

Palliative care for all

Responding to need not diagnosis

Report of a conference of the
Scottish Partnership for Palliative Care
21 November 2001

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Palliative care for all

Responding to need not diagnosis

The Scottish Partnership Agency for Palliative and Cancer Care (SPA) held its 10th anniversary conference “Palliative care for all – Responding to need not diagnosis” at Inchyra Grange, Polmont on 21 November 2001. At its AGM on the same day, the SPA changed its name to the Scottish Partnership for Palliative Care to reflect its commitment to the new wider agenda of palliative care for all.

The conference was attended by 185 delegates from NHS boards and trusts, universities, hospices and voluntary organisations. The delegates included representatives from a wide a range of professions and disciplines including medicine, nursing, chaplaincy, occupational therapy, pharmacy and social work. They were working not only in palliative care but in children’s services, geriatrics, dementia services, neurology, oncology, primary care and psychiatry.

Delegates evaluated the day highly, rating it as informative, interesting and extremely helpful in exploring the issues around palliative care for people with conditions other than cancer.

Speakers from a variety of disciplines highlighted the unmet palliative care needs of people with a range of non-malignant conditions and addressed the challenge of how to make palliative care accessible to all. Key themes emerged from a number of the conference presentations, in particular the common need for pain and symptom management across a range of diseases, and the universal relevance of open, honest communication, and of holistic care and family support. A number of speakers pointed to the huge task which lies ahead for palliative medicine in training and sharing expertise with specialist and generalist practitioners from different fields.

Sir Kenneth Calman, Hon President of the Scottish Partnership for Palliative Care, opened the conference and spoke of the importance of the Partnership’s links with all those local and national organisations which share its aims of improving the provision and quality of palliative care in Scotland. Keynote speakers included Michael McMahon, MSP, Convenor of the Cross Party Group in the Scottish Parliament on Palliative Care and Dr Mac Armstrong, Chief Medical Officer for Scotland. Both emphasised the political commitment to extending palliative care outlined in the Scottish health plan, the Scottish cancer strategy and the coronary heart disease/stroke task force report. Dr Armstrong particularly welcomed the Partnership’s change of name as a signal that the organisation is ready to embrace a new wider focus for palliative care.

The conference also heard a presentation by Benn Jupp of the New Opportunities Fund on NOF Opportunities for Palliative Care Funding. Guidelines for the new programme in Scotland will be published by the New Opportunities Fund in May 2002.

Dr Derek Doyle, Hon Vice President of the Scottish Partnership for Palliative Care, concluded by reminding delegates that it had taken decades, and the overcoming of many difficulties and negative attitudes, to reach the current level of palliative care provision for cancer patients. We should not be overwhelmed by the task ahead, but be realistic in our objectives and recognise that progress can be achieved by a steady series of small but worthwhile steps. Like Sir Kenneth Calman and Dr Armstrong, Dr Doyle was confident that the Partnership would provide the leadership to take this challenging new agenda forward.

Acknowledgement

The Scottish Partnership for Palliative Care acknowledges with thanks the support of the Scottish Executive Health Department in making possible both the conference and the production of this report.

Welcome

and introduction to the conference

Sir Kenneth Calman, KCB, Honorary President of the Scottish Partnership for Palliative Care

Sir Kenneth Calman, Honorary President of the Scottish Partnership for Palliative Care opened the conference by welcoming delegates and thanking the Scottish Executive for their sponsorship of the event. Sir Kenneth said how delighted he was to be present to celebrate the SPA's tenth anniversary, and used his opening remarks to set the occasion in context and acknowledge the developments of the past ten years.

The SPA is an umbrella organisation, which over the years has developed effective links with agencies at local and national level, including the Scottish Executive, and has worked with them to ensure improved quality and wider availability of palliative care services in Scotland. The SPA has always been about meeting the needs of patients and families, about identifying areas for improvement and improving the quality of care, and about promoting partnerships.

Over the last year many people have worked hard to ensure the inclusion of the SPA's proposals for palliative care within the Scottish Cancer Plan. As a

result the Plan contains a dedicated chapter on palliative care, decisions have been influenced at all levels, and we can see the beginnings of proper investment in palliative care through Regional Cancer Advisory Groups. Another important development has been the SPA's joint work with the Clinical Standards Board for Scotland to develop national standards for Specialist Palliative Care.

The current priority, and the focus of this conference on Responding to need not diagnosis, is to widen access to palliative care beyond cancer, and to ensure that the same level of palliative care is available to people with other conditions. This will take time to achieve, in the same way as cancer services took time to develop, and the SPA will need to provide the leadership to take this work forward. The political dimension is also crucial, and the SPA's work with the Cross Party Group on Palliative Care in the Scottish Parliament is important in maintaining strong links with MSPs and ensuring that our political colleagues recognise that this is an area which needs attention.

Palliative care for all

A Politician's View

Michael McMahon MSP

In my role as Convenor of the Cross Party Group on Palliative Care, I have had the opportunity to meet and listen to health professionals, volunteers, patients and families on issues surrounding palliative care. I have found this a richly rewarding experience, but have also experienced a great deal of ignorance about palliative care. I am committed to securing political support for the expansion of palliative care, but before we can achieve this expansion we must improve understanding of palliative care. To do this we have to work together to raise the profile of the “good work” being done and highlight the aspirations which exist in our hospitals, hospices and home care services.

Palliative care is all about responding to need. That is what the Scottish Parliament should also be about. MSPs have a duty to take the issue of palliative care for all forward and ensure that our Health Service in the future addresses shortfalls and meets individual requirements, regardless of particular diagnosis. Much good work has taken place for people with illnesses such as cancer, multiple sclerosis, motor neurone disease, dementia, Parkinson's disease and HIV/AIDS but much more has to be done. The Scottish Executive and the Parliament has played a part in taking things forward so far but have a duty to ensure that more is to follow.

Palliative care should be available to everyone who requires it. This would entail educating people through all available mediums, and the key to making this happen is partnership – partnership between local and national government, between public and private bodies, and between professional and voluntary organisations. This already happens, for example in the way the Scottish Parliament and Scottish Executive are working together with and seeking advice from agencies such as the SPA and the Children's Hospice Association, and in the ongoing negotiations with Health Boards regarding funding of hospices. Funding will always be a major hurdle and we have to make sure that the requirements of palliative care are taken fully into account when the limited cake is shared out.

The Cross Party Group can act as a channel of communication between the Scottish Parliament and people working in palliative care. It provides opportunities for MSPs to learn about needs, to learn about reasons behind the problems faced, and to identify clearly the concerns of the people involved. This process identifies shortfalls in the system, increases awareness, raises the profile of important issues and hopefully leads to the improvements needed to go forward in the future. By keeping in close contact with the SPA and similar organisations, the Cross Party Group is able to provide a voice to those who need it. Parliamentary debate has been instigated and parliamentary questions put forward, culminating in direct influence on legislation and government policy making. One example of this influence is the Regulation of Care (Scotland) Bill, which includes hospices and palliative care as services to be covered by the new regulatory system – a welcome change from the previous regulation of hospices alongside nursing homes.

If our new Parliament is about anything, it must be about equality of opportunity and provision. Priority must be given to the search for an equality-based health service. The Parliament must be about consensus and co-operation, and about giving a voice to the people, and to the patients, of Scotland. Things have, I hope, improved in relation to communication, information and profiling of palliative care issues, but there is still a long road ahead to meet the ever increasing range and growing complexity of palliative care needs.

In conclusion, I should like to state once again my full and utmost support for palliative care initiatives and assure you that I will do all I can as a political representative to ensure that the palliative care issues raised at this conference will be thrust at the forefront of Parliamentary business in the future. I should also like to commend and congratulate all the hard working, dedicated individuals who provide their time willingly and generously, with professionalism and enthusiasm. Working together, I am sure we can continue to look forward with the hope of a brighter future ahead.

Responding to need not diagnosis

Cardiac Failure

The experiences of patients and their informal and professional carers

Dr Scott Murray, Senior Lecturer and Dr Marilyn Kendall, Research Fellow, Department of Community Health Sciences, University of Edinburgh

Introduction

Cardiac failure is a neglected condition in life and in death, whose prevalence is set to increase dramatically and which involves discomfort and distress which is often worse than that experienced by people with cancer. Provision of end of life care for people with cardiac failure however lags far behind that provided for people with cancer.

There has been no previous prospective study of patients' and carers' experiences and needs. The aims of our study, which was funded by the Chief Scientist Office of the Scottish Executive, were:

- To construct a patient and carer centred account of changing physical, psychological, social, spiritual and information needs over the course of the illness.
- To explore patterns of service provision and factors which influence the uptake of services
- To compare issues facing patients with severe heart failure and lung cancer, and their need for generic and specialist palliative care services.

Twenty patients with inoperable lung cancer and 20 patients with end-stage cardiac failure were recruited in hospital. The study was conducted by semi-structured interviews every three months for up to a year with patients, informal carers, GPs and other key professional carers. Interviews were taped and transcribed and analysis was ongoing, guided by research questions and emerging themes and aided by Nvivo qualitative software and techniques of narrative analysis.

Results

A number of themes and paradoxes about living with heart failure emerged from interviews with patients and carers. People spoke of being unable to predict from one day to the next how they would be feeling "one day on top, next day under". They spoke frequently of setbacks "one step forward and two back"

Completed Interviews (from 20 patients in each disease cohort)

	Cardiac failure	Lung cancer
Patients	50	43
Carers	27	21
General Practitioners	28	23
Other professionals	2	7
Bereavement	5	13
TOTAL	112	107
Participants still alive at end of one year	9	6

and of the paradox of "looking good, feeling terrible". Living with heart failure was an endless cycle, not a linear progression as with the lung data, more a circling round "don't know what will happen next, he won't get better, and we don't know how long he's got".

People with heart failure lived in a shrinking social world where they were striving to keep up a social life "you can't do what you did before, things you took for granted are now an impossible dream, I feel useless". A sense of isolation, of loss and of frustration came through the interviews "I would give the world to be able to go out. It's hard watching the wife doing things you should be doing".

Patients talked of keeping the illness at bay, "quite happy as long as I don't get worse". Some had brushed with death, and thought they were going to die "I wouldn't have minded if I had, don't want to see another year like that" and spoke of their life not being worth living "It's a life but it's not much of a life. I'm ready for the knacker's yard".

Patients, carers and professionals saw life with cardiac failure as dominated by the need to try to balance different factors:

- physical activity with rest
- independence with dependence
- hope and realism
- good and bad days
- medicines, fluids, weight, blood tests
- “it’s a very fine balance I’m on”
- “we’re between a rock and a hard place”

They were living two different stories at the same time, preparing for two possible endings. One account was about survival, quality of life, being positive and fighting the illness. At the same time a parallel account was about how things might go very differently and about the burden of responsibility for managing an incurable illness with very little support.

How GPs see their role

Interviews with GPs revealed feelings of frustration, a lack of feeling of being in control and difficulties in explaining heart failure to patients:

- “Just the frustration that there’s not an awful lot we can do for people like him.”
- “It’s been less about illness, more and more about disability.”
- “But who knows what will happen from one day to the next, let alone from one week to the next.”

- “...he hangs on by a thread.”
- “I do see emotional and spiritual needs as part of my job but we don’t tend to talk about them.
- Death and dying... “I suppose I’m really expecting it to be something catastrophic, something that will come out of the blue, and so planning and discussing isn’t really an issue.”

GPs felt isolated and unsupported:

- “There is no-one else involved in his care beyond ourselves, the hospital and his family.”
- “I don’t think there are any others involved at the moment, just the cardiologists.”
- “I don’t know if she has a home help, it’s amazing how ignorant we are about things like that sometimes.”
- “Hospital A, I take a body-swerve around as much as I possibly can, em, because I think the care and communication there is appalling with us.”

GPs identified a need for support in the community for people with heart failure “often what you want is not so much anything terribly high-tec, as simply humane common sense”.

These comparisons point to a model for the care of people with cardiac failure which may be different from cancer. Such a model would take account of the fact that patients with cardiac failure are more prone to sudden death than patients with cancer and do not necessarily have a clearly defined terminal phase. A

Comparing the experience of cardiac failure with lung cancer

Lung Cancer	Cardiac Failure
◆ Cancer trajectory with distinct terminal phase	◆ Gradual decline with ups and downs, different “shape”
◆ Feel well, but told ill.	◆ Feel ill, but told OK
◆ Concern re diagnosis and prognosis	◆ Little understanding of diagnosis and prognosis
◆ “How long have I got?”	◆ “I know it won’t get better, but I hope it won’t get any worse”
◆ Benefits accessible eg. DSI500	◆ Less access to benefits
◆ Anxious relatives	◆ Relatives exhausted
◆ Swinging between hope and despair	◆ Daily grind of hopelessness
◆ Lung cancer overriding concern	◆ Many illnesses to cope with; heart often not seen as main issue
◆ Treatment calendar dominates life, many services and professionals	◆ Shrinking social world dominates life, little contact with health and social services
◆ Specialist services often available in the community	◆ Specialist services rarely available in the community
◆ Patients felt cherished	◆ Patients felt they were low priority in the system

dual approach may be required, with the possibility of death being acknowledged and discussed while active management is continued. However, good palliative care, enhancing quality of life, should not be a luxury only for people with cancer.

What is needed for people with severe cardiac failure?

Patients felt they needed:

- a key person whom they feel cares, really cares, for them and forms a personal relationship with them
- information, which must be personalised around them, their carers and their illness and treatment, and cover what may happen in the future
- clinical balancing, monitoring and advice-giving
- practical help in minimising disability, impact on daily life, benefits, aids and equipment
- emotional and spiritual support for patients and carers (“if we had a gun, we would shoot him”)
- in-patient care with continuity, shared decisions, dignity and privacy

From this we can identify key factors to improve services for people with cardiac failure:

- coherent, shared management strategy based on holistic needs assessment

- key professional who has time to care and listen and explain and co-ordinate
- clinical monitoring of physical and psychological status
- social support for patient and carer
- quality emergency and respite in-patient care
- better training of professional.

Options to consider

Among the options for achieving this kind of service we will need to consider the following in the local context.

One option is not an option: to do nothing.

- the recruitment and training of specialist cardiac nurses, as in Glasgow and Livingston, supervised by cardiologists (but there are disadvantages in “another hospital based specialist nurse, and impractical in rural areas”)
- upskilling of district nurses and health assistants, and giving them time to care (but they are already overworked).
- training and supporting GPs in palliative care is important (but other demands on their time make this difficult)
- specialist palliative care input could be increased (but we need to beware that services for cancer might not best meet the needs of people with cardiac failure).

Action research is required to assess patients’, carers’ and professionals’, views of the benefits and costs of these different models of care.

Additional members of the research team:

Dr Kirsty Boyd, Consultant in Palliative Medicine, Royal Infirmary, Edinburgh

Dr T Fred Benton, Medical Director, St Columba’s Hospice, Edinburgh

Dr Allison Worth, Lecturer, Department of Nursing Studies, Edinburgh University

Mr Hans Clausen, Palliative care Social Worker, Western General Hospital, Edinburgh

Responding to Need not Diagnosis

Dementia

Professor Mary Marshall, Scottish Dementia Centre

I welcome the opportunity to contribute to such a thought-provoking conference programme and am particularly pleased to see dementia included as one of a group of conditions where end of life issues are not adequately addressed.

What is dementia?

Over 60,000 people in Scotland have dementia, and with an ageing population, numbers are increasing. What is dementia? “Dementia is a group of progressive diseases of the brain that slowly affect all functions of the mind and lead to a deterioration in a person’s ability to concentrate, remember and reason. It can affect every area of human thinking, feeling and behaviour.” (Murphy 1990) Dementia may continue for a period of 15 years and is devastating for both the person concerned and their family. Dementia can be viewed in terms of the medical model or the disability model. The medical model takes a limited view, seeing treatment options in terms of drugs only. On the positive side, however, extensive research studies have been carried out, and recent developments have produced new drugs which can improve the experience of a quarter of dementia patients. The disability model takes a wider view and intervenes at many different levels. It attempts to make the experience of the disease less devastating by identifying many things which can be done to help people with dementia function at maximum capacity in as many aspects of their lives as possible, and when this fails by assisting them to live at optimum level with their disabilities.

End of life needs

There are three different groups of people with dementia end of life needs:

- People with dementia who are dying of some other condition
- People who are dying due to a complex mix of mental and physical problems but are not very advanced in their dementia
- People with end stage dementia.

All need appropriate medical, psychosocial and spiritual care. However, the end of life needs of people with dementia are not always met adequately for a number of reasons. In medical care, there is evidence that pain control needs are not met, and there is a shortfall in the palliative care of physical symptoms such as shortness of breath. This may be due to attitudes of ageism, to the stigma attached to dementia, or to the mistaken but still prevalent belief that people with dementia do not feel pain. Meeting psychosocial needs may be reduced to the basics of being kept clean, warm and comfortable, and there is a huge task to be carried out in improving this area. Continuity of care and knowing the patient really well are important, and the fact that staff change rapidly in many care settings is problematic. Psychosocial care should also be extended to relatives, who often struggle with feelings that the person with dementia has already died. The question of addressing the spiritual needs of people with dementia is particularly difficult. Spiritual needs involve more than the opportunity to worship, but are not often met beyond this basic level.

Palliative care and dementia

The patient-centred principles and values of palliative care and dementia care are actually very close and many of the same issues, such as the importance of really listening to the patient and to the family, are crucial to both. However, it is only now that the two worlds are beginning to communicate and share expertise with each other. That meeting of two worlds must be encouraged to continue, and the Dementia Centre will be glad to work with hospices in developing materials and courses.

Key issues in providing palliative care for people with dementia are:

- pain
- communication
- moving the person with dementia.

Pain is less frequently recognised or treated in patients with dementia, and may be a cause of challenging

behaviour and of resistance to intimate care. Communication is made difficult by the patient's inability to use abstract concepts. It is important to ask simple questions, to take time to listen and understand, to be able to use the language of allegory and metaphor, and to believe that the person with dementia can tell you something you need to know. Non-verbal communication is important, and relies on knowing the patient well enough to interpret body language accurately. Advance directives are a particular issue as regards patients with dementia, and it is important for dialogue to take place early in the disease while adequate communication is still possible. People may not know, however, what it is they will want later. Staff assumptions about quality of life also need to be questioned in this regard.

The tendency to move people with dementia when they require palliative care is another key issue. It is known that dementia patients need familiar places and familiar people and that being moved to a new environment leads to huge increases in anxiety and to

diminished competence. Most people with dementia currently die in non-specialist settings. The challenge is to achieve a balance between failing to intervene properly and helping people with dementia to die with good support. There is a need to provide training in the philosophy and approach of palliative care to many more care staff, so that the end of life needs of many more people with dementia can be appropriately met in their existing care setting. At present many people with dementia often fail to receive appropriate medical treatment in care homes – partly because their particular need for care as individuals is both different and challenging. The challenge for the future is to provide good person centred dementia care *and* good palliative care.

Reference: Murphy, Elaine. 1986. *Dementia and mental illness in the old*. London: Papermac. ISBN: 333426886

Responding to Need not Diagnosis

The Unmet Needs of Young People Aged 13-24

Andrea Cail, Head of Care, Rachel House Children's Hospice

The research project

Palliative Care for Young People (Aged 13-24 years): Report of the Joint Working Party (September 2001) is the report of a collaborative research project carried out by the Association for Children with Life-threatening or Terminal conditions and their Families (ACT), the National Council for Hospice and Specialist Palliative Care Services and the Scottish Partnership Agency for Palliative and Cancer Care.

The study focused on the care and support needs of young people aged 13-24 with life-limiting conditions who require palliative care. These young people have a wide spectrum of diseases and disorders: life-threatening diseases such as cancer, chronic diseases such as cystic fibrosis and Duchenne muscular dystrophy, progressive diseases such as juvenile Batten's disease and non-progressive disease such as cerebral palsy. The annual mortality rate for this group is 1.7 per 10,000 young people, but there is a much higher incidence than this of young people who are living under threat of death and who require palliative care.

An expert Working Party, including representatives from a wide range of disciplines as well as young people themselves, met over a 15 month period to consider evidence on care and support needs. An extensive literature search was carried out but very little previously recorded research was identified and most of the evidence in the report comes from healthcare professionals, families and from young people themselves through a Young Persons' Forum.

Issues specific to the care of young people

Many of the issues affecting the young people in the study are not so different from those affecting any other young person. Many were concerned about developmental issues such as new body image, relationships with boy and girlfriends and dependency on parents. However, many young people with chronic progressive conditions reach a crisis in adolescence or early adulthood in terms of their physical deterioration, and many die in their late teens or early twenties. This means they are also dealing with life in the context of

death, with worries about surviving into adult life, about being restricted in participating in normal activities, and about becoming isolated by losing links with their peers. This happens for a variety of reasons – friends being overwhelmed by illness and unsure how to offer help, friends moving on and acquiring a boyfriend or girlfriend, missing time at school or college through illness or treatment, loss of confidence, and feeling different – part of a world of illness, treatment and death.

“You still want the chance to have ‘normal’ friends who have never experienced being sick. You don’t want to be denied those friends...”

One of the key issues for this age group is the clash between the adolescent’s natural and expected development towards independence, and the limitations imposed by illness. At a time when young people in general are becoming less dependent on their parents, young people with life-threatening diseases are as much dependent on parents and other adults as when they were children. A growing desire for independence means that young people want to be involved in decisions about their treatment, but often feel that adults, particularly parents, withhold information and explanations from them.

“It is very important to me that I have all the information available – not the softer option that people think I need, but the straight truthful knowledge and information that they know. I need all the information to make choices, choices that affect me. I don’t want to feel people are keeping things from me.”

Unmet needs

Young people need an appropriate care environment, and a children’s hospice does not necessarily provide this. At Rachel House young people can meet as a peer group without parents and siblings during five weekends a year. Many young people are cared for at home, and there is a great shortage of suitable respite care. Some young people may be able to cope on their own with lots of support but there are shortages in suitable housing and in services such as occupational therapy and physiotherapy. Families are also often reluctant to allow the young person a greater degree of independence.

The transition from children’s to adult services is a particular area of concern. Many young people are now surviving longer as a result of earlier diagnosis and improved disease management. However, since a number of the conditions were previously found only

in children, the required expertise often does not exist in the adult sector, and it can be very difficult to identify an appropriate clinician to take on the continuing care of a young person. This makes the transition from childhood to adult services particularly stressful.

“I felt as if I was cast adrift and became a problem because I had lived longer than anyone thought and now there was no real provision at a time when I would possibly start to hit problems with my metabolic condition.”

The young people in the study identified a need for psychological support, particularly in dealing with parents and families. Young people need to discuss what is happening to them, but are afraid of upsetting parents and siblings. A situation of avoidance, collusion and mutual protection often exists in families, and the report recognises the need for independent advocacy and for emotional support for young people and their families to enable important issues to be expressed and explored. Young people often feel guilty at being a burden on their families and are aware of the grief which their death will cause. Young people do not relate to the term “spiritual needs”, but they have a need for someone to be there for them and help them to overcome feelings of unfairness, guilt, fear and isolation and so to move on. They need a sense of identity and meaning, and to feel useful, even though life is short.

In conclusion, young people need palliative care which puts them at the centre, and which is both flexible and sensitive to the particular issues and needs they encounter in dealing with life-threatening disease during adolescence and young adulthood. They need as far as possible the same opportunities as other young people to engage in education and life goals, and to share in a range of activities with their peers. In the transition to adult services they need enhanced provision and an approach which offers continuity and psychological support, while at the same time recognising their need to be as independent as possible.

Copies of the report are available from the Scottish Partnership for Palliative Care.

Responding to need not diagnosis

Neurology

Dr Richard Petty, Consultant Neurologist, Southern General Hospital

The SPA has stated that “everyone suffering from incurable progressive illness” should be able to benefit from palliative care. I want to start therefore by looking at the prevalence of neurological “incurable” conditions in Scotland. Then I shall move on to describe a brief life with a muscular dystrophy and demonstrate a range of disease specific issues. Finally I shall look at palliation in neurological practice, including its organisation, complexity and the question of when palliative care services should be brought in.

Prevalence of neurological “incurable” conditions

Around 9,000 people suffer from multiple sclerosis in Scotland, of whom approximately 1,500 are severely disabled by the condition. About 6,000 people have Parkinson’s disease with approximately 10% (600) being severely disabled. 24,000 people suffer some degree of epilepsy. The prevalence of neuromuscular disorders, including muscular dystrophies and motor neurone disease, is given in Table 1 below.

Life with muscular dystrophy

Let us take one of the muscular dystrophies as an example of the sort of problems arising during the course of the disorder. Myotonic dystrophy is an autosomal dominant disorder which runs in families

and affects 1:8,000 people. It is a multi-system disorder affecting skeletal muscle, heart, lungs and respiratory control, and often causing problems such as diabetes and cataracts. Different problems arise in different individuals and at varying levels of severity. Patients may attend numerous different services. Table 2 (page 12) shows the increasing disability of someone with myotonic dystrophy over their lifetime, until death from respiratory failure.

A large number of different agencies are involved with the family to respond to this range of problems, and the agencies will differ as the disease progresses:

- Primary care
- NHS neurologist
- MDC family care officer
- Speech and language therapist, occupational therapist, physiotherapist
- Genetics consultant
- Respiratory, cardiac, ophthalmological and endocrine services
- Social workers
- Schools and psychologists

The way care is currently organised means that the neurologist, GP or geneticist may act as co-ordinator of care in both the early and later stages but they are unlikely to have had training in rehabilitation medicine

Table 1
Neuromuscular Disorder Prevalence

Disease	Prevalence	Cases in Scotland
Myotonic dystrophy	1:8,000	633
Other muscular dystrophies	1: 20,000	253
Mitochondrial disorders	1:8,000	633
Duchenne muscular dystrophy	1:3,500 males at birth	250
Congenital myopathies	1:28,000	181
Spinal muscular atrophies <u>incidence</u>	10:100,000	c.25-50
Motor neurone disease	1:20,000	c.250
Metabolic muscle disease	1:35,000	143
Inherited peripheral neuropathies	c.1:3,000	c.1,500

Table 2
Myotonic Dystrophy – timeline

Age	15	30	45	60
Gait		stairs hard	bath/chair	wheelchair
Comorbidity		diabetes	cataracts	
Speech		nasal dysarthria	aspiration pneumonia	PEG
Wife		no future pregnancies	gave up job	fall with fracture
Family		children born expelled from school	daughter has congenitally affected child	

or in palliative care. Crucially, they are also unlikely to have the time for the co-ordinator role or to have access to relevant facilities. We must be able to do better for patients and families both early and late in the disease.

Palliative care in neurological practice

The severity of other neurological disorders varies from minimal disability and normal life span through to death in the first year. There are a number of common features of neurological disease however which have implications for the organisation of palliative care. They include:

- The age ranges affected
- The rate of evolution of disease
- Fear of a “brain” illness – personality change
- Body image – changes in appearance – affect on relationships
- Rarity and isolation

Each of the different neurological disorders brings with it particular problems. Motor neurone disease may involve difficulty with swallowing, PEG tubes, communication and mobility problems and there are issues around new drug therapies. Multiple sclerosis often affects people when they are relatively young and brings problems around spasticity, incontinence, sex, and ataxia and again there are issues about access to disease modifying therapies.

The rarity of multi-system degenerative disorders affecting children and young people is such that individualised systems of care are required for each, eg new variant CJD and Neimann-Pick disorder. The effects of Parkinson’s disease include pain and stiffness and violent oscillations of symptoms requiring careful balancing of drug benefits and toxicities, followed by late dementia. Informed medical involvement is essential for all these disorders.

Planning for care now and in the future

Managed clinical networks are beginning to be established in relation to the early stages of neurological disease, eg the embryonic Scottish muscle network. Colleagues are addressing epilepsy, multiple sclerosis, and movement disorders including Parkinson’s disease. There are increasing numbers of nurse specialists being appointed in this field and practice is being addressed and information made more available. Development of managed clinical networks for late stage disease will be more complicated because of the need to co-ordinate not only the conventional medical specialists but also palliative care services across NHS, voluntary sector and social services. At the moment there is very little joint working between palliative care and neurology and limited networking in neurosciences with only a loose association between neurologists and specialists in rehabilitation medicine.

How then can we improve care for people with incurable neurological conditions? Diagnosis must remain a hospital based function and follow up may also be hospital based if, for example, no diagnosis has been made; diagnosis needs to be given to the patient; there is a possibility of entry into a clinical trial; there are particularly difficult issues; or there are other reasons making it inappropriate to arrange follow up elsewhere. But follow up could be provided in primary care, in a hospice or in a local resource centre. It could be delivered by specialist nurses working with others as appropriate and working to audited protocols. This is already done with some seizure disorder services.

Service redesign such as this is not a cheap option. It requires training, audit and supervision and with improved recognition of need is likely to result in an increase in demands on resources as well as time. If the SPA meant what it said about “everyone suffering from incurable progressive illness” having a right to

palliative care the resource implications will be considerable. Additional needs will be identified but, at the same time, development of palliative care services could beneficially impact on other services, including neurology.

To take matters forward we will need to develop and agree precisely defined lines of responsibility for

different aspects of care, medical and non-medical. We need to consider the most appropriate site for delivery of the service, including the possible role of joint clinics. Agreed systems of audit/governance across disciplines will be needed and funding will have to be found for these and for the agreed changes in practice across agencies.

Responding to the Challenge

A Health Board Response

Jo Bennett, Health Care Planner, NHS Lothian

Planning structures

Recent changes in structures and governance represent changing values and new opportunities for improved planning, decision-making and accountability within the NHS in Scotland. The new unified Scottish Executive Health Department combines the functions of the previous Public Health Policy Unit and the NHS Management Executive, while the unified NHS Boards combine the health improvement responsibilities of primary care and acute services trusts. Each unified board operates a range of many different advisory groups, planning groups and working groups which reflect national and local priorities. Planning structures in NHS Lothian include groups on cardiac disease, multiple sclerosis and cancer, including work on the new Managed Clinical Network in Palliative Care.

Extending palliative care

The commitment to extend palliative care to those with conditions other than cancer may be regarded as something of a Pandora's box. There is a fear that existing services will be overwhelmed and there are difficulties in determining the disease trajectory in some of these other conditions. These fears and uncertainties lead to a number of questions. What is the role of specialist palliative care? Do we know when to intervene? Can we identify the stages of disease which are critical for resources? If we did have enough resources, do we know how we would use them? Do we know what we need and where? Do we know how to organise what we need? Do we know what the services we want will look like? How do we know where to start?

All of these issues are important for strategy formulation and planning, which can be summed up in three further questions:

- Where are we now?
- Where would we like to be?
- How do we get more? (ie resources)

Existing good practice

To guide us, there are a number of existing examples of good practice which we should build upon. These include Ayrshire and Arran Health Board's successful Health Service Accreditation in Care of the Dying, the work undertaken with nursing homes by Jo Hockley at St Columba's Hospice in Edinburgh and by the Marie Curie Huntershill Centre in Glasgow and the introduction of Clinical Nurse Specialists to support patients with conditions such as heart failure and motor neurone disease. There are also a number of helpful publications produced jointly by the National Council for Hospice and Specialist Palliative Care Services and the Scottish Partnership Agency for Palliative and Cancer Care, such as *Reaching Out: Specialist Palliative Care for Adults with Non-Malignant Disease (1998)*, *Positive Partnerships: Palliative Care for Adults with Severe Mental Health Problems (2000)* and *Palliative Care for Young People aged 13 – 24 years (2001)* published jointly with the Association for Children with Life-threatening or Terminal Conditions and their Families. The work carried out by the SPA with the National Care Standards Committee to establish standards for care homes also helps to identify and promote good practice in that context.

New models of care

We should also be guided by a vision of care models for the future which combine the two sides of what is actually a false dichotomy between specialist and generalist palliative care. One example of this approach is contained in the document “Palliative Care in County Durham and Darlington : A Strategy for 2000- 2004”, in which the focus of care for palliative care in both malignant and non-malignant conditions is on primary care led services with appropriate specialist services as needed.

The key issues for this approach are how specialist palliative care can inform primary care, how we can move from the current focus on acute services, and how the differing values of different care providers can be reconciled and brought together. We need to recognise the “deliverables” which influence funders, and encourage sound qualitative as well as quantitative research to produce change. We also need to be clear about what the drivers for these new models of care really are. For example, the recent introduction of cardiac clinical nurse specialists in Glasgow can be seen as motivated by the need to reduce demand on acute services by reducing the number of acute hospital admissions.

We need to deal with the tendency to “plan in bunkers”, and to break down the professional hierarchies which contribute to this attitude. We need to address the additional constraints arising from

competing priorities and the current lack of profile for palliative care in non-malignant disease. And we need to turn our attention to what is becoming the key challenge for health boards – how to care for the generic needs of an increasingly elderly population.

It will require a considerable shift in culture to achieve a general recognition that palliative care for non-malignant disease is an issue, and one that can be addressed. But it is a shift which is closely linked to the challenge of meeting the constantly changing needs of older people, and of doing so regardless of specific disease processes. There is no single right way of doing this, but it is clear that the answers will involve new models of care, and will not necessarily mean simply more of the same.

A number of opportunities currently exist which will help to take these issues forward. These include the joint futures agenda which ensures that health and social care professionals begin to plan and work together, the requirement for health boards to complete palliative care needs assessments by April 2002, and the third round New Opportunities Fund programme which offers the chance to gather the data required in order to persuade funders to support palliative care. The recent integration of health planning structures should be seen as another such opportunity, and in particular one which should encourage the dismantling of bunkers and facilitate planning for models of care which are able to provide services on the basis of need not diagnosis.

Palliative care for all

The Scottish Executive’s view

Dr E M Armstrong, Chief Medical Officer

It is a pleasure to share the platform at this conference, and to congratulate the SPA on its 10th anniversary. The SPA is a most effective organisation and has become a real force for change, fulfilling a vital role and exemplifying true partnership – with the Scottish Executive and between the statutory and voluntary sectors. Its change of name to the Scottish Partnership for Palliative Care is a welcome signal that it is ready to embrace the new wider focus of palliative care for all.

Scottish Executive policies on palliative care

The Scottish Executive is explicit in its commitment to Palliative Care. *Our National Health A plan for action, a plan for change* makes a clear statement that palliative care is not only about cancer care but should be available for everyone who needs it regardless of diagnosis. It states the Executive’s commitment to ensure support for effective palliative care services, and

highlights the development of Managed Clinical Networks, which will focus initially on the management of pain, and the inclusion in the CHD Task Force report of the palliative care needs of those with end stage heart failure. In addition the Clinical Standards Board for Scotland (CSBS) has been working on standards for specialist palliative care, and the National Care Standards Committee has published its first standards for care homes, which include a standard for support and care in death and dying.

Palliative care thus figures as a key element in the Scottish Executive's policies. The development of palliative care is included in the remit of the Scottish Cancer Group. The Scottish Cancer Plan has a separate chapter which recognises the importance of palliative care and its place in the journey of care, and also emphasises the wider application of palliative care beyond cancer.

Health Boards have been asked to complete palliative care needs assessments by March 2002, and it is important that the voluntary sector has a voice in this process. The Executive expects the new NHS Boards to work closely with hospices and others to improve palliative care services. Two key deficiencies have already been identified – the under-resourcing of specialist palliative care in hospitals and the provision of effective palliative care support at home. Finding the right answers to the right problems will vary across Scotland, according to different urban and rural settings, and the Executive welcomes the work Health Boards will be carrying out on palliative care as part of their plans for strategic development.

Palliative care has also been represented on the Scottish Executive's Expert Group on the Healthcare of Older People. The section of its report on nearing the end of life draws on palliative care thinking and emphasises the involvement of statutory and voluntary sectors and of health and social care. The full report calls on the NHS and its partners to plan now to meet the demographic challenge of the next 30 years, which must lead to the mainstreaming of care for older people. Trends show that the number of people over the age of 85 will almost double and people over the age of 65 will form a much larger proportion of the population than they do now. Older people are already the main users of the health care sector, and increasingly expect more from life and from care. In particular, as life nears its end people seek good quality care together with the additional support which enables them to stay at home for as long as possible. Health planners and providers will need to adapt to meet these growing needs. Increasing specialisation will

not work, and a move to more general care will be required. The voluntary sector is used to being innovative and adaptive and I am sure will respond to this challenge.

The importance of standards

It is a hallmark of the new NHS in Scotland that services should be managed and fit for purpose. Scotland is a world-leader in the process of setting standards, and our strength is that the CSBS standards apply across sectors. This is vital, because meeting peoples' needs increasingly involves a mix of voluntary and statutory provision. Meeting standards is not optional – it is at the heart of re-building the NHS. The standards for specialist palliative care will ensure that the NHS and the voluntary sector provide care to the highest standard. The standards for the common cancers also include palliative care as part of the provision of care.

The issue of access is also important – a key commitment of the Scottish Executive is the social justice agenda. This means that every patient who needs specialist palliative care should have a reasonable expectation of access to that care whenever it is needed. The development of Managed Clinical Networks should help to tackle exclusion and ensure access to palliative care. They will also provide the opportunity for people to develop and share what they are doing. The pilot MCN for palliative care in the Borders has been funded for evaluation, and as many others should be encouraged to develop as possible. There were more applications for funding for MCNs in palliative care than in any other discipline. The Scottish Executive will be holding a conference in March 2002 for all managed clinical networks to share information about what they are doing.

Challenges for the future

The main challenge for the future is to make palliative care truly available to all and to move away from the traditional emphasis on cancer. We need to increase awareness of what palliative care means. The World Health Organisation definition of palliative care speaks of active, total care, of support for families and bereavement care; it affirms life and accepts dying as a natural process; and it recognises the importance of meeting psychosocial and spiritual needs and of helping people to live as full a life as possible for as long as possible. This is surely also the essence of good doctoring and nursing and should be the definition of good care.

There are of course practical implications to be considered. There is the issue of increasing workload

and the need for education and training; of applying what has been learned to the disease trajectories of conditions other than cancer, and the need to explore different models of shared care; the need to ensure that a good standard of palliative care is available to all by building capacity, providing support and re-skilling colleagues; and the need to meet the challenge of change and development by responding to demographic change, by continuing to innovate and by developing partnerships. The Scottish Executive is

committed to addressing these issues and will be taking advice on ways of exploring different models to build capacity and increase skills in order to make palliative care available to all who need it.

In conclusion, I welcome the new wider focus for the SPA and its commitment to palliative care for all, and look forward to working with the Scottish Partnership for Palliative Care on this most important agenda.

Concluding Remarks

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

Dr Derek Doyle, Hon Vice President of the Scottish Partnership for Palliative Care, concluded by reminding the conference that it had taken decades, and the overcoming of many difficulties and negative attitudes, to reach the current level of palliative care provision for cancer patients. He urged delegates not be overwhelmed by the task ahead, but to see it in the context of past experience and success.

Today's conference could be seen as engendering both worry and excitement. Worry because there is a feeling almost of being overwhelmed by the scale of the task ahead, by the sense that we are committing to every pathology and every need. Excitement because that feeling is no different from what was felt by the palliative care pioneers of the 1960s. Their approach was characterised by boundless enthusiasm, and a determination to persevere and gradually to overcome

the obstacles and prejudices of the day. Our approach must be the same – we simply have to go for it!

However, we must be realistic in our objectives. Success, in the form of optimum care for all, is not going to be achieved overnight. We must plan improvements in stages, and recognise that progress can be achieved by a steady series of small but worthwhile steps.

We have to recognise that this will take time, so we should not waste time and energy by reinventing wheels or by allowing ourselves to become depressed. Palliative care professionals do not have a monopoly on caring, and we and our colleagues in other disciplines have much to learn from each other as we focus together on enabling and facilitating the changes which will lead to better palliative care for all.

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 tenth anniversary conference on Responding to Need not Diagnosis 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 gives 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