

update

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Palliative Care: moving beyond the comfort zone

The Partnership's annual conference at the Hilton Dunblane Hydro on 8 September attracted over 200 delegates willing to be challenged by new thoughts and to consider entering new realms of professional discomfort.

A range of speakers and workshops under the excellent and thought-provoking chairmanship of Honorary President Dr Derek Doyle delivered a programme which provided ample opportunities for both. Unfortunately Professor Julia Addington-Hall, one of the keynote speakers and leader of the most popular workshop session, was taken ill on the morning of the event and was unable to participate, but despite this disappointment, the majority of delegates enjoyed an interesting and successful day.

In his introduction to the day, Dr Doyle referred to the comfort zones that we all experience in our professional lives. In his own case he had often been led

A date for your Diary!

**Annual Conference
and AGM 2005**

**Next year's conference
will take place on
Wednesday 14 September
at
Hilton Dunblane Hydro**

to question whether being in a comfort zone was a welcome state for his progress as a doctor, and he felt that being comfortable could be interpreted by some as a euphemism for smugness or complacency. He also felt that to bring patients into their own comfort zone it was sometimes necessary for healthcare professionals to go through a period of discomfort in order to learn new ways of doing things, and to better understand the unique needs of each patient. His own experience had been that the role had constantly evolved, as palliative care has itself evolved, from hospice, terminal and continuing care into what it is today.

Professor Nora Kearney looked at the extent to which cancer patients are involved in their care and challenged the official view of the NHS Scotland White Paper 'Partnership for Care' that patients are already involved in their care. She felt that while information has been gathered on patients' experience, patients themselves have had limited involvement in the design of palliative care services and have not been routinely involved in developing services for cancer care. The ageing population and increase in multiple morbidities mean that the number of cancer patients is growing, underlining the need for this group to have a greater say in the provision of their care. Research on patient involvement had also been minimal, in some respects due to ethical difficulties in using palliative care patients for research.



Dr James Rodgers (left) and Dr David Oxenham celebrate an even vote in the conference debate.

In cases where patients had been involved, eg by the three cancer networks, there had often been little staff agreement around the scope and purpose of patient involvement. Professor Kearney felt that there is a need to see palliative care from a more holistic perspective, and allow patients to become more actively involved.

In a wide-ranging and very entertaining talk, Professor John Atkinson explored the difficulties some sectors of the population have in accessing palliative care. One example from his own experience were prisoners, who could not access the high standard of care available in hospices. Professor Atkinson also stressed the need to view palliative care in holistic terms. He felt that a patient's needs and

priorities could be quite different from those perceived by the healthcare team, who tended to focus upon the issues within their remit, ie the patient's health, rather than any wider concerns that the patient may have. He cited the case of a cancer patient who felt his needs were better met by the housing department than by his healthcare team (the housing team arranged for him to have a washing machine).

A new feature for the conference format this year was the inclusion of a debate on the motion: ***'This house believes that palliative care resources should be directed towards patients and families where there are problems with the process of dying.'*** Dr David Oxenham (Medical Director, Marie Curie Hospice, Edinburgh) spoke for and Dr James Rodgers (Consultant in Palliative Medicine, NHS Borders) spoke against the motion.

The debate focussed on the twin issues of an appropriate focus for palliative care and the prioritising of potentially scarce future resources within the context of a future explosion of need. Dr Oxenham put forward the view that palliative care could be better promoted if it was more focused. Since the palliative care profession was best at dealing with issues around the process of dying, where he felt there was also most need, then resources would be best used to address difficulties in that area. Dr Rodgers argued that the focus of palliative care was holistic and that it was inappropriate to single out a specific aspect. He believed effort and resources should be directed at ensuring that palliative care was available to all who need it at any stage in an often lengthy disease process. Discussion revealed a lack of consensus on where limited resources should be directed, and revealed some tension as to the future role and focus of palliative care. There was also a feeling among some delegates that the motion was not sufficiently clear to allow productive discussion, and this was reflected in the vote, which was split 88:86 for the motion. Despite this, only 12.6% of delegates returning evaluation forms felt that the debate had not been a useful addition to the day.

A range of workshops on topics such as palliative care and excluded groups, palliative care out-of-hours, the role of palliative care in care homes, achieving patient-focused palliative care, palliative care education, palliative care in community hospitals and planning for the review of specialist palliative care services completed the programme.

Approximately half of conference delegates completed evaluation forms. Of these, over 98% found the theme and content of the conference quite useful or very useful, and 100% said the event had helped to expand their knowledge and awareness of current and future issues. Despite the absence of one of the key speakers, 85.5% felt that the conference met, met to some extent, or exceeded their expectations. Comments received will be used to inform planning for next year's event.

13th Annual General Meeting

The 13th Annual General Meeting of the Scottish Partnership for Palliative Care was held immediately prior to the annual conference at Hilton Dunblane Hydro on 8 September 2004.

In his Chairman's report, Professor Frank Clark referred to the recently published annual report of the Partnership for the year ended 31 March 2004 and highlighted key areas. He reiterated the important challenges facing providers of palliative care, particularly the provision of palliative care in chronic and progressive illness and in multiple care settings, resourcing palliative care, inter-agency working, education, palliative care for children and young people and public awareness and expectations.

Pat Wallace referred in her Director's report to the conference theme of challenging the familiarity of comfort zones and encouraging the move into new areas of thinking and practice. She reported that the Partnership had already been responding to this challenge by expanding its own comfort zones in a number of directions over the past year and commented that by responding quickly to change, and working with others to encourage and develop change in the right direction, the challenge could be both exciting and rewarding. The opportunity to dialogue and learn together with more and more people and groups characterised much of what the Partnership was doing, and meant that it was likely to be much more productive in its efforts.

The Annual Accounts for the year 2003–2004 were presented by Ian Gibson, Honorary Treasurer, and their adoption approved by the meeting. On behalf of the Partnership, Ian Gibson thanked the Scottish Executive Health Department, Macmillan Cancer Relief, Marie Curie Cancer Care, Help the Hospices and all the member organisations for their continued financial support.

A Special Resolution to adopt an amended version of the Partnership's Articles of Association was approved by the AGM. The amendments reflected the results of recent consultation among members regarding NHS representation to the Partnership following the abolition of NHS Trusts and revised arrangements for the rotation of Council members.

In conclusion, thanks were expressed to the Partnership's staff and Council members for their hard work and support throughout the year.

Care Homes working group

This short-life working group was set up by the Partnership in the autumn of 2003 to develop national standards for non-specialist palliative care in care homes. It has been clarified that the standards will:

- apply to all care homes
- be consistent with the general approach of the Care Commission and relate to the existing national care standards

- take the form of national good/best practice standards in basic palliative care.

A consultation draft of the group's final report will be circulated towards the end of 2004 and it is hoped that the standards will be launched in summer 2005.

Heart failure working group

The Partnership's short-life working group, set up to take forward the recommendation of the Coronary Heart Disease and Stroke Strategy for Scotland that '*palliative care should be made available to people with end-stage heart failure*,' has been meeting regularly since June 2003 with a remit to:

- identify key issues to be considered in making palliative care available to people with cardiac failure
- produce guidelines for good practice and make recommendations on service provision
- circulate and encourage adoption of these via cardiac and palliative care MCNs.

The group, comprising representatives from fields including palliative care, cardiac care, primary care and medicine for the elderly, has been focusing upon four key areas: communication, end-of-life care, practical and psychosocial support, and symptom management. It expects to have a draft report available for consultation by the beginning of 2005 and to produce its final report and recommendations later that year.



Big Lottery Fund Project

The New Opportunities Fund and the Community Fund have recently merged to form the Big Lottery Fund.

Our Big Lottery Fund project 'Increasing access to palliative care for people with life-threatening conditions other than cancer' continues to make good progress. Questionnaires for use in consultation with people with a range of life-threatening conditions other than cancer and their families/carers have been developed and successfully piloted. These will be distributed to participants via the relevant host organisations in the near future. Questionnaires for health and social care professionals are under development and will be piloted in due course.

We have now established two project reference groups. One is made up of people with various conditions other than cancer and carers and the other of health and social care professionals involved in their care. Both groups met for the first time in June. These meetings were very productive, both for the participants and for the progress of the project. The groups will meet again in November this year.

Liaison with host organisations, colleagues in relevant professional areas and related projects continue and we are very keen to hear from you if you would like to be involved in our project. If you would like to find out more about the project, please contact:

Project Manager: **Alison Poole** Telephone: **01968 674862**
Email: **alison_sppc_nof@msn.com**

Scottish Parliament

Cross Party Group in the Scottish Parliament on Palliative Care

The annual general meeting of the Cross Party Group in the Scottish Parliament on Palliative Care took place on Wednesday 9 June 2004 at the Scottish Parliament Headquarters. Michael McMahon MSP was re-elected as Convener, Dennis Canavan MSP was re-elected as Vice-Convener and Pat Wallace was re-elected as Secretary on behalf of the Scottish Partnership for Palliative Care. The meeting was well-attended, and the agenda included a presentation by health professionals and a patient on 'Lymphoedema - a neglected area of health care?' This topic aroused a considerable level of interest among MSPs present, and raised a number of issues to be taken forward in the appropriate way via the Scottish Lymphoedema Practitioners group, the Scottish Partnership for Palliative Care and NHSQIS.

The next meeting of the Cross Party Group will take place on **Wednesday 17 November 2004 at 5.30 pm in Committee Room 1 in the new Scottish Parliament Headquarters** (at the foot of the Royal Mile, opposite Holyrood Palace).

The topic will be '**Assisted Dying: a Palliative Care Perspective**,' and Professor John Welsh will lead a presentation and discussion on some of the issues raised by the Assisted Dying for the Terminally Ill Bill currently under consideration by the House of Lords. (See back page)

members news

Complementary Therapies in Palliative Care

Roxburghe House in Dundee has recently appointed a Complementary Therapies Co-ordinator to develop and administer a complementary therapy service. The aim of the service is to deliver a range of therapies for in-patients and day-patients as well as staff, carers and volunteers.

Volunteer therapists give a few hours each week of their particular chosen therapy, the benefits of which are far-reaching ranging from relaxation to symptom control. Initially a person seeking complementary therapy will be assessed to determine which therapy will best suit them, taking into account their individual needs, medical condition and any contra-indications to treatment.

Within complementary therapy, each person is seen as a unique individual with diverse needs. Although the disease

process with its attendant symptoms are taken into account the person is treated holistically. No two people will be treated the same even though their disease and symptoms are identical.

The reasons a patient might be referred for therapy are to:

- promote relaxation
- alleviate anxiety
- reduce depression
- reduce pain
- reduce nausea
- alleviate symptoms
- improve sleep patterns
- reduce stress and tension
- improve well-being and quality of life
- live with and altered body image
- reduce the side-effects of chemotherapy and radiotherapy
- support the patient in the dying process.

As people who are suffering from cancer and other terminal illnesses often seek complementary therapy, it is preferable if this is delivered within a safe and caring environment. Patients can be referred for complementary therapy by Macmillan nurses or nursing and medical staff at Roxburghe House. Many of our day-patients are now receiving complementary therapies and are benefiting from this experience. The service is currently working with fully qualified and insured therapists who give their time and expertise for the benefit of our patients. We are always looking for more therapists and different therapies to extend patient choice.

Therapies on offer include:

- Aromatherapy - the system of using essential oils to improve physical and emotional well-being. This can be administered in many different ways including massage, inhalation, compresses and baths.
- Therapeutic massage - the manipulation of soft tissue to therapeutic effects including the release of tension from the muscles.
- Indian head massage - this therapy was developed by an Indian physiotherapist and is based on the cultural practice of massage found in the Indian sub-continent. It is useful where there is tension in the neck, shoulders and head. Traditionally oils are used to improve the condition of the hair and stimulate growth.
- Reflexology - it is usual to use the feet but can be done on the hands or face. Uses reflex points and thumb and finger pressure to treat the whole body. It is profoundly relaxing and enjoyable.
- Beauty therapy - although not strictly a complementary therapy it is very useful for relaxation purposes and improving the self-image of patients. It is based on the 'look good feel better' principle and is well received by many patients who have undergone medical treatments. It is useful for rebuilding self-esteem and confidence.

Complementary therapy is available to staff and volunteers, as their need for relaxation and stress-relief is evident. Carers are also offered therapy when there is a need.

Arrangements for this are made on an individual basis. Because this is a relatively new service we are currently developing strategies to cope with a demand that is outstripping supply. Encouraging staff to train in complementary therapies is one way of expanding the service as well as recruiting more volunteer therapists. If you know someone in the Dundee area who is a qualified therapist who can give a few hours of their time we would like to hear from you!

Please contact: [Janis Linton](#), Complementary Therapies Co-ordinator at Roxburghe House, Dundee. Tel: [01382 423156](#)

Cancer patients losing out on millions of unclaimed benefits

More than £126.5 million in disability benefits is going unclaimed by people diagnosed with terminal cancer in the UK according to Macmillan Cancer Relief.

Macmillan is concerned that thousands of cancer patients are not claiming benefits to which they are entitled through lack of information, confusion or embarrassment.

In Scotland nearly £15 million is left unclaimed. Of the total number of cancer patients eligible to claim, only 36% do so, which means Scotland has the lowest claim rate in the whole of the UK.

A report, entitled *The unclaimed millions* shows that more than half of people with cancer (83,000) who die each year (154,000) do not claim their entitled disability benefits. It also indicates a huge variation in take-up across the UK with Scotland having the lowest claim rate overall at only 36%, whereas someone living with cancer in Northern Ireland is more than twice as likely to claim as in Scotland.

The reason for such a low take-up of disability benefits by people affected by cancer is due to issues such as the perceived stigma of claiming benefits from the state and the complicated and confusing claiming process.

Macmillan's findings relate to unclaimed disability benefits of Disability Living Allowance (DLA) and Attendance Allowance (AA) by people diagnosed with terminal cancer. Terminally ill cancer patients automatically qualify for DLA and AA, yet millions more may be going unclaimed by people with cancer who do not have a terminal diagnosis.

More than a million people are living with cancer and many may still be entitled to claim DLA, AA or other benefits such as housing benefit, council tax benefit, income support or Carer's Allowance. But, again, lack of knowledge, embarrassment or the sheer difficulties of claiming, may stop them accessing these vital benefits.

Ian Gibson, Director for Scotland, Macmillan Cancer Relief, said: "Our findings are just the tip of the iceberg. Cancer can have an enormous impact on someone's income. They can plummet from a comfortable lifestyle to one of real financial difficulty. It is appalling that people affected by cancer are faced with the unacceptable extra stress and worry of money problems when they are most vulnerable – especially when that help does exist if only they knew about it.

"In Scotland the picture is particularly bleak. Currently the voluntary sector and Macmillan Cancer Relief in particular, is developing new services to meet the financial needs of people affected by cancer. Whilst it is right that the voluntary sector offers expertise and innovation, the prime responsibility lies with the statutory sector which is currently failing to deliver a holistic service."

Alzheimer Scotland - Action on Dementia

The latest organisation to join the Partnership is Alzheimer Scotland – Action on Dementia. Here Jenny Henderson, palliative care development worker tells us about the organisation.

Alzheimer Scotland is the leading specialist dementia charity in Scotland and works to improve the lives of everyone affected by dementia. We provide information, support and a network of services and support groups around Scotland. We also campaign to improve public policies and services for people with dementia and their carers.

We aim to:

- be the national voice of people with dementia and their carers
- improve public policies for people with dementia and their carers
- provide and secure the provision of high quality services both for people with dementia and their carers.

We:

- speak out for the rights and concerns of people with dementia and their carers
- have nearly 50 projects throughout Scotland with staff and volunteers providing practical services such as day, evening and weekend centres, home care, befriending and support services
- provide a national Dementia Helpline

- support a network of over 40 carers' support groups
- provide information to carers, professionals and people with dementia
- publish a website, leaflets, booklets reports and a quarterly newsletter.



Alzheimer Scotland
Action on Dementia

About dementia

Dementia is an illness which affects the brain, causing progressive loss of mental powers. It is the fourth most common cause of death in Scotland. Alzheimer's disease and vascular dementias are the most common forms of the illness, but there are many other conditions which can also cause dementia.

61,000 Scots have dementia and this number is increasing as people live longer, by 2013 there will be 67,000 people in Scotland with dementia. It is most common in older people but can affect people in their 40s or 50s or even younger.

People with dementia gradually lose their memory and their understanding. When somebody has dementia they may forget the names of family members, not just strangers. They may repeat the same question again and again and again and not know they are doing it.

People with dementia may lose their sense of time, losing track of where they are, and even getting lost in a familiar place. They may fail to recognise people they know well.

People with dementia may be confused. Their ability to think, to reason and calculate can be damaged. They may make odd decisions and find it hard to solve problems. Handling money may become difficult.

Dementia can cause personality changes. Someone who was energetic may become listless, someone pleasant and well mannered may become rude and aggressive.

Gradually over a period of years, most functions of the brain will be affected. Eventually, people with dementia will probably need help with even simple daily activities such as dressing, eating or going to the toilet.

The Big Lottery Fund with the backing of the Dumfries and Galloway Health Board has provided Alzheimer Scotland with two years funding to:

- increase the understanding of where people with the end stage dementia live in Dumfries and Galloway
- identify their palliative care needs
- identify informal carers' needs
- provide information for service planners and commissioners
- identify and contribute towards training strategies designed to meet the specific training needs of care and clinical staff.



For more information about Alzheimer Scotland please visit:

www.alzscot.org

24-hour Dementia Helpline: **0808 808 3000**

For more information about the palliative care project please contact Jenny Henderson at:

Email: Dumfriesservices@alzscot.org

Official opening of new Roxburghe House in Aberdeen



Dr Mhoira Leng, Consultant in Specialist Palliative Medicine at Roxburghe House, Aberdeen

One of Macmillan Cancer Relief's largest building projects was completed in the summer with the opening of the new Roxburghe House development in Aberdeen. The new Roxburghe House is a state-of-the-art cancer care facility with 21 beds and the capacity to expand to 24, and will offer in-patients modern and comfortable surroundings. It will also provide an extensive day care and support network to people affected by cancer from throughout the North East. The decision to move Roxburghe House was taken in order to modernise and improve services. The development, which was completed on time and within budget was subject to a successful partnership between Macmillan Cancer Relief, New Opportunities Fund and NHS Grampian.

publications

Two new reports, *Palliative Care: the Solid Facts* and *Better Palliative Care for Older People* edited by Elizabeth Davies and Irene J Higginson, have been produced as part of the WHO Regional Office for Europe's work to present evidence for health policy and decision-makers in a clear and understandable form. Both booklets emphasise the importance of palliative care as a public health issue.

Palliative Care : the Solid Facts discusses how to improve services and educate professionals and the public, and also explores the varied cultural and health contexts in different countries.

'Better Palliative Care for Older People' considers in detail the needs of older people, their illnesses, evidence of under-

assessment of pain, decision-making and effective palliative care solutions.

To obtain copies please contact:

The WHO Regional Office for Europe
8 Scherfigsvej 2100

Copenhagen, Denmark.

Email: publicationsrequests@euro.who.int

The booklets are also available in pdf format from:

<http://www.euro.who.int/> (web tip: go to health topics, keyword, healthy cities, documentation and books and publications.)

The National Network for the Palliative Care of People with Learning Disabilities

The National Network for the Palliative Care of People with Learning Disabilities aims to facilitate collaboration between service providers and carers who work for the benefit of people with learning disabilities who have palliative care needs.

The Network holds an annual Scottish meeting and this year it was held in Inverness on 28 May 2004. The venue was provided by Highland Hospice and the event was fully subscribed. Speakers included Karen Watchman, Director of Downs Syndrome Scotland (DSS) who reported the results of a pilot study which DSS is undertaking into the end-of-life needs of people with Downs Syndrome. Marguerite Kramers from the L'Arche community described the holistic philosophy of L'Arche and how this is translated in to practice when a resident of the community is facing death. Dr Jeremy Keen, Consultant in Palliative Medicine at Highland Hospice stressed the importance of good quality pain and symptom control but he had found that even basic physical care could be overlooked and distress wrongly attributed to the dying process itself rather than to something which could be remedied. All of these speakers addressed the importance of meeting spiritual needs and the flexible ways in which these can be addressed.

The afternoon speaker was Douglas White who is an advocate with the ACE group of Enable and now is appointed to represent service users on the Mental Welfare Commission. Douglas does not have palliative care needs but he was able to describe some of the difficulties encountered by people with learning disabilities who meet staff from health and statutory services unfamiliar with their needs. Despite his own health needs, he had been the sole carer for his mother who had chronic health problems. He had been patronised when seeking information about her treatment and isolated following her death. After many months he had received bereavement support and now he works with ACE and other

organisations to raise awareness by staff training.

The Network's objectives include the dissemination of information and resources and participants received a copy of the 2003 Glasgow conference proceedings on '*Palliative Care and People with Learning Disabilities*' which had been convened by the Scottish Partnership for Palliative Care, Common Knowledge and St Columba's Hospice, Edinburgh. Spare copies of this report are available if you contact: office@palliativecarescotland.org.uk. Information about recent publications for carers and for the use of people with learning disabilities was also available on the day.

The day was chaired by Fiona Cathcart who is the Scottish representative for the National Network. She welcomed the enthusiasm and interest of the audience but noted that the majority came from the learning disabilities services. More interest would be welcomed from palliative care services if the aim of collaborative partnership was to be achieved. The need for mutual understanding but lack of contact and co-ordination among services was highlighted by all speakers and the Network is aware this was a national not a local problem. If you would like to find out more, view the National Network page on the *Help the Hospices* website.

The next National meeting will be held at Liverpool University on Wednesday 3 November. Information and registration forms available from Stuart Todd at: toddsp@cf.ac.uk If you would like to help organise a Scottish network event in your area, please contact Fiona Cathcart at St Columba's Hospice, Edinburgh. Email: fcathcart@stcolumbushospice.org.uk

MSc Programmes in Palliative Care

Building on a very successful BSc in Cancer and Palliative Care and accredited by Napier University, the Marie Curie Cancer Care Education Team in Scotland has now been working with Napier University to develop two new MSc programmes in Palliative Care, MSc in Palliative Care and MSc in Palliative Care and Applied Education.

The programmes aim to meet the growing demand from a wide range of healthcare professionals for flexible postgraduate education that promotes evidence based palliative care practice, education and research. These programmes are open to health professionals involved in palliative care in a range of settings including hospital care, primary care, nursing homes and hospices. Nurses, doctors, physiotherapists, occupational therapists, social workers and chaplains are all eligible to apply.

The palliative care elements of the programmes comprise four modules delivered by Marie Curie Cancer Care from the Education Centres in our Edinburgh and Glasgow Hospices.

A blended learning approach will be used combining e-learning with more traditional face to face teaching. In this way flexible 'online' student centred learning will be combined with the benefits of access to clinical experts in the specialist Marie Curie Cancer Care palliative care units. Additional modules, including an option to undertake a teaching qualification, will be selected from a range provided by Napier University. These will also utilise e-learning approaches combined with tutorial support and electronic discussion.

The first group of students commenced studies in September 2004 with the 12 participants being drawn from nursing, chaplaincy and occupational therapy. For further information please contact: **The Education Administrator, Marie Curie Cancer Care, 29 Albany Street, Edinburgh.** Telephone: 0131 456 3710 Email: EducationScotland@mariecurie.org.uk

Public Internet Access for Patients and Carers at Renfrew Health Centre

Despite its increasingly well-recognised importance the provision of appropriate information to patients receiving palliative care remains an area of concern.

For patients and their families, having access to information is very important and can help combat the uncertainty associated with their illness. Health information is one of the most common searches on the internet but for many reasons access to the net remains difficult for some people and there is little doubt that some patients and carers require support in understanding some of what they find online.

Internet access for members of the public is now available in Renfrew Health Centre where there is a 'drop-in information clinic' on both Tuesday and Friday afternoons from 1.00 pm until 4.00 pm.

This facility has been made possible by Glasgow Palliative Care Information Network, a New Opportunities funded (NOF) project. The project has supplied a computer, printer and cabinet to house the equipment, together with furnishings for the clinic room to improve the facilities available for patients and carers.

Glasgow Palliative Care Information Network provides a one-stop online entrance point to a range of information on services, service providers and service procedures for patients and carers, and a method of accessing guidelines, protocols and the Glasgow Palliative Care Community for professionals. Cathy McIntyre, Macmillan Nurse, Renfrew Health Centre and John Sweeney, Project Manager, Glasgow Palliative Care Information Network will run the drop-in clinic. For more information on the project visit:

www.palliativecareglasgow.info or telephone **Cathy McIntyre on 0141 886 5806** or **John Sweeney on 0141 945 4968**

Change of name

The National Council for Hospice and Specialist Palliative Care Services, the Partnership's sister organisation for England, Wales and Northern Ireland, agreed at its meeting of 23 June to change its name to The National Council for Palliative Care. This will take effect from 1 November 2004.

Big Lottery Fund Award

The National Council has been awarded £490,000 funding for three years from the Big Lottery Fund to develop its policy capacity for all life-threatening conditions. This award has been backed by an equally matched commitment from National Council and its core funders.

The resulting Policy Unit will produce practical policy solutions for the development of existing palliative care services and the expansion of palliative care services into new disease areas. This will be based upon the continuous collection and analysis of palliative care services data on a national scale for England, Wales and Northern Ireland, together with the informed perspectives of users and professionals.

The Policy Unit will develop a vision of what palliative care services will be needed for each principal disease or patient group by the year 2020, and a strategy for achieving that vision, in partnership with a wide range of organisations from the voluntary, statutory and independent sectors.

In particular, work will focus on the following policy areas:

- data collection and analysis as the foundation upon which to analyse and develop palliative care services in a fully informed way
- the long-term future for palliative care (2020 Vision)
- developing and improving access to palliative care for:
 - people with cancer
 - people with respiratory disorders
 - people with circulatory disorders
 - people with neurological disorders and other long-term diseases
- developing user involvement in palliative care
- the impact of social disadvantage on access to palliative care services
- palliative care needs amongst ethnic minority groups
- co-morbidity (ie the needs of people with multiple life-threatening diseases)
- improving general palliative care in the community.

House of Commons Health Committee Report on Palliative Care

The House of Commons Health Committee's report on palliative care was issued on 22 July. This wide-ranging report produced a number of recommendations and is based upon a belief in the right to a 'good death'. Its key message is that 'if palliative care is to achieve improvements in the quality of the last months of life it will need to operate in a more equitable way.' The Report places much emphasis on enabling people to be cared for and die in the place of their choice. The Committee acknowledged that unless there is a guarantee of 24-hour care and support at home, and access to specialists when needed, the aspiration to enable all people to die at home, if that is their wish, is not realisable. The Committee made reference to the potential savings identified in the recent economic analysis produced by Marie Curie Cancer Care which would arise from a shift towards more patients dying in their homes.

The Department of Health has since responded to the recommendations in the report, taking note of many items from this 'shopping list' for future reference.

Assisted Dying for the Terminally Ill Bill

Assisted dying, euthanasia and related issues have been getting a lot of press recently, partly on account of publicity arising from Lord Joffe's Assisted Dying for the Terminally Ill Bill. An earlier version of the Bill was first put forward by Lord Joel Joffe in early 2003. A select committee in the House of Lords has since met to discuss the amended Bill, taking oral evidence during September / October 2004, with a final report expected in late 2004 / early 2005. When the Select Committee produces its report on the Bill, it will recommend whether the Bill should proceed and, if so, whether or not in an amended form (the Committee has the power to amend the Bill).

There are lots of activities, projects and examples of good practice going on out there and we would like to hear about them.

Copy date for the next issue of update will be 3 December 2004.

Please contact:

The Scottish Partnership for Palliative Care
1a Cambridge Street, Edinburgh EH1 2DQ

Tel 0131 229 0538 Fax 0131 228 2967

Email: office@palliativecarescotland.org.uk