



**SCOTTISH PARTNERSHIP AGENCY**  
FOR PALLIATIVE AND CANCER CARE

# Sharing Good Practice



Report of the Conference  
held at  
Stirling Royal Infirmary  
6th December 2000

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## **INTRODUCTION**

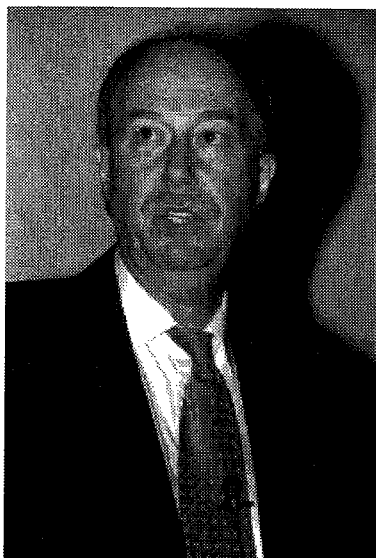
The Scottish Partnership Agency for Palliative and Cancer Care held a one-day conference on the theme of "Sharing Good Practice" in Stirling on 6 December 2000.

The Conference was attended by 130 delegates from across Scotland, including health professionals and managers from health boards, NHS acute and primary care trusts, hospices and other voluntary organisations involved in palliative and cancer care. Delegates evaluated the conference highly for being informative and relevant to their own practice and the Scottish Partnership Agency hopes this report will encourage the continued sharing of good practice.

## **ACKNOWLEDGEMENT**

The Scottish Partnership Agency for Palliative and Cancer Care acknowledges with thanks sponsorship from Janssen Cilag and NAPP which helped to make the Conference possible.

## Malcolm Chisholm MSP Deputy Minister for Health & Community Care



Malcolm Chisholm MSP

"The Minister herself had very much wanted to be here today. She is sorry that other, extremely pressing, commitments have stopped her from fulfilling an engagement she had been looking forward to for a long time. I greatly welcome the chance to be here today in her place.

The Agency's title, with its use of 'partnership', is in tune with a key

element of the Scottish Executive's own approach: working together, sharing.

Our *Programme for Government* highlights the contribution of the voluntary sector in our drive to improve the health of the people of Scotland. That will be carried forward into the Scottish Health Plan, due to be published next week.

Palliative care has been one of the drivers in developing the sort of services all patients expect and deserve: personalised, seamless, of the highest quality across the country as a whole.

The impressive thing about the palliative care approach is the way it addresses the full range of every patient's needs. It's not just about relief of pain and other distressing symptoms, though I don't for a moment underestimate how important that is. It's the fact that the palliative care approach produces a management plan aimed at best quality of life. It also recognises the role of the family, carers and friends. It includes spiritual matters. It faces up to bereavement and its consequences. Care for patients' families and friends after death is an integral part of palliative care. For many people, death and dying are taboo areas, which makes it all the more necessary to address the issues they give rise to.

In pursuit of those aims, I know that you are constantly thinking about ways you can extend your activities, make them more effective.

Traditionally, palliative care developed in response to meet the needs of those with cancer.

That has led to the important work of the Scottish Cancer Group which will continue to inform policy and investment decisions on services for this clinical priority. The Group also provides a strategic framework for the development of cancer services across Scotland.

In looking at how we could best use the New Opportunities Funding money for cancer, we have, as you know, gone for a particular emphasis in Scotland on palliative care projects. The NOF Board will shortly announce the projects which it has approved.

Next year, we will publish our Scottish Cancer Plan. It will draw together current activity, and will tackle the problems we know cause most concern to patients: getting the fastest possible diagnosis, and then getting access to treatment as quickly as possible.

But one of the greatest strengths of the palliative care movement is that it is not content to stand still. It is always looking for new challenges which go beyond the traditional association between palliative care and cancer.

It's now clear that the principles of palliative care have a much wider application. They can inform the management of other progressive conditions. Motor neurone disease and Parkinson's disease are the two most usually mentioned. And it's possible to take things even further than that. The CHD Task Force is raising awareness of the benefits which palliative care can bring to patients with end-stage heart failure, where the symptoms are often extremely distressing. It's a clear example of a need which goes unmet all too often.

The role of palliative care in relation to our other clinical priority, mental health, is well set out in your report *Positive Partnerships*.

Naturally, patients with severe mental illness who then go on to develop a life-threatening illness must have their physical symptoms relieved. They also need psychological and spiritual support. Their families have the same rights as others to support in the terminal phases of the illness and on into bereavement. Tackling a mixture of physical and mental health needs is always a real test of our ability to work together in the best interests of the patient. The palliative care approach gives the best possible platform to build on.

I particularly welcomed the statement in that report about making sure care is provided on the basis of need, not age. That's a real concern of the Executive: the continuing allegations of ageism, especially in the NHS. Providing services according to individual need is a point that must be re-inforced across the entire spectrum of health care.

That's underlined by the fact that palliative care is not the preserve of the elderly. It is a sad fact of life that adolescents and young children may also need palliative care. Again, not just for cancer, but for other chronic conditions such as cystic fibrosis, muscular dystrophy and heart, liver or kidney failure. I applaud the work that is being done to identify the palliative care needs of these young patients.

The Executive also welcomes efforts to raise awareness of what palliative care actually is. You don't need me to tell you that's not an easy task. The word 'palliative' is certainly not well understood. And it's not easy to define. All too often, it's still thought of in narrow terms as care of the dying.

Of course, that's a key part of it. But we need to work together to make clear its wider application, from the time of diagnosis onwards.

Health Boards and local authorities are two of the key bodies in this process. We must make sure that Health Improvement Programmes, Trust Implementation Plans and Joint Community Care Plans reflect the palliative care approach in its broadest sense.

One of the key ways of moving this forward is to make sure those in the voluntary sector involved with palliative care are included in Health Boards' discussions about their HIP. The model is the way the voluntary sector is involved in developing Joint Community Care Plans.

That's why we were pleased to fund the Hospices as Resource Centres pilots: to help the process of raising awareness of palliative care and specialist palliative care.

We're analysing the results at the moment, and hope to be able to roll them out across Scotland. I hope that, in doing so, we'll be encouraging Health Boards to develop an appreciation of the wide range of expertise palliative care has to offer.

I've touched on hospices, so this is probably a good place to say something more about them and their funding. The majority of specialist palliative care in Scotland is of course provided by the voluntary hospices. That's by no means to underestimate the value of the work of specialist palliative care units within the NHS.

If the voluntary hospices are to remain in the vanguard of service developments, you need to be funded at levels which allow you to provide agreed services. You need to have the security to plan future developments. We know that hospices are having to cope with increasing referral rates, and are seeing patients with increasingly complex problems. Services have, as always, been quick to respond. We want that to continue.

The hospice funding agreement was intended to provide hospices with the financial security they need, through the development of services in partnership with Health Boards.

The target that Health Boards should meet 50% of agreed running costs remains in force. It is now over 10 years since the scheme came into effect, and naturally hospices' work has expanded during that time. I therefore welcome the joint efforts by the Department and the Scottish Hospices Forum to review the baseline against which the 50% target should be calculated.

The Executive welcomes the recognition that new costs could fall into one of three categories. There are developments which a hospice wishes to push ahead with, and is willing to pay the full cost of doing so. There could also be developments which the Health Board wishes to take forward, and would similarly meet 100% of the costs. And there are developments, agreed through the HIP process, which the Health Board and hospice formally agree should be funded by them equally. This recognition promotes partnership without inhibiting innovation.

Let me turn now to quality of services. The palliative care approach has shown how standards can be raised. The Executive welcomes the experience which you have been able to bring to the work which the Clinical Standards Board for Scotland is taking forward in piloting standards for palliative care.

We need to get the essentials of the service right. At the very least, we must make sure that all patients get rapid access to prescribed drugs and equipment, to ensure good symptom management. Those considerations apply above all when people are at home.

The palliative care standards are being fully incorporated into the standards for site-specific cancers: colorectal, lung, breast and ovarian. But in keeping with what's been said about the wider application of palliative care, the Standards Board is

clear that the palliative care standards are an underlying core principle of care for all patients.

I also welcome the fact that the Clinical Standards Board is developing national standards for specialist palliative care.

The way in which palliative care is organised at present comes very close to the concept of Managed Clinical Networks. You already fulfil most of the basic principles. You have a wide range of professionals working together. You have the patient's voice at the heart of what you do. You offer services in a very diverse range of settings. You communicate well. You co-operate with one another.

So I was delighted at the positive response to the Department's invitation to think about taking that step further, to see whether you could formalise those good working practices in a Palliative Care Network. I know how much work went into your report. It admirably sets out the case for pilots in a number of contrasting areas across Scotland. The bids that have been received are a clear indication that those of you who provide palliative care endorse this approach.

The list of improvements which should flow from these Networks are at the heart of what we are all trying to do:

- Increased satisfaction of patient choice
- Improved communication
- Improved access to specialist services
- Greater continuity of care
- Feedback for health professionals on their performance

The main reason for embarking on any Network development is, of course, the benefits to patients. You have rightly identified management of pain as the first priority for these Networks. This is the best way of responding to the evidence that pain relief is not uniformly as good as it should be.

The publication in the autumn of the SIGN Guideline on the Control of Pain in Patients with Cancer provides the evidence base. Again, it builds on traditional thinking. It highlights the complex reality of the relationship between cancer and pain. The Networks' initial focus on pain will enable a natural progression to cover other aspects of palliative care. I was pleased to see the reference in the Guideline to the role of Managed Clinical Networks in palliative care in helping implement the principles of good practice in effective pain management.

The development of Managed Clinical Networks is just one example of the ways in which we're trying to modernise the NHS.

You hear a lot from the Scottish Executive about modernisation, about modern health services. But all too often, people think that has to mean hi-tech equipment, or new buildings. That's certainly part of the modernisation process. We are, for example, making sure all hospices are connected to the NHS Net.

But the Executive wants to get across the message that a modern Scotland is also a caring Scotland. That's one of the keys to making us a country to be proud of. Modernisation of the NHS is not just about the acute sector. It's about making all services more patient-centred and

responsive. An NHS which values the views of patients, listens to them, and acts on them too.

The Scottish Parliament gives added impetus to that process. It provides the opportunity to build a society which values everyone. Which treats them as a unique individual. Which makes them feel included. Asks people what their needs are, listens to what they say, and then takes steps to meet those needs.

Palliative care shows that those aspirations can be put into practice, if we have the imagination and commitment.

The Parliament has demonstrated its willingness to listen through the speed with which MSPs have set up a Cross-Party Group on Palliative Care. It will provide a valuable mechanism for keeping the subject in the public eye. The debate Michael McMahon secured on 21 September, for example, has already helped to raise awareness about

current issues in palliative care within the Parliament, and therefore with the public.

Perhaps the thing we should value above all is the role of palliative care in restoring to medicine a human face. One of the things it needs to learn is to face up to people's emotions. Avoiding those emotions stems from the traditional attitude that doctors have failed if they can't provide a cure. You are showing us the limitations of that attitude, and that we can move beyond it.

The title of your conference is well chosen. Sharing best practice is one of the keys to success. That is one of main reasons we want to draw up a Scottish Health Plan. It's a way of taking good ideas from one part of the country and applying them across Scotland. It will have sections on the priority areas, and I can give you a guarantee that it will recognise the vital contribution of palliative care. "

## **Palliative Care for People with Advanced Heart Disease**

### **Dr Frank Dunn, Consultant Cardiologist**

Dr Dunn spoke about his experience of incorporating palliative care into the treatment of cardiac failure, pointing out that palliative care has an important place, integral in the care of people with this condition. As opposed to cancer treatments, chances for cure for this group of people are slim.

Cardiac failure affects 1-2% of the adult population and mortality is higher than in many forms of cancer (60% annual mortality with grade 4 heart failure and an overall five year mortality of 80% in men).

Cardiac failure is similar to cancer in that patients can experience the following conditions:

- Breathlessness, lethargy, cachexia, nausea, anorexia, abnormal taste
- Weight loss (loss of muscle mass countered by fluid retention), constipation
- Poor mobility, insomnia, confusion, depression
- Dizziness, postural hypotension, cough
- Jaundice, susceptibility to infection, polypharmacy, abnormal liver function test
- Fear of the future

Cardiac failure differs from cancer, however, in that:

- Pain not a major problem, there is less need for opioids (advances in antianginal therapy and interventions have reduced the importance of pain as a common characteristic of cardiac failure)
- Predicting life expectancy can be difficult
- Oedema a more common characteristic
- Patients are sometimes relieved to receive a

diagnosis of cardiac failure rather than cancer because they mistakenly consider it as being a less harmful condition

- Anaemia not usually a feature

#### **Management**

- Home care for advanced cardiac failure. Patients with advance cardiac failure face frequent admissions to hospital. Cardiac liaison nurses similar to Macmillan nurses would reduce the number of admissions by discovering worsening clinical features early and by ensuring that patients' homes are equipped with the necessary requirements
- Dietary advice is important since patients may be obese or cachectic
- Reducing fluid intake to 1500ml a day and avoiding very salty foods (but maintaining taste) will help in controlling oedema
- Exercise, individually planned, may lessen breathlessness and improve both quality of life and psychological wellbeing
- Drug treatment is mainly aimed at symptom relief. Opioids, combined with antiemetic drugs; diuretics; angiotensin converting enzyme inhibitors and digoxin are known to improve symptoms in advanced heart failure. Sublingual glyceryl trinitrate is helpful to relieve breathlessness. Influenza and pneumococcal vaccination should be considered, even in advanced disease

#### **Symptomatic management of advanced heart failure**

- Breathlessness – oxygen, opiates, diuretics, digoxin, vasodilators and non-drug measures (fan, positioning, explanation, psycho-social care)

- Muscle wasting – physiotherapy, assess diet and energy intake
- Fatigue – reassess drug regime
- Lightheadedness – check for postural hypotension, check for drug induced hypotension
- Nausea, abnormal taste, anorexia – check drug treatments and liver function, offer frequent small meals, appetite stimulants, such as a small amount of alcohol and possibly metoclopramide.
- Oedema – detect early, loop diuretics, restrict fluid, mild salt restriction, bed rest in early stages – if out of bed raise lower limbs, monitor electrolytes.
- Better, early detection and control of oedema.
- Improved recognition of need for psychological support and counselling. Counselling can be difficult under these circumstances because of the high incidence of sudden death (up to 50%) and patients' misapprehensions about the condition. The principles of palliative care can certainly be adopted to improve and maximise the quality of life of this group of people.

#### Reference

*ABC of palliative care: Non-malignant conditions*

Tony O'Brien, John Welsh, and Francis G Dunn

BMJ 1998; 316: 286-289

[www.bmj.com/cgi/content/full/316/7127/286](http://www.bmj.com/cgi/content/full/316/7127/286)

Dr Dunn concluded by saying that the future of palliative care in advanced cardiac disease should include:

- Development of clinical specialist home support nurses to reduce need for hospital admission.
- Improved understanding of pathophysiology and treatment of nausea and cachexia.

### Multi-professional and Inter-disciplinary Working Jo Hockley, Research Fellow/Clinical Nurse Specialist

Jo Hockley, Research Fellow/CNS at St Columba's Hospice, Edinburgh talked about multi-professional and inter-disciplinary working. Most of her research had been carried out in a hospital setting.

The concept of a **team** is a group that has a task or tasks, the accomplishment of which requires the interdependent and collaborative efforts of all members (Dunlop & Hockley, 1990).

Within the healthcare delivery system staff have more to deal with than just patients and families. 48% of environmental stress derives from the work environment (Vachon 1987, 1995). Stressors include: problems with the actual healthcare system, for example pace of work and physical environment, inadequate resources/staffing, communication problems within the team, the immediate locality and outside system, intra-group and inter-group conflict. The occupational role gives rise to 29% of stress. This is due to role overload, role expectation, role ambiguity and role conflict. Although a degree of stress is good, to avoid conflict staff should set the expectations of their roles and

communicate them to others within the team.

To promote effective teamwork a civilised structure should be developed with, for example, a daily meeting to discuss clinical issues, a weekly organisational meeting and monthly reflective meeting. These would allow for full multi-disciplinary team participation, staff support, team motivation and social interaction. When teams have co-ordination without co-operation, they will only go so far (Heming, 1986). A team however, needs time and stability to build a good working relationship.

Ajemain (1993) describes the characteristics of the effective team as being: stimulating, spurring individual members to greater achievement, fun with members enjoying a sense of belonging, civilised structure encouraging members to submerge their individual aspirations in a larger objective, certain conformity but not uniformity, members sharing their vulnerabilities as well as their strengths, difficult conversations being conducted face to face, "working with" existing health care teams and not over stepping the *advisory* role and sharing difficult decisions.

In conclusion essential components of effective **TEAMWORK** are: working together as a team, supporting and encouraging other team members and learning from each other (Dunlop & Hockley 1990).



Jo Hockley  
Research Fellow/Clinical Nurse Specialist  
St Columba's Hospice

## **The Community Hospital as Focal Point for Palliative Care in a Rural Area**

### **Dr Paul Cormie, Macmillan GP Facilitator**

Dr Paul Cormie presented an overview of the provision of palliative care in community hospitals in the Borders. The community hospital, in areas where there are no hospices, as is the case in the Borders, is the main inpatient resource for palliative care. The community hospital can also be an alternative place of admission where there is a hospice and an alternative to home discharge from a hospice or district general hospital. The community hospital provides care close to a patient's home, family and friends. It also provides continuity of care with the patient's own primary health care team. There is an increasing recognition of the palliative care needs of people with conditions other than cancer, many of whom may be cared for in the last stages of their life in the local community hospital.

Recent research (British Journal of General Practice 1998) compared the delivery of palliative care in a community hospital and a hospice. Of the carers interviewed 90% felt that the "total care" received by the patient and themselves was excellent or good in the community hospital (hospice 100%), however, 40% of carers felt that improvements were possible. The authors of the research expressed the view that it was not surprising that hospices rated higher than community hospitals as the latter had a mixed caseload, a much lower trained nurse/bed ratio, nurses with fewer relevant qualifications, and fewer purpose-built buildings.

To improve standards of palliative care in community hospitals in the Borders the audit group looked at previous research, audits, and the SPA report Palliative Care in Community Hospitals and, in conjunction with other interested parties, assessed the palliative care provision in local community hospitals.

An assessment form was circulated and the following action points were identified:

- Formation of a multi-disciplinary subgroup of the Borders Community Hospitals Strategic Planning Group to investigate, plan and implement new developments, protocols and standards for palliative care
- The identification or appointment of a first level registered nurse with palliative care skills and responsibilities as recommended in section 5.1 of the SPA report
- A co-ordinated ongoing education programme in palliative care
- A relatives' room/quiet room in each community hospital
- A minimum of one single room with ensuite facilities in each community hospital
- Local guidelines and standards for palliative care should be drawn up in conjunction with the local palliative care service
- Current examples of good practice should be shared
- The involvement of community nurses in care and discharge planning whilst patients are in hospital
- Education and/or guidelines for staff on when to call in relatives to a dying patient
- A protocol identifying the circumstances when nursing staff levels should be augmented
- A policy on contacting a patient's spiritual adviser/Minister
- If the voluntary sector is to be utilised then a policy should be developed as to how this should be done.

#### Further information

The full report on "Palliative Care in Community Hospitals in the Borders" is available on *in touch*, Scottish Borders palliative care website at [www.in-touch.org.uk/Palliative Care in Community Hospitals in the Borders2.htm](http://www.in-touch.org.uk/Palliative%20Care%20in%20Community%20Hospitals%20in%20the%20Borders2.htm)



## **An Integrated Care Pathway for Palliative Care Marilyn Cringles, Project Co-ordinator/Home Care Sister**

Marilyn Cringles, Co-ordinator of the Integrated Care Pathway (ICP) Project presented a summary of the development of the project. The Greater Glasgow Health Board's Health Improvement Plan 1998-2003 included for palliative care ... "a strategy to implement services between Primary and Secondary Care." The participating organisations, the Prince & Princess of Wales Hospice, Greater Shawlands LHCC and South Glasgow University Hospitals NHS Trust, formed a Steering Group and obtained funding from the Primary Care Development Fund. The Steering Group carried out a needs assessment which identified an ICP as the most useful mechanism for the project with documentation to be held within a Patient Held Record and pain control as the most universal area of concern for patients and professionals. A postal questionnaire confirmed the lack of use and understanding of pain assessment tools and WHO analgesic stepladder guidelines.

An education pack was prepared prior to the pilots being implemented. The pack included a pain algorithm and guidelines, syringe driver compatibility, referral protocols and a patient held record incorporating ICP

documentation and criteria for entry into the ICP. Permission was sought from the patient and the medical practice before entry into the ICP. Two pilots ran simultaneously and included seven wards in the acute sector, 13 GP practices, ward/home care/day care in the hospice, and a nursing home. Further funding from the Greater Glasgow Health Board will enable the pilot to be rolled out to other wards and other LHCCs within the South Sector.

All documentation will be returned for evaluation. The ICP documentation has an inbuilt audit with variance and outcome codes; a staff questionnaire, a patient interview/questionnaire (when appropriate), guidelines and documentation will then be reviewed and amended accordingly. The initial evaluation has indicated that patients feel more informed and involved in their care, communication with healthcare professionals was improved, and there was uniformity of care using evidence based and best practice guidelines.

In response to questions from the meeting Marilyn Cringles said:

- The use of a Patient Held Record within the ICP had been very positive with patients and with community staff but to date

there had been less of a take up in the hospital setting. Education of ward staff would be vital to the success of the project before it is rolled out in other areas

- The Working Group had looked at other symptoms and conditions but realised it would be too large a task to attempt to cover the entire palliative care episode and it was better to initially concentrate on one specific area—pain, especially with the availability of SIGN Guidelines
- At the moment as the project was working across boundaries duplication of documentation occurred. It was hoped, however, the benefit of the ICP will outweigh the occurrence of duplication. With the advent of CSBS standards and Clinical Governance everyone will have to comply with guidelines. The ICP could be the working tool for implementation of these guidelines on a day to day basis

The pilot would end in March and an audit would be carried out before it was extended to other areas.

## **Developing Links between Specialist Palliative Care and Nursing Homes Lyn Fergus, Clinical Nurse Specialist**

Lynn Fergus gave a presentation on the two year Scottish Office funded project which began in December 1998. The project aimed to improve patient care by increasing nursing awareness of the principles of palliative care through equipment, training, liaison and referral to the specialist palliative care team based at Hunters Hill Marie Curie Centre. Links were initially established with 16 nursing homes in the Glasgow area and eventually increased to a total of 35.

The patient sample focussed on 30 patients, 23 of whom had a cancer diagnosis and some of whom had non-malignant disease. 16 of the evaluated patients also suffered from confusion or dementia.

The largest percentage of referrals to specialist palliative care came from qualified nursing staff none of whom had

known previously that they could refer patients, subject to GP permission.

Various tools were used in evaluation. These included the Palliative Care Outcome Scale (POS) which was used at first (before the involvement of the palliative care team) and third assessment. Several patient/relative interviews were carried out. Questionnaires were sent out to all nursing home staff and GPs involved in the care of evaluated patients two weeks following the patient's death or discharge.

Results of the clinical evaluation showed that pain issues were identified as the main reason for referral. Communication between nursing home staff and the palliative care team was good. Welcome support had been provided by the Primary Care Trust to nursing homes and overall many of the results were positive.

## **Cardio Pulmonary Resuscitation in Specialist Palliative Care Dr Clive Preston, Consultant in Palliative Medicine**

Dr Preston outlined the background to the development and audit of the Cardio Pulmonary Resuscitation (CPR) policy within the Victoria Hospice. The hospice had opened in September 1996 without a CPR policy in place. In November 1996 the need for a policy was discussed as no Trust CPR policy was available. A group was formed to formulate a policy and agreed that CPR would not be carried out during this period but that the doctor on call would be called immediately. The policy was produced in July 1997 and agreed and implemented in October 1997.

Audit of the Resuscitation Policy ran from July 1998 to January 1999 and included all patients admitted to Victoria Hospice. CPR was discussed with every patient wherever possible, entries made in the patient's notes and page 1 of the assessment form completed by the admitting doctor. Page 2 was passed to the named nurse for each patient for follow up discussion 24 hours later. The nurse then completed the form and returned it to the Doctor's office.

### **The completed forms were then analysed to determine:**

- If CPR had been discussed with patients wherever possible
- The number of patients requesting CPR
- The perceived reactions of patients to the discussion of CPR at the time
- The patient's own reactions to the discussion after a period of reflection
- Any changes in patient's views regarding CPR within the first 24 hours after admission

### **Conclusions**

- It was possible to discuss the CPR policy with 2/3 of patients on admission to the Hospice
- The majority of patients were not distressed by discussion of cardiopulmonary resuscitation
- At the time of admission CPR was requested in 10% of cases
- Discussion of CPR often led on to other concerns the patient had about their disease being aired.

## **Moving Palliative Care up the Local Agenda Brendan Gill, Director of Planning and Dr Chris Sugden, Medical Director**

Brendan Gill opened the workshop by explaining the background to palliative care planning in Lanarkshire. Local planning of palliative care services involves discussions with the NHS, hospices and voluntary agencies. Previous planning had taken place under the guidance of the National Panel for the Care of the Dying and the Bereaved with each Health Board having a local task force. This arrangement came to an end in 1997. The current framework for palliative care planning involves guidance on priorities and planning, health improvement programmes, trust implementation plans and SPA networks.

Dr Sugden acknowledged that the Lanarkshire Palliative Care Planning Group was very useful not only to the hospice but to the health board area as a whole. There is now specialist palliative care in all three hospitals in the area.

He went on to describe the Care at Home Scheme which is run from St

Andrew's Hospice Airdrie. This service was set up to facilitate the care of terminally ill patients in the final stages of cancer or motor neurone disease, by enabling:

- The patient to remain at home
- Discharge from hospital to home
- Discharge from hospice to home

It is a flexible service that reflects the changing needs of the patient and their family and aims to avoid the duplication of existing services. It is designed to provide additional nursing care to these patients during the last few days of life when patients and families require most support.

A total of 139 patients, with the agreement of the patient and carer and consent of GP and District Nurse, were referred to the service between April 1999 and March 2000, an average of 11.6 per month. The scheme is staffed by a full-time G grade co-ordinator, a

part-time E grade staff nurse, hospice nursing auxiliary and staff nurses.

Evaluation of the service revealed that benefits to clients and families were usually evident, with the provision of a vital contribution to support of patient and family. There were modest benefits to NHS in avoiding admission or enabling discharge. Benefits of the service justified the cost. The service provided a valuable, timely and flexible response and formed part of a patchwork of care and has received a positive evaluation from local district nurses.

Due to the constraints of available resources, the service can only be provided to patients in the Airdrie/Coatbridge area. People from outside the Monklands area being treated in the hospice cannot at present benefit from the scheme.

Possible future developments include: prospective patient centred audit (POS), further qualitative audit, overnight community nursing service, GP education, and roll out of the scheme throughout Lanarkshire.

**Peer Review Audit of Hospital Palliative Care**  
**Dr Kirsty Boyd, Consultant in Palliative Medicine, Stephen Smith, Clinical Nurse Specialist and Joan Adam, Macmillan Nurse Specialist**

Quality assurance should be intrinsic to the delivery of Specialist Palliative Care Services so that standards of clinical practice are both maintained and evaluated as part of clinical governance. Peer review of specialists by colleagues from the same specialty ensures that assessments are undertaken by professionals who are able to compare the service being delivered with current best practice in that specialty. This is particularly important in Palliative Care where the process of care involves a high level of communication skills and the interaction between professional and patient/family is a core element. Outcomes can be hard to quantify and measurement using questionnaires or rating scales may be difficult and lacking sensitivity. In the acute hospital setting, many patients have advanced disease and complex problems, which compounds the difficulty of incorporating a process of care evaluation.

In 1998, the palliative care teams from the Royal Infirmary of Edinburgh and

St John's Hospital Livingston set up a system of peer review using the Scottish Partnership Agency National Core Standards for Specialist Palliative Care (1997). Standards for symptom management; patient information/psychological support; family/carer support; bereavement care/support; education other professionals and specialist team education were adapted to reflect the staffing and other structural aspects of each team and setting.

The audit process involves interviewing palliative team members, observation, witnessing interviews and reviewing casenotes of a sample of current patients, selected by the auditor.

During the first planned audit day at the Royal Infirmary of Edinburgh it became clear that it was not realistic to try to cover all of the standards in one day. It was decided therefore to commence an ongoing rolling programme of reciprocal audit visits, taking place quarterly, reviewing two standards at each visit (one clinical and one non-clinical).

Following an audit a written report is produced. The host team can then review the audit results and changes in practice can be made, to complete the audit cycle. Both teams meet periodically to review the standards and the audit programme. The audit process continues to be seen very positively by all the participants and has improved working relationships between the teams.

To be successful, local agreement should be reached on the applicability of the standards to the care setting under review. Trusts must also agree to meet the standards laid down. Scoring of observation is a time consuming process and sufficient time must be allocated to allow for meaningful analysis. Evaluating clinical practice is part of the remit of managed clinical networks. Peer review by members of the network was discussed by workshop participants and considered one of the best ways of doing this.

**Improving Public Understanding of Palliative Care**  
**Dr Derek Doyle OBE, Hon Vice President, SPA**

Dr Doyle opened the workshop by saying that "the public", for the purposes of these discussions, will be the general public, the politicians and the media. He raised many questions about the advantages and disadvantages of informing the public about palliative care. These included:

- Do we need to inform the public? Is there any evidence to suggest that they want or need more information?
- What good will be achieved by informing them?
- What negative effects might there be to informing them?
- What information might we want to give them (as distinct to replying to questions)?
- How would we set about informing them?

A spirited debate followed. Issues that were raised by the group were focused around the reasons for raising awareness. These included whether we would be raising awareness with a view to raising funds for voluntary palliative care providers, to advise people what to ask for when problems arise, or to alert people who are affected by life threatening conditions to services that are available to them.

It was suggested that the SPA could have an information officer or employ a PR firm to ensure that public awareness messages are delivered in a way that would be acceptable and clearly understood by the public. Suggested means of informing the public about the values of palliative care included running an information video in GP waiting rooms or on television. This approach was said to be used successfully in Ireland.

## **The Scottish Pain Audit - Discussion of Findings**

### **Dr Marie Fallon, Consultant in Palliative Medicine**

Dr Fallon presented an overview of this audit, the aims of which were to determine the prevalence of pain in patients with active cancer, to determine the level of their pain and to correlate this with the degree of compliance with analgesic prescribing guidelines.

The audit was undertaken using a cross-sectional point prevalence study design. A total of 953 patients of both genders, whose ages ranged from 19 to 95 years, were recruited to the study from community, in-patient oncology centres, acute hospitals and specialist palliative care units in Scotland. Subjects included in the study had active cancer, were mentally competent and capable of giving written informed consent. Patients who were less than 10 days post operative, patients with leukaemia and patients with non melanotic skin cancers were excluded from the study.

#### **Conclusions**

Pain prevalence in the study was 58.2%, with the highest prevalence and severest pain being reported in specialist palliative care units. Specialist palliative care units' compliance with standards, however, was greater than other settings.

There was significant correlation between increased pain severity and adherence to analgesic standards. Only three standards were met in more than 90% of patients. The main deficiencies were around simple issues such as failing to ensure that analgesia was given regularly and in therapeutic doses, failing to prescribe laxatives, and inadequate prescription of NSAIDs and adjuvant analgesics.

#### **In discussion:**

A member of the audience suggested that the correlation between increased pain severity and adherence to analgesic standards raised issues about the validity of analgesic standards. Dr Fallon replied that use of WHO guidelines will control pain if applied properly, with due attention to other methods of pain control. This audit was not carried out to validate the WHO standards and gave no measure of the sophistication of their use. The audit was a point prevalence study and was not carried out under controlled conditions. It cannot therefore be said to accurately reflect the true picture. It is also possible that hospices are inheriting patients with early, uncontrolled pain and resultant neuroplasticity, which may have influenced the results. It may be useful to work through managed clinical networks to encourage practitioners to follow guidelines for pain management. There was no significant relationship in the community between pain control and homecare input.

Pain control is a very complex area. If the study is used only to produce guidelines they are unlikely to be effective on their own. It is necessary to think laterally and look at fundamental issues behind the pain. Older people may believe that cancer pain is inevitable. Patients, carers and professionals may be afraid of opioids. Pain can be influenced without the use of drugs e.g. talking to people, giving them time, listening, feeling cared for can all have an effect on the pain experienced. Studies can be an oversimplification.

## **Poster Presentations**

#### **"In Touch"**

Elaine Peace and Patricia McMahon  
Palliative Care Dept, Borders General Hospital

#### **"Putting a Patient Centred Medicine Administration System into Practice"**

Irene Hillsden and Claire Hastie  
Roxburghe House, Dundee

#### **"Pressure Sore Risk Assessment in Palliative Care"**

Jackie Chaplin and Maria McGill  
Hunters Hill Marie Curie Centre, Glasgow

#### **"Family Centred Care in a Childrens Hospice"**

Andra Cail  
Rachel House, Kinross

#### **"Nurse Led Admissions in Palliative Care"**

Janie Neilly  
Ayrshire & Arran Primary Care Trust

#### **"Developing Guidelines for Symptom Control in Palliative Care"**

Patricia O'Gorman  
Glasgow Royal Infirmary

#### **"The Bridge's Initiative"**

Jo Hockley  
St Columba's Hospice, Edinburgh

#### **"Hospice at Home Pilot Project - The First Year"**

Anna Grady  
Hunters Hill Marie Curie Centre, Glasgow

#### **"Benchmarking Daycare Services in Palliative Care"**

Pauline Farr  
Hunters Hill Marie Curie Centre, Glasgow

#### **"Dying at Home - Community Services Project"**

Gail Edgar and John Fox  
Medical Social Work Dept, Dumfries

## **The Scottish Partnership Agency for Palliative and Cancer Care**

The Scottish Partnership Agency (SPA) is the national umbrella and representative body for palliative care in Scotland. It aims to promote the development, extension and improvement of palliative care services and to ensure that high quality care is available throughout Scotland for people with life threatening conditions and their families.

**The SPA has a membership of 74 voluntary and statutory organisations involved in the provision of palliative and cancer care. They include:**

- Hospices and Specialist Palliative Care Services
- Health Boards and NHS Trusts
- National Charities & Patient Support Organisations
- Associations of Health Professionals

**Through the SPA member organisations work in partnership to:**

- share information and expertise
- communicate on palliative care issues to the appropriate committees and departments of the Scottish Executive
- develop and publish guidance on all aspects of palliative care
- collaborate in joint action
- collaborate with the National Council for Hospice and Specialist Palliative Care Services on UK-wide issues.



**SCOTTISH PARTNERSHIP AGENCY  
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