# Newsletter

September 2013

Issue N°.3

This Issue:

Since our last update in April, research activity has continued to grow - both in terms of developments taking place within the hospice, and through external networking.

Achievements have included a number of publications in leading journals and acceptance of various abstracts at forthcoming conferences.

We've welcomed some new faces to the hospice, who are temporarily joining us for the purpose of research and even made an Australian connection!

*We hope you enjoy this issue of the newsletter - and if you are interested in becoming involved in research, or would like more information about the latest developments, please talk with Dr Christina Faull or email:*

**christinafaull@loros.co.uk**

## Putting Research into Practice:

### Making a Difference to Care

By Jane Pickard

In 2012 a study to explore hospice workers' knowledge of, and attitudes towards, organ and tissue donation was undertaken by Dr Jane Wale, who was then a registrar at LOROS. The study identified that the barriers to discussing tissue and organ donation were multiple and dependent on the knowledge and attitudes of hospice staff. The results highlighted several recommendations for LOROS:

- Increase staff awareness and knowledge
- Introduce guidelines on *who* can donate *what* and *how*
- Increase patient awareness of the option of tissue donation
- Explore *when* is the right time to ask a patient about their wishes relating to organ and tissue donation

To address these recommendations key links have been established with the Organ and Tissue Donation Team from the local acute trust and the National team. This has enabled the facilitation of a teaching and awareness session for clinical staff to enhance their knowledge about who can donate, which tissues can be donated, the process of donation, and what to do if a patient expresses a wish to make a tissue donation.

Exploring when to ask a patient about their wishes was also discussed at the Patient and Carer Participation Group. The general consensus is that it is acceptable to ask patients, but the timing of this needs to be sensitively considered. Ideally, the outpatient setting was seen as the most favourable environment as part of the patient's holistic assessment.

A sample question: *Do you carry a donor card?* might be a very good opening to discussion.

The next steps are now to:

- Consider written information for patients and carers
- Review the most appropriate place to record the patient's wishes within the patients electronic record
- Formulate this information into some clear guidelines for clinical staff to refer to.

# An Australian Visitor.....

*Lottie Chapman, a registered nurse from South Western Australia, who is studying a PhD with Edith Cowan University in Perth, joined us for a visit at the beginning of July.*

*Here are a few words from Lottie about what she made of her visit...*

Following the commencement of study for a PhD in Perth, Australia, my literature review and enquiries via the Motor Neurone Disease Association (UK) led me to Dr. Faull's MND research and LOROS. After a few email exchanges, I gladly accepted the offer of a days visit to LOROS whilst in England visiting family.

Briefly, my research will focus on communication experiences surrounding the initiation, implementation or reasons for refusal of non-invasive ventilation (NIV). The qualitative study will be retrospective interviewing family, carers and clinicians involved with MND patients. Any discussions which took place relating to withdrawing NIV prior to commencement, and whether the communication between clinicians, patient and families was considered adequate to prevent any misunderstanding of the terminal phase of the disease and the eventual removal of NIV. The intended result will be to ascertain whether communication could be clarified and lead to greater understanding of the outcome for the patients and families plus enhancement of patient centred direction for the clinical team.

I would sincerely like to thank all those at LOROS who gave up their time to discuss their roles, research and thoughts relating to palliative care and in particular MND, and for being included within the working day at LOROS. The experience was very valuable for my studies and I was left feeling a little envious of the extensive multi-disciplinary approach which is often difficult to provide in rural WA.

*Thank you all for having me!*

# NIV Withdrawal Project

The first phase of a current study, led by Dr Christina Faull and Dr Cassey Rowe-Haynes, has looked at the issues and challenges that palliative medicine doctors encounter in relation to Withdrawal Of Non-invasive Ventilation (NIV) at the request of a patient with Motor Neurone Disease (MND).

NIV is beneficial for respiratory failure in MND, but some patients may wish to stop the intervention as their disease worsens. Guidance from the National Institute for Health and Care Excellence recommends that research is needed on NIV withdrawal, as there is very little literature in this area of care.

An electronic questionnaire was sent to members of the Association of Palliative Medicine of Great Britain and Ireland. Participants rated how practically, emotionally and ethically challenging they found the process of NIV withdrawal.

76 doctors responding had been directly involved in withdrawal of NIV at the request of a patient with MND.

A high percentage rated the practical, ethical and emotional challenges as 7 or more on a 0-10 scale. Thematic analysis of the free text revealed some common difficulties. Lack of guidance on practical aspects of withdrawal, poor advance care planning and the need to support all involved to prevent conflict were recurrent themes.

Statements relating to the emotional burden were diverse but suggest many palliative care doctors feel significant personal impact.

The withdrawal of NIV in patients with MND appears to pose considerable challenges to palliative medicine doctors; emotionally, practically and to a lesser extent ethically. Development of guidelines and a clear ethical statement of conduct may help but emotional issues appear more complex. As a consequence of this work, the Association for Palliative Medicine has published a position statement on withdrawal of ventilation in advanced neurological diseases.

*For a copy of the full article, published by the BMJ Supportive & Palliative Care, (or for more information about any of the articles contained within this newsletter) please contact:*

idalizagarner@loros.co.uk

# New Research Project on Communication

A researcher, Dr Ruth Parry, from the University of Nottingham is spending some of her time at LOROS at the moment collecting initial data a research project which will later involve analysis of video recordings of consultations at LOROS between doctors and their patients and significant others. The research project's long term aim is to develop more knowledge about how hospice doctors, patients and their significant others communicate about sensitive issues and how they make decisions together. This knowledge, and clips from the video-recordings, will be used to enhance training resources used in communication skills training. The education department at LOROS will pilot the new training resources, and those attending the courses at LOROS will be asked for their views on them.

Ruth worked as an NHS physiotherapist for a number of years before moving into research. Before moving into hospice-based research, she did video-based research on how physiotherapists and people with stroke or head injury work together in treatment. At LOROS, she is currently interviewing various members of staff, patients, their significant others, and service user representatives about how to conduct the video study in a way that is both feasible and sensitive to the needs and concerns of patients and their significant others, as well as those of staff members.

The research is funded by the Health Foundation, and besides staff from the University of Nottingham, Dr Christina Faull, Dr Luke Feathers, and Idaliza Garner are members of the research team.

*If you would like to know more about this research, or to ask about participation, please contact:*
*Ruth Parry at the*
*University of Nottingham*
*ruth.parry@nottingham.ac.uk*
*(tel 0115 823 0873).*

## Sharing Research in Leicestershire & Northamptonshire

### A few words from Jayne...

**Professor Jayne Brown**
**Professor of Palliative Care**
**DMU & LOROS Centre for the Promotion of Palliative Care**

I would just like to tell you how proud I was of the nursing contribution to the Palliative Care Research half day in June. Over half the papers were given by nurses who had been involved in the Masters in Palliative Care programme run and taught by DMU and LOROS.

Of particular note in this context were Tracey Hinde, who gave an overview of her masters dissertation study on nurses and decision making about resuscitation; and Debra Broadhurst, who described the ENTER project in which senior nurses from a range of palliative care contexts are looking to encourage and develop nursing research in our region; Liz Darlison from the UHL, spoke about her Masters thesis, but also praised the multidisciplinary nature of the students in her MSc cohort and the quality of the teaching and the speakers on the course; Kate McClelland, a Chaplin at LPT, spoke about her MSc which explored meeting spiritual needs for palliative care patients in acute care settings.

The skill in presenting, the passion for the topic, and the expertise which was demonstrated was great to see and I'm proud to be associated with these professionals.

# The VALE Project: Volunteers at Life's End


VALE: Volunteers At Life's End,
the LOROS Care Homes Project

One of three LOROS abstracts accepted for this year's Help the Hospices Conference focusses on a pilot service that was developed by LOROS, recruiting and training volunteers to work with care homes to compliment their care of dying residents. The aim of the VALE project (Volunteers at Life's End) was to explore the feasibility and evaluate its added value.

Supporting people in the last hours of their life has a particular importance: a human presence may reduce fear, and agitation and promote a peaceful dying ; provision of a 'sacred space'; performing rituals; or an environment of valuing of the person's way of life and beliefs may be a consideration; and witnessing the passing from life to death.

A three day training programme, along with a support structure, was developed for 9 volunteers, which covered: hand massage; common features of dying; features of dementia; and the role and potential impacts on the volunteer. Volunteers also developed 'comfort packs' containing readings, music, massage oil and religious icons.

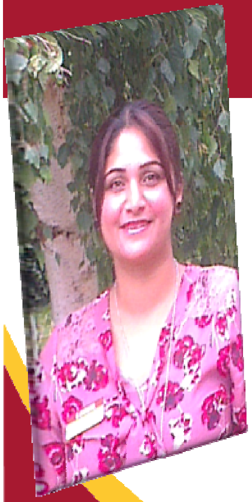
Four care homes developed operational frameworks for contacting and integrating volunteers in to their team. Leaflets provided information to service users and processes were developed to discuss the service with residents and relatives.

Over seven months, three of the four care homes utilized volunteers with 10 residents. Most residents who died did not need the additional support of a volunteer and some volunteers were not utilized. Where volunteers did provide support it was welcomed by care homes as part of their care team for dying patients and highly valued by staff and by relatives. Volunteers enjoyed the work and despite being needed infrequently there was no attrition.

*A copy of the full VALE evaluation report, is now available.*

# Public & Patient Involvement in Research

## By Zoebia Islam



Funders have highlighted Public and Patient involvement (PPI) in designing; conducting and disseminating research improves the overall quality of a research bid and it is essential that people potentially affected by the conduct or the findings of research have a say in its design and delivery.

As part of my role I have been given the challenging task of establishing a PPI research consultation group. I am pleased to inform you that the research team has been successful in obtaining funding from Research Design Service for the East Midlands to run the this group. The first task of this group will be to inform the development of our research to improve end of life outcomes for people from Black Asian and Minority Ethnic (BAME) communities with a breadth of advanced illnesses including cancer, heart disease, and dementia.

# Decision Making for Frail Patients who have Surgical Problems

### Research by Dr Richard Kitchen, CPEP Clinical Education Fellow

*It is a pleasure to be able to write a piece for the LOROS Research newsletter….*

My journey in palliative care began fully as a core medical trainee at LOROS in 2010. This was a fantastic experience and inspired me to follow a career in palliative medicine.

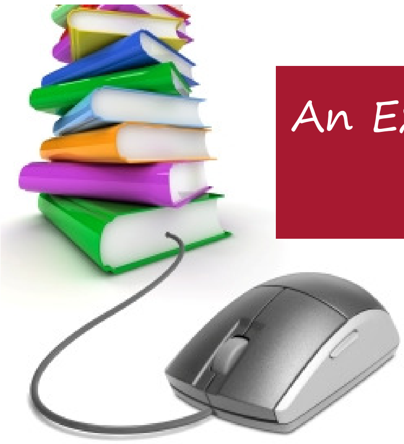
I am now a specialty registrar, based in the West Midlands. I also have the title of Clinical Education Fellow in Palliative Care. I am being supported by the East Midlands Local Education and Training Board, and am completing a Master's in medical education through the Centre for the Promotion of Excellence in Palliative Care.

My research centres on how decisions are made about surgery in frail patients. This is an interview-based study with surgeons and anaesthetists. The aim is to construct a decision making model to clarify how such decisions are made, particularly focussing on aspects such as communication around such decisions and advance care planning. The model will later be used to generate learning interventions in palliative care for surgical and anaesthetic trainees.

*On a separate note….the Research Team would like to congratulate Richard, and his wife, on the recent birth of their son: Cameron Edward Kitchen!*

**If you would like further information about this study, please feel free to contact me at:**

**richard.kitchen@nhs.net**



# An Exciting Learning Opportunity for Non-Registered & Registered Clinical Staff….

An evidenced based practice module, which covers research, is due to start on January 9th 2014 for 11 weeks, ending on 27th March, and is open to all LOROS staff. The aim of the short course is to provide students with the ability to understand the rationale for evidence based practice and to develop the skills required to utilise the available evidence base and to challenge and develop their own practice. The cost of the module is £615 and funding may be available through Help the Hospices. This module is suitable for non-registered or registered clinical staff who hold GCSE English and a Level 3 qualification.

If you would like further information, please speak with Philippa Graham, Education Facilitator (email: philippagraham@loros.co.uk).

# Let's Make a Difference!

Tracey Hinde, Ward Team Leader (Red Team), has organised a growing team of nursing staff who are interested in developing nursing practices, through new initiatives.

Often in every day practice we have ideas of how to do things differently or we question *why* we do things the way we do them. Also, changes are sometimes made and accepted without fully understanding *why*. The idea behind this group is to look at practice: how we can improve and maintain good practice or move forward with new ideas.

**If you would like more information about this group, would like to join, or just have some ideas that you would like to share, please speak with Tracey.**

# Recent Publications

## From LOROS Authors…

We have recently been successful in the publication of a number of journal articles which may be of interest….

If you require any assistance accessing these, or any other guidance on using the LOROS library, please speak with a member the admin team in the education office who will be

- Faull C, Windridge K, Ockleford E, Hudson M, (2013), Anticipatory prescribing in terminal care at home: what challenges do community health professionals encounter?, *BMJ Supportive & Palliative Care* 3 (1):91-97

- Oliver D, Faull C, (2013), Non-invasive ventilation in amyotrophic lateral sclerosis/motor neurone disease, *Minerva Pneumologica* 52 (1):27-38

- Wale J, Arthur A, Faull C, (2013), An analysis of knowledge and attitudes of hospice staff towards organ and tissue donation, *BMJ Support Palliative Care*, Published Online First: 18 April 2013. http://spcare.bmj.com/content/early/2013/04/18/bmjspcare-2012-000416

- Hirsch C A, Marriott J F, Faull C M, (2012), Influences on the decision to prescribe or administer anticholinergic drugs to treat death rattle: A focus group study, *Palliative Medicine*, Published online before print November 21, 2012. http://pmj.sagepub.com/content/early/2012/11/15/0269216312464407

- Faull C, Rowe-Haynes C, Oliver D, (2013), Issues for palliative medicine doctors surrounding the withdrawal of non-invasive ventilation at the request of a patient with motor neurone disease: a scoping study, *BMJ Supportive & Palliative Care*, Published online first 29 July 2013. http://spcare.bmj.com/content/early/2013/07/29/bmjspcare-2013-000470.abstract

- McLaren S, Belling R, Moli P, Ford T, Kramer T, Weaver T, Hovish K, Islam Z, White S, Singh S P, (2013), 'Talking a different language': an exploration of the influence of organizational cultures and working practices on transition from child to adult mental health services, *BMC Health Services Research*, 13:254. Published online: http://www.biomedcentral.com/1472-6963/13/254

**Help the Hospices Conference 2013 - *Hospice Care: Fit for the Future***
**Bournemouth, 21st - 23rd October 2013**
Further details can be found at: http://www.helpthehospices.org.uk

**NHS R&D Event: *Research the Basics***
**The Royal College of Surgeons, London, 3rd - 4th December 2013**
For anyone working in the field of research management and delivery: research management and governance teams, study managers, research nursing staff, research fellows, pharmacists, laboratory managers and ethics committee members; looking for a basic overview and some core competencies around how to ensure high quality clinical research.
Further details can be found at: http://www.rdforum.nhs.uk

**CPEP Palliative Care Conference**
**22nd January 2014**
Details TBC, but for further information, contact Professor Jayne Brown: jbrown@dmu.ac.uk

**The 10th Palliative Care Congress**
**Harrogate International Centre, 12th - 14th March 2014**
Main Call for Papers Closes: Friday 27th September 2013
Further details can be found at: http://www.pccongress.org.uk
*Bursary Support Available (for LOROS Staff) - please ask Idaliza Garner*