

update

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Palliative Care: challenges for today and tomorrow

This edition of the newsletter is devoted to the Partnership's annual conference on 14 September 2005, when over 200 delegates met at Hilton Dunblane Hydro to explore, with the help of a range of speakers and workshop leaders, the theme 'Palliative Care: challenges for today and tomorrow'. You will find a summary on the cover pages and more detailed reports of the main presentations, together for the first time with a pictorial record, inside.

Despite lacking the incomparable chairmanship of our Honorary President, Dr Derek Doyle, who was unfortunately unwell, this year's conference was once again an undoubted success. Professor Frank Clark, Chairman of the Scottish Partnership for Palliative Care, ably took over the role of introducing the guest speakers and guiding delegates through an interesting, informative and enjoyable day. We were delighted to welcome Professor Julia Addington-Hall, Professor Vivienne Nathanson and Dr Marie Fallon as our guest speakers, and grateful to them for their detailed and thoughtful presentations, each of which did indeed outline many of the present and future challenges for palliative care.

A date for your Diary!
**Annual Conference
and AGM 2006**

**Next year's conference
will take place on
Wednesday 22 November
at Edinburgh Conference
Centre, Heriot Watt
University**



From left to right: Professor Julia Addington-Hall, Dr Marie Fallon and Professor Vivienne Nathanson, guest speakers at this year's conference.

Professor Addington-Hall, Professor of End-of-life Care, University of Southampton, addressed the challenges of an ageing population and its implications for palliative care, drawing on a range of research to outline what are likely to be some of the significant changes and issues facing us in Scotland, as healthcare providers and as potential patients, in the decades ahead. She pointed out that many of our current stereotypes of ageing and of older people will need to change, and encouraged the development of much closer working relationships between palliative care professionals and their counterparts in such specialties as medicine for the elderly.

Professor Nathanson, Director of Professional Activities, British Medical Association, considered some of the ethical issues around end of life decision making and helping patients to make choices. She surveyed recent 'headline cases' and current legislation and guidance in decision making on withholding and withdrawing life-prolonging treatments, as well as some of the implications of the Human Rights Act and the range of factors to be considered in assessing best interests. Her presentation included the difficult issues of dealing with disagreement and possible legal action, and her overriding message of advice to colleagues was 'communicate, communicate, communicate'.

Dr Fallon, Reader in Palliative Medicine, University of Edinburgh, gave a wide-ranging and thought-provoking talk on 'Our way forward in palliative care'. Reviewing the achievements of the past as well as the challenges of the future, Dr Fallon emphasised the significance of evidence-based medicine in the adoption of priorities for future funding, and the need for palliative care to begin to address this issue in a systematic way. She outlined a number of current and future developments in palliative care research, indicating that the need for more evidence was both a practical and an attitudinal challenge, and one which, by moving forward together in Scotland, we should now be ready to meet.

The challenges of an ageing population: implications for palliative care

Professor Julia Addington-Hall shared with us in her presentation a thought-provoking analysis of current and future demographic trends and their implications for both providers and consumers of health care in the future, in particular in the context of palliative care and care at the end of life.

Demographic changes

While life expectancy in Scotland is increasing faster than in any other part of Europe, the greatest impact on population is the decreasing birth-rate. Taken together, these trends mean that the Scottish population will age rapidly in the next few decades, with the percentage of over 60s rising from 16% in 2002 to 29% in 2042. Current stereotypes and characteristics of older people will change, with over 85s now the fastest growing age-group in the UK, reaching a total of almost 2.5 million by 2031.

Implications for healthcare

This has serious implications for healthcare, with an increase in demand for state-supplied pensions and health and social care occurring alongside a reduction in the number of people of working age to pay for or provide it. Severe labour market shortages are likely, with a corresponding impact on volunteering if people work for longer. This will have a particular impact on palliative care and especially on hospices.

These demographic changes also have important consequences for the amount and sort of care that will be needed, particularly in relation to length and severity of dependency, number of co-morbidities and length of final illness. The most common co-morbidities are serious chronic conditions such as arthritis, COPD, dementia, diabetes, heart disease, Parkinson's disease and stroke, which cause a wide range of physical, psychological and social problems. Cancer, for which age is the main risk factor, will remain a serious issue, with particular attention needed to cancer care for older people. Currently only 8.5% of the 'oldest old' die in a hospice compared to 20% of all cancer patients. Whether this group actually needs specialist palliative care less is an issue which needs to be addressed and understood.

There is some evidence, particularly from the USA, that more life may not necessarily mean more morbidity, and that in future we may have more healthy years and fewer years of ill health at the end of our lives. This is not conclusive, however. Advances in controlling the progress of chronic diseases are also likely to produce a dynamic equilibrium between decrease in mortality and increase in disability and more people are likely to live longer with less severe levels of disability. Palliative care can play a key role in helping them to adjust.

Preferred place of death

Attitudes to preferred place of death also need to be understood in the context of age. Professor Addington-Hall quoted a study of older people's attitudes to death and dying which indicated that those aged 55 to 75 were as positive about hospice as home death, and those over 75 preferred hospice and hospital to home death. She attributed this in part to fear of dying alone or of being a burden to others, and also to the fact that many older people have already cared for others and know what that means. The desire of many to die in a hospice in fact runs counter to current policy for hospices to provide acute specialist palliative care rather than terminal care, and may indicate a potential conflict between professional and user values.

Palliative care beyond cancer

Professor Addington-Hall also felt that the debate around palliative care beyond cancer needs to be considered in the context of an ageing population, and she

advocated a measured approach and the need for clarity about what is required. She outlined some of the growing research evidence that people with life-threatening diseases other than cancer also have

- uncontrolled symptoms
- psychological and spiritual distress
- poor communications with health professionals
- while their families experience
 - heavy burden from care-giving
 - psychological distress
 - little practical or emotional support and
 - little bereavement support.

Using the experience of patients with heart failure as an example, she highlighted the psychological impact of a continual sense of loss and the need to adjust to changes, together with a lack of information and communication, and pointed out the important contribution which palliative care professionals could make to patient care in working alongside their counterparts in other specialties, including medicine for the elderly.

Future palliative care

The example of heart failure shows how prognostic uncertainty and different trajectories of dying are key factors in the difficulty of extending palliative care and often barriers to even thinking about how palliative care might be provided. The current challenge is to find models of palliative care appropriate to the three main dying trajectories common in cancer, organ failure and dementia or frailty.

Professor Addington-Hall concluded that to do that we need to work with existing care providers in hospitals, community teams and care homes:

- to increase palliative care knowledge and skills, eg in symptom assessment and treatment and
- to provide support, eg in talking to patients and families about prognosis and treatment options and about their psychological and existential concerns.

Helping patients make choices: end of life decision making

Professor Vivienne Nathanson's presentation offered a topical and thought-provoking examination of some current and future challenges around ethical decision-making at the end of life.

Professor Nathanson's first important point was to emphasise the role of doctors in helping patients to make decisions, not making decisions on patients' behalf. The history of a holistic approach to patients in both primary care and palliative care is helpful in maintaining this emphasis. Recent media headlines have given the impression that there are frequent disagreements between doctors and patients around end of life decisions, whereas in fact these cases represent a tiny minority of patients. Instances of a lack of agreement between healthcare professionals and family/patients are exceptional, and focus on either a rejection of or a demand for treatment.

Existing guidance

Recent high profile cases have in particular focussed attention on existing guidance on the withdrawal of treatment, including fluid and nutrition. The recent Court of Appeal judgement on the Lesley Burke case upheld current General Medical Council guidance, **Withholding and withdrawing life-prolonging treatments: good practice in decision-making**, (2002) and emphasised the need for increased awareness. Existing guidance also includes the BMA guidance for decision making on withholding and withdrawing life-prolonging medical treatment published in 1999, and updated in 2001. A third edition is pending. The underlying principle of BMA guidance is as follows: 'Prolonging a patient's life usually, but not always, provides a health benefit to the patient. It is not an appropriate goal of medicine to prolong life at all costs, with no regards to its quality or the burdens of treatments.' The overriding issue is the burden to the patient.

Who decides?

Competent patients are the best judges of whether life-prolonging treatment is able to provide a benefit to them. For incompetent patients the decision rests on an assessment of 'best interests'. In assessing a patient's best interests, due regards must be paid to confidentiality, views should be sought from those closest to the patient, and a consensus should be sought within the health care team. Under Scottish legislation, any appointed health care proxy must be consulted.

Factors to be considered

A range of factors should be considered in assessing best interests. These include:

- the patient's own wishes and values
- the views of people closest to the patient about what the patient is likely to see as beneficial
- the views of the parents, if the patient is a child
- clinical judgement about the effectiveness of the proposed treatment, including the likelihood and extent of any degree of improvement
- whether the invasiveness of the treatment is justified in the circumstances
- the likelihood of the patient experiencing severe unmanageable pain or suffering and
- the level of awareness the individual has of his or her existence and surroundings, as demonstrated by being able to interact with others, by being aware of his/her own existence and having an ability to take pleasure in the fact of that existence and by having the ability to achieve some purposeful or self-directed action or to achieve some goal of importance to him/herself.

Withholding or withdrawing treatment

Professor Nathanson noted that while the Human Rights Act contains in Article 2 a right to life, it does not provide for an absolute right to all medical treatment. Article 3 includes the right to freedom from inhuman or degrading treatment and Article 3 includes the right to die with dignity. As regards withholding or

withdrawing treatment, she indicated that morally they are the same, and the assessment criteria for both are the same. She acknowledged, however, that healthcare professionals may find it easier not to treat in the first place, and may need support in withdrawing treatment. She recommended colleagues to treat if in doubt, to prearrange a period of review, and then to withdraw after this trial period if the treatment proves of no value. As an added safeguard in the case of withdrawal of artificial nutrition and hydration, formal clinical review should be carried out by an independent senior clinician. Legal advice should be sought in the case of persistent vegetative state, and a court declaration, while not required in Scotland, may provide some protection against subsequent lawsuits.

When things go wrong

Attempts should always be made to resolve disagreement by discussion and the offer of a second opinion. Where the disagreement cannot be overcome a court declaration will be required and legal advice should be sought. Decision-making should always be documented and a record kept of

- the way in which the decision was made
- the reasons for the decision
- what guidance was consulted
- whose advice was sought.

Underlying reasons for disagreements often include the fact that time is limited and communication absent or poor, as well as psychological factors such as grief, anger and guilt. In addition, there are common misunderstandings about the success and burdens of medical treatment and its possible outcomes. In Professor Nathanson's view, this situation will improve when we learn to communicate successfully the message that medicine is about improving the quality of life, not about prolonging life. In the meantime, she concluded, it will be impossible to avoid court cases altogether. Our efforts should be directed to minimising their number through 'communication, communication, communication'.





Our way forward in palliative care

Dr Marie Fallon's presentation provided a comprehensive overview of the challenges currently facing palliative care by addressing the twin questions 'Where have we come from?' and 'Where are we going?' She began by addressing the increasing challenge of maintaining clinical relevance through research and education, and offered the view that what is clinically relevant for palliative care is its focus on caring for patients and families.

Where have we come from?

Dr Fallon outlined the challenges inherent in the shifting paradigm in recent years from care of the dying to support and palliation over many years; from cancer only to potentially all life-threatening incurable diseases; from the best care we can offer to the current emphasis on evidence-based medicine; and from fewer expensive investigations and treatments to an NHS overwhelmed by treatment possibilities. Of chief importance to palliative care among these, in Dr Fallon's view, is the increasing focus on evidence-based medicine.

The answer to where palliative care sits in this paradigm is to be found by going back to basics, to the keystones for palliative care laid by colleagues before us. In particular, Dr Fallon highlighted the inclusion of palliative medicine as a medical specialty, the introduction of the Journal of Palliative Medicine and the publication of the Oxford Textbook of Palliative Medicine. She paid tribute especially to the role of Dr Derek Doyle in putting in place these sound starting blocks, which have helped, along with the seminal work of Cicely Saunders, to put us firmly ahead as world leaders in palliative care.

Where are we going?

Recent developments include the National Institute for Clinical Excellence (NICE) guidance on supportive and palliative care for cancer. Although there is an enormous overlap between the two, in this context, supportive care means 'helping patients and their families cope with cancer and its treatment', while palliative care means 'alleviating pain and discomfort when it is not possible to cure the cancer'.

Key recommendations include the following:

- patients and their carers should have access to a range of specialist services that help them cope with cancer and its treatment
- there should be processes in place to make sure that all healthcare professionals involved in a patient's care inform each other about developments affecting that patient and work together to provide co-ordinated care
- people with advanced cancer, and who are dying from cancer, should have access to specialist care 24 hours a day, seven days a week, wherever they are being cared for
- good quality information should be available free of charge to help people affected by cancer make decisions about their care, and
- the needs of family and other carers should be met, including offering support after someone has died.

Of fundamental importance, in Dr Fallon's view, is the recommendation that

- wherever possible, significant information should be given to patients by a senior health professional who has received advanced level training and is assessed as being an effective communicator.

Evidence

However useful guidelines are, however, they will not change practice. Standards of care need to be audited, and audit has to be based on evidence. Evidence will only come from appropriate research, employing appropriate methodologies. Current attention in Scotland is focussed on the recommendations of the Kerr Report, 'A Framework for the future of the NHS in Scotland', and it is clear that whatever services are offered in the future must be evidence-based, or funding will not be

forthcoming. The evidence-base in palliative care is very poor. While clinical aspects of palliative care have been developed considerably in the past 15 years, research aspects have not been subject to the same development. Dr Fallon expressed the view that without more research palliative care may not just stagnate, it may go backwards. We need to focus on aspects of care for which we have, and have not, the evidence.

Research

A recent survey of research in palliative care carried out by the National Cancer Research Institute (NCRI) identified:

- less than 4% of all research funding in cancer care goes to palliative care
- research in palliative care is of variable quality
- research working is fragmented, with a lack of critical mass in any area and a lack of interdisciplinary working
- little collaboration with researchers outside the field of cancer
- lack of research training and structure
- inadequate numbers of funded posts at postdoctoral and senior lecturer level
- lack of infrastructure support, including dedicated statisticians, data managers and administrative staff, and
- lack of agreed outcome measures for specific aspects of supportive and palliative care research.

This last point is extremely important, and contributes to the difficulty in obtaining meaningful data and combining different research projects.

In order to enhance research in palliative care, the NCRI Strategic Planning Group has recommended the establishment of interdisciplinary NCRI Supportive and Palliative Care Research Collaborations (SUPAC) and of a source of dedicated funding of £5m over 5 years from the Department of Health, Marie Curie Cancer Care, Macmillan Cancer Relief, Cancer Research-UK and the Medical Research Council. These collaborations will address the current

fragmentation of palliative care research, and their objectives include achieving a critical mass of research activity with a wide span of expertise and a range of methodological approaches, as well as increasing capacity, achieving maximum positive impact on policy and practice, and nurturing and developing the high quality researchers of the future.

In addition, the NCRI Palliative Care Clinical Studies Development Group has established multi-centre sub-groups in pain, cachexia, prognostication and health services research.

In addressing how to increase the critical mass of researchers and provide support for specialist registrars and nurses, Dr Fallon felt that we need to open our minds to the issues which might be usefully pursued. As an example, she cited the possibility of intervention studies, based on the fact that palliative care rarely involves one specific manoeuvre, but rather a series of interventions. She suggested that the Medical Research Council Framework for Complex Interventions could be used as a basis for such studies.

Can basic science help?

Dr Fallon felt strongly that palliative care teams need to embrace, rather than be afraid of science. We need to incorporate it in our own thinking and move forward with it. There are already successful examples of this. The pathways that mediate 'total pain', a concept developed by Cicely Saunders some 40 years ago in the absence of scientific knowledge, can now be fully understood in the light of research into the mechanisms whereby lamina/neurones are altered by pathology, and Dr Fallon outlined the results of a recent study into the use of the drug Gabapentin for neuropathic pain.

Clinical practice

The translation of research into clinical practice remains a key challenge, particularly in pain management, where despite the World Health Organization and SIGN 44 guidelines regarding management of cancer pain, studies still show a high incidence of severe pain among cancer patients. Issues identified through use of the Edinburgh Pain Assessment Tool included time, funding, and the tension between research and clinical practice. Dr Fallon suggested that we need to integrate thought and action, for example in introducing pain as the fifth vital sign on bedside charts.

Hospital and community services

Dr Fallon also identified the interface between hospital and community services as a key area for improvement and challenged colleagues to consider how palliative care could best integrate into existing services. She outlined some of the results of an audit of one month's oncology admissions involving a total of 110 patients with active advanced cancer. Of these, the majority was admitted by reason of complication of the disease or symptom control. 100 were admitted from home, and 45% of patients had no next of kin present at the time of admission. 40% indicated that there had been no health professional involved in their care in the last four weeks. This study highlighted the challenges palliative care needs to consider in developing better systems, better communication and better out-of-hours cover arrangements.

Moving forward

Palliative care also needs to consider what level of specialism is necessary for the future. In Dr Fallon's view, there is no 'standard palliative care patient'. We encounter patients and families with a spectrum of problems and needs, and should provide a spectrum of services and care depending on those needs. We have a great opportunity to move forward together in Scotland, looking anew at what we are doing, dispelling ignorance and facing the practical and attitudinal challenge of gathering the additional evidence that is required. We must not be afraid of doing so.

14th Annual General Meeting

**The 14th Annual General Meeting,
Dunblane, 14 September 2005.**

Chairman's report

Chairman Professor Frank Clark highlighted the new context for palliative care which would follow from the recently published Kerr Report, from the development of Community Health Partnerships, and from Agenda for Change and the associated Knowledge and Skills Framework. All of these would have an impact on the way in which health care would be delivered in the future, and Professor Clark felt that many of the recent developments in palliative care meant that we were well placed to respond to these changes and challenges. He also referred to the 'three Es' of education, ethics and evidence, which he saw as fundamental to the future development of palliative care, and all of which were featured in the 2005 Annual Conference.

Director's report

Pat Wallace reported on some of the year's work within the Scottish Partnership for Palliative Care, and how these initiatives reflected not a move away from the necessity to improve palliative care services for people with cancer and to make them more universally available to that patient group and their families, but the recognition that those services should be available to anyone who needs them, whatever their diagnosis. She announced that the final report and recommendations from the Big Lottery Fund project 'Increasing access to palliative care for people with life threatening conditions other than cancer' would be launched at the Annual Conference on 22 November 2006.

Honorary Treasurer's report

The Annual Accounts for 2004-2005 were presented by Honorary Treasurer Maria McGill, and their adoption unanimously approved. Thanks were expressed to grant-funders and member organisations for their support.

Election of office-bearers

At the Council meeting on 5 October 2005, the following office-bearers were re-elected for a further year:

Chairman: Professor Frank Clark CBE

Deputy Chairman: Susan Munroe

Honorary Treasurer: Maria McGill

Annual Conference 2005 - Palliative Care: Challenges for today and tomorrow

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Delegates at this year's conference were able to attend two workshop sessions from a choice of eight topics, a number of which highlighted areas of the Partnership's own work.

Professor Frank Clark, Director of Strathcarron Hospice and Chairman of the Scottish Partnership for Palliative Care, explored some of the current issues in the development of a coherent approach to the quality assurance of palliative care education in Scotland. Professor Clark has recently set up a sub-group of the Partnership, working in collaboration with NHS Education for Scotland, to take these issues forward, and his workshop examined the factors influencing demand for palliative care education as well as its shape and content and the characteristics of good palliative care education.

Dr Martin Leiper, Consultant in Palliative Medicine, Roxburgh House, Dundee and Dr Chris Ward, Consultant Cardiologist, Ninewells Hospital, Dundee, presented a workshop on 'Living and dying with heart failure' which examined some of the issues to be raised in the forthcoming report of the Scottish Partnership for Palliative Care working group on palliative care for heart failure. The workshop outlined the current management of terminal heart failure and discussed the crucial role of palliative care in caring for these patients. Provisional recommendations from the forthcoming report were highlighted.

Another forthcoming report by the Partnership, the National Practice Statements for Palliative Care in Care Homes, was the basis of a workshop run by Susan Munroe, Director of Patient and Family Services, Marie Curie Cancer Care, and chair of the working group which developed the statements. This session explored the background and the implications of developing and implementing the statements as a means of assessing and improving the quality of palliative care

received by care home residents. Participants were unanimous in their agreement that those living in care homes should have access to the same quality of care as those living in their own homes, and felt that in general the statements were based on correct principles and should be achievable if resource implications, particularly in terms of education and training, were also recognised and addressed.

Preliminary findings of the Partnership's Big Lottery Fund Project, 'Increasing access to palliative care for people with life threatening conditions other than cancer' were discussed in the workshop led by Alison Poole, Project Manager, and Kate Jones, Education Consultant. Themes relating to priorities and unmet needs emerging from preliminary analysis of the recent consultation with patients and carers were outlined and compared with those identified by delegates from their professional experience. A high correlation was found, with an emphasis on information needs, symptom management, continuity of care and support, and the need for a multidisciplinary approach.

The theme of ethical decision making at the end of life was revisited by Dr Rosaleen Beattie, Medical Director, St Vincent's Hospice and BMA Scottish spokesperson on medical, legal and ethical issues. Following on from Professor Nathanson's presentation earlier in the day, Dr Beattie explored some of the legal issues around refusal of treatment, advance directives, double effect and withholding and withdrawing treatment, emphasising the need for a holistic approach and widespread discussion.

Dr Marie Fallon, Reader in Palliative Medicine, University of Edinburgh, also further developed part of her theme in her main presentation in a workshop devoted to a detailed examination of current issues in the future development of palliative care research. She emphasised the importance of expanding the number of palliative

care professionals with higher degrees currently engaging in research, and outlined some of the mechanisms by which this might be encouraged.

Dr Gill Hubbard and Neneh Rowa-Dewar of the Cancer Care Research Centre at the University of Stirling addressed the challenges of developing a sustainable and effective patient involvement strategy and presented some of the results of a literature review of the involvement of people affected by cancer in policy and planning. They looked at different models of involvement and at some of the barriers and facilitators to successful involvement, as well as noting studies on the impact of involvement on services and on people affected by cancer. The existence of much user involvement experience not yet reflected in the literature was also acknowledged.

Policy and planning was the subject of the workshop run by Nick Brown of the Scottish Executive Health Department, who explained and answered questions on the government policy process followed by the Scottish Executive and Scottish Parliament. He outlined the importance and cyclical nature of the policy process, from examining the rationale for a new policy, establishing its objectives, conducting an appraisal of its likely implications and effect, monitoring all aspects of its implementation and evaluating impact and results, to gathering and analysing feedback to feedback into a further examination of rationale for the future.

Delegates' evaluation of the conference overall was positive, with 69% finding the content and theme very useful and 62% indicating a likelihood that they would follow up or apply in their practice something they had heard that day. An average of 77% rated the speakers' presentations as being very good or excellent, while just over 67% rated the workshops as good or very good. As usual, evaluation feedback will be considered in the planning of next year's conference.