Quality Commission
CYP	Child and Young Person
DTU	Day Therapy Unit
DV	Domiciliary Visit
EOLC	End of Life Care
HDFT	Harrogate District Foundation Trust
HtH	Help the Hospices
HWB	Health & wellbeing board
IMO	In Memory Of
IPU	In Patient Unit
LCP	Liverpool Care Pathway
LGBT	Lesbian, Gay, Bisexual or Transgender
MDT	Multi-Disciplinary Team
MND	Motor Neurone Disease
OACC	Outcome Assessment & Complexity Collaborative
PCT	Primary Care Trust
QIA	Queer, Intersex & Asexual
ROB	Robert Ogden Building
RCT	Randomised control trial
SLA	Service Level Agreement
SCIE	Social Care Institute of Excellence
SOP	Standard Operating Practice
SW	Social Worker
VVS	Volunteer Visitors Scheme