

update

promoting palliative care for all...

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Living and Dying Well at the Partnership conference

The Scottish Partnership for Palliative Care's Annual Conference on 30 September 2009 opened with a speech from Dr Elizabeth Ireland, National Clinical Lead for Palliative and End of Life Care at the Scottish Government. Dr Ireland addressed the question *What difference can Living and Dying Well make to palliative care services in Scotland?*, and began by thanking delegates for their support, drive and commitment since the launch of *Living and Dying Well (L&DW)* last year. There has since been a significant and rapid development in the profile of palliative care, collaboration that has underpinned the engagement of NHS Boards, clinicians, academics, voluntary bodies, patients, carers, politicians and (even!) civil servants. She particularly thanked the Scottish Partnership for Palliative Care for its valued contribution to the whole palliative and end of life care agenda in Scotland, and assured delegates that the Scottish Government remains absolutely committed to achieving the aims of *L&DW*.

She believes that *L&DW* has retained such a high profile because it reflects a range of factors which research indicates will increase the likelihood of successful change in healthcare. Fundamentally, *Living and Dying Well* has ensured palliative and end of life care services are now seen in policy terms as mainstream. Most significantly, the approach is about making the right thing easier to do, and the last 12 months have seen many significant achievements. For the first time:

- there are comprehensive, realistic delivery plans in every NHS Board with accountability through the Executive Leads
- there is engagement with key stakeholders at national level to drive implementation, embed improvement and achieve sustainability across a number of initiatives
- there is consistent communication about the palliative care approach
- there is an educational programme delivered through NES to support the implementation of *L&DW*.

As well as reflecting on the past year it is essential to think about the future, recognising successes as well as identifying challenges. The challenges remain significant in terms of demography, finance, technology, inequalities, epidemiology, growing expectation and the importance of having patients and carers at the centre of all that we do.

L&DW provides direction for the future and linkages to other key policies such as:

- long term conditions, in particular the collaborative work to develop a consistent approach to anticipatory care planning and advance-care planning from diagnosis of a long term condition through to the end of life
- the dementia strategy, where a consistent approach to palliative and end of life care is apparent
- *Better Cancer Care*, especially the *Living with Cancer* group
- bereavement framework
- patient safety programme
- *Shifting the Balance of Care* where palliative and end of life care is one of the eight high impact areas
- transitions of care for children with complex needs



Dr Elizabeth Ireland, National Clinical Lead for Palliative and End of Life Care

- *Better Together*, the Patient Experience Programme
- e-Health and especially the development of the electronic palliative care summary.

The electronic Palliative Care Summary (ePCS) will improve communication between patients, carers & professionals at all stages of the patient journey, by allowing data to be automatically sent daily from GP systems to Out of Hours (OOH) services. The ePCS fits into day to day work of GPs and District Nurses, keeps all information on patients with palliative care needs in one place in the GP record and allows the most up-to-date information to be available OOH for these vulnerable patients. Pilots have taken place in Ayrshire & Arran, Grampian and Lothian, in all GP systems, with positive evaluation. Board wide rollout has started in Lothian from September 2009 with more detailed evaluation to inform national rollout.

(More conference presentations on p2 - p7; more on Living and Dying Well on back page)



Barbara Monroe, Chief Executive,
St Christopher's Hospice, London

Real life challenges of implementing a national end of life care strategy

Barbara Munroe began by explaining that St Christopher's Hospice is still working hard to live up to the challenges set by Dame Cicely Saunders in providing support for patients, family and friends during illness and bereavement. St Christopher's does this by providing care, research and education, and much progress has been made since the hospice opened in 1967. However surveys and research indicate that current approaches are still insufficient, with few people discussing their wishes on dying, a high number of complaints related to care of the dying, and 70% of people dying in hospital when the majority say they would prefer to die at home. The Department of Health (England) published its *End of life Care Strategy* in July 2008. The strategy is designed to be comprehensive, with a focus on communities and an emphasis on disparities. It takes a whole system and care pathways approach, with emphasis on generalists and tools, and links new money to new services and local commissioning. The implementation of the strategy is designed to tackle challenges that are familiar to all working in this field, including poor care in the last days and weeks of life, poor support after death, and lack of dignity and respect for some patients.

There are currently many groups of people more likely than others to miss

out on good care, including black and minority ethnic groups, those living in deprived areas, those with mental health problems, those with disabilities, refugees, asylum seekers, travellers, prisoners, the homeless, and drug and alcohol misusers. Rising expectations of healthcare, changes in demographics and disease, dispersed families, constrained financial and professional resources, and the current recession are all factors that contribute to difficulties in meeting the needs and demands for services. Dementia is increasingly affecting huge numbers of people, and is an additional challenge for service provision.

Working within this environment, Barbara sees it as important that hospices and palliative care services develop their advocacy role and political voice and action. One third of St Christopher's patients are in the top quartile for socio-economic deprivation, and the hospice is working to meet the social needs of this group, for which there is generally poor data, poor access to services, poor outreach and poor understanding.

When people say that they wish to die 'at home' it is likely that they want to die somewhere that is 'home-like', and individuals often change their wishes when they are close to death. Meeting current challenges is not so much about improving access to specialist palliative care as improving wider systems of health and social care. A 24-hour district nursing service is essential to enabling people to die at home, and specialist palliative care should see itself as a resource to enable generalists to help people to be cared for in the most appropriate place.

It is important that hospices respond to the changing needs emerging within society. In the case of St Christopher's, this has included work to support Care Homes to provide good care, including providing training and sharing creative resources. St Christopher's are also involved in action research into dementia, and shifting resources to help generalists, including sharing training and education. They are also looking at improving data, evidence, quality and cost effectiveness, for example, by encouraging patients into outpatient clinics to reduce the time nurses have to spend travelling to visit patients. They are also working to engage more widely with the public, including exploring new forms of volunteering, education of professional groups outside health and social care for example the police, and work to bring children and hospice patients together in meaningful activities.

Barbara concluded by asking whether limitations in care are present because of a lack of money, or because of a lack of will and vision. She believes that Scotland currently has many advantages over England in the ways it provides its healthcare, and urged delegates to make the most of these while they last.

What difference can the Liverpool Care Pathway really make?

In the wake of recent high profile newspaper articles highlighting existing controversies over the use of the Liverpool Care Pathway, Phil Saltmarsh explained why he believes that the LCP is making a positive difference to the care of dying patients by changing the culture and the way care is planned, and making care of the dying a priority.

A care pathway is a complex intervention for the mutual decision making and organisation of care processes for a well defined group of patients during a well defined period. The aim of the LCP is to improve care of the dying in the last hours/days of life. Its two key themes are to improve knowledge related to the process of dying, and to improve the quality of care in the last/hours/days of life. It is split into three key sections: initial assessment; ongoing assessment; and care after death. The LCP highlights four key domains of care: physical, psychological, social and spiritual. It is not a 'one way street', since there have been many instances when patients have been taken off the care pathway when they have shown signs of recovery.

There is currently a gap between people's hopes relating to aspects of dying such as dignity, respect and symptom control, and the reality of people's actual experiences. While pockets of excellent care exist in some areas, there are also places where care can be improved. The LCP is designed to help professionals to raise the standard of care provided to dying patients, and to close this gap between aspirations and reality. Bad communication and conflicting messages are common complaints relating to end of life care, and the LCP has a strong emphasis on

communication. Its five key elements are:

- clinical decision making
- management and leadership
- learning and teaching
- research and development
- governance and risk.

Phil went on to illustrate how use of the Liverpool Care Pathway can make a real difference to individual patients by describing how one individual's care improved dramatically once she was moved to a ward routinely using the LCP.

The national LCP team receives many comments, letters and emails about the LCP, and these usually relate to one of five key themes: sedation, communication, nutrition, hydration, and poor quality of care. The LCP is continually being revised to take account of comments and emerging evidence, and version 12 of the LCP will be launched on 25 November 2009.

He went on to highlight ten key messages of the LCP:

- the LCP is only as good as the people who are using it
- reflect, audit, measure, learn
- the LCP should not be used in an environment without the support of education and training
- stop, think assess, change
- diagnosis of dying should be made by the multi-disciplinary team
- the LCP supports continual assessment
- good communication is pivotal to success
- the LCP does not preclude the use of artificial hydration



Phil Saltmarsh, Assistant Directorate Manager, Specialist Palliative Care Team, Royal Liverpool and Broadgreen Hospitals NHS Trust

- the LCP does not recommend the use of continuous deep sedation
- the LCP neither hastens nor postpones death.

Though we shouldn't ignore the headlines which cast doubt on the use of the LCP, Phil believes that the LCP can and does make a positive difference to the care of dying patients.

Making a difference through network collaboration

Dr Paul Baughan explained the advantages of network collaboration, starting by giving the example of a colleague who designed an integrated palliative care plan to improve provision of palliative care in the community. Though this palliative care plan was validated and published in journals, the colleague received few responses to his email asking doctors to use it. Apparently this was because acute doctors were too busy, GPs thought it was a 'tick box' approach, and district nurses were not allowed to use it because it hadn't been through the appropriate equality and diversity screening. Paul explained that the colleague could have saved himself some effort by taking his plan through an organised network structure, where he would have discovered that a better version already existed and was about to be adopted nationally.

A network is an extended group of people with similar interests or concerns who interact and remain in informal contact for mutual assistance or support. The West of Scotland Cancer Network (WoSCN), of which Dr Baughan is a member, includes various regional and national managed clinical networks, groups and sub-groups. When taken as a whole, the system for information sharing between the different networks that form part of WoSCN appears complex. It is therefore important for appropriate networks to collaborate on specific projects as appropriate.

Collaboration means to work in association with another group. Advantages of network collaboration include:

- reduced risk of overlap and wasting of resources by different networks progressing similar ideas
- sharing of ideas and taking account of a wide range of views
- sharing of workload for big projects
- 'ownership' and 'buy-in' from different networks especially if the project has implications for them. This can also help with the implementation.

The specific advantages for palliative care and primary care collaboration are:

- both are networks where symptom control plays an important part in patient care
- most people requiring palliative care are living at home in a community setting
- up-skilling of generalists by specialists and allowing specialists insight into realities of busy community palliative care.

There are however disadvantages to network collaboration, since it can mean that projects move more slowly, and with so many people wanting to comment it is harder to gain consensus. It can also be difficult to establish who is accountable or responsible for a piece of work. Within the context of palliative care, current network systems can also mean that work is focused on cancer, when collaboration also needs to take place regarding care of those with non-malignant conditions.

Professor John Welsh went on to give some specific examples of where network collaboration has helped with specific projects, including the following:

- there are relatively few psychologists in the West of Scotland, and network collaboration has been helpful in bringing them together to contribute to a Psychosocial Reference Group.
- at a national level, *Living and Dying Well* Short Life Working Group (3) has drawn on the collaborative efforts of existing networks to look at developing a national approach to the use of assessment tools, prognostication, and anticipatory care planning.
- the Regional Specialist Pharmacy Advisory Group has been active in the morphine/diamorphine debate, and is currently working on guidance on Methylnaltrexone and on fast acting Fentanyl formulations.



*Professor John Welsh,
Professor of Palliative
Medicine, University of
Glasgow & Lead Clinician,
WOSCAN Regional
Palliative Care MCN*



*Dr Paul Baughan, Forth
Valley Health Board Lead
Cancer GP & Lead
Clinician WOSCAN
Primary Care MCN*

- although network collaboration has delayed the roll out of West of Scotland guidelines for providing palliative care out of hours, it has allowed a wider perspective to be taken into account, and therefore a higher quality of more useful guidelines to be produced in the long term.

In conclusion, network collaboration promotes understanding of issues affecting others, and allows staff with different areas of expertise and experience to influence change for the greater good of larger numbers of patients.

How can we make a difference to palliative care in hospitals?

Dr Pam Levack spoke from her experiences of providing specialist palliative care within Ninewells Hospital, observing that hospitals are made up of large groups of people, and this can make it slow and difficult to introduce change. She also believes that the large and often impersonal nature of hospitals can easily intimidate people, and that dying patients are very vulnerable to feeling intimidated. Given that 60% of people die in hospital, and 30% of bed days in acute hospitals are occupied by patients in the last year of life, it is essential that hospitals do more to provide good palliative and end of life care to patients, and this is why she thinks that the *Living and Dying Well* short life working group looking at the acute setting is so important.

In order to make changes in hospitals it is important to understand hospital concerns and pressures. Hospitals work to rules about productivity, and their main concerns are money and waiting times. There are no accurate figures about resources allocated to palliative care within hospitals, but this is a disparity that needs to be addressed. Palliative care professionals may be passionate about palliative care, but those working in other specialties have other passions. If a positive difference is to be made to the

palliative care provided in hospitals, we need to find ways of explaining the importance and value of palliative care and engaging with key people. A strategy is essential, and in this respect the *Living and Dying Well* action plan is very important. Each hospital must *own* palliative care, and there is a need to engage with the most senior people. The *L&DW* Acute Setting short life working group (5) is looking at how to make recommendations that will assist this, and currently are considering whether it might be possible to establish a formal national hospital group, establish hospital standards and ensure that each hospital has a palliative care programme, implementation group and management structure.

From Pam's experience, since everyone has increasing workloads and desires more resources, she has found that personal stories illustrating the impact of palliative care are the best way of getting support. She has also found that it is important to work with whatever local support is forthcoming, in the case of Ninewells Hospital, this was three rooms in the middle of the acute service receiving ward. However, Pam has found that she has good support from management, and has managed to get staffing in the form of a consultant, nurses, secretary, plus commitments from allied health professionals, a chaplain and other members of the multi-disciplinary team. Most patients, when asked, are happy to receive visits from all members of the team. Making the changes within Ninewells has not been straightforward, and several staff left early on, finding it difficult to deal with the hospital culture which they were unused to. The team have been collecting data to illustrate the difference they are making, believing that it is essential to illustrate the value of the work being undertaken.

Those used to working in palliative care outwith the acute setting may find that championing these services within hospitals requires an adjustment in terms of culture and attitude. However, it is important to work alongside and gain the respect of others already working in hospitals, since we owe it to patients and families to make it work.



*Dr Pam Levack, Consultant in Palliative Medicine, NHS
Tayside and Co-Chair L&DW short-life working group - acute
setting*

How can we make a difference to palliative care services for children and young people?

Andrea Cail explained that the *Guide to developing Children's palliative care services* published by ACT and the Royal College of Paediatrics and Child Health (updated in 2009) identifies palliative care as being required for children with chronic conditions, children with progressive incurable conditions, children with life-threatening illness, and children with non-progressive conditions. It also identifies four possible patterns for the relationship between palliative/curative treatments:

- as the illness progresses the emphasis gradually shifts from curative to palliative treatment
- highly technical invasive treatments may be used both to prolong life and improve quality alongside palliative care, each becoming dominant at different stages of the disease
- no cure is possible and care is palliative from the time of diagnosis
- at first it is not apparent that this will be a terminal illness and palliative care starts once the realisation dawns.

Cancer remains the second largest cause of death in the 1 to 19 year age group. Deaths due to diseases of the nervous system, deaths due to diseases of the respiratory systems, and deaths due to congenital anomalies almost double the percentage of deaths from cancer. Increasing numbers of children and young people are living with significant chronic illness and disability. Some challenges faced by paediatric palliative care are:

- the focus in paediatrics is still on curing disease
- aggressive treatment provided in tertiary paediatric centres is at odds with the philosophy of palliative care
- end of life decisions represent complex ethical and moral dilemmas that are likely to increase with advances in medical technology.

CHAS aims to provide palliative care for children and families, putting the child and family first, while developing sustainable services, providing equity of access and quality, improving quality and outcomes, and workforce planning effectively. Although providing palliative care for children and young people operates by the same principles as palliative care for adults, paediatric palliative care does have its own challenges and frameworks, and policy documents often don't fully recognise this by making specific reference to children's palliative care. It is important to make *Living and Dying Well* work for children and young people. Investment in managed clinical networks and specialist posts is beginning to increase. Improvements can also be made by identifying training and education needs. Collaboration, including work across the UK, is essential since the numbers of children requiring this kind of care are so small, and networks are working to establish core data on who will have palliative care needs. Four children's nurse posts have also been established, in Tayside, Lothian, Grampian and Glasgow, and part of these roles is to champion children's palliative care at a local level. Currently, not many service evaluations have been made, and this needs to improve. It is hoped that *Living and Dying Well* short life working group 4, looking at transition issues for adolescents and young adults, will also lead to improvements being made.

ACT has done lots of work putting frameworks and documents together, but these have not yet been widely recognised. CHAS has 16 beds and works with hospitals,



Andrea Cail, Director of Service Development, Children's Hospice Association Scotland

communities, local authorities, social work and education to fulfil the social needs of children and their families. The ACT *Family Companion* shows families what standards they can expect from services, and there are agreed standards with outcome measures for: breaking news; planning for going home; multi-agency assessment of needs; multi-agency care plan; and end of life planning.

There is currently a gap in the data collected about children with palliative care needs, and it is hoped that the recently established register for children with exceptional healthcare needs will make a huge difference. The transition from children's to adults' services continues to be a challenge, and many young people feel that there aren't adequate services for them to be "transitioned" to. Working with the whole family as a young person approaches the end of their life is always a challenge, and it is important to remember that though families want to have an idea of what is likely to happen in the future, they also want to live for today.

Making a difference for people with learning difficulties

Linda McEnhill's role as Widening Access Manager is to develop a programme of work which will equip hospices to widen access to currently under-represented groups. She therefore used the conference as an opportunity to describe a 'black hole of need' so that delegates can consider how to respond to these needs within their own areas. A learning disability is a reduced ability to understand new or complex information (impaired intelligence) and reduced ability to cope independently (impaired social function) which began before adulthood and which has a lasting effect on development. Because of improved paediatric healthcare there are more adults with learning difficulties, often with quite severe physical and intellectual disabilities. People with learning difficulties with poorer physical health are likely to live longer than in previous years, and are consequently likely to experience conditions which require palliation. Since a third of people with learning difficulties have carers over the age of 70, many of these individuals may require psycho-social support to help them deal with the implications of having elderly family or carers who require palliative care. Long stay hospitals which previously filled some of the needs of this group no longer exist and therefore these needs will require to be met within the community.



Linda McEnhill, Founder, NNPCPLD and Widening Access Project Manager

People with learning difficulties are likely to have more healthcare needs but less access to healthcare services than other sections of the population. The Disability Rights Commission reports that people with learning difficulties are four times more likely to die of a treatable illness. The BBC News website reports a research study which found that people with learning difficulties are 58 times more likely to die before the age of fifty years. On average, this group is likely to have five undiagnosed conditions at any given time. This group is also likely to have higher levels of mental ill health, schizophrenia, dementia, epilepsy and respiratory deaths. People with learning difficulties also:

- often don't access screening
- more regularly experience 'diagnostic overshadowing'
- tend to be diagnosed late
- have a different cancer incidence (16%:26%)
- have a different cancer profile
- experience inequality in terms of access and range of treatments
- die earlier of their disease.

People with learning difficulties are more likely to get life threatening illnesses early and to die prematurely from them. They are less likely to receive the full range of expected evidenced based checks and treatments. People with learning difficulties from black and minority ethnic (BME) communities are three times more likely to be admitted to psychiatric hospital and 25 times more likely to be admitted to secure accommodation (20-30% prisoners have a learning difficulty).

Linda went on to describe the story of Martin, who had learning difficulties,

and died in hospital at the age of 43 after a catastrophic break down of communication that allowed him to go without food for 26 days. Martin's family are convinced that if he hadn't had a learning disability he would have been given the care he needed to keep him alive.

Work is underway within Scotland to address some of these issues. For example:

- the development of the 'Lothian model' of dedicated learning disability nursing liaison in acute services & NHS Quality Improvement Scotland education modules
- the National Network for Palliative Care for People with Learning Disabilities (NNPCPLD) Scottish group has been re-launched, meets quarterly and is hosting a national conference in Glasgow on the 10th November 2009
- a Lothian group hosted by Marie Curie is bringing together palliative care and learning difficulty professionals to work across boundaries and develop accessible materials.

Linda concluded by urging delegates to consider how they could make a difference by addressing some of these issues within their own area.

Make a difference to the majority of people with palliative care needs: people with non-malignant conditions

Dr Jacquelyn Chaplin highlighted that the majority of people with palliative care needs do not have cancer, but have one of many different non malignant conditions. People with non-malignant conditions are likely to have a different illness trajectory from those with cancer, with different conditions progressing over different timescales, and people's individual palliative care needs changing over time.

Jacquelyn has been involved in work within NHS Greater Glasgow and Clyde to identify the palliative care needs of people with non malignant conditions at a population level. This work has been done using a multi-dimensional approach, and involving an analysis of epidemiological, demographic and socio-economic factors. This work has a comparative dimension, looking at relative need for cancer and non cancer related palliative care. It also has a stakeholder dimension, taking into account the views of patients, carers, professionals and members of the general public.

As a result of this work they have pulled together some very interesting statistics which indicate that each year, over 10,000 people in Greater Glasgow and Clyde will need palliative care, approximately 3500 of these being people with cancer, and approximately 6500 of these being people with other conditions. They estimate that of those with cancer, 84% will need help with pain, 47% will experience breathing difficulties, and 38% will experience depression. Of those with non-malignant conditions approximately 67% will need help with pain, 49% will experience breathing difficulties, and 36% will experience depression.

Figures indicate that although 56% of people say they would like to die at home, only 23% of people manage this, with the majority of people (61%) dying in hospital. However, there are several complexities which need to be considered when considering place of care, place of death and advanced care planning. Most data relate to people with cancer. Preference regarding place of care is different from preference regarding place of death, and there can be People often change their preferences over time, and often, dying at home is not as important as other factors such as freedom from pain, not dying



Dr Jackie Chaplin, Project Manager, palliative care for people with non-malignant conditions, NHS Greater Glasgow and Clyde

alone, dignity and respect. It is difficult to define the optimum way and time for eliciting preferences, bearing in mind that not talking about death is a way of coping for some people. In addition, given the variable access to services, there are issues to be considered regarding the ethics of asking patients their preferences and not having the resources available locally to achieve that preference.

It is important to recognise and utilise the different models of palliative care appropriate for each condition, focusing on specific diseases across care boundaries and sharing successes. Within the community, GPs and District Nurses are key. There needs to be an integration of nursing and social care for people with palliative care needs, and the integration of out of hours services. Within care homes there needs to be proactive planning and a recognition of changing needs. In a hospital setting it is important to support care with dignity, respect and compassion. There needs to be clinical leadership of charge nurses in relation to palliative care, and all staff need to be educated in a holistic approach. Hospices need to continue in their educative and consultative role, as well as giving care and out of hours support.

The Audit Scotland *Review of palliative care services in Scotland* and the Scottish Government palliative and end of life care action plan *Living and Dying Well* provide some hope and direction for the future, and there are many opportunities at strategic, local and individual level to improve palliative care for those with non-malignant conditions, for example by ensuring local disease specific strategic plans and implementation plans include palliative care, and by practicing person centred holistic compassionate care regardless of diagnosis.

Therapeutic encounters – how can you make a difference?

Dr David Reilly concluded the conference with a calming session designed to give delegates some reflective space and at the same time illustrate the importance of mental and emotional factors in influencing outcomes for staff and patients. When asked, most conference delegates agreed that the human side of care is currently under strain, and that the stress of colleagues affects the quality of care they provide. David highlighted that this is a situation that has serious implications, and that burn out within health and social care is common, beginning with disengagement at subtle levels. He asked delegates to reflect on their own 'inner peace' score, and what this means for what they bring to the space they share with others. He questioned how a healthcare worker can provide soothing and sincere care for others if they are feeling stressed and strained within themselves.

There is evidence to suggest that the process of going through medical school causes students to experience a 'hardening of heart', as illustrated by a significant drop in their empathy scores after training in comparison to before training. David questioned how we have arrived a situation where professionalisation can apparently lead to reductions in empathy.

He then described a historical analysis of healthcare in the UK over the last two centuries which interprets four distinct 'waves' of healthcare, associated with three major shifts in thinking and themes of history since the 18th century Enlightenment. The first of these "waves" took place in the first half of the 19th century and involved great public works and municipalism. (For example the introduction of a public water supply to Glasgow reduced cholera dramatically.) Since then, other waves have been: the refinement of scientific approach and the germ theory of disease; the restructuring of institutions and welfare reforms; and most recently, a focus on the risk theory of disease and lifestyle issues such as smoking.

All of these different 'waves' had an incredible impact on the health of the population at the time, however, we are now in an era of diminishing returns, whereby it is difficult to make a difference within the current health system, and professionals feel that they can't positively influence many of the problems they come across. This is a demoralising experience for professionals.

Further, David suggested that a new way of dealing with current issues needs to be



Dr David Reilly, Consultant, the Centre for Integrative Care, Glasgow Homoeopathic Hospital, NHS Greater Glasgow and Clyde

developed, and suggested that this needs to involve care based on continuous caring relationships. He suggested that our 'inner world' is inherently connected to our physical wellbeing and we therefore need to bear in mind emotional and spiritual matters at all times. He cited some examples of placebo trials whose results indicated that a placebo can have a genuine positive effect on outcomes for patients, and suggested that this indicates that 'hope' may be an important factor in recovering from illness. He also highlighted evidence indicating that views from a hospital window can affect recovery rates from operations, and research showing the real effects of certain types of meditation on a person's wellbeing, particularly if the meditation focuses on 'compassion'.

David has done some research which indicates that outcomes for patients are dramatically affected by their first meeting with a doctor and their perceptions of the doctor's understanding of their situation. Within his own practice, David aims to focus not on people's weaknesses, but on the inherent strength of the individual. He believes that individual human encounters can be transformative, and that the consulting professional needs to be calm within themselves and focus entirely on the patient, 'listening to them as if time stopped'. Healthcare professionals cannot provide this kind of care to patients unless they first take care of their own emotional wellbeing.

Living and Dying Well sharing progress event

A full-day conference, *Living and Dying Well - a chance to share progress*, took place at Heriot Watt University, Edinburgh on 3 December 2009. In her opening speech Nicola Sturgeon, Cabinet Secretary for Health and Wellbeing, made particular reference to the dedication and enthusiasm of those involved in the implementation of *L&DW*. She believes that this work stands out as a great example of how well the NHS can work in partnership with stakeholders from a broad range of sectors, with everyone looking to achieve the same results.

The event allowed delegates to receive up-to-date information about the work undertaken to implement *L&DW*, as well as opportunities to give their own views on specific areas of work by completing feedback sheets and participating in workshops, including workshops on the electronic palliative care summary (ePCS) and the developing national Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) policy.

As well as discussing some of the achievements and challenges of *L&DW*, the Cabinet Secretary announced that to ensure that the profile of this work is not lost beyond 2011, NHS Quality Improvement Scotland will develop and implement an improvement programme for palliative and end of life care to build on and ensure an ongoing focus of continuous improvement and quality assurance. This will aim to ensure the right care is provided at the right time and in the right setting in accordance with the wishes of the patient, their family and their carer, and will be undertaken as NHS QIS morphs into the new organisation of Healthcare Improvement Scotland. Nicola Sturgeon also referred to the upcoming NHSScotland Quality Strategy, and felt that the recommendations contained within *L&DW* fit in very well with this strategy and its person centred approach.

A number of *L&DW* short life working groups are now nearing completion, and Nicola Sturgeon looks forward to receiving the recommendations of all the working groups, confident that they will move towards the people of Scotland receiving the care they so richly deserve.

Three of the Living and Dying Well short life working groups have produced consultation documents and are requesting feedback and comments by 22 January 2010.

For more information about how to participate in these consultations, and for other information about Living and Dying Well, and the above event, visit the following website:

<http://www.scotland.gov.uk?Topics/Health/NHS-Scotland/LivingandDyingWell>

partnership news



Partnership Chairman Maria McGill and retiring Director Pat Wallace

New constitution

It's all change at the Scottish Partnership for Palliative Care. A new constitution, streamlining corporate governance procedures and taking account of all the views expressed during a lengthy consultation process with member representatives, was approved unanimously at the AGM on 30 September 2009. The new version makes provision for the first time for a category of Associate Membership, which will be introduced in the new year. Details are available on request from office@palliativecarescotland.org.uk

New Director

A new Director has also been appointed to take over from Pat Wallace, who retires in December after 8 years with the Partnership. Mark, who was until recently manager of Scotland's Mental Health Research Network and previously Director of the Multiple Sclerosis Society Scotland, is looking forward very much to his new role. Tribute has been paid to Pat's contribution to the Partnership and to palliative care in Scotland, and she would like to thank everyone for their very generous gifts, comments and good wishes.



New Partnership Director Mark Hazelwood