

Research NEWS

June 2015

For more information about any of the articles contained within this newsletter please contact: idalizanukis@loros.co.uk

This Issue:

Issue N^o.7

Page 1	A Few Words from the Research Team...
Page 2	Feedback from the 'Spiritual Care in Palliative Care: Recent European Research & Future Developments Conference
Page 2	LOROS Physiotherapists: Evaluation of Breath Stacking Techniques
Page 3	Feedback from the 26th International Symposium on ALS/MND
Page 4	3M Donates £4,000 to LOROS in Support of Research
Page 4	Palliative & End of Life Care Priority Setting
Page 5	CPEP Delighted to Welcome Professor Irene Higginson
Page 5	Hospice UK; feedback from the 2014 conference
Page 6	Dates for the Diary /Bursaries Are Back! /A Final Note...

A Few Words from the Research Team...

It's been a hectic few months for the research team. A very important milestone for us has been completion of the 'Research Impact Report' which looks at how research at LOROS has developed during the period 2011-2014. The report highlights our successes and reflects on some of our challenges. If you would like to see a copy, it can be viewed from our website:

CLICK HERE

Many of our newsletter readers are research colleagues who have worked with LOROS, and we want to thank them for helping LOROS to move forward as a research active Hospice.

We have taken great strides in achieving many of the recommendations suggested in the Hospice UK commissioned report: 'Research in Palliative Care: Can hospices afford not to be involved? A report for the Commission into the Future of Hospice Care 2013':

CLICK HERE

In view of this, a particular highlight of our forthcoming Research Awareness week (June 22nd - 26th), will be the guest speaker at this year's LNR event.... Dr Nancy Preston, co-author of the report. The LNR is open to everyone (not just medical professionals), and we hope that you will be able to join us, and have an opportunity to meet Dr Preston, and share any questions you might have about research within Hospice settings.

Other events planned for Research Awareness week include a *Beginners Guide to Research* study day, which was well received when it ran for the first time in 2014, and a workshop

teaching the basics of MS Publisher. The events are open to all staff. For more information, contact Zoebia Islam: zoebiaislam@loros.co.uk

Research Awareness Week

June 22nd – 26th 2015

Monday 22 nd June	Tuesday 23 rd June	Thursday 25 th June	Friday 26 th June
All Day	1.30pm – 5.00pm	9.30am – 12.30pm	9.30am – 4.30pm
	Leicestershire, Northamptonshire & Rutland (LNR) Research & Audit Half-day	MS Publisher Training	A Beginners Guide to Research Study Day
Venue: Frizelle 1, LOROS	Venue: Frizelle 1, LOROS	Venue: LOROS Library	Venue: PC1, LOROS
Posters of recent research conducted by LOROS staff and collaborators will be displayed (everyone is welcome)	Keynote Speaker: Dr Nancy Preston Senior Lecturer International Observatory on End of Life Care, Lancaster University Co-Author of <i>Research in Palliative Care: Can hospices afford not to be involved? A report for the Commission into the Future of Hospice Care 2013</i>	LOROS Staff only Facilitated by iCan Education, Anna Varley. Learn the basic skills of MS Publisher	Facilitated by Dr Zoebia Islam. Topics include: • Understanding evidence based practice • Identifying problems • Developing techniques for gathering information • Basic evaluation of the existing evidence base • Exploring ethics • Presenting information <i>A timetable will be circulated and staff have the opportunity to book onto individual sessions if they cannot attend the whole day (please ask for details in advance)</i>
	Cost: FREE	Cost: FREE	Cost: Subsidised rate £25 (students £15)



To book a place at any of the above events, please email: research@loros.co.uk /phone: 0116 231 8455

loros.co.uk

Registered Charity No: 506120

LOROS

Hospice Care for Leicester, Leicestershire & Rutland

Being there for you
and your family

Feedback from the Spiritual Care in Palliative Care: Recent European Research & Future Developments Conference

Helen Newman

Spiritual Care Lead Chaplain



Last November I set out, with poster in hand, for this day conference held at the Cicely Saunders Institute at King's College London. I had been encouraged by Professor Christina Faulk to submit a poster on 'Soul Space' and was delighted to receive a research bursary from LOROS to fund my participation in this fascinating conference.

I was one of 100 delegates from many European countries, as well as the USA and India, and my poster was one of 12 presented. Subjects ranged from Silence in Spiritual Care at the End of

Life, to Understanding Spirituality at the End of Life in India.

The conference began and ended with a Mindfulness Meditation which helped us to become fully present to ourselves and each other. A common thread running through the 8 presentations was an understanding that Spirituality is about what it means to be human and that listening with 'authentic interest' is essential in order to address spiritual needs. Dr Lucy Selman's research has shown a high prevalence of spiritual distress in cancer

patients seeking 'peace of mind' 'hope' and 'meaning in life'. While globally, palliative care guidance mandates spiritual care, still spiritual needs are often neglected because of lack of staff confidence and lack of evidence to inform care provision. There is a need for a robust international research agenda.



If you would like to learn more about 'Soul Space', you can read Helen's e-Hospice article:



LOROS Physiotherapists

*Hannah, Kathryn & Isabel,
'inspired' by study day to undertake
evaluation of
breath stacking techniques*

*The day has inspired
us and helped us
continue the
discussion of best
practice in this area.
We are now hoping
to evaluate our use of
'breath stacking
techniques' with
some of our Motor
Neurone Disease
patients"*

LOROS physiotherapists Hannah Poulton, Kathryn Rignall and Bank Physiotherapist Isabel Ashford recently attended a Study Day entitled 'Expanding Respiratory Knowledge in Neuromuscular conditions'. This was made especially accessible by being reasonably priced (only £20!) and local to Leicestershire, as it was run by 'The East Midlands Neuromuscular Respiratory Group'.

It was a great chance for networking as we met with Nurses, Physiotherapists and Doctors who attended the course, and with some familiar faces too. We also had the chance to hear from staff working in other East Midlands areas.

Topics included talks on improving cough strength, end of life issues and excellent demonstrations from a patient, and by staff on non invasive ventilation.

Hannah, Kathryn and Isabel all felt they learnt a



From left: Kathryn Rignall; Hannah Poulton; Isabel Ashford

lot from the day, not least because by attending together they feel they have increased the 'take home' value of the course. The shared learning aspect of how to put theory into practice, this will enhance their future work. So inspired were they, that they are now working together on a service innovation.

*More information
about breath stacking
techniques is available:*



Feedback from the December 2014
26th International Symposium on ALS/MND
Held at 'The Square' Meeting Centre, in Brussels



Professor Christina Faull

Brussels is a vibrant city and in December the Christmas Markets are wonderful. So more than Belgian chocolates to entice me! Every year the 'world' gets together to discuss research about Motor Neurone Disease. The UK Motor Neurone Disease Association is the major lead in this conference and the programme has sessions ranging from genetics, drug development, services to all aspects of clinical care. The big buzz was the 'Ice bucket challenge' which has swept the world and raised millions of pounds. It was great that

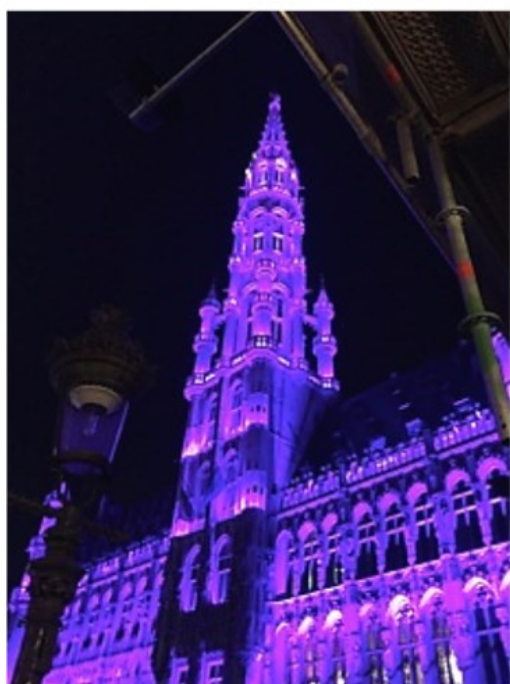
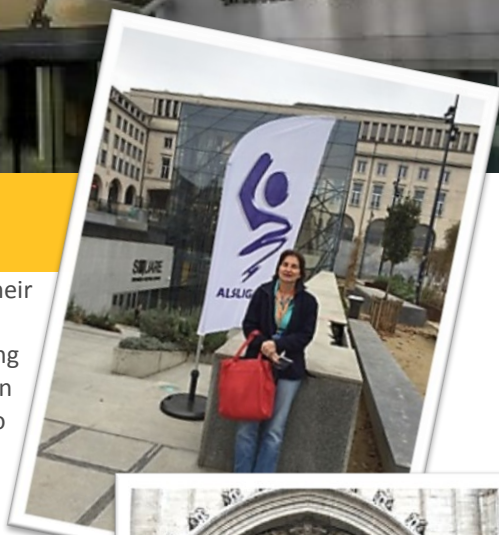
many at LOROS were a part of this.

For the first time since I've been attending this conference there was an afternoon session discussing aspects of end-of-life care. We heard about Netherlands and the experiences of euthanasia and physician assisted suicide. Baroness Ilora Findlay argued strongly about the British position and the dangers that might be an unintended consequence for patients in changing law in the UK. A palliative care consultant from

Switzerland talked of how palliative care supports patients in discussions about the use of ventilation support and how knowing they can ask to stop it is liberating for patients. This led on to a presentation of work from a team in Berlin who described the

technical aspects of their experiences of withdrawing assisted ventilation from patients who were ventilator dependant. Finally it was my turn. I discussed our findings of the ethical, practical and emotional challenges in the experiences of 17 families and 50 professionals who have withdrawn assisted ventilation at the request of a patient with MND.

One of the great things about this conference is that it is attended not only by professionals but also some patients and families. My talk was well received. My lasting memory will be my conversation with a woman from America, whose father has MND, who was so grateful that such choices can be discussed openly and that she can now support her father, in whatever his choices are as his disease progresses.





From left: 3M's Angie Mears, 3M's Martin Arrowsmith, LOROS' Christina Faull, LOROS' Margaret Benson, and 3M's Rebecca Gaskin.

In February, Christina Faull was delighted to accept, on behalf of LOROS, a donation of £4,000 from 3M's Loughborough based Health Care in recognition of its support for research into tackling chronic oedema. The care pathway project, being run in partnership by LOROS, LPT, 3M and the University of Nottingham, could result in significant improvements in the treatment of patients who have swollen legs with fluid retention, often caused by cancer but also heart disease and circulatory and lymph system problems.

Lymphoedema affects approximately 200,000 people in the UK and approximately 3,000 people in Leicestershire. About 1 in 5 women develop lymphoedema after breast cancer treatment. Without the valuable service provided by LOROS at its lymphoedema clinics, almost all of Leicestershire's patients would have to

"3M is committed to improving patients' lives through innovation in care and technology", said Martin Arrowsmith from 3M's Critical and Chronic Care Solutions division.

"We recognise the invaluable, specialist service that LOROS provides to Leicestershire's lymphoedema patients and we are proud to be able to help support this service."

travel to a different county to get treatment. Lymphoedema, and many other conditions, fall under the umbrella term 'Chronic Oedema'. There is limited research detailing the number of people affected by "Chronic Oedema", and the introduction of the

3M donates £4,000 to LOROS in support of innovative chronic oedema research

To view Rebecca Gaskin's 6-monthly video newsletter about this project:



care pathway will investigate the numbers in the region.

Whilst not life limiting, lymphoedema can be severely debilitating resulting in limited movement and often severe cosmetic issues such as cracked and inflamed skin. Collaborative work in developing a community based care pathway will help to provide care to a broader spectrum of chronic oedema patients, alleviating some of their current challenges including; "identification at general practice level... (not enough) specialist nurses....and also the communication factor...(professionals) not being able to talk to each other because of different trusts, or whatever it may be", explains Mark Smith, LOROS Patient and project stakeholder.

"There is no cure for lymphoedema, but it is usually possible to control the main symptoms using techniques to minimise fluid build-up and stimulate the flow of fluid through the lymphatic system", said Professor Christine Moffatt from Nottingham University, "These new developments may help to further control the symptoms and reduce the suffering for cancer patients."



Palliative & End of Life Care Priority Setting Partnership

For the past 18 months, the Palliative and end of life care Priority Setting Partnership has been asking patients, current and bereaved carers, health and social care professionals - to tell them their most important unanswered questions in palliative and end of life care that research should address. Please find attached a copy of a report revealing the Top 10 unanswered questions.

Identifying the best ways of providing care and support to terminally ill people, their families and carers **outside of 'working hours'** has been rated the top priority for the future of palliative and end of life care research.

This was followed in second place by a question about how access to palliative care services can be improved for everyone regardless of where they are in the UK, and what are the benefits of Advance Care Planning? – in third place.



To read the full report:



Left: Professor Irene Higginson, OBE, delivered the annual CPEP lecture entitled 'Hospices and Universities working together: does it raise the game? Reflections from the Cicely Saunders Institute' Centre: Holly Smith is presented with the RCN-CPEP pre-registration nursing award by Tim Baggs, Communications Manager, East/West Midlands, Royal College Nursing; Faculty of Health & Life Sciences, DMU Right: Elaine Wright was presented with the LOROS-CPEP award for postgraduate student excellence in palliative care, presented by Mandy Motley, Director of Education & Training, LOROS

The LOROS/DMU Centre for the Promotion of Excellence in Palliative Care (CPEP) was delighted to welcome Professor Irene Higginson, OBE

Professor Irene Higginson, Director of The Cicely Saunders Institute at Kings College London, inspired all who attended the annual LOROS-DMU Centre for the Promotion of Excellence in Palliative Care (CPEP) lecture. Saunders' vision for improving the care of patients with advanced illness and their families always focussed on research and education. Professor Higginson gave detail to this vision discussing how the care of dying patients in intensive care had been developed by the joint endeavours of clinicians and researchers and hot off the

press (Lancet Respiratory) findings that early, holistic management of breathlessness in advanced disease improves patients' lives and in doing so increases their survival too.

CPEP Award Winners

The LOROS-CPEP award winner for postgraduate student excellence in palliative care is Elaine Wright. Elaine has a consistently high standard of work on the Masters Programme and has shown how she was using this to transform the care of young

people with cancer. The RCN-CPEP pre-registration nursing award winner is Holly Smith who demonstrated how she made a difference to the care provided to a patient on an admissions ward through application of holistic palliative care.

The applications for the awards were of a very high standard and we congratulate the very worthy winners.



hospiceUK Conference 2014

By Simon Proffitt, Former Chief Executive, LOROS

Six senior managers from LOROS attended the annual Hospice UK Conference which in 2014 was held in Leeds from 25-26 November.

The overall theme was "Demonstrating the Value of Hospice Care" and about 400 people attended.

One of the main plenary sessions was on "Building Energy for Change across the Hospice Movement". This was led by Helen Bevan, NHS Chief Transformation Officer, and provided a good stimulus for debate around culture and approaches to making change effectively.

Other sessions included commercial collaboration case studies; highlighting the value of research in improving End of Life Care; maximising the potential for volunteering; the

leader's role in facilitating change; the principles of good evaluation and the need for better outcome measures in palliative care; the way forward for Personal Health Budgets and demonstrating value to Commissioners.

These sessions provided added impetus for, and input to, the current LOROS Strategic Workstream activity. Some specific ideas to follow up have been identified e.g. with respect to an apparently successful volunteer hospice neighbours model in Suffolk which might help to inform and optimise the LOROS recently reconfigured home visiting service.



The conference was opened by Hospice UK's Chair, Lord Howard of Lympne.

Presentations from the day can be viewed:



Good Clinical Practice (GCP) Training

17th June 2015

9:30-11:30am, Frizelle 2, LOROS

Session to be facilitated by Anne Moore,

Clinical Trials Monitor & Trainer, UHL

Cost: FREE



A Beginners Guide to Research, Study Day

26th June 2015

9:30-4:30pm, room PC1, LOROS

Cost: Subsidised rate £25 (students £15)

This event is part of a series of activities planned for Research Awareness week at the Hospice (June 22nd - 26th)

For more information, contact:

Zoebia Islam: zoebiaislam@loros.co.uk



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

Palliative Care/Mental Health Research

29th June 2015

Dr Manoj Kuma

Mental Health Action Trust (MHAT)

Institute of Palliative Medicine in Calicut, Kerala

Transition in Palliative Care

21st July 2015

Simon Hardcastle

Diana Service Team Leader

(12:00 - 1:00pm), Frizelle 1 LOROS Hospice

Cost: FREE



Bursaries Are Back for 2015!

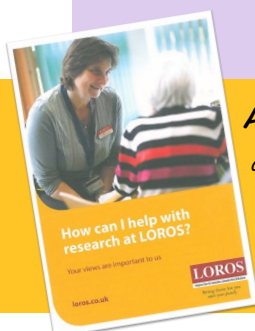
We are excited to announce that the LOROS research bursaries are back for a second year!

If you are a member of LOROS staff who would like to become involved in research to improve LOROS services for the benefit of patients and families that we care for, you are eligible to apply.

It may be that you want to attend, or present at, a conference; go on a research training course; secure funding to backfill your time so that you can develop an idea or a project; or are looking for support with fees to support a research qualification. If you would like further information, please speak with a member of the research team, or email: research@loros.co.uk



The closing date for applications is October 1st 2015 and ALL staff are eligible to apply.



A final note... If you are aware of patients or family members visiting the Hospice, who might also have questions about research at LOROS, we have now developed a leaflet which we would like to encourage you to share.

Copies of these can be found in the patient information boards (located in main reception and near the patient social area), and they cover many of the key questions that patients and their families may have.

Leicestershire, Northamptonshire & Rutland (LNR)

Research & Audit Half-Day

23rd June 2015

1:30-5:00pm (lunch 1:00pm)

Keynote Speaker: Dr Nancy Preston

Senior Lecturer

International Observatory on

End of Life Care,

Lancaster University

Co-Author of 'Research in Palliative Care:

Can hospices afford not to be involved? A report for the Commission into the Future of Hospice Care 2013'

Cost: FREE



CENTRE FOR THE
PROMOTION OF
EXCELLENCE IN
PALLIATIVE CARE
INFORMING PRACTICE. TRANSFORMING CARE.



The LOROS/DMU Centre for the Promotion of Palliative Care (CPEP) Annual Lecture 2015

The Meaning of Afterlife: What archaeology & anthropology can teach us about life after death

6:30pm, Thursday 12th November

Cost: FREE

Details TBC...but if you would like to be kept on the mailing list for information, please ring the LOROS Education Team on: 0116 231 8455 /Email: education@loros.co.uk