

# update

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## *Joined up thinking Joined up care ... 'the future direction of palliative care provision in Scotland'*

*The report of the Scottish Partnership for Palliative Care's three-year Big Lottery funded project, **Joined up thinking Joined up care ...** was launched by the Deputy Minister for Health and Community Care at the annual conference in Edinburgh on 22 November 2006.*

The report summarises the findings of extensive consultation throughout Scotland into the palliative care needs of people with conditions other than cancer, the barriers they currently experience in accessing appropriate palliative care, and ways in which these barriers might be overcome. It identifies increased collaboration and joint working as a key way forward, and proposes a model of care which emphasises a need for the skills of generalists and specialists alike.

Almost 300 conference delegates representing health and social care sectors heard Lewis Macdonald MSP, Deputy Minister for Health and Community Care, welcome the report on behalf of the Scottish Executive. Patricia Wallace, Director of the Partnership, outlined the work of the project and its findings, and Dr Harry Burns, Chief Medical Officer for Scotland, addressed the challenges of implementing the recommendations. A varied programme of presentations throughout the day highlighted the experience of people with a range of non-malignant conditions and focussed on the main themes identified.

The report may be downloaded from the Partnership's website at [www.palliativecarescotland.org.uk](http://www.palliativecarescotland.org.uk)

### *Minister welcomes report*

*Lewis Macdonald MSP, Deputy Minister for Health and Community Care, gave the conference opening address. Welcoming the report on behalf of the Scottish Executive, he described it as pointing firmly in the future direction of palliative care provision in Scotland.*

He referred to the fact that in many people's minds palliative care had become inseparably linked and exclusively associated with the terminal care of cancer patients, and acknowledged that access to palliative care for those with non-malignant conditions can be unfair and inequitable. Living with a terminal diagnosis is something that more and more people will do, as we live longer with better acute medical care. Whether the diagnosis is cancer, heart failure, COPD or dementia, or indeed any other condition, the need for palliative care will require to be addressed.

Mr Macdonald told delegates that the report sets out a clear agenda for addressing these issues and taking forward palliative care services, both at the interface between the voluntary and state sectors and within the NHS itself. He expressed his hope that the voluntary sector, the NHS and local councils could work in partnership to take this agenda forward. In this way, all those living with a terminal diagnosis would be able to access the high quality care that they expect and deserve.



*Lewis Macdonald MSP, Deputy Minister for Health and Community Care*

### *'A challenge to the current system'*

*Dr Harry Burns, Chief Medical Officer for Scotland, addressed the challenges of implementing the report's recommendations, which he welcomed as important goals for organisations and health care teams. He indicated that his own experience as a lead cancer clinician led him to believe that healthcare teams providing palliative care to people with cancer have a great deal to offer patients with non-malignant progressive conditions.*

Dr Burns invited delegates to consider what joined up care would mean for patients, and went on to describe his vision for the achievement of the goals identified through improved integration and joint working between individuals, teams and organisations. He outlined



*Dr Harry Burns, Chief Medical Officer for Scotland*

two types of integrated care which must be present if services are to be truly 'joined up':

- 'vertical' integration, in which appropriate action should be taken at every stage: to prevent a disease where possible, detect it early, treat it effectively, and palliate its effects; and
- 'horizontal' integration, in which patients must be cared for not only when they are within a service, but also as they move across service boundaries to continue their care elsewhere.

He emphasised that it is important to find ways to allow patients to cross organisational boundaries easily, since delays in referral can lead to missed opportunities. Improvements can be facilitated by increasing awareness of the constraints faced by other agencies. Good communication is central to breaking down the barriers that currently exist, and it is important to identify the difference between perceived and actual roles and responsibilities within different organisations.

Dr Burns indicated his awareness that organisations attempting to improve joint working face many difficult challenges, and outlined some of the elements which make the provision of healthcare a complex problem:

- planning often stops at geographical boundaries

- implementation always stops at budgetary boundaries
- planning and priorities differ across boundaries.

Dr Burns also highlighted the fact that there is an ongoing need for training to increase understanding of where palliative care is appropriate, what elements are condition-specific, and what principles can be generalised. Research is also required to increase understanding of how best to involve patients and carers, and to evaluate the effectiveness of previous interventions.

### ***The right solutions***

Dr Burns concluded that the Partnership's report sets a challenge to the current system, offering the right solutions to some difficult problems. Community Health Partnerships (CHPs) will provide an opportunity to take forward some of these challenges. Implementing this vision will require sophisticated interagency collaboration, and space for active dialogue between the NHS, local authorities and the voluntary sector. The CMO indicated his commitment to working with the Partnership in future to take the recommendations forward, and encouraged the Partnership to continue to find the solutions that Health Boards are looking for.

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## ***Recognising the needs of those with non-malignant conditions***

***A panel of speakers took part during the morning in a series of presentations and a question and answer session, chaired by Dr David Carroll, Associate Specialist in Palliative Care, NHS Grampian, on recognising the palliative care needs of those with progressive non-malignant conditions.***

### ***Multiple sclerosis***

Mark Hazelwood, Director, Multiple Sclerosis Society Scotland, told delegates that the Multiple Sclerosis Society was delighted with the publication of the project report but noted that much systematic attitudinal change was needed to implement its recommendations. He described the common symptoms of severe multiple sclerosis and shared some of the findings of research carried out by the MS society into the views of people with multiple sclerosis (MS) and their carers. The key issues emerged as emotional and practical support needs, information needs (including information on available services, aids and adaptation, benefits and financial matters and end of life care), symptom control and care issues (including co-ordination, continuity and quality of in-patient care). People affected by MS felt that help in hospital (including professionals listening to the advice of carers regarding the care of people with MS) and information on disease progression were particularly important. They also felt that they had to fight for things that they should be automatically entitled to.

Mark drew the attention of delegates to two key publications available from the Society: *Support for People Severely Affected by MS* and *Getting the Best from Social Work in Scotland*.

### ***Dementia***

Dr Julia Gray, Consultant Psychiatrist, NHS Greater Glasgow and Clyde, focussed on decision making, pain and carer support in relation to the estimated 64,000 people living in Scotland with dementia.

People with dementia may have little insight into the fact that they have the condition at all. The progressive decline in their ability to make informed decisions and make their wishes known makes early discussions vital. As the condition progresses, understanding of non-verbal communication and support for carers in decision making become increasingly important.

Dr Gray told delegates that pain in people with dementia is under recognised and poorly managed. She discussed the importance of raising awareness of the likelihood of pain and of the signs that someone is experiencing pain.

Speaking of the importance of carer support from diagnosis, Dr Gray reported that informal carers of people with dementia experience more significant strain and are less likely to find care-giving rewarding.

Dr Gray summarised by telling delegates that dementia can legitimately be seen as a terminal illness. There are significant unmet palliative care needs, particularly in respect of symptom control and support for informal carers. She proposed that health and social services need to embrace the challenge to improve the quality of life and death of this particular group of people who early on lose the ability to champion their own cause.

### **Parkinson's disease**

Bob Quilietti, Lifestyle Management Co-ordinator, Thistle Foundation, Edinburgh, gave a thought-provoking and entertaining account of his personal experiences. He told the audience that for many years he had been a professional magician, enjoying success both within Scotland and further afield. Five years ago he began to experience symptoms of Parkinson's disease. He described how these symptoms affected him, making him exhausted and irritable and leading to reduced confidence and panic attacks. The symptoms had a profound effect on his professional life and on his hobbies, which he was unable to continue.

Bob was diagnosed with Parkinson's disease in 2004. He told delegates that the diagnosis seemed irrelevant to him – it is what an illness does to people as individuals and their responses to the symptoms that is so important, and not the name given to the condition.

Following Bob's diagnosis, a friend told him about the Thistle Foundation and he was successful in gaining a place on a lifestyle management course for people with Parkinson's disease. On this course he learned to set goals and through the course he was enabled to manage his situation. On completion of his course Bob became a volunteer at the Thistle Foundation and he is now employed at the foundation developing, marketing and delivering lifestyle management courses and concepts.

Bob described the course content, which is based on a solution focussed approach and includes topics such as developing healthy sleep patterns, dealing with relapses and relaxation and gym activities. The course has now been developed for people with other long term conditions and for carers. Delegates found Bob's account, and his demonstration of the course's impact on his own life, profoundly moving.

### **Renal failure**

Frances Burke, Renal Palliative Care Nurse Specialist, NHS Lanarkshire, discussed the conservative management of people with chronic renal failure. She described this approach as one which improves the quality of life of patients and their families facing the problems associated with life-threatening illness through the prevention and relief of suffering. In language recognised by many of the audience, she explained that this was achieved by early identification and impeccable assessment and treatment of pain and physical, psychosocial and spiritual issues.

Frances explained that the term 'conservative management' was used because many patients did not want to talk about the life-limiting nature of end stage renal disease. The term 'palliative care' was not used as it was often associated in people's minds with imminent death. She told delegates that conservative management was a non-aggressive intervention and that patients referred for conservative management were those with end stage renal disease, those no longer able to withstand the rigours of dialysis and those with non-malignant and malignant co-morbidity.

Frances concluded that because of shortened life-expectancy, end of life care is particularly relevant for people with end stage renal disease. She told delegates that the knowledge and skills to provide palliative care for people with end stage renal disease were available but sadly were not yet in widespread use.

### **Chronic obstructive pulmonary disease**

Andrew Powrie-Smith, Head of British Lung Foundation Scotland and Northern Ireland, told delegates about the prevalence, epidemiology and characteristics of chronic obstructive pulmonary disease (COPD). Primary care data suggest that there are over 90,000 people living with COPD in Scotland, with the incidence of COPD vastly increased in deprived areas (beyond the increase that would be expected from levels of smoking). Andrew discussed the palliative care needs of people with chronic lung disease in comparison to people with lung cancer and said that those with chronic lung disease have higher levels of anxiety/depression and poorer quality of life. Specialist palliative care tends to be available for people with lung cancer, whilst those with non-malignant disease receive intermittent support from respiratory nurses. For both groups information needs remain unmet and community social support is lacking.

Andrew acknowledged that palliative care for people with respiratory disease is challenging as the terminal phase is difficult to define (people may experience many near death episodes) and because palliative care is seen as being for people with cancer who are dying. In addition, the guilt experienced by people with chronic lung disease, 80% of whom are smokers or ex-smokers, leads to low expectations in this patient group. He also indicated that in Scotland there are currently no clinical standards or national strategies for COPD and that it is not seen as a national priority.

With these facts in mind, delegates were urged to do all they could to meet the challenge of providing appropriate palliative care for people with chronic lung disease.



From left to right: Andrew Powrie-Smith, Dr Julia Gray, Bob Quilietti, Frances Burke and Mark Hazelwood

## Questions to the morning panel

Delegates were given the opportunity to ask questions, and this prompted discussion of the following issues:

### Terminology

The panel agreed that the term 'palliative care' is commonly misunderstood as referring only to care provided during the last months, weeks and days of a person's life. Patients can be upset when they hear their care referred to as 'palliative', and can assume that they have cancer and that their death is imminent. There was brief discussion of some of the related issues:

- the misuse of the term 'palliative' is reinforced by NHS MEL (1996) 22, which defines specialist palliative care as being for the 'terminally ill'. The Scottish Partnership for Palliative Care plans to address this as part of its recommendations to the Scottish Executive on palliative and end of life care in March 2007.
- there is a need to increase awareness and understanding of what 'palliative care' actually is, especially since the nature of cancer care is changing, with cancer increasingly becoming a chronic condition
- 'palliative care' is simply 'good care', and there is no need to refer to it as anything else.

### Improving the lives of patients

Each of the panel members outlined the one thing that they felt would most improve the lives of the people they worked with:

- Mark Hazelwood wanted to see lifestyle management programmes available to a wide range of people with long-term conditions throughout Scotland
- Frances Burke hoped for improvements in communication and education among patients, staff and carers
- Bob Quilietti highlighted the need for more empathy and better communication at the time of diagnoses, including directing people to available support mechanisms
- Julia Gray said that she did not want Scotland to follow

England and Wales in their decisions on provision of drug treatment for people with dementia. She also emphasised the need for funding to provide adequate day care for people with dementia, and respite to allow carers to maintain their social networks.

- Andrew Powrie-Smith would like to see early discharge programmes for people with COPD and the provision of COPD nurses trained in palliative care skills.

### 'Carer fatigue'

As extended families become less common, 'carer fatigue' is becoming more common. The panel cited anecdotal evidence of hospital admissions taking place because informal carers are unable to cope at home, and commented that in some ways carers 'catch' the illness of the person for whom they are caring, showing secondary symptoms such as low self esteem and isolation.

There was a general feeling that carers are the ones who are most affected by resource shortages. A tightening of budgets and narrowing criteria for respite is leading to respite becoming something that people get in response to a crisis, rather than a planned episode as a normal part of care.

The panel agreed that there is a pressing need to address the needs of carers, and that policies aimed at improving conditions for carers need to be turned into practical improvements and increased funding.

### Influencing improvements

There was brief discussion of how policy makers and planners can be influenced to promote good (palliative) care for all, given that more 'glamorous' and 'high tech' clinical fields are also competing for the limited resources available. It is essential that patients and carers living with conditions have their voices heard, and that professionals play a key role in influencing matters where carers and patients are unable to.

### Services for people with dementia

The difficulty of delivering good care to those with dementia when this service is provided by social care rather than through the NHS was raised. It was felt that there is a need to move beyond current boundaries with increased joint working between health and social care teams, while avoiding the danger of everyone becoming a generic worker.

### Respite care

There was general feeling that the voluntary sector would be better able to improve the provision of respite care if different organisations worked together towards this common aim. Being able to show evidence of partnership working can make an organisation more attractive to funders. The Neurological Alliance Scotland are demonstrating that neurological charities are better able to articulate their needs when they work as a group, and the Long Term Conditions Alliance Scotland is designed to provide a collective voice for a range of long-term conditions.

## Overcoming the barriers

*The afternoon session began with a panel of speakers and a question and answer session, chaired by Maria McGill, Chairman of the Scottish Partnership for Palliative Care, on overcoming the barriers to meeting the palliative care needs of those with non-malignant conditions.*

### Cystic fibrosis

Cara Doran, Expert Patient Advisor, Cystic Fibrosis Trust, spoke about her own experience and outlined some of the ways in which the Cystic Fibrosis Trust works to overcome barriers to meet the needs of people with cystic fibrosis (CF). CF is the UK's most common life-threatening, inherited disease and affects more than 7500 babies, children and young adults in the UK. The Cystic Fibrosis Trust works to improve the lives of people with CF, raise the profile of CF and fund research into a cure.

The Cystic Fibrosis Trust:

- provides a range of information to help people with CF and their families get the most out of life
- aims to involve everyone, bringing professionals, patients and carers together to discuss ways of improving care
- runs an advocacy project, creating the opportunity for patient advisers to sit in on meetings and influence politicians
- has produced a 'standards of care' document which informs people of the standards that they can expect
- has set up a peer review process of CF units to encourage the spread of best practice across Scotland
- works in a 'joined up' way as a matter of course, improving communication between the various clinical specialties involved in the care of people with CF.

### Community Health Partnerships

Gill McVicar, Chair, Association of Community Health Partnerships (CHPs), highlighted the developing role of CHPs and their relevance to the provision of palliative care and the recommendations in *Joined up thinking Joined up care*...

The Scottish Executive report *Delivering for Health* had outlined the role of Community Health Partnerships in driving the shift in the balance of care towards continuous, integrated care embedded in communities, where patients and carers are supported as partners and self-care is encouraged and facilitated. CHPs have been charged with identifying specific and measurable service improvements, according to local needs, in the following areas:

- easing access to primary care services
- taking a systematic approach to long-term conditions
- providing anticipatory care
- supporting people at home
- avoiding hospital admission
- identifying opportunities for more local diagnosis and treatment
- enabling appropriate discharge and rehabilitation
- improving health and tackling inequalities
- improving specific health outcomes.

Gill explained that in practice this is about facilitating communication and networking and bringing relevant people together. CHPs will also have an important role stimulating changes in boundaries and practice, and supporting new ways of thinking. Improvements will only be possible if the best use is made of all available resources, and so ensuring appropriate evaluation is an essential part of every CHP's role. Gill concluded that CHPs will therefore play an essential role in improving the patient journey and overcoming the barriers to meeting the palliative care needs of those with non-malignant conditions.

### Motor neurone disease

Dr Richard Petty, Consultant Neurologist, NHS Greater Glasgow and Clyde, spoke about motor neurone disease (MND), a rare condition which is caused by the breakdown of the nerve cells in the brain which control the muscles. Dr Petty detailed the progressive nature of the disease, from the initial symptoms through the various stages of the disease, and explained how a patient's outlook, needs and wishes may change throughout the course of the disease.

In his view a significant barrier to meeting the palliative care needs of patients with MND is the current tendency for patients to begin discussions about palliative medicine at a late stage of the disease's progression. He believes that in the future this barrier will be overcome by the involvement of a wide range of professionals throughout the entire course of the disease, including: neurologist, GP, MND care advisor, neurophysiologist, clinical geneticist, respiratory physician, gastrointestinal physician, respiratory nurse, occupational therapist, physiotherapist, dietician, district nurse, speech and language therapist, home help, psychologist, builder and palliative physician and team.

### Heart failure

Lynda Blue, Co-ordinator, Glasgow Heart Failure Liaison Service, highlighted the importance of joint working in the care of people with heart failure. Heart failure affects around 2% of adults (10% of the elderly) and is the most common cause of hospital admission in patients over 64. Heart failure patients report a greater reduction in quality of life than those with any other long-term illness, and have a worse prognosis than that for most forms of cancer.



*From left to right: Lynda Blue, Dr Richard Petty, Gill McVicar, Cara Doran and Dr Elizabeth Ireland.*

Lynda shared the findings of a recent palliative care audit of patients with heart failure conducted by the Heart Failure Liaison Nurse Service within Glasgow, which identified that heart failure patients at the end of life benefit from the co-ordination and continuity of care that inter-professional working can provide. Prognosis remains difficult in heart failure patients and the evidence base to support symptom control remains poor. Further research in these areas is essential, as are symptom management guidelines to help heart failure professionals. Educational initiatives focusing on end of life care for heart failure patients aimed at all health professionals involved in managing this patient group are also required.

### **The Gold Standards Framework Scotland**

Dr Elizabeth Ireland, GP, NHS Forth Valley and Gold Standards Framework Scotland Project GP, welcomed the publication of the Partnership's report *Joined up thinking Joined up care ...* and in particular the close relationship between its findings, the evolving model of care envisioned in the Scottish Executive report *Delivering for Health*, and the approach of the Gold Standards Framework Scotland (GSFS).

The GSFS is a framework of strategies, tasks and enabling tools to help primary care teams deliver high quality care for people nearing the end of their lives. The aim of the GSFS is to develop a practice-based system to improve the organisation and quality of care for patients in the last stages of life in the community, so that more live and die well in their place of choice. The GSFS Project ran over three years from October 2003 to October 2006, and saw more than 70% of GP practices across Scotland sign up to its principles. The GSFS brings about a perceived increase in the quality of care offered to patients with palliative care needs, and an increase in staff confidence in managing this group of patients. Interviews with patients and carers showed that good support from the primary care team gave carers confidence and helped them to feel valued and involved.

Evidence collected during the project shows that implementation of the GSFS can help primary care teams to overcome many of the barriers to meeting the palliative care needs of people with non-malignant conditions.

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## **Questions to the afternoon panel**

Delegates were given the opportunity to ask questions, and this prompted discussion of the following issues:

### **The transition between children's and adult services - ensuring that young adults get the care they need**

This is an enormous challenge, and the panel agreed that there are no easy solutions. One improvement that should be made is better support for patients and carers within their own homes. There is also a recognised need for policy-makers and hospices to work towards ensuring more facilities are available for patients with non-malignant conditions.

### **Applying the principles of the Gold Standards Framework Scotland (GSFS) within the acute sector**

Although the GSFS is designed for use within the primary care sector, given appropriate commitment, the principals of the GSFS could be applied in the acute sector. Certainly, work is currently taking place looking at patient pathways through hospitals, and given that GSFS has already been used in community hospitals, the adoption of its principles for use in the acute sector may be a logical next step to take in spreading best practice.

### **Out of Hours (OOH) services**

Since the introduction of the new General Medical Services (GMS) contract, many GPs have chosen to opt out of providing OOH services, and the panel agreed that this has introduced huge challenges for service provision. District nurses no longer

provide 24/7 care and react only to emergencies, and there is a need to devise 24/7 services that don't rely on the same people that are working during the day. OOH services are increasingly being provided by locum doctors, and it is essential to ensure that these doctors have the level of training and knowledge they require to provide patients with high quality palliative care out of hours.

There is also a need to find ways of ensuring that the specific needs of palliative care patients are addressed during OOH periods, and the GSFS project includes an IT element working with NHS 24 to ensure that specialist palliative care patients are flagged to the system.

### **Information provision**

Many patients and carers are not in a position to be able to investigate what services and benefits may be available to them, and are largely dependent on the information they are given by the healthcare professionals with whom they come in contact. It is therefore the joint responsibility of health and social service professionals to provide patients and carers with the information they require, and this necessitates good joint working between the two sectors, particularly since there may be a tendency of healthcare workers to avoid what they perceive as 'overburdening' social work services.

### **Resources**

A large amount of palliative care is delivered by the primary care team, and if there are insufficient resources to allow primary care teams to provide the service that is currently expected, it may be that a difficult choice has to be made between either explicitly rationing services, or allocating more overall resources to this area.

The panel agreed that there are no easy solutions to this issue, but that given that shortage of resources is a real issue, it is essential to ensure that all resources that do exist are being used to maximum effect. It may be that improvements can be made by service redesign and better use of technology. Other countries are facing similar issues, and it may be that Scotland can benefit from lessons learnt elsewhere.



*Dr Keri Thomas, keynote speaker*

## **Living well to the end of life**

***Dr Keri Thomas, Clinical Director of Community Palliative Care Birmingham and National Clinical Lead of Palliative Care and the Gold Standards Framework Programme, NHS End of Life Care Programme, England, closed the conference with a wide-ranging and informative keynote presentation Living well to the end of life.***

Dr Thomas began by outlining what she sees as some of the current key issues surrounding palliative and end of life care in the UK:

- terminology – there is an ongoing debate about whether the term ‘supportive care’ should be used as an alternative to ‘palliative care’, to prevent common misconceptions about ‘palliative care’ meaning ‘terminal care’
- demographics - more people are living longer, with serious disease and increased symptom burdens. There are fewer young people to care for them, producing an ever-shrinking pool of carers
- choice - currently, about 50% of people are not dying where they choose and many die with poor care
- inequity - cancer patients are much more likely than those with non-malignant conditions to receive support as they approach the end of life.
- inappropriate treatments - there is currently huge overspending on inappropriate hospital admissions

and unwanted treatments.

All of this leads to needless suffering. Given that 100% of the population will die, why are we letting this happen? Better planning and prevention of crises is needed, so more can be expected to die in their place of choice, and a focus on community care and reduction in inappropriate hospital admissions is required.

There is a need to ‘reframe’ how healthcare teams perceive palliative and end of life care. Death of a patient is too often seen as a ‘failure’, when in reality healthcare teams should be working towards giving patients a ‘good death’. Given that 1% of the population die each year, the question that people should be asking themselves is ‘how can we make it their best year of life?’ In order to make this work, the palliative care approach needs to be mainstreamed. This will require:

- a cultural shift, especially in hospitals
- better identification of patients nearing the end of life
- the recognition of the needs of dying patients with non malignant illnesses
- better planning and proactive care, including the use of advanced care plans
- better support and provision – reducing the inequity of access to services
- closer collaboration with disease specialist groups
- case managers/community matrons for patients with long term conditions
- a joined up comprehensive strategy for all patients nearing the end of life.

Dr Thomas continued by setting out the importance of primary care teams in helping patients to achieve a ‘good death’: primary care teams are in a good position to provide continuity of care and a reassuring presence in the face of death. Community healthcare teams already share common values with palliative medicine, providing holistic, patient – centred care in the context of families and the wider community. Given adequate training, resources and specialist advice, community professionals have the potential and ability to provide good palliative care in the community.

High quality community care is one of the key factors in enabling patients to die at home if they wish, and tools such as the gold standards framework and Liverpool care pathway assist primary care teams to provide this high quality care. Advanced care planning is an essential element of both of these tools, and it is essential for teams to be proactive in planning for the future needs of patients.

Dr Thomas concluded with the following ‘take home’ messages:

- care for people at the end of life is important
- specialist palliative care has modelled best practice and can help lead the way
- end of life care must be fully integrated and mainstreamed in the NHS
- a new partnership is needed for patients with non-cancer/long term conditions
- good care at the end of life could be our most important legacy.

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## **‘Challenged but not daunted’**

Dr Derek Doyle OBE, Honorary President of the Scottish Partnership for Palliative Care, opened and closed the conference with some interesting and thought-provoking remarks. He predicted that in the future, people would look back on the current time and wonder why palliative care was so cancer-oriented.

Dr Doyle welcomed the challenges raised throughout the day, and urged delegates not to be daunted by what may seem insurmountable obstacles. He cited some of his own experiences of progress throughout a lifetime working in palliative care, and highlighted the Scottish Partnership for Palliative Care as key to influencing and improving palliative care provision throughout Scotland. He asked delegates to consider how we can ensure that it won’t take us overly long to act on the findings of this report, and concluded by reassuring us that these challenges can be met within a palliative care community that is supportive and caring.

# Joined up thinking Joined up care ...

## background to the report

*Patricia Wallace, Director of the Scottish Partnership for Palliative Care, presented the findings and recommendations of Joined up thinking Joined up care ...*

Pat Wallace explained that the report is the culmination of a three year Big Lottery Fund project entitled 'Increasing access to palliative care for people with life-threatening conditions other than cancer'. The project was set up to address the growing awareness among politicians, professionals and members of the public alike, that the benefits of good palliative care, both at general and specialist level, ought to be available to anyone with a progressive, life-threatening condition, and not just to those with a diagnosis of cancer. Its aims were to raise awareness of the palliative care needs of people with non-malignant conditions, to understand some of the barriers currently experienced by people with non-malignant conditions in accessing appropriate palliative care, and to identify some possible ways of overcoming the barriers and meeting the needs identified.

To begin to develop the understanding required to address these issues, a detailed national consultation exercise was developed involving people with progressive non-cancer conditions and their informal carers, health and social care professionals, all Scottish NHS Boards and local authorities, and a range of charities and support organisations representing the non-malignant conditions in question. Throughout the course of the project almost 3000 questionnaires were issued, with an overall response rate of 30%.

The project focussed on ten progressive life-threatening non-malignant conditions. These included a number of neurological conditions, advanced heart, lung and kidney disease, HIV/AIDS and dementia. The project also encompassed conditions affecting both children and young people and adults.

### Report findings

The project findings can be summarised in the following key messages:

- there is a general consensus of opinion around both problems and solutions
- there are no surprises – consultation responses corroborate existing anecdotal evidence and expectations
- the aim of increasing access to palliative care for people with non-malignant conditions is achievable, and
- there is a huge amount of good practice and effective collaboration already in place around the country which will help to make it happen.

The preferred model of care to emerge from the consultation is one where overall responsibility for care, including general palliative care, remains with the person's usual care team, with established referral routes to specialist palliative care in place for anyone with complex palliative care needs.

Based on the consultation findings, 18 recommendations have been made, linked to the emerging consultation themes of information needs, practical help, symptom management, joint working, psychosocial support and education and training. The Scottish Partnership for Palliative Care believes that their implementation would make a meaningful contribution to improving access to palliative care for people with progressive life-threatening conditions other than cancer. Pat Wallace also indicated that readers of the report would be able to draw further conclusions and recommendations relevant to their own area from the wealth of material in the report.

### Project outcomes

In addition to the final report and recommendations, there are two outcomes from the project. The first is a detailed template for a palliative care study day to meet



*Patricia Wallace, Director of the Scottish Partnership for Palliative Care*

the education needs of health and social care professionals identified through the project consultation. This has been developed with colleagues from the Marie Curie Education Service, and has been successfully piloted in six different locations throughout Scotland with multi-professional groups of health and social care professionals involved in the care of people with progressive life-threatening conditions. An evaluation of the study day, as well as the full programme and lesson notes, is available as a separate item on the Partnership website.

The second outcome, also available as a separate item on the website, is a detailed information support checklist, designed for use in specific geographical areas to identify and record appropriate sources of information which were identified as priorities by the users and carers involved in consultation.

### Conclusion

Pat Wallace concluded that the project has succeeded in casting some light on the palliative care needs of people with life-threatening conditions other than cancer, and on some of the ways in which we might go about increasing their access to palliative care services. She thanked all those who had been involved in the project for their enthusiastic input, hard work and support.