

October 2009

... the God of all comfort, who comforts us in all our trouble so that we can comfort those in any trouble with the comfort that we ourselves have received from God.  
2 Cor 1:3,4

## HIV&AIDS and PALLIATIVE CARE

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AIDSLink 85 explores compassionate and effective palliative care in the context of HIV&AIDS. Thank you to those who share information on 'what works' in their settings, tips, resources, events, training opportunities, and even questions. Let's keep on learning from each other as we live out God's values.

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SIM HIV&AIDS related ministries and HOPE for AIDS

## 1. BIBLICAL FOUNDATIONS – PALLIATIVE CARE

The vaccine world is buzzing with the news that for the first time an HIV vaccine in phase 3 trials in Thailand has shown some protective effect. Scientists have also recently decoded the entire genetic structure of HIV-1 and hope this will pave the way to a greater understanding of how the virus operates, and potentially accelerate the development of drug treatments. We are seeing some great advances in these areas, along with more people returning to healthy productive lives thanks to the push for universal access to treatment. However we are still faced with the serious challenge of quality care for the dying. Sickness, disease, injury, pain, sorrow and finally death, come to us all (Gen. 3:15-19).

The Africa Palliative Care Association Director, Dr Faith Mwangi-Powell, engages audiences outside Africa with the continent's palliative care needs by using the 2007 Hollywood film *The Bucket List*, in which two patients escape from a cancer ward with a 'wish-list' of things to do before they die. She writes, "The very idea of a bucket list shows real imagination: it's all too easy to ignore things that are really important to us in life, thinking that we'll do them 'one day'. An African patient's bucket list would be far simpler and humbler than the Hollywood version. Based around basic human rights and needs, it would probably contain freedom from pain and symptoms; enough decent-quality food; family and community support; a secure future for their children; access to adequate resources to address their illness; and scale-up so that such care would be available to everyone suffering" ([www.apca.co.ug/newsletter/072009/APCA e-Newsletter.html#bucket\\_list](http://www.apca.co.ug/newsletter/072009/APCA_e-Newsletter.html#bucket_list)).

One day the shroud of death will be removed forever and the Lord will wipe away all tears (Isa 25:7,8; 1 Cor 15:54; Rev 21:4). In the meantime Christians are called to work for the alleviation of suffering with its causes and effects, showing the same love and acceptance that Christ demonstrated. We are to point to Christ as the ultimate hope, to his righteous judgment as overcoming all injustice, and to eternal life as the blessing beyond the pain of this life (Isa 1:17; Rom 8:18-21; Phil 3:10-11).

For reflection and discussion:

1. Read Rom 8: 28,35-39. Identify the various forces which Paul assures us will not separate us from the love of God. Which areas are the most challenging to you?
2. Write a "bucket wish-list" for those requiring palliative care in your setting? How might the gap between needs and resources be reduced?
3. What are the obstacles and opportunities for palliative care?

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## 2. PALLIATIVE CARE IN RESOURCE LIMITED SETTINGS

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With anti-retroviral (ARV) treatment becoming increasingly accessible, people with HIV, their families and communities have an important role to play alongside health workers in ensuring effective and sustained treatment.

1. A 2-page fact sheet *ARV treatment fact sheet 18: Palliative care and symptom control*, by AIDS Alliance explains what palliative care and symptom control mean, how they are used to meet the physical, social and emotional needs of people living with HIV (PLWHA) from early stages of illness through to the end of life, and how they relate to and support the use of ARV treatment. This is one of a series of fact sheets AIDS Alliance has developed using non-technical language, to help support PLWHA and their communities on ARV treatment. They are based on experience with treatment support programs in Africa, Asia and the Caribbean. This is available (120kb) from: [www.aidsalliance.org/custom\\_asp/publications/view.asp?publication\\_id=59&language=en](http://www.aidsalliance.org/custom_asp/publications/view.asp?publication_id=59&language=en)

2. The *Palliative Care Toolkit: Improving care from the roots up in resource-limited settings* (2008) by Charlie Bond, Vicky Lavy, and Ruth Wooldridge includes a focus on HIV. The authors have extensive experience in Malawi, Kenya, Sierra Leone, China and India. They write to empower health workers to integrate palliative care into the work they are doing by grafting the missing elements of care onto what is already in place. It takes a 'can-do' approach, showing that basic palliative care can be delivered within existing community and health structures by people without specialist training, and that other members of the community can also be involved. The symptom control guide gives advice for volunteers and carers as well as information on drug treatments. Communication skills and psychological and spiritual support are addressed, with attention paid to the special needs of children. A set of tools includes forms for patient records and data collection, advocacy material, teaching aids and a basic drug list. Download (5.3MB) from: [www.helptheospices.org.uk/EasySiteWeb/GatewayLink.aspx?allId=6147](http://www.helptheospices.org.uk/EasySiteWeb/GatewayLink.aspx?allId=6147)

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## 3. DECENT CARE VALUES in PALLIATIVE CARE

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According to the World Health Organization (WHO), "Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and competent assessment and treatment of pain and other problems, physical, psychosocial and spiritual." See [www.who.int/cancer/palliative/definition/en/](http://www.who.int/cancer/palliative/definition/en/)

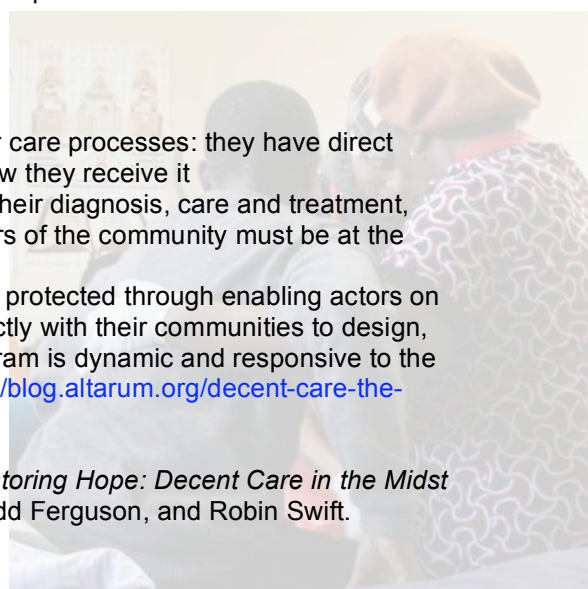
The January 2009 WHO and Ford Foundation-sponsored *Global Consultation on Decent Care Values in Palliative Care Services* brought PLWHA, palliative care specialists, and global health leaders to explore the conceptual alignment between the concepts of decent care and the practice of palliative care. The WHO white paper on decent care explains, "Decent care ... posits an approach to health services which is holistic (meaning comprehensive), inclusive, and responsive to the community and which enrolls the community in the problem-solving and support for care." Decent care begins with three questions that patients should ask of themselves and that providers should bear in mind as they work with patients, families, and communities to develop treatment plans:

- What do I/we need now?
- How do I/we live in the face of disease?
- How might I/we flourish?

Values are described as:

1. Dignity and Agency - Patients/clients are active agents in their care processes: they have direct control over, and direct input into, what care they receive and how they receive it
2. Interdependence and solidarity - No one should have to face their diagnosis, care and treatment, and the possibility of illness and death, alone. Individual members of the community must be at the centre of the care process
3. Subsidiarity and Sustainability - These are best promoted and protected through enabling actors on different levels to act collaboratively. Individuals collaborate directly with their communities to design, develop, and change their care programs ensuring that the program is dynamic and responsive to the individual's needs and desires. For further information see: <http://blog.altarum.org/decent-care-the-key-values-for-health-care-reform/>

An extensive description of decent care values is laid out in: *Restoring Hope: Decent Care in the Midst of HIV/AIDS* (2008), edited by Jeffrey V. Lazarus, Ted Karpf, Todd Ferguson, and Robin Swift. Available through [www.amazon.com](http://www.amazon.com)



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## 4. CHILDREN'S PALLIATIVE CARE in AFRICA

*Children's Palliative Care in Africa* (Oxford University Press, Oct 2009) edited by Justin Amery is new textbook for health and social care professionals to increase access to care for children with life-limiting illnesses in Africa.

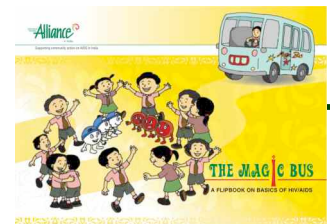
Children's palliative care has developed rapidly as a discipline, as health care professionals recognize that the principles of adult palliative care may not always be applicable to children at the end of life. The unique needs of dying children are particularly evident across Africa, where the scale of the problem is overwhelming and the figures so enormous that they are barely comprehensible: over 400,000 children in Africa died from AIDS in 2003, and out of the 166,000 children a year diagnosed with cancer, 85% of these are in the developing world. Despite the enormous need, provision of children's palliative care in Africa is almost non-existent, with very few health workers trained and confident to provide care for dying children. The challenges of providing palliative care in this setting are different to those in more developed countries, contending with the shortage of physical and human resources in addition to the vast scope of the care needed.

Written by a group with wide experience of caring for dying children in Africa, this book provides practical, realistic guidance by improving access to, and delivery of, palliative care in this demanding setting. It looks at the themes common to palliative care including communication, assessment, symptom management, psychosocial issues, ethical dilemmas, end of life care, and tips for the professional on compassion and conservation of energy. It maintains a focus on the particular needs of the health care professional in Africa. While containing some theory, the emphasis is on practical action throughout the book. *Children's Palliative Care in Africa* aims to provide health care professionals working in Africa and other resource-poor settings with the confidence, knowledge, and capacity to improve care for the terminally ill child in constrained and demanding environments. Available through [www.amazon.com](http://www.amazon.com)

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## 3. THE MAGIC BUS - BASICS of HIV&AIDS for CHILDREN

*The magic bus: a flipbook on basics of HIV/AIDS* (2009) is intended to be used by outreach workers and counsellors in the field who need tools to explain the basics of HIV to children between 8 and 14 years. The flipbook allows children to undergo a journey of information which is fun and easy to comprehend. It was developed and tested with children in the four Indian states of the CHAHA program, Andhra Pradesh, Tamil Nadu, Maharashtra and Manipur, and has been translated in Telugu, Tamil, and Marathi. Downloadable from: [www.aidsalliance.org/custom\\_asp/publications/view.asp?publication\\_id=368&language=en](http://www.aidsalliance.org/custom_asp/publications/view.asp?publication_id=368&language=en)



For information about printed copies of this 30 page book, contact: [info@allianceindia.org](mailto:info@allianceindia.org)

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## 6. BODY MAPPING

What is a body map? It is a picture of the body which can be used to show parts of the body, areas where people feel pleasure or pain, areas where people inject, and the effects of treatment and so on. It is useful to:

- provide a non-threatening way to discuss sensitive subjects including sex and sexuality
- identify common and local names that people use for parts of the body
- explore different perceptions that people have about their bodies
- explore different views and beliefs that people have about well-being and illness
- explore gender norms and expectations

1. Ask participants to draw an outline of the body on the ground or paper. Drawing around a participant who volunteers to lie down on the floor is a fun way to get started, or you draw around their shadow.
2. Agree what to show on the map, depending on the focus of the discussion – for example, reproductive organs, symptoms of illness, areas of pleasure, the effects of AIDS or drug use. Show these features on the map.
3. Discuss the map and clarify any misunderstandings or myths about the body

Take care to create a comfortable environment. People are more comfortable in single sex groups, possibly with people of a similar age or marital status, and in locations with some privacy. Be prepared that body maps may raise traumatic memories for some participants, such as those who have been

abused or suffered violence. This tool has been adapted from Tools Together Now, 2006, p,40 by AIDS Alliance and is available for downloading (2.9MB, 250 pages) at: [www.aidsalliance.org/sw36326.asp](http://www.aidsalliance.org/sw36326.asp)

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## 7. MAKING IT KNOWN – CREATIVITY IN PRACTICE + WHERE THERE IS NO DOCTOR

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1. The 3rd African Palliative Care Association Conference will take place 15-17 September 2010 in Namibia's capital, Windhoek, on the theme of Palliative Care in Africa: Creativity in Practice. See [www.apca.co.ug](http://www.apca.co.ug) for registration.

2. The 2009 edition of *Where There Is No Doctor* continues the tradition of being simply written and generously illustrated. It works to demystify what doctors do and takes into account the political, social, and economic circumstances that people must consider when deciding how to take charge of their health. The new edition contains new and updated information on HIV prevention and medicines, treating serious injuries, the resurgence of yaws, drug resistance and changes in STD and malaria medications, childhood vaccinations, asthma treatment, and much more. See: [www.hesperian.org/Translations\\_and\\_Downloads.php](http://www.hesperian.org/Translations_and_Downloads.php)

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## 8. TIP of the MONTH – M&E: INDICATORS

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One of the key strengths of a log frame approach such as Results Based Management is that it forces the planning team to build into the design how the project will be monitored and evaluated. Indicators and verification are needed to show what data we intend to use to measure progress, and how those data will be collected. They measure how successful activities have been. These can be:

- Quantitative - using numerical data such as numbers, percentages, volumes and amounts, to assess results. For example: The number of brochures produced and distributed; the percentage improvement in take-up of ART amongst young adults aged 18 to 25.
- Qualitative - assessing impact, quality or value, based on personal opinions, feelings and emotions. For example: Evaluating the psychological effect of an education programme on ART amongst women in X, Y and Z provinces: does knowledge about the treatment available give them greater peace of mind?

Set the basic indicator and add Q Q T - Quantity, Quality, Time

1. Add Quantity - an amount or percentage that will be achieved
2. Add Quality – a built-in quality measure to specify the indicator
3. Add Time – when this should be accomplished

Avoid using general phrases such as 'as soon as possible.' It is important to include a balance of indicators for the end of the project (goals or long-term results) and some mid-term indicators (milestones or medium-term results). Examples of typical sources of verification include: feedback from stakeholders including beneficiaries, focus groups, attendance lists and minutes of meetings, surveys, training evaluation questionnaires, project records, newspapers, radio and TV recordings, photographs, national and international statistics.

For additional reading see: Building Skills in HIV & AIDS Documentation & Communication: a Reference Manual (July 2008). Available (2.1MB) at: [www.saf aids.net/?q=node/849](http://www.saf aids.net/?q=node/849)



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