

# update

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## Living and Dying Well underway

Work is well underway to implement Scotland's first national action plan for palliative and end of life care, *Living and Dying Well*. Launched by Nicola Sturgeon MSP, Cabinet Secretary for Health and Wellbeing, at the Scottish Partnership for Palliative Care annual conference on 2 October 2008, the action plan follows the Scottish Government's acceptance, in its December 2007 action plan for health and wellbeing *Better Health Better Care*, of the recommendations made in the Scottish Partnership for Palliative Care's May 2007 report *Palliative and End of Life Care in Scotland: the case for a cohesive approach*.

*Better Health Better Care* stated the Government's commitment to ensure the delivery of high quality palliative care to everyone in Scotland on the basis of need not diagnosis, and according to established principles of equity and personal dignity. In the summer of 2008 Audit Scotland published its *Review of Palliative Care Services in Scotland*, highlighting the variability of provision, access and delivery of palliative care services and the inconsistency of available

information about palliative care services. The development and implementation of *Living and Dying Well* has also provided an opportunity to address the issues raised in the Audit Scotland report.

*Living and Dying Well* makes a clear recommendation for a consistent model of care:

- identify patients with palliative care needs
- assess those needs with the patient plan and communicate across
- relevant care settings

as well as addressing issues relating to education, training and workforce development. It also identifies a number of areas requiring further work, and short-life working groups have been set up as follows to take these forward and to produce recommendations in 2010:

- development of palliative care guidelines and referral criteria to specialist palliative care (Dr David Oxenham)
- assessment tools and advance care plans (Professor John Welsh)
- patient and carer Information on palliative and end of life care (Maria McGill)
- appropriate service configurations to meet the needs of adolescents and young adults with palliative and end of life care needs (Dr Pat Carragher)
- delivery of palliative and end of life care in acute settings (Dr Pam Levack and Dr Stan Wright)
- palliative care from a public health and health promotion perspective (Kate Lennon).

Each group will report regularly to the national advisory group which has been established to ensure appropriate



Nicola Sturgeon, Cabinet Secretary  
for Health and Wellbeing

governance, implementation and evaluation of *Living and Dying Well*.

Additional workstrands include:

- development of palliative care standards by NHSQIS following completion of recommendations by the above working groups
- establishment of a national Palliative Care eHealth Advisory Group and development of a national electronic Palliative Care Summary (ePCS) for Scotland
- introduction of a Direct Enhanced Service for palliative care in primary medical services
- appointment of an NHS Education for Scotland project manager to develop a national education plan for general palliative care skills.

NHS Boards have now completed Development Plans based on the action points in *Living and Dying Well* and Dr Elizabeth Ireland, National Clinical Lead for Palliative Care, will be working with Board Executive Leads and others to take the work forward.

**This year's Annual Conference and AGM will take place on Wednesday 30 September 2009 at the Royal College of Physicians of Edinburgh. Booking form and programme inside this issue.**

## partnership news

### Annual Conference 2008

The Partnership's Annual Conference *Palliative Care: daring to be different*, held on 2 October 2008 at the Royal College of Physicians of Edinburgh, was a busy and enjoyable day which was highly evaluated by the great majority of delegates. As well as the launch by the Cabinet Secretary of *Living and Dying Well* a national action plan for palliative and end of life care in Scotland, delegates were able to hear from a full programme of interesting and informative speakers.

Derek Feeley, Director of Healthcare Policy and Strategy, Scottish Government Health Directorates, spoke about implementation of the action plan, pointing out that it was neither a strategy nor a manual, nor even an end in itself, but rather was about quality improvement in all its aspects. He emphasised the recent change in perception and practice of palliative care, from something that in the past began only once curative care had been abandoned, to something continuous and ongoing, integrated with disease modifying and curative care, and changing as necessary to suit a patient's condition.

Dr Jennifer Armstrong, Senior Medical Officer, summarised the key recommendations from the Audit Scotland's 2008 *Review of Palliative Care Services in Scotland* report and outlined how each would be addressed by *Living and Dying Well*. Dr Armstrong illustrated her presentation with quotations from patients and carers who took part in the Audit Scotland research. These highlighted both the importance of ensuring that services are available in a way that patients can and will access them, and the necessity for healthcare workers to display professionalism in all they do, taking the time to understand what patients and carers really need.

A series of speakers covered issues relating to the palliative care needs of people with dementia, anticipatory care initiatives in primary care, the community nursing review, the Marie Curie Delivering Choice project in Tayside and an innovative project to set up a 'virtual hospice' in the Highlands. The conference closed with a lively and thought-provoking presentation by Dr Harvey Max Chochinov on dignity conserving care at the end of life (see pg 8).

Derek Doyle OBE, Honorary President of the Scottish Partnership for Palliative Care, provided his usual inspirational leadership throughout the day. Reflecting on the reactions of delegates to the new action plan, with some finding it 'really exciting' and others viewing it as a 're-hash of what we've been saying for years'. Dr Doyle said that in his experience, nothing is really new - there are just better ways of doing the old things. This in itself he found truly exciting - there is huge excitement to be found in learning to do things better, and in having the opportunity to change things for the better. Of course, this is always hard work, but every day will be different and exciting - there is no room for despondency in palliative care.

In his closing remarks, Dr Doyle recounted a time when he was working as a church missionary in South Africa during the time of apartheid. Struggling to learn the local language, he asked a Zulu chief how he could communicate with people. He was told, 'just take their hand and hold it to your chest'. Holding a person's hand communicates volumes, and in our journey to find new, better ways to do the same things, we should never forget the basics. Holding someone's hand will always help.

### AGM 2008

At the 17<sup>th</sup> Annual General Meeting of the Scottish Partnership for Palliative Care immediately following the Annual Conference, both the Chairman and the Director reflected on the significance of the launch earlier that day by the Cabinet Secretary for Health and Wellbeing of the first national Action Plan for palliative and end of life care in Scotland. The Action Plan accepted all of the Partnership's earlier recommendations and promised to provide mechanisms for taking palliative care in Scotland closer to the equity and cohesion of approach for which the organisation aimed. All connected with the Partnership should congratulate themselves on being part of the thinking and commitment to improving services that underlay the Action Plan and on being part of the disparate and yet cohesive voice which gave the Partnership its strength and lent weight and substance to its activities and its recommendations.

The Chairman also reported on the Partnership's current review of corporate governance and membership issues, which aimed to ensure that the Partnership remained an organisation fit for purpose in the future and would result in consultation proposals for updating its constitution in 2009.

**The next meeting and  
AGM of the Cross  
Party Group in the  
Scottish Parliament for  
Palliative Care will  
take place on  
Wednesday 17 June  
2009 in Committee  
Room 5 at the  
Scottish Parliament,  
Holyrood, at 5.45 pm.**

# initiatives

## Alzheimer Scotland Palliative Care Initiative 2009

This exciting year-long initiative is a partnership project between Alzheimer Scotland, NHS Dumfries and Galloway and the University of the West of Scotland and is funded by the Scottish Government and NHS Education Scotland (NES).

It builds on Alzheimer Scotland's previous work in raising the profile and understanding of the need of people with dementia in the later stages of the illness and their relatives. Firstly through the Lighting up Lives<sup>1</sup> report (2004 -2006) which identified the unmet palliative care needs of people in this stage of the illness living in Dumfries and Galloway and was funded by the Big Lottery Fund. Secondly through the Beyond Barriers Project (2007-2009) this was a partnership between Alzheimer Scotland, the Care Commission and Dementia Services Development Centre, Stirling and was funded by the Scottish Government. The Beyond Barriers Project has recently won a Mental Welfare Commission Principles into Practice Award for Carer Support and Involvement.

The aim of the Beyond Barriers project was to develop current care practice by supporting staff *and* relatives to meet the palliative care needs of people in the later stages of dementia living in care homes and recognised that this process may be protracted and last up to two years.

The training consisted of an innovative three-day course for both care staff *and* relatives and a further five half-day sessions of supported learning for staff to enable them to implement their learning in practice.

The focus of the course placed communication at the heart of the sessions. It acknowledged the importance of person centred care and examined how a palliative care approach could enhance quality of life at this stage of the illness. An open approach was adopted that dying *with* dementia or *of* dementia will occur. It accepted that dementia is non-curative and for those people who reach the later stages of the illness it will be terminal. It also recognised that there were important lessons to be learnt from this project in managing the care of people with dementia who will die of other unrelated illnesses at any stage of their dementia.

Outcomes of this work have been:

- the development of workbooks linked to knowledge evidence requirements for Health and Social Care SVQ
- a greater understanding of the importance of involving relatives in such a programme of education
- a greater understanding of the palliative care needs of people with dementia
- the importance of providing supported learning to enable change in practice to occur.

The aim of the Alzheimer Scotland Palliative Care Initiative will be to develop the knowledge and understanding of a palliative care approach to care for people with dementia and their families to a much wider audience including health and social care professionals.

The review of palliative care services in Scotland (August 2008) identified that '*specialist palliative care should be available to patients with complex needs while general provision should be available to all*'. One of the key messages from the report identified '*that most palliative care is provided by generalist staff in hospitals, care homes or in-patient's own homes. But palliative care needs are not always*

*recognised or well supported. Generalists need increased skills, confidence and support from specialists to improve the palliative care they give to patients and their families*'<sup>2</sup>

The Initiative will therefore:

- develop the Beyond Barriers workbooks to meet the wider needs of health and social care professionals
- ensure that the workbooks reflect the Living and Dying Well Action Plan<sup>3</sup>
- gain SVQ accreditation for the workbooks
- publish the workbooks
- identify staff providing education within all NHS, voluntary and all social care settings
- provide a free two-day course for up to 60 of the identified trainers. The aim of the first day of the course will be to equip them with the knowledge and skills to deliver the course. This will be followed up by a further day of supported learning.
- there will also be the opportunity for the trainers to participate in an Action Learning Set, this will be optional as it will not be free.

Initially there will be a small pilot session. The courses will then be rolled out throughout Scotland and will be delivered by experienced members of the Alzheimer Scotland Learning Development Team

The University of the West of Scotland will externally evaluate the Initiative.

If any one would like to be involved in the project please contact [jhenderson@alzscot.org](mailto:jhenderson@alzscot.org) or telephone **01387 261303**

Jenny Henderson  
Trainer, Alzheimer Scotland

<sup>1</sup> [www.alzscot.org/pages/policy/palliativecare](http://www.alzscot.org/pages/policy/palliativecare).

<sup>2</sup> Audit Scotland *Review of palliative care services in Scotland* August 2008 ISBN: 978 1 906752 www.audit-scotland.gov.uk

<sup>3</sup> The Scottish Government *Living and Dying Well a national action plan for palliative and end of life care in Scotland* 2008 ISBN: 978-0-7559-5889-4



## special feature

### Cairdeas International Palliative Care Trust

It was a pleasure to be at the last SPPC conference and witness the launch of *'Living and Dying Well'*. Compassionate skilled palliative care and pain control is expected and even demanded in resource-rich countries such as Scotland; but the reality is very different for most resource-poor countries. For many there is little or no access to basic health care far less health care workers trained in palliative care. Despite the huge burden of HIV/AIDS and the increasing incidence of cancer most will not have access to oral morphine. In the vast subcontinent of India less than 0.4% of her 1.2 billion people have access to oral morphine. Thirty-two countries in Africa have almost no morphine distribution at all and only fourteen have oral morphine. Holistic care is seldom taught, communities and families are not supported and the inevitable misery and suffering continues. *'Please do not make us suffer any more!'* is the heartfelt cry uttered by the relative of a patient with cancer and taken up in a recent report on access to palliative care by Human Rights Watch.

#### What is being done to address this need?

*'The provision of palliative care for all individuals in need is an urgent humanitarian responsibility'* World Health Assembly 2005

More than sixty countries now have palliative care services of some kind with many vibrant national associations and a new global alliance. International networks such as the International Association for Hospice and Palliative Care (IAHPC) ([www.hospicecare.com](http://www.hospicecare.com)) offer support and expertise. Cairdeas is a Scottish registered international palliative care trust that seeks to facilitate this growth in palliative care. Cairdeas works in partnership with colleagues and services to build capacity, support education and training and offer specific expertise such as chronic oedema training and curriculum development. Since our inception in 2005 we have been involved in India (with Pallium India) and also in Malawi, Rwanda and now Uganda. Cairdeas is a key



partner in the development of the Palliative Care Unit in Makerere University and Mulago Hospital, Kampala. This exciting project is one of the first in Africa to offer palliative care to patients and families in a national referral hospital and cancer centre alongside University training and research. It will support advocacy, build credibility, care for patients and their families, develop new models of culturally appropriate and affordable palliative care and ensure practice is underpinned by evidence. An exciting part of this project, in partnership with Hospice Africa Uganda and the African Palliative Care Association, is to support the development and delivery of the first BSc a *'Degree for Africa'*.

#### What is it like here in Uganda?

Come with me on a clinical round in Mulago. Having negotiated increasingly gridlocked traffic choked with dust don your white coat – yes it is still essential here! Let's join the team in our tiny office. We may call in to see a Congolese refugee who has been carried many hours in a UN ambulance. Most of her family remains in war-torn Goma and their safety is unknown. Her advanced cancer has few treatment options but we can offer symptom control, talk of her fears via an interpreter and ensure she is not abandoned far from home and family; and of course help her elderly mother who is sleeping under the hospital bed purchase a mattress. Family members carry out much of the care and their dedication and sacrifice is humbling. Our patient seems at peace. *'I feel cared for here for the first time – my greatest fear is you will not come to see me'*. Next we will assess how the young lad with recent trauma



complicating his sickle cell disease is faring, or the young woman struggling with newly diagnosed advanced cancer of the cervix – this is the most prevalent cancer in Uganda. We must visit several patients on the infection ward with cryptococcal meningitis needing analgesia and the ever present Kaposi's sarcoma. Holistic care is a challenge when resources are so limited. Will there be medications in pharmacy today? Are there any dressings or gloves or IV fluids or paper for clinical notes? Yet palliative care is far more than medications; *'when I see you coming with the team I feel so much better. God has answered my prayers and I know that he cares for me. I no longer feel angry and sad. I can sleep at night instead of crying. I now have hope. Thank you.'* We may still have time to meet an elderly man awaiting vascular surgery who loves us to visit and insists we pray with him and join him in singing a hymn!

### How can we get involved?

We can advocate for greater equality and respect for palliative care as a human right. We can develop an understanding of cultural differences that will improve our care in Scotland. We may support financially. We may volunteer our palliative care skills and visit an international programme. International visits have a habit of being life-changing and allow an individual and organisation to develop new skills, challenge values, reflect on cultural diversity and richness, gain new perspective on challenges at home, support and encourage international colleagues and recognise our common humanity. Several fellow Scots have been out to visit Cairdeas projects with our thanks!

Along with Professor Scott Murray we will be holding a study day for international palliative care in Edinburgh on 1 October 2009 just after the next SPPC conference, so register your place. Please look at our Cairdeas website (and my BLOG) and sign up for our newsletters or as a financial supporter. I would love to hear from you.

Dr Mhoira Leng  
Head of Palliative Care Unit  
Makerere University

[www.cairdeas.org.uk](http://www.cairdeas.org.uk)  
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## members news

### Improving Palliative Care Standards through Partnerships

With an estimate that one in five of the UK population over the age of 65 years will in future end their life in a care home (SPPC 2006) the need for improvement in palliative care delivery in care homes has been recognised nationally and is highlighted in *Living and Dying Well*. The Scottish Partnership for Palliative Care in partnership with the Care Commission published national practice statements for palliative care in adult care homes. In response to the challenges facing care homes in the delivery of palliative care Highland Hospice developed a six-day pilot programme specifically designed for key workers in the homes to enable them to bring about change and to meet the SPPC practice statements.

Connect in Care is a network funded by NHSQIS, NES and the Care Commission and was created to support learning and practice development in the care of older people. They selected the Highland Hospice Education Project to partner an innovative intervention involving a facilitator and three actors, who visited the care homes participating in the pilot and worked with their communities including residents, relatives and staff. By acting out relevant and moving scenarios, facilitating discussion and generating questions an understanding and awareness of key palliative care issues was raised with the purpose of laying foundations for the key workers to bring about change. A public display of thoughts, feelings, ideas and experiences was created in the shape of a 'graffiti wall' which was left in the homes so that others in the wider community could respond to the issues raised.

Following the initial project the care homes will continue to be supported through the hospice specialist palliative care link nurses, short courses and study days tailored to meet the education needs of care home staff, the hospice information website and Connect in Care website, which informs best practice and provides resources for learning. The Connect in Care network will bring groups of practitioners together in practice development sites to share their experience and knowledge through learning events and the sharing of stories. The Highland Hospice care home programme is ongoing and to date we have had participation from 37 care homes and 111 key workers within the Highland region and there has been huge enthusiasm from the care home staff to take on board the learning and improve practice.

Further information about the project and evaluations are on the Connect in Care website:

<http://www.connect-in-care.net/practice-development-themes/supporting-a-good-end-of-life>

Paula MacCormack,  
Director of Clinical Services and Education, Highland Hospice

## national council news

*The National Council for Palliative Care, the umbrella charity for all those involved in providing, commissioning and using palliative care services in England, Wales and Northern Ireland, has been asked to lead a new national coalition to improve public awareness of death, dying and bereavement as part of the Department of Health's End of Life Care Strategy for England.*

The strategy, published in July 2008, sets out plans to improve palliative care for all those who need it and emphasises the importance of patient choice at the end of life. While 58% of people who die each year in England die in hospitals, surveys show that 56 - 70% would prefer to die at home. However, with a greater proportion of people dying in old age and in institutions, there is much less familiarity in society with death and dying than in previous eras and a lack of openness and discussion about such matters. The Department of Health believes that this has impacted negatively on the quality and range of support and care services currently available to patients and families. It highlights a range of issues such as the following:

- people may be unnecessarily frightened about the process of dying
- families may be unaware of the wishes of a dying relative
- inappropriate interventions may be tried if carers are not aware of an individual's treatment preferences
- it can be difficult for health professionals to broach issues relating to anticipatory care
- people may not have discussed funeral preferences or made a will
- people may avoid those who are ill for fear of 'upsetting them'
- people are not aware of the possible options that could improve quality of life and restore independence
- lack of public and professional discussion about grief and loss leads to isolation of the bereaved.

The purpose of the new coalition is to promote awareness and support changing attitudes and behaviours to death, dying and bereavement. Membership will be open to all organisations across all sectors and care settings in England with an interest in public awareness. The coalition will be led by a small steering group and by a project team at the National Council for Palliative Care, and will make use of a wide range of 'virtual' expert reference groups to ensure that the work is grounded in the reality and diversity of public experience.

To gauge current experience of raising awareness in organisations with experience in end of life care, the National Council has already carried out a mapping exercise of its own contacts. A systematic literature review has also been commissioned, and it is hoped that lessons can be learned from the experience of previous awareness raising campaigns on sensitive health issues. Work is also underway to identify a range of priority indicators against which the coalition's success may be measured.

Further information is available from:

Rose Parker,

Coalition Co-ordinator, National Council for Palliative Care

email: [rparker@ncpc.org.uk](mailto:rparker@ncpc.org.uk)

or on the National council website: [www.ncpc.org.uk](http://www.ncpc.org.uk)

## members news

*Ardgowan Hospice in Greenock has been placed sixth out of 100 top employers in the UK according to the prestigious Healthcare 100 list released by the Health Service Journal and Nursing Times. This is a tremendous accolade for staff in Greenock, the only UK Hospice to feature in the Top 20 best healthcare organisations in the UK.*

The award is a reflection of the excellent employment practices adopted within Ardgowan Hospice. Staff are motivated and supported to provide first class care to patients and families.

The influential list, researched by Ipsos MORI on behalf of HSJ and NT, and supported by NHS Employers, is based on the results of an exclusive poll of the employees of registering organisations. Open to both NHS and independent healthcare providers in the acute, primary care, mental health and ambulance sectors, the winners and representatives of all those included in the top 100 list celebrated at a special Awards luncheon held at the London Hilton on Park Lane on Monday, 2 March 2009.

Staff at the Hospice submitted information via a survey, from which data was collected. Feedback from the survey indicated that Ardgowan Hospice displays a sense of shared values and focus. Comments from employees included the following: 'Together we strive to make a difference every day', 'We are a forward thinking organisation', 'Our Managers are approachable and have a clear vision of where the organisation is going'.

Dorothy McElroy, Ardgowan Hospice Chief Executive commented: 'I am delighted that our organisation has been recognised in this way. It is a testament to the emphasis we place on ensuring that staff continue to feel supported and recognised for their achievements. The award reflects well on everyone involved with the organisation.'



# quality matters

## NHS Education for Scotland

My name is Liz Travers and I have been seconded to NHS Education for Scotland from Marie Curie Cancer Care until August 2011 as Educational Projects Manager for Palliative and End of Life Care. The overall purpose of this role is to facilitate education and training initiatives to support the implementation of *Living and Dying Well: a national action plan for palliative and end of life care in Scotland* (SGHD 2008).

In order to meet the aims of *Living and Dying Well* and ensure access to high quality, appropriate palliative and end of life care all health and social care professionals will need access to education and training to equip them with the knowledge, skills, competence and confidence to care for the diversity of patients and families living with and dying from any advanced, progressive or incurable condition.

The education project will be supported by a reference group of clinical experts, social care, voluntary agencies and education providers and will work in partnership with NHS Boards and their nominated Palliative Care Education Champions to identify, co-ordinate and facilitate a range of education and training initiatives for generalist staff. The role will support the key strategic themes of developing an educational infrastructure and building workforce capacity for service improvement in palliative and end of life care across NHS Scotland. The Palliative and End of Life Education Reference Group held their first meeting in April and agreed a number of initial areas to take forward. In the first instance short life working groups have been set up to explore the education and training needs of generalists in relation to Advance Care Planning and Communication Skills. The group remit is to identify appropriate education initiatives and interventions to support the implementation of *Living and Dying Well*.

On 1 April 2009 the NES project team hosted a full day event for the nominated Education Board Champions to explore their role remit and also to work with them to identify ways that NES can support their education and training needs and the Board priorities. During the afternoon session the education champions were joined by a range of education and training facilitators currently delivering palliative and end of life care education within the NHS Boards. This resulted in lively discussion and a sharing of experiences and ideas which will be invaluable to the Palliative Care Project going forward.

## Consultations

### GMC consultation: End of life treatment and care: Good practice in decision-making

The General Medical Council is currently running a consultation on new draft guidance for doctors, *End of life treatment and care: Good practice in decision-making*. This will replace earlier guidance on *Withdrawing and withholding treatment*. The consultation runs from 27 March – 13 July 2009.

Further information is available on the GMC website:

[http://www.gmc-uk.org/end\\_of\\_life\\_care/](http://www.gmc-uk.org/end_of_life_care/)

### BMA consultation: General Practice in Scotland: The Way Ahead

The BMA in Scotland is hoping for a widespread response to this consultation which runs until 12 June 2009. Full details are available on the BMA website:

<http://www.bma.org.uk/healthcarepolicy/thewayahead.jsp>

### NHS Quality Improvement Scotland consultation on Draft Clinical Standards: Prevention and Treatment of Coronary Heart Disease

NHS QIS is currently running a consultation on these draft clinical standards. Standard 18 deals with palliative care. The consultation will run until 22 May 2009.

For more information see the NHS QIS website:

<http://www.nhshealthquality.org/nhsqis/5389.html>

## Publications

### National Guidelines on Advanced Care Planning February 2009

The Royal College of Physicians, in collaboration with other organisations has published national guidance on advanced care planning for professionals in England and Wales. Available online at:

<http://www.rcplondon.ac.uk/clinical-standards>

### National Chronic Obstructive Pulmonary Disease Audit 2008 March 2009

The Royal College of Physicians has published a series of five reports emerging from the National COPD Audit 2008. The reports and further information on this UK wide audit are available on the RCP website:

<http://www.rcplondon.ac.uk/copd>

### Nursing and Midwifery Council Guidance for the Care of Older People March 2009

This guidance is aimed at working nurses, but also has implications for pre- and post- registration education and training, and can be used by employers as a benchmark for delivery. Carers and other healthcare professionals may also find the guidance useful and relevant to their work. Available online at:

<http://www.nmc-uk.org/aArticle.aspx?ArticleID=1673>

### End of Life Care Plan August 2008

The End of Life Care Plan, developed jointly by the Scottish Ambulance Service (SAS) and the Scottish Partnership for Palliative Care, provides guidance for all SAS staff involved in caring and arranging transport for palliative care patients and training staff in their needs. It is available on the Partnership website: <http://www.palliativecarescotland.org.uk/links/index.htm>

## events

### *Doing it differently: dignity conserving care at the end of Life*



*Dr Chochinov at the SPPC Annual Conference*

Delegates at the Scottish Partnership for Palliative Care annual conference on 2 October 2008 were privileged to hear Dr Harvey Max Chochinov, Canada Research Chair in Palliative Care, Director of the Manitoba Palliative Care Research Unit and Distinguished Professor, Department of Psychiatry, University of Manitoba, give a keynote address on his 'A, B, C and D of dignity conserving care'.

Dr Chochinov believes that conserving a person's dignity is an essential part of all healthcare, and that we all want to have dignity, and to help our loved ones have dignity, to the very end of life. However, he also believes that 'personhood' is highly soluble within 'patienthood', that when we become patients we are immediately aware of our own vulnerability, and that not being treated with dignity and respect can undermine our sense of value and self worth. To feel that who we are is being threatened or undermined – that we are no longer the person we once were – can cause despair affecting body, mind and soul.

#### **A is for Attitude**

Research has shown that the attitude of care givers can have a profound effect on a patient's dignity. Patients

look towards doctors for some kind of positive affirmation of who they are. The attitude of medical staff can therefore make a huge difference. 'Attitude' in the 'ABCD' model is about imagining yourself in the place of your patient. How would I be feeling in this patient's situation? What is leading me to make those conclusions? Have I checked if my assumptions are accurate? Am I aware how my attitudes affect patients? Could my attitude towards the patient have something to do with me rather than the patient? Do my attitudes enable or disable my ability to establish open and empathic relationships with my patients? Dr Chochinov quoted one study which indicated that 'not being treated with respect or understanding' (87.1%) and 'feeling a burden to others' (87.1%) were the issues most identified as having an influence on a person's sense of dignity.

#### **B is for Behaviour**

Our behaviour will also have an impact on a patient's sense of dignity. Seemingly small things can make a big difference, for example sitting at the bedside rather than standing in a doorway.

It is important to make eye contact, giving people our full attention without becoming distracted. It has been said that 'patients will forgive almost anything, but not a lack of kindness'.

#### **C is for Compassion**

Compassion can be defined as 'a deep awareness of the suffering of another, coupled with the wish to relieve it.' There are many pathways to learning about compassion, including literature and the arts as well as personal experience. Dr Chochinov believes that anything which puts us in touch with our own sense of vulnerability is likely to help. From a distance, things can seem generic and indistinguishable, and it is easy to see a patient just in terms of a collection of ailments that require treatment. However, from up close, things become unique and unforgettable. Once you attach a person to the ailments, that patient becomes special and compassion is possible. Each person has their own story.

#### **D is for Dialogue**

It is important to acknowledge the patient's situation, since just recognising the person beyond the patient in your dialogue with them can really help. For example phrases such as, 'this must be so difficult', 'this must come as quite a shock', 'I'm so sorry to have to be telling you this' or 'this is not the way I hoped things would go' show that you have an awareness of some of the effects your words may be having.

#### **In conclusion...**

The ABCD model can be of use across the healthcare spectrum. It provides a way of teaching those who interact with patients the importance of conserving personal dignity, and is a reminder to us all of how our actions can affect others.

*The full presentation is available on the Partnership's website at:*

<http://www.palliativecarescotland.org.uk/index%20posters.htm>

