



A cloak around the world

A report of the National Hospice and Palliative Care Associations Seminar, held 30 March – 1 April 2003 in The Hague

by David Clark, International Observatory on End of Life Care, Lancaster University, UK

Preface

There are an increasing number of national associations working with services to meet the global unmet need for hospice and palliative care.

This seminar brought together representatives from across the globe to learn about how other associations have contributed to the development of palliative care. Initiated and financially supported by Help the Hospices (the national charity for the hospice movement in the UK) it offers useful and practical insights on developing palliative care.

The seminar was an open, frank and informative exchange of ideas to stimulate the thinking of the various players in this field. It was not the intention of this seminar to push or promote any one way of working. Rather the aim was to exchange ideas and learn from each other to allow reflections on possible options and developments in the future. It is the view of Help the Hospices these aims were achieved.

Help the Hospices would like to take this opportunity for thanking all the speakers and participants who took part in the event and helped make the event a success through the high quality of presentations and debate. A special thanks goes to Louise Gray, Jennie Mcdowall and Nick Pahl for ensuring that everything ran smoothly; and to Professor David Clark for producing such an excellent report of the proceedings.

David Prail

Chief Executive, Help the Hospices

September 2003

About Help the Hospices

Help the Hospices represents the views of independent, charitable hospices to key opinion formers and decision makers. It co-ordinates UK-wide fundraising initiatives; offers information and advice; gives grants to hospice staff and volunteers; and provides and subsidizes specialist training. Help the Hospices raises awareness and understanding of hospice care and supports hospice care internationally, through the sharing of ideas, knowledge and skills between hospices in the UK and overseas.

Help the Hospices assumes no responsibility for any errors or omissions. The views expressed may not be necessarily those of Help the Hospices.

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Contents

1	Executive summary	1
2	National associations: their role and purpose	3
3	National associations: their organisational development	7
4	Specific initiatives	11
5	National associations, government and society	13
6	National associations: the international agenda	18
7	Final discussions, conclusions and action points	21
8	Appendix 1: Delegates list	22
9	Appendix 2: Programme for National Associations Seminar 2003	25
10	Appendix 3: Towards a consensus statement on national association values	29
11	Appendix 4: References	33

1. Executive summary

This seminar, the first of its kind, brought together more than 50 individuals from over 30 palliative care organisations around the world, including national and regional associations, inter-governmental bodies and non-government organisations, as well as major palliative care funders in the international context. The purposes of the seminar were to share information and experiences and to discuss how working together might promote palliative care globally. A wide range of presentations was delivered and many organisations presented posters and other materials during the meeting. There were opportunities for questions and discussion, both formally and informally, and several ad-hoc meetings also took place.

By the end of the seminar participants had increased their knowledge of what other associations have achieved, of where improvements might be made, and of the possibilities for international collaboration. A major outcome of the seminar was the determination to set up a global network to facilitate future working and information sharing. There was a great deal of support for building a hospice and palliative care “virtual network” of national organisations and other groups with a pan-national remit. One way to facilitate this might be to develop a website with the following facilities:

- *A bulletin board*
- *Information on all involved associations with links to their websites*
- *Summary report of the 2003 meeting and plans for future ones*
- *The ability to support consensus working groups via password protected access*
- *The ability to host mini websites for any organisation that does not yet have its own.*
- *An information area*
- *A strong link with the website of the International Observatory on End of Life Care*

It was agreed that the network should approach the World Health Organization for “official relations” – with a view to advocating palliative care in the global context. It was also agreed that a full report of the seminar would be produced for the participants, incorporating summaries of the presentations and that a summary report would be disseminated more widely. Proposals for a further meeting were also considered, to take place within the following two years.

Subsequent to the meeting, it was proposed to establish the following working groups:

- *Quality of care – monitoring tools (data requirements) and standards – moderator*
- *Advocacy*
- *Education and training*
- *Global public awareness raising/public education (e.g. international hospice day)*
- *Workshop 2005 organising group*
- *Funding palliative care*
- *National Association organisational issues – (e.g. structure, governance)*
- *Information*

Sunday 30 March

This was the first meeting of its kind ever to take place, bringing together some of the leading figures involved in national hospice and palliative care associations from countries around the world, as well as representatives of other academic, regional and intergovernmental organisations involved in the palliative care field, including major funders. Participants gathered on the Sunday evening for registration, the distribution of materials, and words of welcome from: David Praill, Chief Executive of Help the Hospices (HtH); Stein Kaasa, President of the European Association of Palliative Care (EAPC); and Eduardo Bruera, Chairman of the International Association for Hospice and Palliative Care (IAHPC). Over dinner there was a palpable buzz as new acquaintances were made and old ones renewed. Fifty-one delegates had registered for the meeting, representing 23 countries (see Appendix 1) and the full programme (Appendix 2) got under way on Monday morning.

Monday 31 March

2. National associations: their role and purpose

The unmet need for hospice and palliative care

Avril Jackson, *hospice information*, UK

Jan Stjernswärd, WHO Collaborating Centre, Oxford, UK

In 1980 at St Christopher's Hospice, London, a conference took place involving 65 people from 16 countries. A dominant theme of the meeting concerned the attempts being made, in many settings, to fashion approaches to the care of dying people which draw on the inspiration of the original founding approaches, but which also adapt these to local conditions and circumstances. The last 20 years have seen continuing efforts to grapple with these issues.

Today, we have a picture of hospice around the world, which can be divided into four categories of palliative care development: operational services; 'bridgeheads' of development; 'interest'; and nothing.

The implications of this uneven pattern of development were thrown into stark relief by a detailed analysis of the global scale of need and the epidemiological, demographic, cultural and economic trends which are in evidence. Some key points are summarised here and a more detailed analysis can be found in the detailed chapter, by Jan Stjernswärd and David Clark, soon to appear in the third edition of the Oxford Textbook of Palliative Medicine (Doyle, Hanks, Cherny and Calman 2003).

- The world's population will increase from the current 6 billion to 8.9 billion by 2050. Growth will be greatest in the developing countries (4.7-7.8 billion). By 2050 1.5 billion will be over age 65, 1.2 billion of them in the developing countries
- Within the 'global village', one quarter of the population live in poverty; 1.2 billion are without access to drinkable water; 2 billion are without electricity; 2.5 billion have no telephone

- Almost one half of the world's population (2.8 billion) live on less than 2 \$US per day
- Socio-economic and cultural solutions will therefore be as important as medical efforts in achieving meaningful palliative care coverage
- There are 56 million deaths in the world annually; 33 million (60 per cent) of dying persons may benefit from palliative care. Taking into account informal carers and family members (1-2 per dying person), some 100 million people might benefit from palliative care provision each year
- The number of new cancer cases in the world each year will rise from the current c10.6 million to 23.8 million by 2050. The greatest rate of increase will be in the developing world (from 5.4 to 17 million)
- At the end of 2002 there were 42 million people in the world living with HIV/AIDS and AIDS accounted for 3.1 million deaths in that year
- Medically institutionalised governmental approaches will not reach all of those in need of palliative care in a society, nor will the established hospice approaches. A combination of both is needed
- Pain relief to 'Rolls Royce' standards for one patient can cost 50-80 \$US per month (2-3 times what a doctor earns in many countries); Morphine sulphate can be available for 1.8-5.6 \$US per month per patient
- Outstanding examples exist of how these problems can be overcome: in Uganda; in Kerala; in Catalonia; in Wisconsin

Discussion

Key questions which emerged at this point included:

- How do we calculate the numbers in a population that might benefit from palliative care and how robust is the figure of 60 per cent of all deaths?
- Can we develop more robust estimates that are resource context specific?

Setting up a national association

Gustavo de Simone, Argentinean Association for Palliative Care (AAMCYP)

The mid-1980s in Argentina saw the ending of years of violence, war in the Falklands and the beginnings of a recovering democracy. The origins of palliative care occur around 1985, primarily through the motivations of practitioners. There has been a societal neglect of the topic, but difficulties have also been compounded by the fragmentation of the healthcare system in Argentina and its current structure: there are more doctors than nurses; more specialists than general practitioners. In the palliative care context opioids are available but not accessible. The Asociación Argentina de Medicina Y Cuidados Paliativos originated in a meeting in San Nicolas in June 1990 and legal recognition for the society was obtained in 1994. The period 1985-93 saw the first isolated palliative care initiatives and the training of the first pioneers; it was also accompanied by the beginnings of an increase in morphine consumption. Between 1994-98 there was a growing community of collaboration, the development of new teams and closer links to oncology, but still no effective national policy. Morphine prices doubled between 1991-92. By 1999-2003 there were a number of internal working groups and committees in existence, with links to government, health authorities and the National Association of Medicine and a growing emphasis on accreditation and certification processes and a focus on research and audit. Recent changes at the health policy level have seen a recognition of financing for palliative care. There are currently almost 80 palliative care teams in Argentina; 11 working with children.

Discussion

Several points were touched on, including:

- Factions and divisions based around 'cults of personality'
- The need for a certain level of development before the politicking starts, because 'the politicking is also important'
- The potential for high level political support (e.g. the Singapore association)
- The possibility that 'networks' may be preferable to palliative care associations and societies

The role of national associations in supporting community services

Liz Gwyther, Hospice Palliative Care Association of South Africa (HPCASA)

This presentation introduced the concept of 'hospice transformation', which signifies the broadening of the ethical coverage of palliative care delivery – a concept of central importance in the South African context, where delivery must break out of the early UK model of free-standing inpatient hospices caring for older people with cancer. In response to the care needs created by the AIDS epidemic, the Association has been active in promoting an 'Integrated Community Home-Care Model'.

South Africa's first hospices were established in 1982 and the Hospice Association of South Africa began in 1987. Today the HPCASA is a not-for-gain company, which has tried to avoid heavy spending on administrative structures and which operates through a number of sub-committees. Major challenges are the absence of national government funding for hospices and the uneven distribution of services, with an acute shortage of palliative care services in the northern regions of South Africa. The Association has been successful in obtaining accreditation for nurse training in palliative care and has good links with the Cardiff-based Diploma in Palliative Medicine. An undergraduate medical curriculum for palliative care is being developed. A HPCASA Development Fund exists which focuses on capacity building and collaboration between member hospices. A mentorship programme has been funded by the Open Society Institute and is part of a developing programme of research and development activities, that must go ahead, even in the absence of appropriate government policies to support them.

The objectives of HPCASA are:

- Palliative care advocacy
- Support for member hospices
- Development of community services
- Communication and information-sharing between members
- Networking with care agencies, funders, departments of health and welfare

Discussion

Palliative care in South Africa developed along non-discriminatory lines, even under apartheid, nevertheless it is perceived as a white activity and very few African doctors are trained in palliative medicine. A recent change has taken place in thinking about the work of volunteers, with a move towards paid community volunteers. A major issue is linking primary prevention of HIV infection to the activity of care-giving; but this requires disclosure of the AIDS diagnosis.

Grass-roots strategies

Jan Stjernswärd (for Suresh Kumar, Pain and Palliative Care Society [PPCS], Kerala, India)

Apologies were received from Suresh Kumar. The important article in *The Lancet* was referred to as a detailed account of the work in Kerala, where c50 per cent coverage had been achieved for those in need of palliative care. Some important aspects of the social context in Kerala were set out: 38m population; 90 per cent literacy; enlightened leadership; communist influence. Screening programmes for breast, cervical, and head and neck cancer have led to a reduction in mortality. The PPCS is now developing needs assessment studies in the community with a field force of some 300 volunteers.

PPCS services are based around 45 community groups, each with 15-25 volunteers. Approximately 20 outpatient clinic days per week are provided and 18 home-care days per week. The PPCS has 50 per cent government funding and has worked hard on sustainability; around 5,000 middle class families regularly give one rupee each to the work. But the WHO 'triangle' of policy, clinical services and education has not been effective: opioid availability policies have been subverted by the introduction of high-cost drugs by the pharmaceutical companies.

Discussion

Kerala was seen as a source of inspiration to others in India, but the growing role of the Christian Medical Colleges in promoting palliative care was also to be noted. It was observed that progress for palliative care in India has been slow; the rotation of Ministers of Health in the Union government is a big problem (a theme that frequently occurred in discussion concerning other countries

at the meeting). The role of large pharmaceutical companies in the developing world was also seen as a major problem, requiring advocacy and collective responses. In poorer countries the costs of opioids are often higher than in the west, both in absolute terms and as a percentage of monthly income. It was suggested that when drug costs per month are, for example, greater than 15 per cent of the average income, then they should be provided free at the point of delivery.

Towards a consensus statement on national association values

This draft paper (Appendix 3) had been circulated to participants before the meeting and was introduced for general discussion. The paper encapsulated a statement of 'overall values' within the context of the 2002 WHO definition of palliative care; it also concerned a set of organisational values for national associations, along with allied professional values.

Discussion

A good deal of discussion focussed upon the WHO definition, with a range of, at times, differing opinions in evidence. The first WHO definition according to one view, carried greater legitimacy as the product of an expert group and as something which had emerged from the EAPC definition. There were also perceived problems with aspects of the wording of the new definition: 'inter-disciplinary', 'impeccable', 'approach' and so on. There was the criticism that the definition is still biased towards cancer. It was unclear why and how the new definition had come about. Others saw the new definition as a significant step forward, or at worst something to be lived with. There was no resolution on these points.

The two sets of 'values' within the draft paper also attracted critical commentary. Some key points made were:

- The statements seemed insular and failed to reflect community capacity to deliver palliative care
- The emphasis should be 'clinical', not 'medical'
- The approach (following WHO) should be needs-based, rather than prognosis, or disease-based

- There should be greater emphasis on tangible outcomes: policy, training, practical projects
- There is a need to distinguish between good affects and side affects. The International Association for the Study of Pain recognises that interventions sometimes have negative side effects and there is a need to give warning about these as they can affect patients and families in a direct way
- There is a need to avoid the 'franchise' approach, whereby services can only operate if they have it
- It was hard to separate the 'organisational' from the 'allied' values, not least in a context of multiple stakeholders in this work
- The 'allied' values should also give more emphasis to the professional viewpoint, as the statements are very patient focussed
- There is a need to emphasise the 'vision', rather than the burden of suffering; the approach is about restoring 'wholeness' in a person
- It was unclear who would be the audience for these statements
- The word 'hospice' should be dropped in favour of 'palliative care'

Overall, there was no agreement about the usefulness of this paper and no commitment was made to taking the draft forward or refining it. In general there was a sense that the draft had been 'dropped in' to the meeting, rather than emerged from it and participants found it hard to see the benefit in working on it further at this stage.

3. National associations: their organisational development

Advancing together in palliative care: national associations' stakeholders and needs

David Prail, Help the Hospices, UK

This presentation drew on experiences in the United Kingdom context and in particular the work of Help the Hospices. Several key areas were addressed. It demonstrated the wide array of stakeholders involved in the delivery of hospice and palliative care: patients and carers; government; our communities; service providers; the wider health community; individual professionals; national organisations. It emphasised the importance of individual choices and preferences and the need to listen to the 'patient voice'. It offered some public opinion survey research concerning awareness of hospices and their work in the UK: 92 per cent were aware of the term hospice; 61 per cent were aware of a specific hospice and 51 per cent could name it; 68 per cent did not know the meaning of palliative care; 74 per cent could imagine visiting a hospice. It addressed aspects of the organisational culture and values associated with hospice/palliative care and included 'a plea for alchemists': with passion; with an ability to leap beyond the rationale to stick with a dream; with a 'third eye' that looks at things differently. It drew on the metaphor of the 'clock' (concerned with commitments, appointments, schedules) and the 'compass' (dealing with visions, values and principles) and the problems that can occur in the gap between them. National associations in hospice/palliative care should address the following needs:

- To prioritise/balance stakeholder demands
- To balance democracy with expertise
- To be 'fit for purpose' by having the most appropriate structure
- To be clear about their mandate
- To have effective funding
- To be visionary and philosophically provocative
- To provide leadership

Two models of organisation might address these: Apollonian (ordered, logical, harmonious) or Federalist (collaborative but independent with

power residing close to the action).

This overview set the scene for eight case studies in a variety of settings: Canada; Kenya; Asia Pacific; Central and Eastern Europe; Western Europe; South Africa; India; Latin America.

Canadian Hospice Palliative Care Association

Sharon Baxter, Executive Director

In Canada 225,000 people die each year, but only 15 per cent have access to palliative care; 90 per cent of Canadians would like to die at home, but only 25 per cent do so. The CHPCA has a mandate 'to provide leadership in hospice palliative care in Canada in the pursuit of excellence in care of persons approaching death so that the burdens of suffering, loneliness and grief are lessened'. This presentation addressed three issues:

- How does the CHPCA meet the needs of the groups it serves?
- What structures has it adopted?
- Meeting needs in the future

The CHPCA has 11 provincial associations and over 3,200 members across Canada; each provincial association has a member on the CHPCA board of directors, which also contains six executive members and five 'at-large' members. The work plan includes advocacy, public policy development, awareness and communications, and good governance.

The hospice movement in Kenya

Bactrin Killingo, Founder and Chief Executive, Meru Hospice

Kenya has about 30,000 new cancer cases per year (though cancer statistics in the country are not reliable in their accuracy); 80-90 per cent of cases are diagnosed in the late stages of the disease. HIV prevalence is c14 per cent nationally, with big variations locally (32 per cent in Meru) and about 700 people die of the disease every day.

The Kenyan hospice movement got under way in 1991 with the foundation of Nairobi Hospice. Subsequently five other hospices have been established: Nyeri (1995); Eldoret (1996); Kisumu (1996); Mombasa (2002); Meru (2003). Some 6,000 patients received hospice care in 2002, but each hospice covers a large population and suffers problems of low human resource capacity, limited medicines and funds, and poor transportation.

The presentation described the services offered (patient care, training, advocacy) and gave details of key foreign and local sources of funds. In general there is at present little or no funding for staff salaries. The point was made about linking primary prevention to the delivery of care, since current approaches based on abstinence and condom use are clearly not working. The impact on the community of hospice work could be identified in several ways: increased awareness and support from public health care institutions; willingness to be involved; evidence of the relief of suffering; training of health workers; increased demand for services. Problems and limitations currently faced include: too many clients for too few resources; poor infrastructure within country; a lack of equipment. Plans are under way to create an Association of Kenyan Hospices. The question was also raised: Is there a need to have a global palliative care association that unites us in purpose? And might this be supported by the International Monetary Fund, World Bank, Global Fund?

The Asia Pacific Hospice Palliative Care Network (APHPC)

Cynthia Goh, Honorary Secretary

The APHPC was legally registered on 1st March 2001, in Singapore. It has 14 geographic 'sectors', 557 individual members and 110 organisational members (March 2003). The APHPC grew out of a series of regional conferences that began in 1989 and the work of the Asia Pacific Hospice Network, Patron Dr Shigeaki Hinohara. Seeking legal recognition for APHPC involved exploring its value base, objectives, and geographical territory as well as the need for paid staff, funding and the choice of place of registration. It also required agreement on structures, membership arrangements and the composition of the management board. Nine key areas of activity were identified for the APHPC:

- Linking individuals and organisations
- Publishing a directory
- Establishing a website
- Clinical fellowship scheme
- Visiting faculty scheme
- Travel bursaries
- Donations of medicines
- Donations of textbooks
- Asia Pacific conferences

Eastern and Central Europe Palliative Care Taskforce (ECEPT)

Jacek Luczak, Chairperson

ECEPT is an international association bringing together palliative care professionals from Eastern and Central Europe and also Central Asia. It operates in a world region which is in transition from communist modes of social, political and economic organisation and in which health care is moving from highly centralised systems to contract models underpinned by insurance-based reimbursement from sickness funds. In 1995 the Vienna Message declared that cancer pain treatment and palliative care are insufficiently developed in this region, principally due to a lack of national policies, insufficient professional education, and inhibitory regulations governing opioid availability. ECEPT grew out of the Poznan Declaration of 1998 and in 1999 held its first general meeting at the EAPC Congress in Geneva. ECEPT has six key tasks:

- Gathering data on palliative care provision in the region
- Sharing experiences on obstacles and achievements
- Influencing government institutions for the improvement of national policies
- Organising training for professionals within the region
- Setting standards of palliative care
- Raising public awareness of the problems faced by palliative care

ECEPT has strong links with a variety of groups: the Polish Association for Palliative Care; the Hospice 'Pallium' Resource and Training Centre, Poznan, Poland; EAPC; the PaCE project at the University of Sheffield, UK. Funding support has been received from the Open Society Institute. The ECEPT network contains c250 members from almost all the countries of Eastern and

Central Europe, as well as from Greece and from some countries in Central Asia. In addition to the survey of the region conducted by David Clark and Michael Wright (2002) the presentation also included results from a 2003 survey of palliative care in the region.

European Association for Palliative Care and Palliative Care East initiative

Stein Kaasa, President; Carl Johan Fürst, Board Member

The aim of the EAPC is to increase the awareness and promote the development and dissemination of palliative care at scientific, clinical and social levels. Its collective members increased to around 30 by 2002, representing almost 50,000 individuals working in palliative care. It promotes the organisation of health care to provide palliative care for all who are in need of it, together with appropriate training of professionals and the development of relevant research, particularly through its research network. EAPC's message for palliative care is "one voice, one vision."

EAPC East, was established in 2001, as a Stockholm-based office of the EAPC. It works with 22 countries in Central and Eastern Europe, 6 of which have national palliative care associations and 3 of which have collective members within the EAPC. The work is supported by Open Society Institute and Stockholm Sjukhem Foundation of the Karolinska Institutet. The project has begun with contact-making, networking and establishing a newsletter and a website (www.eapceast.org). It has organised a variety of meetings and seminars, arranges for the transfer of journals, books and equipment from West to East, promotes the exchange of information and facilitates contacts between individuals and countries. It has participated in the Council of Europe Expert Committee on palliative and promoted work on the collation of standards.

Hospice Palliative Care Association of South Africa; structures, activities and needs (HPCA)

Liz Gwyther

The main work of the association is carried out by three committees and a national advocacy officer.

The Fundraising and Public Relations Committee is involved in national fundraising activities, although to date the sensitive issue of not carrying out any fundraising activities that may clash with local hospice fundraising endeavours has been a major consideration.

The Organisation Development Committee has developed policies and procedures relating to: starting a new hospice; staff development; labour relations.

The Patient Care and Education Committee has developed standards of care and an audit tool to measure quality of care. This committee has also carried out accreditation visits to over half of HPCA's mentor hospices. Education and training programmes for volunteers, community caregivers, nursing staff (registered nurses and enrolled nurses) have been developed and are accredited with the relevant national bodies. HPCA has also been active in collaborating with the University of Cape Town to offer postgraduate degrees in Palliative Medicine and more recently with Cape Technikon (technical college) to offer a post-basic degree BTech in Palliative Nursing.

The advocacy officer is active in developing awareness of palliative care at regional, national and international level and in publicising the work done by HPCA South Africa.

The needs of HPCA South Africa - in order of importance – were described as "Funding, Funding and Funding."

As NGOs, South African hospices are required to raise money to sustain their services, and these have expanded to respond to the HIV pandemic in the country. South African communities have been aware of the needs of people with HIV and have responded with compassion and commitment. The reality is that these needs are so

urgent and so desperate that it is not possible to wait for funding opportunities, action must go ahead with whatever response is most appropriate, moving forward in faith that the funding will be forthcoming.

The hospice response in South Africa is meaningful and effective and the well developed palliative care programmes that have existed since the early 1980s have meant that the structures and policies for efficient governance and accountability are in place.

The current need is to build capacity in human resources as programmes and patient numbers grow and to access sustainable financial resources to enhance the current work.

Indian Association of Palliative Care

Stanley Macaden, Secretary

India has a population of over 1 billion people, of whom 80 per cent live in rural areas with limited access to healthcare. There are an estimated one million new cancer cases per year, of which 800,000 are incurable at the time of diagnosis. India has 11 regional cancer centres, seeing less than ten per cent of patients and mostly city dwellers. With a strong emphasis on curative treatment, only ten per cent of the cancer resources are available for those needing palliative care.

The Indian Association of Palliative Care was founded in Varanasi in 1994 and held its tenth annual conference in 2003. It has a quarterly journal. Its main emphasis is on improving morphine availability; promoting awareness and education programmes; developing minimum requirements for 'recognised medical institutions'; and developing standards of care. It has recently developed a position paper on empowering family members to administer sub-cutaneous injections as 'accepted practice' in home care. Future plans include:

- Encourage the Supreme Court of India to ensure the adoption by state governments of new narcotics regulations
- Initiate a diploma programme in palliative medicine and palliative nursing; and introduce palliative care education into undergraduate curricula

- Development of 'care pathways' for the dying
- Advocate for more government funding for palliative care services
- Improve palliative care services for people with AIDS
- Encourage research
- Promote learning through exchange programmes; encourage 'twinning' and 'networking'

Finally, the important role played by the Christian Medical Colleges in this work was noted, in addition to the acknowledged free-standing hospice 'beacons' and the Kerala WHO demonstration project.

Latin American Association of Palliative Care (LAAPC)

Liliana de Lima, Executive Director, International Association for Hospice and Palliative Care (IAHPC)

The LAAPC developed out of meetings in Latin America that began in 1990, though the association was not formed officially until 2001. In 2002 its conference attracted 380 participants and it will meet in Montevideo in 2004. It has an electronic bulletin published every two months on the website of the IAHPC. The association has promoted a teaching programme jointly with SECPAL (the Spanish Association of Palliative Care) and IAHPC and has held a three day workshop on opioid availability in conjunction with the Pan-American Health Organization. It has also conducted opioid legislation analysis in Peru, Ecuador, Colombia and Mexico and there are plans for an IAHPC/PAHO publication on palliative care by local authors.

Latin America is the world region with the largest income differentials (from Haiti to the Cayman Islands).

4. Specific initiatives

The International Observatory on End of Life Care

David Clark, University of Sheffield, UK

Around the world more than one million people die each week. It is estimated that 60 per cent of these could benefit from some form of palliative care. Yet at the moment only a tiny minority of dying people ever receive the support of hospice and palliative care services and unrelieved suffering persists on a large scale. Palliative care is hugely underdeveloped in most resource poor countries, and it is still significantly constrained even in many countries with otherwise 'advanced' health care systems. At the same time, there is a significant shortage of political leaders and 'product champions' with an interest in palliative care and we lack national and international policies to promote its development. The creation of a trained multi-disciplinary workforce to deliver clinical care, educational programmes to support them, and an evidence base to highlight both unmet need and the efficacy of existing provision are all additional challenges. Now, more than ever, is the time to be thinking globally, as well as acting locally.

Aims of the Observatory

- To provide clear and accessible research-based information on hospice and palliative care provision in the international context, incorporating public health, demographic, epidemiological and health care systems analysis as well as ethnographic, historical and ethical perspectives.
- To disseminate this information through the Observatory website and through published articles, monographs, reports, CDs and other media, in ways that facilitate cross-national comparative analysis and stimulate practical development.
- To undertake primary research studies and reviews to generate such information.
- To develop a small grants programme to support academic work relating to the aims of the Observatory in resource poor regions.
- To work in partnership with key organisations and individuals, nationally and internationally, in order to foster a sense of inclusion and participation in its work.

Features of the Observatory

The idea builds on successful public health observatories, but is unique in being focussed on end of life care and in its mission to go beyond a purely epidemiological frame of reference. Its starting point has been a major review of hospice and palliative care in some 28 former communist countries of Eastern Europe and Central Asia and this in turn has built on another comparative study of palliative care development in Western Europe.

From September 2003 the International Observatory on End of Life Care is to be established at Lancaster University, UK, within the Institute for Health Research. It will be led by David Clark, working with a team of collaborating researchers at the University and in partnership with colleagues and organisations in many parts of the world. In addition to the Observatory's project-based research and development programme it will also house the digital and paper archives of the well-known Hospice History Project and contain an extensive collection of current reference materials. It will concentrate on two streams of activity: global analysis of palliative care development; historical, sociological and ethical studies of hospice and palliative care in specific contexts.

Partnerships

The International Observatory on End of Life Care is seeking active and sustainable partnerships with organisations and individuals committed to the global development of palliative care. It has a growing network of collaborators across several countries and continents and already has key links in India and South America, as well as Eastern Europe, Central Asia and Africa. The Observatory has already received support from: Help the Hospices; International Association for Hospice and Palliative Care; Open Society Institute Public Health Network Programme; Palliative Care Initiative; Oxford University Press; The Project on Death in America; The Diana, Princess of Wales Memorial Fund. Further enquiries and offers of involvement are welcome.

The presentation closed with the official launch of the website, which had gone live for the first time that day: <http://www.eolc-observatory.net>

The Canadian Living Lessons Partnership between GlaxoSmithKline and the Canadian Hospice Palliative Care Association

Sharon Baxter, Canadian Hospice Palliative Care Association (CHPCA)

This presentation described a successful partnership between CHPCA and GlaxoSmithKline, pharmaceutical company and also a major charitable donor in Canada through the GlaxoSmithKline Foundation. The Foundation has taken a strategic decision, supported through a ballot of its employees in 1995, to support the cause of hospice palliative care across Canada. From 1997 it formed a partnership with CHPCA to create a social awareness programme called Living Lessons, a national initiative to increase awareness of hospice palliative care services in Canada, with the following aims:

- To promote awareness and understanding of quality end of life care
- To change attitudes and behaviours about death and dying
- To encourage Canadians to talk openly about needs
- To influence public policy

Living Lessons draws on the techniques of social marketing, using a variety of tools: information; media relations; networking; influencing decision makers. It provides a toll free information line; internet and email service; printed materials; media training; national advertisements and promotional events. It has also developed a campaign by and for physicians; a caregiver guide; and a quality end of life care coalition. Living Lessons is used by:

- Patients, families, informal caregivers
- Health care professionals
- Media
- Educators
- Other individuals and agencies, nationally and internationally

The programme has created increased media attention for end of life issues and a high degree of interest for non-hospice groups. It has also contributed to a supportive environment for other major initiatives, such as the Senate report on

hospice palliative care as well as enhancing advocacy and programme change.

Rosetta Life: worldwide arts project

This presentation described the work of a community arts initiatives working with staff and patients in palliative care settings. Making use of modern information technologies, patients and their families are able to record aspects of their experience through picture making, film, poetry and music.

Tuesday 1 April

5. National associations, government and society

NGOs and the government – a case study

Anne Merriman, Hospice Africa, Uganda (HAU)

Uganda has had a troubled past. A protectorate of the British between 1894-1962, it was embroiled in war, suffering and fear between 1964 and 1968, when Museveni came to power. There is still conflict in the north and north west of the country.

In Uganda, 52 per cent of the population is below the age of 15. The total population is 24 million, of which 90 per cent live in rural areas. HIV was first acknowledged in 1986; by 1993 there was a seroprevalence of 30 per cent, but this had fallen to 6.1 per cent by 2002. Pain has been found to be a common problem among people with AIDS and there is an increasing incidence of AIDS related cancer, such as Kaposi's sarcoma.

Hospice Africa in Uganda began in 1993, at which time its objectives were: to provide a palliative care service; to deliver education; to encourage the development of palliative care in other African countries. At that time there was resistance to the use of morphine. Lobbying on this issue did create antagonisms from within the Ministry of Health, but eventually supplies of powdered morphine were obtained. From this a morphine solution was made up in bright colours (green and pink). Now it is possible to have pain control for three weeks for a cost equivalent to a loaf of bread. The WHO 'triangle' emphasising clinical services, policy endorsement and education, was found to be very useful.

The year 1998 was one of progress and development. In January, a mobile hospice was opened in Mbarara. In June, Little Hospice commenced operations. In September, Mildmay International opened. By October the first meeting took place with the Ministry of Health, organised by Hospice Africa, Uganda and supported by Dr Jan Stjernswärd. This led to contact with Dr Jack Jagwe, who became Senior Advocate in National Policy for Palliative Care and the creation of a steering committee at the Ministry of Health. The

committee worked with the Ministry of Health for two years and this eventually led to the incorporation of palliative care as an essential clinical service in Uganda's Strategic Health Plan for 2000-2005: the first African country to achieve this.

The Palliative Care Association of Uganda was established in 1998, with the following aims:

- Maintaining standards
- Bringing together key players and stakeholders
- Establishing a bi-annual journal (soon to be on CD)
- Quarterly CME update
- Publications

It currently has a membership of over 100 and district branches are planned.

The current chair of the Association is Dr Ekie Kikule, who in 2000-2002 undertook a research study involving over 3,000 people in three different districts. The study identified the needs of carers (financial, nursing and medical); the needs of patients (pain and symptom relief, food, provision for family); and preferences in place of death.

Building on these achievements, early in 1998, the Palliative Care Association of Uganda was started.

In 2001 collaboration began with the Diana, Princess of Wales Memorial Fund, whereby HAU acts as technical advisor to educational projects. These have taken place in Tanzania (funded by the UK Royal Air Force), Malawi, Ethiopia and Nigeria. In 2002 HAU began a distance learning diploma for 20 students in Uganda, Ethiopia, Malawi and Tanzania; the following year, students from Zambia and Cameroon also became involved. HAU also participates in the WHO community palliative care initiative, which involves: Tanzania, Uganda, Ethiopia, Botswana, Zimbabwe and South Africa.

Now, in 2003, it is not intended to multiply the number of hospices, but rather to expand

palliative care through the existing system. The Ministry of Health is addressing the following problems:

- There are insufficient doctors available to prescribe morphine; can prescribing be extended to include nurses?
- There are too few doctors, in the country-side in particular
- Factors governing the distribution and control of drugs (nevertheless, 'we are changing attitudes to the control of narcotics')

For Hospice Africa Uganda, the key lessons learned are about:

- Working with government through existing health care facilities
- Grafting palliative care onto existing support teams for HIV/AIDS
- Palliative care needs a strong commitment to caring for patients and families and for each other
- Palliative medicine can change the attitudes of health professionals to end-of-life care

The example of Uganda is presented as a source of encouragement to other countries, especially in Africa. Nevertheless, the means to such achievements will differ according to the relationship of the NGO with the government, as well as the particular character of the community, and its cultural and economic needs.

In February 2003 the African Palliative Care Association came into being, with a steering committee representing Zimbabwe, Tanzania, South Africa, Kenya and Uganda.

Palliative care and policy: the Italian experience

Franco Toscani

Growth in the hospice movement in Italy since the 1980s can be attributed largely to the work of the Floriani Foundation of Milan, as well as a handful of enthusiastic, idealistic and eccentric young doctors. These doctors initiated new approaches in their hospitals which were quite different in orientation to the normal activities of anaesthetists and oncologists. For its part, the Italian health care system provided no funds for such activities. At this time the attitude of physicians towards their

dying patients was either an embarrassed 'there is nothing else I can do', or a manifest over-treatment of the disease. Indeed as a president of the Italian Association of Medical Oncology claimed: 'Terminal patients don't exist; an oncologist who thinks they do is a depressed one and he had better change job!'

For many years the only way to provide any kind of palliative care was through the creation of charities that raised money to pay nurses and doctors for home care and organised volunteers. These teams became very popular among patients and families, but many physicians saw palliative medicine as a challenge to their usual ways of working. The oncologists saw it as part of the move to relocate oncology wards into general hospitals. The GPs saw it as a further attempt by specialists to erode their own role at the patient's bedside. Most doctors despised the 'palliativists' as bare-foot physicians prescribing old-fashioned medications (not least the sinful, deadly morphine) and otherwise unable to perform sophisticated, invasive interventions. To speak of death and dying was considered inauspicious and inappropriate. Notwithstanding the spread of palliative care, for 18 years nothing concerning end-of-life care was ever mentioned on Italian television; and anchor-men opined that terminal patients on the screen would drive down the viewing share.

Palliative care in Italy, despite its spread, for many years remained at the border of mainstream medicine and was generally regarded more as a worthy, charitable activity than an aspect of sound medical practice. Although a few regional health administrations did produce some documents in support of palliative care, the chief ways in which it was able to develop were through a semi-official mix of tolerated activities within the public health institutions and charitably-funded home-care services.

Then a miracle happened.

In 1996 Italian public opinion was shaken by the rumour that a therapy based on somastatin could have remarkable curative effects on all cancers, including those at an advanced stage. Although the therapy had no clinical or experimental evidence to support it, its creator, Professor DiBella, found support for it among a handful of speculators and politicians. Opposition MPs capitalised on the situation. Patients' and consumer associations and the media attacked the government for denying patients an alternative to painful and

useless oncological therapies. There were demands for the free prescription of the DiBella therapy, despite its high cost. Indeed, the 'DiBella' affair became a popular cause célèbre and a serious embarrassment to the health ministry.

The response of the health minister however was to suddenly 'discover' palliative care and to promote it as the answer. No extravagant therapies, but also no over-treatment or abandonment: in other words, appropriate and effective treatment for terminally ill patients. The minister took palliative care seriously, commissioning the construction of one hospice in almost every region; asking for revision to the restrictive laws on opioids; and appointing a national commission for defining palliative care and for its implementation. The commission produced documents on epidemiological aspects of palliative care, on standards, ethics and training. It made two key proposals:

- A network of assistance would be needed to provide continuous care in hospices, hospitals, nursing homes and patients' own homes
- An educational project would be indispensable to train the necessary workforce (a national curriculum for palliative medicine was established) as well as an information programme for the public

In due course an ad-hoc committee was appointed. After two years of painstaking work, guidelines were written on how palliative care units should be organised, on which staff they should have and the qualifications necessary in the director, and on the training of physicians involved in palliative care. The public information project was also drawn up. In turn the committee had to face four key facts:

- Conflict between the national and regional health administrations (the organisation of the public health system has recently been devolved to the regions and these are very jealous of their autonomy)
- The predictable awakening of several powerful lobbies operating at both national and regional levels and each seeking to have the biggest slice of the cake; these included GPs, geriatricians, anaesthetists and private health care providers – though not oncologists, who had recently obtained the long-coveted hospital wards

- The crumbling of the palliative care front, shaken by ongoing battles between 'parties', representing differing, sometimes opposing, philosophies and styles and embroiled in struggles within the emerging field of academic chairs and associated influence
- The byzantinism of Italian law

Once a palliative care unit/hospice is created, a director is needed. In Italy, to be appointed as a director of a public hospital department or ward, a doctor must have both a specialisation and a given length of service in a public health institution or equivalent discipline. But in Italy there is no specialisation in palliative medicine and only few universities are starting Masters' programmes. Moreover, many dedicated 'palliativists' have worked in non-profit and charitable organisations, thus failing to meet the criteria for public service. As regards the 'equivalence' of palliative medicine, in practice any specialist (in anaesthetics, oncology, neurology, internal medicine) with a suitable record of public service is entitled to become the director of a hospice/palliative care unit, even with no direct experience of palliative care. So what of the position of 'palliativists' with experience, but who fail to meet the formal criteria? The committee suggested giving priority to those who attended at least an 80 hour basic training course; but as the universities pointed out, such training hitherto had been non-official and non-certifiable, even when provided by such private institutions as the Italian School of Palliative Medicine. So the risk was that of having the hospice/palliative care units, but lacking the personnel to run them, with the universities needing years to produce the first qualified 'palliativists'. At this point it was necessary to get the regions to run such a course, with a pilot to be organised by the National High Institute of Health.

The committee's proposals became law, but a change of government saw many projects frozen. Today, the newly appointed National Commission for Palliative Care is languishing and is only seldom summoned to meet. Currently, no specific quality control is performed on hospices and palliative care units and no official accreditation processes are foreseen. Not all regions are planning to open hospices or palliative care units. Moreover the pilot course has been blocked by strong lobbies that have slowed its progress.

On the other hand, all over Italy hospices and palliative care programmes are developing in private hospitals and nursing homes, with no quality

control and often run by inexperienced personnel whilst more experienced doctors are set aside. Many 'palliativists' are disoriented – not understanding the present and fearing for the future. For some, there is a feeling that 'we were better off when we were worse off'; but I am less pessimistic. The seeds have been scattered and sooner or later a proper palliative medicine will spring up in Italy, no matter how and by whom it was started. There is an Italian privilege and malediction: to painstakingly achieve our goals, despite ourselves. Perhaps it is the case that the Italian experience cannot be generalised, since every country has its own peculiarities, policies and styles. Nevertheless, some lessons may be borne in mind:

- Do not rely only on your good reasons. Politicians take decisions based on consensus, and a palliative care-friendly minister is not enough. It is also necessary to create conditions whereby the institution of palliative care becomes politically rewarding, or where its non-realisation would be politically dangerous. It is mandatory, therefore, to work on public opinion. Invest in the culture and don't underestimate the role of volunteers as advocates.
- Persuading the minister is just the beginning and there are many steps to go through between reaching a ministerial decision and putting it into effect. At each step the process can be abruptly brought to a halt, or allowed to go through easily.
- Choose your friends carefully. It is more advantageous to have a ministry official as an ally than a Member of Parliament as a personal friend. Competent help in setting up and drafting a document and in the choice and timing of the steps can transform the progress of a law.
- Beware of vultures. Entire professional groups can suddenly become extremely interested in what you are setting up, especially when they intend taking possession of it.
- Beware of comrades. Even among the palliative care community, united and solid in poverty, as soon as something crops up out of nothing, a war breaks out. Assuring a slice of the something becomes 'an apple of discord'. There is nothing more dangerous than showing disunity at the most vulnerable moment.

- Don't rest on your laurels. When the worst seems to have passed, remember that should something else go wrong – it will! Pressures will be reduced only after years of hard work, when palliative care has become so highly respected that anyone trying to discard it runs the risk of indignation and anger from a public sensing the threat to the fundamental right to die with dignity.

Hospice and palliative care standards

Nick Pahl, Help the Hospices, UK; Stephen Connor, National Hospice and Palliative Care Organization, USA

In the United Kingdom there exist a wide variety of government organisational standards relating to health care and some of these impact directly on palliative care services. Most health care providers are bound by government standards covering health and safety, risk management, fire safety and catering hygiene. In addition, national care standards must be met and these are tested by annual inspection; one aspect of this work has been the need to highlight the special features of hospices in this context. More specific to the core activities of hospices, the government is now producing a set of guidelines for supportive and palliative care services, though there are difficulties in identifying the evidence-base for some areas of palliative care provision. Another sphere of activities are the cancer 'networks' that now exist in many parts of the country and the special relationship of independent hospices to these. Also, the government has 'disease-specific' 'national service frameworks' (e.g. for heart disease, mental health) and these may include special provision for end-of life-care.

At local level, many hospices are engaged in their own audit and standards work and it may be that evidence of satisfactory completion of these may result in a 'lighter touch' approach to national inspections. Such standards may relate to the work of particular members of the multi-disciplinary team, or they may apply to certain clinical issues (opioid use, specific symptom management).

In all of these aspects of standard setting, inspection and implementation there may be a role for national associations supporting hospice care.

National associations may be able to contribute to the setting of government standards; assist in the development of appropriate standards for palliative care; and facilitate monitoring processes. Two important areas of work on standards were highlighted: the review of European standards being undertaken by Urska Lunder of Slovenia, in association with EAPC East, and the work on Canadian norms of practice.

In the United States standard setting is generally of four types: licensing, certification, accreditation, and association. The latter, although voluntary in character, is generally the highest level. The first National Hospice Organization standards were published in 1979 and have been further developed and refined in the intervening years. In 1993 a three part format was used for the first time ('principle', 'standard', 'output'). The current National Hospice and Palliative Care Organization standards were published in 2000, and include chapters on: the interdisciplinary team; leadership and governance; the management of information; performance improvement and outcomes measurement; and infection control. More recently, a palliative care consensus project has got under way to develop consensus standards for emerging non-hospice palliative care providers. Looking further afield, NHPCO has assisted hospices in Romania with the development of national standards and is working on a set of generic tools for national associations to use in infrastructure development.

In both the UK and the USA it can be seen that the development of standards for hospice and palliative care is an evolutionary process. In any country it will be necessary to modify standards to the needs of a specific health care system. It is important to avoid fossilisation and to promote standards that have an effect on palliative care. Standards can help to manage and improve performance; they can help secure resources, bring legitimacy and reimbursement. For such benefits to be achieved, providers and national associations need to 'own' the relevant standards.

6. National associations: the international agenda

The World Health Organization perspective

Amanda Marlin, Cancer Control Programme, WHO

Around the world there are over 20 million people living with cancer and over 40 million living with HIV infection. No one group has the capacity to meet the resulting needs. The size, complexity and urgency of the problem demands action from many sectors and in particular requires collaboration between government and non-government groups. The World Health Organization (WHO) works in partnership at various levels: international, regional, national and local. At the international level, WHO is working with a variety of partners, giving particular attention to countries where resources are most limited. The promotion of palliative care is interwoven into the work of many WHO initiatives. For example, it is highlighted as an essential component of any comprehensive cancer control programme, a necessary addition to prevention, early detection and treatment activities. It has a similar priority for other disease programmes, particularly HIV/AIDS.

Two palliative care initiatives are currently under way within WHO.

In Africa a joint project of the WHO Cancer and HIV/AIDS programmes is being developed in five countries (Ethiopia, Uganda, Tanzania, Zimbabwe, Botswana). Its goal is to move from a situation where few people in need of palliative care get the support they need, to one where the majority of people in need of palliative care get good quality care and improve their quality of life. The project began in 2001 and will continue to 2005. At present in these countries there are several problems:

- Lack of awareness of palliative care as a public health issue
- Many good initiatives but little population impact because of a lack of integration into health policies and systems
- Lack of knowledge and skills among health care providers
- Serious impediments to opioid availability

Nevertheless, there are also significant strengths:

- In Uganda, palliative care has been included in the national health policy and opioid availability has been improved
- There are 'beacons' of good practice
- Community and home-based care networks are being strengthened in response to the HIV/AIDS epidemic

In Europe there are plans for an initiative to strengthen national cancer control programmes, particularly in Eastern Europe. Palliative care is seen as a key component in these programmes. An initial consultation is planned for 2003, possibly to be supplemented by a one day session as a follow-up to the OSI funded study conducted by David Clark and Michael Wright.

Discussion

There was wide-ranging discussion after this session, covering the following points:

- How WHO staff can be educated internally about the importance of palliative care
- How priorities are set for WHO attention relating to palliative care and how world regions are chosen
- How palliative care workers can exert more influence on WHO at country level and internationally

Wider discussion

At this point in the programme (midday Tuesday) David Praill introduced a discussion on how to move forward from the seminar. Invited to the event had been national associations within hospice/palliative care that are not discipline-specific. In addition, other organisations with an international interest had also been asked to participate. Initial ideas to emerge were:

- Publish a report of the meeting with copies of the presentations available on CD
- Establish a web-based virtual 'coalition' of national hospice and palliative care associations

- Repeat the event, in India or Seoul, in 2005. Topics to include: advocacy/global development; public education; standards; a 'world day' for hospice/palliative care; organisational development for national associations

Following this there was a strong view that a new organisation should not be formed and that any future meeting should be held alongside a major scientific palliative care congress.

Thematic discussions

In the final afternoon of the meeting, participants gathered in small groups to consider five specific issues. The key points raised in these discussions are summarised below.

Future international networking and leadership: what action should be taken?

Members of this group had found the meeting of personal benefit, but there were concerns about the 'coalition'; a 'network' may be better. Much of the information presented is already available; it is important not to 'reinvent the wheel'. The purpose of a network would be to support the infrastructure of emerging national organisations. There was a preference for a meeting in Seoul, 2005 (rather than in India) another option would be to link to the EAPC Congress of 2005

Expanding palliative care internationally: the challenges

- Palliative care in the international context is not well understood; it is perceived to belong mainly to the rich world, to be predominantly Christian, and to be a luxury
- National associations for hospice/palliative care are not widely distributed; their personnel are over-loaded; there is a lack of skills, for example in marketing and advocacy
- Palliative care is often seen as a separate issue from health and requires integration within the health care system; cheap drugs need to be made available; an evidence base needs to be provided through demonstration projects, models and 'beacons'; education of professionals and workforce development are important

- There is a need to stimulate public interest, but it is unclear how this is to be done. As Jan Stjernswärd put it: 'Why have we failed? And we have failed. People do not know that freedom from pain is their right' Perhaps the name of the activity is still a problem?

National associations' values: implementing the consensus statement

This group had confirmed a lack of agreement on the draft consensus statement and had highlighted the following points:

- Needs push us forward in our work; values are for us to follow
- We must pay careful attention to differences in language and in definitions surrounding what we do

The group then identified three main themes and grouped elements within these:

1. Stakeholders and relationships

- Promote palliative care to other relevant national bodies
- Share information in an open way with each other
- Involve service users (patients/carers) in developing services
- Facilitate creativity and empower change
- Reflect the views of individual hospice and palliative care providers

2. Partnership/team values

- Value multi-disciplinary teamwork and volunteers
- Lead by example through high standards of work
- Foster mutual respect and integrity between providers of services
- Establish and promote partnerships based on trust and exchange
- Value care for the carer/care-giver

3. Core values and attitudes

- Respect the faith, belief system and culture of each individual

- Respect every individual regardless of sex, age, race, intellectual or socio-economic standing
- Recognise that the individual and family are entitled to make informed decisions about care and end of life care
- Respect the confidentiality of all information arising out of the provision of care
- Believe in empowerment of the individual, the family, the community

National associations and government: producing national strategies

This group admired the Australian strategy document, and posed a number of questions:

- Why have a national strategy?
- Who are the stakeholders?
- How can a strategy be made applicable to all countries?

A strategy should focus on simple things: equipment, social support, drug availability. It should contain a 'vision' statement and focus on 'bottom line' ideas of what we are aiming for: what is palliative care, who is the client group, who are the carers, how are they to be supported? There must be public education. There is a need for evidence of quality and effectiveness through evaluation. All of these points are covered in the Australian document.

Paediatric issues

- There are a number of key areas for collaboration
- Advocacy
- Care standards
- Promoting good practice
- Awareness-raising
- Bereavement programmes
- The work of volunteers
- Impact on care-givers
- Sharing of materials
- Equity of access
- The placement of children

7. Final discussions, conclusions and action points

Each of the five small groups fed back its discussions in plenary.

David Praill summed up a number of points and commented on the valuable dialogue that had taken place outside of the formal sessions. He apologised to those who had not had a chance to present the work of their organisation, and also commented favourably on the valuable contributions made by several individuals present with a long record of distinguished service in palliative care.

The dialogue would be taken forward in various ways:

- Email responses from national organisations about what should happen next
- 'Copying in' wider group of participants to that dialogue and involving others who are not here
- Suggestions for working groups/steering committees
- Moving towards a further meeting in 2005
- Circulating copies of the meeting report

Tonia Barnes thanked the organisers at Help the Hospices for realising an idea first discussed in Geneva in 1999.

Appendix 1: Delegates List

No.	Name	Position	Organisation	Country
1	Ms Tonia Barnes	Executive Director	Palliative Care Australia	Australia
2	Ms Karine Baylan	Public Health Adviser	Netherlands Red Cross	Netherlands
3	Ms Sharon Baxter	Executive Director	Canadian Hospice Palliative Care Association	Canada
4	Ms Heidi Blumhuber	Executive Officer	EAPC Head Office	Italy
5	Dr Eduardo Bruera		Association for Hospice and Palliative Care (IAHPC)	USA
6	Ms Mary Callaway	Associate Director	Open Society Institute	USA
7	Professor David Clark	Chair of Medical Sociology	University of Sheffield	UK
8	Dr Stephen Connor	Vice President	National Hospice and Palliative Care Organization	USA
9	Dr Franco De Conno	Honorary Director	EAPC	Italy
10	Ms Liliana De Lima	Executive Director	International Association for Hospice and Palliative Care (IAHPC)	USA
11	Dr Gustavo de Simone	Founder and President	Argentinean Association (AAMCYP)	Argentina
12	Ms Mary Dempsey	Chairperson	Irish Association for Palliative Care	Ireland
13	Mr Sibusiso V Dlamini			Swaziland
14	Dr Carl-Johan Fürst	Board member and Director	EAPC East Project	Italy
15	Ms Barbara Gelb	Chief Executive	Association of Children's Hospices	UK
16	Dr Cynthia Goh	Senior Consultant	Asia Pacific Hospice Network	Singapore
17	Ms Louise Gray	Courses and Conference Administrator	Help the Hospices	UK
18	Dr Liz Gwyther	Member of the education Association sub-committee	Hospice Palliative Care Association of South Africa	South Africa
19	Ms Peggy Harper	Executive Director	Foundation for Hospices in Sub-Saharan Africa	USA
20	Dr Ednin Hamzah	CEO/Medical Director	Hospice Malaysia	Malaysia
21	Mr Andrew Hoy	Trustee	National Council for Hospice and Specialist Palliative Care Services	UK

22	Dr Amandua Jacinto	Commissioner for Health Services Curative	Ministry of Health	Uganda
23	Ms Avril Jackson	International Information Officer	<i>hospice information</i>	UK
24	Ms Lucinda Jarrett	Chief Executive	Rosetta Life	UK
25	Professor Stein Kaasa	President	EAPC	Italy
26	Dr Bactrin Killingo	Project Co-ordinator	Meru Hospice	Kenya
27	Ms Leanne Kitchen	Community Investment and Philanthropy Manager	The GlaxoSmithKline Foundation	Canada
28	Mrs Ritta Kork	Nurse	University Hospital of Tampere - Dept of Palliative Medicine	Finland
29	Dr Suresh Kumar	Executive Director	Calicut - WHO demonstration project	India
30	Ms Carla Lamadora	Administrator	Hospice Association of Zimbabwe	Zimbabwe
31	Antonella Lio	Congress officer	EAPC	Italy
32	Professor Jacek Luczak	Chairperson	ECEPT, Chair and Palliative Medicine Department, Poznan	Poland
33	Dr Stanley Macaden	Secretary	Indian Association of Palliative Care	India
34	Ms Amanda Marlin	Programme on Cancer Control	World Health Organization	Switzerland
35	Ms Jennie McDowall	Major Project Support Officer	Help the Hospices	UK
36	Dr Anne Merriman	Founder and Director of Education	Hospice Africa, Uganda	Uganda
37	Dr Daniela Mosoiu	President	Romanian National Association for Palliative Care	Romania
38	Mr Geoffrey Mitchinson		The GlaxoSmithKline Foundation	Canada
39	Dr Faith Mwangi-Powell	International Advocacy Officer- Palliative Care Initiative	Diana Princess of Wales Memorial Fund	UK
40	Mr Nick Pahl	Development Director	Help the Hospices	UK
41	Mr Graham Perolls	Executive Director	Hospice of Hope, Romania	UK
42	Mr David Praill	Chief Executive	Help the Hospices	UK

43	Dr André Rhebergen	Executive Director	Agora (National Foundation to Stimulate Palliative Care in Holland)	The Netherlands
44	Dr Thomas Schindler	Counsellor in PM	German Association of Palliative Medicine	Germany
45	Dr Cromwell Shalunga	Head of Department	Chilanga Hospice	Zambia
46	Mrs Anja Smolander		Pirkanmaa Hospice	Finland
47	Dr Jan Stjernswärd		WHO Collaborating Centre	Sweden
48	Dr Arianne Stoppelenburg	Staff Officer	Agora (National Foundation to Stimulate Palliative Care in Holland)	The Netherlands
49	Mr Mick Thorpe	Vice President	Help the Hospices	UK
50	Dr Franco Toscani	Direttore Scientifico	Istituto di Ricerca in Medicina Palliativa "L. Maestroni"	Italy
51	Dr Robert Twycoss	Emeritus Clinical Reader	Palliative Medicine - Oxford University	UK
52	Mrs C Van Tol Veragen	Management	Agora (National Foundation to Stimulate Palliative Care in Holland)	The Netherlands
53	Mr Andre Wagner	Chair	Hospice Palliative Care Association of South Africa - Organisation and Development Committee	South Africa

Appendix 2: Programme for National Associations Seminar 2003

Sunday 30 March 2003

- 6.30pm Registration and distribution of material
- 7.30pm Introduction - David Prail
Opening statements - Eduardo Bruera; Liliana de Lima IAHPC
Stein Kaasa EAPC
- 8.30pm Dinner at The Golden Tulip

Monday 31 March 2003

National Associations - their role and purpose

Chair: David Prail, Chief Executive, Help the Hospices, UK

- 9.00am *The unmet need for hospice and palliative care*
Jan Stjernswärd, WHO Collaborating Centre, Oxford
Avril Jackson, *hospice information*, UK
- 9.45am *Setting up a national association*
Gustavo de Simone, Argentinean Association (AAMCYP)
- 10.30am Discussion on visions when setting up a national association
- 10.45am Coffee
- Chair: Mary Dempsey, Ireland
- 11.15am *The role of national associations in supporting community services*
Liz Gwyther, Hospice Palliative Care Association of South Africa (HPCASA)
- 11.45am *Grassroots strategies*
Suresh Kumar, Pain and Palliative Care Society, India and Executive Director of Calicut - WHO demonstration project
- 12.15pm *Towards a consensus statement on national associations' values*
(document to be circulated previously)
- Outcome Consensus document on existing national associations values
- 12.30pm Lunch

Monday 31 March -2003

National Associations - their organisational development

Chair: Graham Perolls, Hospice of Hope, Romania

- 1.45pm *National associations' stakeholders and needs*
David Prail, Chief Executive, Help the Hospices
- 2.30pm *Presentations 1: National associations' structures, activities and need*
- Canadian Hospice Palliative Care Association, Sharon Baxter
 - Hospice Care Kenya, Bactrin killingo
 - Asia Pacific Hospice Network, Dr Cynthia Goh
 - ECEPT, Prof Jacek Luczak
- 3.15pm Coffee
- 3.45pm *Presentations 2: National associations' structures, activities and need*
- Hospice Palliative Care Association of South Africa, Liz Gwyther
 - European Association for Palliative Care / EAPC East, Stein Kaasa and Carl Johan Fürst
 - Indian Association of Palliative Care, Stanley Macaden
- 4.15pm Discussion - summary of issues for national associations regarding structure, activities and need
- Outcome Summary report of national associations' needs
- Chair: David Prail, Chief Executive, Help the Hospices, UK
- 4.30pm David Clark - presentation on International Observatory on end of life care
- 5.15pm The Canadian Living Lessons Partnership between GlaxoSmithKline and the Canadian Hospice Palliative Care Association explored
Presenters: Geoffrey Mitchinson, Leanne Kitchen, The GlaxoSmithKline Foundation and Sharon Baxter, Canadian Hospice Palliative Care Association (CHPCA)
- 6.00pm Presentation - Rosetta Life worldwide arts project
- 6.45pm Close
- 7.15pm Dinner at The Golden Tulip
- Evening - event in The Hague - meet in foyer at 8.45pm

Tuesday 1 April 2003

National Associations, Government and Society

Chair: Dr Cynthia Goh, Asia Pacific Hospice Network

- 9.00am *NGOs and the government - case study*
Dr Anne Merriman, Hospice Africa, Uganda
- 9.30am *Strategies of working with Government*
Franco Toscani, The experience in Italy
- 10.00am Question and answer session with panel review:
Kathy Foley, Open Society Institute, Project on Death in America
David Clark, University of Sheffield
Sharon Baxter, Canadian Palliative Care Association
- 11.00am *Hospice and Palliative Care standards*
Nick Pahl, *UK forum for hospice and palliative care worldwide* with Stephen
Connor (USA), NHPCO
- 11.45 Discussion and Questions on consensus document
- Outcome Summary report of models of working with Government
- 12.15pm Lunch

National Associations: the international agenda

Chair: Tonia Barnes, Palliative Care Australia

- 1.30pm *National associations and the international agenda*
The WHO perspective - Amanda Marlin, Cancer Control Programme
Jan Stjernswärd, WHO Collaborating Centre, Oxford
- 2.00pm Breakout group work with facilitators
- Group 1*
- Future international networking and leadership: what action should be taken?*
Eduardo Bruera IAHP; Mary Callaway, Soros and Nick Pahl, UK forum for hospice and palliative care
worldwide; Carl Johan Fürst, EAPC
- Group 2*
- Expanding palliative care internationally: challenges (including funding)*
Faith Mwangi Powell, Diana, Princess of Wales Memorial Fund; Liliana de Lima, IAHP and Cynthia
Goh, Asia Pacific Hospice Network

Group 3

National associations values: implementing the consensus statement
Sharon Baxter, Canadian Hospice Palliative Care Association

Group 4

National associations and government - producing national strategies
Tonia Barnes, Palliative Care Australia

Group 5

Paediatric issues
Barbara Gelb, Association of Children's Hospices, UK

3.00pm	Feedback
3.40pm	<i>Plans for write up -David Clark and Nick Pahl</i>
3.45pm	<i>Summary of seminar: conclusions and action points</i> David Praill, Help the Hospices, UK
Outcome	Towards a global action plan

Appendix 3: Towards a consensus statement on national association values

Outcome: Consensus document on existing national associations values

Overall values

Subscription to WHO definition

Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness, in conjunction with anticancer treatment. Palliative care:

- affirms life and regards dying as a normal process;
- neither hastens nor postpones death;
- provides relief from pain and other distressing symptoms;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement.

Radiotherapy, chemotherapy and surgery have a place in palliative care, provided that the symptomatic benefits of treatment clearly outweigh the disadvantages. Investigative procedures are kept to a minimum.

Taken from Cancer Pain Relief and Palliative Care

WHO Website, downloaded August 2002

People have the right to a dignified death that is free of pain and is accordance with their spiritual and religious needs

Resources need to be allocated to meet the needs of terminally ill people so that this is achieved.

Organisational values for national associations

- Reflect the views of individual hospice and palliative care providers
- Catalyst in strategic thinking about the future development of services
- Share information in an open way with each other
- Advocate, enable and facilitate hospice and palliative care services to develop
- Profile raise - to get hospice and palliative care onto the health care policy agenda
- Co-ordinate hospice care where appropriate to avoid duplication
- Work with local services to avoid and reduce duplication where appropriate
- Develop the skills and understanding of medical professionals
- Establish and promote partnerships based on trust and exchange
- Establish benchmarks of individual skills and care standards for organisations
- Foster regional collaboration where appropriate
- Promote palliative care to other relevant national bodies

- Lead by example through high standards of work
- Foster mutual respect and integrity between providers of services
- Facilitate creativity and empower change
- Involving service users (patients, carers, families) in developing services
- Work with local services to increase equality of access to services

Allied professional values

- respect every individual, regardless of sex, age, race, intellectual or socio-economic standing
- value every moment of life and will not support any action that has the intention of shortening a person's life
- recognise that the individual and the family are entitled to make informed decisions about care
- respect the confidentiality of all information arising out of the provision of care
- believe in empowerment of the individual, the family and the community
- respect the faith, belief system and culture of each individual
- respect the rule of law and will work within the law of each country
- facilitate peer support and continuing professional development
- value multi-disciplinary team work and volunteers
- be aware of need to avoid inappropriate interventions
- focus on holistic and patient centred/ led care

Issue

- Care free at the point of use?

Outcome: Summary report of national association needs

Policies

- Worldwide palliative care standards
- Internal governance
- External representation and governance

Skills and Knowledge

- View of hospice needs and financial position
- Information services
- Palliative care professional support
- Volunteer support
- Peer support

Networks and linkages

- Link with patient and carer views
- Partnerships between national bodies
- Regional co-operation
- Link into Government/ Parliamentary groups
- Link with faith groups
- Linkages with medical profession/ other institutions

Direct Support

- Education and training
- Awards programmes

Outcome: Summary report of models of working with Government

There are important issues on how to develop community ownership as well as Government confidence that services reflect the needs of community.

Management of services

- State
- NGO/private management
- Combination

Funding

- State
- NGO/ private
- Combination

Planning services

- Separate - state/private
- Partnership

Issues - do individual services within sectors work together to plan services?
At what level are services planned? - e.g. national/ regional/ local?

Needs assessment

- Is this done? By whom (state, individual services, other)? How?

Innovation, research and development

- Is this planned/managed/ funded differently from ongoing services?

Regulating services

- By State or private
- By service providers?

Depending on the models, national associations may influence services by:

- Campaigning to influence government decisions
- Working in partnership with government to make decisions
- Working with local services

What and aim	When	Resources required	Questions
Information: Write up of this seminar			
Regional workshops			
Joint research			
Joint standards			
Information links e.g. video conferencing			
Basic data collection			
Needs assessment exercise ...			
Other...			
Funding: Joint funding programme			
Joint meeting with funders			
Other...			
Education and training: Web based training project			
Skill sharing project (facilitate visits of professionals)			
National association twinning			
Education and training awards - report			
Other...			
AdvocacyJoint approach to pharmaceutical companies			
Joint parliamentary groups			
Joint faith approach			
Links between medical institutions			
Other...			

Appendix 4: References

- 1 Clark, D Wright, M (2002) Transitions in End of Life Care: Hospice and related developments in Eastern Europe and Central Asia. Buckingham: Open University Press.
- 2 Doyle, D Hanks, G Cherny, N Calman, K (2003) Oxford Textbook of Palliative Medicine 3rd edition. Oxford: Oxford University Press.

A cloak around the world

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