The ICPCN Guide to Children’s Hospice & Palliative Care Partnerships
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A Guide to Partnerships in Hospice and Palliative Care
published by Help the Hospices
Web: www.helpthehospices.org.uk

The How to Guide to Hospice Palliative Care Twinning Projects
Written by Susan Breiddal and published by Health Canada
Web: www.hc-sc.gc.ca

The Foundation for Hospices in Sub-Saharan Africa website
Web: www.fhssa.org

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looking for hope in the hopeless seems pointless, at least to those who don’t understand. Yet we who have worked in Children’s Palliative Care (CPC) know the power at the heart of that paradox. The smile or laugh of a dying child forces us to confront the futility of living in tomorrows, to open our eyes to the joys of existence here and now, and to convert the cold stone of despair into a bright diamond of hope.

This wonderful alchemy is captured in a French proverb that says ‘Hope is the dream of a soul awake’. Practicing CPC can be nothing less than an enlightening experience. But the road to that enlightenment can be a very hard and rocky one, for us as individuals as well as for us as teams and organisations. We have to try to keep our hope alive, without allowing it to drown in sentimentality, to be choked by vanity or submersed by moral exhaustion.

If setting up a CPC service requires hope and trust; running one requires a hard nose and a soft heart. Food needs to be on the table, nurses by the child and medicines in the cupboard. These things don’t appear by magic, but require a steely determination, a quick mind and an artful hand. This is the heart of children’s palliative care, and children’s hospice services are its embodiment.

In almost 20 years of experience in the UK and Africa I have found that there is so much we all share; and so many other ways we can support each other. Children are children wherever they are. They have the same needs, the same delights, the same hopes, and the same rights. But it’s not just the children that are the same. Pain is pain and care is care wherever you live. Workers of all professional backgrounds in all settings in all parts of the world find the same things difficult, have the same learning needs, and are motivated by the same things. From the top paediatricians in the highest tech children’s hospitals in Europe to community volunteers in the poorest shanties in Africa, workers run up against the same problems and fall into the same traps. Hospices are tied up by overbearing regulations in the North, and by different forms of bureaucracy in the South. Stressed, exhausted and demoralised teams can split, scapegoat and fight just as easily in leafy Oxford as in dusty Kampala.

There are, of course, differences, perhaps of style rather than substance, but nevertheless these differences are a gold-mine of potential mutual learning. I felt I got a great education in the techniques and practice of palliative care in Oxford, but it was in Kampala that I had to learn to be creative, resourceful and adaptable. We faced tricky ethical dilemmas in the UK, but I was never tested as much as in Uganda, where the dilemmas are immediate and raw, and where you don’t have the safe legal and regulatory structures and systems to fall back upon. Research is badly needed in both settings – some overlapping and some different, but the skills and resources required are the same the world over. Many tools and drugs used in the richer countries (although by no means all) are too expensive for developing ones, yet nurse prescribing is more widespread in places where doctors are in shorter supply. What is clear is that workers from different settings have so much to teach and learn from each other.

So why are children’s hospice and palliative care partnerships so rare? There is a saying that “He who takes a partner takes a master” and in some respects perhaps this is true. When you commit to another person or institution, you take on obligations and duties. The fear of obligation is, I suspect, the main block to successful partnership. Northern Hospices may look at poorer cousins and see only need, leading to anxiety about possible financial and other resource demands. Hospices in the South may fear being overwhelmed by richer, more powerful and longer established cousins in the North.

Funding is, of course, a very live issue for hospices everywhere. I have never come across one yet that feels financially secure. Having been Medical Director of both one of the wealthiest and one of the least wealthy children’s hospices in the world, I know that you need more than money to provide the right care; but I also know that it’s not a bad place to start!

However, perhaps children’s palliative care partnerships would be wise (initially at least) to leave the issue of funding to one side. Maybe each of us should start by taking a long hard look at ourselves. Do any of us truly believe we have nothing left to learn? Of course not. Those who are proudest and best established might wish for the courage to accept there is a lot they can learn from the poorest; and those who are the poorest might wish for the courage to believe they will not be the ‘little brother’ in any relationship.

In these difficult financial times, it is easy to fall into what the South Africans call the ‘lager mentality’ – to circle the wagons, see off outsiders and cling to what is ours and what we know. But the children’s hospice movement was launched by a determined love and an unflinching belief that hope can rise from the apparent ashes of hopelessness and death. As I write this, peoples from all over the world are visiting Africa for the first time to support their team at the world cup. Every night I listen to Northern visitors expressing delighted surprise that, far from being the grim and demoralising place they imagine, Africa is the birthplace of hope, and a well-spring of optimism. It is no surprise to those who know it that, when the laagers were opened, a Rainbow Nation was born.

Let us hope this publication can be a force for the birth of our own world-wide Rainbow Partnership. Someone somewhere once said: ‘Hope arouses, as nothing else can arouse, a passion for the possible’. I hope we can set aside our concerns, look outwards, and discover for ourselves what joys and benefits partnership can bring.

Justin Amery
The ICPCN Declaration of Cape Town

This declaration originated during the Children’s Hospice International 20th World Congress held in partnership with the ICPCN and the Hospice Palliative Care Association of South Africa in Cape Town in September 2009. It was a tangible response to the desire of delegates present at the congress to find ways to reduce the disparities so evident in the provision of palliative care for children in countries around the world.

It reads:

Palliative care for children is a basic human right.

We believe that all children with life-threatening and life limiting conditions have the right to quality palliative care provided by trained health care practitioners. Holistic family-centred children’s palliative care encompasses individualised assessment, pain and symptom management, psychosocial, spiritual and bereavement support.

As a community of palliative care practitioners we recognise that disparities exist within and between countries and services but collectively we are a rich resource of knowledge, skill and judgement and we commit to share all that we can to achieve this joint vision.

We commit both individually and collectively to identify opportunities for collaboration.

This declaration has been signed by hundreds of children’s palliative care practitioners. But unless the words are turned into actions, it remains little more than a wonderful sentiment.

The publication of this document is intended to provide one avenue in which signatories of this declaration are supported and enabled to match actions to words.

It is our hope that it will also form the foundation upon which many bridges are built and the exchange of information, ideas, skills, encouragement and inspiration will flow in both directions.
Defining a partnership

A partnership can be defined as a link, co-operation, a relationship or a ‘joint venture’ between two individuals, organisations or communities who agree, either formally or informally, to work together in the same activity towards a shared goal.

Partnerships are only as strong as the weakest link involved. Partnerships can be mutually beneficial and empowering and adversely they can be damaging and draining if they are not properly managed and maintained.

In whatever sphere of life one finds oneself, no partnership should be entered into without due consideration of the benefits and challenges of the proposed affiliation.

The history of hospice partnering

Within the adult hospice and palliative care communities, the concept of hospice partnerships, or “twinning”, goes back many years. Dame Cicely Saunders, widely regarded as the founder of the modern hospice movement, encouraged people working in the field to:

“Go round and see what is being done and then see how your own circumstances can produce another version; there is a need for diversity in this field.”

The pioneering work of Dame Cicely Saunders in the seventies led to the creation of many hospices and palliative care services within the United Kingdom, and later to other countries around the world. This development was enhanced and in some cases occurred as a direct result of partnerships between the more experienced and established services within the UK and emerging services elsewhere.

To find more detailed information on the history and present status of hospice partnerships between the UK and other countries and an excellent guide to partnering between hospice programmes, the reader is encouraged to obtain a copy of *A Guide to Partnerships in Hospice and Palliative Care* published by Help the Hospices. ([www.helpthehospices.org.uk](http://www.helpthehospices.org.uk))

The Foundation for Hospices in Sub Saharan Africa (FHSSA) has a Partnership Initiative which facilitates partnerships between hospices in the United States and hospices in Africa. FHSSA connects more than 80 partners from organizations across the US with a hospice in 1 of 13 African countries through their Partnership Program in order to promote comprehensive hospice and palliative care. To find out more about this organisation, visit their website at: [www.fhssa.org](http://www.fhssa.org)

Examples of strong partnerships between children’s hospices have also existed for a number of years, examples of which are documented on pages 17 - 19.

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1 *Essentials for a Hospice, Cicely Saunders and the St Christopher’s Team, 1976*
The philosophy of sharing

A willingness to share ideas, information, skills, and experiential knowledge has always been central to the philosophy of the modern hospice movement, and indeed was the very reason for the founding and development of the ICPCN. The organisation was originally conceived in 2005 by a group of dedicated individuals who wished to facilitate the widespread sharing of useful knowledge and experience within the field of palliative care for children and advocate for the thousands of life limited and life threatened children worldwide whose voices often go unheard.

The stated vision of the ICPCN reads as follows:

Our vision is to achieve worldwide the best quality of life and care for children and young people with life-limiting illnesses, their families and carers, through networking, advocacy, information sharing, education and research.

Towards the fulfilment of this vision the ICPCN has to date:

- Become part of the Worldwide Palliative Care Alliance to ensure the voices of children are heard within the wider palliative care movement
- Launched a relevant, user-friendly and up-to-date information website with over 1000 visitors each month
- Established a global online directory of children’s palliative care services and organisations within the website
- Published regular quarterly eNewsletters
- Created an International Charter of Rights for children with life-limiting and life-threatening illnesses available in 22 languages from the website
- Developed an online training registry
- Established an international and multi-disciplinary Scientific/Research Committee
- Provided administrative support and expertise for international conferences on children’s palliative care
- Funded scholarship for children’s palliative care practitioners in developing countries to attend training and conferences on children’s palliative care
- Been instrumental in the launch and development of palliative care programmes for children with HIV/AIDS in both Malawi and India
- Made representation to WHO and to UNICEF on issues relating to Children’s Palliative Care
THE ICPCN CHARTER OF RIGHTS FOR LIFE LIMITED AND LIFE THREATENED CHILDREN

With acknowledgement to the ACT Charter, the ICPCN Charter sets out the International Standard of support that is the right of all children living with life-limiting or life-threatening conditions and their families.

1. Every child should expect individualised, culturally and age appropriate palliative care as defined by the World Health Organisation (WHO). The specific needs of adolescents and young people shall be addressed and planned for.

2. Palliative care for the child and family shall begin at the time of diagnosis and continue alongside any curative treatments throughout the child’s illness, during death and in bereavement. The aim of palliative care shall be to relieve suffering and promote quality of life.

3. The child’s parents or legal guardians shall be acknowledged as the primary care givers and recognized as full partners in all care and decisions involving their child.

4. Every child shall be encouraged to participate in decisions affecting his or her care, according to age and understanding.

5. A sensitive but honest approach will be the basis of all communication with the child and the child’s family. They shall be treated with dignity and given privacy irrespective of physical or intellectual capacity.

6. Every child or young person shall have access to education and where possible be provided with opportunities to play, access leisure opportunities, interact with siblings and friends and participate in normal childhood activities.

7. Wherever possible, the child and the family should be given the opportunity to consult with a paediatric specialist with particular knowledge of the child’s condition and should remain under the care of a paediatrician or a doctor with paediatric knowledge and experience.

8. The child and the family shall be entitled to a named and accessible key-worker whose task it is to build, co-ordinate and maintain appropriate support systems which should include a multi-disciplinary care team and appropriate community resources.

9. The child’s home shall remain the centre of care whenever possible. Treatment outside of this home shall be in a child-centred environment by staff and volunteers, trained in palliative care of children.

10. Every child and family member, including siblings, shall receive culturally appropriate, clinical, emotional, psychosocial and spiritual support in order to meet their particular needs. Bereavement support for the child’s family shall be available for as long as it is required.

The ICPCN Charter is available in 22 languages and can be downloaded from the ICPCN website at www.icpcn.org.uk
Principles of successful partnering

Patience and Flexibility
Don’t expect too much, too soon. Allow the process to develop at its own pace and find its own level and beware of unrealistic expectations. Be flexible enough to change course should the need arise and circumstance dictate.

Sensitivity and Respect
Behaviour and attitudes need to be openly examined and overly paternalistic advice and actions avoided. One partner should not jump in and try to “fix” the problems of the other. Respectful consultation and collaboration around areas of need can be empowering for both partners.

Sustainability
Ensure that the right plans, people and resources are in place to sustain a partnership for at least long enough for both to gain significant benefit. More harm than good can result from an enthusiastic and exciting launch which all too soon runs out of steam.

Reciprocity
It is vital for each of the partners to identify beforehand what they have to offer and what they wish to gain. Ensure that both partners feel they hold equal control and have equal responsibility in maintaining the relationship.

Communication
Keep the lines of communication open. Partnering is about developing links and friendships with people involved in the same line of work as you in another part of the world. Their circumstances and access to resources may be different, but their desire to make a difference in the lives of the children they serve is the same. Make the time to connect. With the advantage of today’s modern technology, this is not difficult, expensive or time consuming and could mean a quick but regular email, text or Skype call.
Examine your motivation

Children’s hospice and palliative care partnerships should always be motivated by a common desire to provide more life limited children around the world with the best care possible, no matter what the circumstances that may surround that child.

When organisations, and the people who work within them, have a sincere desire to share their knowledge and experiences for no other reason but to improve both the lives and in some cases, the deaths of children living with a life-threatening or life-limiting illness, the partnership will flourish and find its own level.

However, even with these good intentions, time and energy is often a limited commodity in busy organisations. Healthy partnerships will require commitment and effort from both sides.

Types and levels of partnerships

Umbrella Organisations

It is normal and expected for links and associations to be built up between children’s hospices and palliative care programmes within the same geographical regions. In countries where the children’s hospice movement is well established, there are most often umbrella bodies or organisations to provide coordinated support to management, staff, patients and families while speaking in a united voice when advocating to government and policy makers.

Examples of such associations are ACT and Children’s Hospices UK within the UK, Bundersverband-Kinderhospiz e.V. in Germany and the HPCA Paediatric Sub-Committee (PAESCO) within South Africa.

Geographical considerations

Partnerships could occur between organisations of similar status within close geographical proximity and could perhaps include the sharing of advice, information, services and access to resources, or more commonly, partnerships between organisations where one is more established than the other. The latter group may find themselves in the same country, on the same continent or on other sides of the world.

Socio-economic considerations

Partnerships struck up between children’s palliative care programmes in the developed and developing world probably have the most challenges, but also the most social impact. In this instance, we do not believe that the established organisation should always take the lead or the better resourced expected to adopt the other simply as a charity, but we do acknowledge that where the greatest differences exist, the more opportunities would present themselves for mutual learning and growth.
The ICPCN Declaration of Cape Town clearly states that “…collectively we are a rich resource of knowledge, skill and judgement..” and whatever form this collaboration will take, we envisage partnerships which enrich the performance of both organisations involved.

The value of reciprocity
Well established children’s hospice and children’s palliative care programmes will have a great deal to offer in the way of guidance in areas such as the drawing up of financial management and business plans, policies and procedures, best practice models, care pathways and access to resources. Children’s hospices and children’s palliative care services from poorly resourced world regions can often educate their more affluent counterparts on resourcefulness and innovative problem solving.

Passing on the baton of knowledge and inspiration
There are instances of children’s hospices in developing countries that over the years have enjoyed beneficial twinning partnerships with hospices in the UK and the USA. These hospices could now be well placed to propose a partnership with less established hospices within their own geographical regions.

Having an existing relationship with another hospice should not preclude an organisation from looking at the possibility of a second partnership with an emerging hospice. Only in this way can we reach our ultimate vision of:

“Quality palliative care for all life-limited children”

However, such hospices will need to guard against diluting the effect of one partnership by taking on another.

“Links can be built at any level within the organisation, whether they are, for example, between medical professionals, chief executives, fundraisers or volunteers. There is no set formula for creating relationships between services: the level of involvement and form of support should vary according to the needs and cultural context of the developing service and the resources available within the established service.

The concept of ‘partnership’ as applied to hospice and palliative care is really the formalisation of links and affiliations that quite often develop in an organic way through motivated individuals.”

While some partnerships may evolve from chance meetings, such as may occur at international conferences, there is enough evidence to believe that a worthwhile partnership can be formed through deliberation and after purposeful research. This will also improve the chances of such a relationship being sustained for a reasonable time period and beneficial to both parties.

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2 Nikki Slater in “A guide to Partnerships in Hospice and Palliative Care” published by Help the Hospices
The Scale of the Activities
The activities involved within a partnership do not have to be on a large scale in order to bring about important improvements or changes in the way in which the programme is run. Even small scale links can be beneficial, such as the sharing of good practice models, care pathways and policies and procedures.

The level at which the partnership will function should be decided upon by both parties before entering into an agreement through a Memorandum of Understanding. You can find an example on page 20.

It is reasonable to expect that the level and intensity of the partnership will alter and evolve over time, and should in fact come under regular evaluation by management teams on both sides.

Regularly re-evaluate
All relationships require work and commitment and in a healthy partnership, the results of such input will always outweigh the time and effort spent. When the relationship is no longer of benefit to one or both of the partners, it is time to re—evaluate the terms of the agreement signed and a decision made to either change or end the partnership.

The benefits of partnerships

Benefits for an established partner
- Satisfaction in the knowledge that insights, knowledge and experience gained over the years can be used to develop other services around the world. Partnerships provide more experienced practitioners an opportunity to share encouragement as well as their knowledge and skills with counterparts, often working in difficult circumstances.
- A greater understanding of how palliative care can be offered in low resourced settings which could encourage service managers to find more cost effective ways to provide palliative care within their own setting.
- Firsthand experience and knowledge of illnesses and conditions not normally treated within their organisations, for example HIV/AIDS, MDR TB and malnutrition.
- A deeper appreciation for their own circumstances and ease of access to resources and palliative care drugs.
- Insight into the manner in which palliative care is provided within different socio-economic and cultural contexts.
- Sensitivity to diversity and cultural practises which informs attitudes and behaviours to different cultures found within their own hospice or geographical location.
- The possibility of exchange visits and volunteering opportunities which could prove inspiring to health care professionals and bring a deeper sense of value to the work carried out within their own service.
Benefits for a less established partner

- Knowing there is somewhere reliable to turn to for support, advice and assistance
- The possibility of exchange visits where volunteers from the partner organisation assist with specific projects
- The possibility of employees from the established organisation providing training to staff either through exchange visits or through multi-media channels such as video conferencing
- Assistance and guidance around advocacy work to the relevant decision makers
- Assistance and guidance on drug availability and formulary
- The possibility of receiving material support which could take the form of financial support, medical books, equipment or various donations in kind

Challenges and barriers to healthy partnerships

Any worthwhile partnership will face challenges and come up against obstacles which will put the relationship in jeopardy. While ICPCN would like to encourage all children’s hospices and children’s palliative care services to consider participating in this project, we do not imagine that the partnership will be without its challenges.

These may include:

- Staff overload where the partnership could take time away from their own work commitments
- Extra financial considerations where the agreement signed calls upon one hospice to provide some form of financial or resource support for the other
- Partnerships often come about through the vision, enthusiasm and drive of one motivated individual. If this person leaves the hospice, the partnership may falter if there is nobody willing to take over the lead.
- Established organisations attempting to impose their standards and ideas on their partner organisation without a genuine understanding of their circumstances, cultural norms and resource constraints
- Lesser established organisations with a high dependency on funding, resources and knowledge from their partner
- Language barriers where documents and discussions may call for the skills of a translator
- Raised expectations which cannot be met
- Information and training given that is not applicable to the culture or circumstances of the partner
Dr Frank Falk, from Hold me Africa, gives some sound advice on partnering with an organisation in a developing country in “The How To Guide to Hospice Palliative Care Twinning Projects”, published by Health Canada.

- Remember that your twin is the expert on the needs, values and processes of their community and organisation
- Simply handing over large amounts of money can have a negative and disempowering effect on the growth of the organisation receiving the donation. There should be collaboration and an expectation that the partner receiving the donation will contribute financially or in kind towards any planned projects.
- Guard against emotive responses to the needs of a partner organisation. Partnership activities based on sympathy are doomed to failure as they promote dependency and destroy mutual respect.
- Wherever possible, empower people rather than systems by helping them to see how they can access new resources and develop effective systems to maintain their development. Build the capacity of people and build strong friendships.

Choosing the right partner

Experience has shown that a partnership’s chances of prospering and bearing fruit are dependent on some important factors.

Here are some helpful pointers:
- Canvas staff members to see if they have formed informal partnerships which could be expanded upon and formalised
- It is reasonable to expect that there will be a greater benefit to the sharing of knowledge where at least some similarities exist between partners. Look for these in areas such as patient load, size and the provision of services.
- Communication between partners will be of paramount importance so it will be beneficial if at least some members of each team are able to communicate in a common language.
- Carry out as much research and find as much anecdotal evidence as possible about the service with which you intend to partner. A first hand visit before the signing of any agreement would be the most responsible first step, although with geographical and financial constraints, this may not be a possibility.
Taking the first step

The first step on any journey is often the most difficult one. In the case of hospice and palliative care partnerships, the first step may already have been taken. It is often the case that the person motivated to lead a partnering project has already made some contact or connection to another hospice or palliative care programme and through discussion with fellow staff members may find a number of connections which could be pursued and researched. If your town has a twin city or town in another country, you could pursue the possibility of partnering with a children’s hospice organisation there.

Before embarking on this journey, discuss your plans with colleagues with experience in partnerships so that your organisation’s goals and strategies can be clearly identified.

STAGE 1: PLANNING & PREPARATION

This stage is more likely to be carried out by an established hospice looking to partner with one that is less established.

Step 1: Read and Research

On page 23 you will find a list of resources and information you may find useful. Read and research as much as possible on the topic.

Step 2: Share the idea

Activities you may engage in before proposing partnerships could include the following:

- Discussing the idea with others to gauge their response
- Give a presentation or invite a speaker to talk on partnering to the relevant stakeholders within your organisation. Find the right time and place to do this, for example, at a board meeting or AGM.

Step 3: Form a task team.

Once you have rallied support for your idea, it is vital to ensure that you have the full buy in of the staff, management team and board members before going ahead with partnership plans. With their support, you can actively recruit volunteers to the task team by asking for a written commitment which indicates what skills each person has and what they are prepared to offer to the project. Volunteers can come from outside of the organisation as well – make use of your own networks to recruit suitable volunteers. Once this task team has been formed, choose a project leader who has both the time and the motivation to see the planned project through.
**Step 4: Create a vision statement**
You may find it helpful to come up with a vision statement which will be motivating and allow people to visualise the scope of the proposed project.

**Step 5: Draw up a project plan**
Brainstorm the following items with the task team:
1. Define the purpose, goals and objectives of the project. Make these clear, obtainable and easily evaluated.
2. Establish the scope of the project which clearly identifies what activities will be included and what will be excluded.
3. Draw up the criteria you will use for choosing a partner, such as language, geographical area, financial needs and scope of practice.
4. Draw up a time line for the launch of the project.

**STAGE 2: ESTABLISHING A PARTNERSHIP**

**Step 6: Find your hospice partner**
If you have not already done so, you are now in a position to find yourself a suitable partner. If there is no natural choice based on past acquaintances, the ICPCN is keen to assist member services by matching them up to appropriate partners. (See page XXX for the registration form.) Based on the criteria you have already drawn up, shortlist a selection of organisations to discuss with members of the task team, matching your capacity to the needs of the other organisation. Once a decision has been made, make contact with your proposed partner and open up the discussion. Once you are satisfied that both organisations are willing to enter into the proposed partnership, go ahead and...

**Step 7: Arrange a meeting**
Wherever possible, arrange a face to face visit. Should this not be a viable option, try to organise a teleconference, video conference or Skype session with the partner organisation. At this meeting, you will discuss the project plan as set out in Step 5. If both parties feel comfortable that this partnership is viable, items under discussion at this meeting will include:
- An agreement to pursue the partnership
- A shared vision
- Needs assessment
- Expected benefits to both partners
- Identification of expected challenges and ways to minimise their effect on the partnership
• Consensus on both long term and short term goals for each partner. These may be different, according to the resources and circumstances of each of the partner organisations.
• Agreement on a timeline for the completion of milestones in the establishment of the partnership

Step 8: Draw up and sign a MOU
Taking decisions made at the first meeting into account, key people within the two organisations need to work on the drawing up of an Memorandum of Understanding (MOU). This should clearly outline the responsibilities and expectations of each partner and not be signed until all are aware of and willing to accept the implications of what is written. See page 20 for an example of a hospice partnership agreement which organisations can adapt to their own needs and circumstances.

Step 9: Define roles and responsibilities
Each organisation needs to establish a project task team, with a project leader. Members of these teams need to have their roles clearly defined and given to them in writing.

STAGE 3: MAINTAINING & EVALUATING

Step 10: Commit to regular communication
Identified people must be tasked with the responsibility for maintaining the communication and partnership links between the two organisations. Regular and open communication between individuals will be the key to the success of the partnership and can be accomplished through letters, telephone calls, text messages, email or Skype.

Step 11: Put financial checks in place
Should your partnership include the transfer of funds or donations from one partner to another, a system of financial accountability should be put in place early in the partnership. Both partners should agree on who will take responsibility for dealing with any money, how the funds can safely and most cost effectively be transferred and who will be held accountable for reporting on the spending of this money.

Step 12: Review your progress
At the end of an agreed period of time, it is important for both partners to review the progress that has been made towards the original goals and objectives. Look at what has been accomplished and which areas need more attention. This information can be used to modify the action plan going into the future.
Step 13: Plan for the future
Regular reviews and reporting on a partnership project will inform project leaders and task teams on progress being made, projects completed, benefits and challenges and how best to plan for the future. At the end of the agreed period of time both organisations may wish to terminate or continue the partnership. Any termination should be handled with great sensitivity and care taken to explain the reasons behind such an action.

Step 14: Share the lessons learned
Whether your experiences are good or bad, or a little of both, be willing to share the lessons you have learned with others in the international children’s palliative care community and hopefully encourage those who are considering taking a similar journey.

PARTNERING PROGRESS FLOWCHART

Stage 1 Planning & Preparation
1. Read and research
2. Share the idea
3. Form a task team
4. Write a vision statement
5. Draw up a project plan

Stage 2 Establishing a Partnership
6. Find your partner
7. Arrange a meeting
8. Draw up an MOU
9. Define roles & responsibilities

Stage 3 Maintaining & Evaluating
10. Communicate regularly
11. Financial checks
12. Review your progress
13. Plan for the future
14. Share lessons learned
Suggested partnership activities

So now that you have set up a partnership, what kind of activities can you expect to participate in with your partner? Here are some ideas:

- The exchange of literature, medical journals and articles on research which would be relevant to the other hospice.
- Assistance with training by swapping educational materials for the partner hospice to adapt to their circumstances.
- Alerting your partner on any opportunities for grants, scholarship and funding opportunities which may be relevant.
- Share information on how you deal with areas of practice such as pain control, symptom management, short breaks, disclosure and emotional support, family support, bereavement and spiritual care.
- Exchange and compare information on cultural practices, customs, norms and daily life in your part of the world.
- Where appropriate and it forms part of the partnership agreement, one hospice may fundraise and/or gather resources to send to its partner. It would be prudent to source this kind of funding from outside your hospices own normal funding streams.
- Doctors may wish to exchange suggestions about patient care, drug usage and dosages.
- Inform a partner hospice on the latest methods and advances in paediatric medicine.
- Set up exchange visits. A better resourced hospice may fundraise in order to sponsor a key worker from the partner hospice to visit their programme for one or two weeks.
- Mentoring and support.
- Encouraging one another.
- Setting up contacts between parents or young people within the respective programmes.
- Awareness raising events.
- Shared presentations at conferences.
- Research across countries and cultures.

Suggested questions for the process of review

Have more children received better quality palliative care as a result of your partnership?
What has your organisation benefited from the partnership?
What new skills have been learned by staff as a result of the partnership?
How has your partner organisation benefited from the partnership?
What were the unexpected challenges you had to face and how could these be avoided in the future?
What was the financial cost or benefit to your organisation?
Was there financial accountability?
Should the partnership continue?
Is it possible to sustain and improve the partnership?
What are the plans for the future?
Existing Partnerships
The best teacher is experience. The following children’s hospices have experience in partnerships and have agreed to share information and ideas with anyone who is interested in exploring the feasibility of setting up a similar project.

Richard House Children’s Hospice, London, UK and Belarussian Children’s Hospice, Belarus
UK Contact: Peter Ellis, CEO of Richard House
Email: petere@richardhouse.org.uk
Belarus Contact: Anna Garchakova, Director of Belarus Children’s Hospice
Email: hospicepall@mail.belpak.by

Activities include:
• Exchange of information by email
• Partnership/buddying of individual staff
• Transfer of redundant equipment
• Opportunity for children from the Belarussian Children’s Hospices to spend a week at Richard House as part of their visit organised by Chernobyl Children’s Project (CPP) UK Programme

Anna reports: “The Belarus Children’s Hospice has enjoyed a partnership with Richard House in London, UK since 2006. We work very closely and partnering activities include exchange visits where our doctors and nurses have made visits to London, and their doctors came to us to see our system and gain an insight into our health care systems in Belarus. At present we continue our connection using Skype and in general work together intensively.”
Sunflower House Children’s Hospice, Bloemfontein, South Africa and
Vitas Innovative Hospice Care (Corporate Head Office) USA

South Africa Contact: Joan Marston, Founder and Consultant to Sunflower House Children’s Hospice  
Email: joan@hpca.co.za  
US Contact: Robin Fiorelli, Senior Director for Bereavement and Volunteers  
Email: robin.fiorelli@vitas.com

Joan Marston reports, “This partnership is an example of two organisations which appear to be completely mismatched on paper, but has in fact been most successful for a number of years.” The partnership, which began in 2002, has been sustained through reciprocal visits and the development of a relationship between members in the two organisations. Other activities have included
• Sharing of information on bereavement in children
• Sharing stories of children to enable Vitas to help meet the needs of the children
• Fund Raising activities for Sunflower Children’s Hospice

Demelza Hospice Care for Children, and Ambuya Day Centre for Children and the Children’s ward at Jon Hospice both in Kamwala (Lusaka) Zambia

The following story appeared in the October 2008 Issue of Network News and reports on a partnership initiated by Corine Koppenol-Lyndon, former Head of Care Community at Demelza Hospice Care for Children in Kent, UK.

It tells of a partnership between Demelza Hospice and Jon Hospice in Kampala, Zambia. The volunteers who participated in this exchange visit described the experience as life changing.
If you have ever considered twinning with another hospice here is a story that warms the heart as it describes the rewards of such a partnership. An information pack on twinning can be obtained from Help the Hospices Write to: info@helpthehospices.org.uk

Demelza Hospice Care for Children had established a good working relationship with American Dr Tim Meade based in Lusaka, Zambia through efforts by Corine Koppenol-Lyndon, Head of Care Community. From this link plans developed with the events fundraiser, Sarah Marsh, to explore the feasibility of an official twinning link with Ambuya Day Centre for Children and the Children’s ward at Jon Hospice both in Kamwala (Lusaka) Zambia. The Ambuya Day Centre for Children operates a programme that offers care and support to around 170 orphans and vulnerable children living with HIV/AIDS through medication, nutrition, education and limited recreation facilities with inspirational staff doing their best to make a difference with the financial support offered. They have a aim for this twinning was to link with a place not as privileged in being able to provide quality care to their very sick children and families as we are able to do in England; to exchange our knowledge gained, to share our experiences and passion for Paediatric Palliative Care alongside the creativity of people volunteering to give something which would have a lasting impact on the children.

The international link started back in 2004 with a fact finding visit, funded by ‘Smith & Ouzman’ in Eastbourne. From that visit it was clear that Demelza could make a difference by building onto the good care already being provided and by inviting people outside Demelza to join in with the contribution of their skills and enthusiasm. After two years of preparation, thirty-six people gathered at Terminal 4 of Heathrow Airport in September 2007. They were men and woman of different ages, backgrounds and professions, all willing to take on the challenge to build a playground for the children attending the Ambuya Day Care Centre in Lusaka, Zambia.

Meeting these lovely children tugged at every heart string. Simple balloons and bubbles brought huge smiles. They have so little compared to what we know in our own lives but like any child they just love to play and sing and their eagerness to hold a hand and to reach for a hug was a universally understood need for affection. These thirty-six fantastic volunteers were inspired by meeting the people and children in Zambia and their goal was a shared one: a project to build the children a playground, to allow those children to swing so high they feel like they can touch the sky or to experience how good it feels to fly down the slide and to forget their sorrows and pain. We wanted to allow them to experience the joy of just being children.

Along with the container filled with the playground materials, there were many bags of donated clothing, toys, books, bedding and tools which were gratefully received. The group also painted murals at the Day Care Centre and the Butterfly Room at the hospice where they care for children needing overnight observations or end of life care.

The official opening and the signing of the documentation to mark the twinning between two Hospices was the highlight of this visit.

It is impossible to describe the impact this trip had on everyone involved. Plans are already underway to revisit the children and the staff in the future and to build onto the life changing experience and to consolidate the twinning and I am sure there will be a lot of familiar faces to join us.

Information on opportunities to volunteer or to provide much needed funding can be found at the website: www.tinytimandfriends.org

Corine Koppenol-Lyndon
Head of Care Community
Demelza Hospice Care for Children
www.demelza.org.uk

A letter of Thanks from Dr Tim Meade

I went to the hospice/day care yesterday to see for the first time the completed project, while you were all on the airplane flying home. It was so impressive, even moving, to see the kids playing on the new equipment. It was so beautiful, I could not stop taking photos. All the children were very happy and came up to me and asked if they could have a photo with me. I was so touched. I must say that I was in tears when I saw the painting the volunteers did. It is a fantastic place and I hope it brought a smile to all the children. I was so impressed and so moved, I wish I could come back again.

Tim Meade

A volunteer gets a helping hand with the mural on the wall in the Day Care Centre

Volunteers and children in the playground

Corine formalises the twinning with a friendly handshake

Information on opportunities to volunteer or to provide much needed funding can be found at the website: www.tinytimandfriends.org

Corine Koppenol-Lyndon
Head of Care Community
Demelza Hospice Care for Children
www.demelza.org.uk
Richard House Children’s Hospice (London, United Kingdom) and the Belarusian Children’s Hospice Service Twinning Programme - Key Objectives
June 2008

Richard House Children’s Hospice and the Belarusian Children’s Hospice Service established a twinning agreement in May 2006. Peter Ellis (Chief Executive, Richard House) and Anthea Hare (Founder and Life President, Richard House) visited Belarus in 2006 to commence the twinning.

To date, an exchange of staff has occurred both ways. Anna Garchakova (Director, Belarusian Children’s Hospice Service) and two nurses visited Richard House in May 2007. Tanne Campbell, Care Team Manager visited Belarus in November 2007. Following these initial exchange visits, a review of the twinning relationship has identified key objectives for the ongoing twinning of the two hospice services.

These objectives are:
• To support Belarus in training and development of staff and volunteers in the principals and practice of children’s palliative care;
• To enable staff from both hospice services to have opportunities to experience different approaches, different experiences and different cultures and how this influences the practice and delivery of children’s palliative care;
• To facilitate short breaks for children and their families from Belarus in the UK.

To achieve these objectives it is proposed that:
• Belarusian care staff visit Richard House on a regular (perhaps yearly) basis to work within the Hospice and with other UK organisations to acquire new skills and understanding of children’s palliative care. This could include conferences and other events when and where appropriate. Care staff from Belarus will come prepared with clear and mutually agreed learning objectives.
• To share relevant information about children’s palliative care (arising within the UK) with the Belarusian Children’s Hospice service.
• Richard House and other organisations (e.g. Great Ormond Street Hospital Symptom Care Team) visit Belarus to acquire new skills and understanding of children’s palliative care, especially in a resource poor country. Again, learning objectives should be clearly articulated prior to the visit;
• Children and families accompany staff from Belarus to visit Richard House and the UK as part of a programme of holiday breaks for their benefit.
• To consider joint research and development work between Richard House and the Belarusian Children’s Hospices service, when it meets the need of both organisations.

These proposals are for agreement between the two hospice services (Peter Ellis and Anna Garchakova), and once agreed will form an outline plan for establishing an ongoing mutually beneficial relationship between Richard House and the Belarusian Children’s Hospice Service.

Peter Ellis
Chief Executive
Richard House Children’s Hospice

Anna Garchakova
Director
Belarusian Children’s Hospice

June 2008
### AFRICA

#### Regional Associations:
**African Palliative Care Association (APCA)**
- Tel: 256 (0)414 266251
- Fax: 256 (0)414 266217
- Email: info@apca.co.ug
- Website: [www.apca.co.ug](http://www.apca.co.ug)

**Foundation for Hospices in Sub-Saharan Africa (FHSSA)**
- Tel: +1 703 647 5176
- Email: info@fhssa.org
- Website: [www.fhssa.org](http://www.fhssa.org)

#### National Associations:
**Hospice Africa Uganda**
- Tel: +256-414-266867/510089
- Email: info@hospiceafrica.or.ug
- Website: [www.hospiceafrica.or.ug](http://www.hospiceafrica.or.ug)

**Hospice Association of Zimbabwe (HOSPAZ)**
- Tel: +263 (0)4 705771/2
- Fax: +263 (0) 4 705775
- Email: info@hospaz.co.zw

**Hospice Palliative Care Association of South Africa (HPCA)**
- Tel: +27 (0)21 5310277
- Fax: +27 (0)21 5311706
- Email: info@hpca.co.za
- Website: [www.hospicepalliativecaresa.co.za](http://www.hospicepalliativecaresa.co.za)

**Island Hospice and Bereavement Service - Zimbabwe**
- The core of Island Hospice services is providing comprehensive health care to underserved children.
- Tel: +263 4 701676/7
- Fax: +263 4 700930
- Email: info@islandhospice.org
- Website: [www.islandhospice.org](http://www.islandhospice.org)

**Kenya Hospice & Palliative Care Association**
- Tel: +254 20-2729302
- Fax: +254 20 271204
- Email: info@kehpca.org
- Website: [www.kehpca.org](http://www.kehpca.org)

**Pasada, Tanzania**
- Pasada is an international charity, specialising in quality care, compassionate services and support to people affected by HIV and AIDS.
- Tel:+255 022 286 5451
- Email: pasada@intafrica.com
- Website: [www.pasada.or.tz](http://www.pasada.or.tz)

### THE AMERICAS

#### LATIN AMERICA
**Asociación Latinoamericana de Cuidados Paliativos (ALCP)**
- Tel: 54 (3461) 433351
- Fax: 54 (3461) 433351
- Email: Info@cuidadospaliativos.org
- Web: [www.cuidadospaliativos.org](http://www.cuidadospaliativos.org)

### NORTH AMERICA
**Canadian Hospice Palliative Care Association (CHPCA)**
- Tel: 1 613 241 3663
- Fax: 1 613 241 3986
- Email: info@chpca.net
- Web: [www.chpca.net](http://www.chpca.net)

**National Hospice and Palliative Care Organization, Inc. (NHPCO)**
**Children’s Project on Palliative Hospice Services (ChiPPS)**
- Tel: 1 703 837 1500
- Fax: 1 703 837 1233
- Email: nhpcoc_info@nhpcoco.org
- Web: [www.nhpcoco.org](http://www.nhpcoco.org)

### ASIA
**Asia Pacific Hospice Palliative Care Network (APHN)**
- Tel: 82 2 792 1150
- Fax: 82 2 792 1140
- Email: aphpn@nccs.com.xg
- Web: [www.aphn.org](http://www.aphn.org)
**OCEANIA**

**Palliative Care Australia (PCA)**
Tel: 61 (0) 2 6232 4433
Fax: 61 (0) 2 6232 4434
Email: pcainc@pallcare.org.au
Web: www.pallcare.org.au

**Hospice New Zealand (Hospice NZ)**
Tel: 64 (0) 4 381 0266
Fax: 64 (0) 4 381 0264
Email: Rachel@hospice.org.nz
Web: www.hospice.org.nz

**EUROPE**

**Regional Associations**

**European Association for Palliative Care (EAPC)**
Tel: +39 02 2390 3390 / 91
Fax: +39-02 2390 3393
Email: Chantal.wood@rdb.aphp.fr
Web: www.eapcnet.org

**Palliative Care in Children – EAPC Task Force**
Email: international@maruzza.org
Web: www.maruzza.org

**National Associations**

**GERMANY**

**Bundersverband Kinderhospiz e.V.**
Tel: +49 (0) 8 00 - 8 86 87 88
Fax: +49 (0) 8 00 - 8 86 87 89
Email: info@bundesverband-kinderhospiz.de
Web: www.bundesverband-kinderhospiz.de

**NORWAY**

Yes to Palliative Care for Children in Norway
Tel: 99 16 22 33
Email: np@palliativbarn.com
Web: www.palliativbarn.com

**RUSSIAN FEDERATION**

**Belarussian Children’s Hospice Association**
Tel: +375 17 505-27-46
Email: hospicpall@mail.belpak.by
Web: www.hospice.by

**Regional Society for Palliative Care**
Tel: +7 831 4366197
Email: evveden@rambler.ru
Web: www.pallcare.ru

**INTERNATIONAL**

**Foundation for Hospices in Sub-Saharan Africa**

One focus of FHSSA’s strategic plan is the Partnership Initiative, which matches African healthcare programs and American organizations. The goal of the partnerships is to form a mutually beneficial relationship that leads to an exchange of expertise and insight, and to provide avenues of funding and other forms of assistance for the partners.
Tel: 703-647-5176
Fax: 703-837-1233
Email: info@fhssa.org
Web: www.fhssa.org

**Help the Hospices & Hospice Information Service**
Tel: +44 (0) 20 7520 8200 / 8222
Fax: +44 (0) 20 7278 1021
Email: info@helpthehospices.org.uk
Web: www.helpthehospices.org.uk

The international programme supports the development of hospice and palliative care worldwide, particularly in developing countries. The hospice information service can provide information on planned travel abroad for patients, hospice partnerships, volunteer opportunities and the setting up of a new hospice.
The International Children’s Palliative Care Network (ICPCN)
The ICPCN’s vision is to achieve worldwide the best quality of life and care for children and young people with life limiting illnesses, their families and carers, through networking, advocacy, information sharing, education and research.
Tel: +27 (0)82 897 4420
Fax: +27 (0)21 5311 706
Email: info@icpcn.co.za
Web: www.icpcn.org.uk

The International Association for Hospice and Palliative Care (IAHPC)
The IAPC advances hospice and palliative care programmes, education, policies and research in order to improve the quality of life of patients with life-threatening conditions and their families.
IAPC members are able to apply for bursaries for scholarship and mentorship purposes.
Tel: +1 (936) 321 9846
Fax: +1 713 880 2948
Email: info@iahpc.com
Web: www.hospicecare.com

The Worldwide Palliative Care Alliance (WPCA)
The Worldwide Palliative Care Alliance promotes universal access to affordable quality palliative care through the support of regional and national hospice and palliative care organisations.
Tel: +44 (0)20 7520 8200
Fax: +44 (0)20 7278 1021
Email: cmorris@thewpca.org
Web: www.thewpca.org

The following resources will provide sound advice and information on the formation of effective partnerships.

A Guide to Partnerships in Hospices and Palliative Care
Published by Help the Hospices
Email: info@helpthehospices.org
Web: www.helpthehospices.org.uk

Guideline to the Partnership Initiative
Published by the Foundation for Hospices in sub Saharan Africa (FHSSA)
Email: info@fhssa.org
Website: www.fhssa.org

The ‘How To’ Guide to Hospice Palliative Care Twinning Partnerships
Written by Susan Breiddal with funding from the Health Canada
This excellent guide to hospice palliative care partnerships can be downloaded free of charge from the Health Canada website:

Toolkit of Good Practice – Opportunities and Challenges
A useful toolkit and resource made available by UK One World Linking Association (UKOWLA) with a wealth of information on linking organisations of all kinds.
Email: info@ukowla.org.uk
Website: http://www.ukowla.org.uk/toolkitmain/toolkit.asp
THE ICPCN PARTNERSHIP SERVICE

In order to achieve its ultimate vision of the best quality of life and palliative care for children around the world the ICPCN is eager to play an active role in facilitating the formation of effective partnerships by:

- Keeping a register of children’s hospices and other children’s palliative care organisations looking to partner with another
- Advertising requests for partnerships on the website and newsletters
- Suggesting suitable matches between children’s hospice services and other palliative care programmes.
- Facilitating introductions between suitable partners
- Providing advice, support and guidelines on realising the most benefit from partnerships

Partnership request page

For hospices and palliative care services wishing to find a partner but without a natural lead to follow in this endeavour, we have set up a partnership request page on our website where an application form can be downloaded and emailed to our International Information Officer at info@icpcn.co.za

Once received and checked, your request for a partnership will be uploaded onto the website and may also be advertised in our quarterly newsletter. ICPCN will send details of suitable organisations to potential partners that have registered with the scheme.

The ICPCN does not have the capacity to contribute financial aid in the setting up of a partnership nor can it accept liability should a breakdown occur in the partnership further down the line. We are however, willing to offer support, advice and access to relevant information in order to facilitate the proposed partnership between the two organisations.

Readers are also encouraged to make use of the online directory of children’s hospices and children’s palliative care organisations as a rich source of information about what exists around the world. This can be accessed via our website at www.icpcn.org.uk. Follow the link to members.

You will find the application form for this service on the following pages. A fillable pdf copy of this application form is also available from the ICPCN website.

Completed forms should be marked ICPCN PARTNERSHIP PROJECT and can be faxed, emailed or posted to:

Fax: +27 21 5310277
Email: info@icpcn.co.za
Post: P.O. Box 38785, Pinelands, 7430 South Africa
ICPCN PARTNERSHIP APPLICATION FORM

Contact Details
Name of your hospice or organisation: ________________________________
Address: ____________________________________________________________
City: ____________________________ State or Province: ___________________
Postal/Zip Code: ________________ Country: _____________________________
Telephone: ______________________ Fax: _________________________________
Website: ________________________
Contact Person: ____________________
Position in organisation: ________________________________
Telephone: ______________________ Cell: _________________________________
Email: __________________________
2nd Contact person: ____________________
Position in the organisation: ________________________________
Phone: __________________________ Cell: _________________________________
Email: __________________________

Organisation Details
Area served by your organisation (tick)
☐ Urban   ☐ Rural   ☐ Mixed

Please tick which services your organisation offers:
☐ In patient unit   ☐ End of life care
☐ Home based care   ☐ Bereavement care
☐ Respite Care      ☐ Occupational Therapy
☐ Day Care          ☐ Music and/or Art Therapy
☐ Support Groups    ☐ Sibling Support Group
☐ Care of Orphans and other vulnerable children

Describe any other services offered: __________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
How long has your organisation been in operation? ________________

Do you have an inpatient unit? ___________  How many beds? ________________

Tick that which best describes your programme:
- ○ Independent Hospice
- ○ Hospital palliative care team
- ○ Home Based care team
- ○ Other (Please describe)

Tell us more about your organisation:

No. of full time staff members: ________  No. of part time staff members: ________

No. of volunteers: ________________  Budget size in US Dollars: __________

No. of children in your programme:___  Age range of children: ________________

Do you have an existing partner? ________

If yes, please supply name and country: __________________________

Is there a specific country in which you wish to find a partner? If so, please give reason/s:
________________________________________________________________________

What do you feel your organisation or hospice could bring to a partnership?
________________________________________________________________________
________________________________________________________________________

What does your organisation expect to benefit from the partnership?
________________________________________________________________________
________________________________________________________________________

Why do you wish to partner with another organisation?
________________________________________________________________________
________________________________________________________________________

Completed forms should be marked ICPCN PARTNERSHIP PROJECT and can be faxed, emailed or posted to:
Fax: +27 21 5310277  Email: info@icpcn.co.za  Post: P.O. Box 38785, Pinelands, 7430, South Africa