

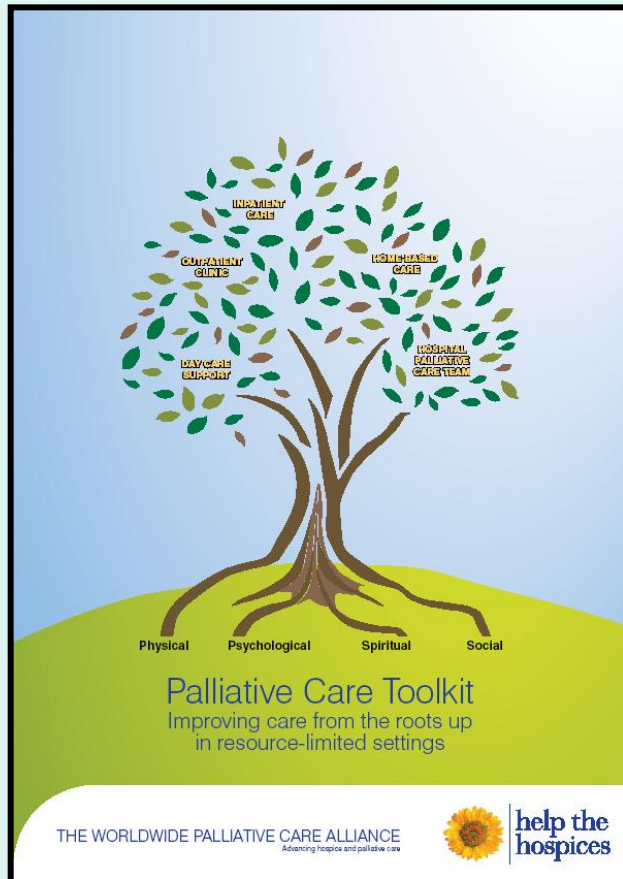
The Palliative Care Toolkit – a manual for all settings

Dr Charlie Bond

Dr Gillian Chowns

Ruth Wooldridge OBE

Developing a Toolkit for all Seasons



Authors:

Dr Charlie Bond

Dr Vicky Lavy

Ruth Wooldridge OBE

Why this toolkit?

- Vast unmet need for palliative care
- Home Based Care often lacks palliative care skills
- Many health workers have no knowledge of palliative care and no access to formal training
- Much can be done even with minimal resources
- There is **always** something you can do



The Global Palliative Care Burden

- 36 Million people have HIV/AIDS
 - 95% live in the developing world.
 - 25 million in sub-Saharan Africa
- By 2020 15 million people will develop cancer every year
 - 60%(10 million) will live in the developing world
 - This will rise to 17 million by 2050
- Most will present late, be incurable and will not have access to adequate medical services
- By 2020, chronic conditions will be responsible for 78% of the global disease burden in developing countries
- **100 million people need palliative care at this moment**

What is the Toolkit?

A manual introducing the principles of palliative care.

It brings together approaches, skills, clinical information and practical tools for implementing palliative care in a grass-roots setting

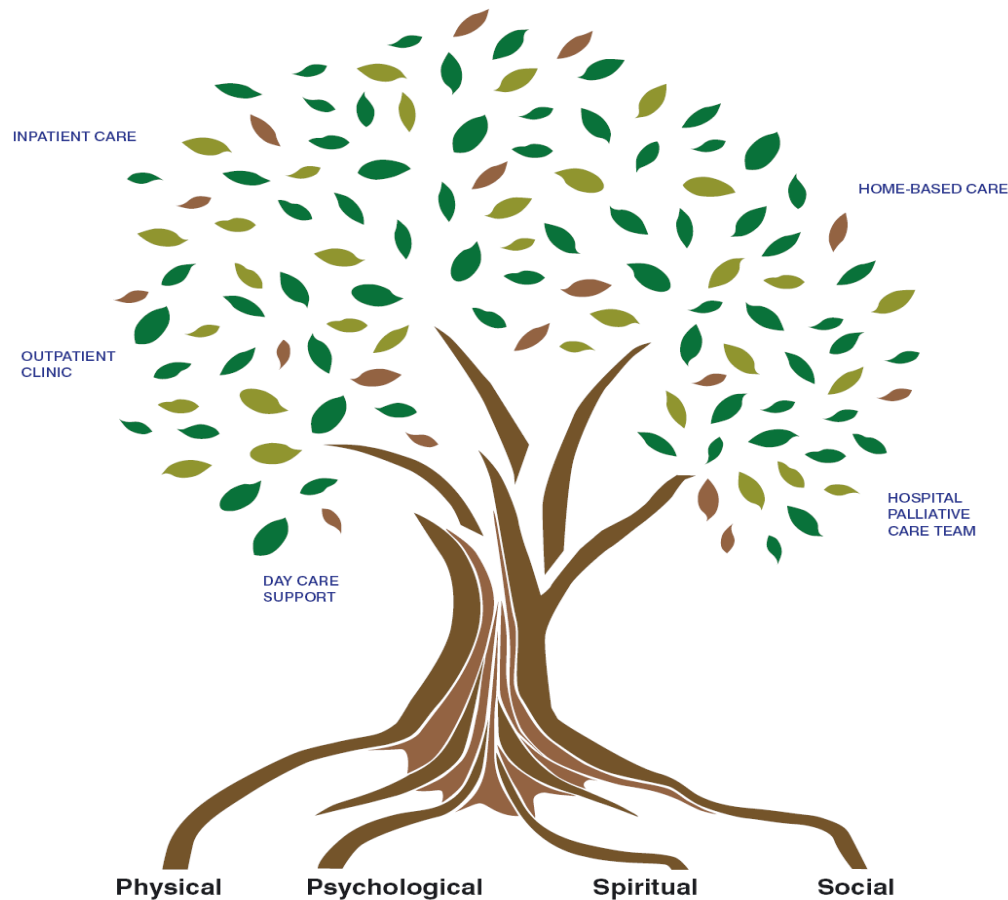
- Presumes little or no knowledge of palliative care and limited resources
- Accessible to health workers and others involved in patient care
- Encourages integration of palliative care into existing community programmes and health services
- Flexible models of care

The family economics of incurable illness



- Money spent on medical treatment
- Long hospital stays
- Frequent funeral attendance
- Chronic ill health
- Food shortage
- Funeral expenses
- Orphans and widows
- **Home based care essential**

Growing a model of care from available resources



Physical	Psychological	Spiritual	Social
<p>PHYSICAL</p> <p>PATIENT CARE Health centre Local hospital Private clinics Traditional healers NGOs doing healthcare Art clinic</p> <p>DRUG SUPPLY Hospital pharmacy Local pharmacy shops</p> <p>ADVICE AND SUPPORT Local doctor/nurse/clinician Local physiotherapist National palliative care association</p>	<p>PSYCHOLOGICAL</p> <p>COUNSELLING Social worker Trained volunteer HIV counsellor Patient advocates – others with the same illness</p> <p>SUPPORT GROUPS PLHIV group Women's group Youth organisations</p> <p>SUPPORT AT HOME HBC volunteers Family members</p>	<p>SPIRITUAL</p> <p>INDIVIDUALS Local religious leaders Volunteers from faith communities Social workers Family members</p> <p>GROUPS Faith community eg church, mosque, temple, synagogue Women's groups Hospital visiting team Children's groups</p>	<p>SOCIAL</p> <p>Non-governmental organisations Faith-based organisations Food supply work Orphans and vulnerable children groups Income generation schemes Small loan schemes</p> <p>INDIVIDUAL PROFESSIONALS Social worker Legal advisor, for making wills</p> <p>INVOLVING OTHERS Community leaders Local schools and colleges Community groups</p>

Aims of the toolkit

- Inspiration
- Holistic approach
- Empowerment of health workers
- Accessible language and style
- To provide basic teaching material
- To provide a user-friendly symptom control guide
- To supply ready-made tools for care delivery and advocacy



Making the toolkit

- Steering group
- Reviewing existing material
- Framework and writing
- On-going feedback
- Targeted consultation
- World Palliative Care Alliance
- African Palliative Care Association





A P C A

2nd APCA Palliative Care Conference

Palliative Care in Africa: Making it Real



Challenges along the way

- Keeping it short but useful
- Bringing a fresh approach
- Writing for a wide audience
- Writing for different health structures and resources
- Different drug availabilities
- Getting feedback



WHO Definition of 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.

What's in the Toolkit?

- What is palliative care?
- You can do palliative care in your setting
- You can build a team
- You can talk about difficult issues
- You can control pain and other symptoms
- You can help children and families
- You can tell others

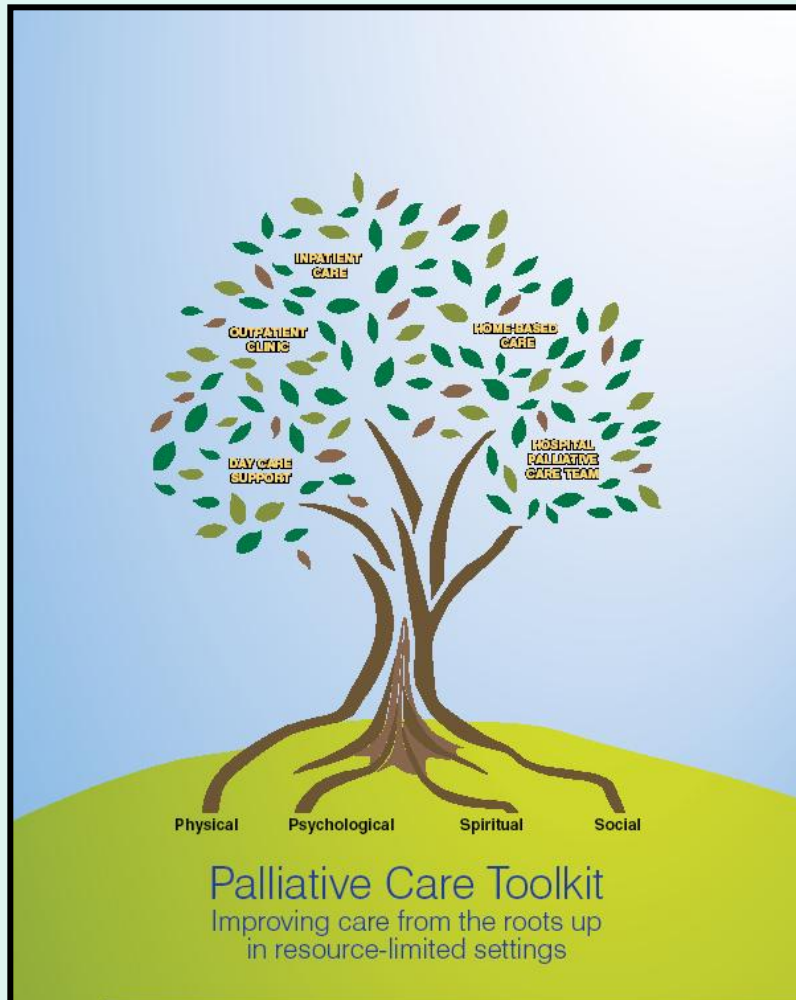
Practical tools to be copied / adapted

What is Palliative Care?

Palliative care is all about looking after people with illnesses that cannot be cured, relieving their suffering and helping them through difficult times



The Holistic Approach



- Physical
- Psychological
- Social
- Spiritual

Palliative care works alongside and within other programmes

- Starts at diagnosis
- ARV programmes
- Cancer treatment
- Community programmes



There is never nothing we can do

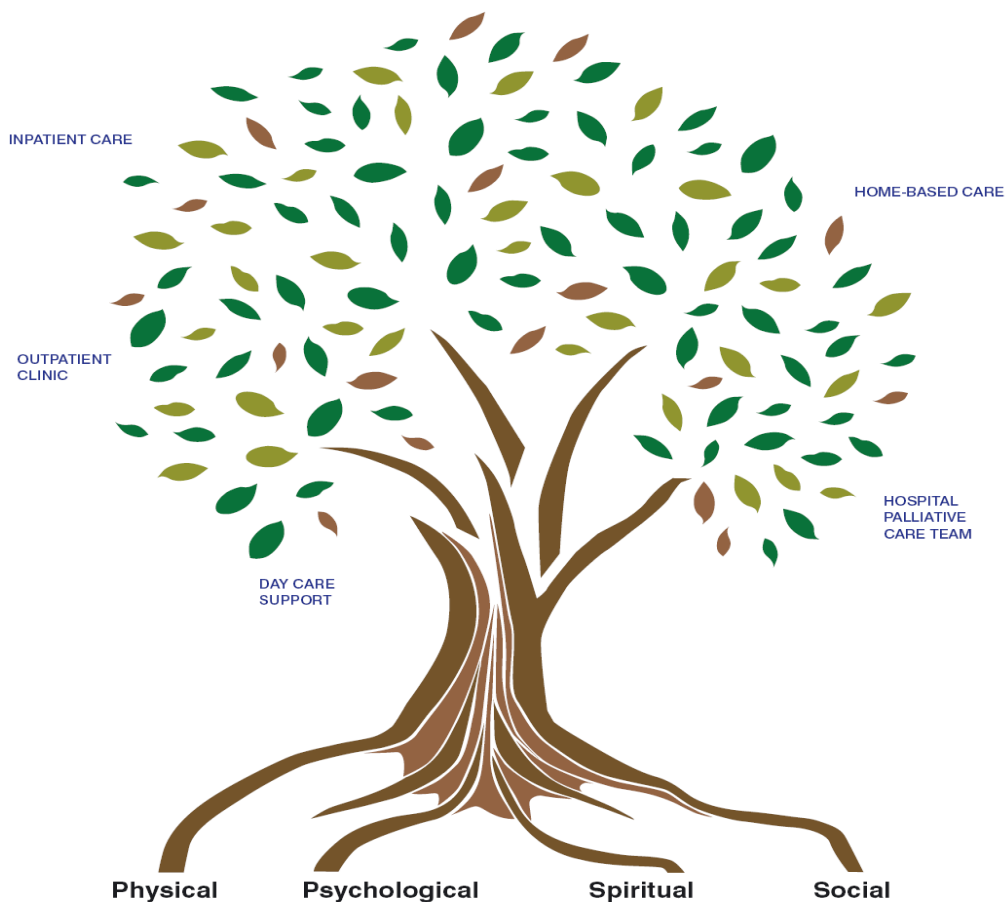


You can do palliative care in your setting





Growing a model of care from available resources



PHYSICAL

PATIENT CARE

Health centre
Local hospital
Private clinics
Traditional healers
NGOs doing healthcare
Art clinic

DRUG SUPPLY

Hospital pharmacy
Local pharmacy shops

ADVICE AND SUPPORT

Local doctor/nurse/clinician
Local physiotherapist
National palliative care association

PSYCHOLOGICAL

COUNSELLING

Social worker
Trained volunteer
HIV counsellor
Patient advocates –
others with the same illness

SUPPORT GROUPS

PLHIV group
Women's group
Youth organisations

SUPPORT AT HOME

HBC volunteers
Family members

SPIRITUAL

INDIVIDUALS

Local religious leaders
Volunteers from faith communities
Social workers
Family members

GROUPS

Faith community eg church,
mosque, temple, synagogue
Women's groups
Hospital visiting team
Children's groups

SOCIAL

Non-governmental organisations
Faith-based organisations
Food supply work
Orphans and vulnerable children groups
Income generation schemes
Small loan schemes

INDIVIDUAL PROFESSIONALS

Social worker
Legal advisor, for making wills

INVOLVING OTHERS

Community leaders
Local schools and colleges
Community groups

Making the most of local resources

- Government health service
- NGOs
- Traditional healers
- Local pharmacies
- Spiritual leaders
- Faith communities
- Counsellors
- Volunteers
- Support groups
- Income generation schemes
- Orphan programmes
- Youth organisations

When you want to eat an elephant, you need to decide where to start and then eat a little bit at a time



You can build a team

If you want to travel quickly, go alone.

But if you want to travel far, you must go together.



You can talk about difficult issues

Be quick to listen and slow to speak



“Truth is one of the most powerful medicines available to us, but we still need to develop a proper understanding of the right timing and dosage for each patient.”

You can control pain and other symptoms

....a head-to toe guide

- **Treat** what is treatable
- **Care** for the patient
- **Prescribe** palliative drugs



Pain assessment tool

Choose the pain score that is most helpful for your patient:

Five-finger score

Ask the patient to show how bad the pain is with their hand



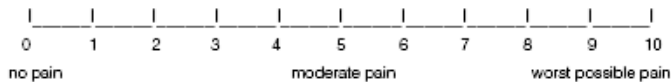
Faces score

Ask the patient to point to the face which shows how bad their pain is



Number score

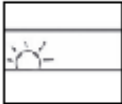
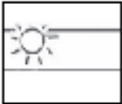
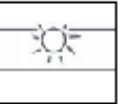


Ask the patient to show where their pain comes on the scale of 1 – 10



Seven important questions to ask the patient

- **Where** is the pain? (there may be more than one pain)
- **When** did it start?
- **What** does it feel like? (eg stabbing, cramping, burning, etc)
- **Timing** - Is the pain there all the time or does it come and go?
- **Treatment** - Has any treatment been tried and has it helped?
- **Changing** - What makes it better or worse (eg movement, eating, time of day, etc)?
- **Causing** - What do you (the patient) think is causing the pain?

Patient-held drug chart

PATIENT NAME	DATE CHART GIVEN				
Number of tablets or ml of liquid to take at each time of day					
NAME AND PURPOSE OF DRUG	Early morning (6am) 	Mid morning (10am) 	Afternoon (2pm) 	Evening (6pm) 	Bedtime (10pm) 

- Keep all medicines out of reach of children
- Do not give your medicine to anyone else
- Do not stop taking your medicine without consulting the health worker

You can help children and families

My neighbour's child is my child too



- Children are not small adults, they have their own needs
- Children are people, they have opinions and choices



- Children usually know much more than we realise and are more capable than we think

You can tell others



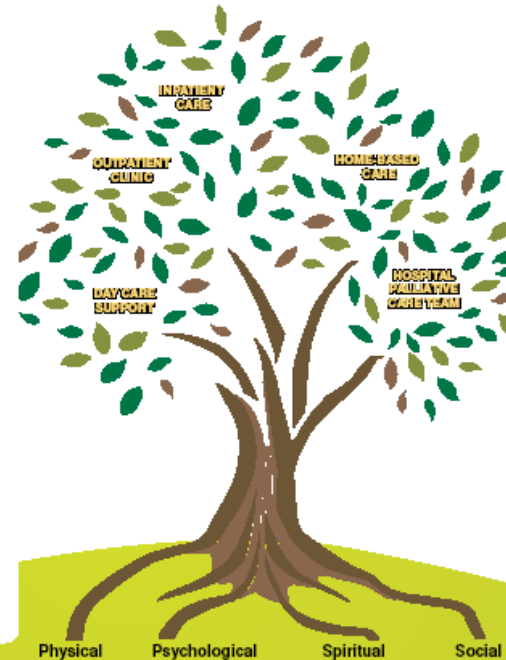
Palliative care

...is care for people with illnesses that cannot be cured.

Improving quality of life for those with advanced disease

...by helping with:

- Pain and other physical symptoms
- Psychological and spiritual distress
- Social problems.



There is no need for people to live with pain

Palliative care can help people with a variety of illnesses and can be practised in different settings: in hospital, clinics and at home

Adding life to days, not just days to life

controlling pain

sharing problems

relieving suffering

giving support

“Start doing what’s necessary, then do what’s possible, and suddenly you are doing the impossible”

Physical Psychological Spiritual Social

INPATIENT CARE
OUTPATIENT CLINIC
DAY CARE SUPPORT
HOME-BASED CARE
HOSPITAL PALLIATIVE CARE TEAM

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

THE WORLDWIDE PALLIATIVE CARE ALLIANCE
Advancing hospice and palliative care



help the hospices

IS YOUR JOURNEY
REALLY
NECESSARY?

MANUAL



RAILWAY EXECUTIVE COMMITTEE

Teaching and Training

- Art or science?
- Caught or taught?
- Can the printed word inspire?

- Pros and Cons of a Trainer's Manual

Using the Toolkit

It's hard work – but someone has to do it..



Experience

- Pilot workshop – Tanga (Tz) 2008
- India 2009
- Sierra Leone 2009
- Kenya 2010
- Tanzania 2009, 2010, 2011
- Others?

Evidence – words and numbers

- *‘Referrals and use of morphine have gone up’ (K)*
- *‘Hospital has experienced a fourfold increase in patient referrals’ (SL)*
- *‘A positive change in outlook towards their patients and an improvement in their communication skills’ (I)*
- *‘One participant has helped start a palliative unit in another public hospital and is looking to do a diploma course’ (K)*

Evidence – words and numbers

- *‘Increased interest from medical officers - four physicians in public and private health services have contacted the Hospice to be part of the pain task force’ (SL)*
- *‘Mwanakombo (volunteer with Korogwe pc team) has 5 pc patients herself and many others she sees for HIV ARV adherence. The toolkit has been very useful and she says she refers to it daily’ (Tz)*
- Approach highly rated – role plays, sketches, groupwork
- Content highly rated - Morphine, communication, pain assessment, children (paediatric and families)

Could do better....

- Selection of participants
- Language – students' level of English
- Mobile phones
- Punctuality
- Follow-up - 3 months on

Could do better....

- Too short
- More on.....
- Spirituality
- Ethics – largely absent
- The power of the printed word



A Manual for all settings



UK Palliative Care

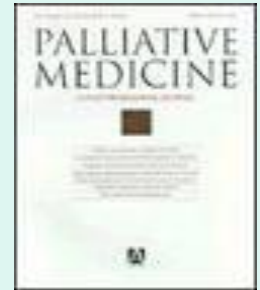
Total Pain



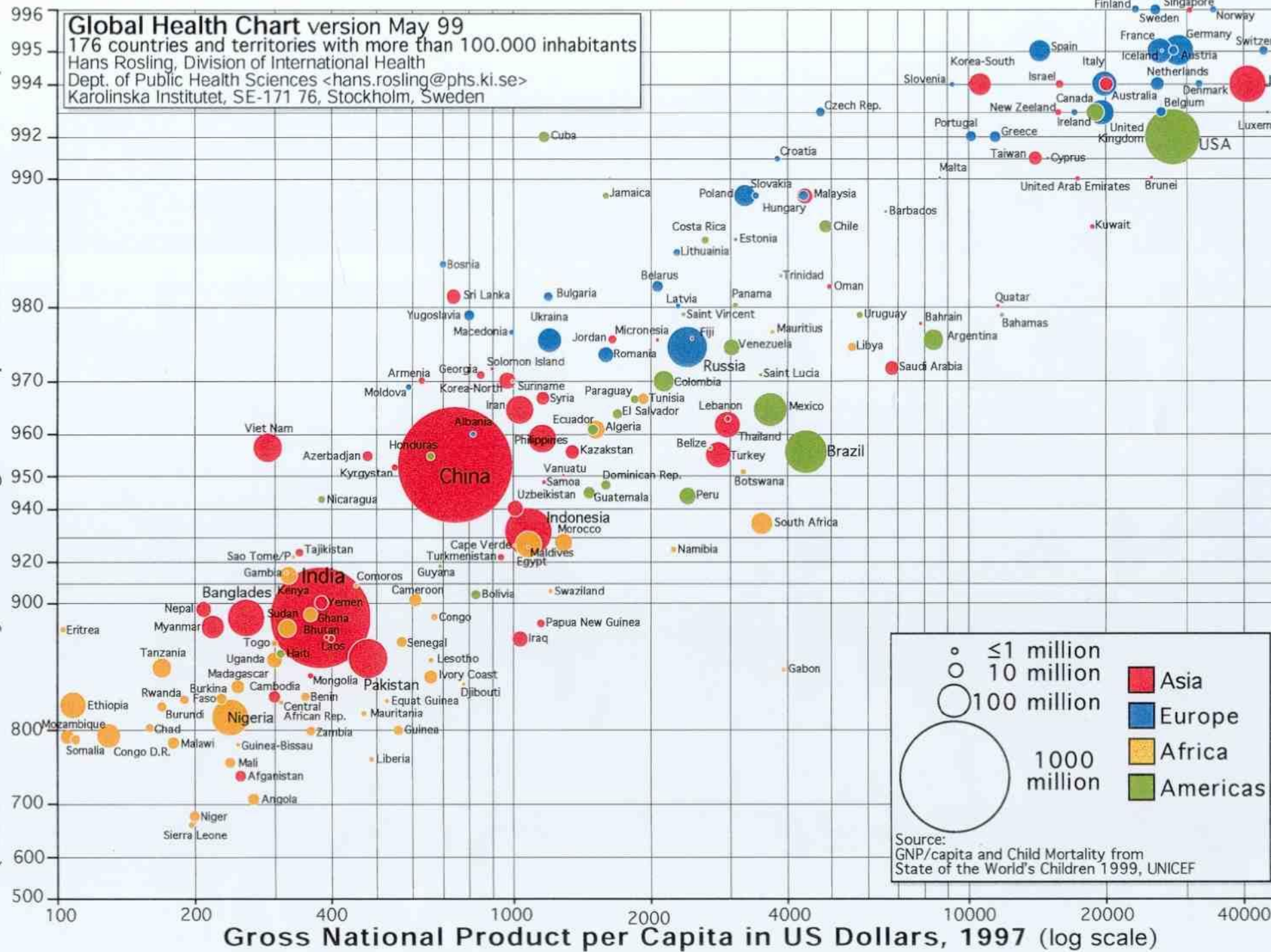
Holistic approach



Hospital teams	Academic units Research
Inpatient palliative care	A photograph of a modern, multi-story building with a large courtyard area, possibly a hospital or care facility.
Day centres	
Community teams	



Global Health Chart version May 99
 176 countries and territories with more than 100,000 inhabitants
 Hans Rosling, Division of International Health
 Dept. of Public Health Sciences <hans.rosling@phs.ki.se>
 Karolinska Institutet, SE-171 76, Stockholm, Sweden



○ ≤ 1 million
 ○ 10 million
 ○ 100 million
 ○ 1000 million

■ Asia
■ Europe
■ Africa
■ Americas

Source:
 GNP/capita and Child Mortality from
 State of the World's Children 1999, UNICEF

UK Palliative Care

- Does palliative care have something to offer resource-limited settings?
- How does the UK model translate to:
 - Different cultural contexts?
 - Resource-limited settings?
- When introducing palliative care to these settings:
 - What is appropriate/helpful?
 - What is inappropriate/unhelpful?

Models of Care



Preferred vs actual place of death

PRISMA Survey of preferences

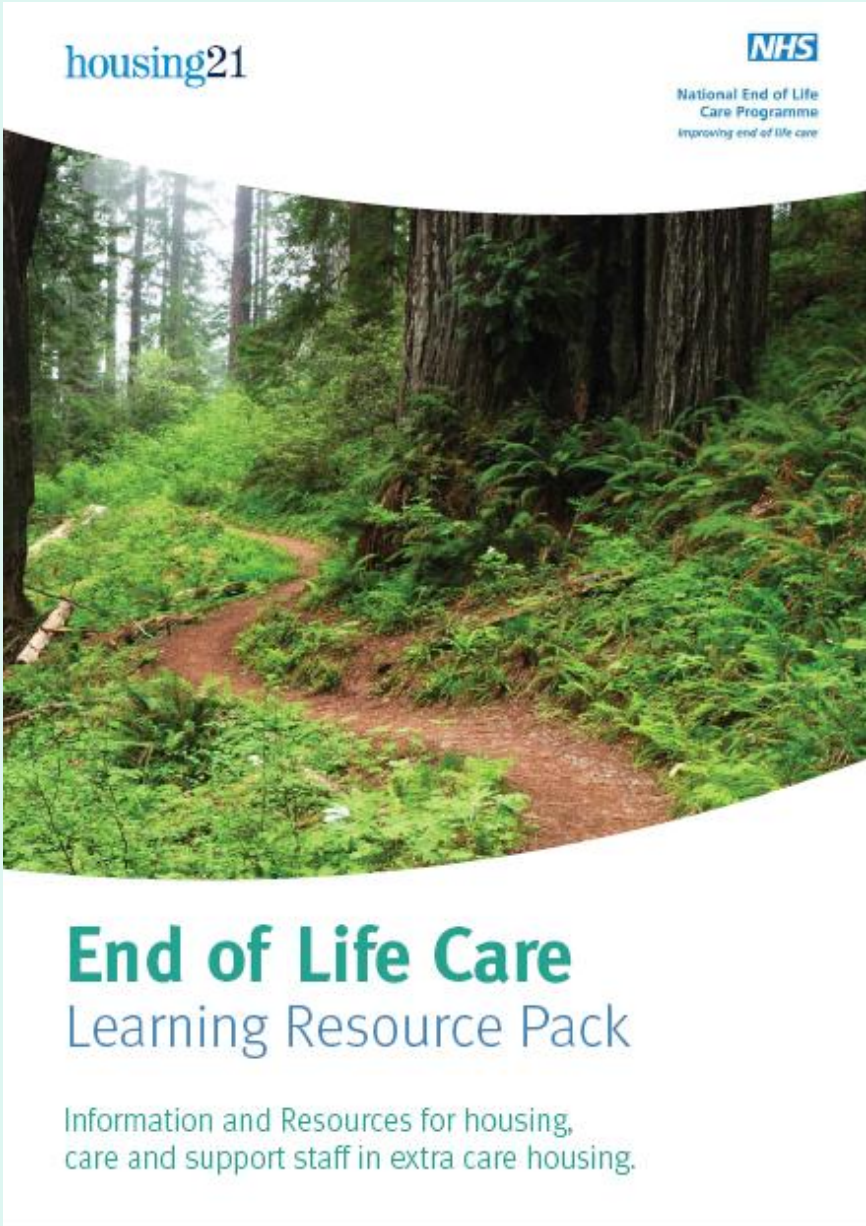
Preferred place of death	45-64 years (actual)%	65-74 years (actual)%	75+ years (actual)%
Home	63 (32)	56 (28)	45 (17)
Hospice	32 (11)	37 (9)	41 (3)
Hospital	1 (50)	4 (54)	6 (54)
Care home	1 (3)	2 (7)	5 (25)

Causes of death England 2007-9

Cancer	Cardiovascular	Respiratory	Other
28 %	30.1 %	13.9 %	28 %

Is there a place for a UK version of the Toolkit?

- ? Residential Homes
- ? Nursing Homes
- ? Community Hospitals



housing21

NHS
National End of Life
Care Programme
Improving end of life care

End of Life Care

Learning Resource Pack

Information and Resources for housing, care and support staff in extra care housing.

Summary

- Designed for resource-poor settings but.....
- Flexible, practice-based, adaptable
- Highly accessible and interactive
- Key issues addressed
- So – make it work for you!
- **PS We don't get any royalties!**

- Palliative Care toolkit
- Trainer's Manual
- Charlie Bond
- Gillian Chowns gpatgc@aol.com
- Ruth Wooldridge
- Palliative Care Works www.palliativecareworks.org