

GLOBAL PALLIATIVE CARE

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Palliative care; a Christian response

- **Why?**..global imperative and calling
- **What?**..palliative care needs, holistic care
- **How?**...models, resources, examples

- Then the angel showed me the river of the water of life, as clear as crystal, flowing from the throne of God and of the Lamb down the middle of the great street of the city. On each side of the river stood the tree of life, bearing twelve crops of fruit, yielding its fruit every month. And the leaves of the tree are for the healing of the nations. *Rev 22v1-2*



Global imperative and calling

- Sustainable development goals
 - 17 SDGs and 169 targets to end extreme poverty, fight inequality and injustice, and protect our planet by 2030.
- *‘The healing of the nations’*
- *‘Preferential options for the poor’*
- *‘Leaving no-one behind’*



Global imperative and calling

■ WHA Resolution

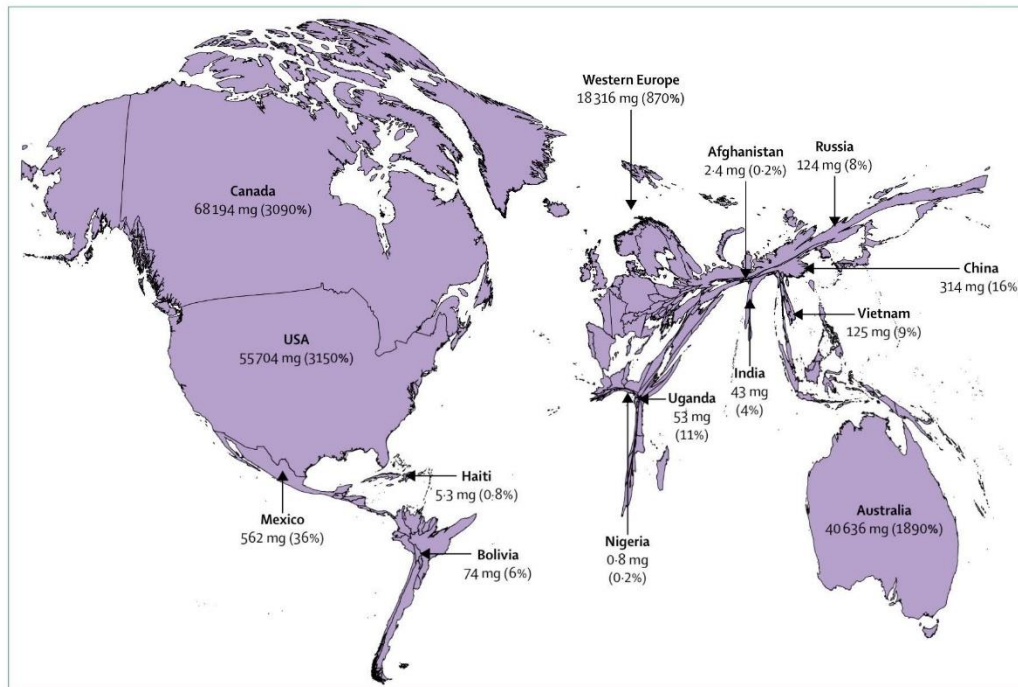
- to develop, strengthen and implement, where appropriate, palliative care policies to support the comprehensive **strengthening of health systems** to **integrate evidence-based, cost-effective and equitable palliative care services in the continuum of care, across all levels, with emphasis on primary care, community and home-based care, and universal coverage schemes**

June 2014



Global imperative and calling

- Lancet Commission report Oct 2017

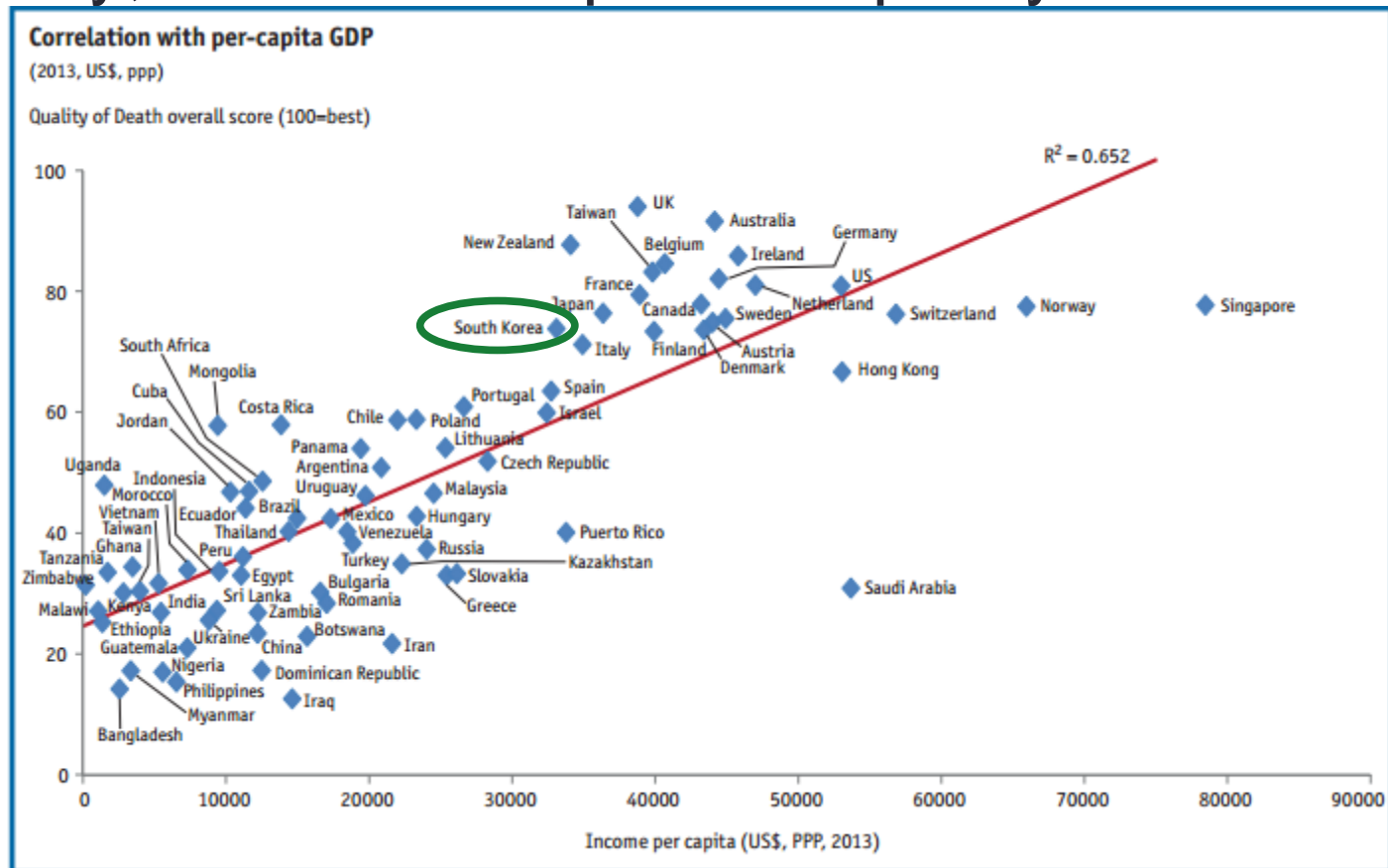


‘Alleviating the access abyss in palliative care and pain relief-an imperative of universal health coverage’

Figure 1: Distributed opioid morphine-equivalent (morphine in mg/patient in need of palliative care, average 2010-13), and estimated percentage of need that is met for the health conditions most associated with serious health-related suffering
Source: International Narcotics Control Board and WHO Global Health Estimates, 2015. See additional online material for methods.

Global imperative: poverty

- Poverty; economic impact on quality of death

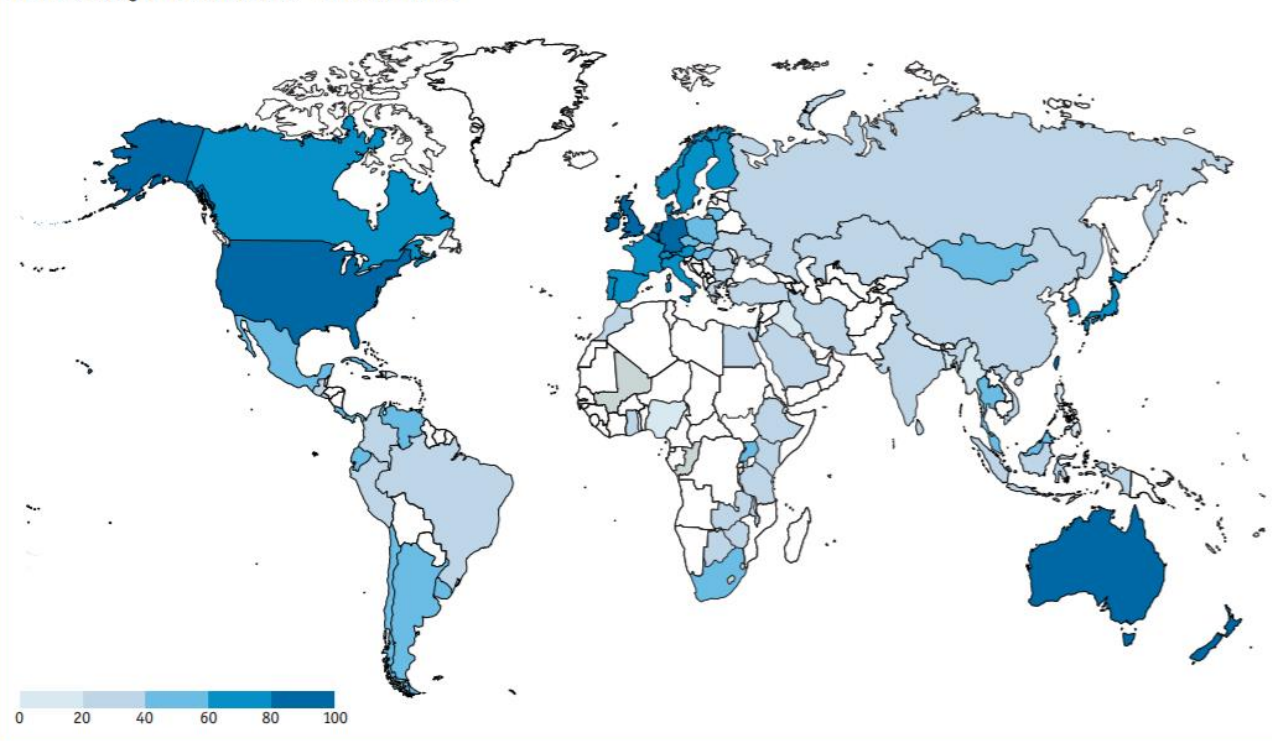


Global imperative; quality of death

- Quality of death index

Figure 1.1

2015 Quality of Death Index—Overall scores



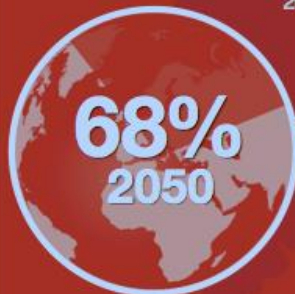
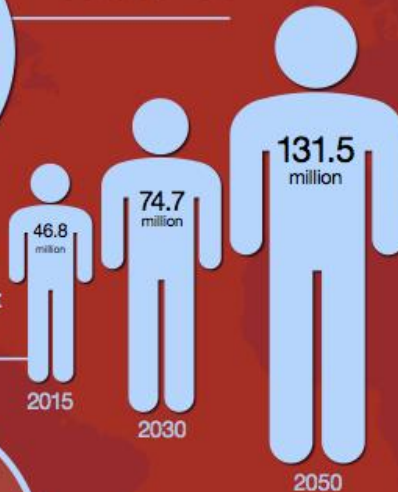
Global health issues

INFOGRAPHIC

The global impact of dementia



46.8 million people worldwide are living with dementia in 2015. This number will almost double every 20 years.



Much of the increase will take place in low and middle income countries (LMICs): In 2015, 58% of all people with dementia live in LMICs, rising to 63% in 2030 and 68% in 2050.

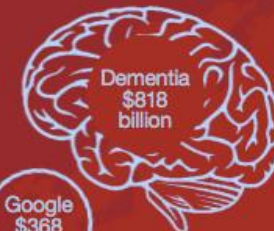
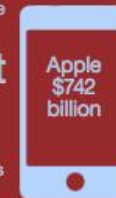


The total estimated worldwide cost of dementia in 2015 is US\$ 818 billion. By 2018, dementia will become a trillion dollar disease, rising to US\$ 2 trillion by 2030

If global dementia care were a country, it would be the

18th largest economy

in the world exceeding the market values of companies such as Apple and Google



Google \$368 billion

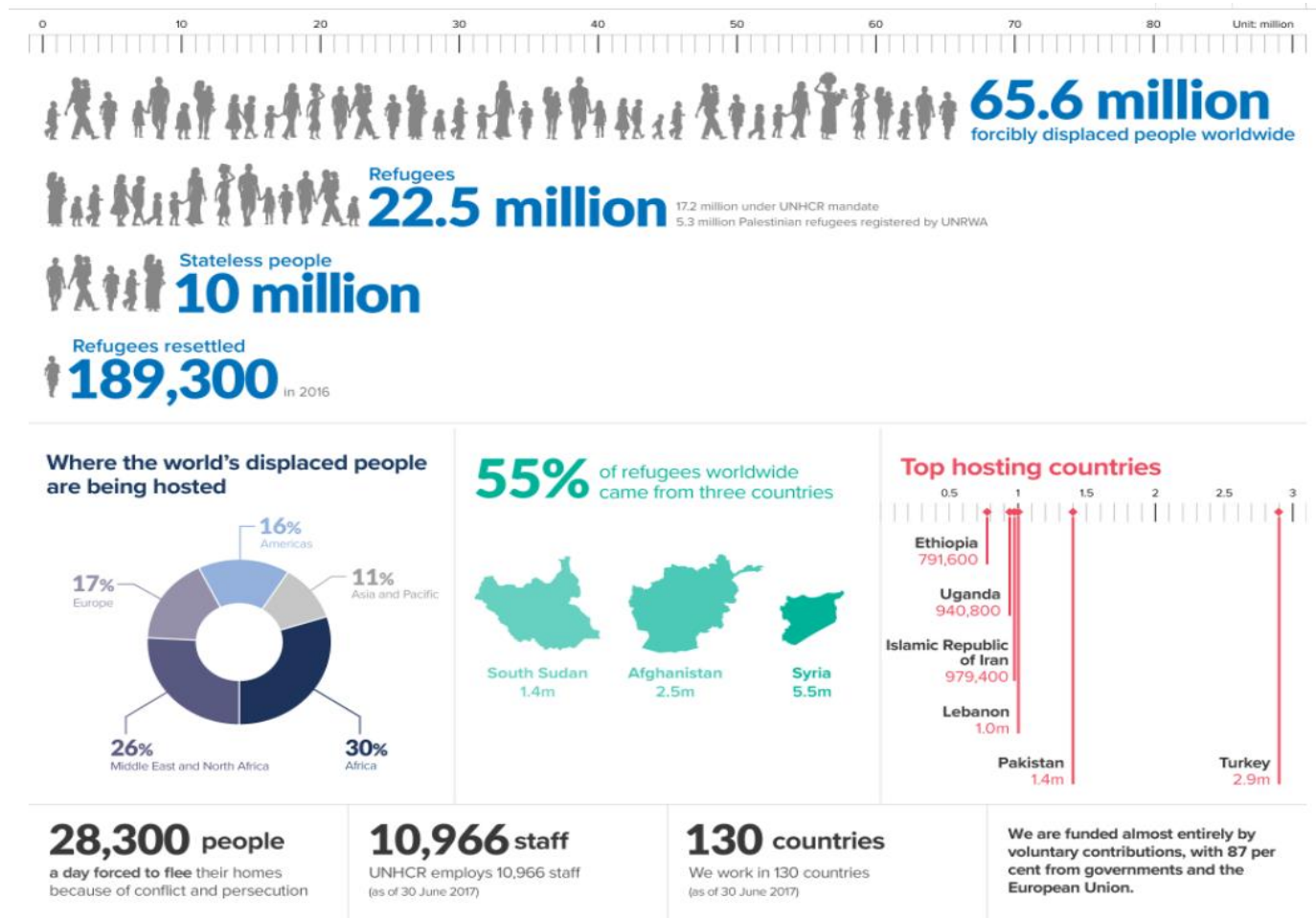
(source: Forbes 2015 ranking)



This map shows the estimated number of people living with dementia in each world region in 2015.

We must now involve more countries and regions in the global action on dementia.

Chronic humanitarian needs



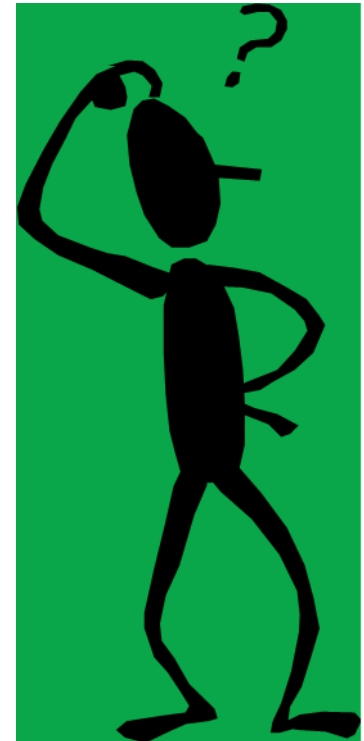
Source: UNHCR / 19 June 2017





Palliative care for all

- **Why?**..global imperative and calling
- **What?**..palliative care needs, holistic care
- **How?**...models, resources, examples



Who needs palliative care?

Progressive
neurological
conditions

HIV and AIDS

Cancer

End stage lung
disease

Heart failure

Any other
progressive
incurable illness

Renal failure

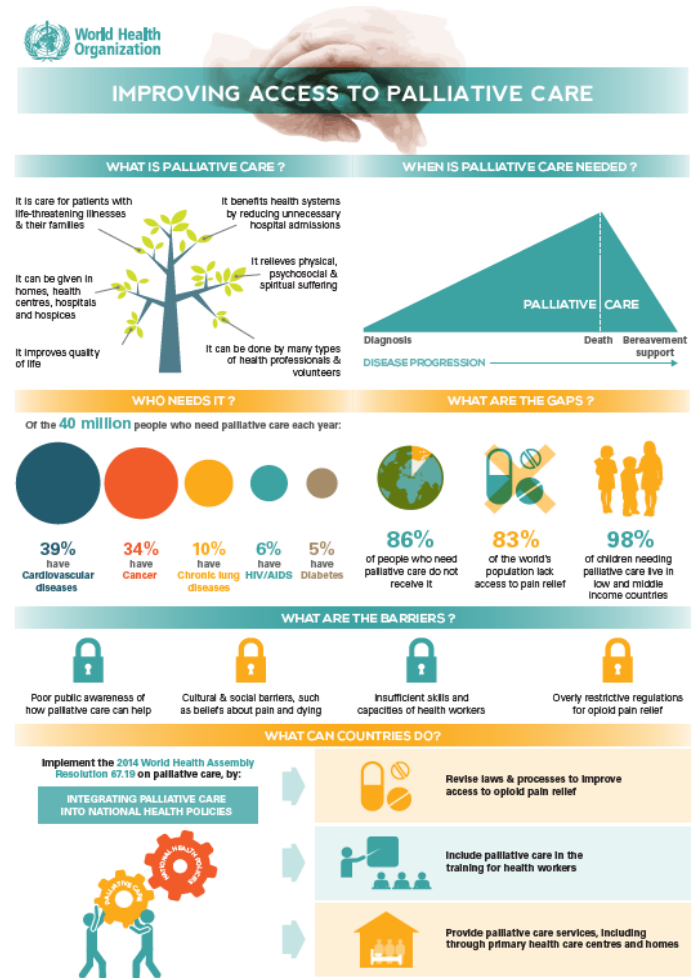
Palliative care needs

- What?
 - 40 million in need each year
 - barriers
 - poor public awareness
 - cultural and social issues
 - inadequate capacity health care workers
 - restrictive regulatory framework

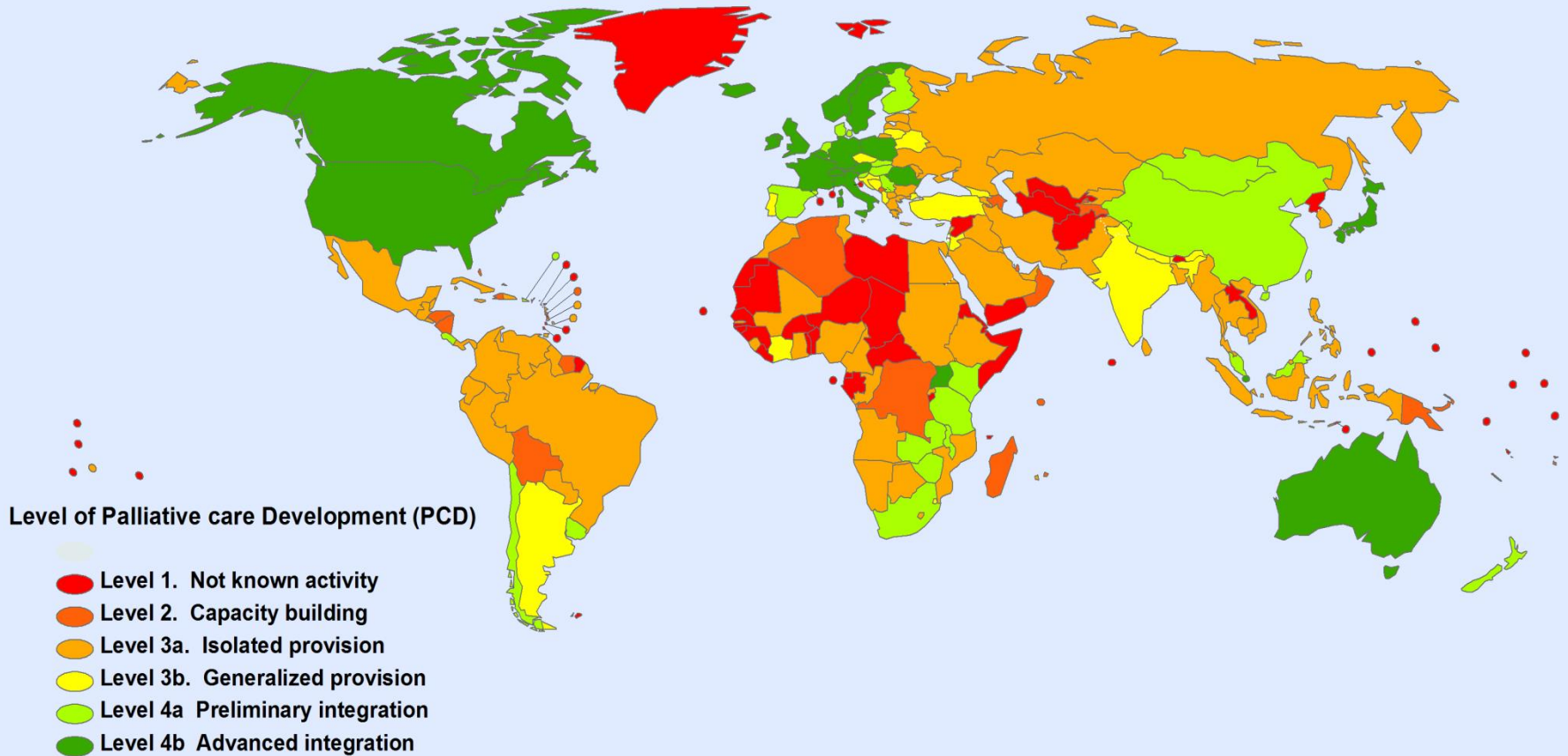
WHO fact sheet and infographic

WHPCA global atlas

WHPCA World Map PC development



WPCA Palliative Care Development All levels (n = 234)



The boundaries and names shown and the designations used on this map do not imply the expression of any opinion whatsoever on the part of the WPCA concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dotted lines on maps represent approximate border lines for which there may not yet be full agreement.

Palliative care needs

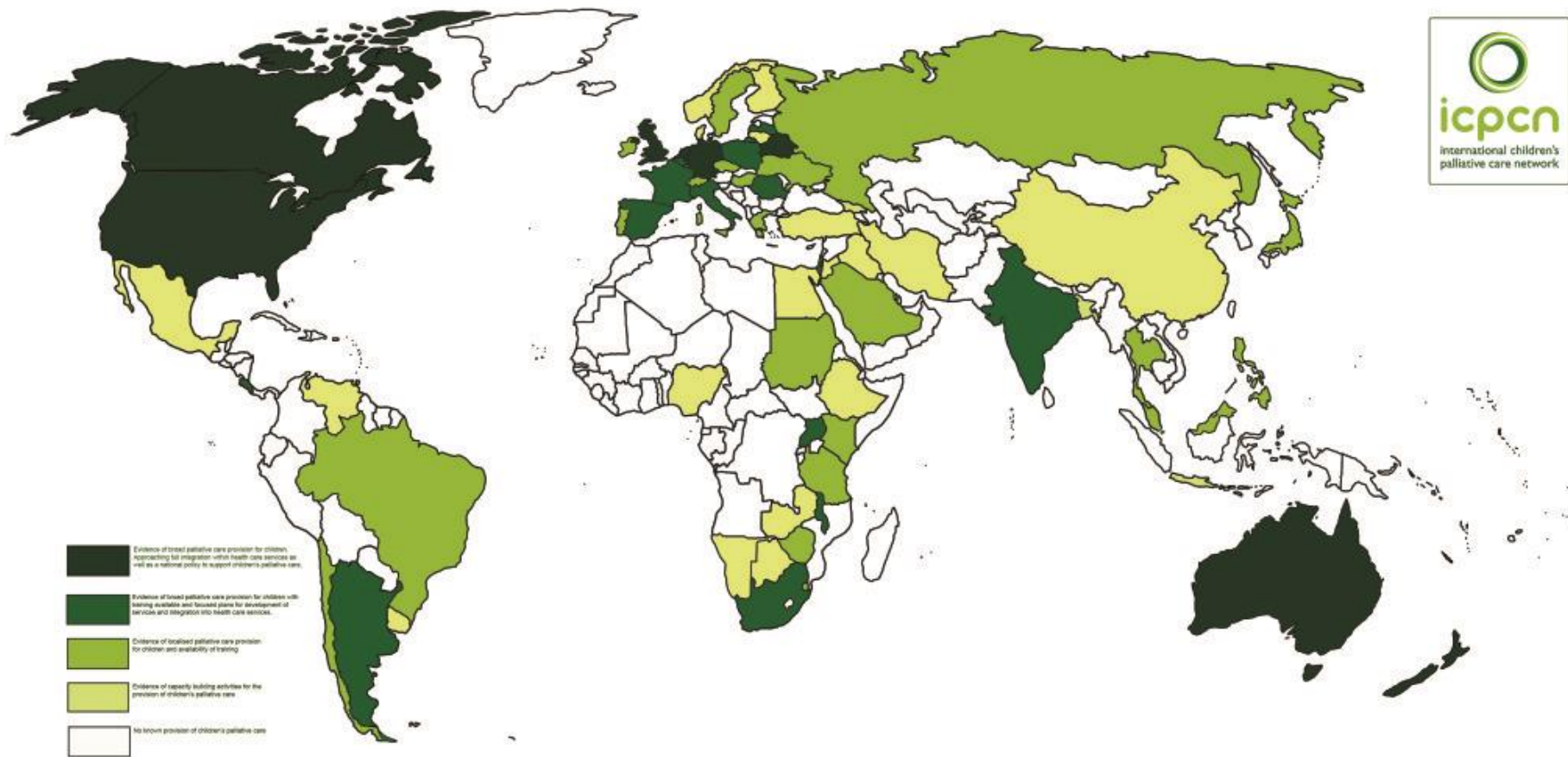
- Hidden people
 - older people and children
 - chronic mental health
 - dual epidemic with HIV
 - prisoners, people with disabilities, sex workers, substance users, conflict areas
 - poverty, geography, language and exclusion



 **HIDDEN LIVES,
HIDDEN PATIENTS**
World hospice & palliative care day
10 October 2015

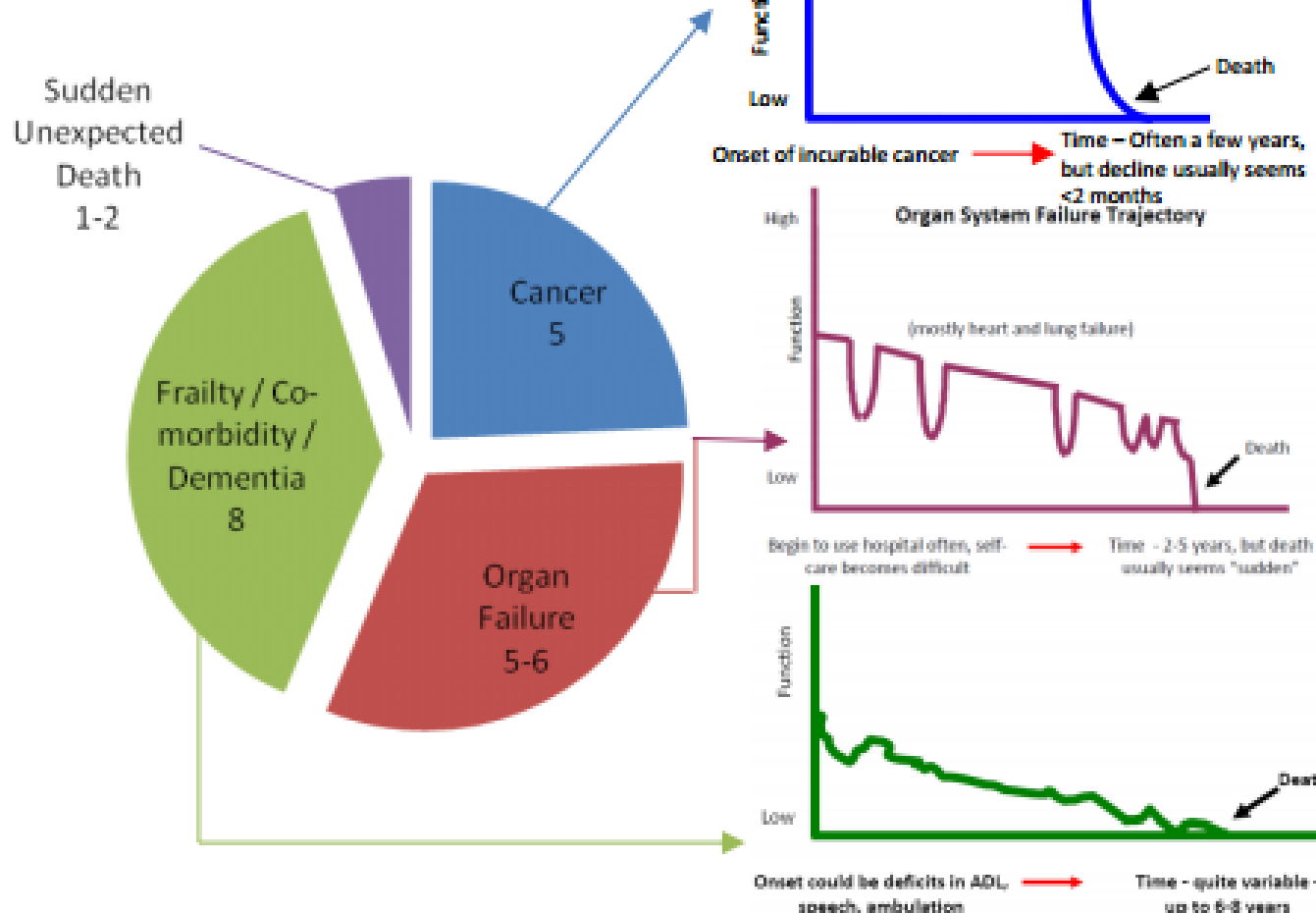
Grant L et al BMJ Supportive & Palliative Care (2011).

Palliative care needs; children



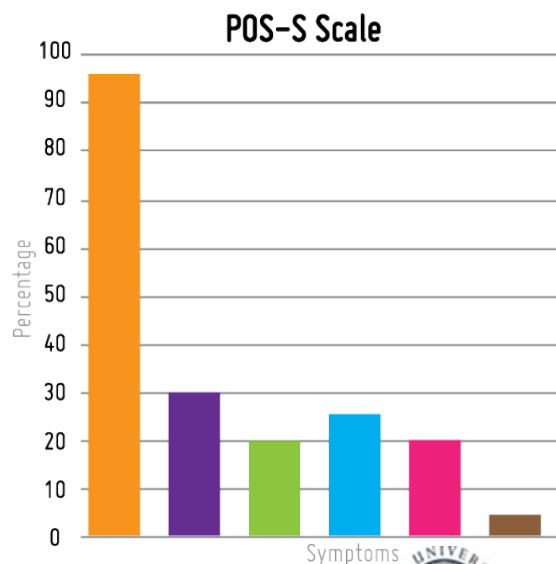
Palliative care needs; UK

Average GP's workload – average 20 deaths/GP/year approx. proportions

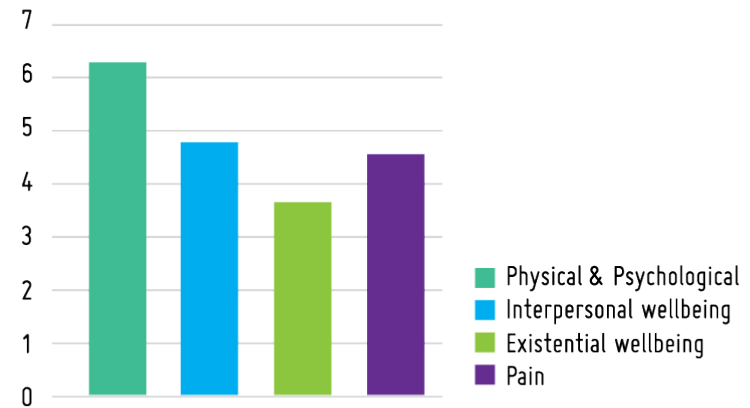


Uganda; palliative care needs

- Point prevalence needs assessment studies Uganda
 - national hospital 40%
 - oncology settings 95%
 - provincial hospitals 25%



APCA Palliative Care Outcome Score

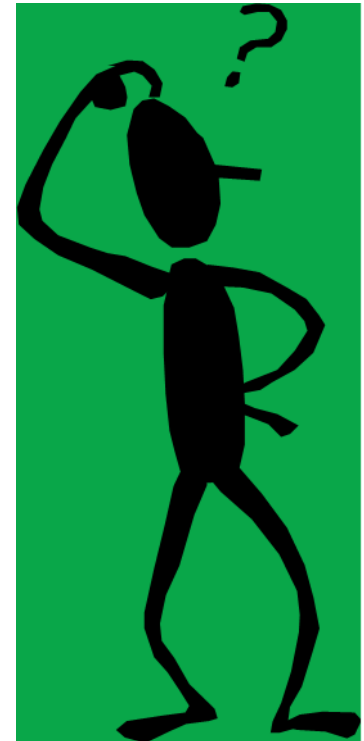


- one or more symptoms
- 1-2 symptoms
- 3-4 symptoms
- 5-6 symptoms
- 7-8 symptoms
- 9 symptoms



Palliative care for all

- **Why?**..global imperative
- **What?**..palliative care needs, holistic care
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Holistic care

physical

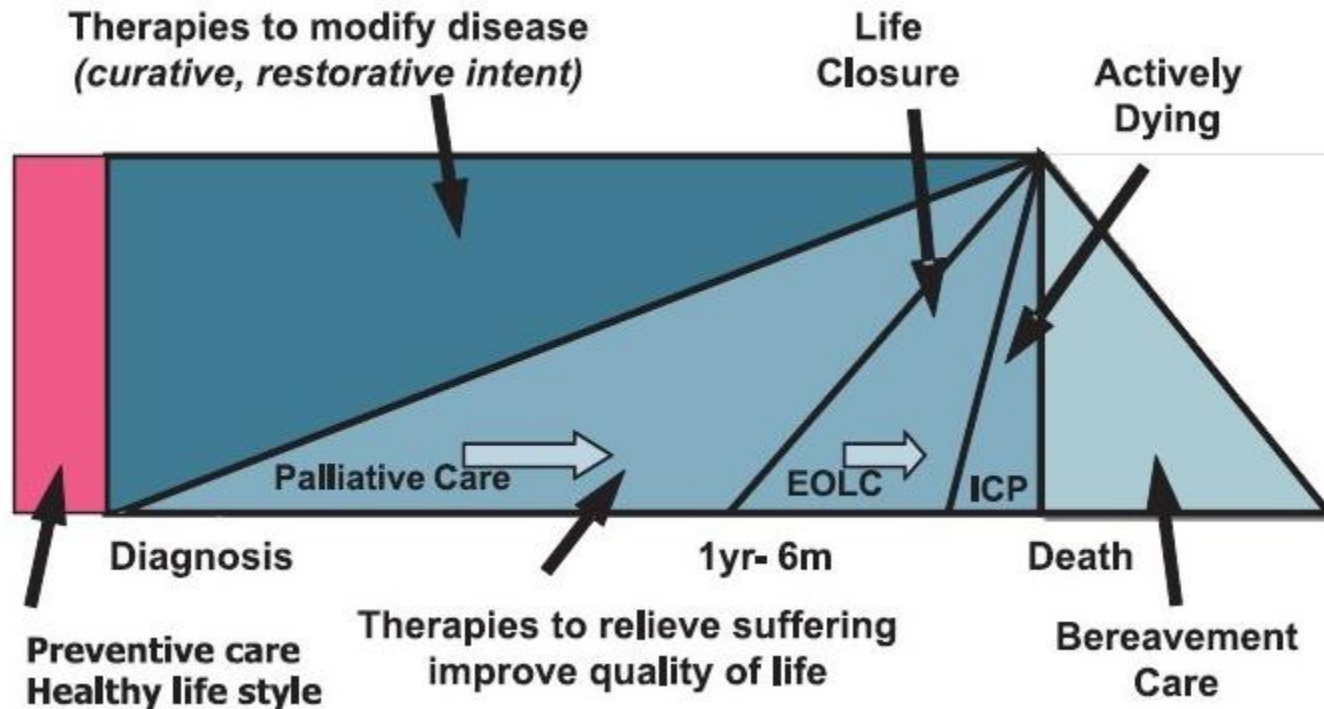
emotional



social

spiritual

Palliative care; chronic disease model



Transforming lives; Swaibu's story

*'when I see you
coming with the team I
feel so much better.
God has answered my
prayers and I know
that he cares for me. I
no longer feel angry
and sad. I can sleep at
night instead of crying.
I now have hope.
Thank you.'*



Transforming lives; Simon's story

"It is like my world is full of pain and suffering I am alone and nobody seems to care. It feels like life had no meaning."

"These guys talk to you, they talked to me, encouraged me, and helped me to get medication. The pain has also become manageable. There was tremendous improvement. I did not feel like the way I was when they first found me,"



Transforming attitudes and practise

- *'The palliative care training has made a huge impact; I now see the patient as a person and not a disease, I don't avoid difficult conversations, I don't order unnecessary investigations, I see them as part of a family, I do holistic care. It was not like that before.'* MMed doctor Makerere.



Transforming attitudes and practice

- *“Before I had the training patients who were dying could be neglected as the staff thought they could do nothing for them. But since the teaching I realised **there is much I can do for these patients...It has changed me. It has changed my attitude.**”*

Downing et al. A palliative care link nurse programme in Mulago Hospital, Uganda: an evaluation using mixed methods BMC Palliative Care (2016)



Transforming practise

- A humanitarian doctor '***it has been a key lacking point.*** Many times there is a patient crying in pain. The approach of integrating palliative care into the medical practices of prevention and cure is the way to go. The more people we train, the more people we will reach in community.'



Transforming systems

- **Integration and empowerment**
 - across levels of health care
 - within systems
 - break down barriers



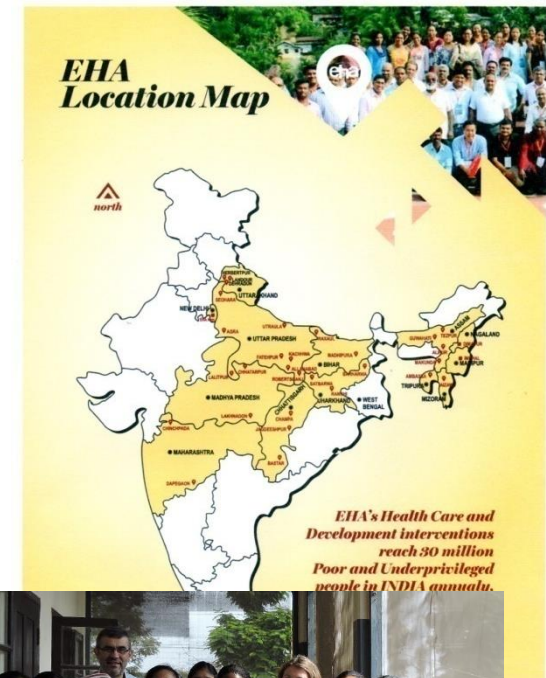
Grant L et al Integrating palliative care into national health systems in Africa: a multi-country intervention study June 2017
Journal of Global Health

Transforming systems

- Emmanuel Hospital Association
- integrate essential clinical services with primary health care
- *‘They look after people whom everyone else has rejected’*

Add AMO Lalitpur

www.eha.org



**Striving to Serve –
Stretching to Love**

Transforming societies

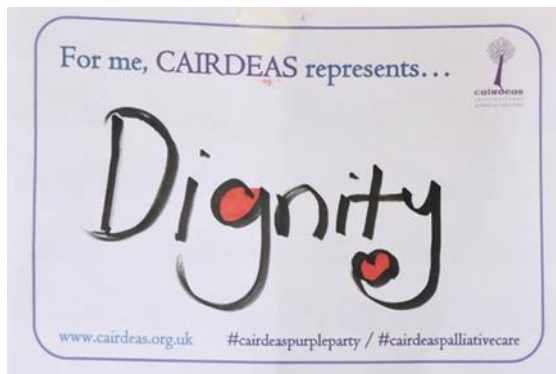
- Innovation and empowerment
- compassionate communities



Kellehear A. 2005 Compassionate Cities. Public Health and end of life care. Routledge Oxford

Transforming fractured societies

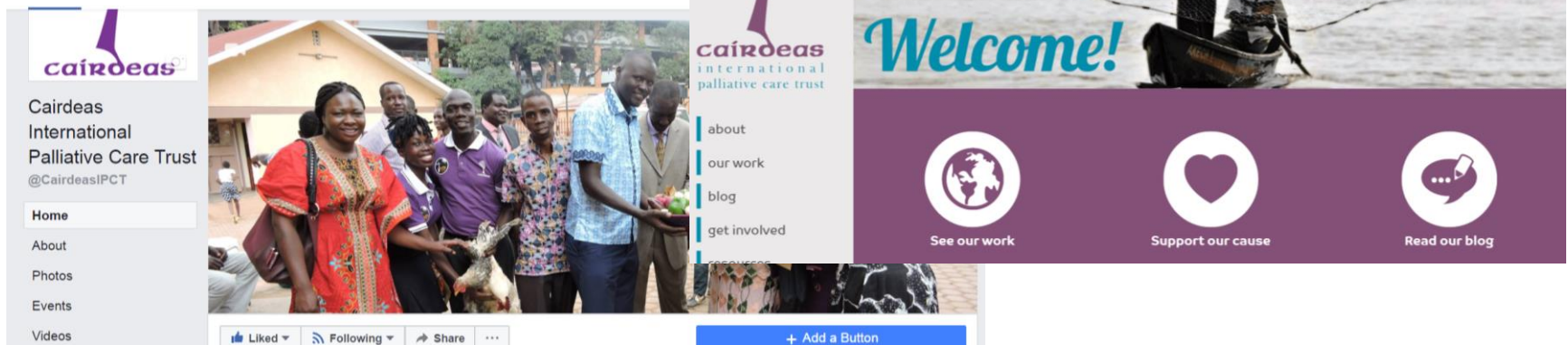
- *‘Our people are in pain; we have no choice but to act.’*
Dr Sobhi Skaik, Gaza





Palliative care: resources

- CairdeasIPCT
- working in partnership to mentor and train the future health care workers and health system leaders.
@CairdeasIPCT, FB
- join Cairdeas faculty
- www.cairdeas.org.uk



Palliative care: resources

- World Hospice and Palliative Care Alliance
 - <http://www.thewhpc.org/>
- International Hospice and Palliative Care Association
 - <http://hospicecare.com/>
- International Children's Palliative Care Network
 - <http://www.icpcn.org/>
 - E-learning



Global Atlas of Palliative Care at the End of Life



January 2014



Palliative care: resources

■ Palliative Care Toolkit and Training Manual

Toolkits

Palliative Care Toolkit - Improving care from the roots up in resource limited settings

The 'Palliative Care Toolkit: Improving care in resource-limited settings' was written to empower health workers in resource-poor settings to integrate palliative care into the work they are doing.

[Spanish](#)

[Portuguese](#)

[Mandarin](#)

[Russian](#)

[Swahili](#)

[French](#)

[Bengali](#)

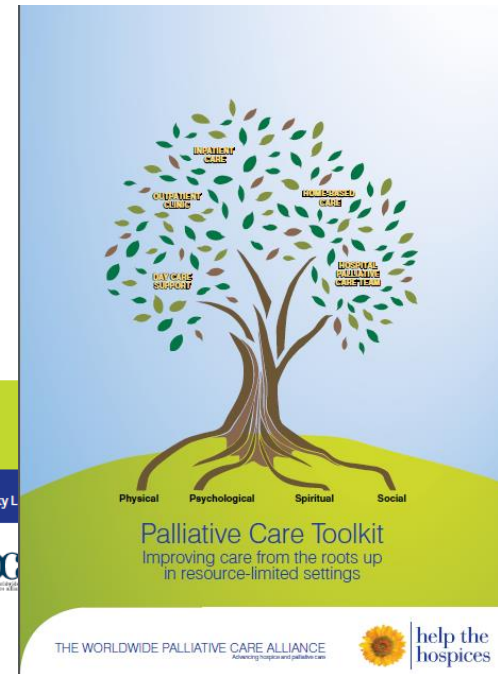
Training Manual for the Palliative Care Toolkit

The Training Manual was produced to accompany the Toolkit. It contains structures teaching modules and resources which can help others use the Toolkit.

[Spanish](#)



Trainer's Manual By Dr Vicky L

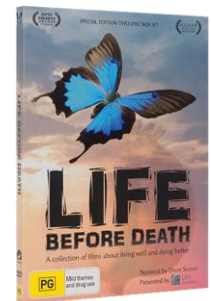


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Palliative care: resources

- PRIME
 - <http://www.prime-international.org/services-palliativecare.htm>
- Global Health Academy
 - <http://www.ed.ac.uk/schools-departments/global-health>
- Palliative Care Formulary
 - www.palliativedrugs.com
- Primary Palliative Care Research Group
 - <http://www.cphs.mvm.ed.ac.uk/groups/ppcrg/>
- Life before Death
 - <http://www.lifebeforedeath.com/movie/short-films.shtml>



Palliative care; a Christian response

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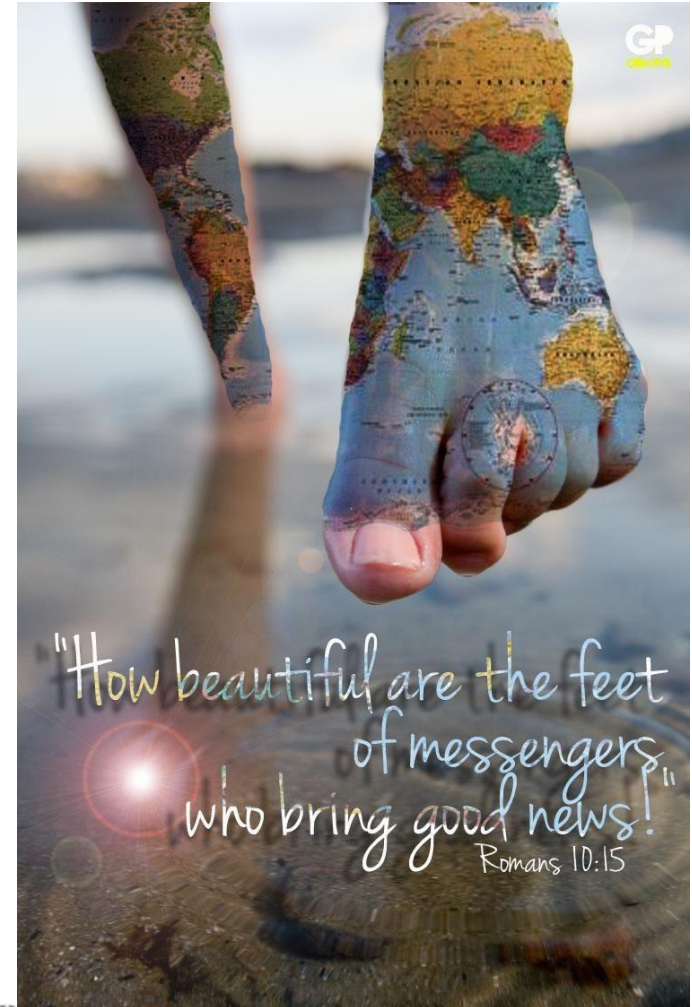
- *..tree of life and the leaves of that tree were for the healing of the nations*

- What can you contribute?



Healing for the nations

- What is our role?
- **Messengers of the good news of Jesus**
 - Fight for justice
 - Care for the broken and the vulnerable
 - Agents of love and hope
 - Be salt and light in our world
 - Peacemakers



- Lewington J, Namukwaya E, Limoges J, Leng M, Harding R. Provision of palliative care for life-limiting disease in a low income country national hospital setting: how much is needed? *BMJ Support Palliat Care*. 2012;2:140–4.
- Grant L, Downing J, Luyirika E, Murphy M, Namukwaya L, Kiyange F, Atieno M, Kemigish-Ssali E, Hunt J, Snell K, Murray SA and Leng M. (2017) Integrating palliative care into national health systems in Africa: a multi-country intervention study. *Journal of Global Health* 7(1).
- Namukwaya E, Murray SA, Downing J, Leng M and Grant L. (2017) 'I think my body has become addicted to those tablets'. Chronic Heart failure patients' understanding of and beliefs about their illness and its treatment: a qualitative longitudinal study from Uganda. *PLOS One*.
- Namukwaya E, Grant L, Downing J, Leng M and Murray SA. (2017) Improving care for people with heart failure in Uganda: serial in-depth interviews with patients' and their health care professionals. *BMC Res Notes* 10:184. DOI 10.1186/s13104-017-2505-0
- Downing J, Batuli M, Kivumbi G, Kabahweza J, Grant L, Murray SA, Namukwaya E, Leng M (2016) Evaluation of a palliative care link nurse programme in Mulago hospital, Uganda: An evaluation using mixed methods. *BMC Palliative Care* 15:40 DOI 10.1186/s12904-016-0115-6
- Downing J, Leng M and Grant L. (2016). Implementing a Palliative Care Nurse Leadership Fellowship Program in Uganda. *Oncology Nursing Forum* 43(3) 395-398. DOI: 10.1188/16.ONF.395-398
- Downing J, Grant L, Leng M and Namukwaya E. (2015) Understanding models of palliative care delivery in sub-Saharan Africa: Learning from programmes in Kenya and Malawi. *Journal of Pain and Symptom Management*. 50(3): 362-370.
- www.cairdeas.org.uk (all results in Resources section)