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## This Issue:

Page 1	Internationally groundbreaking work at LOROS
Page 2	Maggie Fay joins the LOROS Education Team and aims to get people talking about Dying Matters
Page 3	LOROS Chief Executive, John Knight: Feed back from the Hospice UK Conference 2015
Page 3	Continuing Bonds: Archaeology Meets Palliative Care
Page 4	Karen Ashcroft, LOROS Director of Strategy & Development Achieves a Master's in Hospice Leadership
Page 4	Stop the Pressure...Make the Move
Page 5	A few words from the LOROS Research Team...
Page 5	Dates for the Diary

Issue N°9

# Internationally groundbreaking work at LOROS...



*Improving the care and the experiences of families and health professionals when a patient with Motor Neurone Disease (MND) requests withdrawal of their ventilation by Professor Christina Faull*

MND is a progressive neurological condition which affects the function of muscles including those needed for breathing. When breathing problems occur many patients with MND choose to use non-invasive ventilation (NIV) to improve their quality of life. The NICE guidance in 2010 identified the lack of evidence on providing information to family and patients using NIV in relation to end of life

and that more research is needed on the rare scenario of withdrawal of NIV at the request of a patient who has become very dependent on it and without it will become very breathless.

Over the past 3 years, supported by funding from LOROS and the Motor Neurone Disease Association, Professor Faull has worked with Kay Phelps and Emma Regen from the University of Leicester to explore the experiences of close family and health professionals.

All the participants identified that this is a very challenging part of the journey of care for a person with MND. The project identified examples

of where things had gone well and also examples of where outcomes were not satisfactory.

The findings of this work have led to National Guidance for professionals published by the Association for Palliative Medicine of Great Britain and Ireland in November 2015.

There is a multi professional group continuing to collate information about withdrawal of ventilation to make further recommendations for the care of patients and their families. Please contact Professor Faull for more information and see our webpage.

### Withdrawal of Assisted Ventilation at the Request of a Patient with Motor Neurone Disease

Guidance for Professionals

Association for Palliative Medicine of Great Britain and Ireland

November 2015



**Endorsements**  
The Education and Standards Directorate at the GMC have advised us that this guidance is consistent with the standards of good practice set out in their guidance on Treatment and Care towards the End of Life.  
The Guidance has been reviewed by the medical legal secretary of the General Society of England and Wales for compatibility with current law and principles.



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# LOROS

Hospice Care for Leicester, Leicestershire & Rutland

Being there for you  
and your family

I am passionate about engaging with members of the public to talk about the 'D' words (death and dying) and have organised events in Peterborough for Dying Matters Awareness Week; which provides an opportunity to place the importance of talking about dying, death and bereavement firmly on the national agenda. The 2016 Awareness Week will run from 9-15 May and have the theme of 'The Big Conversation'. Find out how you can support it [here](#).

“Before I die I want to \_\_\_\_\_. ”  
 Passers-by could pick up a piece of chalk, reflect on their lives, and share their personal aspirations or ‘bucket list’.

Over 1,000 Before I Die walls have been created in over 35 languages and over 70 countries, including Kazakhstan, Iraq, Haiti, China,



In the UK and Ireland, *Before I Die* boards have appeared in High Wycombe, Liverpool, Hebden Bridge, Leeds, London, Peterborough, Leamington Spa, Wolverhampton, Dublin, Cork, Galway, Edinburgh and Glasgow.



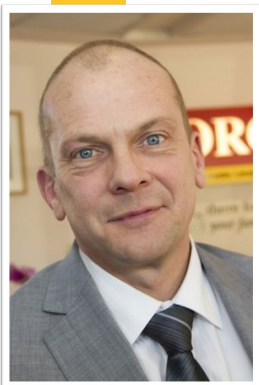
Ukraine, Portugal, Japan, Denmark, Argentina, and South Africa.

Some of the people who come to write their aspirations will have experienced bereavement or be facing bereavement. Others may have survived serious illnesses or accidents or be newly diagnosed or in the middle of treatment. It is important that the people who are facilitating the boards are confident and experienced in having what can be difficult conversations with people about death, dying and bereavement.

You can find out more Candy Chang's work here.



# LOROS Chief Executive, John Knight: Feed back from the Hospice UK Conference The Art & Science of Hospice Care Liverpool, 2015



In early November I had the opportunity to attend my first ever Hospice UK Conference with colleagues from the Senior Management

Team. In addition LOROS had successfully submitted three abstracts and I was delighted that colleagues Andrew Lowden, Debbie Broadhurst and Veronica Mickleburgh had the opportunity to present their posters at the event.

The three days were a well organised carousel of central presentations followed by themed workshops. As you might have guessed these all set about to explore the science behind new innovations in palliative and end of life care, as well as some of the creative therapeutic approaches being used in the hospice sector. There were opportunities to get involved in creative arts and also some live performances which reflected current practice.

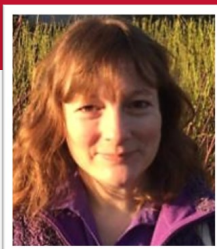
As a LOROS team we organised ourselves to attend a variety of different workshops covering as many subject areas as possible. A high degree of enthusiasm was generated by the 'creative' presentations around storytelling, music therapy and a demonstration of an innovative approach to education through Skype-style conferencing. Presentations on the potential future of fundraising regulations and a focus on the support of volunteers in the community were both thought-provoking and relevant.

More detail about the conference and some images of the event can be found on Hospice UK's website ([www.hospiceuk.org](http://www.hospiceuk.org)). As a Senior



LOROS poster abstracts from the event can be viewed [HERE](#)

Management Team we certainly intend to act upon some of the great ideas we gathered from the Conference and see them become reality during 2016. I trust that they will further develop the brilliant services that we offer to our patients and their families.



## Continuing Bonds: Archaeology Meets Palliative Care

Dr Karina Croucher, Lecturer in Archaeology, University of Bradford

In April an exciting new project, is set to launch: 'Continuing bonds: exploring the meaning

and legacy of death through past and contemporary practice'. It will investigate an entirely new approach to thinking about communication, through the use of archaeological and historical case studies.

The project between researchers at the University of Bradford and LOROS/ University Hospitals Leicester is a unique collaboration between archaeology and palliative care professionals and looks to use archaeological narratives to stimulate conversations around death and rituals, with the hope that this can change how

comfortable we are about discussing death in the present. The aims are to demonstrate how archaeology can inform our current attitudes to death and dying, and thereby help shape policy and practice; and to explore the value of collaboration between health care professionals and archaeologists.

The diverse methods of dealing with death and the dead uncovered by archaeologists will bring a different



A burial with grave goods, from the Sabi Abyad Project - an example of the types of archaeological evidence that will inform the new study

perspective to our current attitudes and therefore contribute towards a necessary re-examination of today's near-taboo status of discussing death, even though an inevitable human experience.

The project team consist of Dr Karina Croucher, a Lecturer in Archaeology at the University of Bradford, Professor Christina Faull, Laura Middleton-Green, Marie Curie Clinical Academic Research Fellow at the University of Bradford, and Lindsey Büster, Research Assistant.

The research, funded by the Arts and Humanities Research Council, will begin in April 2016 for 28 months and will initially involve a series of workshops with health care professionals in both Bradford and Leicester.



## Karen Ashcroft, LOROS Director of Strategy & Development achieves a Master's in Hospice Leadership

Filled with trepidation, I finally agreed. The course was extremely intensive and needed a serious level of commitment - six residentials, each followed by an assignment and finally a 15,000 word dissertation – all in 18 months!

On reflection, it was a fantastic opportunity for which I am extremely grateful. I am most certainly better at my job and much more confident in my own ability. Yes, there were challenging times - when I felt I couldn't see a way forward and almost gave up. To be honest, it is difficult balancing work and studying. Seeking the support of my action learning set, university supervisor, work colleagues and my family saw me through it.

I was 56 (I'm now 57) and at that point in my life, the thought of returning to study filled me with dread. Was I up to it? Would I fail and let myself and all those who were supporting me down? So many doubts and concerns, but I was secretly quite excited too...

Throughout my career, a recurring theme was my lack of self-belief and the previous CEO believed that a way for 'me to see what others saw in me' was to seize an opportunity to study for a Masters in Hospice Leadership.

*Things have changed at the Hospice as a result of the research I undertook*

Change management has been introduced, a Hospice strategy is being developed and my dissertation is being used to inform a piece of national research on the impact of Hospice UK commission.

My advice - keep at it, planning is essential, seek support before you get to 'the dark place' and most importantly, believe in yourself. Two years on I have a Masters Degree with Distinction. What does the future hold? Who knows, but I am so proud of how far I have come.

## Stop the Pressure...Make the Move

By Sally Newman, Tissue Viability Lead, LOROS

LOROS has taken part in an initiative to raise the profile of preventing pressure ulcers within the local community. This has involved joint working across organisations throughout Leicester, Leicestershire and Rutland (LLR) including; Leicestershire Partnership Trust, University Hospital of Leicester, LOROS, and the local authorities. This joint working is targeted at facilitating the streamlining of pressure ulcer prevention across the local area, highlighting its importance to both health care workers with a direct patient care role and the general public.

The group have worked cross-organisation with the aim of finding solutions to challenges common to all areas. One example initiative has seen the development of a harmonised

pressure ulcer prevention teaching package, facilitating common learning between nursing and allied health professionals from the local organisations they work within. This ensures that wherever a health professional is working they should have received the same level of training regarding the essential knowledge and skills of pressure ulcer prevention and treatment. The aim of this harmonised package is that patients within LLR all receive evidence based, consistent care which is tailored to their individual needs and meets standards set by local and national guidelines.

The group have also developed a campaign to highlight pressure ulcer prevention to the general public, sharing key messages about preventing pressure ulcers. The

campaign entitled 'Stop the Pressure, Make the Move' uses photographs to show patients and carers common signs that may indicate pressure damage. These are displayed within clinical areas and given to patients/carers at risk of developing pressure ulcers, and a leaflet is used to support verbal information given to patients regarding preventing pressure ulcers.

The campaign poster won first prize in a poster competition run by the Tissue Viability Society to raise awareness of Pressure Ulcers. [CLICK HERE](#) to see a copy of the poster.

To learn more about this initiative, visit the Tissue Viability Society [website](#)



## A few words from the LOROS Research Team...



The last few months have continued to be busy ones for the research team; but especially so for our Research Fellow, Zoebia Islam, who welcomed a baby daughter in October; Amelia, Maya,

Aisha, Islam arrived safely, weighing a healthy 8lb 4oz. We're sure you will all join us in wishing Zoebia and her family well.

It has also been a busy time for the publications: of prominence, new guidance around the withdrawal of non-invasive ventilation for people with motor neurone disease (discussed on page 1).

Other research with which LOROS is involved is to be shared at this year's

Palliative Care Congress, taking place from 9-11 March in Glasgow. LOROS is linked to 10 abstracts accepted for poster presentation, and 1 accepted for oral presentation. (Look out for more about this in issue 10!).

The research pages of the LOROS website, continue to grow with information about our latest achievements, and developments. To follow our latest news, visit us [HERE](#).

### A Cup O' Learning & A Slice O' Cake:

*Being Involved in the VERDIS Project: A 'thank you' event and discussion opportunity*

Becky Whittaker; Marco Pino  
& Prof. Jane Seymour,  
from the University of Nottingham  
16th March 2016,  
2:00 - 3:00pm, Frizelle 1 LOROS



*Humara Safar ('Our Journey'):* Thinking about the experiences of South Asian communities

Anjana Vaja, Cultural Support Worker, LOROS  
24th March 2016,  
2:00 - 3:00pm, PC1 LOROS

Cost: FREE

To book, email: [research@loros.co.uk](mailto:research@loros.co.uk)  
(cake is provided!)



### Good Clinical Practice & Research Consent Training

Dates below, facilitated by the University Hospitals of Leicester, to be held in the Professorial Seminar room, LGH. For information, or to book, email: [RITraining@uhl-tr.nhs.uk](mailto:RITraining@uhl-tr.nhs.uk)

Wed 09 <sup>th</sup> Mar	GCP 1	09:30-12:00
Wed 09 <sup>th</sup> Mar	GCP 2	09:00-12:00
Wed 09 <sup>th</sup> Mar	Consent	12:30-14:45
Wed 06 <sup>th</sup> Apr	GCP1	09:30-12:00
Wed 06 <sup>th</sup> Apr	GCP 2	09:00-12:00
Wed 06 <sup>th</sup> Apr	Consent	12:30-14:45
Wed 11 <sup>th</sup> May	GCP 1	09:30-12:00
Wed 11 <sup>th</sup> May	GCP 2	09:00-12:00
Wed 11 <sup>th</sup> May	Consent	12:30-14:45
Wed 08 <sup>th</sup> Jun	GCP 1	09:30-12:00
Wed 08 <sup>th</sup> Jun	GCP 2	09:00-12:00
Wed 08 <sup>th</sup> Jun	Consent	12:30-14:45



CENTRE FOR THE  
PROMOTION OF  
EXCELLENCE IN  
PALLIATIVE CARE

**LOROS**  
Research Centre for Leicester, Leicestershire & Rutland

### The LOROS-DMU Centre for the Promotion of Excellence in Palliative Care (CPEP) Annual Lecture 2016

*The thing about life is...*

Laura Middleton-Green, Marie Curie Clinical  
Academic Research Fellow in End-of-Life Care,  
University of Bradford

5:30pm, Wednesday 9<sup>th</sup> November,

Edith Murphy, DMU

Cost: FREE

To reserve a place, contact the LOROS Education

Team on: 0116 231 8455

Email: [education@loros.co.uk](mailto:education@loros.co.uk)



\*GCP 1 is for Non-CTIMP studies

GCP 2 covers both Non-CTIMP and CTIMP studies