

Briefing for Assembly Members: Assembly Debate on the Liver Disease Delivery Plan, Tuesday 12 May 2015

11 May 2015

Purpose of this briefing:

To provide Assembly Members with further information regarding palliative and end of life care for people with liver disease in Wales in advance of this debate.

What do we know about the needs of people with chronic liver disease?

Over 400 people die each year in Wales from chronic liver disease. In contrast to almost all other causes of death, the mortality rate for this condition for people aged under-65 is increasing.

Unlike terminal cancer, chronic liver disease often has no clear terminal phase. This means decisions about when to introduce palliative and end of life care can be complicated. People with liver disease may benefit from palliative care delivered in parallel with disease-focused treatment, but evidence suggests they often miss out.

Research funded by Marie Curie at University College London found that people with liver disease are typically not referred to palliative care until they are in the last few days of life and, of the 30 patients reviewed, all died in hospital. Planning for end of life care is also often limited with intensive treatments pursued instead. Although this research was carried out in England, there is no reason to assume that people with liver disease in Wales do not face similar problems with late referral to palliative care and limited support with end of life care planning.

What does the delivery plan say about palliative and end of life care for people with a terminal liver disease?

Delivery Theme 4, 'Living with liver disease', includes that "where appropriate, early discussion and arrangements should be made for palliative and end of life care" for people with chronic liver failure (p18). The plan includes a priority action to "support the provision of palliative care services for patients with chronic liver failure" (p19).

What would you like me to do?

We would be very grateful if you could use this opportunity to raise the importance of ensuring that the palliative needs of people with chronic liver disease remain a firm priority as the delivery plan is implemented. This requires targeted action within each health board's delivery plan, including:



- a robust measurement of levels of met and unmet need for palliative care in this group, which is reported on in the delivery plan annual report, to guide effective service planning;
- a commitment to providing appropriate training so that everyone involved in a person's care can recognise the signs that they may benefit from palliative care and support with end of life care planning as early as possible.

Marie Curie is here to help. We provide community nursing, hospice care, information and support, and volunteer-led support services to people affected by terminal illness and we are campaigning to ensure that everybody affected by terminal illness gets the care and support that they need to live well for as long as possible in the place of their choice.

If you have a constituent who needs information about living with a terminal illness, either for themselves or a loved one, then please point them in the direction of the Marie Curie Information & Support service, which can be reached by phoning 0800 090 2309 or through www.mariecurie.org.uk/help.

If we can provide any further information about how to improve care for people affected by terminal illness in your constituency, then please do get in touch:

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We're here for people living with any terminal illness, and their families. We offer expert care, guidance and support to help them get the most from the time they have left.

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Care and support
through terminal illness