

[Inquiry into the progress made to date on implementing the Welsh Government's Cancer Delivery Plan](#)

Evidence from Marie Curie Cancer Care – CDP 19



April 2014

## **Inquiry into progress made to date on implementing the Welsh Government's Cancer Delivery Plan**

### **1 A response from Marie Curie Cancer Care**

1.1 Marie Curie Cancer Care welcomes the opportunity to report its views in this response to the Health and Social Care Committee's inquiry into the progress made so far on implementing the Welsh Government's Cancer Delivery Plan.

1.2 Marie Curie provides hospice and community-based care and support to terminally ill people, their families and their carers in Wales and the rest of the UK. In the last year, just under three-quarters of the people our nursing service supported in the communities of Wales (about 1,300) had a cancer diagnosis.

1.3 We obviously welcome the fact that cancer survival rates in Wales continue to improve, but the needs, wishes and care of those whose illness does become terminal must not be overlooked. In this response, we raise concerns regarding whether enough is being done to achieve two of the plan's five outcomes for people diagnosed with cancer who require palliative care in Wales. These are:

### **2 Putting people with terminal cancer at the heart of care (Outcome 4)**

2.1 This year's publication of the Wales Cancer Patient Experience Survey represents a positive step towards ensuring people's views on services are sought and can be used to plan and inform future improvements. Yet this survey tells us very little about the experiences particular to those with terminal cancer as they reach the final stages of their lives. At present there is no satisfactory system in place to ensure that the views of these people and their families and carers can be effectively heard.

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2.2 To improve outcomes in relation to Caring at the End of Life, the Cancer Delivery Plan sets out that LHBs are to 'Support participation in cancer patient experience surveys, in particular the iWantGreatCare survey of palliative care patients and their families', and Health Boards have made improvements to this end (as stated in the Cancer Delivery Plan Annual Report for 2013). However, Marie Curie has serious concerns about this method for the following reasons:

- Very low response rates
- Significant, unmonitored variations in survey distribution, skewing responses
- Ratings of care typically very high, therefore the data cannot inform service improvements and may even obscure matters of concern
- Limited scope of questions asked
- Failure to collect patient characteristics for important analysis, e.g. effects of gender, diagnosis, area deprivation

2.3 Over the coming weeks Marie Curie will be putting together a full report on how we can better listen to the voices of those who use palliative care services in Wales, including the introduction of a VOICES-style survey of the bereaved as is done to great effect in England. Without a reconsideration of the current approach, we are at risk of developing serious blind spots with regards to the range of needs and experiences of the nearly 9,500 people who die with a cancer diagnosis each year. This knowledge is vital to delivering well-planned person-centred care and thus achieving the outcomes set out in the delivery plan.

**3 Ensuring people approaching the end of life feel well cared for and pain and symptom free (Outcome 5)**

3.1 There is still much to be done to ensure that people's needs and wishes are properly recorded and given a central role in guiding the end of life care pathway. Identifying that a person is in their final 12 months of life can be very complex, however it is essential that the number of people who are on a palliative care register is significantly improved. This is recognised in the Welsh government's End of Life Care Delivery Plan. Yet less than half of those who died with a cancer diagnosis in 2013 had been given a palliative diagnosis or treated within the speciality of palliative medicine, meaning that potentially 5,000 people missed out on the most appropriate and effective care for their needs.

3.2 It is crucial that more is done to encourage Advance Care Planning (ACP) so that more people have appropriate plans in place which will support them to receive care and die in the place that they choose. However, there must also be adequate services in place to make sure that people who decide to remain at home are well cared for and pain and symptom free. Of the 46 Welsh GPs who responded to a recent survey commissioned by

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Marie Curie and Doctors.net.uk, only 40% felt that the majority of their patients being cared for at home in the final three months of life were completely free of pain all of the time. Less than a third felt that patients were able to get adequate access to care at night and weekends.

3.3 The just under 9,500 people who died with a cancer diagnosis in 2013 accounted for over 20,300 emergency admissions which in turn led to over 240,000 bed days in their final year of life. Admission to hospital can be incredibly stressful for a dying person, and may well be clinically unnecessary. It is also very costly, not just financially, but in terms of the impact on the terminally ill person and their family.

3.4 Whilst we are pleased that the Cancer Delivery Plan Annual Report 2013 provides some evidence of improvements in the end of life care provided to people with a cancer diagnosis, Marie Curie believes that there is much more that needs to be done to make sure everyone with a terminal illness is able to live their final days with dignity and free of pain. It is also essential that the views and experiences of those with terminal cancer and their families and carers are more effectively sought and understood if informed service development and improvement is to be achieved.