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icpcn
international children's palliative care network

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LETTER FROM THE CHAIR

Dear Friends,

My favourite poet of all time is Mattie J T Stepanek, an inspiring young man who died a few years ago, having lived life to the full despite having a rare form of muscular dystrophy. Mattie, a Poet and Peacemaker, was the fourth child in his family to have been born with the same condition, and had experienced the loss of all his siblings, and seen his beloved mother, his "grown-up best friend" developing this condition as well. Despite all this he published an anthology of poetry entitled "Celebrate through Heartsongs" – a book of such joy and delight in all things, that it never fails to fill me with wonder at the resilience of children and adolescents despite their illness. Mattie was able to express what many children with life-limiting conditions experience but are unable to share.

Trying to select one poem or an extract that displays his remarkable spirit is so difficult because all he wrote gives such a wise and positive message.
In his poem "About things that matter" Mattie wrote:
"It matters that the world knows
We each have a song in our heart
That can inspire us in good times and
Hard times if we take the time to listen."

It is children like Mattie who need us to stand up for, to fight for, and to protect their rights - rights such as those identified in the new ICPCN Charter. 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 and life threatening illnesses worldwide, and their families.

The Steering Group of the ICPCN believes that the Charter will prove to be a useful instrument for all of its members and for those who campaign for the development of, or for improved hospice and palliative care services for children around the world.

Our sincere thanks to Sue Boucher for all the activities involved in compiling the Charter, acknowledging everyone's comments and advice, getting it translated into 17 languages, and distributing it for use in different countries around the world in time for World Hospice and Palliative Care Day on the 11 October.

We hope that this Charter will be used to advocate for the millions of children who need palliative care and will raise awareness of their special needs; and we urge you to use this and share it widely.

If you find a book of Mattie Stepanek's poetry, buy it immediately, treasure it, read it and share it. I would like Mattie to have the last word in this letter, representing the voice of all the children in the world who have the right to palliative care.

"It matters that the world knows that
A person by my name and being existed
With a strong spirit and an eternal mindset
To become a peacemaker for all,
By sharing the things that really matter."

Let's all take Mattie's advice and listen to and share our own Heartsongs!
Yours in celebration of World Hospice and Palliative Care Day on the 11 October.

Joan Marston

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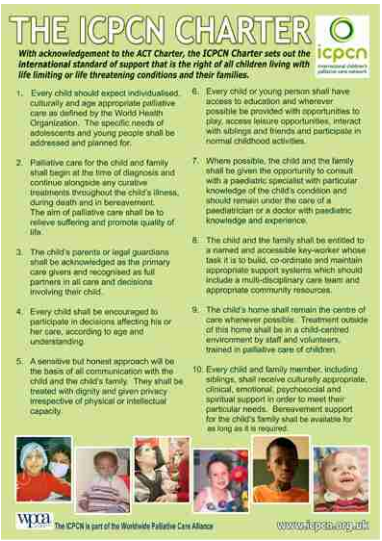
Celebrate through Heartsongs by Mattie JT Stepanek. 2002 Hyperion books. New York

EVENTS CALENDAR: OCTOBER, NOVEMBER & DECEMBER

Further information and contact details for all these conferences, courses and events can be found on our website. Go to: http://www.icpcn.org.uk/events

October		
6-31	Bereavement Support Groups for Children and Families	Online USA
8	Working with children after a bereavement	Hull, UK
9-10	15th Annual Pediatric Nursing Conference	Ohio, USA
11	World Hospice and Palliative Care Day	Worldwide
16	World HIV/AIDS Conference	Sandton, SA
26-29	Canadian Hospice Palliative Care Conference	Prince Edward Island, Canada
November		
5	Where are they now? The voice of the child in bereavement	Berkhamsted, UK
7	Children and Loss - Time to Listen	Hull, UK
12-14	20th ANTEA Worldwide Palliative Care Conference	Italy, Rome
16-19	CHI's 19th World Congress	San Francisco, USA
17-19	Pain Management for Children in Hospice and Palliative Care	Online, USA
20-21	Look forward, Think Together – Children's Hospices UK 2008 Conference for Children's Hospice services	Birmingham, UK
27-8/12	Psychosocial care – supporting people through loss, grief and bereavement	Strathcarron Hospice, UK
December		
16	Working within a hospice – what families value from staff when a parent or child dies	West Wycombe, UK

ICPCN Launches its International Charter


THE ICPCN CHARTER

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 Organization. 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 recognised 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 wherever possible be provided with opportunities to play, access leisure opportunities, interact with siblings and friends and participate in normal childhood activities.
7. Where possible, the child and the family shall 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 wherever 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.

wpca The ICPCN is part of the Worldwide Palliative Care Alliance www.icpcn.org.uk

The ICPCN launches its International Charter for the Rights of Life Limited and Life Threatened Children to coincide with World Hospice and Palliative Care Day on 11 October 2008.

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 and life threatening illnesses worldwide, and their families.

The Steering Group of the ICPCN expects that the Charter will prove to be a useful instrument for all of its members and for those who campaign for the development of or for improved hospice and palliative care services for children around the world.

The ICPCN Charter has been translated into a number of African and European languages and can be downloaded from the ICPCN website at http://www.icpcn.org.uk

Members willing to translate the charter into any additional languages are asked to make contact with the ICPCN Information Officer by email at: sue@icpcn.co.za

A Joint Declaration and Statement of Commitment for the recognition of palliative care and pain treatment as Human Rights

The International Association for Hospice and Palliative Care (IAHPC) is collecting signatures for the recognition of palliative care and pain treatment as human rights.

Every week more than one million people die with chronic and progressive conditions who do not receive any palliative care and pain treatment. In spite of the advances, many doctors, insurance programs, social security systems and national health policies do not cover or recognize palliative care as a component of care. The vast majority of people die abandoned by the system without ever receiving palliative care. Developing countries, where about 80 percent of the population lives, registers only about 6% of the total worldwide consumption of morphine, which indicates a huge disparity in access to pain treatment.

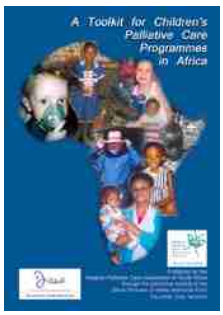
Several organizations have joined together and developed a Joint Declaration and Statement of Commitment for the recognition of palliative care and pain treatment as Human Rights. You are invited to sign this Declaration to help in this effort. The more signatures they are able to collect, the greater the chance that they will be able to bring this to the attention of the United Nations bodies and governments.

You can read the Declaration at:
http://www.hospicecare.com/resources/pain_pallcare_hr/docs/jdsc.pdf

To sign the Declaration online, click on http://www.hospicecare.com/cgi-scripts/csFormbuilder/forms/declaration.htm

REGIONAL REPORTS & UPDATES

Launch of Toolkit for Children's Palliative Care Programmes in Africa



At a cocktail party on the evening of Tuesday 12 August, ***A Toolkit for Children's Palliative Care Programmes in Africa*** was launched at the Hospice Palliative Care Association of South Africa's annual international conference. The conference venue was the Cape Town Convention Centre in central Cape Town. The toolkit consists of a manual and a CD with information relating to palliative care programmes for children gathered from a number of South African hospices. ***A Toolkit for Children's Palliative Care Programmes in Africa*** was compiled by HPCA's National Paediatric Palliative Care Manager and ICPCN Chair, Joan Marston, HPCA's Paediatric Palliative Care Officer, Maraliza Robbertze and Sue Boucher, the International Information Officer for ICPCN. It is meant as a tool to assist sites both within South Africa and across the African continent to begin or to develop palliative care programmes for children.
Speaking at the launch, Joan Marston announced that the toolkit is "an attempt to share knowledge, policies and practices that have proven to be effective in an African setting." Her hope is to encourage all hospices, hospitals and clinics to consider the development of a palliative care service for children.

From left to right: Sue Boucher, Joan Marston and Maraliza Robbertze with the Toolkit at the launch held on Tuesday 12 August in Cape Town.

"We have a few excellent children's hospice programmes in different countries in Africa, and some really expert practitioners, but these resources are few and scattered. The need for paediatric palliative care programmes on our continent is immense and growing," she stated. Joan went on to acknowledge the very generous support of the Diana, Princess of Wales Memorial Fund, for making the funding available for the Toolkit. The fund was represented by their programme and policy officer, Laura Ross-Gakava, who had flown in from the United Kingom to attend the launch. For further information regarding the Toolkit or to order a copy, you are welcome to contact: Joan Marston at joan@hpca.co.za
Maraliza Robbertse at maraliza@hpca.co.za
or Sue Boucher at sue@icpcn.co.za

LIVING WITH HIV IN THE UK

How adolescents in the UK are making the successful transition into adulthood

The total number of children known to be living with HIV in the UK and Ireland is estimated at around 1,400 but it is London which has the largest numbers. How do children living with HIV in Britain today face the challenge and stigma of being HIV positive through no fault or direct action of their own?

In the heart of London, there is a very special clinic which is helping HIV positive adolescents from all over the country move through this journey from childhood to adulthood. The clinic, at St Mary's Hospital in Paddington, is simply known as the '900'. Its central focus is to manage the successful passage of HIV positive kids from childhood to adulthood through multidisciplinary care. The average age in the paediatric clinic is 10, and there are now up to 50 young people who are aged 16 and above.

St Mary's, part of the Imperial College Healthcare NHS Trust, runs the largest paediatric clinic for children born with HIV in the UK. It currently treats around 250 children, many of whom come to the clinic from considerable distances with shared care established with district general hospitals, allowing both the sharing of clinical care, expertise and education.

Children are typically expected to move from paediatric to adult health services between the ages of 16 and 18. This is traditionally acknowledged amongst health professionals as a complex time to turn children over to adult care, especially for those with chronic diseases such as cystic fibrosis, diabetes and heart problems, which used to have high mortality rates in childhood. For young people who are HIV positive, the 900 aims to make this transition as successful as possible, and it is a UK first in shaping a new approach to the treatment and management of HIV.

Problems for young people with HIV range from having to live with a chronic disease, adhering to medication which may cause side effects such as lipodystrophy which can be unsightly, as well as psychosocial issues such as the death or ill health of family members and the complex issues of negotiating relationships and your first sexual experiences with HIV. There is also the ever present issue of disclosure, as HIV remains a stigmatising disease.

To fulfil their potential, these children now need both medical and psychosocial help. Thus, typical treatment will involve anti retroviral drugs to suppress the virus and also support with problems that tend to come in the teenage years, for example in relationships with friends and family members especially, as this is very much a family disease.
Whilst these problems cannot be underestimated, there is good news too.

There is a wave of young people born with HIV who are surviving on treatment, transitioning, moving into adult services, getting through school to university and who are fully engaged in getting on with their lives.

Information taken from press release from Imperial College Healthcare NHS Trust on 12 September 2008

The True Colours Trust

ICPCN acknowledges with gratitude the funding received from the True Colours Trust for the furtherance of its work in developing paediatric palliative care worldwide.

Update on events in Germany

Achievements and Challenges in Germany
Negotiations about better conditions for children's hospices are ongoing. We are still in the middle of negotiations with the national welfare organisations and the national public health insurances to develop a new framework for the children's hospices. We are the only pure children's lobby organisation at that table and experience great difficulties because all other welfare organisations represent both adults and children. Finance for home-service hospice work for example comes out of one pot for both children and adults. There will be two frameworks, one for the purpose built hospices, the other for the home services. In Germany home-service hospice work is strictly separated from care or nursing.

Negotiations and new law about palliative care
A law that was instituted last year guarantees specialised palliative care for every person in Germany. There have been two round table discussions with about 50 social organisations, all of them being represented: medicine, care and hospices as well as the children's lobby. The law says that the special needs of children must find their place in the regulations but during the discussions the health insurers, who are also responsible for the negotiation of this framework, have always said there is ***no need*** for special regulations for children. Although we have consolidated and pushed from all sides they have decided to leave it by saying only that *the special needs of children have to be taken into consideration*. Nobody really knows how this will work and how it will be financed. We must wait and see what kind of services of specialised palliative care for children will evolve and be publically financed.

Projects
We have participated in many public events, one of which proved to be most moving. We were invited by a sponsor to invite twelve children to the football game between Schalke 04 and Glasgow Rangers. Twelve Children, most of them in wheel-chairs, were allowed to be ballkeepers right on the playground. They got matching training tracksuits and shoes and you should have seen the smiles on faces where one might think a smile is no longer possible.

We are presently setting up an educational training course in paediatric palliative care as an additional module to be taken if trained in palliative care. For this we are cooperating with the University for Social Studies in Freiburg. We are also trying to standardise the training for volunteers by setting up a modular course which enables each hospice organisation to build up their own training according to their needs, while still achieving certain standards. Every person with a certificate from such a course can then move within Germany and the certificate, signed by the regional and national organisation, will be accepted. Just a small unit covering the specialities of the organisation will be necessary for retraining.

Home built hospices
There are new hospices evolving all over and powerful discussions are happening along with that. Existing hospices are afraid of the competition on the donation market and are afraid that there might not be enough people wanting to use the services. Our policy towards that is twofold: Firstly we offer advice to people if we feel there is no need for a hospice or if the place is not the right one. If that does not hinder the initiative we will invite them to become a member because we feel that as a member we can influence the quality rather than encourage further separation. Sadly, some organisations have quit their membership with us over this. Secondly, we are preparing to introduce a certificate for children's hospices which fulfil certain standards. This initiative has already been passed at the annual meeting.


Twelve intrepid ballkeepers show off their new kits

National Association of Children's Hospices
Finances remain a challenge. Whenever members leave it leaves a big hole in our household because we try to finance the national organisation strictly by membership fees only. Because there are not many children's hospices we must charge high membership fees, which makes it so much harder to bring solidarity to the movement. We must urgently find other ways of financing our organisation, which is difficult because we direct all donations to the members to avoid additional competition on the donation market between the own members and their national organisation.

The political challenge is to set up paediatric palliative care teams but as the number of cases is small we have some difficulty convincing the health department of the importance of this.

Sabine Kraft
National Children's Hospice Association
Germany

USA Update

The American Academy of Pediatrics approved a special section for hospice and pediatric palliative care in May, 2008. A pediatric palliative care list serve is available and active to all practitioners. If the section is approved permanently, it will be open to all disciplines. For questions on becoming a member please contact Marcia Levetown, MD. Chair, AAP Provisional Section, Hospice and Palliative Medicine at Mlevetown@earthlink.net

Congressman James P. Moran and his colleagues, introduced a new bill to the United States Congress this month. The **ChiPACC Bill, HR 6931**, aka **Mattie & Melinda Bill**, was developed in loving memory of Mattie Stepanek and Melinda Lawrence. The ChiPACC Bill is based on the collaborative model of care developed by Children's Hospice International (CHI), the Children's Program of All-inclusive, Coordinated Care (ChiPACC) which provides each enrolled child an *individualized* treatment plan that includes and manages services across the health care spectrum. ChiPACC services will improve upon the inconsistent care that is currently available to seriously ill children under Medicaid, doing so at a savings to taxpayers. The states of Florida and Colorado have implemented ChiPACC demonstration programs. CHI and CMS currently are working with California, Illinois, Maryland, New Jersey, New York, North Dakota & a growing number of states toward development of ChiPACC waivers from CMS. **The ChiPACC Bill, HR 6931, will make ChiPACC a Medicaid state option.** CHI also is working with the **U.S. Department of Defense** toward the development of ChiPACC for Military families. The **U.S. Department of State, USAID, PEPFAR**, and others are interested in ChiPACC as a model for programs overseas.

Children's Hospice international is holding it's 19th World Congress in San Francisco, California November 16-19, 2008. Keynote speakers include The Rev. Mpho Tutu, Board Member, Global Aids Alliance; Founder & Executive Director, The Tutu Institute for Prayer & Pilgrimage. Complete conference schedule, and registration information can be found at www.chionline.org

The National Hospice and Palliative Care Organization published the first set of Pediatric Standards for Hospice and Palliative Care Programs in September 2008. These are currently up for review to members, and can be viewed at: www.nhpco.org/pediatrics. NHPCO Clinical Team Conference / Scientific Symposium and Faculty-Based Hospice Forum is being held in Dallas Texas October 22-25th, 2008. Please see www.nhpco.org for registration and information. This years' conference is deemed a Pediatric Intensive Event, celebrating 10 years of ChiPPS Advisory Council. (NHCPO's Children's Program for Palliative and Hospice Services) Pediatric resources can be accessed on the NHPCO website at www.nhpco.org/pediatrics

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HOSPICE TWINNING - AN AFRICAN ADVENTURE

Corine Koppenol-Lyndon

If you have ever considered twinning with another hospice, here is a story which 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

Volunteers and children in the playground

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. The overall 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 2009 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

Corine formalises the twinning with a friendly handshake

Playtime with a parachute

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 grounds, and how visually beautiful it is; the paintings, the new general splendor of the place, compared to its former self.

Our gratitude is mixed with amazement at the speed and efficiency that such a huge and high quality project was completed. Gratitude when mixed with anything is always nice, but when mixed with admiration and wonder it is a potent feeling that has kept me on a high note since the day you all arrived.

In my line of work you meet a lot of nice people with admirable qualities, and sometimes you get the feeling that you have met them all. And then, suddenly, one meets a group such as yourselves, and the world returns to normal; a place where people of privilege love and care about others and just basically do good deeds. On the deepest personal level, it renews my hope and my own energy to move forward, having met and worked with all of you. Every one of your group have some exceptional quality within them that has allowed this amazing adventure to come off so well and with essentially no complications and such brilliant results.

I hope and feel confident that I will meet many of you again in the future. You are ALWAYS welcome at the farm as our guest and I promise you will not be asked to build or paint a single thing. For those of you that I barely got a chance to meet, I want to remedy that somehow, some day, so please give me that chance. You always have a second home in Africa and everyone one of you will always have our deepest, deepest gratitude. This was the most unique volunteer adventure I have ever seen and the results are stunning.

Tim Meade

Demelza
Hospice Care for Children

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

A diary of events to launch Rachel House Pilot Pediatric Hospice

By Lynna Chandra

Lynna Chandra is an advisor to businesses across Asia specialising in acquisitions, divestitures and corporate restructuring. She strongly believes in the power of children to influence and change the world; that kindness shown to a child in need today may sow the seed for future greatness.

In 2004, while caring for a close friend who lived through 13 long years of battle against cancer and finally witnessing her passing, Lynna began her journey to explore the need for a safe haven to provide end of life care for children in the poorest parts of Asia.

It is her sincere hope that Rachel House will commemorate the life of her friend, Rachel Malcomson, who showed those around her that no matter how sick you are and how little time you have, life deserves to be lived to the fullest with dignity and joy, surrounded by love and care.

Her mission has brought together a dedicated group of highly qualified people from all walks of life who share in the vision. The first Rachel House pediatric hospice facility will be established in Jakarta (Indonesia) to provide a safe haven and end of life care to vulnerable children and children with life-threatening conditions, and to provide support for their families.

Rachel House Pilot Pediatric Hospice prepares to launch in South Jakarta
The first 6 months in 2008 saw the team busy with preparations for the launch of Rachel House's pilot pediatric hospice operations, located in the existing premises of Yayasan Kanker Indonesia ("Cancer Foundation") in South Jakarta. We expect to be able to accommodate up to a maximum of 13 children and their accompanying parents/family members.
We were fortunate to have the assistance of Dr Lily Soehartono in the beginning of the year to draw up all the initial preparations required for the pilot operation.

In a few short months, Dr Lily moved us forward with the following accomplishments:

- Detailed list of set up requirements and costs
- Staffing requirements - 5 nurses, 4 caregivers and 4 support staff for 3 -shift operations
- Detailed operational expenses
- Hospice manager recruited in April - a doctor from Carolus Hospital in Jakarta
- 5 Nurses recruited in April including Head Nurse & Assistant Head Nurse
- Established a 2-week pediatric oncology training arrangements with Dharmais Hospital for our nurses
- Nurses tasked with preparations of job descriptions/allocations supervised by Sr. Heny - senior nurse trainer, Carolus Hospital
- HIV related teaching materials (WHO resource materials) translated into Indonesian for the Hospice Manager and nurses

Palliative Care Training Program from Singapore
There are presently no qualified palliative care professionals in Jakarta. As part of the pre-launch preparations, we have been busy laying out palliative care training programs for our medical team, for the immediate and medium term.

The Singapore palliative care team has been most supportive towards Rachel House since our inception. It is to this group of wonderful souls that we have turned to once again for the critically needed training support and guidance for our team. The training program is currently being planned and formulated by the team, headed by Dr Cynthia Goh and Dr Rosalie Shaw.
Concurrently, we are also in discussions with Singapore International Foundation ("SIF") for their project management and funding support in the palliative care training program.

Show of Support from Medical Community in Jakarta
We have been very encouraged by the support we have received from several doctors within the medical community in Jakarta, in particular two doctors from the general hospitals:

- Dharmais Hospital (pediatric oncology unit headed by Dr Edi Tehuteru) and
- Rumah Sakit Cipto Mangunkusomo (pediatric care unit, Dr Nia Kurniati)

These doctors have shown strong support for palliative care by embracing the total philosophy of pain and symptom management as part of the total care that should be provided to patients. It is with these hospitals that we are currently working on patient referral arrangements.

Home Visits Launched in May
While waiting for the Pilot location to launch its services, our nurses have been working with Dr Utari Simanjuntak from Yayasan Kanker Indonesia to care for children at home. These children are referred by the Pediatric Oncology unit from Dharmais Hospital.

September update
Challenges in building the first pediatric hospice in Indonesia continue - changes taking place faster than we have had the time to review the past. Perhaps emotional exhaustion has finally taught us, after 2 years of battling, to trust in the "Hand of Life", and to remain flexible and go with the flow.

Services
In July, after failing once again to rent an in-patient facility, we decided to turn our attention to home care service. Our team of 1 doctor, 5 nurses and 1 social worker, although having no experience in home care and untrained in palliative care were all keen to begin the work.

In early August, funded by Singapore International Foundation ("SIF") and organized by Asia Pacific Hospice Palliative Care Network ("APHN"), we welcomed the first palliative care training by 2 nurses from Singapore, one of whom was a pediatric palliative care nurse. We invited other members of the medical community to participate in the training, such as the pediatric oncology unit from the national cancer centre, Dharmais Hospital and the Cancer Foundation.

The 4-day training involved the nurse trainers observing the home visits conducted by our nurses, followed by group debriefing sessions. In hindsight, the timing was amazing as the team learned the essentials of palliative care in the context of home care a few weeks after we launched the service.

The essentials included:

- What is palliative care, in practice? What does it "look" like?
- What are the roles of doctors and nurses in a hospice palliative care team?
- What are the roles of doctors and nurses in home visits? What should nurses be empowered to do? (A huge cultural challenge in Indonesia, as nurses here are often no more than glorified helpers to doctors with zero authority)
- Body posture to adopt and critical points to observe/query when assessing patients, patient and family background information that may be valuable in understanding the patients;
- General attire for caregivers;
- Basic hygiene and infection control SOP;
- The most challenging of all – compassion – what it means and what does it look like?

There have been incredible changes in our nurses since they undertook the training – they are more enthusiastic and eager to learn, they begin to ask questions and most of all, they show genuine care – stepping out of their cultural barriers and ordinary comforts zone and stepping up to care for patients and their families from the heart.

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Making a difference with music - a group experience

By Simon Lolliot

Increasing a psychological sense of community amongst HIV/AIDS orphans through group music making

HIV/AIDS statistics for South Africa are staggering. One of the most worrying statistics is that of the number of HIV/AIDS orphans in South Africa, with the *Epidemiological Fact Sheet on HIV and AIDS 2008 update* (2008) reporting an estimated 1.4 million children orphaned in South Africa owing to this virus. This, coupled with the shortage of formal education, poverty, stigma, discrimination (HIV/AIDS/STD Strategic Plan for South Africa 2000-2005) that accompanies the disease, the increase in child-headed households, and various other socio-economic factors, poses a multifaceted problem that needs to be approached eclectically and holistically. The effects of the pandemic are felt in numerous areas of South African life, such as in both the social fabric of already stressed communities and the health sector. In the mental health sector, a vital role player in the successful handling of the psycho-social problems faced by bearers of the disease, there is one psychiatrist for every 130 500 people (Swartz, Gibson, & Gelman, 2002). As the authors mention, this last statistic is misleading, as more health professionals reside within the richer provinces, meaning that this number is greater in some of the poorer provinces in South Africa and smaller in the richer ones (Swartz, Gibson, & Gelman, 2002). Upon review of these statistics (and the many others that I have not included in this article), it is clear that what South Africa needs is a mass approach to the challenges that the HIV/AIDS pandemic is posing. However, when dealing with any type of mass intervention, it is easy to overlook the individual experience. The rest of this article will deal with one attempt at developing an intervention that tries to answer some of the challenges that many South African orphans face, especially that of community building.

The research in question was completed as part of my BA Honours in Psychology degree. It dealt with increasing a psychological sense of community amongst (HIV/AIDS) orphans using group music-making as an intervention. A quick word on the theory and assumptions that the project was based upon is necessary. Hunter and Williamson (2000, 2002; cited in Richter, Manegold & Pather, 2004) outlined some of the many impacts that HIV/AIDS has on children, one being a loss of identity while others comment on the stress that communities feel owing to the impact of HIV/AIDS (see Crewe, 2001; Michael; 2001; Richter, Manegold & Pather, 2004). The psychologist Erik Erikson understands identity as a feeling of being at home within one's own body in combination with positive affirmation from others (Hergenhahn & Olson, 2004). This 'positive affirmation from others', as I understand it, can be seen as manifested in the community within which one finds oneself. I assumed that finding oneself in a community provides a basis on which one is able to (re)build an identity. Therefore, I was interested in increasing a sense of community amongst a group that is (almost) worst affected by not only the HIV/AIDS pandemic, but a multitude of other socio-economic challenges. For this research project, Sarason's (cited in Duffy & Wong, 1996) definition of psychological sense of community was adopted and is defined as

> *"The perception of similarity to others, an acknowledged interdependence with others, a willingness to maintain this interdependence by giving to or doing for others what one expects from them, the feeling that one is part of a larger dependable and stable structure."*

The design was a simple pretest-posttest natural control group design using the short form of the Sense of Community Index (Chavis, Hogge, McMillan & Wandersman, 1986, cited in Chipuer & Pretty, 1999; see also Chavis & Pretty, 1999; McMillan & Chavis, 1986) to measure the psychological sense of community. A local orphanage (intervention group) and safe house (control group) in the Western Cape, South Africa, were identified, contacted and thus formed the two aforementioned groups. Group music-making was chosen as the intervention because it provided a means through which many children could be accessed while providing space for each child to be acknowledged as an individual. This was mainly achieved through a "Hello" song that was sung at the beginning of each session. This created an opportunity for each child to introduce themselves to the group and be welcomed into the group, while also allowing each child to welcome other group members into the group.

The analysis was done using both the Whitney U Test and the Wilcoxon Signed-Rank Test in order to provide control for some potential errors in the collection of the data. The alpha levels were set to 5% sensitivity, one-tailed probability. For the group receiving the intervention, overall sense of community was significantly higher posttest, than those of the control group posttest, $z = -2.714$, $p<.05$, $r = -0.68$. There was no significant change in the control groups pretest-posttest scores, $z = -1.000$, $p>.05$, $r = -0.25$. The Mann-Whitney U analysis produced similar results showing that the group music-making intervention was successful in increasing a psychological sense of community amongst the intervention group in the predicted direction.

However, I would like to discuss some of the experiences that do not often appear in reports or articles, but are manifestations of the effects that we seek in the data that we analyse.

One of my fondest memories of my time with the orphans is related to a child who was not technically part of the intervention. Round about the second week, a severely mentally disabled child, who will be referred to as John, joined us in the room where we had our sessions. When the music started, John would light up; his back would straighten, he would smile, he would start moving in his chair, he would smile, and he kept the best rhythm out of all of us. What was most amazing was that John started pairing my and my helper's voices with the music-making experience, so much so that at the sound of our voices, all of the above mentioned changes took place.

Another fond memory is that of the beginning of the intervention. Being an English speaking person working with Xhosa speaking children made communication difficult at the best of times. Furthermore, the obvious difference between me and the children, especially those pertaining to cultural nuances, complicated the first few sessions. However, after the third session upon my and my helper's arrival, the children started running into the room where we had our sessions. The fourth session, when I got out the car, a few of them were waiting to help carry instruments into the room (I had started bringing drums, tambourines, shakers and similar instruments). By the sixth session, all the children participating ran out to the car and before grabbing the instruments, we were greeted by hugs and a few lines sung prematurely from the ìHelloî song. By the end of the intervention a bond was formed between me and my helpers and the children, two culturally diverse groups, all through the (not fully understood) devices of music.

The last story that I would like to relate is almost the most impressive. The last thing that I wanted to happen for my time with the children was to come to the orphanage, make music with the children, measure the construct(s) that I wanted to measure, and then leave as quickly as I came. So since then, I have tried to remain as involved with the orphanage as circumstance would allow. I have subsequently worked with a local Primary and Secondary school to raise funds and other necessities for the orphanage. On one of my visits, I pulled up in my car and was welcomed by the children gathering round. However, this time I was welcomed by some new faces amongst the children who had taken part in the intervention, and as I stepped onto the property, all the children, old and new, broke into a thundering rendition of the ìHelloî song. The other children had taught the new children the song!

The research in question, being my first proper research project, provided insight into the whole methodology and process of conducting research. When setting up this research project, I did so with more focus on the process than on the actual experienced effect of the intervention. I suppose a good question to ask is why we do research in the social sciences. Do we do it primarily to understand the processes behind the human experience, or to add to the growing body of knowledge and understanding? Do we do it to better other's lives or to get the needed credits for a degree? I am sure that there are a number of reasons why we perform research, but for me, the most important reason is to make a difference, not only in our own community, but hopefully, in the global community The various debates regarding generalisation of research effects are taken into consideration.

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