

P 58

Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd,
Gofal Cymdeithasol a Chwaraeon

Inquiry into the Priorities for the Health, Social Care and Sport
Committee

Ymateb gan: Gofal Canser Marie Curie

Response from: Marie Curie Cancer Care

Marie Curie response to the Health, Social Care and Sport Committee's longer term forward work programme.

Marie Curie welcomes the opportunity to influence the future work of the new Health, Social Care and Sport Committee.

Introduction

At Marie Curie believes everyone should have the right to the palliative care they need.

Yet we know from our research that, even with all the care and support the NHS and its partners provide, 6,200 people across Wales who need palliative care miss out on it each year because their needs are not recognised and they are not referred on to the right services.¹

Marie Curie provides a range of services across of Wales, including:

- A nursing service providing hands on care day and night for people at the end of their lives in their own homes.
- A care home support service in west Wales enabling people to avoid being admitted to hospital who are living in supported accommodation.
- A Freephone advice line offering practical advice and support for patients and their loved ones.
- A 30 bed hospice providing in patient clinical care and day services for people across Cardiff and the Vale and beyond.
- A discharge liaison service in Velindre Trust which supports people returning to their own homes.

In providing all of these and the other services across Wales, Marie Curie makes a financial contribution (usually at least a matching one) out of its own charitable funds to augment those provided by NHS commissioning bodies. All of the clinical services in Wales are provided as a result of being commissioned by the NHS in Wales and all of them would be regarded as core services by the public.

Policy and Legislation

Marie Curie would like to draw to the committee's attention the lack of focus on end of life care by the committee's predecessor/s. There has been a considerable amount of focus by the government on end of life care since the publication of the Sugar Review in 2008. For example they published an end of life care delivery plan which is currently in the process of being refreshed. In setting priorities for primary care the previous Minister identified end of life care as one of three key priorities. Each LHB now has a designated EoL Care lead and is obliged to produce and publish its own EoL delivery plan, (something Health Boards in England are not required to do). We have welcomed this however, we have also drawn attention to the lack of specific outcome based assessment of end of life care in Wales.

Marie Curie firmly believes that everyone who needs Palliative Care should have access to it. There are still too many people nearing the end of their lives not getting the palliative care they need¹. Seven out of 10 carers say people with a terminal illness do not get the care and support they need.

In terms of equity and access the picture is startling. Factors completely unrelated to your illness can also affect how easy it is for you to get the care you need². Access to suitable or appropriate care can be more difficult if you have a disability³, if you are from a Black or Minority Ethnic background⁴ or if you are LGBT⁵. The same is true if you're homeless⁶, in prison⁷, or you're from a deprived area⁸. This simply must improve.

In advance of the May 2016 elections, Marie Curie launched a manifesto which we encouraged political parties and individual candidates to sign up to.

We stated our desire for the next Welsh Government to:

1. Commit to ensuring everyone who needs palliative care has access to it by the end of the next Assembly (the current one).
2. Take a public health, compassionate communities approach to developing new services for those living with a terminal illness.
3. Commit to a bi-annual survey of bereaved people to provide a fuller picture of end of life care in Wales.

As a starting point an inquiry into the available levels of Palliative Care across Wales would be welcome, with a particular focus on equity looking at, but not limited to, the demographics and communities listed above (footnotes 3-8).

NHS England have successfully undertaken three surveys called 'VOICES' which aims to assess the quality of care delivered in the last three months of life⁹ by contacting the individual who registered a death. A pilot study taking a broadly similar approach is being undertaken currently in the Cwm Taf LHB area. We would encourage the committee to both study this pilot and the wider survey in England.

We would also be interested in assisting the committee into an inquiry looking at the role of the care home sector in providing end of life care in Wales. As individuals are living longer and longer, many are dying with more complex illnesses and with patients often dying with more than one condition, we are concerned that in the future residential and nursing care homes will be unable to effectively cope with both the demand in terms of numbers but also to provide adequate care.

We very much hope that the Health, Social Care and Sport Committee will consider enquires into these topics.

We will be pleased to continue to work with Committee to help them understand the issues and improve conditions for patients and their families. We would be happy to give evidence either through written or oral means.

Marie Curie
September 2016

Simon Jones

Director, Policy & Public Affairs
Marie Curie
Marie Curie Hospice, Cardiff and the Vale
Bridgeman Road
Penarth
CF64 3YR

Paul Harding

Policy & Public Affairs Manager
Marie Curie
Marie Curie Hospice, Cardiff and the Vale
Bridgeman Road
Penarth
CF64 3YR

1 On behalf of Marie Curie, Ipsos MORI interviewed a quota sample of 1,067 adults aged 16-75 online who had cared for a family member, friend or neighbour who was, or is, terminally ill in the last three years. This sample was screened from a nationally representative sample of 6,136 online adults aged 16-75 within the UK. Interviews took place between across the UK using i:omnibus, Ipsos MORI's online omnibus between 3 and 29 October 2014. Data are weighted by age, gender, region, working status and social grade to match the profile of the target audience

2 Dixon J. et al. (2015). *Equity in the provision of palliative care in the UK: Review of evidence*. Personal Social Services Research Unit, LSE. March 2015.

3 Marie Curie Policy and Public Affairs (2014). *The experiences of caring for disabled people at the end of life*. Marie Curie, 2014 [unpublished]

4 Calanzani et al (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*. June 2013.

5 Fuller et al (2011). *Open to all? Meeting the needs of lesbian, gay, bisexual and trans people nearing the end of life*. National Council for Palliative Care, Consortium of Lesbian, Gay, Bisexual and Transgendered Voluntary and Community Organisations.

6 Davis et al (2011). *Are the homeless dying without access to palliative care?* BMJ 2011;342:d3018.

7 Peacock (2014). *Dying in prison: 'Both sides of the fence' study*. eHospice, 12 June 2014. Online at – <http://www.ehospice.com/uk/ArticleView/tabid/10697/ArticleId/10878/language/en-GB/View.aspx>

8 Barnet et al (2012). *Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study*. The Lancet 2012 Jul 7;380(9836):37-43

9. <http://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/previousReleases>

10. <http://www.cwmtafuhb.wales.nhs.uk/sitesplus/documents/865/AI%203.2%20Appendix%205%20End%20of%20life%20care%20delivery%20plan%20UHB%2027%20Jan%2020161.pdf> (Page 13, paragraph 4)