



**bwrdd gweithredol
gofal lliniarol cymru**
**palliative care cymru
implementation board**

The Neuberger Review of the Liverpool Care Pathway July 15th 2013

Wales Palliative Care Implementation Board - Response July 15th 2013

This interim response has been compiled to act as a support for professionals in Wales who will need to address concerns that may be raised regarding the Neuberger review of the Liverpool Care Pathway by colleagues, patients and the wider public.

The Palliative Care Implementation Board Interim response:

The Palliative Care Implementation Board (PCIB) welcomes the Neuberger report on the Liverpool Care Pathway (LCP) and will use the recommendations within the report to review arrangements in place in Wales to care for patients and their families at the End of Life. The Board particularly welcomes the recommendations relating to how care is provided for elderly people as they approach the end of life. Work in Wales to address this area of concern has already commenced following a request by the Minister for Health and Social Services Mark Drakeford to Baroness Finlay to begin a National Conversation on how we care for elderly people, looking at the changing needs of an ageing population, with a specific focus on the older persons experience of unscheduled care throughout Wales.

Benchmarking Wales to the Report

Report comment: The report upholds the core principles of good end of life care upon which the LCP was developed. However it recommends the term Liverpool Care Pathway is abandoned altogether.

Response: Wales is the only country within the United Kingdom where the LCP is not used, having adopted an Integrated Care Priorities approach. Based on the same sound principles as the LCP, the Integrated Care Priorities for the Last Days of Life was developed to clarify issues around sedation, hydration and range prescribing. The approach focuses on patient centred care, reflecting the importance of ensuring that the patient's and families' "priorities" are elucidated and met, keeping the focus of care very much on their wishes. The "Integrated Care Priorities" document is available online accessible to the public.

Report comment: Unavailability of suitably trained staff, no access to proper palliative care advice outside of 9-5 Monday to Friday.

Response: Seven day working by Clinical Nurse specialists and access to Special Palliative Medicine advice 24/7 365 days a week was made available throughout Wales in 2009 and is now embedded within core End of life services. This was followed with a National End of Life Care Helpline launched in 2012 to support patients and their families who were concerned regarding the care being received.

Report comment: Prospective testing of the LCP has not yet been carried out after nearly 10 years of its dissemination.

Response: The continual cycle of the Last Days of Life Audit in Wales, carried out since 2000 has enabled analysis, reassessment and redesigning of the Integrated Care Priorities approach. Evidence accrued over 12 years from 27,876 patients cared for using the Integrated Care Priorities approach, demonstrates care delivered is of high quality. The latest analysis of 2124 variance sheets from all sites using the ICP in Wales shows that variances related to pain, agitation and excess respiratory secretions or rattle remain dominant. The audit cycle is continually being reviewed to improve quality of data. The use of this 'real-time' audit has provided a mechanism to further audit any areas of concern that may be highlighted. An annual meeting is held in 3 areas across Wales by the Last Days of Life Audit team, offering all professionals the opportunity to update themselves and comment on the use of the ICP.

In view of the Neuberger report, published yesterday on the Liverpool Care Pathway, we shall be working with colleagues across Wales, to review our guidelines in the interests of high quality patient care.

Report comment: Fully independent assessments of End of life care in England are required, focusing on the outcomes and experience of care, as reported by patients, their relatives and carers, as well as the quality of dying.

Response: All patients and their families and have the opportunity to comment on care while it is being provided and following the patients death through the National 'I want great care survey' This feedback is used to review and revise the way care is delivered. End of Life Care Peer Review was introduced in 2012; to date 3 services have been reviewed with the intention to review all services by 2015.

Report comment: Further research into the biology and experience of dying is needed.

Response: In Wales the Marie Curie Centre for End of Life Care research leads on developing studies to improve patient care and recruiting patients into these studies. The work to date has seen 294 patients recruited into a portfolio of trials that include, quality of life, quality of care and symptom management outcomes. No study into the biology of the last days and hours has yet been undertaken in Wales, but the opportunity exists for closer collaboration between the University departments of biochemistry and clinical teams in Wales. This provides an important research area to be developed.

Report comment: Care of the dying requires not only substantial technical knowledge and clinical skill, but above all it needs excellent communication skills. Adequate training and continued support is the key to getting this aspect of care right.

Response: Training in Wales has been encouraged and supported through the Diploma in Palliative Medicine, Communication Skills courses and the GP short course, a total of 312 GPs have enrolled on the course since it started in 2009. Concern that there is inadequate curriculum time for care of the dying has already been raised with the healthcare schools; this will be followed up again.

A full formal response to the Neuberger review of the Liverpool Care Pathway will be provided following consultation with providers in Wales. In the interim any queries regarding this work can be addressed to veronica.snow@wales.nhs.uk