Palliative care is everbody's business

Annual Conference Report
Scottish Partnership for Palliative Care
Thursday 29 October 2010

Scottish
Partnership
for Palliative Care

Conference Opening

Mark Hazelwood, Director, Scottish Partnership for Palliative Care

Mark Hazelwood

Mark Hazelwood warmly welcomed delegates, reflecting on the remarkable progress that has been made over recent years to bring us to a place where we can usefully hold a conference on the subject of palliative care being *'everybody's business'*.

The Scottish Government continues to make palliative and end of life care a high priority. In the Scottish Parliament there is also increased interest in palliative care, a recent example being the Public Audit Committee's request for evidence on improvement. Developments such as Margo Macdonald's *End of Life Assistance (Scotland) Bill*, Terry Pratchett's Reith Lecture, and the Director of Public Prosecution's publication of an assisted suicide policy have all been part of an increasing and ongoing public discourse about end of life issues.

This new, higher profile brings with it new challenges, and through parallel workshop sessions the conference provided an opportunity to identify some of these challenges and think through and discuss their implications.

Capturing both aspirations and realities in its title, and with a strong participative element, the conference set out to interest and stimulate delegates.
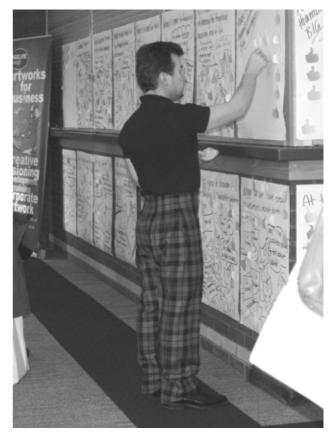
To inspire delegates to think creatively, Graham Ogilvie, a graphic artist from Ogilvie Design, was present throughout the day, capturing in pictures the themes, events and talking points of the conference. Delegates were able to reflect on these images, and vote on the illustrations that captured the most important points. The images will also be available for delegates to take and use as tools within their own workplaces.

Graham Ogilvie

Palliative Care was Everybody's Business

Professor David Clark, Director of Dumfries Campus, University of Glasgow

Professor David Clark provided delegates with a contextual background for the discussions of the day by tracking the development of palliative care from the mid 20th Century to the present day.

The post-war period was a watershed in the development of the modern view of palliative care:

> 'A paradoxical and awkward situation has been reached in which death is commonly occurring at advanced age (when dying is said to take longer) and also where medical and nursing skills are contriving to prolong life … relatives are not available or willing to undertake care at home… However desirable it may seem to some that all old people should obtain the best skill and care in their dying moments, it seems pretty clear that this will remain an ideal for a long time to come …'
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> Leak, W.N. (1948). The care of the dying.
> *The Practitioner* 161(962), 80-87.

This issue of *The Practitioner* was significant in bringing together several pieces of writing by GPs and providing an insight into their problems caring for dying patients. Soon after, in 1952, the newly formed Marie Curie Memorial institute formed a Joint National Cancer Survey Committee which gathered data on hundreds of people and revealed a devastating picture of the home conditions in which people were living and dying, for example:

Professor David Clark

> '… house was dirty as she was too ill to clean it, and her clothing filthy with neglect and discharge from the ulcer … gave food to her pets which she needed herself.'

> '… loses faith in every possible way as he feels he is gradually worsening, and that no-one is taking any interest.'

This was a very significant report in beginning to raise awareness of cancer at the end of life. In the 1950s there was very little in the way of systematic or informal support for people who were dying, or for health professionals who wished to provide such support. A quote from Dr John Berkley (first Vice-Chairman of the Scottish Partnership for Palliative Care) evokes a sense of the helplessness felt by many doctors when dealing with people dying in pain:

> 'I can very clearly remember, within the first year or two of going into practice, a lady with advanced cervical carcinoma dying at home. And we were giving quite large doses of morphine … I think we were giving adequate doses but not frequently enough and they were intermittent. And my feeling of utter helplessness, of trying to help, not only this woman, but her husband and her daughters, and feeling that I had not got the skills at that time to actually deal with this situation. It made quite a profound impact.'

In the 1960s this began to change, and the literature started to reflect a growing recognition of the unmet needs of dying people. Most significantly, Cicely Saunders published her first paper in 1958 (Saunders, C. (1958). Dying of Cancer. *St Thomas's Hospital Gazette*, 56(2), 37-47). She published around sixty papers

between 1958 and 1967, and set out all the issues we are still dealing with today. The work of Saunders provided and provides a rallying point for all those who care about palliative care.

Perhaps most original and enduring of all concepts to have emerged from palliative care is Cicely Saunders' concept of Total Pain. This was particularly inspired by the words of one patient, Mrs Hinson, who said *'all of me is wrong'*. Talking to Mrs Hinson helped Cicely Saunders to realise that, if we are truly to help a person, we have to try to understand the *whole* person – their physical symptoms, mental distress, social problems, and emotional issues.

Cicely Saunders founded St Christopher's Hospice in London in 1967, and it became a beacon of practice, research and education. Previously, dying patients had heard from doctors *'there is nothing more we can do for you'*. Cicely Saunders and her colleagues changed this to *'there is so much, with imagination, we can do'*.

The response to the increased awareness of the medical neglect of the dying is clearly illustrated by figures showing that between 1965 and 2001, palliative care services in the UK and Ireland have grown dramatically. Institutional provision was spearheaded by the voluntary sector, while NHS provision came later. The growth of services has been accompanied by a diversification of services. Palliative Care's recognition as a medical specialty in 1987 was a very important achievement, and was followed by the establishment of academic centres in palliative care. Since the 1980s palliative care has established considerable advocacy strength through national organisations such as Help the Hospices, the Scottish Partnership for Palliative Care, the National Council for Palliative Care, and professional groups.

Constantly evolving, the palliative care paradigm provides a philosophy of care, regardless of disease, age or stage of life, and could be described as a specialty with generalisability. Professor Balfour Mount played a significant role with his work looking at how to take palliative care principles and apply them to wider settings such as hospitals, and notably established a palliative care unit within Royal Victoria Hospital in Montreal in 1974. Understandings of what palliative care is and what it should provide differ greatly around the world. However, one belief that is shared is that palliative care has important work to do.

It could be said that we are currently experiencing 'the age of integration' for palliative care as it achieves increased policy recognition and is increasingly 'mainstreamed'. It is now widely accepted that palliative care should be provided to people on the basis of need rather than diagnosis. Palliative care is also now the subject of various standards, guidelines and 'preferred golden pathways', and though much of this progress is good it is important to recognise that there are risks of palliative care becoming too formulaic. The palliative care research infrastructure is growing, and palliative care is increasingly being framed as a 'public health' issue.

A SWOT analysis for palliative care could be presented as follows:

Strengths: unprecedented levels of interest in end of life issues; specialist workforce exists for education and clinical care; growing interest in 'rights' argument for palliative care; increasing levels of global collaboration.

Weaknesses: low public recognition of palliative care; weak evidence at service level –especially economic; inequitable access; global need vastly exceeds capacity to respond - eg access to opioids; the medicalisation of dying?

Opportunities: innovative models, for example Hospice Friendly Hospitals , Neighbourhood Networks, Project on Death in America, social marketing; civil society and state partnerships; societal conditions for 'starting the conversation' may now be right.

Threats: limited vision and preoccupation with health service solutions to cultural problems; philosophy of palliative care is reduced to technical procedures and what is auditable; assisted dying debate fragments effort and obscures public understanding of palliative care.

Professor Clark finished his lecture with a quotation from Dame Cicely Saunders:

> *'A society which shuns the dying must have an incomplete philosophy'*

Session A: What if ...? What would we do if the End of Life Assistance (Scotland) Bill was to be passed?

Nora Kearney, Professor of Nursing and Cancer Care, University of Dundee

Professor Nora Kearney

The End of Life Assistance (Scotland) Bill aimed to 'permit assistance to be given to persons who wish their lives to be ended' and at the time of the conference was in Stage 1 of its process through the Scottish Parliament, the outcome of which was uncertain. Nora Kearney, Professor of Nursing and Cancer Care at the University of Dundee provided some context for delegates, relating the Bill to *Living and Dying Well*, Audit Scotland's *Review of Palliative Care Services in Scotland*, and sharing some views on the proposed legislation. Delegates then formed small groups and were assigned one of the following tasks.

Group A: Clinicians and managers responsible for delivery of palliative care

Several small discussion groups were asked to imagine they were clinicians and managers responsible for delivery of palliative care. They were asked how implementation of the End of Life Bill would work within the framework of current palliative care, and to develop a protocol for physician assisted suicide (PAS) for their organisation taking account of all involved in this care pathway. Discussions were varied and covered a breadth of the issues raised. Delegates agreed that patients requesting PAS would likely be vulnerable, and to ensure that every request was handled properly and sensitively, it would be essential that clear procedures and protocols were in place to guide all members of the multi-disciplinary team. However, delegates found the logistics of progressing PAS from request to death difficult to visualise: What timescales would be involved, and how can the NHS ensure time commitments are met? How are roles allocated to members of the multi-disciplinary team, and how would conscientious objection be factored in? How and where do PAS discussions happen, and what must they include? What exactly would be required of a physician 'assisting' in a person's death, and what involvement would be required from other member of the multi-disciplinary team, for example pharmacists? How would referral criteria be defined?

Delegates were clear that the involvement of so many individuals in such a sensitive issue necessarily brings with it numerous complications and conflicts that would be difficult to account for through any defined protocol. However, it was agreed that any such protocol would have to take into account:

- staff training, contractual issues, role allocation, support and counselling
- support and/or counselling for relatives
- support and advocacy for patients, including discussions of palliative care and assessment of feasible alternatives to PAS
- assurances that patients were acting autonomously and fully understood the implications of their decisions.

Group B: Patients and carers facing end of life decisions

Several groups were asked to imagine they were patients or carers facing end of life decisions, and to answer the question: 'What do you want to have in a care pathway protocol for PAS to ensure the best care for you?'

Most groups considered the question from the perspective of a patient considering PAS, and suggested that they would want a care pathway protocol for PAS to provide answers to a number of questions:

- How do I go about requesting PAS? When do I know if I am ill enough to ask for this? What if my own doctor is not in favour of PAS? How much will it cost to request a PAS? Relevant information should be easy to access and include links for counselling.
- Do I need to tell my family? Would there be information and support for my family if I decide to go ahead with PAS? If I had no family support would support be available for me elsewhere? Can a carer oppose my request? Might my carer be accused of coercion?
- Will there be time for a proper discussion of PAS with my doctor before I make my decision? Can I change my mind? When would my current treatment stop? Will mediation services/counselling be available? Are there any alternatives to PAS? If I'm unhappy with certain decisions can I appeal against them?
- What will an assisted death feel like? Where will it take place? Can I choose who I'd like to be there with me? What method will be used, or do I have a choice of methods? Can I choose a doctor I know to assist me? Will there be any pain? What if it is not successful first time? Can a dignified death be guaranteed? How can you assure me of the expertise of the physician involved? What quality standards relate to PAS?
- How do I make a request if I cannot write or speak? Can you make an advance directive on PAS? How long would the decision last for based on the capacity when making the decision? How do I predetermine what is intolerable?

Group C: Palliative care professionals who oppose the Bill

Group C was asked to consider, from the point of view of palliative care professionals opposed to the Bill, how they would practice within a comprehensive palliative care framework if the Bill became law. Many groups had questions regarding the logistics of introducing such a comprehensive framework, reiterating many of the points made by **Group A** and **Group B.**

In addition, delegates were clear that it would be stressful for palliative care professionals (and others) who opposed this to have to work within a system which incorporated PAS, and several groups suggested that such a Bill would have significant negative effects on the trust and relationships built up between professionals and patients, and that this might lead to a loss of staff and the disintegration of teams. It was strongly felt that those in opposition to this law should be able to opt out of any kind of involvement.

Having noted these challenges, groups approached the task constructively, and many groups listed a number of possible opportunities that could be brought by such a new law. For example, it was suggested that exploring concerns with PAS patients may lead to improvements in palliative care, especially for more

neglected groups, and stimulate more collaborative working. A new law of this kind may also lead to a raised awareness of specialist palliative care, and opportunities to address some of the misconceptions and fears people currently hold about palliative care. The law would also present an opportunity to raise public awareness of dying, bereavement, death and advanced care planning and strengthen the public health approach to these issues.

Such a law would be likely to bring more work and new responsibilities to specialist palliative care, for example in looking at ways to ensure everyone has access to and information on specialist palliative care, and through increased referrals as part of the protocol for dealing with PAS requests. If this was accompanied by greater investment in palliative care, then some positive effects might be seen.

Session B: Raising public awareness of death, dying, loss and bereavement

Hilary Fisher, Director of the Dying Matters Coalition, National Council for Palliative Care

Based in England and Wales, Dying Matters is a broad based coalition of just under 12,000 members, which aims to change public knowledge, attitudes and behaviours towards death, dying and bereavement. Delegates learned about some of the work that this coalition has undertaken, and then split into small groups to discuss their views on raising awareness of dying, death and bereavement in Scotland. More information about *Dying Matters* is available at: **www.dyingmatters.org**

If work was undertaken in Scotland to raise public awareness of death, dying, loss and bereavement, who should the key target audiences be?

Several groups suggested that since this is an issue that affects everyone, it is not possible to pick out a few key target audiences. Age group was often seen as a relevant feature, but taken as a whole, responses suggested practically every age group as a potential key target audience. Several groups mentioned the relevance of this issue to spiritual and religious matters, and therefore suggested target audiences such as spiritual and pastoral carers, churches, faith leaders, religious, cultural and humanistic groups. Other suggestions included: bankers, carers groups, charities, client groups, community groups, civil servants, disadvantaged groups, emergency services, employers, financial advisors, healthy people, hospices, lawyers, local authorities, the media, minority groups, opticians, parents, patients, politicians, public health, retailers, social groups, teachers, undertakers, and voluntary organisations.

What messages do you think would help begin a conversation about dying, death and bereavement?

Some suggestions were given of questions that may help begin a conversation about dying, death and bereavement, with professional colleagues, family, friends or other professional groups, for example:
'If you only had a year to live, what would you want?'
'Have you thought about your money?' (practicalities can be easier to discuss)

'Have you thought about what you want to happen before and after you die?'
'We talk about patients dying all of the time, have you thought about your own death?'
'What music would you like played at your own funeral?
'Do you think that was a good death?'

It was suggested that health professionals often face situations within their working lives that could be seen as opportunities to begin a conversation about dying, death or bereavement, either with patients, families or with other colleagues. For example, the behaviour of patients or family members may indicate that the time is right for such a discussion; decision-making about planning future care could trigger a discussion about the kind of plans people may wish to make for their death; and staff may find that reflecting on the death of a service user may lead them to wider discussions with colleagues on this subject. Several other examples were suggested of times when professionals might be able to open up opportunities for patients to discuss these issues, and it was suggested that it might be helpful for professionals to recognise their role in initiating and facilitating these conversations, and to work on their own self-awareness and confidence in talking about these issues.

How can key target audiences best be engaged with?

Delegates suggested many ways to get people engaged with the idea of talking about dying, death and bereavement. The more specific of these suggestions were aimed at raising awareness among those working within health and social care settings, mainly through various forms of training and education. There were also several suggestions that children, teenagers, young people and young adults should be engaged through formal education, as well as some less formal routes such as volunteer opportunities, youth groups and student unions.

Most of the suggestions given were not aimed at any one specific group, but were ideas for engaging large sections of society. For example:

- It was suggested that life events such as marriage, buying a house, diagnosis of an illness, pregnancy or getting a bus pass could in some way be used as a trigger for opening up this subject.
- Meeting places (for example pubs, cafes, football matches, sports clubs, day centres, workplaces, libraries and gyms) were suggested as appropriate places to attempt to engage people, as were places that people go for advice (eg solicitors, benefits agencies, community centres and GP surgeries) and other busy places (eg public transport and public toilets) .
- Many suggestions were made of engaging with people through various forms of media, for example the internet (including blogs and social networking sites), television (including soaps, debates, reality TV, adverts), print media (including newspapers, free newspapers, internal newsletters, leaflets, magazines and bill boards), drama, films, debates and radio.
- Other creative suggestions included: public events; celebrity endorsement; open days and talks; creative arts competitions; organ donation awareness week; funeral bonds; screen savers; messages within payslips; community projects.

There were some suggestions that an organised campaign could be run to engage people with these issues, and many of the suggestions above could be seen in the light of such a campaign. It was also suggested that projects should be targeted to specific groups, public information would be helpful, and that it might be helpful to show people what can go wrong if you don't make plans for death.

Though delegates were encouraged to focus their discussions around a number of key questions, there was plenty of opportunity to air more general opinions, and the views expressed were diverse. Many felt that it is important that death is 'normalised' as opposed to 'medicalised', and that children should grow up thinking that death is normal. There were also wider discussions of how individual and societal responses to these issues are related to cultural, religious and spiritual matters, and how any steps to engage people more widely in discussion of these issues must take all of this into account. There was a very strong feeling that this is a matter that needs to be approached with the greatest of care, since there will always be people who do not want to discuss these matters, and that these people should not be pressurised in any way.

Session C: Exploring the challenges of belief, culture, organisation and self in delivering compassionate care

Dr Stephen Smith, Lead Nurse, Leadership in Compassionate Care Programme, Napier University

Stephen Smith

The Scenario

Delegates watched a short play, in which the main characters were:

Alice: a 91 year old woman who is very ill, and lying in bed in an acute hospital ward. A syringe driver is connected to her wrist, and she is wearing an oxygen mask.

Paul: Alice's son.

John: a Staff Nurse with 15 years experience, who works two nights on the ward each week.

Before the play began, delegates learned that though the characters would be played by actors, the scenario acted out was based on the real-life experience of a staff nurse working in one of NHS Lothian's Beacon Wards. These wards are supported through the Leadership in Compassionate Care Programme to become centres of excellence in compassionate nursing practice.

As background to the scene it was explained that within Alice's ward, staff are encouraged to interact with patients and their families in a personal, caring and compassionate manner. When Staff Nurse John came on duty to start his nightshift, Paul had been by his mother's bed all day, and she had been deteriorating very quickly. After a handover at the start of his shift, John arranged for himself and Paul to meet with the doctor to plan for Alice's care throughout the night. The play begins with Paul and John emerging from their meeting with the doctor and discussing the situation, and quickly moves on to a scene with Paul and John at Alice's bedside...

When Paul asks John if there is anything the nurse can do to ease his mother's discomfort, John gives Alice a dose of morphine which had been prescribed earlier by the doctor. Paul is holding his mother's hand, and John notices that he looks uncomfortable and awkward. Paul explains that he is worried that if he touches his mother's hand the wrong way he will disturb the syringe driver and cause her discomfort. Thinking it will no longer be used to administer drugs, John decides to remove the syringe driver to make it easier for Paul to hold Alice's hand. Paul asks the nurse if it would be ok to also remove the oxygen mask, since Alice looks uncomfortable. John removes the mask, and tells Paul that his mother is ready to die. John asks if Paul would like him to stay with him until Alice passes away. Paul says yes.

The next scene shows a discussion between Staff Nurse John and a nurse from the Compassionate Care project. The Compassionate Care Nurse asks John to write down what happened and share his experience with others. John is worried that he could be disciplined for some of his actions, such as removing the syringe driver and oxygen mask.

This gripping and thought-provoking session intrigued and involved delegates from the outset. Having watched the scenario being acted out, delegates were encouraged to consider the different perspectives of those involved, and the feelings they might have experienced during this particular incident. Delegates had the opportunity to explore the culture, beliefs and actions of the characters in the scenario, ask actors questions about their characters' feelings and motivations, and to consider alternative ways of approaching this situation. Working in groups and reflecting on their own roles and organisations, delegates discussed how individuals and organisations can focus on compassionate ways of working.

Some delegates were made uncomfortable by the scenario, for example by the possibly inappropriate removal of the syringe driver and oxygen mask, the discourse that was taking place over but not involving the patient, and at the apparent lack of structured advanced care planning. It was pointed out that support seemed to focus more on Paul than on Alice.

However, alternative views were expressed that John made the right decision, since John's shift handover meeting and meeting with the doctor had clearly indicated that Alice was unlikely to last the night. Precious time could have been wasted waiting for additional confirmation from a doctor who may not have experienced someone dying before. The nurse was praised for the compassionate way in which he prioritised spending time with Alice and Paul at such a difficult time, and for the relationship he had built up with the family which allowed him to provide such timely practical help and emotional support to Paul.

For some delegates, the scenario brought home the vulnerability and lack of confidence experienced nurses such as John can feel when dealing with dying patients, and regret was expressed at the lack of training and support that is provided in acute hospital wards to help staff to deal with situations such as this. John exposed some of this vulnerability in his interview with the Compassionate Care nurse. It was the view of delegates that compassionate, well-intentioned and experienced nurses such as John should not have to experience this kind of guilt and doubt.

Integrating themes from earlier in the day, a presentation of recent work on the role of dance and touch with people with MND, including a short film

Lucinda Jarrett, Artistic Director, Rosetta Life and Wellcome Trust Clore Leadership Fellow

'When you become locked in by neuro-degenerative illness, meaningful touch may become a thing of the past, silently grieved for. Willed movement may also be lost as the joys of the body are increasingly forgotten. Here Patrick Duke learns how to dance again...'

You-Tube introduction to film *From the Heart*, a Rosetta Life Production.

Lucinda Jarrett spoke of how she has often noticed that people with motor-neurone disease (MND) stay on the edge of the room, as if left out. She has experienced people with neuro-degenerative illness saying that their body is 'dead already'. Yet, through Rosetta Life's *Moving into Being* project, Lucinda met Patrick Duke, a man with MND who found that working with touch as an art form 're-connected' him. For Patrick, keeping moving is about keeping in relationship.

Rosetta Life has recently worked with several individuals with MND, enabling the production of some powerful and moving films that challenge public perceptions of dying. *From the bathroom to the bedroom, passing white owls in flight* is one such film:

'*A remarkable fusion of movement and poetry led by Sue who has motor neurone disease. Pushes the envelope of dance to reveal intimate words about the inner state of this unjust condition. Reinstates the concept of slow. A Rosetta Life Production for the Cultural Olympiad.*'[1]

Rosetta Life enables people with life-threatening illness to explore their experiences through the art form of their choice, to give expression to something that matters, and if they wish, to share this creative expression with a wider audience. Rosetta Life believes that the creative process is a healing process, and that it can enable participants to find their voice, to regain self-esteem and re-establish some control over their life.

Rosetta Life has undertaken many different projects, enabling people with life-threatening illness to express themselves through art. In her address to conference delegates, Lucinda concentrated on their *Moving into Being* project, speaking passionately about her work with people with MND using facilitated touch, dance, and poetry. Touch and movement games can also play a great healing role for some children, and the film *Learning to Fly* was entirely made by and with young carers and young bereaved people. Lucinda is currently working with a play centre for dance to see how dance can be used in palliative care.

Lucinda spoke of the importance of touch, particularly compassionate touch, and especially in the context of children who may be accustomed to being touched only with embarrassment or pity. However, cultural attitudes to touch have created barriers which can make it difficult for Rosetta Life to work with touch, especially with children.

Lucinda is currently undertaking research at the University of Warwick looking at the role of touch. She believes that within our culture touch has become complex, and as a society we've allowed the language of sex and abuse to colour our views of touch, and that this has affected compassion. She asks the question: *how can we re-appropriate and re-claim the language of touch?*

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[1] You-Tube introduction to film *From the bathroom to the bedroom, passing white owls in flight*, a Rosetta Life Production.

Lucinda Jarrett