

# I WAS SICK AND YOU CARED FOR ME

A church-based  
response to palliative  
care in Tanzania



## Foreword

The Palliative Care Initiative of The Diana, Princess of Wales Memorial Fund, is delighted to be supporting Tearfund's work to introduce palliative care into the hospitals and communities in Tanzania's lake zone. Since 2001, the Initiative has been working in seven sub-Saharan African countries to ensure that palliative care is accepted as an integrated and essential part of care and treatment for people with HIV, cancer and other life-limiting illnesses.



Palliative care services have been pioneered by independent charitable organisations, which continue to provide excellent services. But the demand is overwhelming. Many hundreds of thousands of people will only get access to palliative care if it is an integrated part of the health system of all countries.

In Tanzania, as in many other sub-Saharan countries, the churches are an important part of the health system. Local congregations have been central to the community response to HIV. They provide many of the volunteer home-based care workers who help ensure that individuals and their families get the best possible palliative care. Churches can help address HIV related stigma, changing attitudes and demonstrating what can be done to support people with life-limiting illnesses.

International NGOs like Tearfund are vital to this response, working through their local partners to integrate palliative care into their health-based work. Through their wider connections, they also have the opportunity to influence government policy.

Over 80% of Tanzanians live in rural areas. Tearfund's programme of creating effective multi-disciplinary palliative care teams and ensuring the provision of home-based palliative care with clinical oversight, is an excellent model of how palliative care can be made available to more people in remote rural areas. It also demonstrates how international NGOs can effectively integrate palliative care into their health policies.

I hope this case study will encourage other faith-based organisations and international NGOs to look at the benefits palliative care can bring to the people with whom they work.

Olivia Dix  
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The Diana, Princess of Wales Memorial Fund

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**Tearfund** is a Christian relief and development agency building a global network of local churches to help eradicate poverty.

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### Acronyms

<b>AICT</b>	African Inland Church of Tanzania	<b>HBC</b>	Home-based care
<b>AIDS</b>	Acquired immunodeficiency syndrome	<b>HIV</b>	Human immunodeficiency virus
<b>APCA</b>	African Palliative Care Association	<b>NGO</b>	Non governmental organisation
<b>ART</b>	Antiretroviral therapy	<b>OVC</b>	Orphans and vulnerable children
<b>ARV</b>	Antiretroviral drugs	<b>PC</b>	Palliative care
<b>BMC</b>	Bugando Medical Centre	<b>TFDA</b>	Tanzania Food and Drug Authority
<b>DMO</b>	District Medical Officer	<b>WHO</b>	World Health Organisation

Tearfund is a leading relief and development charity working in partnership with Christian agencies and churches worldwide to tackle the cause and effects of poverty.

The Diana, Princess of Wales Memorial Fund continues the Princess' humanitarian work in the UK and overseas. By giving grants to organisations, championing charitable causes, advocacy, campaigning and awareness raising, the Fund works to secure improvements in the lives of the most disadvantaged people in the UK and overseas.

## Introduction

Since 2009 Tearfund has been supporting church-based partners to implement palliative care as part of a two-year pilot initiative in Tanzania's lake zone. Palliative care aims to address the multiple challenges faced by people with life-limiting illnesses, providing pain and symptom management, and emphasising quality of life for people and their families.

This case study identifies the approaches used, describes the main successes and challenges of a church-based model and draws some conclusions as to ways forward. It will be of interest to those seeking to engage in palliative care in other contexts, particularly working through a church or community-based response as demonstrated in this pilot.

The Diana, Princess of Wales Memorial Fund (the Fund) is the main donor of the pilot through its Palliative Care Initiative. Tanzania is one of seven focus countries where the Fund works to ensure that palliative care is available to those with HIV, cancer and other life-limiting illnesses.

The ethos of palliative care is one that never says 'there is nothing we can do'.

World Health Organisation's definition of palliative care



Marcus Perkins / Tearfund

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness. It does so 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. Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten nor postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient's illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

## Tearfund's response to overwhelming needs

The availability of antiretroviral drugs (ARVs) in sub-Saharan Africa has provided immense hope for people living with HIV. However, universal coverage has still not been reached, and those who take ARVs often face complications and problems in following their treatment. HIV remains an incurable and progressive illness. Life expectancy has increased for those with HIV, but many people still experience considerable pain from HIV-related illnesses and cancers. Access to pain relief medication is a significant challenge in sub-Saharan Africa, with many pharmacists having little more than paracetamol to offer.

**'Illness and death are facts of life, but suffering need not be.'**

*Easing the Pain; Open Society Foundations Report, 2010*

Palliative care has been neglected for many years in sub-Saharan African countries. Tearfund is committed to ensuring access to quality care for people affected by and living with HIV. Palliative care is part of our church-based HIV response to ensure that people experience holistic care from the point of diagnosis to the end of life. We believe the church is well placed to provide a holistic response to suffering, addressing spiritual, social, psychological and physical care needs, and to work towards providing greater care and dignity for people with life-limiting illnesses.

**Tearfund believes the church is well placed to provide greater care and dignity for people with life-limiting illnesses.**

### Pain relief

Improving access to morphine (an opium-based pain relief drug) is a significant challenge in the provision of palliative care services. Morphine is defined as an essential drug by the World Health Organisation (WHO) because of its value in relieving pain. It costs very little, but few hospitals in Africa have supplies. This is partly due to fear, as clients and medical staff are concerned about its use and addictive potential, and partly due to inadequate management of supplies, leading to a lack of stock in many pharmacies. Health professionals, clients and their families all need opportunities to discuss the use and implications of using morphine to relieve pain. While controls are important to prevent abuse, they can present considerable difficulties for health staff trying to obtain regular supplies.

### Care and support for people living with HIV and cancer

Universal Access commitments, included in the Millennium Development Goals and other international agreements, outline the response of the international community to HIV prevention, treatment, care and support. However, care and support have become the 'forgotten pillar' of the HIV response despite the fact that in reality they underpin every other component of HIV services.<sup>1</sup> Without the immeasurable contribution of those who provide care, the gains made in all other areas of response would not be possible.

Due to the wider availability of ART access, the majority of home-based care and support is focused on ensuring clients follow their ART treatment correctly.

Another major concern is the rapidly growing number of projected cancer cases in sub-Saharan Africa. In 2008 there were 12.7 million new cases of cancer per year world-wide. Statistics from the World Health Organisation's global cancer report stated that 56% of these occurred in sub-Saharan Africa, where

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<sup>1</sup> UK Consortium for AIDS and International Development (2011). Edited Albone R et al. *Care and Support: The Forgotten Pillar of the HIV Response*

Palliative care volunteer caregivers who work tirelessly with AICT Geita Diocese and Geita District Hospital to provide palliative care in the pilot sites



two-thirds of patients will die within a year of diagnosis. Many cancer patients experience moderate to severe pain. Communities and the church need support to respond appropriately.

## The responsibility of the church

Tearfund realises the potential of church-based partners to integrate palliative care within the array of services they provide to people, in particular those living with HIV and AIDS. The holistic nature of palliative care, and the accompanying journey alongside people who are suffering, captures both the responsibility and the strength of the church.

Through scaling up services, and delivering education, training, advocacy, research and evaluation, Tearfund is seeking to ensure that palliative care becomes:

- a key component of the church's response to HIV and life-limiting illness
- fully integrated into national health policies, systems, and district budgets
- incorporated into the strategic plans of stakeholders working with HIV, AIDS and cancer in sub-Saharan Africa
- a high-quality programmatic response which improves quality of life for palliative care clients.

## Choice of pilot site

Tearfund's motivation to pilot palliative care in Tanzania (a country identified as a key focus for the Tearfund HIV team) was based on the presence of strong and committed partners already engaged in home-based care activities and who presented a demonstrable need for palliative care services among beneficiaries.

# The lake zone pilot process

## 1 Selection of sites

Tearfund's lead partner in the palliative care pilot, the Christian Council of Tanzania (CCT) selected the lake zone region of Mwanza for the pilot project. There were several reasons for their choice: the region had a high prevalence of HIV, low access to health services and a lack of adequate services. The region had both church and mission hospitals, and there were several Tearfund partners who were keen to become involved in palliative care. Though the region was underserved, the presence of Bugando Hospital, a large regional hospital, provided potential to build on existing links.

## 2 Scoping visit

In February 2009, Tearfund carried out an assessment of partners in the lake zone of north-west Tanzania to determine their capacity for integrating palliative care into their programmes. The needs assessment confirmed the need for comprehensive palliative care to be included within existing home-based care (HBC) programmes. The nature of the linkages between church, hospital and government varied in each site, thus enabling the pilot to explore the different experiences.

Three different sites were selected for the pilot within the lake zone. These were:

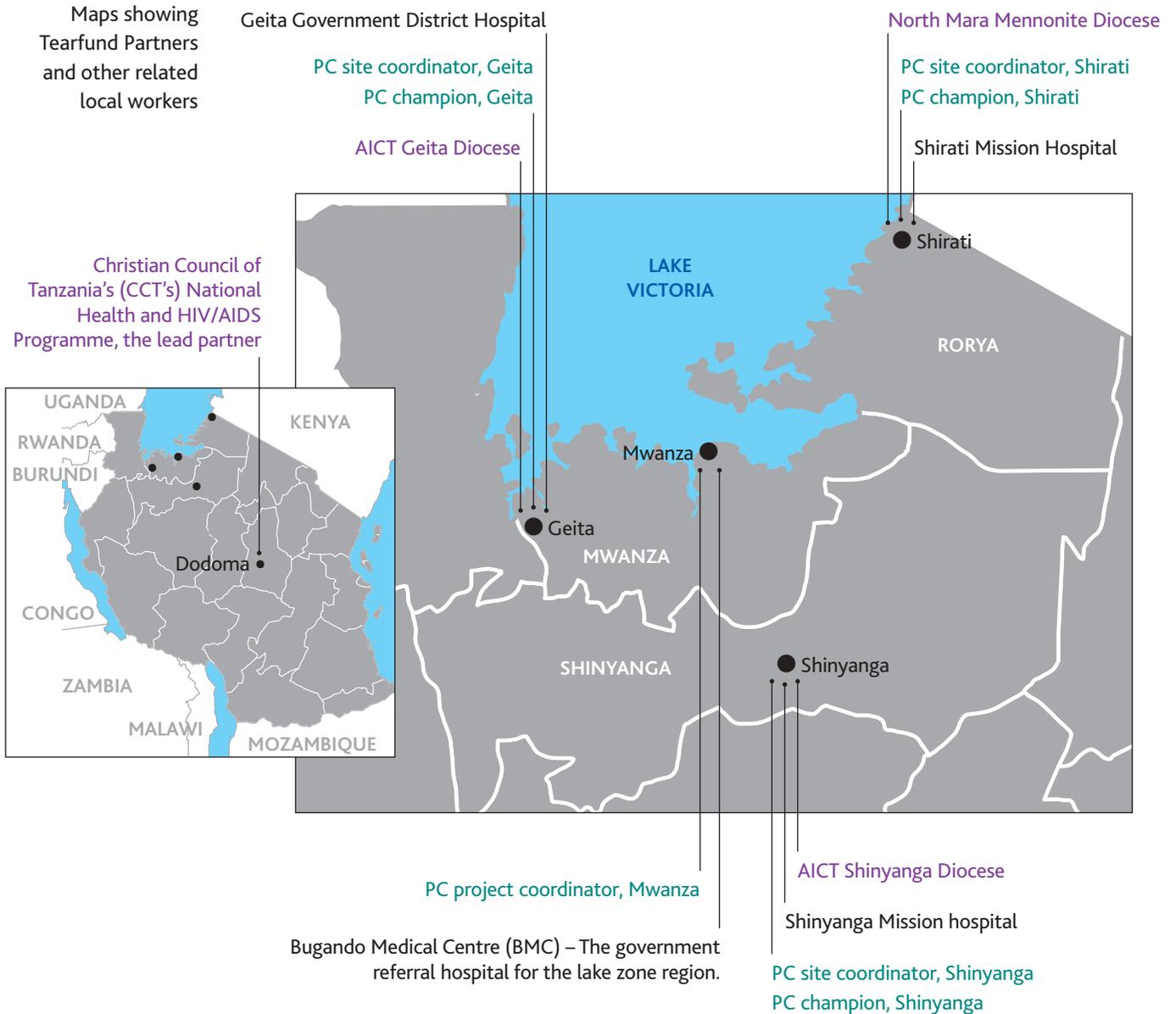
- **Shirati** Shirati was close to the Kenyan border with a high HIV prevalence. The North Mara (Shirati) Mennonite Diocese was based here. The mission hospital (the only hospital in the district) and the home-based care service of the Mennonite Church were linked and sited in the same compound.
- **Geita** Geita district had high HIV prevalence, challenging demographics and huge care needs. The African Inland Church of Tanzania Geita Diocese had a strong home-based care initiative with links to a government hospital.
- **Shinyanga** In Shinyanga Diocese, the African Inland Church of Tanzania had both a mission hospital and home-based care programme. However both functioned separately.

Amida Yindi, Geita PC champion with a student nurse carrying out a palliative care assessment in Geita District Hospital



Amani George

The pilot study aimed to scale up access to good quality palliative care for 4,000 people in the lake zone region of Tanzania through building the capacity of partner programmes.



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

### 3 Initial planning

Tearfund and Christian Council of Tanzania facilitated the design of an implementation plan in September 2009 with stakeholders including diocesan church leaders, hospital personnel and diocese HBC coordinators, to address three major needs:

- poor links between government-run medical services and community HBC programmes
- sub-standard quality of care due to lack of resources and support systems for caregivers
- lack of access to pain relief.

Tearfund took the role of facilitator for the pilot. This role included capacity building, donor liaison, overall programme management and risk management for the donor. Tearfund was also a donor.

The Christian Council of Tanzania was the lead partner and provided good local knowledge. They have a credible national network of churches in Tanzania and an established track record in mobilising churches in HIV response. They took responsibility for coordinating programme implementation.

Tearfund's local partners were responsible for identifying needs, for implementing the programme and for service delivery. They also engaged in local advocacy.

## 4 Establishing regional palliative care teams

Multi-disciplinary PC teams were created at each site which included representatives of: doctors, nurses, social workers, clinical officers, pharmacists, pastors, community officers and the HBC coordinators.

These teams meet regularly to enable effective referrals between the hospitals and home-based palliative care volunteers.

*'In Geita the PC team met once a month for 2–3 hours but members met informally more often as we visited patients. At our monthly meetings we talked about client needs, services, referrals, challenges and how to make the project sustainable. We documented all this. The hospital doctor came occasionally but usually only when we met in the hospital.'*

*Mary Makaranga, PC site coordinator, Geita*

## 5 Setting up support mechanisms

The PC project coordinator (Amani George) oversaw the effective implementation of palliative care in all three sites.

Each partner site appointed a PC site coordinator from the church. They were responsible for programme implementation and supervision at their site. In addition PC champions were selected. These were members of the PC teams who demonstrated real potential to advocate for the integration of palliative care within the district.

## 6 Palliative care training

The Help the Hospices *Palliative Care Toolkit* was used as the basis of training (see Appendix A). A five-day training course for all members of the PC teams was provided by the toolkit authors or contributors: a palliative care doctor, nurse and social worker. All of the training facilitators worked with Palliative Care Works, an independent consultancy group committed to the development of palliative care in resource-limited settings. Topics that were most appreciated by participants were: communication and listening skills, breaking bad news, and talking to children. Participants articulated discomfort with morphine, which the facilitators worked to challenge and discuss. Participants indicated a good level of comprehension and retention of knowledge in the end-of-course assessment.

A three-day palliative care training course was provided for all new and existing volunteers, again based on the *Palliative Care Toolkit*, by PC team members who had benefited from the initial training.

The PC champions were encouraged to consider applying for a Distance Learning Diploma in palliative care course to build up their experience and training. Some have already applied, ensuring the building up of local skills and capacity and this should contribute to longer term sustainability of palliative care in the region.

**'The training gave me skills and confidence to care for clients, even those you might run away from when you see their condition.'**

*Patrice Kundole, PC volunteer caregiver, Geita*

## 7 Mentoring and follow up

Following the training, palliative care medical mentors were appointed and spent three months at each site. All of the mentors were UK doctors recruited through Palliative Care Works. They helped build the capacity of the palliative care teams. They spent time mentoring the PC site coordinators to engage with district health officials, aiming to ensure palliative care was embedded in health systems. The mentors provided refresher training for PC teams and volunteer caregivers, and modeled effective palliative care skills and use of appropriate palliative care criteria while visiting clients in the community. After their return to the UK, the mentors have been keeping in touch, continuing to offer support in a variety of ways to project staff and participating health professionals. Mentorship modelling continues to evolve and needs to be flexible and responsive to the needs of the PC site coordinators.

## 8 Advocating for access to pain relief (morphine)

Caregivers identified their number one need in providing care for people with life-limiting illnesses as being able to provide pain relief to their clients. Morphine was available in Tanzania but only to a select few organisations that had direct links with the main cancer hospital. The oncologist at Bugando Medical Centre (BMC), Dr Nestory Masalu, agreed to act as a conduit for access to morphine at the three project sites. Pharmacist training in the provision of morphine was provided and reinforced with further training and mentorship on administering morphine. Tanzania Food and Drug Authority (TFDA) licenses have now been obtained at each of the project sites, allowing pharmacists to manage procurement and dispensing.

## 9 Delivery of palliative care activities

The palliative care services provided were an integrated combination of hospital services and home-based care. The care incorporated:

- **physical care** – home-based care volunteers provided physical care support with clinical members of the palliative care teams providing clinical back up
- **psychological and social care** were provided through the home-based care volunteers
- **spiritual care** was given by the pastors on the PC team.

After the palliative care training courses the teams were equipped to carry out needs assessments, firstly with their existing HBC clients to determine those who required palliative care, and later with newly identified palliative care clients.

## 10 Monitoring the palliative care work

Monitoring happened at various levels. The PC site coordinators in the PC teams were responsible for day to day monitoring.

The patient tracking card or outcome scale (Appendix B) was used by caregivers to capture progress and needs.

The PC project coordinator, Amani George, was responsible at overall programme level for CCT. He carried out monthly visits to each site, sometimes more. He provided quarterly updates to Tearfund and wrote six-monthly reports.

## Building on the church's foundations

'I was sick and you took care of me' (*Matthew 25:36*)

Church volunteers are the backbone of health care provision in many communities, providing essential care for those who face life-limiting illnesses. By reaching out to those who have been forgotten, volunteers journey into the difficult places of pain and suffering, ensuring that no one has to walk that road alone.

### Diocesan response

Tearfund had an existing relationship with the dioceses that participated in the palliative care pilot. The bishops in each of the three districts: Bishop Nkola, of Shinyanga AICT Diocese, Bishop Nyagwegwe of the Mennonite Church, Diocese of North Mara, Shirati and Bishop Magwesela of Geita Diocese, all gave their full support to this initiative. The bishops had the ability to encourage an enthusiastic response to palliative care within their dioceses and have become essential advocates for palliative care.

All three partners had well-structured HBC services available through the diocese, working with trained medical personnel and volunteers.

### Home-based care volunteers

The ability to provide palliative care in clients' homes was a key component of the pilot project. Existing HBC volunteers were trained, as well as volunteers who were identified via church and village leaders. Nominations were put forward and volunteers were invited to receive palliative care training.

The Geita project team encouraged involvement of any volunteer regardless of faith affiliation, and trained both Christian and Muslim volunteers. Both men and women were encouraged to participate. As Mary Makaranga, PC site coordinator in Geita, explained; "We care about gender and want to ensure that care is available for people of all faiths".

**'Listening is one of the most important tools we have for giving spiritual support. Our role is not to tell people what they should think, but to be with them as they seek answers to their questions.'**

*Palliative Care Toolkit, 2008*

The participating local church in Shinyanga, one of the sites of the palliative care pilot project



Shannon Thomson / Tearfund

## Focus on Geita Diocese

Geita Diocese was one of the three project sites. This case study focuses specifically on the work there – partly because it was the most developed and was the first to succeed in accessing morphine, and in order to focus the learning on one site.

Geita Diocese already had an HIV unit when the palliative care pilot began. The unit provided support for orphans and vulnerable children, ran a HBC programme, and provided economic empowerment for people living with HIV. An effective partnership existed between Geita Diocese and the district government hospital prior to implementing the palliative care programme, which aided implementation immensely. The PC team in Geita held an introductory meeting for 30 district leaders to inform them of the programme, to build relationships further and gain their support.

**'God wants us to provide health services; he is the one who created us. Jesus himself was involved with people – comforting them and healing them. The role of the church is to care for the sick, following Jesus' example.'**

*Bishop Mussa Magwesela, Geita Diocese*

Bishop Magwesela did not realise the extent of the burdens on people with poor health and their families until the palliative care project started. Now that he has gained awareness, he is better able to empathise with their struggle. The palliative care project has helped him to understand that support extends beyond the spiritual to physical, social and emotional needs.

### Geita Diocese key facts

- Geita has 446 clients on their palliative care register. 45 of these are bedridden clients.
- The Geita PC team has nine committed members and works closely with 47 palliative care volunteer caregivers.
- Geita was the first site to receive a TFDA license and now has three clients currently using morphine.<sup>2</sup>

AICT Diocese of Geita had a good working relationship with the government-owned district hospital. Its clinicians and health professionals helped to provide palliative care



Shannon Thomson / Tearfund

<sup>2</sup> Project data as of December 2010.

## CASE STUDY

**Accompanying clients on their journey**

Tulinagwe had breast cancer. She already had one breast removed but then developed another large tumour. She needed surgery to remove this tumour but could not afford the fees.

Tulinagwe's needs were identified when she was visited by a palliative care volunteer, Faraji, who heard from another person in the community that she was confined to her bed because of pain. He referred her to a doctor on the PC team in the district hospital.

Faraji benefited from training and as a home-based palliative care volunteer felt accepted in the community and able to advise people on care and treatment. He visited Tulinagwe two or three times each week, even though it was a journey of five kilometres to her home. He also supported five other clients, all as a volunteer. Two of them have since died.

Faraji struggled with his frustration at the cost of surgery to remove Tulinagwe's tumour. He found comfort in being able to provide her with pain relief medication after her referral visit to the doctor. Tulinagwe commented; "I have hope now, I am no longer in pain. I was confined to my bed and unable to walk before."

**What changes has palliative care brought?**

There has been impact at community level, particularly through lessening the stigma around home-based palliative care and in creating awareness of the role of the church in responding to palliative care needs. Volunteers reported that the expansion of their remit to provide care for anyone with a life-limiting illness, has created greater acceptance for them in the community. The previous focus on HIV in home-based care was reported to be a barrier to acceptance.

**IMPROVED LINKAGES AND REFERRALS**

The pilot has facilitated user-friendly referral systems. Volunteers easily get in touch with professional PC team members, such as doctors and pastors, for home-based or medical services to their clients. In Geita, volunteers first contacted their PC site coordinator, Mary Makaranga. Mary found the appropriate PC team member and referred the patient to them. "Some volunteers are Muslim. If a client is Muslim then we bring in the Imam for prayer if needed." PC team members usually travelled to patients' homes to complete assessments. When this was not possible, patients travelled to the hospital to see the PC team member.

**VOLUNTEER CAREGIVERS SUPPORTED AND TRAINED**

Volunteer caregivers formed the basis of the palliative care programme. Without the dedication of the palliative care volunteers, the project would not have had the capacity to reach those who were bedridden, nor to have offered care in clients' own homes. Previously volunteers spent much of their time in ensuring that clients followed their ART treatment correctly. They had done very little to provide pain management, psychosocial or spiritual support.

All the caregivers involved in the pilot benefited from palliative care training and gained an understanding of how the multidisciplinary skills needed for holistic palliative care are interconnected: responding to social, physical and spiritual needs are all essential components.

**Savings and credit groups**

In Geita the HBC volunteers began savings and credit groups in 2007. All 47 volunteers are members and everyone contributes 1,000 shillings each month from their own pocket. With their savings they bought pigs and land in 2010 to generate income for members. They gain more income by lending out funds at 10% interest. The groups are well organised with appointed officials and a savings account in the bank.

CASE STUDY

**"One day I too may be in need"**

Sadiki Lambek is a volunteer working in Karangalala ward in Geita District. He currently has 19 HBC clients and one palliative care client. He visits each patient at least once a week and spends around three hours each day doing this. He commented; "Sick people are human just like me. One day I too may be in need". He found the palliative care training gave him more confidence, especially when a client was close to death.

When he began working as a volunteer he was seen as 'the HIV person'. People now realise he is caring for all who are sick, not just people with HIV. "They no longer point the finger".

Training and supporting volunteer caregivers extended the reach of palliative care services and decreased the burden of care on hospital-based health professionals. This meant more patients were supported.

The training and referral systems gained volunteers respect from medical staff and provided them with access to pain medication for their clients. This increased their work satisfaction and helped retain their voluntary support.

**MENTORING**

Strong mentorship was key to introducing palliative care in Geita. The mentor, Dr George Smerdon, was immensely valuable in building the capacity of the palliative care teams and in ensuring quality of care. He played a central role in advocating for access to morphine and in solidifying referral systems between the hospital-based PC team and the community-based volunteers. He worked with the teams to clarify palliative care criteria, ensuring that resources and efforts were well utilised. Modelling of palliative care skills and supporting advocacy with district health officials served as beneficial aspects of the mentoring process. "Our mentor in Geita, Dr George Smerdon, has been outstanding. He has done more than we could have expected during this three months, ensuring access to morphine and initiating the process of creating a day hospice within Geita District Hospital" commented Mary Makaranga.

A nurse from the children's ward, Geita District Hospital being taught by Amida Yindi to use the pain assessment tool from the Palliative Care Toolkit



Amami George

## CASE STUDY

**Eunice's motivation**

Eunice Mamuya is a volunteer in Kasamua ward, Geita Diocese. She has 44 HIV clients and 16 palliative care clients that she visits in the community. Eunice has had to be creative to see so many clients, so she meets them as a group once a week. Any who cannot attend the group she visits once a week in their homes. For clients needing palliative care she may visit several times a week if the family needs support. She spends an average of 15 hours a week with her clients, providing physical care, spiritual, social and psychological support. The palliative care training has contributed to her confidence in discussing difficult things like pain and dying with families and palliative care clients. "Through the palliative care training I have learnt to encourage conversations about death."

When asked what motivates her, Eunice replied "It is the love in my heart that makes me so committed. If the patient has nothing and you give them something, the patient will pray for you, saying 'you have brought me something when no one else has'. That in itself is a blessing."

As a result of growing awareness of palliative care, she has noticed that whereas before the family had to use most of their time and resources in caring for the sick person, now others are coming to provide services without cost and that has been helpful.

Palliative care volunteers in Geita initiated a savings and loans group to which Eunice belongs. As a result she is raising pigs and poultry and is hoping to sell eggs soon. She loves being in the group – it has become very important to her, both as an emotional support for the difficult work she undertakes, as well as an economic support to allow her to continue to volunteer to care for clients.

**'Our mentor, Dr George Smerdon was much appreciated. His teaching methods were good and we would love to have him return.'**

*Dr Dihenga, DMO in Geita district*

**EMBEDDING PALLIATIVE CARE INTO DISTRICT HEALTH SERVICES**

By integrating palliative care into the existing infrastructure, the pilot built on existing knowledge, access and motivation. This helped to reduce costs and avoided duplication. Clinical staff gained motivation, personal growth and ownership through embedding palliative care into the hospital sites.

The palliative care teams helped build a strong referral network which enables everyone to play to their strengths and mitigates against disconnected parallel structures which often existed previously. Embedding palliative care into the hospital system helped develop long term sustainability and palliative care integration across the national health service mandate. Medical staff themselves became the advocates.

The District Medical Officer (DMO) in Geita has now included palliative care into the district council plans, (though it has not yet been included in district funding). Another exciting development is the approval of a new day-hospice by the DMO, which will act as a service centre for palliative care in Geita. At present it opens for one day each week, staffed by a palliative care nurse. "A centre to provide medical services on a day-to-day basis is good," comments Bishop Magwesela.

**'We have reached the people who have been abandoned. Most people think that if somebody has cancer, there is no need to take care of them because they are going to die. But now people are feeling better and people value their life. It gives them hope.'**

*Mary Makaranga, PC site coordinator, Geita*

## Key achievements

### CONFIDENT COMPASSIONATE CAREGIVERS

As a result of training and mentoring, caregivers were able to provide an increased standard of care for their clients. This work was not only cost-effective but provided a wonderful example of Christian compassion.

### CHANGING ATTITUDES TO PAIN RELIEF

Awareness and knowledge gained through training and experience sharing facilitated a transformation process in all PC team members, from the mind-set of viewing morphine as a dangerous and unnecessary drug, to viewing it as an important drug for severe pain management. Pain relief enables people to function better, lessening the burden on caregivers and the health system. Trained caregivers have been able to provide an improved quality of care and access to pain relief.

### MORPHINE PROVISION

As a key component of an effective palliative care programme, negotiating access to morphine supply chains was an advocacy objective. A meeting was held in March 2010 to create a partnership agreement with the palliative care programme and Bugando Medical Centre, working closely with Dr. Nestory Masalu, the lead oncologist at BMC. One pharmacist from each team was trained in September 2010 for three days at BMC on the preparation of morphine and the regulations governing its usage.

In October 2010, oral morphine became available in Geita, through the support of BMC. This was a significant achievement and the result of much hard work from the staff and mentors. Funds were budgeted for the pharmacist to travel to Bugando four times a year to collect morphine. BMC now provides morphine to 300 palliative care clients and Geita has three clients on morphine.

### BENEFITS TO CLIENTS

A network of care was built involving hospital staff, volunteer caregivers including people living with HIV and church members. Even clients living in remote rural areas benefitted from the referral system established.

### NETWORKING

The programme allowed for collaboration among palliative care practitioners both within Tanzania and in other countries in Sub Saharan Africa: through joint training sessions, experience sharing, and collaboration in provision of services. Each of the partners in the pilot became members of the Tanzanian Palliative Care Association.

Tearfund were keen to foster dialogue between church-based organisations, to explore and discuss their role in bringing palliative care into resource-limited settings.

#### Achievements of the lake zone pilot

- PC teams well established in each of the project sites, with 25 health professionals and three faith leaders trained.
- Tanzania Food and Drug Authority (TFDA) licenses obtained at each of the project sites, allowing pharmacists to manage the procurement and dispensing of morphine for pain relief.
- A total of 127 volunteer caregivers trained in quality palliative care (75 women and 52 men). Through these caregivers, the pilot has provided palliative care to 711 clients after one year, of whom 158 were bedridden.

## Challenges

As a pilot project, there have been challenges in effective implementation, which have provided valuable learning opportunities on how to best move forward. The project aimed originally to reach 4,000 patients and 711 were reached by November 2010. This was partly because all existing HBC clients were included in the original figure. However, with more understanding of palliative care and the ability to discern between clients who require palliative care and those who do not, the targets have reduced. In addition the first PC project coordinator appointed died after just two weeks of working with the pilot. This sad loss delayed implementation by a number of months.

### Long term sustainability

One concern in the current palliative care pilot project in Tanzania is long-term sustainability. Discussions with implementing partners and key stakeholders, such as Bugando Medical Centre, have led Tearfund to conclude that there is need for continued investment in palliative care in order to build towards long-term impact.

### Expansion of palliative care training

The burden of care in the pilot districts is simply greater than the capacity of the PC teams to respond. There is a need for additional health professionals and volunteer caregivers – all of whom will require good quality palliative care training. In addition, trained staff and volunteers need support and encouragement to ensure their services are retained.

### Incentives for volunteer caregivers

Providing creative and sustainable incentives for volunteer caregivers is a crucial issue and one that Tearfund faces in its other health programmes. Retaining trained palliative care caregivers over time is challenging without the provision of financial incentives. This issue is compounded when other programmes (such as AIDSRelief) do provide financial incentives.

The majority of caregivers commit to at least 15 hours per week of voluntary caregiving. In addition many volunteers support clients from their own resources and face challenges in generating income.

### Food insecurity for palliative care clients

Food insecurity is a serious issue for clients. The economic impact on families caring for someone with a life-limiting illness can be immense as time can be lost for productive labour. Many caregivers had concerns about the futility of administering pain-relieving drugs when clients lacked adequate nutrition and food supply. Volunteers often provided money or food for clients and their families out of their own pockets.

**'You reach the patient and they have nothing to eat and the client is hoping you will bring something. If I have money then I feel I have to give it or I go home and bring some food back.'**

*PC volunteer caregiver, Geita*

## Morphine supplies

Access to morphine must be negotiated early on in the project cycle. Good relationships are crucial to procure morphine – Tearfund’s connection with Dr Masalu at BMC allowed for access to morphine in each of the three sites within the first year.

## Cost of treatment

Vulnerable clients often lack money to pay for transport and medical fees. For example, clients can be referred for services at the district hospital or at Bugando Medical Centre in Mwanza but cannot afford the treatment or operation or the transport to get there.

**‘We struggle with the costs of treatment for our clients. At the District Hospital, only elderly people (60+), children under five and pregnant women can access free treatment. This makes it very difficult for us if we need to refer someone to Bugando Medical Centre. Many people just do not have funds to pay for transport and treatment.’**

*Dr Dihenga, DMO in Geita District*

## Transport

Transport for home visits is an ongoing concern because of the distances involved in rural areas. Following training, partners used portions of their grant budgets to purchase bicycles for volunteer caregivers and motorcycles for PC team members. However the challenging rural roads result in rapid wear and tear.

In Geita the diocese used funding from their palliative care grants to purchase a vehicle to assist in transportation to clients’ homes. Geita District’s Executive Director had made a commitment to facilitate transport for the palliative care team whenever possible. This has helped but transport needs remain a challenge.

Palliative care volunteers provide each other with friendship and emotional support



Peter Caton / Tearfund

## Conclusions

### The potential of church-based palliative care

By working through church partners and by strengthening home-based care to incorporate palliative care, Tearfund has seen a marked improvement in the quality of available care in the three pilot districts. There is also greater integration and partnership between government medical providers (PC teams) and volunteer home-based caregivers.

**'We have started to train pastors to care for the sick. We want the church to own the programme, so they will see this as their responsibility. We did a one-day training in January for 75 pastors in the diocese.'**

*Mary Makaranga, PC site coordinator, Geita*

The church can have an important role in facilitating and advocating for palliative care within health facilities. Through awareness-raising within the three dioceses, church members have been encouraged to think about their responsibility to care for neighbours and for the sick. The church is well placed to provide motivated and compassionate volunteers. As Mary Makaranga, PC site coordinator in Geita commented: "Committed volunteers who give numerous hours out of their week and travel long distances to visit clients are able to provide hope for those who had previously felt abandoned."

**'The church and faith communities are well placed to respond to those who have been forgotten through the provision of palliative care.'**

*Mary Makaranga, PC site coordinator, Geita*

Pastor Methusela Ndaki, Geita Diocese, has been very encouraged by the palliative care programme. "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. Members of my own church have started visiting people and raising money for sick people." The palliative care training helped him in his role as pastor, in caring and praying for people.

### The need to build capacity at all levels

The central roles of PC site coordinators and PC champions have been key to implementing this project and to the ongoing development of palliative care provision. Continued investment in the salary and expenses of the PC project coordinator would help ensure capacity is built in each district for long-term palliative care.

Refresher training allows opportunities for caregivers and PC teams to reconvene and reinforce learning, enriching the quality of care in the community.

Ongoing mentoring at regular intervals was of great value in building capacity. The pilot used expatriate mentors but ideally local mentors would have been recruited. "Dr Smerdon's commitment and skills really helped the diocese in improving linkages," commented Mary Makaranga. "He helped create good systems in the diocese, hospitals and villages. He was so patient and showed us how to deal with clients; how to tell the truth about death."

## The way forward

Tearfund believes the church is well placed to provide care and dignity for people with life-limiting illnesses. Through the learning from this pilot several important themes have developed:

### Build on the existing strengths of the church and other faith groups

This pilot has worked well and shows real potential for replication in other locations in that:

- The church already has a good track record in delivering healthcare, including established infrastructures, home-based care provision and local ownership especially in rural, hard to reach communities.
- The ethos of palliative care integrates spirituality and spiritual care which plays to the strengths of faith communities.
- The church can play a strong leadership role in drawing different stakeholders together.

These strengths provide the potential to build a sustainable, locally owned and driven response to meeting palliative care needs. At a time when projected palliative care needs in sub-Saharan Africa are growing rapidly, the need for a sustainable response becomes critical in ensuring services reach more isolated communities. Since this pilot builds on existing structures it is a low cost model.

### The role of advocacy

Tearfund is committed to advocating amongst peer organisations, donors, governments and churches with the following messages:

- High quality palliative care is absolutely critical to meet the immediate and future needs of people with life-limiting illnesses in in sub-Saharan Africa.
- Palliative care has an important role to play in HIV treatment, care and support; integration into wider HIV programmes is crucial.
- There is a clear role and potential for churches to be key players in providing and scaling up palliative care.
- Greater access to pain relief is urgently needed.

### The need for further integration into health services

Palliative care will be further integrated into the health systems in the three pilot sites. Links will be strengthened at all levels: between community and health systems, through effective referral networks and through the various partner relationships (between churches, hospitals, health centres, other organisations, community leaders and other faith groups).

Palliative care is now being incorporated within governmental district health service plans. Whether this is backed up by adequate funding to ensure the ongoing provision of administrative and support services and additional palliative care training, is by no means certain. However, the pilot has sought creative and sustainable solutions to ensure palliative care services are maintained: through building capacity, replicating training and improving livelihoods for caregivers.

Continued investment in Tearfund partner grants will allow partners to pay for transport, refresher training, morphine procurement, palliative care kits, monitoring and evaluation.

An extension of palliative care training beyond the hospital team to clinical officers and nurses in health centres and dispensaries would decentralise services and relieve the burden on the PC teams, as well as easing transport issues for clients. With more trained palliative care health professionals, additional volunteer caregivers could be trained to extend the reach of palliative care.

## Long-term sustainability

The retention of palliative care caregivers and team members must be approached in a creative and sustainable manner. However, without the provision of financial incentives, the demands on voluntary caregivers are considerable.

The provision of training in income-generating activities may prove useful in supporting them in a sustainable manner. For example caregivers could be trained in effective income-generating activities, including developing business plans and bookkeeping. PC site coordinators could oversee income-generating groups, visit regularly and provide refresher training and support.

Partners have developed proposals to other donors for agricultural and livestock initiatives that may help provide palliative care clients with low-input mechanisms for sustainable subsistence food supplies to address this ongoing need. Geita Diocese is considering a demonstration centre where community members can go to learn about handicrafts, small livestock and how to cultivate nutritious plants like moringa. Plants could be grown there and used to prepare meals for clients.

## Regional and national palliative care strategies

Tearfund is eager both to engage more regional and national church-based stakeholders to support palliative care, and to strengthen collaboration between church-based partners, national palliative care associations and organisations, and health services. Tearfund plans to host a regional meeting in Mwanza to offer learning opportunities for the current partners and five other church dioceses interested in palliative care. Regional lake zone stakeholders, including NGOs, government officials, potential donors, and community-based organisations will also be invited to attend with the goal of developing a lake zone collaboration strategy to provide palliative care services and advocacy.

Tearfund staff held a consultation workshop at the African Palliative Care Association (APCA) Conference in Namibia in September 2010. This proved key in advancing Tearfund's advocacy commitment to ensure churches' involvement in palliative care. As a result, Tearfund has agreed to partner with APCA to develop a pan-African church-based palliative care strategy. Stakeholder meetings will be held to develop national strategies and implementation plans for palliative care in the countries selected.

Church palliative care volunteers are well placed to provide care and dignity for people with life limiting diseases



Shannon Thomson / Tearfund

## References and further reading

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Palliative care volunteer, Albert, visits one of the clients he sees regularly. Volunteers give significant amounts of time to care for clients



Kath Hayward

## APPENDIX A Palliative care training

The *Palliative Care Toolkit* published by Help the Hospices was used as the basis for palliative care training and includes the following subjects:

- What is palliative care?\*
- Palliative care in your settings\*
- Improving communication skills\*
- Breaking bad news well\*
- Spiritual care\*
- Bereavement support
- Assessment of pain and other symptoms\*
- Treat, care, and prescribe\*
- Pain control
- Morphine use
- Symptom control 1\*
- End of life care
- Children and families\*
- Symptom control 2
- Telling others
- Building a team
- Implementation of palliative care

\* Content covered in three-day training

# APPENDIX B Monitoring sheet used for tracking clients

## Palliative care service – Patient tracking card\*

Patient's number	Date	Patient's name	Location	Name of Caregiver	Main problem	Service given	Other issues raised

### Codes for service given

- 1 Helping the patient with bathing
- 2 Helping the patient with moving
- 3 Helping patient with pressure sores
- 4 Feeding the patient
- 5 Helping the patient with mouth cleaning
- 6 Helping the patient with toileting
- 7 Washing patient
- 8 Assessing the use of drugs
- 9 Helping with physical exercise
- 10 Explaining drug use

\*Based on source material by Dr Vicki Lavy from the Help the Hospices' Palliative Care Toolkit

Diana

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