CENTRE FOR THE PROMOTION OF EXCELLENCE IN PALLIATIVE CARE

Informing Practice, Transforming Care

Annual Report 2012-2013

Introduction

The Leicestershire and Rutland Hospice (LOROS) and De Montfort University established the Centre for the Promotion of Excellence in Palliative Care (CPEP) to influence the quality of palliative care for people approaching the end of their life and the support provided to their friends and families. The launch at the House of Commons in March 2012 provided a wonderful platform for the subsequent 12 months and this report provides an overview of the many achievements of CPEP's first year.

Providing world class education and undertaking research on a multi-professional basis to inform practice are central to the delivery of CPEP's mission. Simultaneous to these, raising the profile of the importance of palliative and end of life care amongst the general public, the wider health and social care community, both locally and nationally, is an equally important role for CPEP.

CPEP is focussed on improving practice and thus the transformation of care. Excellence in the palliative, supportive and end of life care for patients and their families drives our work. The CPEP operational group has established its membership and terms of reference (see appendix*). Alongside core members from DMU and LOROS the group includes a researcher from University Hospitals of Leicester and a lay member with experience as a carer. Vacancies remain to be filled for student members to further inform the work.

Achievements

It has been an exciting and challenging first year for CPEP. During this time the relationship between two different organisations settled and the partnership 'found its feet'. The year has led to a better understanding of organisational values and a clarification of the mission and purpose of CPEP. The new understanding has also laid new ground and paved the way for a successful future. The key achievements are briefly discussed.

1. Profile Raising Activities

Launch at the House of Commons

This event was supported by a broad range of health and social care professionals including many involved in workforce development. The event provided an effective platform to publicise the anticipated work of CPEP amongst a large number of key contacts. Several approaches were made to CPEP on the basis of the profile raised by this event.

The event also allowed the partnership to be celebrated more widely in the two organisations with staff from a range of departments attending and enjoying the evening. This has lead to a more nuanced understanding of the intentions of CPEP and has opened doors and opportunities.

Specialist palliative care practitioner open door lunch

28 health and social care professionals from across Leicestershire and parts of the East midlands came to see what was happening at CPEP. The event was informal and networking was a key feature. Many new contacts were made for CPEP enhancing our mailing list as well as providing a number of follow-up opportunities to explore possible future developments. The role of CPEP as a place where practitioners might go to be informed and network with others seemed to be both formally and informally supported.

The event was supported by a pharmaceutical company providing refreshments.

A selection of feedback from the event is given below:

What are the challenges that you face in your work with people with palliative care needs?

- *Increasing numbers of children living longer with life limiting conditions and how we provide support to his over a longer period of time with increased clinical needs.*
- *Children's respiratory palliative care; working closely with Rainbows.*
- *Not being aware of prognosis/aims of treatment co-ordinated care. Sudden deteriorations.*
- *Expectations, patient and carers perceived thoughts on the subject.*
- *Reducing hospital admissions. Raising awareness with non-cancer professionals and general public and family focus approach.*
- *Making contact with patients earlier in their illness*

What do you perceive the priorities are in palliative care especially with respect to
a) education?

- *Identification of care education & training needs of workforce*
- *Transferring knowledge / skills into practice.*
- *To educate primary care professionals to a) enable "a good death" through underpinned practice*
- *Formalising codes of practice, consultant acceptance of palliative care.*

b) research?

- *Research around success of what already taking place and to identify areas needing more development.*
- *Research into pain management and psychological aspects of caring for someone life limited (especially children and young people).*
- *Linking the 2 together but to be relevant to current issues and practice i.e. dementia.*
- *Using research to achieve the education priorities*

How can CPEP most support you in your role?

- *Share learning and provide learning opportunities.*
- *Enhancing the value of research use in practice. Help to set valuable standards that mean something.*
- *Education / training / support / research.*
- *Forming alliances (where appropriate) to cross-fertilise skills, expertise and knowledge to co-create.*
- *Guidance on link to research, overall links, information sharing.*

How should CPEP work with the general public?

- *Engage them – provide lots of opportunities to find out more.*
- *Kept in touch with current research and priorities and working with children's issues.*
- *Promotions in unexpected places 'normalize death' – help see realistic situations. Work with other national initiatives and locally.*
- *Raising awareness of end of life.*
- *To demystify death and dying.*
- *Awareness-raising through local events / programmes workshops etc.*

How would you like to be involved or linked with CPEP?

- *Happy to be part of education / training development for children's palliative care and young people.*
- *Opportunity to share own areas of interest with others and raise profile of children and young people and families in palliative care*
- *Research opportunities.*
- *Regular contact / support / keep up to date / education.*
- *To gain an understanding and be aware of how this can work in line with mandatory training.*
- *Meet to explore possibilities.*

Official opening and inaugural lecture

Professor Mayur Lakhani, a local GP, who is also Chair of The National Hospice Council and previously President of the Royal College of General Practitioners, opened CPEP, unveiling a brass plaque. The CPEP room is on the 7th floor of Edith Murphy House. Key stakeholders attended the opening ceremony from LOROS and DMU and educators and researchers in palliative care across the East Midlands.

A 'café' event preceded the lecture. The ambition had been that lay members of the public, linked to organisations such as Age UK would attend but this was not achieved. It was attended by 30 local health and social care professionals, mostly working in fields other than palliative care and some of whom were nursing students at DMU. However, participants had a fruitful discussion exploring the priorities in improving the palliative, supportive and end of life care for patients and their families .

Those attending the café event were asked to offer their thoughts on four questions. Work such as this helps CPEP to develop a grounded approach to its strategy. A selection of the responses is given overleaf…

Thinking about a care professional you have met, describe what it was that they did or what it was about their manner which made the experience positive

- *They spoke to me in a way I could understand using the language of a human and not a medical dictionary. They allowed time to ask questions and check my understanding.*
- *Felt they listened and heard what was said. Gave time for you to tell your story. Showed compassion/empathy. Plan of care that could be understood.*
- *Honesty kindness, included everyone involved in care – holistic assessment.*
- *The friendliness and openness of the person, the fact I was treated as part of the conversation and care.*
- *They seemed interested in me; they listened to my needs, offered to give me information and support.*
- *They showed they cared by listening and spending time with the patient, they seemed to know that they made a difference by just being there, holding a hand, stroking they head. They didn't just do what they had to do they went the extra mile and responded to the patient by answering questions properly and with honesty.*
- *Illustrated problems using diagrams. He was aware that in our distressed state it was difficult to process so many details. Visual presentation helped. We felt respected when he showed my grandfather's scans.*
- *Made me feel that I was the most important person in that few moments. Listened properly.*
- *Listened to the questions that family members asked. Did not make assumptions about a patient's wishes/expectations*
- *They did what they said they would, they were honest and if they didn't know they found out. Good listener*
- *Smiled when greeting me, they explained and signposted me in what was going on. They made no assumptions even though I am a nurse. 'Can do' attitude.*
- *They were happy to question their practice, reflect on it and improve their standards. They were able to admit when things didn't go well and want to resolve it.*
- *Not imposing their views. Being empathetic – trying to understand the experience from the patient's perspective. Understanding that all children are different – that age does not necessarily dictate understanding.*

If you were in a position of being able to influence care professional training, what would you include in their training programme?

- *Promote individuality and holistic awareness*
- *Raise awareness – I don't believe that empathy is easily taught – I am not certain if this is possible actually – but awareness of common concerns and problems others may face is possible.*
- *Touch, importance. Helping relatives to touch and provide comfort. Encouraging relatives to be more involved. Cultural shift. Carers are forgotten systems.*
- *Hearing good experiences from patients is more important/as important as hearing horror stories – we can learn from what is already good. Listening to patients – already included in training, not always done.*
- *How they would want a family member to be treated. Simulation.*
- *Communication skills and the importance of touch. Having been on the other side I was grateful that someone used the word dying. Something that people fail to do.*
- *Teaching healthcare professionals to not make assumptions and ask leading questions that may influence decisions*

What kind of questions should research in palliative care be investigating?

- *How to "sign post" be central point to give information/care.*
- *Why nurses are no longer "nurses" and why are they academic driven not care driven?*
- *In an environment of such low morale, an ever increasing system of stress, how do we keep fighting for our patients?*
- *How can the experience for carers be improved? Is early planning helpful? What title aspect can help?*
- *Impact of multiple illnesses on patients and family. Lived experiences of carers caring for dying patients. Has to recognise, prevent and manage stress and bereavement among HCP.*
- *What is important to the patient and their family?*
- *How proactive are care professionals in delivering care.*
- *Older people – why are their needs not always met.*
- *How can we provide the same person centred care to all end of life/palliative care patients regardless of ages, gender, culture, religion and sexuality*
- *What is patient experience? What do patients want at the end of life? What is important?*
- *Patient satisfaction. Quality of life improvement. Admissions avoidances. Achieving outcome measures.*
- *What really makes a positive end of life experience for both patients and families?*
- *Patient/relatives/carers experiences into what is a 'good death'.*
- *Dispelling myths. Being able to talk about 'death' openly.*
- *What is means to be a true professional – qualities; what are the links to personality types. How do we manage the systems?*

How could CPEP engage the general public in its work?

- *Hold public meetings and invite viewers and colleagues. Involve the public in talking about death and dying. Make death a practical as well as social priority.*
- *Asking for stories – patients and carer stories are very powerful and then sharing those stories.*
- *GP groups. Ward representatives*
- *Market the purpose/function/invite opinions – not necessarily the experience of receiving care but rebate about the subjects that generate polarised views e.g. euthanasia, assisted dying.*
- *What is important to carers and patients? Open days and ideas sharing at events linked to the hospice and university.*
- *Forums, study groups, workshops.*
- *Patient/career groups. Representation at steering groups. Surveys etc. Discussion forums.*

The inaugural lecture was delivered by Professor Mike Nolan from the University of Sheffield. His lecture "New ways to create partnerships promoting excellence in palliative supportive and end of life care" explored how academic units can engage with older people to improve the quality of the care they receive. The lecture attracted an audience of diverse background including student nurses, nurses and other health professionals in palliative care and related specialties, researchers and educators.

Macmillan financially supported the events.

Care and Compassion

CPEP contributed to events at DMU from 8-11th May 2012 emphasising the importance of care and compassion within health and social care professions. The week was an opportunity to showcase developments occurring within a wide range of care settings.

Friday 11th May was given over to exploring care and compassion specifically in relation to palliative and supportive care. CPEP was heavily publicised during this event. Collaborative educational projects were showcased that had increased the confidence and competence of nurses and other professionals in the care of people at the end of life. There was a workshop discussion on care and compassion in palliative care followed by Professor Jayne Brown's inaugural lecture entitled "Compassion; A Virtue but no Substitute for Justice"

Twenty four people attended the displays and workshop discussion and 47 attended Professor Brown's lecture.

2. Research Activities

Most excitingly Professor Jayne Brown, Professor of Palliative Care commenced in May 2012. She successfully bid for a ***PhD studentship*** with Dr Faull. The post attracted 6 applicants and the successful candidate started in October. Sadly for personal reasons the student has now resigned and the post will be recruited to for autumn 2013.

A 2 year ***medical education fellow*** was funded by the East Midlands Health care workforce Deanery and Dr Richard Kitchen commenced in post in October 2012. Dr Kitchen is undertaking a Masters in Medical Education at De Montfort University, supervised by Dr Simon Moralee. His research is focussing on improving decision making by surgeons and anaesthetists for frail patients with surgical problems, supervised by Dr Faull with Dr Rakesh Patel at the University of Leicester and Professor Gordon French at the Healthcare Workforce Deanery.

In January 2013 a ***Macmillan clinical academic nurse researcher*** was appointed. This is a permanent post jointly appointed to the UHL palliative care service and CPEP. The ambition is for the researcher to work clinically in the palliative care team and academically work towards an NIHR postdoctoral fellowship grant based on research questions coming directly from practice .

Leicester City Clinical Commissioning Group (CCG) has commissioned a programme for improvement in the end of life care provided for their patients. Three GP's have been recruited to be mentors to practices in their locality to support them in implementing the locally enhanced service. The ***GP mentors*** are supported by Dr Faull and team at LOROS and have enrolled in a Masters in Palliative Care Module. Their honorary appointment with CPEP supports a longer term relationship with both educational and research ambitions.

Leicester City GP's end of life baseline evaluation - £20k

Professor Brown and Dr Faull were successful in a £20,000 bid to Leicester City CCG to provide a baseline evaluation of end of life care in primary care. The funding has allowed recruitment of two part-time researchers. The work will be completed in May 2013. The CCG is planning to call for an on-going evaluation and it is hoped that the group can continue this work.

Evaluation of the Trainee Assistant Practitioner Role - £10k

LOROS was funded by the Healthcare Workforce Deanery to work with Leicestershire Partnership Trust to pilot a novel service delivered by Assistant Practitioners. Professor Brown was asked to undertake the evaluation of this with funding of £10,000 which has supported employment of a part time researcher. The work will be completed in April 2013.

ENTER - Enabling Nurses To Engage in Research- £10k

In February 2013 a 2 day research workshop for nurses was delivered by Debbie Broadhurst (LOROS) and Professor Jayne Brown; a follow up day will take place in April. The aim of the project is to empower senior nursing staff to confidently guide their teams on research processes in order to maintain a long-term philosophy of enquiry within their individual healthcare settings. Seven nurses from around the East Midlands region are involved and will contribute to the testing and development of a resource package that can be used by others to encourage research activity for all, in clinical environments.

Education Activities

University Certificate in Continuing Professional Development (UCPD) End of Life Care

The UCPD Programme was validated in January 2012. A 60 credit degree-level award consisting of two thirty credit modules. Each module runs twice a year.

The two modules are:

Fundamentals of Palliative Care (NMAH 3501)
Enhancing Communication Skills in End of Life Care (NMAH 3502)

Two students have successfully completed the certificate and 9 are currently in the programme.

Overall, 21 students have taken the Fundamentals of Palliative Care module and 12 students who have taken the Enhancing Communication Skills in End of Life Care module .

Masters level learning

21 students enrolled in the academic year 2011-12 with the intention of completing the MSc of whom 10 are continuing their studies. Of the 11 who have left the programme, 3 had completed a PgCert and 6 satisfactorily completed a number of modules gaining institutional credits. One student has deferred her studies and on student left without gaining any award.

Of these ten students who are currently within the programme 4 have completed the PgDiploma and 3 others have completed a PgCert.

Some students enroll only to take individual modules as continuing professional development . Five students did this in the academic year 2011-12

Three students commenced the dissertation year of their Masters programme in palliative care. They are researching the role of senior hospice nurses in the discussion of DNAR orders with patients and families, the bereavement needs of family carers of mesothelioma decedents, and the perception of nurses of the role of the Chaplain in secondary palliative care. These are the first students ever in this programme and it feels an exciting achievement for the Masters team. This has also required the development of new supervisors at this level within the speciality leading to growth in two aspects of our local community of Scholars.

1st Annual CPEP Lecture

In November Jane Seymour Sue Ryder Care Professor of Palliative and End of Life Studies, at the University of Nottingham was invited to give the first annual CPEP lecture. Professor Seymour, spoke about the challenges for delivering excellence in end of life care to the frail elderly. The lecture was attended by 35 people and supported by a grant from Macmillan. We were especially pleased that DMU student ambassadors have played a key role in making this event and the other profile raising events detailed above so successful.

CPEP award for excellence in palliative care nursing

The Royal College of Nursing have agreed to support a CPEP preregistration award for excellence in palliative care. The first award will be made in May 2013.

Looking Ahead

CPEP has got off to a great start, has been welcomed by the local education and health communities and now has some strong achievements to build upon. The operational group is established and in the year ahead a key focus will be to articulate the vision and strategy for CPEP.

CPEP has very limited resources and its ambition certainly outstrips what it currently has capacity to undertake. This tension will hopefully be able to be channelled in to successful bidding for funds to support its work. Partnership working will be key to this.

CPEP needs to consider its role in the strategic plan for DMU as a truly international university, building influential global relationships to enrich our research, teaching and cultural collaborations.

This report was written by the CPEP Operational Group.

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