

# I was sick and you cared for me



Comprehensive HIV care and support: A faith-based response to palliative care needs in Africa

Addis Ababa, Ethiopia

December 2nd, 2011

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Slide 1

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ST1

New photo...

Shannon Thomson, 11/24/2011

# What is palliative care?

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 impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

- World Health Organisation definition

**Palliative care aims to 'add life to days, not days to life'**

**– Dame Cicily Saunders**

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# Improving Quality of Life

- A response to pain, encompassing spiritual, social, psychological and physical pain
- Pain and symptom control + psychosocial support = palliative care
- Aims to improve quality of life for those with life-limiting illness

“We will do all we can, not only to help you die peacefully, but also to live until you die.” – Dame Cicily Saunders

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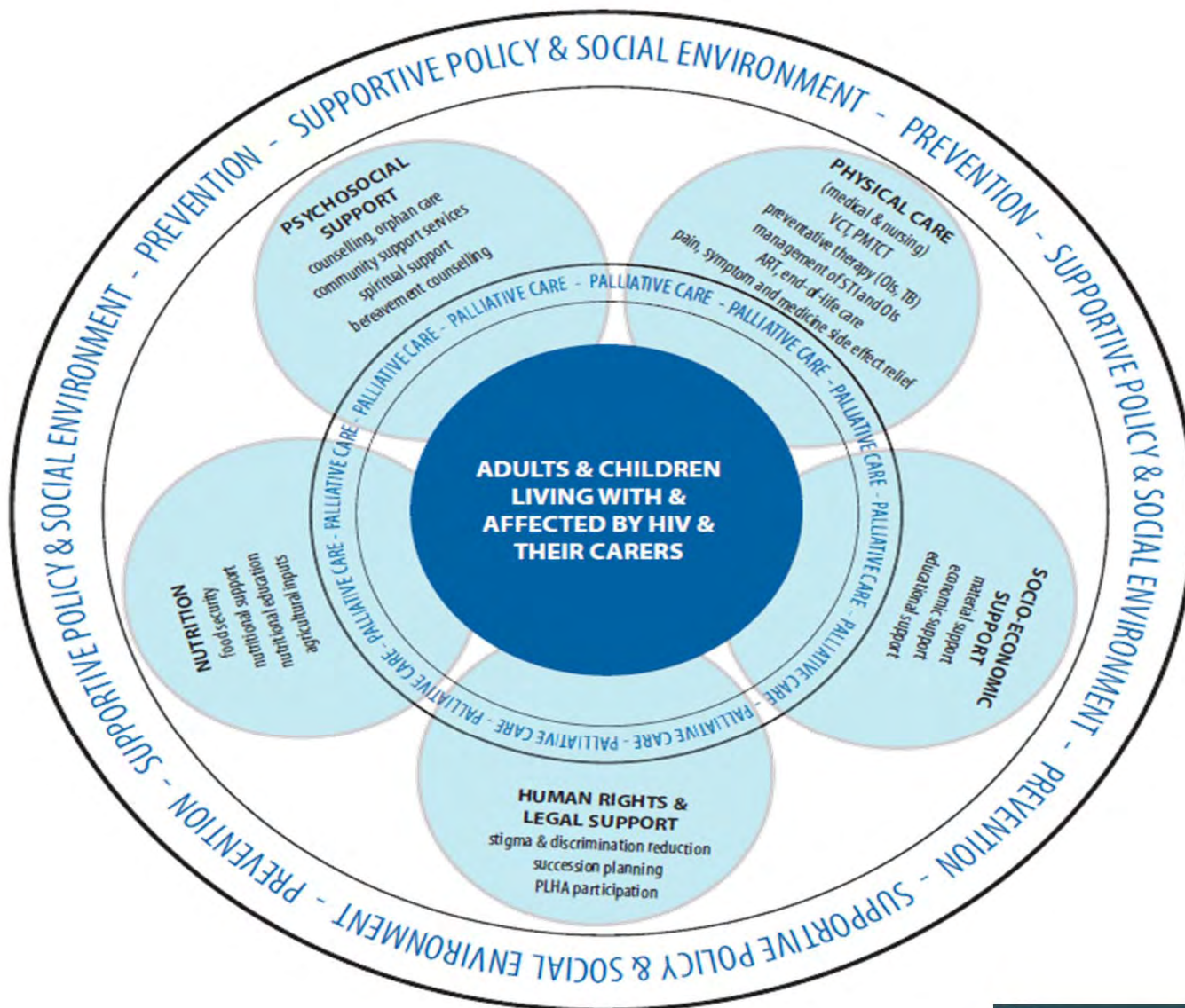
# Why palliative care in the context of HIV?

- Increasing rollout of ARV treatment has changed the landscape of home-based care, often reducing it to adherence support
- Co-morbidities, side effects, pain management and opportunistic infections have overburdened caregivers capacity
- Inadequate access to ARVs and continuing fear of testing perpetuates late stage diagnosis

# HIV Care and Support – the forgotten pillar of Universal Access

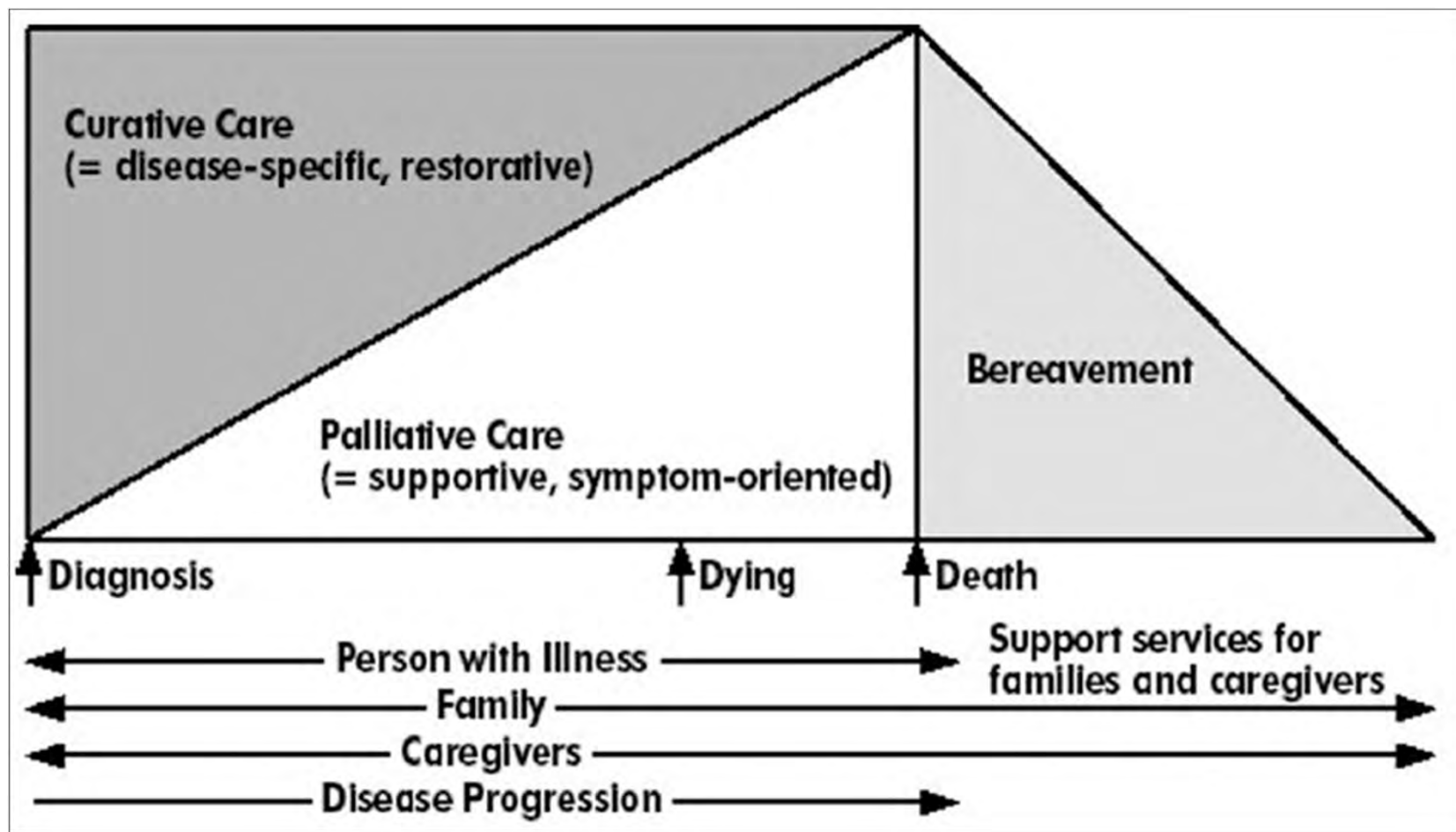
- HIV Care and Support underpins effective HIV response (treatment and prevention)
- Care and Support is crucial in its own right as a mechanism of responding to multi-faceted needs
- Contributions of communities, families, faith groups, and particularly, volunteer caregivers have gone largely unnoticed and often unappreciated in the response effort

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UK Consortium for AIDS and International Development, Care & Support:  
 The Forgotten Pillar of The HIV Response, 2011, pp. 7

# Continuum of Care – Diagnosis to End of Life



Mudigonda, et. al, 2010; Indian Journal of Palliative Care

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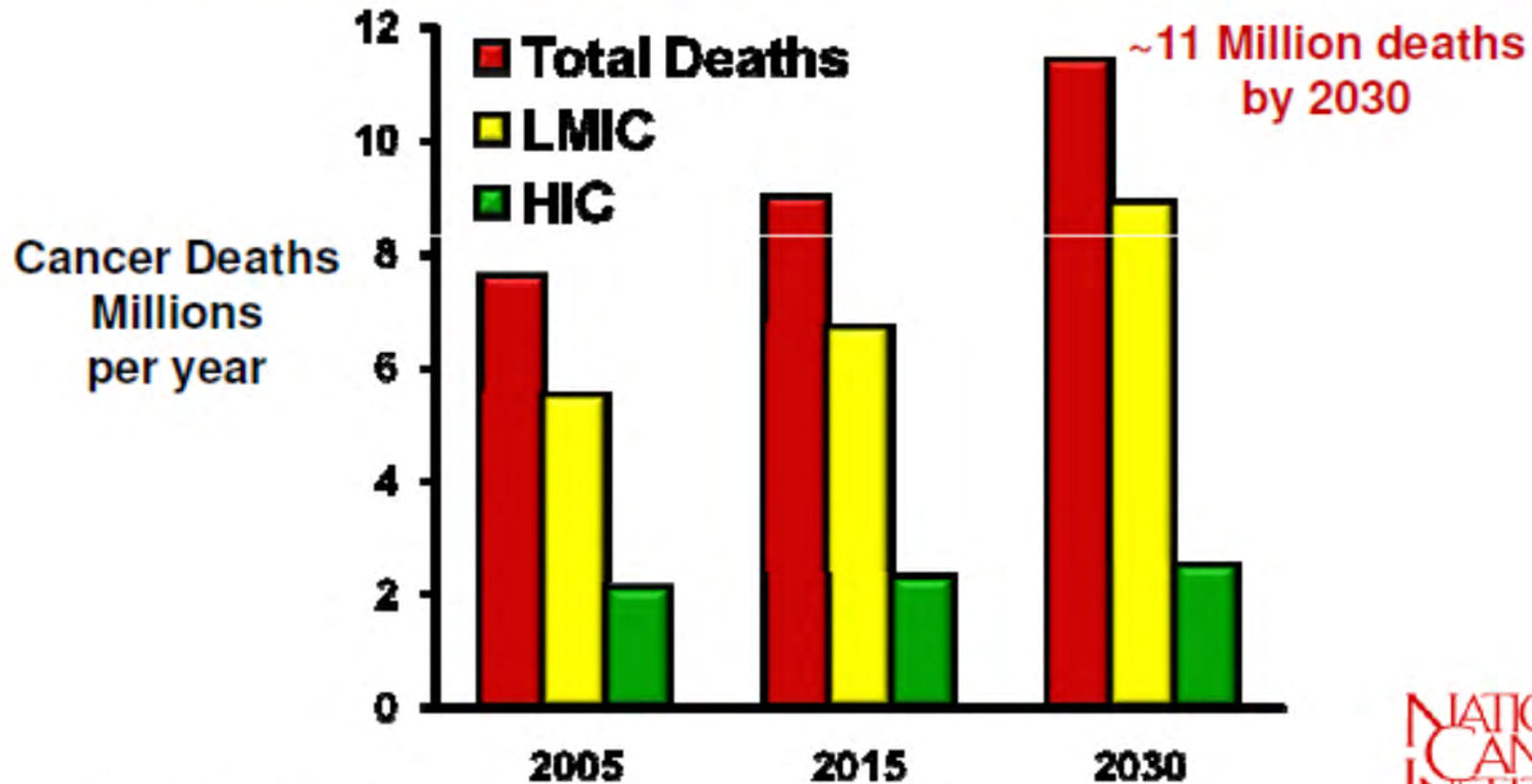
# A growing need for palliative care in Africa

- 22.5 million people living with HIV in sub-Saharan Africa in 2009
- 1.3 million AIDS-related deaths (UNAIDS Global Report 2010)
- 50% of AIDS-related deaths are in moderate to severe pain
- 60-100% of people living with HIV will experience pain at some stage of their illness (Brennan et. Al (2007) Pain Management)

# Increasing incidence of cancer in Africa

- The global incidence of cancer is projected to rise from 12.7 million in 2008 to 21.4 million by 2030 (UICC 2011)
- Cancer deaths will double worldwide by 2013 (UICC 2009)
- 70% of cancer deaths and 99% of AIDS-related deaths occur in low and middle income countries (WHO 2010)
- Demonstrated link between cancers and HIV (Kaposi Sarcoma, non-hodgkins lymphoma, cervical cancer)  
(Mbulaitey, et. al. (2006). Int. J. Cancer)
- Cancer burden in Africa expected to increase by 400% in the next 50 years (Morris, K. (2003) Lancet)

Cancer currently accounts for ~12.5% of global deaths.  
~80% of these individuals experience >moderate pain near end of life.



Data Source: Globocan 2002

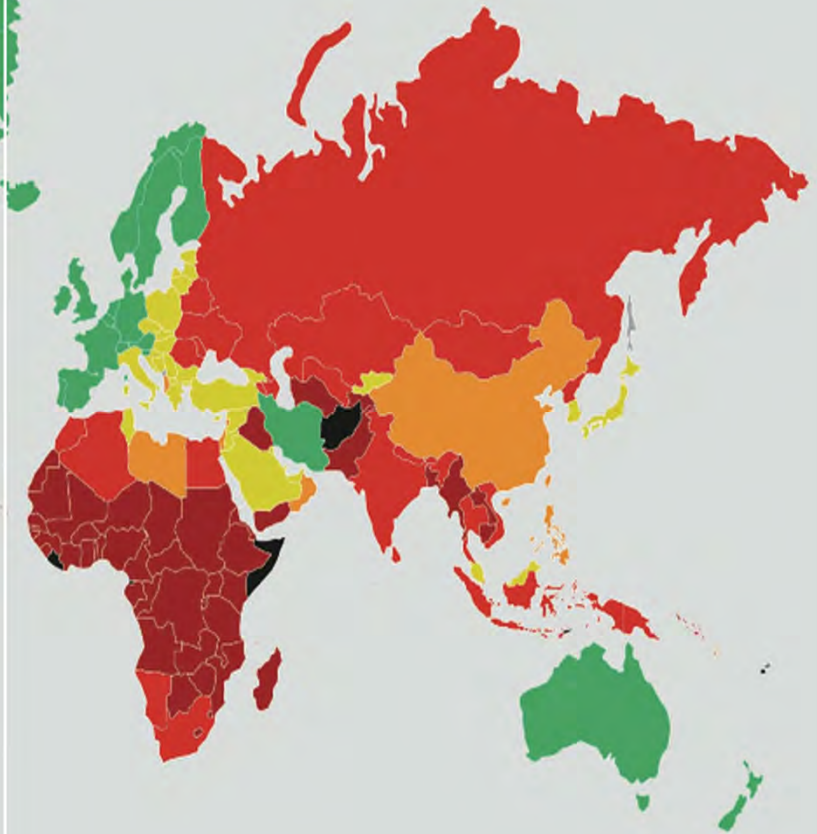
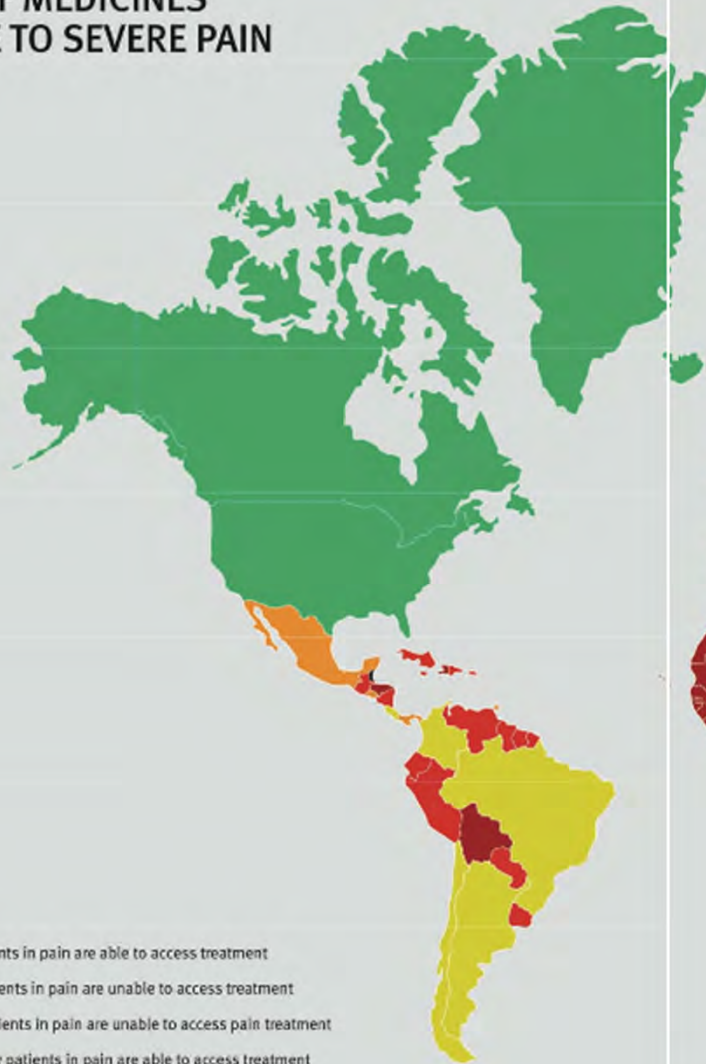


# Access to Pain Relief

- As a key element of palliative care, access to pain relief remains in many areas an unmet need
- 70% of cancer deaths and at least 50% of AIDS-related deaths are in moderate to severe pain (Brennan et. al. (2007), Pain Management)
- Fear of morphine dependency and unnecessary national regulations can restrict access



## AVAILABILITY OF MEDICINES FOR MODERATE TO SEVERE PAIN



# Providing palliative care

- Can be in-patient (hospice or hospital)
- WHO emphasises the need for home-based palliative care in resource-limited setting
- As a component of task shifting, home-based palliative care offers a cost-effective possibility in low-resource settings



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Maps showing Tearfund Partners and other related local workers

Christian Council of Tanzania's (CCT's) National Health and HIV/AIDS Programme, the lead partner



Geita Government District Hospital

PC site coordinator, Geita  
PC champion, Geita

AICT Geita Diocese

North Mara Mennonite Diocese

PC site coordinator, Shirati  
PC champion, Shirati

Shirati Mission Hospital



PC project coordinator, Mwanza

Bugando Medical Centre (BMC) – The government referral hospital for the lake zone region.

AICT Shinyanga Diocese

Shinyanga Mission hospital

PC site coordinator, Shinyanga  
PC champion, Shinyanga

Dr Nestory Masalu, the medical oncologist at BMC, was a supportive and key contributor to the pilot, assisting each partner with obtaining Tanzania Food and Drug Association (TFDA) licences. While these were in progress, he tracked patients through BMC to provide morphine on a case-by-case basis.

KEY

Partner programme

Key coordinating roles

# Why the church?

- Core strength is providing holistic care and support
- Spiritual support is a critical element of palliative care,
- Churches have a unique relationship with communities, potential for trust, safety and comfort
- Existing structures to incorporate palliative care into HIV response (ie: HBC, HTC, volunteer caregivers, pastoral support)
- Influence in communities to build links with health services, improving the quality of care in the home and opportunity for referral to hospitals

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“Patients come to the point where they have hope again. It is a good thing for the church to see that we are responsible for sick people.”

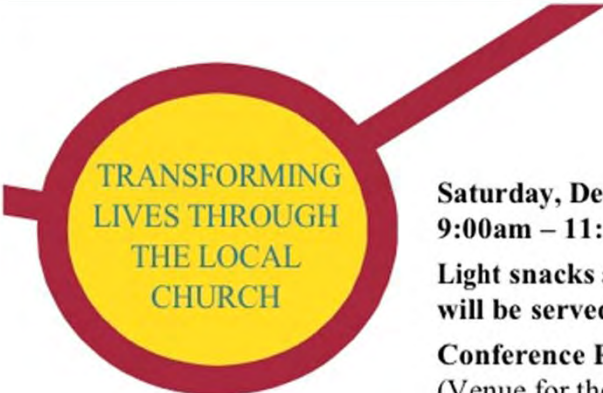
Pastor Methusela Ndaki, Geita Diocese  
Palliative Care Multi-disciplinary Team member

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# Pan-African church-based response to palliative care

- Palliative care builds on the strengths of the church
- The need for palliative care is immense and will continue to grow
- The church is well placed to contribute to meeting the growing needs
- Collaboration is critical to respond effectively to these needs
- It is about preparing for the needs now and for those to be faced in the future.

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TRANSFORMING  
LIVES THROUGH  
THE LOCAL  
CHURCH

**Saturday, December 3, 2011  
9:00am – 11:00 am**

**Light snacks and refreshments  
will be served**

**Conference Room, Desalegn Hotel  
(Venue for the 2011 PACANet pre-  
ICASA Conference)**

### **CHURCH-BASED RESPONSES TO PALLIATIVE CARE**

Tearfund would like to invite you, as a key stakeholder, to a discussion on palliative care provision in Africa.

The session will aim to:

- Present learning from Tearfund's pilot palliative care projects
- Provide an opportunity to consider the feasibility of including palliative care in existing HIV work
- Map out possibilities for shared learning in developing a palliative care response
- Explore the potential for a collaborative faith-based approach to palliative care across Africa

The session will include presentation of a case study highlighting the successes and challenges of a church-based response to palliative care from Tearfund partners in Tanzania.

For further information on the event or the work of Tearfund partners in palliative care, please feel free to contact Shannon Thomson, HIV Projects Officer, [shannon.thomson@tearfund.org](mailto:shannon.thomson@tearfund.org) or Ephraim Kabsay, HIV Advisor 0911121871

**STOPPING AIDS. ALL TOGETHER**

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- Saturday,  
December 3, 2011
- 9am-11am
- Coffee, tea and  
refreshments  
available at 8:30am
- Conference Room,  
Desalegn Hotel

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# References

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