Developing a Toolkit for all Seasons

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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
PATIENT CARE
- Health centre
- Local hospital
- Private clinics
- Traditional healers
- NGOs doing healthcare
- Art clinics

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
- PCU 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 advice for making wills

INVOLVING OTHERS
- Community leaders
- Local schools and colleges
- Community groups
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
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
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
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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
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SOCIAL
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- 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

- No hurt
- Hurts little bit
- Hurts little more
- Hurts even more
- Hurts whole lot
- Hurts worse

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

- Happy face
- Neutral face
- Slightly sad face
- Very sad face
- Crying face

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

- No pain
- Moderate pain
- Worst possible pain

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? (e.g. 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 (e.g. movement, eating, time of day, etc.)?
- Cause - What do you (the patient) think is causing the pain?
### Patient-held drug chart

<table>
<thead>
<tr>
<th>PATIENT NAME</th>
<th>DATE CHART GIVEN</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number of tablets or ml of liquid to take at each time of day</td>
</tr>
<tr>
<td>NAME AND PURPOSE OF DRUG</td>
<td>Early morning (6am)</td>
</tr>
<tr>
<td></td>
<td>![Sun]</td>
</tr>
</tbody>
</table>

- 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, their 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”
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

[Diagram with the following categories:
- Hospital teams
- Inpatient palliative care
- Day centres
- Community teams
- Academic units Research
- Total Pain
- Holistic approach
- Volunteers]

[Images: Macmillan Cancer Relief, Palliative Drugs, Palliative Medicine]
Global Health Chart version May 99
176 countries and territories with more than 100,000 inhabitants
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Gross National Product per Capita in US Dollars, 1997 (log scale)

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

- Islands of excellence
- Care within present health structures
- Community home based care
# Preferred vs actual place of death

**PRISMA Survey of preferences**

<table>
<thead>
<tr>
<th>Preferred place of death</th>
<th>45-64 years (actual)%</th>
<th>65-74 years (actual)%</th>
<th>75+ years (actual)%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home</td>
<td>63 (32)</td>
<td>56 (28)</td>
<td>45 (17)</td>
</tr>
<tr>
<td>Hospice</td>
<td>32 (11)</td>
<td>37 (9)</td>
<td>41 (3)</td>
</tr>
<tr>
<td>Hospital</td>
<td>1 (50)</td>
<td>4 (54)</td>
<td>6 (54)</td>
</tr>
<tr>
<td>Care home</td>
<td>1 (3)</td>
<td>2 (7)</td>
<td>5 (25)</td>
</tr>
</tbody>
</table>
Causes of death England 2007-9

<table>
<thead>
<tr>
<th>Cancer</th>
<th>Cardiovascular</th>
<th>Respiratory</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>28 %</td>
<td>30.1 %</td>
<td>13.9 %</td>
<td>28 %</td>
</tr>
</tbody>
</table>
Is there a place for a UK version of the Toolkit?

• Residential Homes
• Nursing Homes
• Community Hospitals
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