network news
issue 1
April 2008
icpcn
international children's palliative care network

LETTER FROM THE CHAIR

Welcome to this our first e-newsletter of the International Children's Palliative Care Network.

The establishment of the ICPCN was inspired by a passion for children and children's palliative care, and an understanding of the way it improves the quality of life of children with life-limiting conditions. As concerned children's palliative care practitioners from around the world, we are working together to improve access to skilled palliative care that recognizes the specific needs of children; to promote education and training; to support the development of more programmes, and to strengthen existing programmes.

As the children's voice on the Worldwide Palliative Care Alliance (WPCA), we have a wonderful opportunity to advocate for children's palliative care to be an integral part of all palliative care, and will be presenting the palliative care needs of children at a meeting organized by the WPCA with UNAIDS and WHO in Geneva in April. As part of our development, the African Children's Palliative Care Network has been established, in collaboration with the African Palliative Care Association (APCA), and a new textbook on Children's Palliative Care for Africa, to be published this year, as well as a training curriculum for Africa, are the first concrete results of this collaboration with Hospice Africa Uganda, the Hospice Palliative Care Association of South Africa, and APCA.
We will also be working together on a Children's Palliative Outcome Scale, to measure the effect of palliative interventions on individual children and adolescents, and on a survey of children's palliative care in Africa. We hope that more regional networks will be established so that we can all share our knowledge and learn from each other, for the benefit of the children of the world.
Our aim is to promote shared knowledge and experience, and we hope to be able to provide scholarships that will facilitate participative learning between programmes through visits and training.

At present, the ICPCN is run by a dedicated steering group with members from different areas of the world, and our newly appointed International Information Officer, Sue Boucher. My sincere gratitude to each one of them for their commitment and enthusiasm.

The inspiration for all we do is the children who challenge their life-limiting illness with so much courage and laughter, but whose voices have often not been heard even by those working in the field of palliative care. The Korea Statement on Palliative Care for Children asks that

"...the voice of these children and adolescents is heard, respected and acknowledged as part of the expression of hospice and palliative care world-wide."

As the ICPCN we have taken on the challenge to make sure their voices are heard, respected and acknowledged and that children receive the best possible children's palliative care.

We encourage you to raise your voice on behalf of our children, and to participate in the activities and development of the ICPCN. We look forward to hearing your comments and suggestions to improve our services.
With kindest regards,

Joan Marston

E-mail: joan@hpca.co.za
Cell: +27 822964367

ICPCN NEWS

Since the launch of the ICPCN website in October 2007, there have been some exciting developments within the organisation. Some of these being:

* ***The appointment of an International Information Officer whose tasks include the co-ordination of the work of the ICPCN, keeping the website updated with news and events related to palliative care for children, the publication of a quarterly e-newsletter and rapid and relevant responses to enquiries & requests***

* ***Membership of the organisation has grown and to date we have more than 100 individual members and over 80 organisations belonging to the ICPCN***

* ***Members of the steering group met in London on 28 January 2008 to discuss strategic planning. Their vision for the future of the ICPCN includes, among other strategic initiatives:***

- *The provision of relevant information to donors on the needs of people and organisations working within paediatric palliative care worldwide,*
- *The development of an international online training directory,*
- *The growth and maintenance of a high quality virtual resource where people can easily access information the formation of an internationally recognised "charter of rights" for life-limited children,*
- *The development of an online international research directory to identify ongoing research projects and the identification of gaps in research related to paediatric palliative care*
- *To hold a biennial international "advocacy" conference*

By joining ICPCN you become part of the international network of individuals and organisations working to improve the quality of life for children with life-threatening and life-limiting illness. As members you are entitled to upload any research findings, news or event information onto our website, thus creating global awareness of your projects. Through the website and e-newsletters you will be kept informed of new developments and events relating to palliative care for children.
Existing members are encouraged to make use of the website to access and publicise any information which they feel would be of benefit to an international audience.

Membership is free and is open to all individuals and organisations working within the field of palliative care for children. Join us online at: www.icpcn.org.uk

EVENTS CALENDAR: APRIL, MAY & JUNE

16/04	Living with Grief Teleconference	USA
24/04	Motor Neuron Disease Conference 2008	London, England
29/04 - 1/05	The 7th Palliative Care Congress	Glasgow, Scotland
08/05	The Art and Science of Palliative Medicine Conference	Limerick, Ireland
16/05	ACT: Networks, Pathways and Maps: A Year in Progress	Cardiff, Wales
24-27/05	EAPC Research Forum"s: Pre-Conference Seminar	Lofoton Isls, Norway
29-30/05	Junior International Forum	Trondheim, Norway
29-31/05	5th Research Forum of the EAPC	Trondheim, Norway
03/06	ACT: The First Scottish Children's and Young Peoples Palliative Care Conference	Edinburgh, Scotland
09/06	ACT: England's National Conference: "Networks, Pathways and Maps: Navigating our way to Better Care: Better Lives	London, England
11-12/06	Kaleidoscope International Palliative Care Conference	Dublin, Ireland
12/06	What Works? Candle 10th Anniversary Conference	London, England
16-19:06	PEPFAR Annual Meeting	Kampala, Uganda

More information and links can be found on our website www.icpcn.org.uk
Keep checking the website for information on conferences and events in your area. If you would like to promote your events or conferences to an international audience, you can fill in the upload form on the website.

ICPCN Steering Group decides to become the Children's Voice on the Worldwide Palliative Care Alliance

After thoughtful and considered deliberation, members of the steering group of the ICPCN made the decision to become a part of the Worldwide Palliative Care Alliance (WPCA) as its voice for children.

The WPCA is a network of hospice and palliative care organisations from around the world and works to support efforts to develop hospice and palliative care services globally. Its stated Mission is to promote universal access to affordable quality palliative care through the support of regional and national hospice and palliative care organisations.

As palliative care is so often neglected by global and national policy makers and funders the WPCA feels that a global voice is vital to ensure that funding streams flow to palliative care services and that governments and multilateral organisations develop appropriate palliative care policies and strategies.

Within the WPCA are a number of workgroups, focusing on key issues which affect hospices and palliative care services worldwide. These are:

- Quality and Standards
- Education and Training
- Information
- Children
- Policy/Advocacy
- World Hospice and Palliative Care Day

Members of the ICPCN steering group felt that joining the WPCA would enable paediatric palliative care to develop as an integral part of the worldwide palliative care movement (as opposed to an "add on") while still recognising the distinct and unique needs of children. To ensure this happens, members of the ICPCN steering group will be represented on all the above WPCA sub-committees to ensure that the needs of children are included in all strategic discussions and plans.

The ICPCN will maintain its own identity and logo, and will hold a position on the Board of the WPCA.

For more information on the WPCA, you can visit the website at www.wwpca.net

DON'T FORGET

World Hospice and Palliative Care Day – 11 October 2008
www.worldday.org

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.

Meet the Steering Group

Joan Marston
Chair of the ICPCN
Former palliative care nurse, midwife and nurse educator. Joan obtained her Bachelor of Social Science degree majoring in Nursing Science, Social Anthropology and Sociology at the University of KwaZulu Natal. At present she holds the position of National Paediatric Manager for the Hospice Palliative Care Association of South Africa (HPCA) and is responsible for advocacy and the development of paediatric palliative care within South African hospices as well as providing support to other African countries. Joan has nineteen years experience in the field of Palliative care and HIV and AIDS. She was the founder of The St Nicholas Children's Hospice in Bloemfontein, South Africa. She is the children's representative on the Worldwide Palliative Care Alliance. Joan has contributed to numerous publications and conferences.
Email: joan@hpca.co.za

Dr Delia Birtar graduated with a degree in Medicine in 1990, and in 1995 completed her training as a paediatrician. She started working in palliative care for children in 1996, when she joined Hospice Casa Sperantei Brasov, to start the first PC service for children from Romania.

Since then she has contributed to the spread of palliative care in Romania, teaching courses and being involved in different projects which support the opening of Palliative Care services in other parts of Romania and surrounding countries. Delia is a member of the steering committee of ICPCN, representing South-Eastern Europe.
Email: Birtardelia@yahoo.com

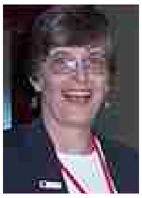
Barbara Gelb
Joint Vice-Chair of the ICPCN
Barbara is the Chief Executive of the Association of Children's Hospices (ACH), the national voice for all of the 43 children's hospice services in the UK. She joined ACH in 2001 as its first chief executive and at a critical point in its development. Barbara's background is in social work and prior to joining ACH she led the development and implementation of a range of strategies to modernise services for children and families as a Senior Social Services Manager in a Unitary Authority in England. Barbara is currently undertaking an MSc at Bristol Business School in Leadership and Organisation of the Public Services.
Email: barbara@childhospice.org.uk

Avril Jackson (Observer)
Avril Jackson is the International Information Manager, Hospice Information (a joint venture between Help the Hospices and St Christopher's Hospice)
Avril trained originally as a French teacher and began to work for the hospice movement in 1979. She has played a key role in the development of Hospice Information, which provides a comprehensive information service for anyone involved in hospice and palliative care in the UK and around the world. She is editor of the magazine, *Hospice Information Bulletin* which includes a column presented in collaboration with ICPCN, and the international email news resource, *Worldwide Hospice and Palliative Care Online*. ***Email: avril@hospiceinformation.info***

Sabine Kraft Sabine has studied Social Pedagogic and Economics and has a further education diploma in Project Management. She has been involved in Self-Help Groups, Kindergarten, Children's Homes, Youth Care, German Planned Parenthood Organisation and an advisor for NGO's. Since 2005 she has been the Director of the National Children's Hospice Association in Germany.
Email: info@bundesverband-kinderhospiz.de

Lizzie Chambers
Joint Vice-Chair of the ICPCN
Lizzie (BA (Hons), MA) has worked in the voluntary sector for eighteen years, eight of which have been for ACT (Association for Children's Palliative Care). Lizzie was appointed Chief Executive of the organisation in April 2005 and prior to this was ACT's Information & Projects Manager, responsible for the development of a number of ACT's documents, including the Guide to the Development of Children's Palliative Care Services (2003 edition), Voices for Change (2003), ACT Family Information Pack (2004) and, most recently, the ACT Care Pathway (2004) and Transition Care Pathway (2007).
Lizzie is passionate about ensuring that every life-limited child and their family, wherever they live, have access to the best quality palliative care.
Email: lizzie@act.org.uk

Dr Mary Ann Muckaden MBBS – St John's Medical College – (Bangalore University) MD (Radiotherapy) – AIMS, New Delhi – 1982. Diploma in Palliative Medicine – University of Wales. Dr Muckaden presently holds the following positions: Professor in the Department of Radiation Oncology at Tata Memorial Hospital; Secretary of the Indian College of Radiation Oncology; Officer-In-Charge of Palliative Care Services; Executive Member of the Indian Association Palliative Care and a Member of the NMAC (National Morphine Availability Committee) Her areas of interest are: the planning, treatment and research in patients with Hodgkin's Disease, Malignant Lymphoma, Leukaemia and Multimodal approach to Paediatric Cancers. She is a recognised teacher at Tata Memorial Hospital and Mumbai University in her field of Radiotherapy, Medical Oncology as well as Palliative Medicine. She is the author of over 50 publications in National and International Indexed Journals, has attended and participated in over 100 National and International conferences and is involved in numerous research projects. ***Email: muckaden@vsnl.net***



Mary Callaway (Observer)
Mary is the Director of the International Palliative Care Initiative (IPCI) of the Network Public Health Program at the Open Society Institute. Prior to joining OSI, Ms. Callaway was the Administrator for the Pain and Palliative Care Service at Memorial Sloan-Kettering Cancer Center in New York City for 16 years while also serving as the Executive Director for the World Health Organization's Collaborating Centre for Cancer Pain Research and Education. She is on the Board of Directors of the United States Cancer Pain Relief Committee and a member of the International Association for Hospice and Palliative Care, the International Association for the Study of Pain, the African Palliative Care Association, the Asia Pacific Hospice and Palliative Care Association, the European Association for Palliative Care, the European Task Force for Palliative Care, and is in both the Steering Group and the Advocacy Committee of the Worldwide Palliative Care Alliance.
Email: Mcallaway@sorosny.org

Dr Julia Downing PhD, MMedSci, BN(Hons) RGN FILT is an experienced palliative care nurse and educationalist, with a PhD that evaluated palliative care training in rural Uganda. She is currently working as the Deputy Executive Director of the African Palliative Care Association based in Kampala. She has been working in palliative care for the past 17 years, originally in the UK where she developed an interest in palliative care in children and adolescents. She worked for 5 years at the Mildmay Centre, Uganda, as the Director of training and set up training programmes focusing both on adults and paediatrics.
She has extensive experience in presenting at conferences and writing for publication, and is a co-editor of the *APCA Journal of Palliative Care* and the *PCAU Journal of Palliative Care and is on the editorial board of the International Journal of Palliative Nursing*. ***Email: julia.downing@apca.co.ug***

Nick Pahl supports advocacy / policy work for the Worldwide Palliative Care Alliance, supported by Help the Hospices and with a grant from the Open Society Institute. Nick was recently team leader of a Dfid Consultancy on HIV/AIDS and Palliative Care. Nick has a Masters in Public Health from the London School of Hygiene and Tropical Medicine. He previously worked in the UK National Health Service, his last post being Associate Director of Public Health in a London Health Authority. Between 1992 and 1998 Nick worked for Marie Stopes International as Senior Programmes Manager and Technical Adviser, establishing clinics across Africa and Asia. This included consultancy work with the United Nations. Nick is trustee of the Tropical Health Education Trust.
Email: nickpahl@btinternet.com

Dr Rut Kiman obtained her degree as a physician at the University of Buenos Aires (UBA), Argentina in 1981 and a diploma in Palliative Medicine in 1997 (Pallium and University of La Plata). She holds the position of Chief Paediatric Palliative Care Team at "Professor A. Posadas Hospital" in Buenos Aires, is a professor of the Paediatric Department at the University of Buenos Aires, a member of Pallium Latinoamerica and the secretary of the Paediatric Palliative Care Group of the Sociedad Argentina de Pediatria (SAP) 2006 – 2009
Email: rutiki@netizen.com.ar

Susan M. Huff, RN, MSN
of Pediatrics at Home, a Pediatric Home Care Program of Johns Hopkins Medicine, in Baltimore Maryland, USA. Susan also serves as a consultant and co-chair of ChiPPS, the Children's Advisory Council for the National Hospice and Palliative Care Organization, in Washington D.C.; teaches internet courses for Mount Ida College in Boston and the National Center for Death Education; consults for Children's Hospice International, and is a steering committee member for the International Children's Palliative Care Network.
Email: Shuff@palliativecare.org

Sue Fowler-Kerry is a tenured, Full-Professor in the area of Child and Youth Health, College of Nursing, University of Saskatchewan, Canada. Her research programme over the past 22 years has focused on Paediatric Pain, Palliative Care and Children's Health and Well-being. Extending from her programme of research and practice, she has collaborated with WHO, SOROS, PAHO and Middle Eastern Cancer Consortium to develop and evaluate community based programmes focused on paediatric palliative care needs. This work has resulted in numerous publications, grants and key-note lectures. On 1 July 2007 she took over the Directorship of the *Royal Bank of Canada Community Development Program in Child and Youth Health* at the College of Nursing, University of Saskatchewan.
Email: susan.fowler.kerry@usask.ca

Dr Anna Garchakova holds a PhD in Psychology. She started the Belarussian Children's Hospice in 1994. She was also the initiator of four children's hospices in Belarus: Gomel Children's Hospice; Vitebsk Children's Hospice; Mogilov Children's Hospice and Pinsk Children's Hospice. In 2000 Anna developed educational courses in palliative care for children for both Doctors and nurses and in 2004 was responsible for the introduction of the first mobile palliative care service for adults.
Anna contributes regularly to both conferences and publications within the field of palliative care and palliative care for children. She received the Errol Grollman award from Children's Hospice International in 2004 for her work in developing bereavement services for children and their parents in Belarus.
Email: hospicepall@mail.belpak.by

Belarusian Children's Hospices lead the way

By Anna Garchakova

The Belarusian Children's Hospice (BCH) was established in 1994 as a hospice only for children with cancer related diseases. However in 1995 40% of our patients had diseases unrelated to cancer.

The Belarusian Children's Hospice began as a home hospice and provided only home-based palliative care for three years. Home care is provided for 24 hours 7 days per week as we use an on duty system.

After three years, the organization saw the need to expand the service to include Respite care. One of our motives for launching the Respite Care Programme was the suspicion with which the people in Belarus regarded Hospice as it reminded them of the unpopular Policlinics or Out-Patient Hospitals.

To begin with we had only one room with two beds in our Respite Centre. The success of the programme led to expansion and at present we have a room for three children who have no family members staying with them and two rooms for families, where the children can stay with their parents or caregivers. When a child comes in for respite care, he or she is provided with essential medical and psychological care and is constantly under the control of the medical staff. This provides rest and relief to their relatives and caregivers.

When the child is transferred to the Hospice from a hospital or Oncology Centre we use the following model of transfer:
Hospital ⟶ Respite Care ⟶ Home Palliative Care

Thus, Respite Care unexpectedly became a very good link between hospital and the Home Care provided by the Hospice.

But Respite Care was not the only solution we decided upon in order to promote an understanding of the Hospice and its philosophy to provide quality of life for its patients. We also began the Day Care Centre Programme. Our Day Care Centre was opened in the Hospice building in 1997 and caters to children with cancer related diseases, disabled children and children with special needs whose condition allows them to participate in specially prepared psychological and rehabilitation programmes. The centre is opened 5 days a week from 10 a.m. to 4 p.m.

Meanwhile, our patient numbers increased and a certain percentage of the people were parents of the cancer affected children who lived outside of Minsk, in other regions in Belarus. (At that time, Minsk was the only area that Hospice covered with its service) We had heard how Austria used a Hospice Ambulance and we adapted this model of care to increase the area we were able to cover. We called it a Pilot Programme where a small mobile team consisting of a doctor, a nurse and a driver could be transported to provide pain control to one of our patients living within a radius of 250 km around Minsk.

But it still was not enough. We recognized that one Hospice could not cope with the problems of the whole of Belarus and that is why we began thinking about creating a network of hospices. And in 2000, our dream started to come true. We found groups that were keen to create Hospices in their cities as well as find sponsors for them. The newly founded Hospices were legally independent and have remained that way. Our role in relation to those Hospices is to provide education. Belarusian Children's Hospice provides courses on palliative care for doctors, nurses and psychologists. Workers from the newly founded hospices all take the course.

In 2000 we established a Hospice in Gomel. Gomel region was most affected with radioactive substances after the Chernobyl catastrophe. Medical nurses predominate in this Hospice as 70% of its patients are children with cancer. Gomel Hospice functions as a home model. It is a small Hospice but very successful due to the programme of McMillan nurses, upon which its functioning is based. The essence of this programme is that Hospice involves medical nurses of that region who are trained in palliative care. When they admit an ill child, the manager of the Hospice makes contact with a nurse who lives in the same city and asks her to provide palliative care to the patient.

Another Hospice was founded in the city called Vitebsk in 2001. Patients with cancer comprise a very small percentage, while children with special needs and disabled children prevail. Vitebsk Hospice functions more like a Fund. It has been established at the initiative of the parents who live in Vitebsk region and who have lost their children, once having been the patients of the Belarussian Children's Hospice. Thus the specific feature of Vitebsk Hospice is that they mainly provide social and psychological help. They work a lot on attracting the attention of the population to the needs of the children who have been affected by the Chernobyl disaster. When the Hospice faces difficult cases related to a disease they either invite our specialists for consultations or transfer the child to our hospice.

Later the Hospice in Mogilev was set up; it is the fourth hospice in the Belarusian Hospice network. Mogilev Hospice was created based on the governmental polyclinic. The correlation of cancer and chronic patients is 50/50. The main direction of their work is a Day Care Centre but the creation of in-patient care with three beds is planned.

The other regions (Brest region and Grodno region) that do not have local centres providing palliative care are also supervised by BCH. All the patients, that leave the Republican Oncology Centres for in-home care, are registered in a special data base. BCH creates links with medical specialists, who have taken courses on palliative care and live in the same area as these children, and direct nurses to provide palliative care to the affected children.

Belarusian Children's Hospice in Minsk also functions as an Information and Methodology Centre. One of our most important functions is the provision of education. This is not financed by the government, but is financed from the budget. The course is aimed at doctors, nurses, social workers and psychologists who are training and preparing to work in palliative services. A data base of specialists has also been created. People who have completed the Palliative Care Course, the region of their allocation and those who wish to assist in the provision of palliative care are indicated in this data-base.

All the Hospices receive additional education and literature from BCH. On average, twice a year BCH organises educational seminars that are given by foreign lectures to the Belarusian specialists in the sphere of palliative care. BCH spends a lot of time promoting exchange experiences between different regions for its specialists.

In contrast to European countries where Hospices for adults were initially created and only after that children's hospices appeared, our country has had the reverse experience.

Up to now we have only had Hospices for children, but with TACIS support Belarusian Children's Hospice is starting a new programme to create the first Hospice for adults in the Republic of Belarus.

Belarusian Children's Hospice has been in existence for ten years and we have gained a great deal of experience due to the continuous and extremely enthusiastic hard work of a number of faithful and devoted specialists and volunteers. We are ready to continue the work we are doing for the benefit of the people of Belarus.

Psychological stresses and strains of nursing staff and home carers in purpose-built children's hospice work in Germany. First Results of a pilot study.

By: Sabine Kraft

Introduction
In August, 2007, a pilot study started at the Steinbeis-University Berlin (SBA, Kuppenheim) in co-operation with the National Association of Children's Hospices (Bundesverband Kinderhospiz e.V.) of Germany. The pilot study is sponsored by the Helix Children's charitable Foundation (DGL Helix Stiftung Kinderhilfe) in Essen. Director of the pilot study is Prof. Dr. Christian Loffing.

The aim of the research assignment is to analyse the main stresses and strains of employees and their available options for coping. A specific intervention method shall be developed. The availability of it shall contribute significantly to ameliorate the coping of employees in purpose-built children's hospices with the specific and extreme stresses and strains inherent in the work.

First Results
The qualitative analysis already allows first statements.

Stresses and strains of employees are predominantly experienced in areas that are related to working in institutional conditions, e.g. their team. Furthermore, stresses and strains are also directly related to the closeness of death and mourning and the challenge of dealing with the families of children with life-limiting conditions.
These aspects have to be seriously considered while children's hospice work in Germany is on its way to receiving professional status and recognition. The psychological health of employees is one of the decisive factors in effective caretaking. With the proviso that strains and stresses ought to be reduced; only a holistic and systematic approach seems to make sense – an approach in which all areas mentioned above are covered.

cont…

Prof. Dr. Christian Loffing

Psychological stresses and strains of nursing staff and home carers in purpose-built children's hospice work in Germany. First Results of a pilot study.

cont...

REMEMBERANCE
'Frog King Font' in the children's hospice Regenbogenland in Düsseldorf

Visions of a specifically designed intervention method

An intervention method aiming at minimizing stresses and strains in a purpose-built children's hospice therefore must correspond by being complex in structure. Organisational conditions and the environmental surroundings of the employees have to be questioned. Also, the art of leadership and communication methods in the organisations will be critically questioned.

An intervention method that exclusively aims to reduce or cope with strains and stresses will have only little success.

Discussion

The complete evaluation of the quantitative study is not yet available. Therefore, definite statements towards the differences of stresses and strains in comparison to other professional groups may not be stated as yet. However, in some areas initial significant results are already prevalent, for example the disposition to suffer "burn out " and the difficulties experienced in being able to keep ones distance as a professional.

Sabine Kraft, Bundesverband Kinderhospiz e.V.
Director, National Association of children's hospices in Germany:
We appreciate so much that scientists have discovered children's hospices. Thanks to this study we will be able to implement optimal methods of intervention for all the staff in the children's hospices to be able to cope better with the strains and stresses that, no doubt, come along with the confrontation of complex problems related to children with end-of-life-diagnoses.

Talk About Change – launched 19 February 2008

Film-makers the Kosh and UK children's palliative care charity ACT have just launched a new groundbreaking DVD resource called *Talk About Change* made by young people with life-limiting conditions. *Talk About Change* aims to show the reality of making the transition from childhood to adulthood knowing that you have a life-limiting condition.

Talk About Change is based on a series of interviews and video diaries made by eight young people with life-limiting conditions, aged between 12 and 26 years. The film has been designed to give children and young people the opportunity to talk publicly about their hopes and fears as they make their journey into independence; exploring how their health condition impacts on this and affects key areas of their lives including: leaving home; further education and work; relationships and sexuality; planning for the future and end of life issues.

"It's different when you're young. The world seems a much more fairer and innocent place. Being younger with a disability – you don't think about the consequences of that. But as you get older you realise, hang-on, this is holding me back. But it's adapting to that and understanding this that allows you to succeed." (Greg, young person with Duchenne Muscular Dystrophy).

Talk About Change has been developed as a key resource for children, young people and families, and it's hoped that it will help professionals develop more appropriate services and responses as children make the transition from children's to adult services.

The DVD comes with training and guidance notes for parents, young people and professionals. Divided into six sections, *Talk About Changes* covers:

- Introductions - Meeting the young people in the film.
- Disability - What their condition/disability means to these young people.
- Independence - Is this different for young people with life-limiting conditions?
- Brothers and Sisters - How they see each other.
- Friends and Relationships - Going out, a social life, sex and sexuality.
- The Future – Planning for the future, end-of-life issues, education and ambitions.

You can buy a copy of *Talk About Change* for £10.00 from The Kosh.
Tel: +44 (0) 20 8374 0407 Email: info@thekosh.com www.thekosh.com

4th International Cardiff Conference in Paediatric Palliative Care

"Speaking of Dying, What are we Saying?"
7 – 9 July 2008, Cardiff University

ACT and ACH Palliative Care Forum are working in partnership in 2008 to present this conference highlighting the need to understand the subjective experiences of children and young people with life-limiting conditions, so that the services provided can be tailored to meet their own individual and particular needs.
Click on this to find out more.
http://www.bacch.org.uk/downloads/conferences/Cardiff-Conference_july2008.pdf

John and Peter, two of the stars in Talk about Change

The first children's palliative care strategy for England

Better Care: Better Lives, the new Department of Health strategy for improving the care and support given to children in England with life-limiting and life-threatening conditions, was launched on 19 February 2008. The strategy builds on the Independent Review of Children's Palliative Care Services published in May 2007. The strategy was accompanied by an announcement that a further £320 million will be made available to children's hospice services in England in 2010 and 2011.

At the launch Care Services Minister (Department of Health England), Ivan Lewis, described the provision of support for children and families with palliative care needs as "the test of an effective, modern, compassionate health and social care system".

Leading children's palliative care agencies welcomed the strategy and said that the implementation of it will test whether the new devolved Health Service can work for those children whose needs are greatest but whose numbers are small.

Primary Care Trusts (PCTs) in England have been given significant new funding to implement the strategy. However, this money has not been identified separately to PCTs and there are worries that this may reduce its impact. The Children's Palliative Care Alliance, a consortium of leading children's and healthcare charities, has called for the government to spell out exactly how much new funding individual PCTs have been allocated for children's palliative care.

The strategy offers commissioners a resource for providing services for life-limited children and their families, setting out priority actions for those who are commissioning local children's palliative care services in England.

These include actions to improve:

- Equality of service access to all children regardless of their condition;
- Choice of place of care;
- End-of-life care and support;
- The long term sustainability of services in the long-term;
- The successful transition between children's and adult services; and
- The planning and development of an effective and responsive workforce.

To find out more you can download a copy of Better Care: Better Lives from the website.

Formation of the African Children's Palliative Care Network

By Dr Julia Downing

The African Children's Palliative Care Network was formed at a recent meeting held in Johannesburg South Africa. The meeting was held from the 19th – 21st February 2008 and brought together fifteen participants with an interest in and expertise in children's palliative care, from Malawi, South Africa, Uganda, Zambia and Zimbabwe. The meeting was organized through the ICPCN, APCA and Hospice Africa Uganda and was funded through the Diana Princess of Wales Memorial Fund, the Open Society Institute and CRS.

The aim of the meeting was to bring together experts in children's palliative care from across Africa in order to

- share what they are doing and learn from each other,
- look at issues around education and training for children's palliative care,
- work on a children's palliative care book for sub-Saharan Africa,
- address the way forward in developing a paediatric palliative outcome scale.
- Look at future areas for working together, sharing and collaboration

On the first day of the meeting participants were able to share their involvement and experiences in children's palliative care work. Participants heard about the development of children's palliative care at Hospice Africa Uganda, including implementation of services and training; the Umodzi palliative care service for children at Queen Elizabeth Hospital in Blantyre, Malawi; developments within Zambia promoting children's palliative care in the different services and training efforts; the challenges to providing children's palliative care in Zimbabwe and the variety of services available in South Africa. Much has been achieved within South Africa and it was helpful to hear how services for children and training has developed.

APCA and ICPCN also spoke of their vision regarding children's palliative care within the region and ideas for collaboration. Following these presentations it was possible to look at similarities and differences in the structure and content of training materials.

PARTICIPANTS IN THE COLLABORATIVE MEETING OF PEOPLE WORKING WITHIN PALLIATIVE CARE FOR CHILDREN IN AFRICA.
Back (l-r): Dr Justin Amery, Dr Jennifer Ssenbooga; Dr Ivy Kasirye, Colette Cunningham, Dr Mary Bunn, Dr Michelle Meiring, Dr Julia Downing
Front (l-r): Carla Horne, Eunice Garanganga, Joan Marston, Maraliza Robbertze, Nkosazana Ngidi, Dr Rene Albertyn, Sue Boucher

Palliative Care for Children Text Book

During the second day work groups were set up to review chapters for a children's palliative care text book and draft additional chapters. Dr Justin Amery from Hospice Africa Uganda had set the process moving by writing an initial draft of a book which was reviewed and amended. Participants worked hard at revising the chapters and a second draft of the book is being formulated for further review. It is hoped that the book will be available from July 2008.

Palliative Outcome Scale for children

Over the past couple of years APCA have developed an APCA African Palliative Outcome Scale (POS) for measuring the outcomes of palliative care in adults. They are now in the process of developing a similar tool for use with children. A literature review on paediatric scales has been completed and the next step, once funding has been received, will be to develop the tool and pilot it. Discussions were held related to the next steps in taking this forward.

Development of a Pain and comfort scale

Dr Rene Albertyn shared her experience in measuring pain and comfort in children and the TVP scale that she has developed. It is hoped that the ACPCN will be able to help take this forward over the coming months.

Formation of the African Palliative Care Network (ACPCN)

Participants felt encouraged that they no longer needed to feel isolated working in children's palliative care within the region and were positive that we could share and learn from each other, negating the need to 'reinvent the wheel'. There was a general feeling of excitement that we are beginning to solidify and standardise what we are doing and that the meeting was energising.

The group recognised the importance of having a special interest group in children's palliative care within the region hence the African Children's Palliative Care Network was formed, which will be co-ordinated jointly by the ICPCN and APCA.

Dr Justin Amery - Author and past Managing Director of Helen House and founder of Douglas House in UK
Dr Jennifer Ssenbooga – Mildmay Paediatric Care Centre in Kampala, Uganda.
Dr Ivy Kasirye – Mildmay Care Centre in Kampala, Uganda.
Colette Cunningham – Senior Technical Manager for Palliative Care (PEPFAR/CRS) Zambia
Dr Mary Bunn - Umdozi Palliative Care Services for children, Malawi.
Dr Michelle Meiring – Soweto Hospice and founder of the Big Shoes Foundation
Dr Julia Downing – Deputy Executive Director of APCA, Uganda.
Carla Horne – Psychologist with Family Health International
Eunice Garanganga – HOSPAZ Zimbabwe
Joan Marston – Paediatric Palliative Care Manager for HPCA
Maraliza Robbertze – Paediatric Palliative Care Officer for HPCA
Nkosazana Ngidi – Education and Research Manager for HPCA
Dr Rene Albertyn – Director: Paediatric Pain Management at the Red Cross Children's Hospital in Cape Town
Sue Boucher – ICPCN International Information Officer

Hospices in South Africa take on the battle against HIV/AIDS for the children

By: Maraliza Robbertze, Paediatric Palliative Care Officer (HPCA)

There are estimated to be over 5,2 million South Africans infected with HIV/AIDS.

HIV infection and AIDS continues to spread at an alarming rate within Sub-Saharan Africa, and increasing numbers of children and youth in South Africa are infected with HIV, vulnerable to HIV infection, or affected by HIV and AIDS due to the impact of the disease on their families and communities.

We are in the "death phase" of HIV/AIDS and to date we have only seen the tip of the iceberg. In the near future the full impact of this syndrome will be experienced – more deaths will result in an increase in orphans and vulnerable children and more children will present with the virus. Sadly, many adults in South Africa are still ambivalent to the use of antiretroviral treatment for themselves or their children.

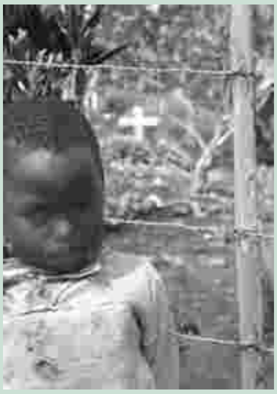
For a number of years, Hospices throughout South Africa have been involved in caring for children on their palliative care programmes. As Hospice staff work with adult patients, they are more likely to come across children in severe distress because of the HIV/AIDS pandemic.

Pilot Programme

A pilot project was started in Oct 2007 to strengthen existing children's palliative care services and to develop a toolkit for the establishment and integration of children's palliative care. While still in the planning phase, it is hoped that from October 2008 the programme can be expanded into other sites.

The objectives of the pilot program are:

- To identify models of excellence
- To provide training and mentorship in order to enhance the quality of service to orphans and vulnerable children
- To document best practices and procedures, in order to capacitate hospice organisations
- To ensure quality services to orphans and vulnerable children



For the pilot, HPCA has already identified 18 sites of member hospices in South Africa rendering services to Orphans and Vulnerable Children. The innovative models of care provided by these sites include: in-patient facilities, day care centres, community based services and residential facilities.

As part of the Pilot Research Project, documentation and research has been done to identify the barriers which hinder hospices in their provision of quality care to children.

The ultimate goal of this project is to assist and strengthen hospices in Sub Saharan Africa to ensure quality care to orphans and vulnerable children, infected and affected by the AIDS pandemic.

> **"THE UNHEEDED CRY OF A CHILD IN CRISIS IS AN ACCUSATION AGAINST HUMANITY"** *Elize Coetzee 2004*

The Beacon of hope project

By Dr Delia Birtar, Romania

New developments in paediatric palliative care in East European Countries

Hospice "Casa Sperantei", as pioneer of palliative care services for adults in Romania, is working now towards extending the palliative care for children as well. In 2005, we started the three-year "Beacon of Hope" project with the support of a grant provided by GlaxoSmithKline International.

The purpose of the project is to contribute to the development of palliative care services in Romania and the surrounding countries in order to improve the access to specialised care of children with life-limiting or life-threatening diseases.

Background

Our national and international recognition during the past 15 years confirmed our contribution to promoting palliative care in the region and to implementing high standards of care for services in various settings (home care, in-patient units, and day centres). Hospice "Casa Sperantei" Brasov, Romania, was founded in 1992 in Brasov as a Romanian charity, at the initiative of Graham Perolls and in partnership with a British hospice based in Kent. It was the first organization to pioneer palliative care for terminally ill patients of all ages in Romania and to support further development of palliative care in the country and in the region.

In 1996, the first home care service for children with life-limiting diseases was initiated. Over the following years further developments included a day centre and an in-patient unit in 2002. We currently provide a complex range of services for around 120 current paediatric patients. These services include: home-care services for 80 current patients, day centre (play and occupational therapy), in-patient unit with 6 beds, out-patient clinic, and educational centre for 20 children not enrolled in another form of education, support group for parents and peers.

Project objectives

During the "Beacon of Hope" project, the paediatric centre for palliative care in Brasov is currently focused on four objectives:

I. To develop a Regional Centre of Training in Palliative care for children, where professionals from Romania and the surrounding countries will be trained.

II. To develop the "Bagpuss" Children's Hospice Unit in Brasov, as a Centre of Clinical Excellence for children's palliative care in the South-Eastern Europe.

III. To set up a mobile hospital and home care team in Bucharest, to serve as a pilot project for the region, a project that can be eventually replicated in other parts of the region.

IV. To establish a network of Paediatric Palliative Care providers in Romania.

Outcomes

As a result of this project we were able to raise the awareness the general public, professionals and public authorities about the needs of paediatric patients with life-limiting diseases from Romania.

The project helped two existing services of paediatric palliative care (PPC) to develop and three new services to start. Initially our objective was to help five centres in Romania to develop PPC services. However during the second year of the project we received requests for training in our unit from two other centres and therefore included them in our project.

A special challenge was to set up the first mobile hospital team in Romania in a large university children's hospital from Bucharest. We had to overcome the resistance of the hospital staff to introducing another type of care ("Isn't our care good enough?", they wondered). Establishing the partnership of care for children with life-limiting and life-threatening diseases took a lot of hard work and diplomacy. In the first year of activity the team had 30 children in their care, in co-operation with the oncopaediatric department, respiratory disease department, neurology, nephrology and orthopaedics; after discharge the care of the children continued in their homes.

We also provided training for the staff in the oncopaediatric department of two children's hospitals (Timisoara and Oradea), in response to their interest in providing palliative care to children dying with cancer in their hospitals.

The national network

With the view of setting up a network of palliative care providers for children in Romania, we contacted the NGO's and other institutions involved in this area and invited them to attend the first Paediatric Palliative Care Conference from Romania in June 2006. About 40 participants responded and took part in the round the table discussion about the need to initiate the network. The participants agreed to join this network with its three main objectives:

1. Improving the access to palliative care for children with life-limiting or life threatening diseases.
2. Access to information and support for professionals and institutions willing to develop services offering paediatric palliative care
3. Promoting international standards in palliative care for children in Romania.

Hospice Casa Sperantei, Brasov, was accepted as the network co-ordinator. In April 2007 the network web page was launched, as part of the Hospice Casa Sperantei web site.

In 24-26 May 2007 the second Paediatric Palliative Care Conference was attended by 55 participants from 14 different organizations in Romania and a Hospice from Moldavia. The conference confirmed the current state of paediatric palliative care in Romania, with 9 functional hospices for children, 3 hospital departments and one independent day-centre, all providing palliative care for children with different incurable conditions.

The S-E Europe outreach

The outreach of Hospice Casa Sperantei in the region developed with further professional support to Albania, Moldavia, Kosovo, Serbia and Bosnia. In November 2006 we held courses at Palliative Care and Educational Centre in Lezha, Albania, the first Albanian hospice for children. It was encouraging to see the interest of a large number of community doctors and nurses attending the training courses

We established close links with the "North Carolina" Hospice in Zubresti, Moldavia, and provided training for both staff working with adults and children. Their services initially offered home care for children with life-limiting diseases and were recently complemented by the addition of an in-patient unit.

There is particular interest for developing the palliative care services in Kosovo, Bosnia and Serbia, while support is being sought for the financial resources needed in setting up the services. The promoters of the projects in these countries visited the Brasov Hospice to become acquainted with the services and intend to replicate the model services in their countries as soon as the appropriate resources are identified.

Conclusion

To conclude, the "Beacon of Hope" project enabled our hospice to move from being a highly appreciated local hospice for children in Brasov to a national promoter of paediatric palliative care in Romania and in Eastern Europe. The challenge is to help other countries in the region to progress from the project phase into opening new functioning palliative care services for children.

Contact: Dr. Delia Birtar, paediatrician specialising in Palliative Care

"Beacon of Hope" Project co-ordinator

Hospice Casa Sperantei Brasov – ROMANIA

Phone / Fax: +40-268-474 467

Email: delia@hospice.bv.astral.ro

Children in the day centre at the CASA SPERANTI Hospice in Brasov, Romania

Participants at Romania's 2nd National Paediatric Palliative Care Conference in May 2007

Children's Palliative Care in North America

By Sue Huff

For the first report representing North America, I will include news from mainly the United States and Canada. In the future, I hope to gather reports on the development of children's initiatives from other areas in North America. Any correspondence can be sent to my email address at: shuff2@jhmi.edu

The Field of Hospice and Palliative Care across the United States and Canada has drawn interest and shown growth over the last few years following the Institute of Medicine report released in July, 2002. http://www.iom.edu/CMS/3740/4483.aspx

Pediatric practitioners have agreed, we do a not provide the best comprehensive care across settings for infants, children and adolescents when they are living with a life threatening conditions or when they are dying. Identifying the population of children served; providing evidence of needs; reimbursement of health care services to improve access; patient and family advocacy; along with, professional education have been at the heart of this movement between various organizations. I chose to focus only on five groups representing this field, who are leading efforts to support professional caregivers, children of all ages, their families and communities in which they live. There remains many challenges; however it is an exciting time to be a part of this developing field of care. The following will briefly highlight the latest efforts of the National Hospice and Palliative Care Organization (NHPCO); Children's Hospice International (CHI); Children's Institute for Pain and Palliative Care (CIPPC); Institute of Pediatric Palliative Care (IPPC), and the American Academy of Pediatrics (AAP). Additional information is available on their web sites given below.

THE NATIONAL HOSPICE AND PALLIATIVE CARE ORGANIZATION

NHPCO provides numerous resources for both professional caregivers and families of children that can be found on their site www.nhpco.org, search 'pediatrics' for information. The newest resource for pediatric hospice providers is a set of Pediatric Standards of Care, which will be available to members in April of 2008. The most recent initiative is the formation of Partnering for Children. This is a collaborative effort between the Children's Hospice and Palliative Care Coalition, National Hospice and Palliative Care Organization and the National Hospice Foundation. This is a national campaign aimed at increasing awareness, rallying healthcare providers, mobilizing parents and raising funds to support pediatric hospice and palliative care initiatives. Current activities of this campaign include: free outreach materials and strategies to engage parents and healthcare providers; free on line information for families and caregivers, an on line catalog of educational resources, communication tools to engage members of the media, publicize outreach, raise funds and gain credibility.
Go to www.partneringforchildren.org for more information.

CHILDREN'S INSTITUTE FOR PAIN AND PALLIATIVE CARE

In June of 2007, pediatric palliative care providers from the US and Canada met in Minneapolis, MN for the first Forum on Pediatric Palliative Care. The Forum was hosted by CIPPC. CIPPC is a center for training, resources, and consultation to providers who are seeking to enhance skills and services in pediatric palliative and end of life care in the five state upper Midwest region of the United States. This event aimed to gather experienced providers in the field of pediatric palliative care to reflect upon the state of the art of this area of practice five years after the publication of the IOM report, "When Children Die."

Ninety-nine people representing fifty-one programs in the US and Canada attended. Those programs cared for over 2600 children in 2006. The Forum's intent was to encourage interaction and the exchange of ideas among participants. Outcomes from the meeting include:

- A national registry of existing programs and services in pediatric palliative care that will become web-based and web accessible to providers, families, and others.
- A report on the State of the Field: models of care, successes and challenges, and directions for future efforts.
- A proposed plan for the field to meet annually at the American Academy of Hospice and Palliative Medicine (AAHPM) meetings, alternating with the Bi-annual International Congress on Palliative and End of life care in Montreal.
- Develop Special Interest Groups (SIGS) at the American Academy of Pediatrics and AAHPM for pediatric palliative care
- Plans to develop a research collaborative for pediatric palliative care
- A task force will explore the feasibility of identifying a "common curriculum" for pediatric palliative care across disciplines, and applicable to practice across the US and Canada in an effort to standardize core competency training.
- A statement from parent delegates regarding the role of families in the future of pediatric palliative care is pending

Information about CIPPC is available at CIPC@Childrensmn.org

INITIATIVE FOR PEDIATRIC PALLIATIVE CARE (IPPC)

IPPC is an education and quality improvement project spearheaded by Education Development Center, Inc. (EDC), and is entering its tenth year as a national leader in pediatric palliative care. Developed in collaboration with the Association of Medical School Pediatric Department Chairs (AMSPDC), the National Association of Children's Hospitals and Related Institutions (NACHRI), the New York Academy of Medicine (NYAM), and the Society of Pediatric Nurses (SPN), IPPC's peer-reviewed curriculum and award-winning video series is being used in health care organizations across the U.S. and internationally. Since March 2005, IPPC has disseminated its curriculum through a series of educational retreats, sponsored by children's hospitals, pediatric palliative care coalitions, and other healthcare organizations, with additional retreats planned for 2008-2009. Fourteen retreats have been conducted, including more than 1,400 participants, representing over 300 institutions. During those retreats, 200 family members have participated equally with professionals as co-learners and co-teachers which has significantly enhanced the learning experience. IPPC is collaborating with partners in the U.S. and internationally to adapt its unique approach to the education of health care professionals. EDC and IPPC are also working closely with Gems of Care (GOC), a new project aimed at improving systems for continuity and coordination of care for children with life-threatening conditions and their families. GOC offers a variety of resources, including workshops, consultation, and tools, to networks and groups seeking to strengthen coordinated care within their own communities. Initiated by The Jason Program in Portland, ME, Gems of Care receives funding from Jewelers for Children, the jewelry industry's national charity organization. Information on IPPC can be found at www.ippcweb.org

CHILDREN'S HOSPICE INTERNATIONAL

With funding from the U.S. Congress and technical assistance from the Centers for Medicare & Medicaid Services, CHI developed the CHI Program for All-inclusive Care for Children with Life-Threatening Conditions and their Families® (CHI PACC®). This is only one of CHI's initiatives. Additional information on their numerous resources can be found at www.chionline.org . Overcoming barriers to appropriate care for children with life-threatening conditions, CHI created CHI PACC to allow children and families to pursue curative and traditional hospice/home care services concurrently. CHI PACC allows for these services to be covered under Medicaid and hopefully private insurance will follow suit. Currently 18 states are impacted by CHI PACC, including Colorado, Florida, Kentucky, New York, and Utah. California, Maryland, and Pennsylvania are planning to move forward with CHI PACC initiatives this year. CHI is also working with the Department of Defense to develop CHI PACC within the military health care system for military personnel and their families.

CHI also provides ongoing technical assistance to nations and programs developing children's hospice and palliative care services worldwide. The following countries are among those:

Argentina
Australia
Austria
Belarus
Bermuda
Bulgaria
Canada
China
Costa Rica
England
France
Germany
Guatemala
Hong Kong
Hungary
Ireland
Israel
Italy
Japan
Jordan
Kenya
Korea (South)
Kuwait
Latvia
Mexico
Namibia
Netherlands
New Zealand
N. Ireland
Pakistan
Philippines
Poland
Romania
Russia
Scotland
Singapore
South Africa
Spain
Sweden
Switzerland
UK
Ukraine
Zambia
Zimbabwe

AMERICAN ACADEMY OF PEDIATRICS

The AAP has had a number of presentations at its national meetings on the topics of pediatric hospice and palliative medicine (PHPM), and has a number of policy statements on related topics as well, but there has been no entity within the AAP that provides a professional home for PHPM practitioners, researchers, and advocates. Due to growing interest, in part related to the 2007 approval by the American Board of Medical Specialization of PHPM as a legitimate subspecialty, a group of members has proposed the development of a Section on PHPM within the AAP. Sections are membership entities that provide educational programming within the AAP and also can serve as an advocacy arm. Thus far, in preparation for and in anticipation of the application for section status being approved, a list serve was formed. This list serve has already had over 450 unique individuals participating, including 330 physicians as well as other health care providers, parents and other advocates. This list serve enabled the rapid gathering of data for the application and proved that the respondents are hungry for education, the development of resources (such as a brief literature review biweekly service, assistance with billing codes, tips on developing fellowship training programs, etc) and networking. The final determination regarding whether the section is approved will come some time in May 2008. Exploration of a collaborative relationship between the AAP and the AAHPM have been initiated as well.

Building the Pain Puzzle

By Dr Rene Albertyn

The first in an ongoing series of articles by Dr Rene Albertyn on Paediatric Pain Management

Dr Rene Albertyn is the Director: Paediatric Pain Management in the department of Paediatric Anaesthesiology and Paediatric Surgery at the Red Cross Children's Hospital in Cape Town, South Africa. The first dedicated pain management unit in South Africa and on the continent of Africa.

Originally a Social Worker, in 2002 Rene obtained her PhD from the University of Cape Town Medical School in Pain Management and Assessment Strategies. She developed a Burn Pain and Anxiety Scale for children (BOPAS), which led to her PhD degree.

Rene is a member of the International Paediatric Pain Research Group and an expert member of the WHO forum on policy making for the prevention, management and rehabilitation of burn survivors. This year she was invited by the WHO to join the extended panel of pain experts in developing policy on the management of acute and chronic pain in adults and children. She is involved in ongoing research and conducts weekly lectures on hospital palliative care to medical students. She regularly gives talks on her subject both locally and abroad.

Rene would be happy to communicate with anyone interested in learning more about managing paediatric pain, particularly within the African setting. She can be contacted via email on: rene.j.albertyn@gmail.com

The pieces you will need

Adequate pain management, for either the adult or paediatric patient, continues to be a challenge to health care providers. The fact that pain, particularly in the paediatric patient, is often inappropriately managed is widely known and acknowledged.[1] Part of the problem is the complexity of pain assessment and monitoring due to the subjective and individual nature of the pain experience. Several areas (e.g. lack of training, inability to assess pain and anxiety, inability to evaluate management efficacy and the inability to understand the psychosocial dimensions of pain) were identified as being responsible for the problems encountered in providing adequate pain management. Pain management is a complex process. In practice providing for the patient's pain needs is often dependant on the interpersonal experiences and attitudes of the health care provider, and not on specific training and insight.[2] Unfortunately, the gold standard of pain management is still too often based on the health care provider's knowledge of pharmacology, where it is erroneously assumed that very little else other than drug management is needed. In addition, myths and misconceptions [3] In particular the fear of prescribing drugs such as opioids, and administering those drugs, particularly from a nursing perspective, contributes hugely to the inadequate management of pain in both adult and paediatric patients.[4] Additionally, the physiological and emotional consequences of untreated pain, (e.g. increased energy expenditure, prolonged hospital admission and psychological problems such as depression and withdrawal), do not receive enough acknowledgement.[5,6] If drug management is not the only requirement for adequate pain management, what then is needed to provide for this essential service? A sound understanding of the consequences of untreated pain will provide the need to explore management options. But in the bigger picture, much more is needed. The health care provider, wishing to engage in pain management needs to understand the definition[7] the classification (acute or chronic pain)[8] and types of pain (nociceptive, neuropathic pain or psychogenic pain) he/she will encounter in practice, as well as the pharmacological (e.g. opioids, non-opioids and adjuvant drugs)[9,10] and non-pharmacological options (e.g. touch therapy, distraction, breathing techniques) available for treatment. From this follows an in depth understanding of disease pathology, the pre morbid personality of the patient and related psychosocial issues, in addition to the specific assessment and measurement strategies that will be deployed to develop pain management strategies. Planning for the individual needs of each patient is essential. Children of all ages deserve compassionate and effective pain management. Pain management is not a luxury but is a basic human right. Health professionals must realise that effective pain management and assessment is essential and a concerted effort should be made to understand, reduce and eliminate pain. The alternative to adequate pain management is not only prolonged suffering but also the possible development of psychological problems such as anxiety, fear, phobias and a lack of trust.

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Barriers preventing pain management

Children do experience pain. Health professionals caring for children have the ability to recognise pain as well as the resources to alleviate suffering by providing adequate pain control. Yet, and despite available resources and technology, they often not only deny the presence of pain in children, but are also hesitant to prescribe or administer analgesic drugs. It is unfortunate that several barriers (e.g. lack of education and training, inability to differentiate between pain and anxiety[1], myths and misconceptions) preventing the provision of adequate pain control still exist.[2] However it is not surprising that that these barriers do exist, given that we live in a society that places a certain value on the importance of pain. We still have, for example, the "no pain, no gain", and the "grin and bear it" attitude. But despite societal values, it is important for the sake of the patient, and more so for the paediatric patient to not only recognise these barriers, but also to provide the knowledge that will eliminate them. Barriers to optimal pain management can be divided into three broad categories: barriers due to the system/or hospital setting, to patient attitude and the health professional's skill, insight, training and value system.

The System or Hospital Setting: Pain management, especially in children, is still seen as a low or no priority in many hospitals, both in South Africa and abroad. Part of the reason for this is the staff shortages and subsequently extended workload experienced in many South African hospitals. Patient care in these circumstances focuses primarily on issues such as emergency care, disease and symptom management, with little thought spared for pain.[3] Another reason often mentioned is the lack of resources in many hospitals, with staff often having to cope with little or no drugs or the absence of essential equipment such as cardiac monitors for children on continuous IV Morphine. Existing myths and misconceptions around drug prescription (e.g. opioids) & administration are due to a lack of training and a shortage of educational material.[3,4] Health professionals are not trained to assess and measure pain and as a result fail to treat it as pain indicators often go unrecognised.[3]

Patient attitudes: Patients, especially adults and adolescents, are reluctant to admit to the presence of pain for fear of being told that their disease pathology has worsened, or in fear of being labelled as being "difficult to work with". These patients rather choose to minimise or ignore the presence of pain, with sometimes disastrous consequences. Adult patients and very often mothers of paediatric patients are hesitant to take or give drugs for fear of addiction, tolerance and drug side effects. Ignorance plays a big part here and can be minimised through the giving[2] of information and support. For their part, children are often also reluctant to communicate pain. Contributing factors are an inadequate pain vocabulary, fear of the treatment of pain such as injections or bitter tasting medicine, or fear of displeasing their caregivers when admitting to pain. [5]

Attitudes of health professionals: Many health professionals draw their pain management abilities and insight from their own personal experience. One of the biggest stumbling blocks in the arena of pain management is the existing lack of training, in particularly the use of opioids in infants and young children and the inability to recognise pain, anxiety and discomfort. This has a great influence on the health professional's understanding of drug choices, combinations, tolerance, addictions and side effects. In addition, inadequate training leads, as a result, to poor pain assessment and measurement skills. Existing myths and misconceptions complicate pain management, particular in paediatric medicine.[6] The idea that young patients do not need pain medication because of their age and immature nervous system and the child's perceived inability to remember painful events, are still prevalent today[1]. Many people still feel that a little pain is character building, and that the use of strong analgesics such as opioids can either cause respiratory distress and death or addiction in later life. A bio-psychosocial approach is needed to reduce the impact of existing barriers on pain management. Children's reaction to, and interpretation of pain should be seen as the sum total of their unique personalities and previous history of pain experiences. While the biomedical model focuses on albeit important issues such as the biological aspects of pain (e.g. the signs, symptoms, diagnosis and attempts to treat pathology), it excludes very significant psychosocial factors (e.g. social factors, interpretation of pain behaviour, cognitive developmental level of the child, and cultural aspects). [2] The above mentioned stumbling blocks in pain management can be either minimised or eradicated with proper training in analgesia, non pharmacological management choices as well as the ability to do a proper pain assessment and measurement. It is believed that with the right training, support and adequate knowledge, health professionals will change from "no pain, no gain" to an attitude of "no pain, all gain", and from "grin and bear it" to "learn and share it."

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Should you wish to contribute to ICPCN Network News please contact the Editor:
Sue Boucher • Email: sue@icpcn.co.za • Cell: +27 (0)82 089 4420
PO Box 38785, Pinelands Cape Town, 7430 South Africa

ICPCN is administered from the offices of the Hospice Palliative Care Association of South Africa (HPCA) in Cape Town.
Phone: +27 (0)21 5310277
Email: hpca@iafrica.com