

Research Update

Newsletter of the Northern Ireland Hospice & University of Ulster Research Committee

Newsletter 2010
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Committee Members

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Mrs Cathy Payne (Hospice/Ulster)

Dr May Stinson (Ulster)

Mr Stephen Ward (Hospice)

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Evelyn Whittaker (Hospice)

Welcome to the third edition of our newsletter to update you on our work and encourage you to bring your research ideas to us.

We would like to pay tribute to the Director of Clinical Services, Helen Chambers, who is leaving Northern Ireland Hospice. We thank her for her work with this committee and wish her well in her retirement. We would also like to welcome our new consultant, Dr Clare White, to Northern Ireland Hospice.

In this issue, Dorry McLaughlin describes developing her research idea to work on specialist palliative care and learning disability services and her success in achieving a three year R&D Office HSC Doctoral Fellowship, whilst Sue Foster gives an account of the All Ireland International Conference on 'Pushing Boundaries in Palliative and End of Life Care' which was held in October.

We are very pleased to announce that the twelve member consortium including UU, QUB, Marie Curie and the Northern Ireland Hospice from Northern Ireland has been successful in winning the bid to run the All Ireland Institute. The bid will be signed off in a couple of months and the process of advertising for Institute staff will begin.

Committee members have taken part in the recent consultation on the DHSS& PS document 'Palliative and End of Life Strategy for Northern Ireland. 'This five year strategy emphasises the importance of public and health professional understanding of palliative and end of life care, identification of patients and families' needs in these areas, the best and appropriate care supported by responsive and competent staff, timely information, choice and co-ordinated care.' It strongly recommends the concept of a Palliative and End of Life Pathway as a vehicle for delivering high quality care. The strategy will be published within the next couple of months. Meanwhile, the new 2010/2011 Priorities for Action are expected to be published next month.

A handwritten signature in blue ink, appearing to read "George Kernohan", with a horizontal line underneath.

A handwritten signature in blue ink, appearing to read "Max Watson", with a horizontal line underneath.

Projects

Current Projects

Specialist Palliative Care and Learning Disability Service: promoting collaborative working, (Dorry McLaughlin)

Involvement in the soon to be established All Ireland Institute of Palliative Care Research and Education, (Dr Max Watson)

Overview of Interventions for Managing Fatigue & Weight Loss in Adults with Advanced Progressive Illness, (Cathy Payne)

NCRI trial development into the use of Melatonin in patients with Lung Cancer, (Dr. Max Watson)

Review of Drug Prescribing (Stephen Ward)

Palliative Care Needs of People with Parkinson's Disease

Aim: To explore the PC needs of the person with Parkinson's disease (PD), their informal active and former carers and their healthcare professionals' views.

Findings:

Patients and Carers:

- Suspicions that palliative care is just terminal and end-of-life care;
- Coping with their PD by adopting a positive attitude, with support from family, friends, and their faith community.

Health & Social Care Professionals:

- Different views on the meaning of palliative care. Most agreed that it was care of the 'whole' person taking in physical and emotional needs throughout their condition while some saw it as mostly end-of-life care;
- Barriers which would prevent them from recommending palliative care to people with PD included: lack of experience of PD in the palliative care services, lack of available resources to provide such a service and (in some cases) their own lack of knowledge;
- Many were hesitant about introducing palliative care options to patients with PD because of its negative associations with end-of-life:

Participants recommended practical and educational approaches to dealing with these difficulties and thereby improving patients' quality of life. Copies of the study's full report are available online:

<http://www.science.ulster.ac.uk/inr/pdf/parkinsons09.pdf>,
www.nihospiceeducation.org

All Ireland International Conference Pushing Boundaries in Palliative and End of Life Care

Over 130 delegates from Ireland and Britain attended this conference last October which was opened on the first day by Mr Michael McGimpsey, Minister for Health, Social Services & Public Safety, and on day 2 by Ms Ainé Brady, Minister for Older People & Health Promotion.

Northern Ireland Hospice would like to thank NICaN, Belfast HSC Trust, Educare, Irish Hospice Foundation, Our Lady's Hospice, St Patrick's and Marymount Hospices, key stakeholders in the organisation of the event.

Sue Foster, Lecturer in Palliative Care stated "We were particularly pleased that there were 23 poster presentations displayed in the areas of Research; Service Improvement; Clinical Innovation and Audit and Arts and Creative Approaches to Care. If anyone has carried out a study/research/ project / research/audit and would be interested in becoming part of a Special Interest Research Group, then please contact the Education Team."

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Research News

Northern Ireland Hospice Courses

Commencing Monday 26 April 2010
European Certificate in Essential Palliative Care
£350

Tuesday 11 May 2010
Integrating Spiritual Care into Clinical Practice £90

Wednesday 12 May 2010
Certificate in Essential Palliative Care – Update Day
£120

Friday 21 May 2010
Communication Skills for Administration Staff £90

Friday 4 June 2010
Managing Bereavement in Schools £90

Wednesday 10 June 2010
Breathing Easier in Advanced Disease £90

Tuesday 15 June 2010
Assessing and Managing Nutritional Needs in the Last Years of Life £90

Friday 18 June 2010
Introduction to Palliative Care for Pharmacists (½ day) £50

Applying for funding: My Experience by Dorry McLaughlin

I have been with Northern Ireland Hospice for almost 20 years- first, as a community based palliative care nurse and more recently as a Lecturer in Palliative Care, working collaboratively with the University of Ulster. I obtained a three year R&D Office HSC Doctoral Fellowship Award based at the School of Nursing/ Institute of Nursing Research at the University of Ulster. In October 2008 I began work on my research study entitled:

‘A study to develop and evaluate an educational resource in palliative and end-of- life care for specialist palliative care and learning disability services: promoting collaborative working’

My interest in this area grew with raised awareness of how much end of life care for people with learning disabilities was recognised as a development priority area. The Joint University of Ulster/ Northern Ireland Hospice Research Group encouraged taking me to take this idea forward. Working closely with Dr Owen Barr, Dr. Sonja McIlpatrick, and Professor Roy McConkey from the University of Ulster, I wrote and circulated my draft proposal for peer review and feedback. I received helpful advice on statistics and intellectual property rights from the Clinical Research Support Centre and the University of Ulster.

The HSC R&D Office issued the annual call for doctoral research proposal funding applications in the late spring of 2007. With the combined support of Dr. Nicola Armstrong, from the R&D Office and Owen, Sonja and Roy, as the supervisory team, the proposal was refined and the application form and relevant paperwork were submitted for the deadline of October 2007. I also obtained a letter of preliminary approval from the Trusts and Hospices, who would be involved in the study. Short listing took place in January 2008, followed by the interview two weeks later. I learned from this process the importance of attention to detail while being mindful of the criteria against which the proposal and application would be measured. This is not difficult and is clearly laid out in the application pack. It is about addressing key issues such as:

- ***How relevant is this project to the DHSSPS?***
- ***What is the scientific merit of the project?***
- ***How adequate is the applicant's research environment?***
- ***Is the proposed training programme adequate and appropriate?***
- ***What is the applicant's potential as a researcher?***

The application process was well worth doing for this excellent scheme. It's a gift to be allowed time out to focus on a research area and on developing your skills as a researcher. Funding includes salary, research expenses, tuition fees, training and dissemination costs. If you are thinking of applying for such funding, look closely at its criteria, link up with the relevant people and submit your application!

Other News

What's New on the Northern Ireland Hospice Website?

Courses 2010/11

- European Certificate in Essential Palliative Care
- Certificate in Clinical Care for Care Homes
- Certificate in Essential Palliative Care for Allied Health Professionals
- Pilot – Certificate in Essential Palliative Care for Paediatrics
- Seven Week Training course in Bereavement Care
- Advance Care Planning/Mental Capacity Act
- Workshop: Transition to Care Homes
- Management of Bereavement in Schools
- Bereaved Children – how can we help?
- Adolescent/Transition Care
- Breathing Easier in Advanced disease
- Palliative Care for Older People
- Palliative Care: Emotional Impact on Families & Self
- Certificate in Essential Palliative Care – update day
- Communication Skills for Administration Staff

Have You Any Research Ideas? Would You Like to Become Involved in Research?

If you have a research idea arising from your work, we can provide you with advice, support and assistance with securing funding. For a Research Ideas Form please go to www.nihospiceeducation.org/research

Other News

- 8th Palliative Care Congress, Bournemouth, 9th to 11th March
Prof Kernohan presented a concurrent session at the conference. His paper "Do people with Parkinson's disease need palliative care?" revealed the findings of recently completed qualitative research with over 100 professionals: doctors, nurses, and AHPs. It was well received by a packed audience who heard about the very mixed views on palliative care: professionals differed on when or how to introduce palliative care to patients with Parkinson's disease. This raises issues for further research into this area to explore opportunities for liaison between palliative care and Parkinson's specialists.
- Cathy Payne and Cochrane Fellowship
The overview protocol 'Interventions for fatigue and weight loss in adults with advanced progressive illness' has been published in The Cochrane Library, Issue 3, 2010.
Citation: Payne C, Martin S, Wiffen PJ. Interventions for fatigue and weight loss in adults with advanced progressive illness (Protocol). *Cochrane Database of Systematic Reviews* 2010, Issue 3. Art. No.: CD008427. DOI: 10.1002/14651858.CD008427. The development of the protocol has been supported by a two year Cochrane Fellowship from the Northern Ireland, Health & Social Care Research and Development Division.
- 'Home Comforts' Resource
Northern Ireland Hospice recently secured funding from DHSSPS to produce this resource entitled: End of Life Care Learning Resource for Care Homes. It has been sent to every care home across Northern Ireland and includes a DVD and other tools to enable care home staff to work together to develop action plans to enhance and improve end of life care within their home setting.
- Irish Association of Palliative Care 10th Annual All Ireland Education and Research Seminar, Drogheda, 4th February.
Professor Kernohan presented a poster presentation of the qualitative research undertaken into Parkinson's disease and palliative care. The poster entitled 'Palliative Care Everywhere and Nowhere: Interviews with over 100 Professionals' was one of 35 poster presentations and 12 platform presentations at the seminar which showcased palliative care research from across Ireland.