

Rethinking palliative care

An opportunity to explore new challenges

Report of a conference of the
Scottish Partnership for Palliative Care
6 November 2002

Acknowledgement

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Contents

	page
<i>Rethinking palliative care - an opportunity to explore new challenges</i>	2
<i>Welcome and introduction to the conference</i>	3
Dr Derek Doyle OBE, Honorary Vice-President, Scottish Partnership for Palliative Care	
<i>Innovations in palliative care</i>	4
Professor John Welsh, Professor of Palliative Medicine, Beatson Oncology Centre	
<i>Care of people by people - what does the future hold?</i>	6
Peter Cardy, Chief Executive, Macmillan Cancer Relief	
<i>Introducing new health technologies - understanding the needs of patients and carers</i>	8
Ann Single, Director of Communications and Public Involvement, Health Technology Board Scotland (HTBS is now a part of NHS Quality Improvement Scotland)	
<i>NHS 24 - challenges and opportunities</i>	9
Dr Drew Smart, Associate Medical Director, NHS 24	
<i>Workshop 1 - Reconfiguration of community palliative care services in Glasgow</i>	11
Susan Munroe, Caring Services Manager, Scotland, Marie Curie Cancer Care Anna Grady, Project Manager, Reconfiguration of Community Palliative Care Services in Glasgow	
<i>Workshop 2 - Cardio pulmonary resuscitation - a continuing dilemma?</i>	12
Dr Clive Preston, Consultant in Palliative Medicine, Fife Palliative Care Service	
<i>Workshop 3 - New wine in old bottles - redesigning intermediate care</i>	13
Gail Black, Co-ordinator, Scottish Association of Community Hospitals Dr David Carroll, GP Facilitator in Palliative Care, NHS Grampian Dr Mhoira Leng, Consultant in Palliative Medicine, Roxburghe House, Aberdeen	
<i>Workshop 4 - Supporting carers at home- the Macmillan Crossroads Carers Project</i>	15
Fiona Murdoch, Co-ordinator, Macmillan/Crossroads Carers Scheme, Edinburgh Ruth McCabe, Service Development Manager, Macmillan Cancer Relief	
<i>Workshop 5 - Adults with Incapacity (Scotland) Act 2000 - enabling or disabling?</i>	16
Dr Rosaleen Beattie, Medical Director, St Margaret's Hospice	
<i>Workshop 6 - End-of-life palliative care for older people in care homes</i>	18
Jo Hockley, Research Fellow/CNS, St Columba's Hospice, Edinburgh	
<i>Concluding remarks</i>	20
Dr Derek Doyle OBE, Honorary Vice President, Scottish Partnership for Palliative Care	

Rethinking palliative care

an opportunity to explore new challenges

The Scottish Partnership for Palliative Care's Annual Conference in Stirling on 6 November 2002 gave over 140 delegates the opportunity to explore new challenges by "Rethinking Palliative Care" in a series of plenary and workshop sessions throughout the day.

In his opening remarks Honorary Vice President Dr Derek Doyle, chairing the event in his usual inimitable style, drew on his experience of over 30 years in palliative care to point out that while change is nothing new, the key challenge now is whether those working in palliative care can be flexible enough to respond to the changes ahead. A series of keynote speakers then outlined some of the areas in which those changes would lie.

Professor John Welsh spoke of current and forthcoming innovations in palliative care, both from the perspective of potential new developments in symptom control arising from current scientific research and from the strategic viewpoint of changes in service configuration. Reminding delegates of the major successes already achieved in the increasing recognition of palliative care and the integration of voluntary hospice and NHS provision, he suggested that the time had come for a Scottish strategy for palliative care to ensure access to the high quality palliative care that is the right of all. Such an initiative would need political will, strategy, tactics and resources to succeed, and Professor Welsh challenged delegates to question some of the assumptions of the past and to be prepared to leave the safe but possibly dull realm of the known and move to the excitement of the future.

Peter Cardy, Chief Executive of Macmillan Cancer Relief, aroused considerable interest with his talk "Care of People by People: what does the future hold?" He drew attention to the rising demands for palliative care caused by an ageing population living longer with cancer and a range of non-malignant chronic conditions and to the escalating workforce pressures already apparent. He suggested that widespread changes in roles and upskilling of professionals would be necessary to make the most effective use of existing staff resources, and advocated a multi-faceted and patient-centred approach to creating the service of the future. Macmillan had taken the view that forthcoming developments, including the fact that most people with cancer will be living at home, meant a shift in priority to helping people live with cancer, and a shift in focus to include social care. Mr Cardy outlined some of the innovative community projects with which Macmillan is already involved.

Ann Single, Head of Communications, Health Technology Board Scotland, shared some of her work on understanding needs of patients and carers and the

mechanisms of public involvement. She encouraged delegates always to be clear about why they wished to involve people, and outlined her view of public involvement as part of the process of the formulating of new ideas and the chance to learn and to build understanding, to see things differently and to challenge assumptions. It also required the flexibility to face change, uncertainty and unpredictability. For patients and carers it could mean the opportunity to be valued and to do something worthwhile. Ms Single concluded her talk with some practical suggestions for making this happen.

There were a number of questions from delegates for Dr Drew Smart, Associate Director of NHS 24, who gave a presentation on the structure of NHS 24 and the service it provides and discussed some of the implications for palliative care. Describing NHS 24 as a new and exciting NHS initiative, Dr Smart explained that NHS 24 is an integral part of the NHS and is designed to complement existing services by providing nurse-led advice, guidance, referral and information on health and healthcare services from three leading edge contact centres in the North (from May 2002), West (from November 2002) and East (from August 2003) of Scotland. The new service is patient-focussed, and provides an opportunity to reduce inappropriate workload in the NHS by assisting people to access the most appropriate care. Dr Smart outlined the training provided for NHS nursing staff (which includes a module in palliative care), the on-screen clinical assessment tool which is used during calls, and the direct and indirect referral routes available.

All four speakers then took part in an open forum session, responding to a wide range of questions from the audience.

In the afternoon delegates attended their choice of workshop from a range of topics including reconfiguration of community palliative care services, cardio-pulmonary resuscitation, intermediate care, supporting carers at home, end-of-life palliative care for older people in care homes and the Adults with Incapacity (Scotland) Act 2000. Most found these extremely valuable. Each workshop was asked to identify three key priority areas for future development.

The conference was evaluated highly, with 98% of responses indicating that the content was relevant or very relevant to delegates' work and 96% indicating that the conference would affect delegates' thinking or work practice. Individual comments included widespread appreciation for Dr Doyle's skills and style as chairman, and for the educational, networking and thought-provoking value of the day.

Welcome

and introduction to the conference

Dr Derek Doyle OBE, Honorary Vice President, Scottish Partnership for Palliative Care

Dr Derek Doyle, Honorary Vice President of the Scottish Partnership for Palliative Care, opened the conference by welcoming delegates and setting in context the current and future challenges in palliative care.

The title of today's conference is an exciting one. However, if we look back over the last thirty years we will see that there have been many changes during the development of palliative care and the terminology we use to describe it - a constant sea of change, in fact. Moves to replace the terms "terminal care", and "hospice care" with "palliative care" have been part of a continuing evolution. Now there is a new movement to introduce the term "supportive care", and to suggest that palliative care is part of supportive care. Instead, of course, supportive care has always been an integral part of what we do in palliative care. There are in fact almost 100 definitions of palliative care, yet there is no single definition that is really satisfactory. What we do is of course much more important than what we call it.

During its evolution, palliative care has moved from focussing exclusively on cancer to caring for those with motor neurone disease, HIV and AIDS and more recently,

anyone with far advanced disease. So far, however, there has been little training available addressing palliative care needs of those with non-malignant conditions, and this is one of the challenges we face.

Another change is the gradual move from a focus on in-patient palliative care to helping more people who want to die at home. This has brought with it a whole spectrum of new innovations and services, such as community care teams, and respite care services, and a whole range of new challenges to the way we do things.

Education is also a major place of change, and one where we already have a good record, being the only country in the world where every nursing and medical school teaches its students about palliative care.

What the past thirty years have reminded us is simply that in life all things constantly change. What is necessary is that we should be sufficiently flexible and willing to respond to the challenges that flow from change. Are we flexible enough? How should we prioritise? For how long can we recruit palliative care staff able to face these continuing changes? The challenge for today is to look at change and how best to rise to the challenges we identify.

Innovations in palliative care

Professor John Welsh, Professor of Palliative Medicine, Beatson Oncology Centre

My aim in this talk is to look at some recent innovations in symptom control and physiology and at some thought-provoking aspects of future strategy development. We are all different. Some of us live in the past where we know what is going to happen, but this can be dull. Some live in the present, keeping our feet on the ground and moving with the crowd, where we feel safe. However, in contrast, living in the future – dreaming, with our heads in the clouds – can be exciting. I would like to share with you some thoughts and visions of the future.

Symptom control

The modern theme has to be about relating science in the laboratory to the clinical picture.

Improved imaging techniques are giving us a greater understanding of physiological changes and of therapeutic interventions and their relation to clinical outcomes. For example, we can look at an image showing the effect of applying Capsaicin to epidermal nerve fibres (Fig 1).

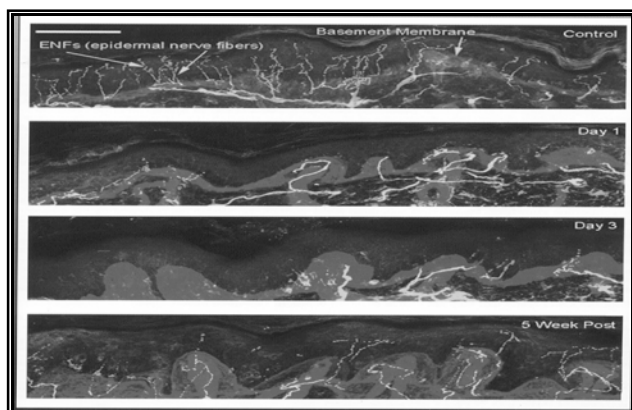


Figure 1

Brain imaging is also important, because much of what happens in humans happens in the brain. New imaging techniques, such as SPECT (single photon emission computed topography) and PET (positron emission topography), enable us to observe changes in the central nervous system when a person is in pain. A great deal of new information will come from such developments, leading to improved clinical decisions about physical interventions.

New developments in pain relief include vertebroplasty or cementoplasty, developed in France in 1984 to stabilise collapsed vertebrae. In selected patients it produces 80% pain relief. Polymethyl methacrylate cement is injected into the vertebra, buttressing and strengthening weakened bone. In addition, new neuromodulators and nociceptive transmitters are being discovered constantly. Fig 2 shows a picture of the release of endothelial I (ETI), which is released by pain-producing bone cancers and activates cytokines which promote the inflammatory process. Obviously, therefore, one target for improving analgesia would be to block the release of ETI. In the past we have had a lack of good animal models in the development of analgesia. Now, however, this is changing and we have

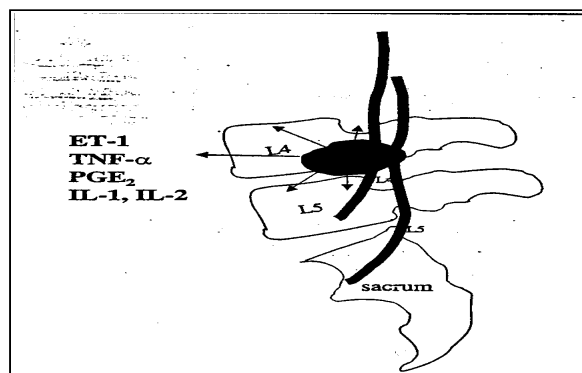


Figure 2

good models which will allow differentiation between different drugs. Adenosine, for example, is a ubiquitous chemical and has been shown to be a potent analgesic in animals, blocking purine 1 and purine 2 receptors.

Symptoms other than pain can also be addressed. Gastroparesis can be a problem due to neuropathy and cancerous infiltration, but pacing wires can now be placed in the stomach with some benefit.

In addition, gene genetics will become more important over the next 30-50 years, and some aspects of variability and sensitivity to pain, individualised pain therapy and novel pain related genes may be unravelled. In the future, it will be possible to predict by DNA sequencing which patients will respond to which analgesics. For instance, although such tests are not yet routinely available, it is possible to identify the 10% of the population who do not metabolise codeine.

Strategy

Turning to strategy, our view of the future also needs to reflect on and learn from the past, and the birth of the modern hospice movement that developed, or resurrected, the 'whole person' approach to care. The modern hospice movement was founded by Dame Cicely Saunders and has become widely accepted throughout the world. It grew from pressure and discontent at NHS treatment of cancer patients; now increasing public acceptance and professional awareness mean that it is being drawn back into the NHS due to the success of its approach and the expertise that it can offer. The fact that the voluntary sector and the NHS now work in similar ways is a success story of major dimensions.

Specialist palliative care

All services have grown over the last 40 years (Fig 3). But, if new services are now to be developed, it is worthwhile considering where they should be developed, whether the hospices that were built then are still in the right place, and whether we ought to follow the same pattern that was developed in the 1960s and 1970s or not. The majority of people with cancer requiring specialist palliative care are, in fact, in the acute setting rather than the community.

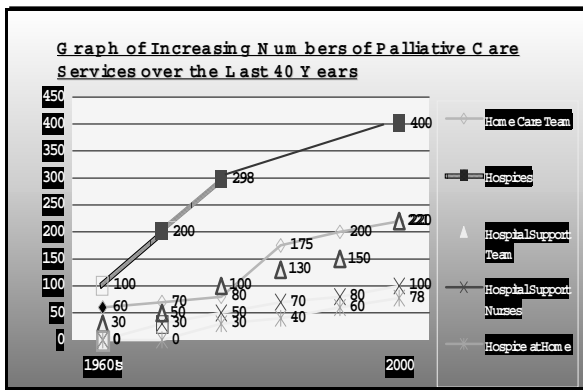


Figure 3

Specialist palliative care was well accepted at its outset by the public. It is now becoming accepted by the statutory sector too. This acceptance and promotion has been greatly aided by the Scottish Partnership for Palliative Care. It all started in Scotland in 1991, with Tom Scott, founder of the Partnership, chairing the Scottish Committee on the Care of the Dying and Bereaved which produced a report for the Scottish Executive with the strap line 'Everybody's death should matter to someone'. Since then palliative care has been represented on the Scottish Cancer Co-ordinating and Advisory Committee and the Scottish Cancer Group, and promoted in the Scottish Health Plan and Scottish Cancer Plan.

Palliative care has become increasingly well established, with palliative medicine accepted as a specialty in 1987 and the creation of the Association of Palliative Medicine, of which Derek Doyle was the first Chairman. In nursing, the Nursing and Midwifery Council Specialist Practitioner Qualification in Palliative Care and the Royal College of Nursing Palliative Care Forum were set up. The Patient's Charter issued under the Thatcher government was really based on palliative care philosophies. More recent developments in Scotland have included the Scottish Intercollegiate Guidelines Network (SIGN) Guideline on Control of Pain in Cancer Patients, the Clinical Standards Board for Scotland (CSBS) Specialist Palliative Care Standards, and the creation of Managed Clinical Networks in palliative care.

Palliative care for non-cancer patients

Many things have been achieved, but considerable challenges remain. The palliative care workload is set to increase, due to anticipated increasing numbers of cancer deaths over the next ten years, and increasing incidence and prevalence of cancer due to people living longer. However, it is ethically and morally wrong that it is predominantly cancer patients only who receive specialist palliative care. Others with progressive, incurable conditions are equally entitled and should receive the same level of input and care. This is not a new concept and it is high on the agenda in contemporary discussions among voluntary hospice and statutory health and social care providers. Needs rather than diagnosis should lead palliative care. "Terminal care should not only be part of oncology but of geriatric medicine, neurology, general practice and throughout medicine".¹

Place of death

Another issue that we are not meeting at present concerns the wishes of patients regarding their place of death. There is incontrovertible evidence that patients wish to die at home if at all possible. But figures from the

Health Boards show that this is not happening and that more people die in hospital than at home. Hospitals are changing in their purpose and are streamlining in terms of admitting, assessing, investigating, diagnosing, treating and discharging patients rapidly. Additionally, changes in GP practice, with the loss of 24-hour responsibility of GPs for their patients, impacts on the care of patients at home. We need, therefore, to consider different ways of working. It is important that adequate resources for specialist palliative care are positioned in acute trusts. But good and equally well-resourced systems and models of care must be provided in the community, and be supported in an integrated manner by specialist palliative care units. In redesigning services, Clinical Nurse Specialists in palliative care, who provide care in the community, could be based in Primary Care and supported by specialist palliative care units. Specialist units, if they are to be built, should be linked geographically to acute trusts, where the need and volume of work is greatest, especially as palliative care promotes early involvement. Possible alternative roles for the use of hospices could comprise caring for patients with intermediate needs. Specialist palliative care is now very active and often rehabilitation-based, involving investigations to determine the cause of particular symptoms. It makes sense to concentrate the combined resources of both the specialist palliative care unit and the acute trust on one site. Meanwhile, the outreach services from the specialist palliative care units would function as previously.

Scottish Palliative Care Group

It is my view that a Scottish Palliative Care Group should be formed for all conditions requiring palliative care. This group, possibly a development of the present Partnership, should be supported by ring-fenced funding from the Scottish Executive Health Department, which would mean that palliative care no longer had to battle with the cancer budget. This new group would provide a Scottish Palliative Care Strategy, which would exist in its own right, rather than as a chapter or a mention in cancer and other plans. Data on palliative care should be collected nationally, and ISD resourced to collect and collate the minimum data set agreed between the Scottish Partnership for Palliative Care, ISD and NHS QIS. All of this would require political will, strategy, tactics and resources.

Concluding thoughts

High quality palliative care is every person's right. In a modern, progressive society such as Scotland we should be leading the way to have this principle accepted, valued and resourced. We need to develop palliative care for all. But things keep changing, people are afraid, and events can wreck our predictions for the future. So we need to reflect, to educate and to continue to develop cross-team, inter-professional working as a way of thinking outside of what is currently assumed and accepted. After all as someone once remarked, if you don't call the dogma into question, you'll never change it.

And so - dull, safe or exciting? The choice is ours. Which is it to be?

¹ Calman K.C., Welsh J., Physical aspects of terminal care, in Saunders (Ed.), The Management of Terminal Illness (1983) Arnold pp31-42

Care of people by people:

what does the future hold?

Peter Cardy, Chief Executive, Macmillan Cancer Relief

A story

Let me begin by telling you about Michael and Karen and their two daughters, Jo and Lucy. They lived in a small village not far from here: Michael and the girls still do, but Karen died earlier this year. When Karen was diagnosed it turned their lives upside-down. She began a gruelling round of investigations and treatment that left her more unwell and debilitated than the disease had seemed to. There seemed no time to get to grips with what was happening and to catch up with events. They couldn't grumble though; the nursing staff were very kind, the doctors too busy to talk for long, but treatment was prompt and Michael knew they were doing their best for Karen.

Michael felt very isolated. He knew Karen was frightened, but he found it difficult to really talk about it with her. He was nervous she was in pain or might have a relapse and he wouldn't know what to do. He was afraid of making things worse. A district nurse came after one operation and helped Karen to manage her colostomy bag. Michael would have been happy to help but he found himself standing on the sidelines, sure that Karen would have more idea if the roles were reversed. Later he was taught to feed her overnight via the PEG that was inserted in a later operation.

As time went on, there were more things Michael really wanted to know. Often, because of work, he couldn't be with Karen for appointments. Though Karen would always tell him what had been said, there were things he wanted to ask without bothering her. His employers were sympathetic but now Karen was no longer working, he couldn't afford to have too much time off. And now he was awfully tired. As well as his job, he had to get the girls ready for school in the morning and help Karen. Sometimes a neighbour would look after Lucy and Jo after school before he managed to get home, but he couldn't impose, and often he arranged a baby-sitter. He began to worry that the costs were mounting up. Then there was the washing; Karen's sheets and clothes often needed washing every day. Karen's elderly mother, now quite frail, only lived a few miles away, but a regular eye had to be kept on her.

When Karen acknowledged that she was dying, they talked as a family about making preparations for her to die at home. Karen spoke to her district nurse and to her GP, and they were understanding. Money was tight,

but with a small grant from a charity they managed a weekend away with the girls before Karen became too unwell. Still, when the end came, Karen had breathing difficulties and Michael panicked. They called the GP who admitted her to hospital in the early hours of the morning. The family were together, but it wasn't quite what they planned.

Karen's initial diagnosis was bowel cancer, but if you omit the speed, frequency and range of therapeutic interventions it could equally have been MND, primary progressive MS, late stage Huntington's or CJD. I'm sure you recognise that story. Life's a lottery, but sadly so too is care. Too often patients and their families do not feel in control of their treatment and care, and the process is more frightening than it need be. Relatives feel unable to take as great a role in looking after their loved one as the family would wish.

And when it comes, for many of us the end of life will still be premature, confusing and distressing, with too much improvisation, both for the person dying and for those left behind to suffer the repeated pain of loss. New drugs and machines are very important but there are no operations for the fear, no drugs for the loneliness, no radiotherapy for the isolation, no gene therapy for the spiritual despair that can contribute so much to the suffering of people at the end of their lives. The end of life is one of the few certainties: as someone once said, life is a sexually transmitted condition with 100% mortality. I haven't heard a better argument for palliative care.

A vision for palliative care

Palliative care is a 'people' practice; it is the care of people by people. Palliative care is a way of thinking and organising support for patients and those close to them. It requires us to see the whole person, not a bundle of symptoms each of which is to be treated separately. Over many years I've seen for myself what a holistic approach to a person's care can do in terms of conferring dignity and independence to people in the direst of conditions.

At Macmillan, we have a vision:

'Imagine a time when every person in the land has equal and ready access to the best information, treatment and care for cancer and unnecessary levels of fear are set aside'.

We look forward to a time when decisions about care are made in genuine partnership between the patient and the healthcare professional. We also have a vision for palliative care:

'Imagine a time when the principles of palliative care

are adopted by all health professionals, and it is no longer just considered for people with cancer or a few others who are dying.'

I think, therefore, that palliative care has a message for all in healthcare, and it is a message we should be ambitious about promoting. It is as relevant on the day of diagnosis with a life-threatening condition as on the last day of life. It is also equally relevant for conditions that are not generally thought of as fatal.

The demand curve

The demand for palliative care services is going to increase; cancer in Scotland is expected to rise by 25% over the next 10 years according to *Cancer Scenarios*. But it isn't going to kill so many people. That means that more and more of us will experience cancer as a chronic disease, never quite well, often quite ill, over a long period. And more of us will need supportive and palliative care to help us to live with our disease and disability. There will also – quite rightly – be rising demand for provision of palliative care for non-cancer diseases. Awareness of the benefits of palliative care is growing in other fields just as the incidence and survivability of other diseases is rising. With general ageing of the population in coming years we face a huge expansion of people with chronic heart failure and other cardiac diseases and an epidemic of age-related neurological diseases such as Parkinson's, MND and Alzheimer's. What has been learned primarily in cancer will have to be transferred and shared; it will require a huge effort and development of mechanisms that don't exist at present.

The resource slope

While demand for care is rising, we are finding it more and more difficult to find the resources we need to meet that challenge. Highly trained, well-qualified staff are retiring or resigning faster than we can train and replace them. Unless the laws of supply and demand cease to operate, this combination of ageing workforce and ageing population will force up the cost of care and the 'tending trades' to unprecedented levels.

There are other changes in the healthcare professions. Now most of the entrants to medical schools are women, many of whom are looking for different career trajectories as they seek to balance work with life. In addition, the nursing workforce is predicted to decline 20% below our requirements. The importance of palliative care in private sector nursing homes will inevitably rise. My guess is that as the proportion of single people requiring care grows, nursing homes will become more significant - perhaps predominant - as the location of palliative care provision.

My conviction is that we must plan for these changes. But we must plan *ahead* of the game, using data already in our possession. Not all the trends I've outlined are bad news. Changes in attitudes to healthcare, combined with resource pressures and technological advance are leading to a new approach to care, where patients, carers and professionals work in partnership and in changed roles. I

want to persuade you that the way forward is to harness those energies, to help patients and carers to help themselves and reinforce the trend to upskill professionals – so they can concentrate highly trained expertise on the tasks that require it.

Helping patients and carers to help themselves

The likely future for people with cancer is of living mostly at home with occasional visits to acute units. Macmillan's view is that this means our priority has to be helping people to live with cancer, so we are shifting our focus to include social care.

There are several themes here:

- financial support
- carer support
- information
- self-care.

Information and support are key to a vision of care where patients and their carers feel in control of their illness and its treatment. Information must go hand-in-hand with support. The huge amount of information available, and the range of emotions you feel when you are vulnerable and ill, are a bit like a maze. Information and support are essential during treatment, but most critically important at the end of life. If the aim of enabling more people to die at home is to be achieved, then better education and information will be essential if people are not to find themselves improvising in panic. Macmillan recognises the crucial role informal support networks play. Since our merger with Cancerlink last year we now offer a range of resources to self-help and support groups. The schemes concerned are working towards self-care.

Supporting professionals

We commissioned Dr Keri Thomas to look at the issue of supporting professionals, and she published a highly influential report, *Out of hours palliative care in the community*. The report highlighted the central role of the GP and primary care in supporting people with cancer diseases and concern about the provision – or continued lack of provision – of out of hours palliative care in the community. The Gold Standards framework, devised by Dr Thomas (working first with a group of 12 practices in the North of England) is a practice-based system aiming to improve the organisation of care of people living with cancer in the last 6-12 months of life. Many primary care practices have taken up the model spontaneously. A second phase has now been agreed and the project will be evaluated with the intention of future general availability throughout the UK.

We need a radical investment in our workforce. As demands for palliative care increase, expertise will increasingly be needed among generalists – GPs, practice nurses, district nurses, and social workers. The principles of palliative care and good practice must be mainstreamed. Health care professionals still need to think wider and include the patient, carers and informal networks of support in their thinking and planning.

Finally, we need to develop more rigorous methods of evaluating our work to confirm the importance of supportive and palliative care. The National Cancer Research Institute's first annual report demonstrated the lack of research in this area, but a lack of research also bespeaks a lack of tools. We have struggled to persuade NICE of the importance of involving patients, and also of the need for palliative and supportive care to begin from the perspective of users.

Look beyond the disease

I believe that the key to a health service of the future is to ensure that its policy-making is truly driven by its users. The growing network of CancerVOICES representatives is trained and supported under Macmillan's aegis to enable them to make use of their personal experience and interact with the policy-making process. Getting patient voices heard is key to getting healthcare provision right. I want to finish by going back to the vision for palliative

care, which has a message to teach the entire health service. We are at a time when every government is talking the talk on patient choice, and coming round to the idea of patient-centred care. However, when responding to Government policy consultations both in Scotland and England, we get the feeling that the talk is still just skin-deep. I know it is difficult but that isn't a reason for not doing it. The shift to an approach that enables patients and carers to help themselves is radical. But it is also one that has a huge potential for win-win: for taking the burden from an overstretched health service, for enabling people to feel more in control, and for lessening crises and providing greater stability.

As palliative care professionals you are pioneering care. We have a message for the health service as a whole and we should be evangelical about promoting it. I say again: let's look beyond the disease to the person, look beyond the patient to their surroundings. This, in my view, is the real essence of palliative care.

Introducing new health technologies: understanding the needs of patients and carers

Ann Single, Director of Communications and Public Involvement, Health Technology Board Scotland (HTBS is now a part of NHS Quality Improvement Scotland)

Context

The purpose of HTBS as an organisation is to provide NHSScotland with advice about value for money of various health interventions such as drugs, devices, clinical procedures and healthcare settings. Public involvement forms an important part of fulfilling this remit, helping to ensure that HTBS is open and answerable to the public. Further, this involvement ensures that decisions are based on patient/carer expertise, and that we focus on the needs of patients, their families and carers.

Our aim is to achieve a health service where: people are respected and treated as individuals involved in their own care; where individuals, groups and communities are involved in improving the quality of care, in influencing priorities and in planning services; and which is designed for, and involves, users.¹

A vision of public involvement

Beyond these policy statements, engaging the public comprises visions of engagement:

- **involving the public is a conversation.** It is more fundamental than a static, discrete entity. Involvement is about the chance to interact and talk – it is a process that is more two-way than simple evidence-gathering for research purposes;
- **involving the public offers us a lesson** through the chance to learn from the public's experiences. It allows us to look for a variety of new and different views; not everyone thinks the same and when HTBS makes judgements we need to understand what the

public thinks. It is not decision-making by popular vote. Public involvement represents the scope for us to build shared understanding;

- in addition, **involving the public is a window** that provides a chance to see things from a different perspective from our own. It encourages us to question our existing assumptions. Further, while not an end in itself, it complements and challenges other sources of knowledge for a broader overall perspective;
- **public involvement is also an opportunity** for those that engage in it. It offers a chance for people to be involved if they wish to do so. It should not be a chore or a burden for those involved, but rather an opportunity for people to do something that they find valuable.

However, the vision of public involvement also creates challenges for all concerned:

- **involving the public generates uncertainty.** It is part of a process of change which demands that we should explore new paths. In so doing, it is important that we should remain flexible in our approach and response in order to gain the benefits lying therein. It is not about people becoming experts in your area or organisation, but about gaining new perspective and building mutual understanding.

Working to that vision

How then might we put this vision into practice?

Firstly, public involvement must be built into processes – this may be through relatively small ways of involving people that link in to existing networks of patient and voluntary groups. It is important that we offer the opportunity for people to influence work programmes or agenda, for example by proposing topics for HTBS advice. Further, there are different ways of communicating with the public and a range of these may be relevant: using focus groups, interviews, meetings and so on. It is also essential to develop processes of providing feedback and explaining the value of sharing information through public involvement. In essence, putting the vision into practice is about balancing the various sources of knowledge. In each HTBS Health Technology Assessment Report, the 'Patient Issues' section contains a record of the lessons we learnt from patients and carers. The lessons are reflected in the advice given to NHSScotland.

Barriers and solutions

However, barriers exist which inhibit successful public involvement. These barriers span a range. For example, there may be a lack of interested participants where no-one wants to be involved, or we cannot find anyone to approach, or simply that nobody turns up. Alternatively, there may be a lack of diversity among those participating making the group non-representational as a cross-section of the public.

There may also be time and budget constraints which restrict participation. Finally, even where a suitable group of participants is identified and available, there may still be barriers to communication. These may flow in either direction, for example, the participants may not understand what we are talking about, or they might provide us with lots of information through their involvement but none of it meets our needs for

assessment.

How do we overcome these barriers? Possible solutions are equally wide-ranging.

First, we may link-up with others who have carried out similar public involvement exercises or with any group that has a complementary need. In this regard, it is vital to be alert for existing and ongoing opportunities. Finding suitable patients can be addressed by finding out where those patients, families or carers go and by us then going there.

We can also broaden promotion through use of newsletters, flyers and local newspapers. It is essential to sell the benefits and set boundaries; that is, to highlight what is in it for the patient and to be clear about limitations. Finally, flexibility is key. Being flexible about times, dates, locations, modes of engagement (for example, drawings / diagrams, photographs, tick-boxes and interviews) may expand the scope for participation.

Lessons learnt

Several lessons have been learned during our experience of public involvement. Fundamentally, it is best to start early. It is also essential to ask for help where it is needed. And we shouldn't be afraid to try something new and to explore different approaches. We should worry more about ensuring diversity, and worry less about the outcomes being generalisable. Above all, we can put the vision into practice by doing what is practical and working to what is possible.

¹ Patient Focus and Public Involvement, The Scottish Executive Health Care Division (2001).

NHS 24:

challenges and opportunities

Dr Drew Smart, Associate Medical Director, NHS 24

A new clinical service for Scotland

NHS 24 will set up and operate a new patient-focused service, providing the people of Scotland with nurse-led advice, guidance, referral and information on health and healthcare services. This will take place through a network of leading-edge contact centres. The base in the North, at Riverside House in Aberdeen, opened on the 8 May 2002, the Clyde Contact Centre (HCl) in the West opens on 12 November 2002, and finally in the East area the centre at Norseman House, South Queensferry will be operational from August 2003. The service will employ the equivalent of 400 full-time nurses, 70 full-time call handlers, and 20 health information assistants. Coverage is expected to extend to 1.5 million people by 12 November 2002, and to handle 2.5 million calls per year.

Our approach

Our approach has been developed in partnership with

NHS Scotland, taking into account the service's relationship with GP out-of-hours services, accident and emergency, paediatrics, Scottish Ambulance Service, dentistry, pharmacy, palliative care, and public representation. The aim is to produce a quality service through the people, processes and technology that we put in place, and to provide an integrated service with other providers.

Core services

Initially, calls are addressed by a call-handler who takes basic information. They will divert the call to the ambulance service if necessary. Two services are available: health information assistants may respond to general enquiries, while the main strand of the service rests with nurse consultation, where symptoms can be assessed and advice given. This advice may take the form of self-care, or referral to the Scottish Ambulance Service, an acute

trust / A & E or to a GP out-of-hours. All of these are integrated services.

Making a difference

By the time that the NHS 24 programme is rolled-out, every patient will have access to healthcare advice 24 hours a day, 7 days a week, thereby bringing equity of access across Scotland. The service is not a replacement for, but complementary to, other existing services. It essentially provides additional capacity in the healthcare system. Furthermore, NHS 24 provides the opportunity to get people the most appropriate care by reducing inappropriate workload on the NHS and maximising the use of other health professionals such as pharmacists.

Nursing staff

Nurses in NHS 24 must have a minimum of 5 years experience. They are recruited through an Assessment Centre to ensure that they are suitably experienced. Of the nursing staff employed, 65% are part-time, with nurse-advisers being 'G' Grade and team leaders 'H' Grade nurses. Staff training comprises 14 modules, including a palliative care module which is delivered at Roxburghe House in Aberdeen and by Macmillan Facilitators in Glasgow. A range of competencies is incorporated within a training period of 6 weeks full-time (14 weeks part-time) plus a consolidation period.

Clinical assessment system

Quality assurance is provided by NHS CAS, a clinical assessment system comprising an evidence-based 'tool' developed to ensure structure and consistency in supporting the nurse-advisers. It is based on a series of logical questions structured as an algorithm that provides a range of possible end-points depending upon clinical need, timescales and levels of care. NHS 24 led a multi-professional review and adaptation of this system, and

Guardian Groups provide evaluation and updating.

NHS 24 and palliative care: the challenge

NHS 24 is committed to a holistic approach to healthcare: nurses look at the whole picture. The service is not simply about assessing a patient's symptoms, but also assessing his/her current history, previous medical history, and current and past medication. The service seeks to provide a 'focused period' in which to 'engage / communicate' with the patient.

NHS 24 is also committed to the concept of 'appropriateness', that is we recognise that standard NHS 24 dispositions may not be appropriate for patients who are terminally ill. On this basis, a 'priority patients' scheme is already built-in so that, when a patient - who has been notified to the service as having a particular need such as a terminal illness - calls, his/her consultation can be individualised for action to be taken or specific professionals to be contacted. The 'Not Sure' campaign also encourages patients who are uncertain about whether to contact their GP to contact NHS 24 in the first instance so as to talk through their situation with a nurse. NHS 24 provides opportunities for signposting, via the ready availability of the Health Information System database and of nurse advice, 24 hours a day, 365 days a year. There is also scope at professional level for joint training projects and joint employment appointments, which may be particularly appropriate in palliative care.

Conclusions

NHS 24 is a new and exciting NHS initiative. To be effective it requires partnership working: NHS 24 is part of the NHS, not a separate entity. It is simply about making nursing expertise accessible to the public, with the use of computers acting as a supportive tool.

Workshop 1: Reconfiguration of community palliative care services in Glasgow

Susan Munroe, Caring Services Manager, Scotland, Marie Curie Cancer Care

Anna Grady, Project Manager, Reconfiguration of Community Palliative Care Services in Glasgow

The objective of this workshop is to provide an overview of the project that is currently taking place in Glasgow as a means to generating discussion around the topic. In addition, we seek to identify three key issues for future development in reconfiguring community palliative care services.

Why redesign services?

At present, in terms of patients needing palliative care, emergency admissions occur for a number of reasons. These include:

- inadequate carer support
- inadequate symptom management, and
- inadequate communication.

Despite this, most palliative care is delivered within the community setting. All patients have the right to die at home if they choose and it seems that around 65% of patients would prefer this option. However, in actuality, only 25% of patients do die at home. In addition, among those that live either in deprived areas or that live alone, a higher proportion will die in hospital. It is to overcome these differences that redesign of community palliative care services is needed. Services need to be flexible to allow for, and to better reflect, patient choice.

Expected outcomes

The anticipated positive outcomes of any such redesign are threefold:

- to reduce the number of patients admitted to hospital or hospice as an emergency out of hours
- to facilitate discharge from hospitals and hospices
- to increase the proportion of patients dying at home.

Two recent Scottish Executive strategy documents promote redesign - *Our National Health: a plan for action, a plan for change* (December 2000) and *Cancer in Scotland: Action for change* (July 2001). The latter seeks to promote 'programmes of services redesign and improved ways of working so that real benefits for patients are delivered'.

Glasgow project

The process in Glasgow was initiated through a meeting and 'brainstorming' to raise issues and ideas for redesign. Then, following a questionnaire issued to health care professionals, a steering group was established. A sub-group developed options for reconfiguration, and a further sub-group addressed the issue of direct referral to Marie Curie Nursing Service from acute services. Having secured funding for the project through a bid to the New Opportunities Fund, a Project manager was then appointed (funded by Greater Glasgow Health Board).

This has allowed the assessment of service redesign in Glasgow to now get underway.

Delegate discussion

In terms of patients dying at home, an earlier pilot scheme known as Hospice at Home aimed to improve palliative care services but had proved very expensive. However, it had enabled us to learn more about what patients want. While we do not want to recreate the same service model, it highlighted the importance of locating evidence of needs through patient/carer feedback. Retrospectively it also highlighted the significance of the carer figure in palliative care provision, the patient's choice often being influenced by the degree of support available for his/her carer. It is essential, therefore, to be clear about addressing two distinct but related sets of needs - those of patient *and* carer.

We can ask two questions:

- where do patients really want to die, and
- where do carers want patients to die?

It is important to note that if suitable support systems are not in place then we preclude patient ability to choose.

Any reconfiguration needs to involve and consult everyone who has a stake. Furthermore, everyone needs to believe in the role of palliative care. In chronic disease management this can be difficult as a barrier occurs in the ability to recognise the 'palliative care stage', and education is required amongst professionals to overcome this. District nurses can often play a key role in overcoming any communication difficulties between services that arise among those involved. In essence, the services need to be in place, and health care professionals need to know about them. We need to recognise the needs of patients, carers and professionals, including their needs for education.

We also need to look at the reasons for re-admission or failed discharge. This means engaging acute service providers as well as primary care services, as there can often be a lack of awareness of what is available in the community setting. The objective is to *link* services to overcome existing gaps, rather than creating a 'new' service.

Stakeholders' workshops, where people can come together to participate in a forum (regardless of who employs them), enable pathways to be developed and services mapped. This improves the responsiveness of palliative care services. It also enables gaps to be identified and helps to overcome inequity of access to

services. In addition, it is important to prepare patients and carers to address the palliative care needs that they are likely to have. If we are to provide a service based on need rather than diagnosis it is essential to ensure that everyone involved in community palliative care knows all that is currently going on. This might be achieved through use of information technology/websites and noticeboards as well as through educational groups.

Key issues

Delegates identified three key issues to be taken forward in any redesign of community palliative care services:

- asking carers and patients what *they* want
- providing for unified working across different services, and
- offering access to information about services, groups and activities.

Workshop 2: Cardiopulmonary resuscitation – a continuing dilemma?

Dr Clive Preston, Consultant in Palliative Medicine, Fife Palliative Care Service

The principal purpose of this workshop is to explore whether cardiopulmonary resuscitation (CPR) remains a continuing dilemma, or whether all issues have now been resolved.

Guidance on CPR

Clearly, there are significant benefits flowing from modern medical techniques such as cardiopulmonary resuscitation. However, these techniques raise dilemmas about when to cease or withhold such interventions. The Department of Health (England) made it a requirement that, by 2001, all hospital doctors must be given Trust guidelines on resuscitation decisions. Local guidelines should be based on guidance drawn from the British Medical Association (BMA), Royal College of Nursing (RCN) and the UK Resuscitation Council.

This includes requirements that:

- decisions should be made by senior and experienced doctors, supported by senior nursing colleagues;
- there should be 'sensitive exploration of patients' wishes' which are documented appropriately; and
- decisions should be made as early as possible following admission, and be reviewed regularly.

In addition, the BMA issued advice (January 2002) that all establishments facing decisions about attempting CPR should have in place a policy about resuscitation. It is the responsibility of chief executives of NHS Trusts to ensure that those policies respect patients' rights, and that policies are accessible to and understood by all staff that need them. While overall responsibility for decisions about CPR and Do Not Attempt Resuscitation (DNAR) orders rests with the relevant consultant or GP, s/he should always be willing to discuss any particular decision with other health care professionals involved. The BMA also advised that written information about resuscitation policy should be issued to patients.

The General Medical Council (GMC) has also emphasised the importance of ensuring that decisions are properly and promptly documented. Recorded information should include clinical aspects, together with discussions with the patient, members of the healthcare team, or others involved in decision-making. Records should also be

accessible to the patient, team members and others involved in providing the patient's care. Furthermore, any DNAR order should be subject to regular review to ensure it remains appropriate to the patient's condition. Both the BMA and GMC have advised (2002) that, in decisions about CPR, it should be made clear to the patient and to people close to the patient and the healthcare team that the decision applies *only* to CPR and that other forms of treatment and care are unaffected.

Delegate discussion

Even in the light of guidance several questions arise for discussion:

- Should CPR be discussed with every competent patient?
- Is there an obligation to discuss CPR with patients and/or carers even if it is believed that the procedure would be futile?
- When might CPR be regarded as futile and when should discussions with the patient take place?

Competence

What is a 'competent patient'?

First, it is unclear what defines a person as 'competent'. There is no template or algorithm for assessing competence/capacity validated for use in Scotland. The BMA view (January 2002) is that because patients' own views about risks and benefits of treatment are of considerable importance, then the wishes of competent patients (who are at foreseeable risk of cardiopulmonary arrest or who have terminal illness) should be sensitively explored with regard to CPR.

Futility

What if we consider it to be futile to attempt CPR?

The concept of 'futility' is not clearly defined. As the GMC acknowledge (August 2002), although CPR may be effective in restarting the heart and lungs of some patients, its success rate is low for those patients that have serious conditions and poor health. Moreover, its inappropriate use may risk harmful complications and side-effects. In the context of CPR, 'futility' describes situations where attempted resuscitation has little chance of successful outcome.

Futility may have various effective meanings:

- immediate death
- non-survival to discharge
- survival with unacceptable quality of life or
- survival for a very limited time.

CPR of hospital patients has survival rates through to discharge of 15-25%. Any negative predictor (e.g. diagnosed cancer, dementia, or age over 70 years) reduces survival rate to less than 10%. Indeed, the most significant predictors (e.g. advanced/metastatic cancer) have survival rates of 0-2.5%.

What if a patient opts for CPR when such attempts would be deemed futile?

In this situation there seems little point in discussing CPR if it is not being offered (on grounds of futility). While the above guidance advocates discussion with all patients, this position contrasts with the view of the Association for Palliative Medicine, which suggests that discussion need not take place if CPR is not being offered. Perhaps this area should be addressed on an individual patient basis. Certainly, the GMC and BMA (2002) both acknowledge that doctors are not obliged to give treatment if doing so contradicts their clinical judgement. Delegates suggested that, in practice, discussion and review would also only take place with patients who favour resuscitation. On this basis it may be that the BMA statement is not in line with current medical practice. It is also noteworthy that the majority of patients concerned in such situations are not in hospices. Whatever policy we adopt in palliative medicine in Scotland it must apply across the range of service providers.

Should CPR be discussed with a patient prior to admission to a specialist palliative care unit?

The Association for Palliative Medicine (1997) advises that discussions should take place *before* the patient is transferred to a hospice. This discussion should include the extent of any CPR facility and expertise within an

admitting unit. While delegates agreed about the proactive timing of discussion, this raises the issue of how to manage a situation where the patient refuses to discuss CPR. The BMA recommends (2002) that information should not be forced on unwilling recipients, and the patient's unwillingness should be respected and recorded in the notes.

We must also bear in mind that recent legislation influences the DNAR/CPR context. The Human Rights Act 1998 protects patients' rights to life and protects them from inhuman or degrading treatment. In addition, where a patient's wishes are unknown, the BMA guidance suggests that all reasonable attempts will be made to revive the patient, bearing in mind the support of other medical/nursing colleagues and being mindful of acting in the patient's 'best interests'. However, in Scotland, we must also be aware of the provisions now in force under the Adults with Incapacity (Scotland) Act 2000. This legislation provides for involvement of a patient's proxy and/or nearest relative and primary carer in the decision process as a means to ascertaining the patient's likely views. Hence, blanket policies on DNAR are no longer feasible and decisions should be made on an individual basis.¹

Key issues

Several problems still persist in the context of CPR and DNAR. However, three conclusions can be reached:

- blanket policies covering DNAR are not acceptable - everyone has to be involved in the decision
- we should consider discussion of policy prior to admitting a patient to a hospice, and
- a senior doctor or nurse should lead those discussions.

¹ The BMA advice (January 2002) suggests that blanket policies may now be unlawful under the Human Rights Act which prohibits discrimination in individuals' enjoyment of Convention rights.

Workshop 3: New wine in old bottles – redesigning intermediate care

Gail Black, Co-ordinator, Scottish Association of Community Hospitals

Dr David Carroll, GP Facilitator in Palliative Care, NHS Grampian

Dr Mhoira Leng, Consultant in Palliative Medicine, Roxburghe House, Aberdeen

What is intermediate care?

The title of this workshop echoes a paper by Professor Lewis Ritchie in which he pointed out that every time there is a change in terminology it is simply a case of new wine in old bottles.¹ Community hospitals and the thinking behind them are not new, and neither is intermediate care, which is today's 'new wine'.

Recent policy development in England and Wales has taken intermediate care to apply specifically in the context of care for older people. In Scotland we continue

to use the wider definition developed by the Oxford and Anglia Intermediate Care Project in 1997 :

“Intermediate care can be described as those services which do not require the resources of a general hospital but are beyond the scope of the traditional primary care team. This includes :

- **Intermediate care which substitutes for elements of hospital care (substitutional) and**
- **Intermediate care which integrates a variety of services for people whose health needs are complex and in transition (complex care)”.**

This approach was confirmed in the Scottish Health Department Management Executive Letter (MEL (1999)10).

Palliative care in intermediate care

There are a number of recent developments highlighting the importance of palliative care in intermediate care. The Clinical Standards Board for Scotland (CSBS) Community Hospital Standards, currently issued in draft, contain a standard for palliative care. In addition, the Scottish Partnership Agency (SPA) report *Palliative Care in Community Hospitals* (1998) has now been followed by a stocktake report, *The Provision of Palliative Care in Community Hospitals in Scotland* (2002), which was commissioned by the Scottish Association of Community Hospitals and carried out by the Centre for Health and Social Research. This will in turn be followed by the production of a *Framework for Good Practice* guide in 2003.

The core of palliative care is basic general practice done well, with the additional need to access specialist resources when required. The CSBS standard requires community hospitals to maintain links to specialist palliative care. Specialist units are located only in population centres, however, and if the demands of equitable access are to be met, then appropriate palliative care must be available in community hospitals and in nursing homes.

Much symptom management, and some complex palliative care, could be done in community hospitals. But it can be difficult to determine when complex needs become specialist palliative care needs. The provision of good intermediate care requires a mixture of knowledge (through courses and/or diploma level studies) with skills and experience. There is still a need for more education in palliative care, for example among GPs.

Adequate staffing levels are also needed to provide good intermediate care. This may be addressed via the CSBS standards, but overall workforce shortages will still have an impact in the foreseeable future. It is important to know, therefore, how to access additional resources and expertise when required. Strategies like developing community links and making full use of multi-professional teams (for example in the same way as staff in acute hospitals, who also deal with dying patients, draw on the support of hospital chaplains) may be useful. It may also be possible, where appropriate, to access the Marie Curie nursing service for individual patients. Difficulties can arise, however, not only because of low staffing levels, but also because nurses do not want to give up the care of patients with whom they have formed a bond to the care of others during the terminal stage.

Delegate discussion

The workshop identified a number of possible issues in redesigning intermediate care, including:

- Where a community hospital is threatened with closure, what should be the new model for intermediate care?
- Should community hospitals become community resource centres incorporating a GP surgery?

Which is the best model?

- In terms of good practice, where do the Gold Standards Framework and co-ordinated pathways such as the Liverpool Care Pathway for the Dying Patient fit in? What should be the principles for inclusion in the proposed Framework for Good Practice?
- What should be the relationship between intermediate and specialist palliative care? What about community hospitals with no access to palliative care?
- Should community hospitals have dedicated palliative care beds?
- What is the answer to the resource and staffing issues which will arise, given that community hospitals routinely deal with all conditions, including non-cancer admissions for palliative care?

Not all of these could be covered in detail. However, delegates agreed that a community hospital essentially is a community resource centre and that this represents the preferred model. It is merely that some facilities are still based in outmoded buildings.

Key issues

Discussion concluded that future priorities to ensure good intermediate care should focus on three key issues: staffing, training, and the character of intermediate care.

Staffing:

- staffing levels need to be improved – also in general facilities there is a need for multi-tasking practitioners in all disciplines
- the available extended team should be used as efficiently as possible, and
- national recommendations (such as those from CSBS) should be employed to assist in achieving appropriate staffing levels.

Training needs to be of the right kind – that is:

- delivered locally
- practical for staff within their own context, and
- aimed at a variety of levels (not necessarily diploma level).

Intermediate care:

- intermediate care is already happening, as community hospitals are the traditional home of this 'new' idea
- links between professionals and various networks should be formalised
- community hospitals provide services up to a certain level and complement other facilities
- if enhanced services are to be provided in intermediate care, we need to identify the additional training which will help to make this happen, and ensure the availability of appropriate facilities and knowledge.

¹ Ritchie LD, Robinson K. Community hospitals: new wine in old bottles? BJGP 1998; 48: 1039-1040

Workshop 4: Supporting carers at home: the Macmillan Crossroads Carers Project

Fiona Murdoch, Co-ordinator, Macmillan/Crossroads Carers Scheme, Edinburgh
Ruth McCabe, Service Development Manager, Macmillan Cancer Relief

Caring about carers

The Scottish Executive Strategy for Carers in Scotland (1999) identifies several factors that help carers to cope successfully. These include:

- time off from caring
- relief from isolation
- satisfaction with the help they receive from their families and others
- receiving reliable services
- availability of information and
- recognition of their role and contribution.

Crossroads (Edinburgh) was established in 1983 to offer respite care in the home to carers of the frail, elderly, disabled and chronically sick. It now has three sections to it: the main Crossroads, Macmillan Crossroads, and a rural project. Crossroads Caring for Carers Edinburgh is one of more than 50 schemes in Scotland, each of which is autonomous. Macmillan Cancer Relief and Crossroads Edinburgh came into partnership in 2000. The Edinburgh project is one of three that Macmillan began at that time, the others being in Glenrothes and Glasgow (West). Macmillan Cancer Relief is funding these projects until 2003. The Edinburgh scheme, through a team of six Macmillan Crossroads Support Workers, aims specifically to support carers of people living with cancer within the city. By virtue of Macmillan's funding, we are able to offer this support as a free service to carers.

Referral

All people with cancer and their families who are living at home and who require assistance with personal and practical care may benefit from the service that we provide. The scheme seeks to prevent readmission due to family stresses and to provide support during crisis periods. The service is available from the point of diagnosis onwards to all ages, including children.

The reasons for referral to this service vary. Support from the team may be requested, often through other agencies, in order to enable the person with cancer, their family and other informal carers to cope with the additional practical problems created by the illness. Alternatively, the care demands may be such that the family/carer simply needs additional support, or the care needs of the person with cancer are such that they limit the family/carers' opportunities for respite. Sometimes the person with cancer, or their family, is experiencing practical problems rather than an overriding clinical need. This may occur at any time from point of diagnosis through to terminal stage. Following referral, the project co-ordinator will visit

to discuss the needs of both the carer and the person being cared for. The project co-ordinator's role is to assess and allocate support, publicise the scheme, liaise between services and manage funding. Support workers, once allocated, provide the care.

Role of support workers

A support worker's role is wide and varied. It is tailored to meet the needs of a referred individual, and may include:

- befriending
- providing a sitter service
- personal care (such as washing and dressing, moving and handling, and toileting)
- offering emotional support to the person with cancer and/or the carer
- taking people on outings within the community; and working and liaising with other agencies.

Thus, support workers provide a flexible approach to an individual's and a carer's needs. Support workers are trained and adaptable in taking over the caring role and assisting in care packages. Through liaison with other staff, such as district nurses and agency staff, support workers contribute to providing uninterrupted help and minimising unnecessary stress.

Apart from adhering to the tasks set out in the care plan, this involves building a relationship with all concerned. Support workers are well placed to listen to the fears and concerns of both sufferer and carer, while remaining neutral and non-intrusive. Listening is often more important than having answers. By relieving the carer of his/her duties, the carer is given time for themselves to enable them to recharge their batteries, helping them then to support the wishes of the cancer sufferer to remain at home as long as possible. The support worker is also able to observe the situation and report any changes which might merit reassessment, thus helping to ensure that maximum comfort is maintained. S/he also provides monthly written reports of clients' progress to the co-ordinator to enable information-sharing.

Evaluation

Evaluation, through feedback from carers using the service, has been positive. The service has shown rapid response, both for initial and subsequent referrals. The service is needs-led rather than task-oriented, allowing the sensitivity to match provision closely with individual need. The range of activities that support workers are able and willing to undertake (as and when necessary) reinforces this. Flexibility in range of support and times is an important feature in responding to the changing needs of clients and

carers. In particular, the level of training and experience of support workers means that carers are better able to relax during their respite time. Additional features of the service which users find important are the reliability and continuity of staff. Offering the same support worker for each visit is appreciated and helps identification of changes.

Clear benefits accrue to the client and carer. Carers gain a feeling of freedom and spontaneity by being able to go out, while clients look forward to hearing about the carer's outings. In essence, the support provides both client and carer with space. In addition, the relationship built with a support worker is more like that of a friend, providing another person for the client and/or carer to talk with, yet retaining a professional knowledge of their support needs.

Delegate discussion

Discussion centred around four questions:

What do carers need to support them in providing palliative care?

In responding to the first question, delegates felt that carers need information and education to overcome myths about cancer (and other conditions). Further, they need to know where to find out about services, and who is available to help. In addition, they need respite provision in all its forms (with immediate access when required), which is flexible in its location and consistent in the carers provided.

How are their needs being met?

It was felt that needs were not being met at present. Provision seems highly dependent on locality and is

inconsistent across the country. There is a perceived lack of trained carers and resources. Furthermore, people with cancer currently receive better services than those with other conditions.

What are the gaps in services?

The perceived gaps in services were identified as overnight care provision, together with limited budgets and resources. Again, geographical location is an issue; for example, the gap between surgery and oncology depends very much on area.

How could these gaps be addressed?

In addressing these needs, service provision was seen as being of prime importance. Beyond this, the use of a co-ordinator within an area could improve communication. In addition, the development of an integrated pathway for returning home was seen as a valuable way of addressing existing deficits.

Key Issues

The key points arising from delegate discussion were that:

- *equity of provision should prevail across all illness groups, all ages and all geographical areas*
- *the interface between acute and primary care could encourage creation of a suitable integrated care pathway*
- *services should be based on needs: as needs can change, the service must be flexible enough to accommodate those changes, and sufficient resources are required to support this flexibility.*

Workshop 5: Adults with Incapacity (Scotland) Act 2000 – enabling or disabling?

Dr Rosaleen Beattie, Medical Director, St Margaret's Hospice

Principles of the Act

The purpose of the Act is to protect the rights and interests of the most vulnerable and voiceless members of society. Medical treatment, under Part V, forms only a small part of the Act.

The principles of the Act focus on:

- benefit
- minimum intervention
- encouraging the patient to exercise his/her residual capacity,
- the importance of taking into account their wishes and feelings
- consulting widely with relevant other people.

The Act applies to adults (aged over 16 years) who are incapable of understanding and making decisions,

communicating decisions, or retaining the memory of their decision because of mental disorder or physical disability.

Assessing capacity

The guidelines within the Code of Practice supersede any previous guidance on assessing capacity, although, prior to the Act, there were no algorithms or other tools available in Scotland.

In assessing an adult's capacity, a medical practitioner should determine whether an adult:

- is capable of making and communicating his/her choice
- understands the nature and purpose of what is asked
- is aware of alternatives
- is able to retain information

- understands the likely risks and benefits involved, and
- is aware that the information relates to him/her personally.

Furthermore, she/he should be aware of his/her right to refuse treatment and the consequences thereof. The practitioner should also consider whether the patient is expressing views consistent with his/her former moral, cultural and experiential background.

Consulting others

The practitioner must consult widely to determine whether the patient has ever expressed (during capacity) any relevant wishes. Consultation should involve any appointed proxy, the nearest relative (from a list), the primary carer, and any person claiming an interest. Under the Act, for the first time, an appointed proxy can consent to, or refuse medical treatment on behalf of an adult who lacks capacity.

Certifying incapacity

The doctor primarily responsible for medical treatment certifies incapacity. The form, which bears a maximum duration of one year (renewable), should be completed even if there is a proxy with power to consent. The certificate must specify treatment but one certificate may cover several treatments within a Treatment Plan. However, the certificate of incapacity does not permit use of force / detention, detention under the Mental Health (Scotland) Act, nor any action inconsistent with a court decision.

Medical treatment:

Subject to the requirements therein, the Act authorises carrying out any procedure or treatment designed to safeguard or promote the physical or mental health of the adult. Where a welfare attorney, guardian or intervener with treatment powers is appointed, the doctor must consult with them, where 'reasonable and practicable', and seek their agreement. If the proxy agrees then treatment may proceed. If the proxy disagrees then the doctor must request a second opinion from a Mental Welfare Commission nominated medical practitioner, who must consult the proxy and a person nominated by the proxy.¹ Where the nominated medical practitioner agrees, then treatment can go ahead despite proxy disagreement. If the nominated medical practitioner disagrees then the doctor can go to the Court of Session.² However, anyone able to demonstrate an interest can also appeal any treatment decision to a sheriff and thence the Court of Session.³

It is noteworthy that emergency treatment is excepted, and certain exceptions also exist where application for guardianship with treatment powers is underway. Certain treatments are also specifically excluded from the Act's authorisation (including neurosurgery for mental disorder, surgical hormonal implants, drug treatment with hormones, ECT, abortion, sterilisation, and treatment for mental disorder for persons aged 16-17 years). The act does not permit force or detention in order to carry out treatment; action inconsistent with a court decision; or

detention which would normally come under the Mental Health (Scotland) Act. The legal situation as regards Advance Directives, and withholding/withdrawing treatment remains unaltered by the Act.

Research:

The Act limits research on incapacitated adults. Under section 51, research can only proceed if it cannot be carried out with capable adults; or it investigates the cause, diagnosis or treatment of the incapacity. It must offer a real and direct benefit to the adult (or improve understanding to benefit others with the same incapacity). Furthermore, research can only proceed if the adult does not indicate unwillingness, there is no (or minimal) foreseeable risk or discomfort to the adult, consent has been obtained from any empowered proxy/nearest relative, and there is Ethics Committee approval.

Delegate discussion:

Do certification forms protect the doctor or the patient?

Delegates raised concerns about completion of certification forms. While there is no legal obligation to complete the forms (the duty upon doctors being to uphold the principles of the Act), the role of the forms remains unclear. Most incapacity in palliative care arises not in those who permanently lack capacity because of learning disability or mental illness, but because of deteriorating condition as the end of life approaches. In palliative care there is a considerable focus on written records generally, and upon continuing discussion and consultation.

The Act seems 'enabling' in the sense that it is about 'doing the right thing', which includes consultation with those designated.

The certification form is a shorthand way of saying "Although this patient is no longer capable of consenting we are carrying out the following treatment, for their benefit".⁴ However, the lack of consecutive numbering on the forms, and problems regarding dating them are felt presently to undermine their value. This is exacerbated by concerns about where the forms should be kept once completed; should they remain with a patient's records or be placed with administration?

What is the scope of the Act?

In palliative care questions also arise about the scope of the Act. As patients are informed about how they are going to die (if they wish to know), it is questionable as to whether such discussion could amount to an Advance Directive by the patient, which would lie outwith the provisions of the Act. The current status of such discussions remains unclear.

How do procedures under the Act differ from former consent form procedures (sometimes signed by a relative)?

The main difference is that if a proxy disagrees with proposed treatment then the list of appointees should then be considered. Furthermore, certain designated

treatments require adherence to special safeguards. Future proposed amendment to the Act might incorporate a 'named nurse'.

Key points

The following conclusions were reached:

- the certificate does not replace good record-keeping
- the Act is 'good' for patients and doctors because it enables patients and doctors, and encourages

consultation. We need to consider: do we really already consult in palliative care as much as we think we do?

- given the Act's complexity, perhaps we also need help to manage our responsibilities under it.

¹ Adults with Incapacity (Scotland) Act 2000: Section 50

² Adults with Incapacity (Scotland) Act 2000: Section 50

³ Adults with Incapacity (Scotland) Act 2000: Section 52

⁴ But if a patient resists a procedure then the treatment team cannot proceed.

Workshop 6: End-of-life palliative care for older people in care homes

Jo Hockley, Research Fellow/CNS, St Columba's Hospice, Edinburgh

What is palliative care?

Palliative care is defined by the World Health Organisation as the active total care of patients whose disease is no longer responsive to curative treatment.¹ Its goal is the achievement of the best quality of life for patients and their families. From this general definition of palliative care, certain more specific terms have now evolved. 'Specialist palliative care' services are those services that have palliative care as their core specialty. A significant minority of people whose deaths are anticipated need such specialist services. Specialist palliative care may be provided either directly through specialist providers, or indirectly by specialist advice being given to a patient's usual professional advisers/carers (NCHSPCS & SPA 1998).²

'The palliative care approach' (NCHSPCS & SPA 2000)³ aims to promote both physical and psychosocial well-being. It is a vital and integral part of all clinical practice. Whatever the illness or its stage clinical practice is informed by knowledge and application of palliative care principles. These palliative care principles include:

- a focus on quality of life, which includes good symptom control
- a whole-person approach, in terms of both past life experiences and current situation
- caring for the person with the life-threatening disease and for those close to that person
- respect for patient autonomy and choice, and
- emphasis on open and sensitive communication with patients, informal carers and professional colleagues.

However, particular issues arise when palliative care is provided in the context of nursing homes.

Palliative care in nursing homes

Nursing homes differ significantly from specialist palliative care service settings, and offer a different philosophy and culture of care. The promotion of palliative care in the context of nursing homes is based on four key assumptions:⁴

- that the transfer of the palliative care model from the specialist setting to nursing homes is unproblematic
- that palliative care, derived from a cancer care model, is applicable for all residents dying in nursing homes
- that nursing home staff lack relevant knowledge about caring for dying residents, and
- that education is sufficient to bring about changes in practice.

Each of these assumptions may be questioned.

The size of the problem

The nursing home setting has seen substantial variation in size over the past thirteen years. In 1990 there were 9,901 nursing home beds (figures include private hospitals/hospices in Scotland), and 8,997 long stay hospital beds. By 1999, while the number of long-stay beds in hospitals had decreased to 4,924, numbers of nursing home beds had increased significantly to 23,294 (figures include private hospitals/hospices). However, in 2001, some 9,600 places were lost in independent sector care homes, with 2,300 lost in local authority run residential homes. Meanwhile, 1,200 places were also lost in continuing care facilities in NHS hospitals.⁵

A survey of palliative care within 74 nursing homes⁶ across the Lothian area provides valuable information about the current role of palliative care within this context. From a 68% response rate, there was a 37% turnover of beds due to deaths in nursing homes. Furthermore, 54% residents died within two years of entering a nursing home, of which 10% of deaths occur in hospital, only 7% being recorded as resulting from cancer. Despite these significant numbers of deaths only 28% of nursing homes provided a policy on 'care of the dying', and only 6 nursing homes used the services of Macmillan nurses/clinical nurse specialists. However, 53% (i.e. 26 nursing homes) had accessed 'palliative care education'.

Quality end-of-life care

Fundamental differences arise between dying at the 'end-

of-life' (from multiple medical problems), in contrast to dying in 'mid-life' (from cancer). These are discussed in full elsewhere,⁷ but may be usefully summarised here. In cancer-oriented palliative care, the focus is on one disease, and both the patient and his/her family often want the patient's life extended. In the end-of-life scenario in nursing homes, however, the patient is often experiencing a multiple disease process and there is a greater notion of the risk of becoming a burden. There is also a sense in the former of life being 'cut short', whereas in the latter the natural ending of life is clearer. In addition, in the context of cancer the patient often remains cognitively intact, while a greater percentage of cognitive impairment occurs in end-of-life patients in nursing homes.

The model of care also differs. While cancer patients receive a multi-disciplinary model of palliative care, those patients needing end-of-life care in nursing homes receive most care input from nurses and care workers. Such patients often see these care staff as 'family', while cancer patients generally benefit from good familial support. Time-scales between the two patient groups also contrast significantly, with cancer palliative care often taking place over months, while nursing home patients have a longer dependency (of perhaps 1-2 years). However, their eventual death often goes unnoticed.⁷

Key issues

In view of these distinctions, improving the quality of end-of-life care for patients in nursing homes demands our focus upon five central domains:⁸

- receipt of adequate pain and symptom control

- avoidance of inappropriate prolongation of dying
- achievement of a sense of control
- relief of the burden on others, and
- strengthening of relationships with loved ones.

At an older age there is a greater expectancy of death and many older people will already have experienced the death and loss of old friends and siblings. Many are less frightened about death but more about the process of dying. Being well cared for with attention to the above five domains is only what many ask for and it is our responsibility to make sure that this area is developed.

¹ WHO (1990) *Cancer Pain Relief and Palliative Care: report of a WHO expert committee*. Technical Report Series, No 804: World Health Organisation, Geneva

² NCHSPCS & SPA (1998) *Reaching Out: specialist palliative care for adults with non-malignant diseases*. National Council for Hospice and Specialist Palliative Care Services, and Scottish Partnership Agency for Palliative and Cancer Care, Occasional Paper 14, NCHSPCS; London.

³ NCHSPCS & SPA (2000) *Positive Partnerships: palliative care for adults with severe mental health problems*. National Council for Hospice and Specialist Palliative Care Services, and Scottish Partnership Agency for Palliative and Cancer Care, Occasional Paper 17, NCHSPCS; London.

⁴ K A Froggatt, (2001) Palliative care and nursing homes: where next? *Palliative Medicine* 15: 42-48

⁵ Laing and Buisson (2002) *Care of Elderly People: Market Survey 2001*. Laing and Buisson, (<http://www.laingbuisson.co.uk>)

⁶ Hockley, J (2003) *Death and Dying in Nursing Homes; a survey* (in press)

⁷ Hockley, J & Clark, D (2002) *Palliative care for older people in care homes*. Open University Press, Buckingham

⁸ Singer P, Martin D K, & Kelner M (1999) Quality end-of-life care. *Journal of the American Medical Association*, 281 (2): 163-8.

Concluding remarks

Dr Derek Doyle, OBE, Honorary Vice President of the Scottish Partnership for Palliative Care

Dr Derek Doyle, OBE, Honorary Vice President of the Scottish Partnership for Palliative Care, concluded by emphasising some of the principal issues and challenges raised during the day's conference.

The excellent presentations and workshops in which we have been able to participate today have proved to be both informative and thought provoking. They serve to remind us that many challenges, and many questions, remain for palliative care.

For example, we might ask ourselves general and far-reaching questions such as:

- ***Do we currently respond to demand, or to need, in providing palliative care?***

Or we could ask specific questions like:

- ***Will the innovation of NHS24 enhance, or limit, flexibility? Is the expertise of nursing staff restricted by a technology-based approach?***

We could also ask ourselves:

- ***How we are going to provide palliative care for non-malignant conditions?***

We in palliative care still know relatively little about the natural course and symptom pattern of many of these diseases. We need a collaboration of expertise, for example with other specialists and, with staff at multiple sclerosis respite centres, if we are to work successfully towards a better understanding of how best to care for and support those with non-malignant conditions.

Scottish Partnership for Palliative Care

The Scottish Partnership for Palliative Care works to ensure that people in Scotland who have a progressive life-threatening condition, such as cancer, motor neurone disease or advanced heart failure, receive good palliative care. Palliative care aims to achieve the best possible quality of life for patients and their families or carers by:

- controlling pain and other distressing symptoms
- helping patients and families cope with the emotional upset and practical problems of the situation
- helping people to deal with spiritual questions which may arise from their illness
- helping people to live as actively as possible despite their illness
- supporting families and friends in their bereavement

The Scottish Partnership for Palliative Care brings NHS bodies and voluntary and professional organisations together to promote better understanding of palliative care, to make it available to all those who need it and to improve standards of care everywhere for patients and families. It contributes to national thinking and policy in relation to palliative care, and promotes improvements in service delivery at local level. Following its eleventh annual conference on Rethinking Palliative Care, the Scottish Partnership for Palliative Care is taking the lead in Scotland in promoting access to palliative care for all.

Membership

The Scottish Partnership for Palliative Care has a membership of over 70 organisations involved in palliative care in Scotland in both the statutory and voluntary sectors.

Membership is open to:

- NHS Boards and Trusts
- Voluntary hospices
- National charities
- Patient support organisations
- Local authorities
- Professional bodies

Membership entitles organisations to be represented in the Partnership's regional and special interest groups which give them access to a unique multi-professional and multi-agency network. Through this network members share information and good practice, receive professional support and take joint action on issues of concern. Members also receive regular publications and notification of courses and conferences. The Scottish Partnership for Palliative Care Council is elected by the membership through the regional and special interest groups.

Find out more at www.palliativecarescotland.org.uk

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