



ASSOCIATION OF CHILDREN'S HOSPICES



UK forum for hospice and palliative care worldwide



help the
hospices



“Every child is my child”

A report of the workshop -
Hospice services for children around the world

3 March 2004
Hospice House, London

EXECUTIVE SUMMARY

In their introductions Barbara Gelb, Chief Executive of the Association of Children's Hospices (ACH) and Mick Thorpe, Chairman of the UK forum for hospice and palliative care worldwide declared this workshop the first of its kind – the first collaborative event between Help the Hospices, the UK forum and ACH to look at the issues around children's hospice and palliative care worldwide.

The workshop was inspired by a seminar convened by Help the Hospices, of National Hospice and Palliative Care Associations in The Hague, 29 March – 1 April 2003. Barbara Gelb said many of the issues highlighted by the Hague seminar were relevant to children's hospices i.e. support for building a 'virtual network' of national organisations and other groups to facilitate future collaboration, and approaching WHO to advocate for palliative care.

March 3 2004 brought together more than 35 individuals - chief executives, heads of care and education staff from children's hospice services in the UK, members of the UK forum and UK based Children's NGOs. The purposes of the day was to practically facilitate shared learning and understanding on the possibilities for international collaboration on children's issues, and to identify tangible action points.

It was particularly poignant that Sr. Frances Dominica, the founder of the first children's hospice in 1982, Helen House took part in the workshop.

There were presentations from ACT, the UK forum, Save the Children and the Hospice Association of South Africa, and the afternoon consisted of break-out groups looking at specific issues. There was opportunity for questions and discussion, both formally and informally, and networking during lunch.

By the end of the workshop, several action points were proposed, including

- Hospices/ palliative care services need to position their response in the wider context and build a relationship with the wider policy environment, they need to bring their 'experiences' to the appropriate fora and use 'vignettes' as evidence of what works
- Creating an International Directory of Children's Hospices/ Palliative Care Services, an International Guide on the Development of Children's hospices/ services, a dedicated International Information Bulletin (further action points included under breakout summary)
- Piloting a global children's hospice and palliative care 'network'
- ACH, ACT and the UK forum could collaborate on an education and training capacity development project.
- ACH/ UK forum might facilitate a "twinning working group" to co-ordinate and mobilise multi-professional teams (made up of individuals from different children's hospices) to visit children's hospices/services internationally

ACH and the UK forum in partnership with ACT will work on a 'next steps' strategy looking at the proposed action points, identifying activities/ resources to undertake these.

THE UK FORUM FOR HOSPICE AND PALLIATIVE CARE WORLDWIDE

Nick Pahl, Development Director , Help the Hospice

The UK forum for hospice and palliative care worldwide is the national umbrella and representative body for organisations and individuals working in the UK involved in supporting hospices and palliative care services overseas. Established, and funded by Help the Hospices it promotes a national, strategic and collective response in the UK to the needs of hospice and palliative care worldwide.

Membership is free, and open to individuals and organisations working in the UK with links overseas, and associate membership is available to individuals and organisations around the world. There are currently 145 members from over 17 countries.

The UK forum is governed by a management committee, supported by three sub-committees

- Advocacy
- Funding
- Education and Training

The UK forum is a member of BOND (British NGOs Overseas for Development); the IAHPC (International Association for Hospice and Palliative Care); the UK Consortium on AIDS and International Development; and a corporate member of EAPC (European Association for Palliative Care). It maintains close links with the Open Society Institute, New York and the Diana, Princess of Wales Memorial Fund.

The UK forum's key activities include:

- **Education, Training and Awards**
 - Education Activities e.g. workshop on twinning issues
 - Training events and conferences - Clare Short as key speaker at 2002 Annual Conference, Jim Sherry UNAIDS 2003
 - Worldwide Education Grants Programme – to date the disbursement of US\$ 200,000
- **Advocacy**
 - With World Bank, DFID, EU, UK Government, NGOs, WHO and governments worldwide
- **Information**

With ***hospice information*** (a partnership between Help the Hospices and St Christopher's Hospice)

 - Worldwide Hospice and Palliative Care Online (monthly email news bulletin edited by Avril Jackson, International Information Officer at ***hospice information***)
 - Page on the Hospice bulletin
 - Policy papers – HIV/ AIDS and hospice/ palliative care, Models of care, and Information papers - twinning
 - Enquiry service/ Resource area
 - Web-site
- **General Projects**
 - Support to International Observatory on End of Life Care
 - International Skills Database (in conjunction with ***hospice information***)

- Reviewing drugs issues
- Supporting nurse training in Ghana
- Volunteer needs assessment in West Africa
- Supporting projects funded by others/ supporting new project development

ACT

John Overton, Chair

ACT, registered in 1993, is an umbrella organisation which seeks to influence, coordinate and promote the provision of the best possible care and support for children and their families, through:

- Promoting partnership between professionals and between families and professionals
- Expanding membership to enhance its representative voice
- Advocating on behalf of affected children and families
- Supporting families with information
- Supporting professionals through information and education
- Promoting knowledge and awareness
- Providing a forum for the exchange and development of information between parents and professionals

ACT currently has 348 members, including families, and from the voluntary and statutory sectors. (membership is open to any individuals or organisations living or working with children with life-limiting conditions who agree with ACT's mission). It has a growing international membership, including representation from Albania, Australia, India, New Zealand, Romania and the US amongst others.

Moving into International Advocacy

ACT having campaigned over the past 10 years for improved children's palliative care services in the UK would like to extend this role on an international basis. It sees its advocacy as double-edged – campaigning for the rights of children to have services that are planned around their needs, and promoting the concept of palliative care (not a recognised medical speciality when ACT was founded(1993))

Publications and Website

ACT has published a series of documents:

- ACT Charter for Children with Life-limiting Conditions (1993)
- Guide to the Development of Children's Palliative Care Services (1997, republished 2003)
- Palliative Care for Young People, aged 13-24 (2001)
- Assessment of Children with Life-limiting Conditions (2003)
- Voices for Change (2003)

ACT also produces "PaedPalLit" twice a year. Free to members, it is a collation of research abstracts from 120 international journals.

ACT's website (www.act.org.uk) hosts "PaedPalLit" as a searchable database, and offers publications free to download.

Future developments

- ACT plan to evolve "PaedPalLit" to form an International Journal of Children's Palliative Care.
- Work is currently underway to develop a new international site which will include international news and listings of overseas organisations and events

ACH and International Training Initiatives

The 16th World Congress “Completing the Cycle of Care” in September 2004 is being organised by Children’s Hospice International in partnership with ACT, ACH and CHAS (Children’s Hospice Association of Scotland). ACT is also involved with the European Conference on children’s palliative care to be held in Bratislava in April 2005.

Facilitating the sharing of knowledge and expertise internationally

ACT launched an international email listServ “PaedPalCare” in 2003, which has over 500 members from different disciplines all over the world. It aims to launch in 2004 a new list for families “PaedPalFamily” to enable mutual support and information sharing.

International Collaboration

No single organisation can work alone to promote the needs of children with life-limiting conditions and their families all over the world. ACT’s UK co-ordinating role can be expanded to help co-ordinate and facilitate initiatives for children internationally.

It is working with the EAPC to set up a children’s wing, and the David Baum International Foundation to set up international education and training initiatives.

CARE AND TREATMENT STRUCTURES FOR CHILDREN WITH SPECIAL REFERENCE TO HIV/AIDS AND AFRICA.

(What are the particular/ special issues for children's hospices in developing countries)

Douglas Webb, HIV/ AIDS Adviser, Save the Children UK

The HIV/ AIDS Epidemic

There are an estimated 40 million people living with HIV/ AIDS worldwide and each day approximately 3,500 children are infected with HIV or die of AIDS. In December 2003, 2.5 million children aged under 15 were living with HIV/AIDS.

By 2010, there will be 44.2 million total orphans of AIDS and other causes of death. 90% of these total orphans will be in Sub-Saharan Africa.

Apart from the exceptions of Rwanda (over 25%) and Burundi (just below 20%), (attributable to the genocide in the 1990s), prevalence of orphanhood is greater in Southern African countries (HIV prevalence in adults is at its greatest (20 – 39%) in Southern Africa). There is a continent-wide predominance of paternal orphans.

Impacts of AIDS on Children

Children have reduced access to

- Education
- Health care
- Protection
- Nutrition

There are adverse psychological impacts due to early bereavement, lack of counselling and lack of parental support.

The degree of impact differs throughout the continent. In Lesotho 30% of total orphans (0 – 4 years) are underweight compared with 17% of non-orphans (0-4 years), whilst in Sierra Leone, 34 % of total orphans (0-4 years) are underweight compared with 27% of non-orphans (0-4 years).

Traditional home and palliative care structures include pain management, symptom control, wound care, hygiene and diet support, psychosocial care and support of the family, accompanying patients to AIDS clinic.

Possible future structures in responding to needs of children with HIV/ AIDS?

- **A possible future: 'triage?'**
 - Which children are positive?
 - Individual child centred interventions as opposed to community wide based interventions.
 - Involves child sponsorship
 - Child patient selection based on child care patterns in the home
 - Typically <1% coverage
 - Titanic principle of 'women and children first' for treatment
- **Child focused home care**

Issues/ challenges for children's hospices and palliative care services in developing countries

- How can home care be more child focused?
- How can hospices outreach into the community?

Child focused home care 1

Developing home care structures to identify

- Vulnerable children (identify sick children through sick adults)
- Psychosocial support
- Accessing paediatric health care
- Household vulnerability monitoring
- Succession planning as appropriate

Child focused home care 2

- Rapid participatory assessment to identify community criteria of vulnerability and priority target groups/ households (grandparent/child/widow headed) with follow up actions
- Informal fostering process
- Welfare worker(s) to facilitate community based monitoring of especially vulnerable households

Residential care

- "a group living arrangement for children in which care is provided by remunerated adults who would not be regarded as traditional carers within the wider society"
- Organised and deliberate structure
- Arrangement between children and adults that is 'professional', not 'familial'

The global estimate is of 8 million children living in residential care with this number rising due to increasing poverty, HIV/AIDS, armed conflict and rapid urbanisation.

In Russia 1% of all children are in residential care and in Eastern Europe rates have risen by 20% since 1989.

Donors and Foundations are becoming increasingly interested in funding residential care, especially in Africa.

'A Last Resort' – the growing concern about children in residential care (Save the Children's position on residential care)

- Long term care can disturb sense of identity and development of appropriate social behaviour.
- Staff in the institutions are not appropriately trained or equipped to deal with children who have experienced traumatic loss, serious abuse or handicaps
- Most children in 'orphanages' in Africa are not abandoned. In Uganda in 1997, of 3,000 children in homes, 85% had traceable relatives.
- Communities are continuing to provide basic support

- Estimates that residential care is 6-14 times more expensive than community based care.

Desired Response (1)

The significant global reduction in the use of institutional care for children in need of protection, and the growth of durable and sustained forms of community based social and health care. Donors and policy makers to recognise and understand why residential care is a last resort.

Desired Response (2)

Children have right to live in a caring family environment – first priority for resources and interventions, and child care and protection should be considered **a basic service** – more social workers a priority.

(Where should children’s hospices and palliative care services situate themselves in these responses?)

Plenary discussion:

- Ethiopia differs from its neighbours in terms of higher rates of HIV/AIDS due to wide-scale migration and a more developed sex industry
- Christian/ Muslim countries -differing prevalence rates (Muslim countries have higher rates of circumcision – protective of transmission)
- Hospices/ palliative care services have a critical role – need to position their response in the wider context and build a relationship with the wider policy environment, necessary to bring ‘experiences’ to the right fora and use ‘vignettes’ as evidence of what works
- Hospices/ palliative care services should be more conscious of demonstrating their ‘impact’, being critical of coverage
- Hospice/Palliative Care Day Centres for children – keeps children in the communities where they live, offers respite for carers, support for siblings.
- What models of care work? - need to understand cultural responses (there might be a cultural predilection to institutional care?)
- Should not separate response from the community - find an entry point into the community

CHILDREN IN THE GLOBAL VILLAGE

(How can countries such as the UK work with other countries?)

Joan Marston, Advocacy Officer, Hospice Palliative Care Association of South Africa

The St Nicholas Children's Hospice, founded in 1998 in Bloemfontein, South Africa is the first Children's hospice in South Africa and in Africa. The St Nicholas Programme includes home-based care, Day Care Centres, and Sunflower House, including research, bereavement support and care for orphans.

What hospice can do in the face of the epidemic

Thabo was three, and showing symptoms of HIV/AIDS when he first had contact with St Nicholas' Hospice. During his life he received day care, home based care and when at the age of 11 he began to deteriorate he came into the hospice as an in-patient. He was a lively, affectionate and assertive character, and viewed the hospice as his family. He was very much loved by all who came into contact with him.

Children are children wherever they may be (although the setting might be different)

Children everywhere have the same needs (research for Save the Children in South Africa showed their **greatest needs were for food and play.**) Families have the same dreams for their children. The principles of palliative care are the same.

The Differences between South Africa and the UK

- The impact of HIV/AIDS
- Orphans and vulnerable children (Where do orphans fit into the programme?)
- Many in one household/ family affected
- Child-headed households
- Few resources and extreme poverty
- Overwhelming numbers
- Most work done by volunteers
- The role of Grannys

Response: thinking creatively to cope

- Care should be in the community and needs to be acceptable to the community and involve community leaders
- We need to use the spirit of "Ubuntu" (basic respect and compassion for others)
- Traditional healers play an important role
- We need to strengthen community responses and support grass-roots initiatives
- Granny's need to be supported

❖ Community Palliative Day Care

Providing developmental stimulation, holistic care, grants, neurological stimulation, nutrition and foster care.

❖ Orphan and Vulnerable Child Support and Child-headed households

❖ Support for Grannies

Grannies are looking after their dying children and the grandchildren – they are not enjoying a peaceful old-age. Grants are small and difficult to access, and many live in inaccessible rural areas and in informal settlements

- ❖ **Bereavement Care & Support on a large scale**
Memory Work – where they came from, memory of family and place of birth (Memory boxes and bags); Sunflower House’s Wall of Remembrance – when they die they will be remembered
- ❖ **Home - based care**
Leading community training – carers, youth – teach about simple care, infection control
- ❖ **Networking programmes**
Partnerships with Departments of Health, Social Development, Education, Labour and Agriculture; training courses; awareness projects; volunteers; university and school involvement; other NGOs and CBOs

How can Children’s hospices in the UK support hospices in developing countries?

- Developing countries are keen to learn and share lessons learnt in the UK
- AIDS is so overwhelming - you can help us to focus on the needs of other children
- There is little literature from Africa – needs to be adapted
- Partner with children’s programmes in Africa
- Share ideas

What can children’s hospices in developed countries learn from colleagues in developing countries?

- To make the most of every resource!
- To deal with bereavement issues on a large scale
- Memory Work
- To mobilise community responses – involving young people
- Training and supervising lay care workers
- Working with volunteers
- The importance of Grannies

Ideas on how UK based organisations and individuals can work on international issues

- ❖ Facilitate a dialogue with children’s hospices and palliative care services internationally
- ❖ Promote the ‘two-way’ exchange of information and ideas
- ❖ Look at organising skills programmes on particular areas of care /developments with other countries
- ❖ Bring together individuals and organisations from different countries – in South Africa from surrounding countries (provide bursaries) – *talking within the environment where individuals are living and working*
- ❖ Collaborate with individuals/ organisations in countries – they are in the position to disseminate skills and share knowledge
- ❖ Use the ***hospice information*** bulletin

BREAKOUT GROUPS

In the afternoon, participants gathered in small groups to consider five specific issues. The key points raised in these discussions, and fed back in the plenary, are summarised below:

TOWARDS A HOSPICE INFORMATION PUBLICATION ON INTERNATIONAL CHILDREN'S ISSUES

Facilitator: Avril Jackson, International Information Officer

The group presented a list of action points:

- ❖ Collate a Directory on Hospice and Palliative Care (through ACT; existing contacts; other journals; on-line newsletters; national associations; CHI)
- ❖ To produce an International Guide on the Development of Children's Hospice and Palliative Care
- ❖ Produce an International Bulletin/Newsletter on Children's Hospices – through ***hospice information***
- ❖ Engage a Children's hospice representative on to the UK forum's management committee
- ❖ Information to be made available on ACT and ACH's respective websites e.g. Directory; International events
- ❖ Information sharing meetings via telephone conferencing on international level
- ❖ Develop an international email network
- ❖ Work towards an International Journal

THE ROLE OF TWINNING

Facilitator: Dai Roberts, Director for Education, St Ann's Hospice, Cheadle

“A formal or informal agreement between two communities or organisations to work together to develop friendship links, exchange experiences, knowledge and skills, and develop mutual understanding, tolerance and respect”

Taking this as its starting point, the group focussed its discussion around the following points

- Why do you want a “twin”/ “twinning relationship”? – what is the motivation (on both sides)?
- A partnership – it must be mutually beneficial, expectations on both sides should be explicit to avoid misunderstanding/ ill-feeling (i.e. the partnership is

based on information sharing and not on financial support), both organisations are equal in the partnership.

- Starting up and making contact – ***hospice information*** can provide contact details, ACT, engage in preliminary discussions – work out a draft memorandum of understanding
- Sensitivity and awareness – of culture, differing attitudes to death/ dying and bereavement; awareness of staff safety when visiting the “twin”
- Benefits to overseas partner – information, sharing of skills and expertise, cross-learning, problem sharing/solving, materials
- Benefits to UK based partner – staff motivation/ feel enriched, learning
- Types of support – refining need, refining your role – Trustee support, staff ‘on board’ from the outset, looking at resources implications (staff time)
- Longevity of relationship – what if the person responsible for cultivating the partnership leaves, is the responsibility included in their job description?
- Pitfalls – mis-management of expectations, working out potential pitfalls and drafting solutions

The group proposed that ACH might facilitate a “twinning working group” to co-ordinate and mobilise multi-professional teams (made up of individuals from different children’s hospices) to visit children’s hospices/services internationally – to engage in problem sharing sessions/ training workshops with staff and volunteers there, and to facilitate follow up.

NETWORKING ISSUES

Facilitators: Joan Marston, Advocacy Officer, Hospice Palliative Care Association of South Africa, and Nick Pahl, Development Director Help the Hospices

The group discussed what they thought networking is - learning from others’ experience, adding value, raising awareness of work to avoid duplication, combating professional loneliness, sharing best practice, advocacy and policy possibilities; and what it isn’t - prescriptive, critical, competitive.

Networking must acknowledge the (resource) context of all partners. Where is it most appropriate for networking to take place? - sometimes coming out of your usual environment can be inspiring, sometimes demoralising. Networking should be empowering for all partners.

They suggested ways for networking: meetings (but to avoid excessive paper), the Internet (issues around confidentiality), conferences, workshops, telephone conferencing, visits. Issues around language and culture must be considered, and people joining a ‘network’ should give sufficient information, which is shared across the network with permission

Discussion raised the following questions/comments:

- ❖ Do we want a specific network for international paediatric palliative care? Is that wide enough?
- ❖ What else is out there? Who should take it forward (statutory/voluntary – this relationship varies in different countries)?
- ❖ Could ACT and ACH work in collaboration? (ACT's mission statement has no geographical boundaries) – ACT/ ACH also to work with UK forum.
- ❖ Networking from UK outwards – what about the other direction – how to facilitate and encourage this?
- ❖ How should a network incorporate learning from other cultures?
- ❖ It is important to document and record activities, and to explore alternative methods to do this

Action: The group proposed working on a pilot network, involving 6 organisations (e.g. South Africa, Eastern Europe, ACH, ACT and the UK forum). The aim would be to explore how a network might look, its structure and how it would operate

EDUCATION ISSUES

Facilitator: Helen Bennett, Senior Palliative Care Lecturer, Oxford Brookes University

The group firstly outlined issues to be considered

- Understanding what children's palliative care education here in the UK is – can this be applied internationally
- Need to avoid re-inventing the wheel,
- What does the translation of education and training internationally really mean?,
- the evidence base of a model of care, and the qualitative nature of the research base.

The group listed what it knew currently existed worldwide:

- Children's palliative care course (Oxford Brookes University and Kenya),
- Medway/ Croatia –education link,
- South Africa – course on oncology for children,
- ACT's 'PaedPalLit',
- e-choices from ***hospice information***.

Developing education and training resources:

- follow a multi-disciplinary approach,
 - but the delivery to be tailored to local settings (recognition of gender/cultural issues)
 - recognition that often the care deliverers are volunteers/ non-professionals
 - If they are professional, are the most needs in psycho-social nursing?
- Tailoring education and training so it does not exclude people
- Assess what is available locally, regionally.
- How can education and training be undertaken to empower people to make positive change – is the education and training sustainable?
- Be aware that children's services should take a broad approach to care

- What are the lessons from other international organisations re. infrastructure, support, community development?

Action: The group proposed that ACH, ACT and the UK forum should collaborate on an education and training capacity development project.

NEXT STEPS AND CLOSE

Barbara Gelb and Mick Thorpe thanked all those who attended the workshop, and for their contributions to a valuable dialogue which had produced some tangible action points. ACH and the UK forum, in partnership with ACT would work out a 'next steps' strategy in looking at the action points and identifying the necessary activities/resources required. Delegates, would be kept posted.

A warm thank you was extended to all the speakers and facilitators, in particular to Joan Marston.

APPENDIX A

Hospice services for children around the world

03/03/2004

Help the Hospices, London

Delegate's list

Name	Organisation	Job Title	Email
Helen Bennett	Oxford Brookes University - Oxford	Senior Lecturer in Palliative Care	hebennett@brookes.ac.uk
Simon Brasch	Help the Hospices - London	Information Officer	s.brasch@helpthehospices.org.uk
Erica Brown	Acorns Selly Oak - Birmingham	Head of Research and Development	erica.brown@acorns.org.uk
Lizzie Chambers	Association of Childrens Hospices - Bristol	Acting Chief Executive	lizzie@act.org.uk
Wendy Dodds	South East Essex Christian Hospice - Westcliffe-On-Sea	Director of Care	wendy@littlehavens.org.uk
Sister Frances Dominica	Helen House – Oxford		
Jacque Duffy	Medway Maritime Hospital - Kent	Social Worker	jacque.duffy@medway.gov.uk
Jayne Dulson	Ty Hafan Children's Hospice - Wales	Director of Care Services	jayned@tyhafan.org
Peter Ellis	Richard House Children's Hospice - London	Chief Executive	petere@richardhouse.org.uk
Sonja Ezergailis	Association of Childrens Hospices - Bristol	Care Development Manager	sezergailis@childhospice.org.uk
Pamela Fowler	East Anglia's Children's	Nurse Manager	Pam.fowler@each.org.uk

	Hospice - CAMBRIDGE		
Barbara Gelb	Association of Childrens Hospices - Bristol	Chief Executive	bgelb@childhospice.org.uk
Ted Gladdish	Demelza House Childrens Hospice - SITTINGBOURNE	Chief Executive	Ted.gladdish@demelzahouse.org
Anne Grinyer	Lancaster University - Lancaster	Lecturer	anne@grinyer35.freerve.co.uk
Anthea Hare	Richard House Children's Hospice - London	Founder	
Margaret Hickie	Francis House Children's Hospice - MANCHESTER	Head of Care	margareth@francishouse.org.uk
Avril Jackson	Hospice Information - Sydenham	International Information Officer	avril@hospiceinformation.info
Mike Keel	Pasque Hospice - Luton	Director of Nursing	mkeel@pasque.org
Joan Marston	Hospice Association for South Africa – South Africa	Advocacy Officer	advocacy@palliativecare.co.za
Jennie McDowall	Help the Hospices - London	Major Projects Support Officer	j.mcdowell@helpthehospices.org.uk
Ann McMurray	Wisdom Hospice - Rochester	Senior Practitioner/Manager Social Work Team	Ann.mcmurray@medwaypct.nhs.uk
Louise Mitchell	Richard House Children's Hospi - London	Director of Care	
Faith Mwangi-	Diana Princess of Wales Memorial	International Advocacy Officer	

Powell	Fund - London		
John Overton	Acorns Children's Hospice Trust - BIRMINGHAM	Chief Executive	
Nick Pahl	Help the Hospices - London	Development Director	n.pahl@helpthehospices.org.uk
Selina Palm	Mildmay International - Southend on Sea	Business Development and Promotions Officer	selina.palm@mildmay.org
Alison Penny	Childhood Bereavement Network - London	Network Development Officer	apenny@ncb.org.uk
John Quill	Pasque Hospice - Luton	Chief Executive	
Adrian Redshaw	Naomi House (Wessex Children's Hospice) - WINCHESTER	Play Specialist	
Dai Roberts	St Ann's Hospice - Cheadle	Head of Research and Development	droberts@sah.org.uk
Carolyn Rubens	Trinity Hospice - Clapham	SHO	crubens@doctors.org
Jayne Saunders	Ty Hafan Children's Hospice -	Hospice Manager	jaynes@tyhafan.org
Vivien Shaw	Jessie May Trust - Bristol	Cultural Development Worker	Vivien.shaw@jessiemaytrust.org.uk
Mick Thorpe	Help the Hospices - London	Vice President	
Bridget Turner	C.H.A.S.E - Guildford	Director of Care	Bridget.turner@chasecare.org.uk
Megan Watkins	Ellenor Foundation - Kent	Specialist Nurse	megan.watkins@ellenorfoundation.org
Douglas Webb			

APPENDIX B

Hospice services for children around the world - Group List

Group 1: Red stickers

Avril Jackson (hospice information) – towards a hospice information publication on international children’s issues

Seminar Room 1

Simon Brasch
Lizzie Chambers
Peter Ellis
Ted Gladdish
Anthea Hare
Margaret Hickie
Kathi Scott
Megan Watkins

Group 2: Green stickers

Dai Roberts (St Ann’s Hospice, Cheadle) – the role of twinning

Seminar Room 2

Erica Brown
Jayne Dulson
Jennie McDowall
Louise Mitchell
Carolyn Rubens
John Quill
Jayne Saunders

Group 3: Blue Stickers

Joan Marston and Nick Pahl - networking issues

Basement

Sister Frances Dominica
Sonja Ezergailis
Barbara Gelb
John Overton
Selina Palm
Alison Penny
Vivien Shaw
Mick Thorpe

Group 4: Yellow stickers

Helen Bennett (Oxford Brookes University) - Education issues

Basement

Wendy Dodds
Jacquie Duffy
Pamela Fowler
Anne Grinyer
Faith Mwangi-Powell
Adrian Redshaw
Bridget Turner

APPENDIX C

Hospice services for children around the world 3rd March 2004 at Hospice House, London

Programme

- 10.30am Introduction
Barbara Gelb, Chief Executive, Association of Children's Hospices
Mick Thorpe, Chairman, UK forum for hospice and palliative care worldwide
- 10.40am ACT and the UK forum for hospice and palliative care worldwide
John Overton, Chair – ACT and Nick Pahl – Help the Hospices
- 11.00am What are the Particular/Special Issues for Children's Services in Developing Countries?
Douglas Webb- Save the Children
- 11.25am Discussion
- 11.35am How can countries such as the UK work with other countries?
Joan Marston, Advocacy lead, Hospice Association of South Africa tbc
- 12.15pm Discussion - Ideas on how UK based organisations and individuals can work on international issues
- 12.45pm Lunch
- 1.45pm Breakout groups
Avril Jackson (hospice information) – towards a hospice information publication on international children's issues
Dai Roberts – the role of twinning tbc
Barbara Gelb and Mick Thorpe - networking issues
Helen Bennett - Education issues tbc
- 2.45pm Feedback
- 3.15 Barbara Gelb and Mick Thorpe – next steps

