

Open Access Online Resource

‘Widening Access to Palliative and End of Life Care for People with Intellectual Disabilities’

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(From left to right- Karen Charnley, Director of All Ireland Institute of Hospice and Palliative Care, Professor Donna Fitzsimons Head of School of Nursing and Midwifery, QUB and Dr Dorry McLaughlin, Formerly Lecturer in Palliative Care and Chronic Illness, School of Nursing and Midwifery, QUB)

‘Widening Access to Palliative and End of Life Care for People with Intellectual Disabilities’ is an evidence-based, open access, online resource with a strong service user perspective, which aims to promote optimal palliative and end of life care for people with intellectual disabilities in any care setting. The development of this resource was led by Dr Dorry McLaughlin, Lecturer in Palliative Care and Chronic Illness, School of Nursing and Midwifery, Queen’s University, Belfast and was undertaken in partnership with Ulster University, All Ireland Institute of Hospice and Palliative Care (AIHPC) and through consultation with an expert reference group. This resource is targeted specifically at the palliative and end-of-life care educational and training needs of Health and Social Care Professionals. These training needs were identified from the findings of a doctoral research study within which information was collected from people with intellectual disabilities, active and bereaved family carers and Health and Social Care Professionals. The resource brings together good practice standards and published international research findings. Examples of good practice, in relation to end of life care for people with intellectual disabilities, some of which have been

nationally recognised are also highlighted within the resource. Dr Dorry McLaughlin said 'Grateful thanks to the AIIHPC for funding both the development of this resource and an educational fellowship. This funding enabled me to visit Scotland to gain insights into two nationally recognised examples of best practice for end of life care of people with intellectual disabilities, which are signposted and video podcasted within this online resource. A big acknowledgment to Matt Birch, E-Learning Developer, QUB for his expertise, time, advice and contribution to the development of this resource. I am also grateful to the HSC Research and Development Division in Northern Ireland for funding my Doctoral Fellowship at Ulster University, which enabled me to research this area of practice and to develop a DVD and Manual, most of which is now embedded within this resource. It is hoped that this resource will play a meaningful part in enabling people with intellectual disabilities, and those who matter to them, to have equity of access to palliative and end of life care and that Health and Social Care Professionals, across care settings, will be empowered in promoting 'a good death' for this group of people.

Professor Donna Fitzsimons, Head of School of Nursing and Midwifery, QUB said 'I am delighted to see the development of such an innovative educational resource within the School. Dr Dorry McLaughlin's leadership and dedication to this issue has ensured the translation of research knowledge into a very practical and much called for tool. I hope it will be widely disseminated and have a real impact on palliative and end of life care for people with intellectual disabilities'.

Karen Charnley, Director of AIIHPC said 'I am delighted that the Institute was able to support Dr Dorry McLaughlin to develop this valuable online educational resource, which will support Health and Social Care Professionals with providing palliative and end of life care for people with intellectual disabilities.'

This open access, online resource can be accessed through the AIIHPC Palliative Hub Learning Platform by clicking on the following link:

<https://learningplatform.thepalliativehub.com/course/view.php?id=72>

Some comments from professionals who have used this online resource can be seen below:

'Extremely useful- excellent starting point-very informative introduction to the area- confidence building'

'Excellent resource to support learning'

'Very practical-lots of good resources and best practice advice'

'There was information that I would apply to my practice- would recommend to my colleagues'

'Person-centered and holistic approach uniting both areas'

