

Report of the 2nd Global Summit of National Hospice and Palliative Care Associations
15-16th March 2005, Seoul, Korea

Advocating hospice and palliative care:
challenges, contexts and changes

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Preface

It is now recognized that national associations have a key role in supporting care of the dying around the world.

In April 2003, linked to the European Association of Palliative Care (EAPC) conference in The Hague, Help the Hospices facilitated the first global summit of national associations.

Key outcomes of the first summit were a shared understanding of strategies for expanding palliative care in respective countries and the development of national associations and joint advocacy strategies (e.g. the development of world hospice and palliative care day).

The organising committee members for the second summit included Dr Cynthia Goh (Singapore) – co-Chair; David Prail (UK) – co-Chair; Sharon Baxter (Canada); Stephen Connor (USA); Dr Dinesh Goswami (India); Dr Liz Gwyther (South Africa); Dr Daniela Mosiou (Romania); and Dr Faith Mwangi Powell (Uganda). Our thanks go to this group and particularly Tonia Barnes from Australia for their support and inspiration in getting this process started. Financial support was received from NHPCO – US, IAHPCC and OSI for some participants for which we are grateful.

We were pleased that during the summit the participants agreed it would be useful to meet in two years time, and to continue exploring future national association links, perhaps in a more formal way. This organising committee is planning to meet in November 2005 to explore future plans for the network - not least the 2007 meeting.

The summit produced a declaration - available in this document and at www.hpc-association.net (also on the website in French, Spanish and Portuguese). National associations are encouraged to ratify this for advocacy purposes. We are beginning to realise that there is much to be gained from our working together globally.

I hope you find this report useful and helpful in developing your work.

**David Prail
Help the Hospices
June 2005**

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Executive Summary

This summit was the second global summit of national associations of hospice and palliative care. The previous one was held in the Hague in 2003. The summit was attended by 72 individuals from over 30 palliative care organisations around the world. This included national and regional associations, non-government organisations, and major palliative care funders.

The aims of the summit were to share information and experiences, to assess the progress of the international networks of national associations that have developed since the first global summit in 2003, and to strengthen future working relationships in order to further develop palliative care across the world. A wide range of presentations were delivered and many organisations presented posters and other material during the conference describing the contexts and challenges of palliative care in their individual countries. There were opportunities for discussion and debate, both formally and informally, and some ad-hoc meetings also took place.

Throughout the conference the challenges of developing palliative care services were highlighted. The impact of poverty, HIV/AIDS, limited access to education and training, barriers to opioid use, and government inertia were all factors which were presented as hindering the development of palliative care.

Advocacy emerged as a strong theme. Those working in hospice and palliative care around the world in different cultural contexts face a variety of challenges in determining the most effective and appropriate strategies for change to improve care

The major outcomes from the conference reflected both the desire for change and also underlined the extraordinary commitment and energy of the individuals developing hospice and palliative care around the world. There was support for continuing to bring together national associations every two years to think about the most effective ways of working together.

Conference outcomes:

- **The endorsement of the Korea Declaration (see Appendix 4)**
- **Agreement to organise a 3rd Global Summit of national associations of hospice and palliative care in 2007 in Africa**
- **The possible formation of a more formal global coalition to be explored by the national associations planning group**
- **Dissemination of the Advocacy Tool Kit**
- **The formation of a number of new working groups including the International Children's Palliative Care Network**
- **The organisation of interactive discussion groups to e.g. promote World Hospice and Palliative Care Day October 8th 2005; and drugs issues.**

This was the second conference to bring 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. The participants were welcomed to Seoul and the conference by Professor Kyung Shik Lee, President of the Organising Committee of the 6th Asia Pacific Hospice Conference (APHC).

David Prail, Chief Executive for Help the Hospices, UK opened the conference by thanking APHC 2005 for providing hospitality for the 2nd Summit. 72 delegates were present at the conference, representing 32 countries (see Appendix 1 for a full list of attendees). The full conference then began, the programme for which can be seen at Appendix 2.

1. Hospice and Palliative Care around the world

Liliana De Lima, International Association for Hospice Palliative Care (IAHPC), USA

The global context for hospice and palliative care was broadly outlined which demonstrated the unequal conditions in which developed and developing countries are providing hospice and palliative care. For example:

- **Mortality in 2001 was recorded at 56.5 million deaths worldwide and 76% in the developing regions, where over three-fourths of the world's population live**
- **Of those diagnosed with cancer, 80% die of the disease in developing countries**
- **There were approximately 14,000 new HIV infections a day in 2002, more than 95% of which were in developing countries**
- **4 billion of the total world population live in poverty - 75% live in developing countries**

For developing countries, hospice and palliative care is often provided by health professionals in addition to their regular full-time job and without reimbursement. Palliative care is not incorporated into the health care system and there is limited access to active care, technology, new developments and research. Additionally, there is poor availability of opioid analgesics, demonstrated by 70% of global consumption of morphine occurring in Australia, Canada, France, UK and USA.

Avril Jackson, Hospice Information, UK

Hospice Information (HI) is an international resource on hospice and palliative care for professionals and the public. It is a joint venture between St Christopher's Hospice and Help the Hospices. The aim of the service is to provide a broad range of information services and to facilitate informal networking and information-sharing. A unique feature of HI is its enquiry service, which deals with over 6,000 enquiries each year, of which around 33 per cent currently relate to international matters. Signposting is also a strong point and, where appropriate, HI connects people and organisations to other key players such as: national, pan-national, and regional palliative care associations and information/resource centres, including: IAHPC; Open Society Institute; International Palliative Care Initiative; International Observatory on End of Life Care, Lancaster; Pain and Policies Group, Wisconsin; other academic centres and St Christopher's Hospice library.

Through membership and circulation of electronic newsletters, HI reaches some 6,000 readers in around 105 countries of the world. Other HI publications include c. 30 fact sheets relating to planning and organisation of palliative care services ranging from art therapy guidelines to helping patients to travel safely on international flights, UK and international directories, HI's magazine "Hospice Information Bulletin" and 'getting started' information packs. Membership and access to HI products are free to poor countries.

2. National Associations Update: Challenges in Advocacy

Sharon Baxter, Canadian Palliative Care Organisation
Joan Marston, Hospice Palliative Care Association of South Africa

This presentation reported on the work of the Advocacy Committee of the National Associations of Hospice and Palliative Care which was formed in the summer of 2004. The committee's advocacy goals were:

- **Access to hospice palliative care programs and services worldwide**
- **Access to pain and symptom management**

In an attempt to develop a way of facilitating collaboration between national associations the committee had drafted the 'Korea Declaration' (Appendix 4). Delegates were encouraged to read and comment upon the draft declaration with the aim of signing the document at the end of the conference. It was proposed that this 'globally endorsed' declaration could then potentially be utilised as an advocacy tool to press for change. A final version of the declaration would be announced for World Hospice and Palliative Care Day, 2005.

It was argued that hospice and palliative care should be viewed as a development issue, and that advocacy was central to this approach. Delegates were reminded that the major problems facing the developing world are predominantly HIV/AIDS and poverty. In particular, advocacy was proposed as a key strategy to securing resources for paediatric palliative care for the increasing numbers of children infected and affected by HIV/AIDS. It was maintained that a significant challenge is to bridge the gap between the hospice and palliative care movement and the HIV/AIDS field. Global funds for HIV/AIDS, TB and malaria must include hospice palliative care initiatives. It was recommended that developed countries should try to influence their governments' international development agendas to include HIV/AIDS, essential medicines and hospice and palliative care.

A further proposal was that international agencies such as WHO and UNAIDS incorporate hospice and palliative care in their agendas. At the World AIDS Conference in Bangkok, Thailand, there had been only a handful of palliative care workshops and only 20 posters out of 10,000. Palliative care needs a higher profile and it was proposed that a satellite palliative care meeting be organized at the Toronto 2006 meeting. Attention was also drawn to the draft Advocacy Tool Kit which had been written by Helen Sida for Help the Hospices summarising advocacy tools from around the world. It contains case studies which could be utilized to affect change.

The presentation finished with some thought provoking questions for discussion:

- **The goals – are they valid? What needs to be done around the world?**
- **The declaration – can you sign it?**
- **The Advocacy Tool – will you use it?**
- **The strategy for dealing with international organizations – can we create a global strategy?**
- **Toronto 2006 satellite proposal – do you want to be involved?**

Discussion

There was a short discussion focussing upon the importance of placing palliative care initiatives on the HIV/AIDS agenda in developing countries. It was suggested that advocacy was an important tool which should be used to encourage governments to develop palliative care, and that the advocacy tool kit could assist in the lobbying of governments.

3. National Associations: The Story Thus Far

David Prail, Help the Hospices, UK

Stephen Connor, National Hospice and Palliative Care Organisation, USA

The national associations of hospice and palliative care had been brought together with the idea of networking, sharing knowledge, and to find ways of improving the effectiveness of working together. It was noted that the enthusiasm demonstrated by participants at the conference illustrated the need for this type of collaboration and also that national associations are developing and maturing.

The results of a national association survey were reported. The aim of the survey was to collect baseline information about the work of national associations across the globe. A scoping exercise found 93 national associations operating. A simple questionnaire was distributed to these associations and 50 countries returned the completed survey. A key finding was that in 2002 only 8 countries had national palliative care standards, but that three years later 19 countries had developed national standards.

Participants were asked to discuss the future of collaboration between national associations of hospice and palliative care. A questionnaire had been distributed and delegates were requested to return the completed survey as soon as possible.

Discussion

There was some debate about the problems of collecting comparative national data in countries with various levels of development and different ways of delivering hospice and palliative care. Difficulties were also identified where national associations were run without paid employees, because completing such surveys had resource implications.

The importance of access to information was re-emphasised. It was suggested that technological advances such as distributing information through websites could facilitate changes in the attitudes of people and governments. For example, in Costa Rica the existing pain clinics were seen as providing palliative care, and this made progressing the wider notion of palliative care difficult. It was suggested that web-based information could help develop an understanding of palliative care to mean more than pain control. The problems of translating internet resources were highlighted.

The discussion then returned to the issue of how to influence national institutions and governments to take positive action in developing palliative care, and to ensure that governmental bodies were not 'all talk and no action'. It was suggested that perhaps the hospice and palliative care movement in developing countries could learn from other social movements. It was noted that there were limits to the ways in which national associations could affect change, and the impetus might need to come from a number of different directions. One proposal was that palliative care should be demanded as a human right and that an international coalition of groups around palliative care should be formed to press for change. This was not envisaged as a 'quick fix' solution but more a long-term strategy.

Some delegates queried the purpose of forming an international coalition and there was uncertainty about whether palliative care could be demanded as a basic human right. However, there was a general consensus that global discussions at an event such as the 2nd Summit were extremely useful for national associations.

4. National Association Updates: Obstacles and Achievements

In this session the national associations from each country participating at the Summit were given three minutes to provide an overview of hospice and palliative care developments in their individual countries. This information is summarised below:

Europe – Lead: André Rhebergen

Netherlands – André Rhebergen, National Support Centre for Palliative Care

- Immense growth: 200 organisations; > 700 beds; 9 regional consultation teams; €25,000,000 research; 72 palliative networks; palliative departments; Government funding high
- Place of death: home - 58% (highest in Europe); hospital - 31%; nursing home / home for elderly - 11%
- Challenges: quality, ageing population, specific groups (e.g. Muslims), education, research

UK – Lead – Avril Jackson, Hospice Information

- Over 220 hospices linked to palliative care networks (part of National Health Service Cancer Networks)
- 80% of in-patient care provided by independent hospices (charitable institutions)
- Government funds less than one-third of adult hospices and less than 5% of children's hospices
- Challenges - Barriers to accessing palliative care for minority ethnic groups
- World Hospice and Palliative Care Day is a primary focus of development.
- Hospice information has more information about UK palliative care

Romania – Daniella Mosoiu, Romanian Hospice Association (RHA)

- RHA established in 1997, now has 200 members
- Utilised WHO triangle model in 2000 to develop palliative care as a sub-speciality
- Run a training program with more than 3,000 people
- Palliative care services = 25; 4,000 patients a year but this is less than 3% of need
- Success: Palliative care legislation so people have rights to palliative care; translation of material
- Challenges: funding in-patient services

Hungary – Katalin Hegadus, Hungarian Hospice-Palliative Association

- Patients receiving palliative care in 2004: 2,400
- 10 hospice in-patient units with 133 beds, 28 hospice home care teams, 2 day care centres, 4 hospital support teams (mobile teams), special hospice services in 6 nursing homes (46 beds), 50 organizations, 179 beds
- Achievements: minimum standards (March 2004); two years financing pilot programme for hospice/palliative services by the National Health Care Insurance Fund (April 2004); National Palliative Plan (from 2004 to 2008)

Lithuania – Dr Arvydas Šeškevičius

- 7 supportive treatment and nursing hospitals; 70 nursing hospitals; 5 oncology centres and 2 university's oncology clinics
- **Challenges:** Ministry of Health to ratify the standards of palliative care and palliative medicine so hospices can be established; ratify the standards of qualification for specialists in palliative medicine; Senate of Universities should ratify the standards of teaching for specialists in palliative medicine

Israel – Dr Michaela Bercovitch

- 164 doctors affiliated to palliative medicine society
- 67 beds, one hospice for children only four beds
- Some clinics provide palliative care - department in Jerusalem and in two hospitals
- Palliative medicine is taught at two universities

Ukraine – Association of Palliative Care

- Aim to organise palliative care
- 3 hospices with in-patient care
- **Challenges:** education, limited support at national level
- Need to increase awareness in medics, public and at national level

Poland - Peter Krakowiak, National Chaplain of Hospices in Poland

- 108 non-government, non-profit hospices
- Run by 63 lay associations and 45 church associations
- 93 provide home care; 12 day care; 32 in-patient (approx. 565 beds)
- 45 rely exclusively on volunteer workers; 108 hospices employ 2,500 volunteers
- 72 hospices signed contract with National Health Fund
- www.hospicja.pl/en portal (now in English) leading forum for hospice staff, palliative medicine centres, and patient families

Americas – Lead: Stephen Connor

Canada – Sharon Baxter, Canadian Hospice Palliative Care Association

- CHPCA represents 11 provincial associations, over 410 hospice palliative care programs and 3,000+ members
- **Challenges:** access and availability; in most provinces hospice palliative care services not core funded
- **Key achievements:** national norms of practice; national strategy on palliative and end-of-life care; four new fully funded home and community based end-of-life care services in September 2004; National Compassionate Leave Program – 8 weeks leave, 6 weeks paid by government; National research program

USA – Stephen Conner, National Hospice and Palliative Care Organisation

- First hospice: 1973
- 29% of all deaths received hospice care in 2003; 51% of hospice admission for non-cancer illness

- **Currently over 3,300 programs delivering care**
- **Problems: short length of service; curative treatment restriction; eligibility limitations; variability in quality**
- **Challenge: increase access for underserved populations**

Costa Rica - Dr Lisbeth Quesada-Tristán, Costa Rican Palliative Care Movement

- **First palliative care clinic: 1990**
- **26 Palliative care clinics (1 paediatric) at various stages of development**
- **Free funding: non-profit NGO, 17 receive funds from the lotto**
- **Success: Law 7756 - carers for terminally ill patient receive state benefits of 60% salary for 6 months**

Uruguay – Dr. Eduardo García Yanneo

- **Palliative care services 17, 9 in Montevideo (5 private, 4 public health); 8 outside Montevideo**
- **20-30% of all the cancer deaths, mostly in Montevideo**
- **Challenge: to increase coverage; service quality; medical education**

Latin America – over view by Dr. Roberto D. Wenk (Programa Argentino de Medicina Paliativa-Fundación FEMEBA, Argentina)

- **70% Latin America, palliative care is not a priority in health policies**
- **80% Latin America, palliative care is not yet recognized as a discipline**
- **Palliative care is often inaccessible and unaffordable: patients and families can not pay for the services or the medication**
- **Definite barriers to opioids use in Colombia, Peru, Mexico, Argentina, Costa Rica**
- **Palliative care overwhelmingly provided in cities, rural provision poor**
- **There is a lack of palliative care medical training**

Africa and Middle East – Lead: Anne Merriman

South Africa – Dr Liz Gwyther, Hospice Palliative Care Association of South Africa

- **First hospice established: 1980**
- **Provision: home care, day care, (including out-patient care), in-patient care, 6 hospital palliative care teams, Provincial Palliative Care Development teams**
- **Challenges: funding and sustainability**
- **Goals: to develop hospice service in each health sub district-174**

Uganda and African Palliative Care Association (APCA) – Anne Merriman

- **HIV greatest burden on palliative care, not cancer**
- **46 countries in sub-Saharan Africa only 16 have palliative care**
- **In Uganda free oral morphine from Government when prescribed by specific doctor. Nurses and Clinical Officers, after 9 month training with Hospice Uganda are able to prescribe morphine since 2004. The first country to allow this.**
- **Malawi developing fast in the last three years**
- **Nigeria developing University Teaching Hospital service (UCH, Ibaden) but no home-care service yet**

- **Mission: to promote and support affordable and culturally acceptable palliative care throughout Africa. APCA now has new premises**

Asia Pacific (including Australia and New Zealand) – Lead: Cynthia Goh

Korea – Professor Jun Suk Kim, Korea University Medical Centre, Seoul

- **Approximately 100 hospice organisations**
- **37.5% of these provided by non-medical organisations**
- **Challenges: lack of hospice legislation, quality standards and finances**
- **Outcomes of 2-year government funded hospice and palliative care demonstration project should address these problems**

Mongolia – Professor Davaasuren Odontuya, President of Mongolian Palliative Care Society

- **64.3% cancer patients die within one year diagnosis**
- **Mongolian Palliative Care Society established in 2000**
- **2 in-patient hospices (20 beds); 2 palliative care beds in each region (24 beds); 2 out-patient services, 21 oncology out-patient cabinets in regions; 6 home care services**
- **Problems: availability of essential medicines and nursing supplies; fear of morphine; lack of government financial support**

Japan - Dr Kenji Nishitatenno, Peace House Hospice, Tokyo

- **Palliative care is embedded in medical practice and part of health policy. It has been developing over the last three decades, funded by health insurance**
- **There are 131 units, 2,449 beds mostly in hospitals; home care just starting**
- **Hospice Palliative Care Japan has developed quality standards.**

Taiwan – Dr Sheau-Feng Hwang, Palliative Care Unit, Taichung Veterans General Hospital

- **Cancer is the leading cause of death**
- **29 in-patient units with 448 beds; hospice home care teams in 44 hospitals (both reimbursed by national health insurance); hospital-based consultation teams in 33 hospitals**
- **coverage rate 20%**

Hong Kong – Mrs Yvonne Siu Sun, Society for the Promotion of Hospice Care

- **One of first places in Asia to introduce hospice care**
- **99% patients receiving palliative care have cancer**
- **10 in-patient units, 9 home care teams, day care service, consultant teams**
- **Duration of service: 70-80 days of patients' last journey**
- **Coverage of 65% of all cancer deaths**
- **Strengths: well developed professional training for palliative care doctors and nurses and the majority of patient services under government funding**
- **Difficulties: Health finance constraint**
- **Challenges: palliative care for non-cancer patients and life and death education for the public**

China – Dr Frieda Law, Li Ka Shing Foundation, Shantou University Medical School

- 20 hospice sites run by the Li Ka Shing Foundation in mainland China; 17 attached to hospitals
- 142 front line staff; 1880 volunteers
- Hospice service includes free, home-based care
- Challenges: increase patient numbers; reduce medication costs; increase awareness; increase volunteer involvement

Philippines – Ms Asuncion B Kalalo, National Hospice and Palliative Care Council of the Philippines (NHPCCP)

- Mission: To promote networking and cooperative linkages with local and international agencies through advocacy, education and training, standardization of care and service, research and registry
- 16 member organisations; 9 home care services; 8 hospital-based services, 2 out-patient services; 4 provide training
- Future activities: increase government support for morphine access; facilitate the accreditation of the hospice with the national medical insurance system; increase funds; widen service access

Indonesia – Professor Sunaryadi Tejawinata, Indonesia Palliative Society

- Palliative care services began in 1992
- Currently 6 palliative care centres providing in-patient, out-patient and home care services (mainly cancer patients)
- current coverage less than 1%
- Aim to increase population coverage through training, raising funds and political will

Malaysia – Dato' Dr T Devaraj, Chair, Malaysian Hospice Council (MHC)

- Hospice care started outside public health services in 1992
- Increase of hospice organisations from 11 to 20
- Ministry of Health accepts palliative care as service provision and starts palliative care units in all district hospitals in 1998, total 88 beds
- coverage less than 10%
- Challenges: to increase service provision and public and professional awareness, funding, training and staff

Singapore – Dr Chen Ai Ju, Chair, Singapore Hospice Council

- First hospice started 1985
- Current service provision: 4 home care services (2,802 referrals per annum); 4 in-patient services (129 beds); 3 day care services; 4 hospital consultative services; 4 specialist outpatient services; for population of 4 million
- coverage 75% of cancer deaths; 19% of total deaths
- Challenges: lack of trained physicians; accreditation of palliative care as speciality; public education

Thailand – Dr Sakon Singha, Prince of Songkla University Hospital, Hatyai

- New national association set up in February 2005
- Hospice and palliative care in infancy; coverage less than 1%
- Small amount of hospice and hospital provision
- Palliative care is supported by the Ministry of Health
- 1st PC conference held in 2004

Vietnam – Dr Hoa Hai Hoang, Cho Ray Hospital, Ho Chi Minh City

- Palliative care services started 1997
- Hospital units and homecare services
- Coverage of the population in need under 1%
- Cancer deaths: 70,000 per annum
- Important issues: lack of public and professional awareness; lack and under-use of opioids
- Training courses being organised with overseas help

India - Dr Suresh Kumar, Institute of Palliative Medicine, Calicut, Kerala

- Less than 100 palliative care units in whole of India with population 1,065 million
- Estimated 2-3 million people with advanced cancer – less than 3% have access to palliative care services
- Neighbourhood Networks in Palliative Care (NNPC) adopt philosophy of palliative care as primary health care
- 64 NNPC palliative care units in Kerala - 59 are owned and run by local community
- Lessons from NNPC: Look beyond palliative care – cannot ignore the social; palliative care ‘models’ can be misleading – rely on the community

**Australia – David Currow, Chair, Palliative Care Association of Australia, Adelaide
National association formed 15 years ago**

- Palliative care integrated across the system; over 320 services covering in/out patient, consultative, and community care
- 56% of ‘expected’ deaths access specialised palliative care services; 1 out of every 6 people referred do not have cancer as their life-limiting illness
- Challenges: facing increasing community expectations; coverage for remote rural and some metropolitan areas.

New Zealand – Professor Rod MacLeod, Hospice New Zealand, Wellington

- First hospices opened in 1979 in Wellington and Auckland
- 38 hospice programs with a wide variety of activities; 5 hospital teams for population of 4 million
- Between 2003/04 number of patients rose by 8%; non-cancer patients increased from 12% to 14%
- Challenges: insufficient state funding; increased hospice access

Asia Pacific Hospice Palliative Care Network (APHN) – Dr Rosalie Shaw, Singapore

- APHN aims to promote the development of hospice palliative care in the region
- Diversity of population, race, language, wealth

- **More than 600 palliative care services in the region; variation in the level of service**
- **Pakistan: Shaukat Khanum Memorial Cancer Hospital in Lahore needs a palliative care physician**
- **Nepal: Attempting to develop service awaiting training, Hospice Nepal in Kathmandu and interest in hospitals in Bharatpur and Kathmandu**
- **Bangladesh: Ashic Foundation program in Dhaka**
- **Myanmar: 40 bed in-patient hospices in 2 cities (Yangon and Mandalay) another being built in Taunggi**
- **Sri Lanka: in-patient hospice in Colombo (Shanta Sevana) has requested professional and volunteer training**

5. National Association Focus Sessions

On the second day of the conference delegates divided into groups to discuss specific issues and then a summary of these was fed back to the plenary session at the end of the day.

Quality of care including monitoring tools and standards
Stephen Connor, USA

In this group European (André Rhebergen), African (Liz Gwyther) and USA (Stephen Connor) perspectives on defining and measuring quality in palliative care were outlined. Attention was drawn to the differences between countries and global regions in defining and measuring quality standards. Of particular concern were questions regarding how to determine quality of care and which measures (such as reported patient satisfaction, staff training or patient/staff ratio) were appropriate. What outcomes are measurable for palliative care services in different settings was at the centre of the discussion. In the USA, it was reported that accountability was high on the agenda and the public production of palliative care measures was advocated. There was also debate about what constitutes a good death. The group consensus was that a 'good death' meant the individual was cared for holistically – that is their physical, social, psychological and spiritual needs were met, across settings of care, and that there was care for the family after death.

The specific challenges in measuring quality in resource-poor settings were raised, but it was also emphasised that patients and families have the right to quality care and support. It was suggested that there was a need for an agreed framework for measuring quality internationally and key to this was the collaboration of palliative care experts across the world. A meeting of world leaders in researching quality measures was scheduled to meet shortly.

Advocacy to governments and policy makers
Sharon Baxter, Canada; David Joranson, USA

Four case studies were presented to share experiences of using advocacy to effect change. The Ugandan model of palliative care demonstrated a culturally acceptable and affordable model of palliative care which could be extended to other African countries where oral

morphine was available. In South Africa, the 'advocacy through mentorship' programme was a formal process to support palliative care workers and build capacity across the country. The scheme provided training and gave a voice to the community and enabled palliative care to be brought into wider geographical areas. It was stressed that the accreditation for hospices to participate in the mentorship programme required meeting standards across the structure of the service including levels of care, governance and management. The Canadian case study outlined the process of establishing compassionate leave for people caring for dying family members. It illustrated the powerful potential of collective organisation to press governments for change. Another case study suggested that the World Health Assembly (WHA) was an advocacy opportunity for individual countries.

A key advocacy tool was guidance on developing national opioids control policy from the WHO Pain and Policies Studies Group. This information could be used to contact government representatives at the WHA and it might accelerate the rate of change of national palliative care and narcotics policy in an individual country.

The most important aspects of advocacy from these case studies were summarized as:

- Working with both the grassroots and the political level at the same time could make a difference
- Timing – lay the foundations
- Coalitions and networks
- National associations could lead from behind – involve traditional and non-traditional partners
- Champions – be they political, folk hero or respected medical practitioners

At the plenary feedback session there was a substantial debate about the ways in which advocacy for palliative care could be promoted globally. This is summarised below:

World Health Organization (WHO)

WHO was seen as a key organization through which advocacy could affect change. The problem of getting the issues of palliative care to remain on the agenda of the WHO was raised. There was great concern that WHO no longer had a 'champion' for palliative care. The point was made that leadership from WHO was very important to developing countries because it was a powerful tool which could be utilised to open communications with governments about the need for palliative care.

The 58th World Health Assembly (May 16-25, 2005) attended by ministers of health worldwide was suggested as a place to lobby for palliative care to be included in global cancer strategies. It was suggested that participants could develop recommendations for the Assembly which could then be used to approach their own ministers attending the Assembly. There was a commitment to develop some key recommendations on how to strengthen the WHO document. Associations were encouraged to meet with their individual governments to move these changes forward.

Korea Declaration

The draft declaration which had been available for the duration of the conference was promoted as a tool for advocacy. It was proposed that the declaration could be used in an individual country to press governments to address the specific palliative care needs of the country. In addition, the use and uptake of the declaration could be monitored and reported to the 3rd Global Summit of national associations in two years time. Delegates were urged to give their comments on the draft as soon as possible. A press release was being written and a press conference was scheduled at the 6th Asia Pacific Hospice Conference the following day.

Some problems were raised about using the declaration in different countries. This was particularly an issue for Korean delegates because of the North Korea and South Korea divide. It was emphasised that however small a country, if the message was similar the advocacy effect would be powerful.

Advocacy Tool Kit

A new draft of the Advocacy Tool Kit for Hospice and Palliative Care Organisations (full document available from Help the Hospices), which summarises advocacy from around the world, would be available shortly and a dissemination plan would be developed. This document was written by the Advocacy Committee of the NAHPC in response to the issue of global access to palliative care.

Education and training – Liz Gwyther, South Africa

It was agreed among those attending the session that there should be an attempt to bring together the experience and expertise in training and education for professionals and non-professionals in palliative care. The key issues presented were:

- The development of a core curriculum
- Development of standards in education and training
- Evaluation methods to assess knowledge, skills and feedback to learners
- Palliative care as a separate discipline
- Further palliative care development for clinicians
- Validity of education/training programs
- Organise an expert interactive discussion group coordinated through Help the Hospices

World Hospice and Palliative Care Day – Claire Morris, UK; Mick Thorpe, UK

World Hospice and Palliative Care Day was to be held on October 8th 2005 and was a unified day of action to celebrate and support palliative care around the world. The aim was to increase the availability of hospice and palliative care around the world by raising awareness and funds. The symbol for the day would be a sunflower and there were plans for a similar day every one or two years. A message of support had been received from Archbishop Desmond Tutu and Dame Cicely Saunders had agreed to be patron for the day.

The discussion focussed upon how the day should be used and developed. The experience in Holland of organising a World Hospice and Palliative Care Day which started in 2003

indicated that planning should begin more than a year in advance. Some countries were better prepared than others. In Africa, through Hospice Africa Uganda the day has been advertised through a newsletter. A sponsored walk and a “grow a sunflower” event have been organised. It was hoped that a senior advisor to the president would send a message of support. The African Palliative Care Association was planning events through all African countries.

It was agreed that the day provided fantastic potential to raise awareness especially in countries where palliative care is not available. A range of initiatives was suggested to raise awareness and funds for the day, including classic car racing, working with schools and the media, song writing, asking a celebrity such as Elton John to write a song for the day, designing a special pin. It was important to seek recognition for the day from communities, organisations and governments. It was felt that the role of national associations should be to provide leadership – to initiate, coordinate and facilitate.

Funding national organisations and palliative care services - Mary Callaway, Open Society Institute, USA; Anne Merriman, Africa; David Prail, Help the Hospices, UK

In this focus session the financial arrangements between donors and recipients were debated at length. The experiences in Africa of receiving donor funding demonstrated a number of factors which palliative care organisations might need to take into account:

- Many donors were political
- Donors might have their own agenda
- Donors might change the definition to suit political goals
- Donors might want to change services to meet their own output goals and this may be a condition of funding

Applicants to donors need to be sure of their objectives so that they are not influenced to change these, only to ensure increased funding, by the donors.

The importance of delivering the palliative care services outlined in any agreements and proposals with donor organisations was also underlined as essential. A further problem of accessing donor funding was varying definitions of what constitutes palliative care. A particular concern was the difficulty and resource implications of completing funding applications while delivering services. It was suggested that training for both donors and recipients might improve the situation. There was also concern expressed about sustainability, and dependence on external funders. While some services might not have any choice about this situation, there might be a danger that the community ownership of services would be undermined by the expectations of donor organisations. It was suggested that a way of clarifying the relationships between donors and recipients would be for organisations to draft guiding statements to donors.

Another difficulty regarding fund raising was that it relied on the internal capacity of a country; it might not be the culture of all countries to give to charitable organisations. Marketing was highlighted as an essential aspect of income generation for hospice and palliative care services. The messages used to generate funds were fraught with difficulties, for example photographs of death might be culturally inappropriate and there was a need to think creatively about how to present palliative care provision.

Children's services – Joan Marston, South Africa; Barbara Gelb, UK

The discussion and networking around children and palliative care had been palpable for the duration of the conference. Excited by substantial interest and enthusiasm, a workshop had been held at 8am on the second day of the conference. The debate about the best way to develop children's palliative care services globally was continued into the afternoon focus group and a statement and objectives were developed. The statement declared that:

“Children and adolescents with life-limiting conditions have very specific palliative care needs which are often different to those of adults. If these children's physical, emotional, spiritual and developmental needs are to be met, the carers require special knowledge and skills. We ask that the voice of these children and adolescents is heard, respected and acknowledged as part of the expression of palliative care world-wide.”

Objectives for 2005-2007 were outlined:

- **To establish an international steering group to develop the following:**
- **To launch the International Children's Palliative Care Network**
- **To pilot and review a programme of expertise-sharing**
- **To ensure that children's palliative care is included in international meetings, journals and the work of national associations**
- **To develop a fund to support these activities**
- **To carry out a basic survey of existing children's hospice and palliative care services and from this to identify gaps in provision**

National Association Organisation Issues - Stephen Connor, US; David Praill, UK; André Rhebergen, Netherlands

The development of national associations of hospice and palliative care was portrayed as a graph with different stages: beginnings, growth, maturity and decline. It was noted that each stage of the development of a national association needed different people with a variety of skills, such as leaders, innovators and financiers. It was pointed out that decline is not always a negative development because it may indicate that an organisation has reached its goals.

A draft outline for a hospice and palliative care national association development toolkit (see Appendix 6) was put forward which categorised various factors required to develop and sustain a national association. These categories included, for example: resources for establishing an association, resources for fund development, membership options, global relationships and sustainability. It was anticipated that this tool kit may need to be adapted to take account of different country and organisation contexts. The sustainability of national associations in resource-poor countries was raised as a central issue to the debate.

Information issues including setting up an information service
Nick Pahl, UK; Liliana de Lima, USA; Avril Jackson, UK

This session addressed information issues regarding information services and information gathering. Presenters from the Hospice Information service based in the UK and the International Association for Hospice and Palliative Care related their experiences of setting up information services electronically. A presentation on the Nandi Hospice Project, India, demonstrated the complexities of developing a patient care information system. The aim of the system was to collate information on palliative care services with a view to improving them. A presentation from the International Observatory on End of Life Care outlined the range and depth of global information on hospice and palliative care that was available through its website.

The session discussed the difficulties of both generating and accessing reliable information on hospice and palliative care especially education and training material. It was maintained that resources and experiences should be shared to avoid 're-inventing the wheel'. Problems of the availability of information were particularly acute for those without access to the internet (only a small percentage of the population has access) and therefore information should be available in non-electronic forms. Similarly, the limited translation of material was a barrier to the widespread dissemination of information.

6. Summary of Issues to Take Forward for National Associations

David Prail, UK with Cynthia Goh, Singapore

In the final session of the conference the results of the questionnaire distributed to delegates were reported to show overwhelming support for a national associations' conference to be held every two years (35 questionnaires were returned and there were 35 positive responses to a biennial summit). It was suggested and agreed that the next meeting should be held in Africa.

The questionnaire results also demonstrated substantial support for the idea of forming a coalition of national associations (29 of 35 in favour). The planning group proposed that it develop terms of reference for a coalition and then initiate a process of consultation with national associations. The terms of reference would attempt to outline what a formalised network would seek to achieve. It was also noted that the planning group would widen its representation to include Latin America and Australasia. The issue of including a representative for children on the planning group was also raised but it was agreed that there were already members of the planning group with sufficient expertise in this area.

In subsequent discussions the following concerns were raised which the planning group agreed to take on board when it meets:

- the resource implications of a coalition (cost and time)**
- the specific nature of the coalition's aims.**
- concern was expressed about the danger of duplication, and it was argued that there would need to be clear additional benefits to forming a coalition. For example, in the Asia Pacific region, the national associations were working to develop palliative care in the resource-poor regions of the area. It was suggested that building links between countries in the same continent might be a more effective form of organisation.**
- there was also concern that any structures developed should not absorb excessive resources. Any coalition should also avoid being a 'talking' shop.**

It was pointed out that the current informal working relations between national associations required a degree of resources, especially time. For example, the working groups participated in teleconferencing and email discussion. Participants were reminded that the current working groups of national associations included: advocacy (and drug sub-group); information group; education and training; World Hospice and Palliative Care Day; funding; quality and standards; governance and organisational structures; and that subsequent to the summit a children's working group would be formed.

Members of the planning group from resource-poor countries argued that the benefit of a global coalition would be to share resources and experiences and spread resources more effectively. The move to a formal coalition would keep costs low, e.g. summits are piggybacked onto other conferences. So a coalition would mean time would be spent more effectively rather than wasted. There was some support for this point of view with speakers

from resource-poor countries describing how they had benefited from working internationally.

It was stated that a prime function of the coalition might be to help develop palliative care in parts of the world where it was absent or undeveloped. The coalition could champion service provision. It was possible that the coalition could access new sources of global funding which were not open to regional and national associations or local hospice and palliative care services. It was felt that outside input enabled people in their own countries to pressure their Governments for change, or that Governments might listen more to global organisations.

There was some discussion regarding the difficulties of addressing different cultures in palliative care and the problems of donor expectations in various cultural contexts. Many people coming into resource-poor countries experienced deep culture shock and were unable to work. In addition, there were problems connected to importing cultural expectations of palliative care into different cultures e.g. assuming patient autonomy when the patient's decision-making unit was the family. It was noted that within palliative care debates the patient perspective was often forgotten. It was suggested that the coalition might be able to assist in the development of patient groups (not duplication but multiplication).

As a result of the discussion and the differences of opinion regarding the role of, and the need for, a coalition, it was agreed that the planning group consider the issues and at the 2007 summit of national associations present a draft proposal for the development of a coalition.

David Praill drew the conference to a close and thanked everyone who had participated in the Summit for all their hard work and enthusiasm.

Appendix 1: Delegates List

Name	Organisation	Job Title
Ms Sharon Baxter	Canadian Hospice Palliative Care Association – Ottawa	Executive Director
Dr Michaela Bercovitch	Israel Palliative Medical Society – Israel	Chair
Dr Agnes B Bausa	Supportive Palliative and Hospice Care Programme, University of Philippines – Philippines	
Ms Mary Callaway	Open Society Institute – New York	Director
Dr Ai-Ju Chen	Singapore Hospice Council – Singapore	Chairman
Professor Wha Sook Choe	Home Hospice Care Centre – Seoul	Director
Dr Youn Seon Choi	Department of Family Medicine, Guro Hospital – Seoul	Director
Dr Stephen Connor	National Hospice and Palliative Care Organisation – USA	Vice President
Professor David Currow	Palliative Care Australia – Deakin West	President
Professor Odontuya Davaasuren	Mongolian Palliative Care Society – Ulaanbaatar	President
Ms Liliana De Lima	Association for Hospice and Palliative Care – Houston, USA	Executive Director
Dato' Dr T Devaraj	Malaysian Hospice Council – Kuala Lumpur	Chairman
Mr Peter Ellis	Richard House Children's Hospice – London	Chief Executive
RN Ret. Brendan Flahive	St John of God Brothers – Renminlu youju, China	Advisory
Ms Barbara Gelb	Association of Children's Hospices – UK	Chief Executive

Dr Cynthia Goh	Asia Pacific Hospice and Palliative Care Network – Singapore	Honorary Secretary
Dr Dinesh Goswami	Indian Association of Palliative Care – India	Secretary
Ms Louise Gray	Help the Hospices – London	Conference Organiser
Dr Liz Gwyther	Hospice Palliative Care Association of South Africa – Cape Town	Director Education & Research Coordinator
Dr Ednin Hamzah	Hospis Malaysia	CEO/Medical Director
Dr Katalin Hegedus	Hungarian Hospice-Palliative Care Association – Budapest	Board Member
Dr Hoa Hai Hoang	Cho Ray Hospital – Vietnam	Director of Training Dept
Professor Young Seon Hong	St Mary's Hospital – Korea	Director
Dr Sheau-Feng Hwang	Palliative Care Unit, Taichung Veterans General Hospital – Taiwan	
Ms Avril Jackson	Hospice Information – Sydenham, UK	International Information Officer
Mr Stephen Jones	Cardiff University – UK	Learning Resources Manager
Mr David Joranson	University of Wisconsin – USA	Director of Pain and Policies Studies Group
Ms Asuncion B Kalalo	National Hospice and Palliative Care Council of the Philippines – Manila	President
Sr Hai Ja Kim	Division of Hospice, St Mary's Hospital – Daejeon, Seoul	Director
Ms Susie Kim	College of Nursing Science, EWNA Womans University – Seoul	Professor
Dr Suresh Kumar	Palliative Care Society – Kerala	Advisor
Mr Kam Fan Kwan	Society for the Promotion of Hospice Care –	Executive Director

Hong Kong		
Dr Luzyiminda Kwong	St Luke's Medical Centre – Philippines	
Dr. Y.L. Enoch Lai	Asia Pacific Hospice Palliative Care Network – Taiwan	Chairman
Dr Frieda Law	Li Ka Shing Foundation – China	Consultant
Professor Kyung Shik Lee	Division of Oncology, St Mary's Hospital – Korea	Professor
Dr Jacek Luczak	Eastern and Central Europe Palliative Care Task Force (ECEPT) Polish Association for Palliative Care, Poznan, Poland	President Chief of Palliative Medicine Chair & Dpt of University of Medical Sciences, Poznan
Ms Urska Lunder	Palliative Care Development Institute – Slovenia	Assistant at Medical Faculty
Professor Rod Macleod	Hospice New Zealand – New Zealand	Professor in Palliative Care
Ms Joan Marston	Hospice Palliative Care Association of South Africa – Cape Town	Advocacy Officer
Ms Tatsuko Matsushima	Hospice Palliative Care Japan – Japan	Executive Director
Dr Liz Mcdermott	International Life Observatory – Lancaster, UK	Research Associate
Dr Anne Merriman	Hospice Africa Uganda – Uganda	Director of Policy and International Programmes
Ms Barbara Monroe	St Christopher's Hospice – Sydenham, UK	Chief Executive
Ms Claire Morris	Help the Hospices – London	International Project Officer
Dr Daniela Mosoiu	Hospice 'Casa Sperantei' – Romania	Director
Mr Vladyslav Mykhalsky	Association of Palliative and Minimally Invasive Therapy – Ukraine	Vice President
Dr Kenji Nishitateno	Hospice Palliative Care– Japan	Director
Dr Rhodora Ocampo	Madre de Amor Foundation – Philippines	Medical Director

Mr Nick Pahl	Help the Hospices – London	Development Director
Mr David Prail	Help the Hospices – London	Chief Executive
Ms Lisbeth Quesada	Palliative Care Foundation – Costa Rica	
Dr M Rajagopal	Department of Pain & Palliative Medicine - Kerala	Professor & Head of Department
Mr André Rhebergen	National Support Centre for Palliative Care – Holland	
Ms Rachael Rosario MD	University of the Philippines – Philippines	
Professor Arvydas Seskevicius	Lithuania Palliative Medicine Association – Kaunas	President
Dr Rosalie Shaw	Asia Pacific Hospice Palliative Care Network – Singapore	Executive Director
Dr Yasuo Shima	Hospice Palliative Care Japan - Japan	Vice President
Dr Sang Won Shin	Korea University Anam Hospital – Seoul	Associate Professor
Dr Sakon Singha	Prince of Songkla University Hospital – Thailand	Chairman of the Palliative Care Unit
Dr Odette Spruyt	Australasian Palliative Link International (APLI) - Australia	Founder
Mrs Ana Stambuk	Croatian Society for Hospice / Palliative Care - Zagreb	
Mrs Yvonne Siu Sun	Society for the Promotion of Hospice Care – Hong Kong	Executive Committee Member
Professor Sunaryadi Tejawinata	Indonesian Palliative Society – Indonesia	President
Professor Netty Tejawinata	Indonesian Palliative Society – Indonesia	
Mr Mick Thorpe	Help the Hospices – London	Vice President
Dr Bee Wee	Sir Michael Sobell House – Oxford, UK	Academic Lead and Senior Lecturer

Dr Roberto Wenk	Fundación FEMEBA – Buenos Aires, Argentina	Founder
Dr Fumio Yamazaki	Hospice Palliative Care Japan – Japan	President
Dr Eduardo Garcia Yanneo	Uruguayan Society of Palliative Care – Montevideo	Board of Directors
Wook Hee Yoon, MD	Emmaus Palliative Care Centre, Junju – Korea	President
Dr Andrew Young	Academy of Hospice and Palliative Medicine – Taiwan	Chairman

Appendix 2: Programme for 2nd Global Summit of National Hospice and Palliative Care Associations

15th March 2005

Pre meetings	
9:30 – 12:00	Organising committee to meet
10:00 – 11:00	Children's issues
2nd Global Summit	
11:30	Registration and coffee
12:30	Lunch
Afternoon – Session 1	
Chair: Dr Cynthia Goh, Asia Pacific Hospice Network, Singapore	
13:30	Welcome David Prail, Help the Hospices, UK
13:35	Hospice and Palliative Care in the World Liliana de Lima, IAHPC, USA Avril Jackson, Hospice Information, UK
14:00	The Opportunities of Working Together, e.g. Advocacy Sharon Baxter, Canadian Palliative Care Organisation Anne Merriman, APCA, Uganda
14:30	National Associations – The Story Thus Far David Prail, Help the Hospices, UK Stephen Connor, NHPCO, USA
15:00	Discussion
15:20	Tea
Afternoon – Session 2	
Chairs: Dr Mick Thorpe, UK Forum for Hospice and Palliative Care Worldwide Mary Callaway, Open Society Institute, USA	
15:45	National Association Updates – Obstacles and Achievements
	Europe – Lead: André Rhebergen
	Americas – Lead: Stephen Connor
	Africa and Middle East – Lead: Anne Merriman
	Asia Pacific (inc. Australia and New Zealand) – Lead: Cynthia Goh

17:45	Finish
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16th March 2005

National Association Focus Sessions	
9:00 – 9:55	Quality of care including monitoring tools and standards Chair: Stephen Connor, USA
	Advocacy to Governments and policy makers (covering morphine issues, etc.) Chair: Sharon Baxter, Canada; David Joranson, USA
	Governance Chair: David Prail, UK
10:00 - 10:55	Education and Training Chair: Liz Gwyther, South Africa
	World Hospice and Palliative Care Day Chairs: Claire Morris, UK; Mick Thorpe, UK
	Funding national organisations and palliative care services Chairs: Mary Callaway, USA; Anne Merriman, Africa
10:55	Coffee
11:20 – 12:20	Children’s Services Chairs: Joan Marston, South Africa; Barbara Gelb, UK
	National Association Organisation Issues Discussion led by Stephen Connor, David Prail and André Rhebergen
	Information issues including setting up an information service Chair: Nick Pahl, UK; Liliana de Lima, USA; Avril Jackson, UK
12:20	Lunch
Afternoon Session Chair: Daniela Mosoiu, Romania	
13:30	Plenary – Key points and next steps from focus sessions Quality of care – Stephen Conner Advocacy including declaration – Sharon Baxter, David Joranson Education and training – Liz Gwyther World Hospice and Palliative Care Day – Mick Thorpe Children’s issues – Barbara Gelb, Joan Marston Funding – Mary Callaway Organisation issues – André Rhebergen

	Information issues – Avril Jackson
15:00	Tea
15:30	Summary of issues to take forward for national associations Chairs: David Prall, UK; Cynthia Goh, Singapore
17:45	Close
Outcome – Summary report by International Observatory on End of Life Care	

*Appendix 3: Pre-Conference Meeting:
Children's Issues*

The purpose of the session was to develop a vision of increased international collaboration for those working with children in hospice and palliative care.

An overview of children's hospice and palliative care in the UK and the international context – Barbara Gelb, Association of Children's Hospices, UK

The presentation made several important points about the definitions and character of hospice and palliative care for children and young people in the UK. It offered a definition of palliative care as an active and total approach with a focus upon the quality of life for the child and support for the family through death and bereavement.

It showed the broad types of illnesses for which children require palliative care including both life-threatening conditions such as cancer as well as those which limit life and are likely to lead to premature death, e.g. cerebral palsy. In the UK, 12 out of every 10,000 children aged 0 to 19 suffered a life-limiting condition, a national total of over 15,000. Children's palliative care in the UK involved only a small number of children dying, compared to adults, but care might continue over many years and embrace the whole family. The problems of cognitive and emotional development on children's understanding of their own condition and the provision of education and play were raised as significant aspects of children's palliative care in the UK.

The presentation demonstrated the rapid expansion within the UK of the children's hospice and palliative care movement over the last two decades. The world's first children's hospice was opened in Britain in 1982 (Helen House in Oxford) and the UK now had the world's first consultant in Paediatric Palliative Care based at Great Ormond Street Hospital in London. There were now 36 operational children's hospice services plus another 7 in project stage and organisations such as the Association of Children's Hospices continued to work to improve provision and practice.

An overview of international collaboration showed that the first children's hospices outside Britain opened in 1994 in Warsaw, Poland and Minsk, Belarus. Now, children's hospice services existed all over the world. The International Children's Palliative Care Network (ICPCN) was a joint venture between the Association of Children's Hospices (ACH), the Association for Children with Life Threatening or Terminal Conditions (ACT) and Help the Hospices. It was a web-based collaborative project which aimed to facilitate information sharing and best practice development

Children's Hospice in South Africa – Joan Marston, Hospice Palliative Care Association for South Africa.

Palliative and hospice care were described as pressing issues for children in South Africa with official statistics estimating that 6 million people, including 800,000 children were infected with HIV, and 1 million children were orphaned due to AIDS. Bereavement in children was poorly addressed. As a result of these circumstances more attention was being paid to children's needs in palliative care and hospice services, such as the importance of play and emotional expression.

Currently, St Nicholas Children's Hospice in Bloemfontein, Free State, was one of a few independent children's hospices in South Africa, but there were some programmes attached to hospices or other services for children with AIDS. These services provided predominantly home-based care carried out by community caregivers and supervised by nurses. There was some concern regarding the ways in which clinical and psychosocial issues were provided in these services. Unfortunately, palliative care education and training was limited in South Africa and there was very little paediatric literature relevant to the African context. However, there was a paediatric palliative care course being piloted for professionals and another for community caregivers. Training in psycho-social issues and "memory work" was particularly important.

The challenges for South Africa were summarised as a lack of understanding of the need for children's hospice and palliative care services, the difficulty of access to care in rural areas, limited access to palliative care drugs, and the problems of integrating palliative care into anti-retroviral treatment programmes, education and poverty. The presentation suggested future work should focus upon:

- Further education & training
- Better access to palliative care drugs
- Government policies
- Public/private partnerships
- Expansion of bereavement training – including schools
- Nutrition of children in need
- Expansion into Africa through the African Palliative Care Association (APCA)

DISCUSSION

An enthusiastic discussion focussed upon the diverse international experiences of providing and developing children's hospice and palliative care services. Attention was drawn to the contrast between countries such as the UK with a range of paediatric services, and Mongolia

where children constituted 45% of the population but there was no specialist hospice provision. Key points of the discussion included:

Bereavement needs of children

Accessing education and training

Ways to develop services

Spiritual care of children

The emotional impact on professionals of caring for children

The importance of family – especially siblings

At the end of the session the participants decided they needed to continue their discussions and information sharing and arranged an impromptu one-hour breakfast meeting (8am) the following day.

Appendix 4. Korea Declaration

The problem

Worldwide more than 52 million people die each year, including adults, children and young people. Approximately one out of ten deaths is due to cancer. Over 40 million people, including over 29 million Africans, are infected with HIV/AIDS and are living with the disease. Also, there are growing numbers of individuals with other chronic diseases and life-threatening conditions. These people will all need hospice and palliative care at some time. It is imperative that all governments fund and develop plans of action that support the continuum of prevention, treatment and palliative care. Of patients with advanced cancer 70% have pain and 70% - 90% of those with advanced AIDS have uncontrolled pain. In developing countries the majority of people with cancer are diagnosed after their disease has become incurable. Due to the stigma of an HIV/AIDS diagnosis, many do not take advantage of care and support programs (if available at all) until the final stages. Limited access and availability also results in advanced diagnosis and no treatment. Unrelieved suffering on this scale is unacceptable and unnecessary.

Access to trained hospice and palliative care health care professionals, community volunteers and careworkers (family caregivers, carers) via existing health care infrastructures is a worldwide problem. Access to pain and symptom management is also a global problem.

What we know

Major advances have been made in pain and symptom management in people with progressive incurable diseases. Great strides have taken place in understanding the psychological social and spiritual aspects of dying and death. Health professionals, family members, volunteers and others are working together to create dynamic partnerships for the relief of suffering. Hospice and palliative care supports families at the time of death and in the bereavement period.

Hospice and palliative care is based on meeting the physical, social, spiritual and psychological needs in all settings. Hospice and palliative care is also based on interdisciplinary care that incorporates medicine, nursing, social work, psychology, pastoral care, physiotherapy, occupational therapy and related disciplines.

We agree that:

Governments must:

- Include hospice and palliative care as part of all governmental health policy, as recommended by the World Health Organization (WHO).
- Make access to hospice and palliative care a human right
- Make resources available for hospice and palliative care programs and services.
- Establish clear, informed and self-standing policies with action plans for implementation.

- Include hospice and palliative care in their national cancer control programs.
- Include hospice and palliative care in the management of progressive life threatening diseases.
- Include palliative care in their national AIDS strategies.
- Integrate hospice and palliative care education and training into the undergraduate and post-graduate curricula of medicine, nursing, research, and other disciplines.
- Provide training, support and supervision of non-professional careworkers
- Make necessary drugs available, including affordable and available morphine to the poorest.
- Make oral opioid analgesics available and accessible for patients with life limiting illnesses.
- Identify and eliminate barriers in the laws and regulations in different countries to the adequate use of opioid analgesics such as morphine.
- Ensure systematic assessment of needs of hospice and palliative care to precede, when appropriate, the establishment of service at the local, regional and/or national level.
- Make hospice and palliative care services comprehensive in nature and better integrated into the health care system
- Strive to make hospice and palliative care available to all citizens in the setting of their choice including acute care hospitals, long-term care facilities (nursing homes), and residential hospices and in the patient's home.

Every individual has the right to pain relief. Since affordable and effective methods exist to relieve pain and most other symptoms, cost should not be an impediment. Hospice and palliative care must be provided according to the principles of equity, irrespective of age, race, gender, sexual preference, ethnicity, faith, social status, national origin and the ability to pay for services. Palliative care must be available to all populations including vulnerable groups such as prisoners, sex workers and drug users.

The experience gained from the hospice and palliative care of cancer should be extended to the care of people with other chronic incurable diseases worldwide. Families and other informal care givers are essential contributors to the delivery of effective hospice and palliative care. They should be recognized and empowered by government policy.

National hospice and palliative care organizations have a key role to play in advocating for good health policy development in their countries. Governments and these organizations (NGOs) must work together to further develop hospice palliative care programs and services.

The progress on this declaration will be assessed and made public in two years time.
Seoul, Korea – March 16, 2005

Based on The Barcelona Declaration on Palliative Care - December 9, 1995

Appendix 5. Draft outline for hospice and palliative care national association development toolkit

Proposed Elements of the Toolkit

Introduction to the role and importance of national associations
Resources for establishing an association
Sample articles of incorporation and bylaws
Resources for business planning, budget development and tracking
Role of the Board / Governing Body
Job descriptions for key leaders including Board members, administrator, chief financial officer
Internal policy and procedure development
Information technology, web capacity
Resources for strategic planning
Vision, mission, values, goals & objectives
Needs assessment/SWOT
Resources for fund development
Dues, grants, governmental support, corporate, philanthropic
Revenue from educational activity, provision of services, product sales
Membership options
Individuals, providers, affiliates, states-regions-countries
Dues/membership structure
Communications
Development of position statements
Resolutions of the membership/organization
Creation of policy papers
Press relations, press releases
Standard setting, leadership in clinical excellence, quality, and research
Public policy and advocacy
Lobbying for hospice and palliative care
Legal/regulatory/governmental framework
Model policy on opioid availability
Strategies for inclusion in national health care systems
Provider support and capacity building
Guidelines for delivery of care
Professional certifications
Educational programming
Conferences
Distance learning
Development of guidelines for care
Public engagement
Community awareness
Media: news, TV, radio
Strategic relationships – other key national NGO's, medical societies
Global relationships
Sustainability