“Have your say on research priorities for end-of-life care”

Palliative care helps people with advanced, progressive, incurable illness to live as well as possible until they die. It includes management of pain and other symptoms as well as the provision of psychological, emotional, social, spiritual and practical support. As nurses, most of us will have had some experience of providing this support to patients and their families.

Unlike in many other clinical areas, much of our practice in palliative and end-of-life care is not supported by good evidence. It is an under-researched area and requires greater attention. There are many unanswered questions to be addressed.

With scarce resources, it is important that researchers and research funders strive to answer the questions that will bring direct, tangible benefits to patients, carers and health and social care professionals - those who the research is intended to benefit.

To this end, Marie Curie Cancer Care has come together with many other organisations to launch a groundbreaking partnership facilitated by the James Lind Alliance, a non-profit making initiative that aims to identify and prioritise “unanswered questions” about treatments. The Palliative and End of Life Care Priority Setting Partnership is co-funded by 10 partners including the National Institute for Health Research, the Motor Neurone Disease Association, the Chief Scientist Office in Scotland and the National Institute for Social Care and Health Research in Wales. The project will establish what palliative and end-of-life care research is important to people who are likely to be within the last years of life, their families and the professionals who work with them.

This means that for the first time, people directly affected will get the chance to have their say in setting research priorities for palliative and end-of-life care.

With these priorities in mind, research funders can better direct their resources to bring tangible benefits as well as evidence-based treatments to patients, as well as benefit their carers and health and social care professionals. We hope the project will shape the palliative and end-of-life care research priorities and act as a catalyst for more funding opportunities for research in this area.

We have gathered responses from 1,400 patients, carers and professionals and are analysing this valuable data. We have received questions on access to services, how best to manage symptoms and medications, and ways to address communication needs, among many others. Soon we will launch a prioritisation survey to shortlist the research questions to identify those that are of the highest priority. We will then hold workshops in the autumn that will determine the top 10 interventional research priorities for palliative and end-of-life care. A report with the results will be published in January 2015.

To keep up to date with the progress of the project or to take part in the prioritisation survey or workshops, email PeolcPSP@mariecurie.org.uk or call 020 7091 4153. See www.palliativecarepsp.org.uk.

Dee Sissons is director of nursing at Marie Curie Cancer Care.

Eye drops are as important as other drugs

Drug administration is a core nursing skill. Yet how much attention is given to topical administration of eye drops and eye ointments?

Drops and ointments are the main treatment for most eye conditions and it is vital that patients achieve the maximum therapeutic effect from them. The author of our article on page 16 explains why eye medication must have the same priority as drugs administered systemically.

The standards for topical eye treatment administration are the same as those for other routes, and nurses must know about these treatments’ therapeutic effects, side-effects and interactions.

Many of us have struggled to administer eye drops and ointments to patients who find them difficult to tolerate and this article offers some useful tips to help overcome these barriers to effective treatment.

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