Inspiring Hope

Helping churches to care for the sick

A palliative care handbook from Africa

Dr. Jane Bates

Foreword by Archbishop Thabo Makgoba

EMMS International
Health for Today, Hope for Tomorrow

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Helping churches to care for the sick

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EMMS International
7 Washington Lane
Edinburgh
EH11 2HA
(0131) 313 3828

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www.emms.org

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or have suggestions for additional publications,
please contact EMMS International on
info@emms.org or Dr. Jane Bates on
mjanebates@gmail.com . Your comments will
help us to improve the quality of future resources.

About the author

Dr. Jane Bates has worked as a medical doctor in South Africa and Malawi over the last fifteen years, following God's call to care for people with HIV and AIDS. She describes herself as a Pentecostal Anglican. She currently works as part of a vibrant palliative care team in a government teaching hospital in Blantyre, Malawi.

Contributors

James Wells and Cathy Ratcliff (EMMS International), Joe Kapolyo (Lead Minister Edmonton Baptist Church), Shannon Thomson (Tearfund) and Vicky Lavy (Christian Medical Fellowship) have contributed to and guided content during its formulation.

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The People Mentioned In This Handbook

The author wishes to thank all of the people who have contributed their case studies and understanding to help produce this handbook.

All real names of people in this handbook and all photographs of vulnerable adults and children are used with their explicit consent or with the explicit consent of their families.

To God be the Glory.

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Foreword

Jesus came so that people might have ‘life in abundance’ (John 10:10) and I have no doubt that his loving concern for the dignity and quality of life of every single one of us continues through to our very last breath – no matter what physical frailty or other indignities age or illness may bring our way.

This handbook is a wonderful guide to how we can communicate Christ’s tender compassion and care, which circumstances cannot diminish, to those who are coming to the end of their lives. No matter what our situation, in our living and in our dying we remain equally precious and valuable in the eyes of the Lord – and God’s people, through God’s Church, have a special vocation to be channels of this message of hope, dignity and respect.

This handbook is designed to be a practical manual for the use of congregations throughout Africa, and may also be valuable in other settings. In clear, tangible, down-to-earth, ways, it assists church communities, leaders and members to understand more about palliative care, and how we can best contribute. It helps us review what we are currently doing and provides resources so that we may be more effectively engaged.

Though the challenges we and our communities face can often be daunting, we should never doubt that, across the continent of Africa, the people of God constitute a vast resource to support unmet needs. God calls and equips us to respond to the profound spiritual, emotional, mental, physical and relational needs of the incurable, the terminally ill and the dying. There is so much that we can do that is often about the simple things in life – providing consistent care, a listening ear, a persistent presence. We can also offer basic teaching of practical lessons in how to make people more comfortable, through, for example, positioning and massage. Through good education, we can also challenge the stigmas and taboos around death and dying which leave both

carers and those they care for trapped in unnecessary fears and helplessness.

Churches can also make a significant difference through raising our voices in advocacy, and encouraging the wider community to join in lobbying governments and all who make policies around health care and its delivery. Here the handbook helps us focus our resources for maximum impact. One particularly important area for advocacy is effective access to adequate pain relief. Nowadays, no one should suffer in pain, but ensuring this is so in practice can be one of the greatest challenges to palliative care providers.

Most of all, we must not forget the unique vocation of the Church. We are called to build God's kingdom, spreading Jesus Christ's good news of love, forgiveness, salvation and hope, through the power of God's Spirit at work among us. We do not deny the awfulness of death, but we declare that we need not despair, for we know the greater assurances of the promise of heaven, and of the transformative power of God's love at work among us all, in this life and for the life to come.

The Most Rev Thabo Makgoba
The Archbishop of Cape Town
Anglican Church of Southern Africa

Preface

“For I was hungry, and you fed me. I was thirsty, and you gave me a drink. I was a stranger, and you invited me into your home. I was naked, and you gave me clothing. I was sick, and you cared for me. I was in prison, and you visited me.”

Matthew 25:35-36, NLT

The need for palliative care around the world is overwhelming, and as the African Palliative Care Association points out, challenges us to respond. This handbook is intended to inspire and inform churches across Africa and beyond to play their part in caring for people during some of the most vulnerable times of their lives.

The disease burden in sub-Saharan Africa is huge and has been exacerbated by the devastating impact of HIV and AIDS. In addition, as people live longer, non-communicable diseases such as cancer, hypertension and heart failure are expected to increase significantly over the next decade and beyond.

So often we think about healthcare as being about treatment and care. However, at its best, it is also about dealing with the unique needs of those living with a life limiting illness and their families, valuing the dignity of every life. Palliative care is as important as safe maternal and child health and disease prevention and control.

Churches are uniquely placed to take a lead on the provision of palliative care. They have a ready-made network for local and national advocacy, for challenging taboos about death and dying, and providing high quality home-based or clinic-based care. As an African colleague recently remarked – “Where the church leads, Africa follows.”

This handbook has been developed in Africa. It is built on the

experience of churches and other Christian organisations, and encourages solutions that are right for each local context. It's not a "one size fits all" resource, but is instead a tool that, with prayerful consideration, will enable churches and communities to respond in the best way to meet their circumstances.

As Christians, we are called to respond to the needs of those who are vulnerable. Those who are thirsty and hungry, those who are abandoned, whose dignity is being challenged, and who are ill – all of this speaks directly to the need for palliative care, and how we should respond to the needs of those who are ill and their families.

It is our privilege as children of God to love one another, pray for one another, help one another and be with one another. Palliative care is about doing all of this, for all of our neighbours.

It is our prayer that this handbook will be a tool that will be well used, will inspire, inform and challenge. We also hope it will be an encouragement to all those who wish to care for their friends, families and neighbours when they are at their most vulnerable.

To God be the Glory.

James M. Wells
Chief Executive
EMMS International

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1

Palliative care and the church

Handbook outline

The purpose of this handbook is to assist church communities, leaders and members to understand more about palliative care, to review what we are currently doing and to provide resources so that we may be more effectively involved. It is designed to be a practical manual for the use of congregations throughout Africa, and may be applicable for other settings.

It is split into five sections.

- The first section explains more about palliative care and outlines the role of the church.
- The second section provides inspiration for reflection, teaching and motivation for involvement. It is suitable for use for personal or group devotions or by church leaders seeking material for sermon preparation.
- The third section provides short stories about what churches are doing. It contains questions and activities and is designed to be used in a group setting.
- The fourth section contains resources for action.
- The final section provides a list of further reading and useful contacts.

What is palliative care?

Palliative care is a special kind of care for people with progressive, incurable illnesses. It is commonly helpful for, but not limited to, sick people with advanced cancer, HIV and AIDS, heart failure, liver or kidney disease and stroke.

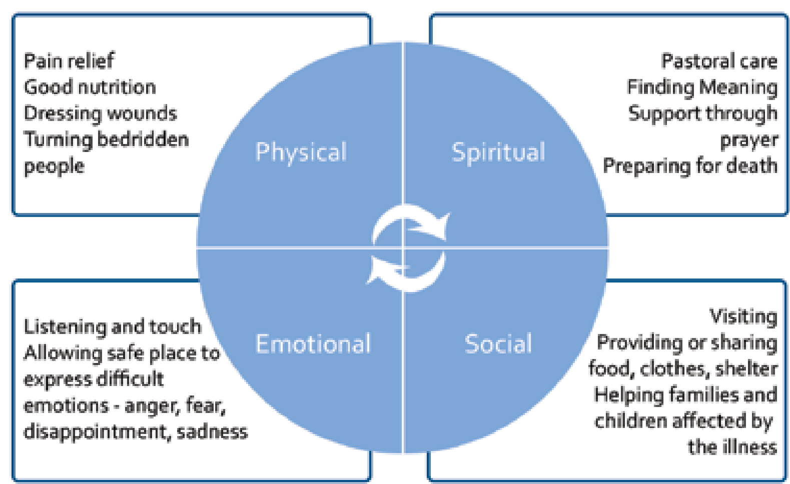
Palliative care:

- helps people with incurable illness and their families to live more comfortable, active and hopeful lives,
- provides care for the whole person, looking at the physical, emotional, social and spiritual needs of the patient and family (this is called holistic care),
- works to prevent and treat pain and distressing symptoms,

- relies on teamwork involving the community in care-giving and support.[1]

It is provided in patients' homes (home-based care), in clinics and in hospitals, involving families, volunteers, nurses, clinicians, doctors, pastors, church members and others. It supports the patient and the family with the aim of improving quality of life rather than to lengthen (or shorten) life. It can be given at any time, from the time a person first becomes ill and even after they have died, by providing care for those who are bereaved.

Some examples of holistic care:



Palliative care is an approach that improves the quality of life of patients and their families facing the problem 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.[2]

World Health Organisation, 2002

Hospice care is another term used alongside palliative care. The word 'hospice' can refer to a place where care is given, but it also refers to the whole philosophy of palliative care.

Why pain relief matters

Long term pain leads to distress, despair and desperation. It is very difficult to address any other needs of people who are in severe pain unless relief is found. Untreated pain from cancer, HIV and other illnesses remains an enormous problem around the world, not least in Africa.

In recent years much work has been done by those involved in the palliative care movement to provide adequate pain relief for those with progressive incurable diseases. The process of relieving pain involves proper assessment, treating any reversible causes and giving medicines to reduce the pain.

Morphine is recognised by the World Health Organisation as the drug of choice for relief of severe pain in diseases such as cancer and HIV.[3] The majority of people who have cancer, and many of those with HIV and AIDS, will need morphine – a cheap and effective pain killer – at some time during their illness in order to control pain.[4] It must be prescribed by a legally registered prescriber for a particular patient under their care. Prescribers are usually doctors or clinical officers, though regulations vary from country to country. For example, in Uganda they have introduced laws which allow specially trained registered nurses to be prescribers.

Sadly, many countries still have extremely restrictive regulations which prevent people from getting adequate pain relief in time. When used at the right dose, given by mouth to sick people under palliative care review, research and clinical practice have shown that addiction and diversion of drugs (i.e. selling for illegal use) is extremely uncommon[5].

Attention should be paid to providing prescribed drug treatments such as morphine and relevant non-drug treatments such as positioning and massage. Any interventions should be discussed with or explained to the sick person. It is important to remember that there are many things which contribute to the experience of pain in advanced illness, for example, fear, isolation, anger and guilt which must also be attended to.

People have many different needs when they are sick:

Amos is 16. He is an orphan and lives with his 12-year-old sister about 5km from the main hospital. He has wounds on his feet. At the hospital they have told him he has a cancer that cannot be cured but may be helped by weekly injections. Church members visit Amos at home and they provide him with money for transport to get to the hospital and with food for him and his sister.

Annie is 46. She has advanced cancer and HIV. She is being visited by the palliative care team at home. She tells the team that her main concern is for her six-year-old child: according to local cultural practice this child would be taken away from her husband after she has died, but she wants them to stay together. The team suggest that the village chief should come to hear about her concerns. She dictates a letter expressing her wishes which is signed by the chief. She is at peace when she dies knowing she will be able to get the care she wants for her child.

The provision of holistic care includes washing someone, changing a wound dressing, offering prayers, and staying at the house while family members go to get vegetables at the market. We can assess pain and monitor progress, helping people to get the medications they need. We can provide a radio for distraction from pain or other distressing symptoms, help someone get their hair done or move their weak body to prevent pressure sores. It's all part of palliative care.

In palliative care we *never* say, "There is nothing we can do."

Role of the church

The church in Africa is uniquely placed to respond to the needs of patients and families affected by progressive, incurable illnesses for a few simple reasons:

- We are part of our communities, with congregations in each and every village, town and location across the continent,
- We speak the same language as our neighbours and we understand local needs and cultural practice through our daily life together,
- We have the gospel – good news – to proclaim, of God's love for us and of love for our neighbours through Jesus Christ,
- We are called to be involved during times of sickness and grief, providing a window of hope for our communities.

> "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, Gelta Diocese, Tanzania[6]

The church in Africa also has a long history of provision of excellent healthcare through networks of clinics and hospitals, often operating at a local level. It may be the first place where serious illness is identified. If disease progresses and death occurs, the

Care is provided as part of a team.[1]

church community provides hope, comfort and encouragement to the bereaved at the time of the funeral and beyond.

The reality is that the church is already taking the lead in many places in the provision of palliative care. But is there more we can do? And how well do we understand what is meant by palliative care? How can we respond better to the needs of those with incurable disease? And what can we learn from what other churches have already done?

> "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."
>
> Palliative care site coordinator, Tanzania[6]

Providing palliative care in the home

Across Africa the extended family has been the fabric of society, providing a foundation for holistic care in the home setting. Churches have pastoral care and visitation programmes for prayer and support of the sick. Church members take time visiting the sick at home. Pastors and church leaders

know the family over time and can help to link people into services when the need arises. A cost-effective way of starting palliative care is to **integrate** activities rather than building up new services from scratch.

Home-based care is a model of care that is suitable for delivery of palliative care in Africa. It involves the family alongside church and other community members linking with health facilities to support the care of the sick person in their home setting. In the church community, local knowledge and improved networking will help people find health workers who can assess and treat pain and other problems. Community-based services can rarely provide complete palliative care for a sick person but play a crucial role, especially since people with progressive, incurable illnesses will spend much of their time in the home setting.

Home-based care volunteers may undergo some short training courses to help improve the quality of care that they give. Church

buildings may be used to house a regular clinic or day care facility staffed by suitably qualified church members. Depending on local needs and the availability of funds, a nurse or doctor trained in palliative care may be employed. Health personnel need to be trained in culturally relevant palliative care. Creativity and persistence are often needed to access essential medicines, including morphine for the relief of severe pain, since these may only be available some distance away from the home-based care team and the patient. Proper assessment and follow-up should be in place.

In Uganda, HIV services such as Reach Out Mbuya Parish include nurses certified in palliative care and opiate-prescribing working in the out-patient clinic and supervising home-based care. They store oral morphine and a range of other palliative medicines. The parish has a referral relationship for specialist palliative care through Hospice Africa, Uganda.[7]

The Palliative Care Toolkit (see Section 5) provides resources for an introductory five-day course. It has been widely used in Africa and is available in a number of different languages including French, Swahili and Portuguese.

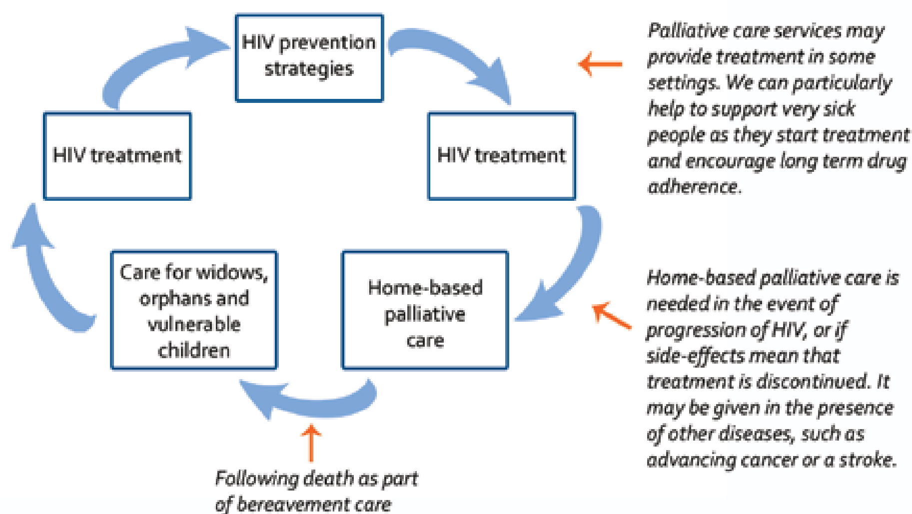
Integration with HIV care

Many home-based care programmes were started in response to the devastation of communities caused by the HIV virus. Antiretroviral medicines (referred to as ARVs or HAART) have dramatically changed the length of time people can stay alive and well with HIV, as well as reducing the risk of spread of HIV. Sadly, fear, stigma and discrimination still hold people back from finding out whether they are infected until quite late in the disease when they are already sick. For those who have tested HIV positive there can also be problems getting regular supplies due to poor availability of medicines or transport costs.

Home-based care programmes that were started for people with HIV are very well suited to care for people with other progressive

incurable illnesses such as cancer, heart disease and stroke. Many of the people we look after will be infected with HIV while others will not. The lessons learned about HIV and AIDS, such as dealing with stigma and discrimination, infection prevention and care for the carers, are all important to apply in the palliative care setting. Several aspects of palliative care, including pain and symptom control and the holistic approach, are essential for looking after people affected by HIV. Church and para-church groups such as the Ecumenical HIV and AIDS Initiative in Africa[8] and Strategies for Hope[9] have produced many useful resources on these important topics.

Where does palliative care fit into existing HIV and AIDS programmes?



Providing spiritual care

Much of our prayer ministry focuses around the fact that our God heals, around believing that all things are possible with God, and giving the person hope that they are going to receive total physical healing. Our emphasis is on Scripture verses about healing, and any talk of death seems inappropriate as it would make it seem that we have given up hope that God can heal. However, while total physical healing may be longed for, heaven is our true home where we will be with God and where "there will be no more death or mourning or crying or pain" (Revelation 21: 4). It's not a blank ending but a glorious future to embrace!

"Living with incurable progressive disease such as HIV infection and advanced cancer has implications far beyond the physical dimension. The experience of illness can have a profound effect on one's spiritual well being, leading to times of crisis as well as opportunities for growth."

Archbishop Desmond Tutu[10]

"As Christians we are people of hope. We should always hope but we also know that death can occur. As much as we don't want to think about it, it will occur."

Pastor, Malawi

The reality is that we will all die (even those who are at one time or another physically healed), and while we don't force this fact onto people with incurable illness, failure to acknowledge this at some level can add unnecessarily to distress. Leaders and church members may even abandon sick people, leaving them with a sense that they have failed, lack faith or are sinful as they have not received physical healing.

"Hope for healing – prepare for heaven"

Towards the end of his ministry on earth, Jesus spoke truthfully to his closest friends about the fact that he was going to die, though they were unwilling

to grasp the warnings he gave them. We should not be afraid or disappointed when someone who is sick starts talking about preparing for the end of life. They may keep quiet to protect their families from getting upset, despite feeling anxious, uncertain and aware of their declining physical health and of unfinished business they want to attend to. As church leaders and members offering practical help, we must also provide time to listen. We can offer a 'safe place' for sick people to express their concerns, helping to relieve their anxiety.

Healing itself has a variety of dimensions, considering not only physical healing but also psychological, social and spiritual healing as having great value in God's sight. We can help people to 'hope for healing and prepare for heaven' as we assist them to make preparations for their final days, whenever these may come. This may include writing a will but it goes beyond this. There may be a need for the sick person to meet with relatives or friends to forgive or be forgiven. Others may be encouraged to share special stories of personal and family history. Some people make choices about where and how they wish to be buried. Others can be helped to prepare memory books to leave for their children, to be read in the future.

At the end of life: supporting the family through their time of loss

Pastors are among the first to be told of the death of a family member. They respond by providing support to the family, helping to plan the funeral, and accompanying mourners over long distances to provide guidance, direction and support at the graveside. The training that pastors and church leaders receive for this is variable: some learn on the job, while others have the opportunity for more formal training before they are ordained. As well as providing words of hope and comfort, pastors may share

> "The burden of care on churches is immense. I met recently with a pastor who was conducting three funerals the next day. Another said to me: "I trained in theological college to do evangelism but I spend most of my time conducting funerals and counselling bereaved families. Theological college did not prepare me for this."
>
> Veena O'Sullivan, Tearfund HIV and AIDS adviser[11]

information about some of the stages of grieving that family members can experience. Wise counsel may help to mitigate exorbitant funeral expenses, which can otherwise result in further poverty for grieving relatives.

Church members help to support the family at the funeral assisted by the community and local cultural patterns of grieving. The church needs to stand with a bereaved person to reject harmful cultural practices such as widow cleansing involving sex with a surviving relative. Support for those closest to the one who has died continues after the funeral through visiting, prayer and discussion as they try to adjust to the reality of the situation. The church may help identify or run programmes to support orphans, widows and widowers who are left after the death.

Tasks of grieving for the family members who are close to the one who has died:

- accepting the reality of the loss,
- experiencing the pain of grief (sadness, anxiety, anger),
- adjusting to the situation in which the deceased is no longer around,
- becoming involved with other activities or relationships

from Worden[12]

Advocacy: getting the message out

Telling others is a very important part of the process of developing palliative care. We need support from all sections of the community and church leadership to get the job done.

Church leaders provide oversight and vision to carry palliative care forward, directing planning and funding towards service development. Some denominations have appointed an AIDS desk at national level to support the response of local churches. A similar or more integrated approach could be taken for palliative care. Regular church services and other gatherings of the congregation (e.g. Mothers' Union or ladies' meetings) play a key role in disseminating important messages, particularly in rural areas. Community members who have benefitted from palliative care services provide powerful first-hand testimony of the difference that such care has made for them.

2

Inspiration

About this section

This section is designed for personal or group reflection, for example for use during a regular church prayer meeting or other small group meeting. Alternatively it may be used at the start of the day during a home-based care or palliative care training course. The material can also be used by pastors and church leaders preparing sermons or teaching for congregations on topics relating to palliative care, adapting the contents to the local situation.

The aim is to help us to consider:

- the God who calls us,
- the reason we have to hope,
- the reason we have to care.

Each of these sections is divided into Read, Think, Discuss, Reflect and Pray, in that order. The text and passages provide readings during a short reflection or devotion. These are interspersed with activities. The prayers and readings can be printed out for groups to read together.

We are called by the everlasting God

Read

"The Lord reigns, let the earth be glad, let the distant shores rejoice."
Psalm 97:1

"I lift my eyes to the hills, where does my help come from?
My help comes from the LORD, the Maker of heaven and earth."
Psalm 121:1-2

In Africa we know how to celebrate: to sing, to dance and make a joyful noise unto the Lord.

Take time to worship God, thanking Him for all He is and all He has done in our lives.

Think

Many of us have been through hard times, given until we feel we can give no more, prayed fervently and with expectation. We can testify to the presence of God who answers our prayers and encourages us in our weakness. We may be living through hunger, war or conflict of various kinds. We need each other and we need God. Jesus promises never to leave us or forsake us whatever our circumstances.

Discuss

- What are the needs in your life right now?

Reflect

During his ministry on earth, Jesus took time to find a quiet place to pray. It wasn't easy, life was busy, the crowds were pressing around him and his time for ministry was short. Our lives are also busy with daily tasks, multiple requests requiring our attention and deadlines to meet. As we seek inspiration and on-going wisdom for our involvement in palliative care we should begin in the same manner as Jesus: in prayer. Our lives and ministries risk being fruitless unless we remain in Christ (John 15:4). He is the source of our life, our hope, our grace and our joy.

Pray

"Do you not know? Have you not heard? The Lord is the everlasting God, the Creator of the ends of the earth. He will not grow tired or weary, and his understanding no-one can fathom. He gives strength to the weary and increases the power of the weak…those who hope in the LORD will renew their strength."
Isaiah 40:28-31

- Light a candle, keep silent, and draw aside for a few moments.
- Rest in the peace of knowing God.
- Finish by reading the following prayer followed by a time of silence.

We know O Lord that all things are ordered by your wisdom and love.
Grant us in all things to see your hand,
that we may walk with Christ in all simplicity, and serve you with a quiet and contented mind.[13]

We are called to an everlasting hope

Read

"Death has been swallowed up in victory. Where O death, is your victory? Where O death, is your sting?
The sting of death is sin, but the power of sin is in the law. But thanks be to God! He gives us the victory through our Lord Jesus Christ."
1 Corinthians 15:55-57

He is not here; he has risen.
Matthew 28:6

"Praise be to the God and Father of our Lord Jesus Christ! In his great mercy he has given us new birth into a living hope through the resurrection of Jesus Christ from the dead, and into an inheritance that can never perish, spoil or fade – kept in heaven for you."
1 Peter 1:3-4

Think

Christ was crucified. On the third day he rose again. This is the cornerstone of our faith.

Eternal hope radically changes our perspective. Though we experience the sadness and the pain of loss we know that this is not the end of the story. The hope of the resurrection provides us with encouragement to continue to care for those in difficulty, seeking God's wisdom to bring them comfort. God uses our presence to bring His hope, comfort and love.

Discuss

- How does this reality help in our day to day lives?

Reflect

In Christ we have hope beyond the grave. We take hold of this hope by faith. Looking forward, the grave does not have the last word in our lives. Looking back to the empty tomb, we have confidence that Jesus is the Christ, truly the Son of God. The sting of death has been removed and we are no longer enslaved to the power of sin and death in our lives.

Are we sometimes tempted to base our hope on opportunities to accumulate rewards, wealth, power and status? The parable of the rich fool (Luke 12:13-21) shows us that to place our hope in such things is ultimately fruitless. Many times it seems as though the wicked triumph at the expense of the weak and powerless (Psalm 73:12, 16-20). Jesus warned his disciples, "In this world you will have trouble. But take heart I have overcome the world." (John 16:33) In the end God's rule and His kingdom take priority and will overcome.

Pray

- Take time to praise Him for this living hope!
- Use the words in the following prayer:

Lord,
the resurrection of Your Son
has given us new life and renewed hope.
Help us to live as new people
in pursuit of Christ-likeness.
Grant us wisdom to know what we must do,
the will to want to do it,
the courage to undertake it,
the perseverance to continue to do it,
and the strength to complete it.[14]

We are called to care

Read

"'Teacher, which is the greatest commandment in the Law?' Jesus replied: 'Love the Lord your God with all your heart and with all your soul and with all your mind. This is the first and greatest commandment. And the second is like it: Love your neighbour as yourself. All the Law and the Prophets hang on these two commandments.' "
Matthew 22:37-40

"Then the King will say to those on his right 'Come you who are blessed by my Father, take your inheritance, the kingdom prepared for you since the creation of the world. For I was hungry and you gave me something to eat, I was thirsty and you gave me something to drink, I was a stranger and you invited me in, I needed clothes and you clothed me, I was sick and you looked after me, I was in prison and you came to visit me. I tell you the truth, whatever you did for one of the least of these brothers of mine, you did for me.'"
Extracts from Matthew 25:31-40

Think

It's difficult to read far through the Gospels without coming across Jesus' examples of care and compassion. Such care was most often directed to those individuals on the margins of society, the ones that others have forgotten or those who are hard to forgive: children, lepers, tax collectors and prostitutes. We are called to care not because of the benefits we will gain but because we follow the example of Jesus. However in the parable of the sheep and the goats (Matthew 25: 31-40) Jesus makes it clear that our care of others carries eternal significance.

Discuss

- Think of a time when you received care. Who gave it to you? What did they do? What difference did it make?
- How are you involved in giving care to others?

Reflect

"To care for others as they become weaker and closer to death, is to allow them to fulfil their deepest vocation, that of becoming ever more fully what they already are: daughters and sons of God. How do we say this? The ways are countless. There are words, prayers and blessings; there is the gentle touch and the holding of hands; there is cleaning and feeding, and listening and just being there. Some of these forms of care may be helpful, some not. But all of them are ways of expressing our faith, that those we care for are precious in God's eyes." [15]

Pray

- Give God thanks and praise that He cares for every aspect of our lives, and that He uses us in His work.
- Use the words of the Lord's Prayer:

Our Father in heaven,
Hallowed be your name,
Your kingdom come,
Your will be done on earth as it is in heaven.
Give us today our daily bread.
Forgive us our debts as we also have forgiven our debtors.
And lead us not into temptation
But deliver us from the evil one.

3

Stories to make us think

About this section

Life is about community. What affects one person affects everyone. Each household and community has its own experiences of dealing with poor health, sickness and death. Each family's story is different. We can learn more about palliative care together as we listen and think about each other's stories of caring for someone with a progressive, incurable illness.

In this section we hear stories relevant to church-based palliative care from a number of places in Africa and beyond. Some stories are about congregations and communities; others are about church-based hospitals. A few stories of individual people are included at the end.

Using these stories

If you are leading a group, you may want to prepare in advance by reading through each of the stories presented here, selecting ones which are most relevant to your situation.

You can use the stories to:

- Identify different aspects of palliative care being offered,
- Consider which aspects of palliative care your church might be able to do,
- Look at the motivation and character qualities of those involved,
- Look at the resources used,
- Look at what can be done with limited resources,
- Discuss how churches can develop good partnerships with other churches or organisations.

You don't have to cover all the stories in one session. Some groups may want to see the material in advance so that they can prepare their thoughts before coming together for discussion.

Begin a group session by listening to your own stories of caring for people with progressive, incurable diseases. You may use

the questions below, collecting answers on a piece of paper for everyone to read. You can then go on to look at some of the stories further on in this section.

The answers gathered in your group discussions should be kept for use when completing the action plan in section 4.

What do we learn from our own stories?

What was our experience of looking after people with progressive incurable illness?

- Did we care for a child or an adult?
- Did they visit the clinic or hospital or was all the caring done at home?
- What challenges did we face during that time?
- How did we cope?
- Can we remember what people said to us around that time?
- How did our church community assist us?
- Is there anything we would like to have done differently in our caring?
- Is there anything we would like others to do differently to help carers in a similar situation?
- What made a difference – for better or for worse?
- Did the sick person prepare for the end of life? If so how?

Stories of working together

Story 1: Getting started

In Zambia key leaders from some churches and volunteers from their communities were identified and trained in palliative care. This trained team goes out into the community to work with people with HIV and AIDS and their families, assisting with hygiene and infection prevention advice, spiritual care and preparation for the end of life. Both the sick person and family members are counselled and helped with legal issues such as writing a will. Assistance is given to help with transport to healthcare facilities.

- How did the church in Zambia get services started?
- What help were they able to give?
- Do you know of any palliative care training that exists nearby?

"I tell you the truth, whatever you did for one of the least of these brothers of mine, you did for me."

Matthew 25:40

Story 2: Building through partnerships

Building on existing home-based care services, Tearfund brought together The Christian Council of Tanzania, trainers from Palliative Care Works and other partners to pilot the development of palliative care teams in the Lake Zone region of Tanzania. One pastor was very encouraged by the new 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." Palliative care training helped him in his role as pastor, in caring and praying for people.

- How were people in Tanzania brought hope again?
- In what ways do you currently serve sick people as a church community?
- Are there forgotten people among the sick in your congregation or area?
- How might you be able to meet their needs?

"It takes teamwork to make the dream work."

John Maxwell

Story 3: Inspiring leaders

One of the best known palliative care services in Africa – Hospice Africa, Uganda – was started in response to Dr. Anne Merriman undertaking a survey of patients who were sent home from hospital 'because there was nothing more to be done'. The work in Uganda started with one doctor and one nurse seeing patients in a small room of a house on the outskirts of Kampala in 1993.

From these humble beginnings, with a burning passion and a strong faith, Dr. Anne has guided the development of a model site for palliative care training and development in Africa, with services at three different sites in Uganda, offering care to adults, children and their families.

- What inspired this doctor and her team?
- What characteristics do you think she needed to start such a work?
- Do you have a place – a room or office – where palliative care services can be based?
- What practical steps can you take to get something going in your area?

"Every pain that is relieved and every symptom that is improved is a little resurrection for our patient."

Dr. Anne Merriman, Uganda

Story 4: From hospital to home

Kondwani was a clinician in a busy mission hospital in Malawi. He met a doctor who explained to him how to help control the burning foot pains that he had previously been unable to control for his patient. That doctor told him more about palliative care and he became interested.

Kondwani spoke to his hospital management and over time they were able to get funds to train all their staff in the basics of palliative care and start a weekly clinic for people with incurable diseases. Home-based care teams linked to the hospital included staff trained in palliative care on their visits in the community.

- How did things get started at the hospital where Kondwani was working?
- Make a list of the needs of patients with incurable diseases under your care.
- Who would you need to involve in order to help meet those needs?

"Adding life to days, not just days to life."

Nairobi Hospice

Story 5. Community involvement

The north of India has a huge population and almost no palliative care services despite enormous levels of need. The Emmanuel Hospital Association (EHA) is a Christian health organisation with a network of hospitals and clinics in that area. EHA took the bold step of integrating palliative care into their existing services starting with a pilot service in a small mission hospital in Lalitpur district. A team was established, led by one of the senior mission doctors. Awareness was raised in and around the hospital through talks and drama presentations. In time, some relatives of patients enrolled into the programme became active volunteers and advocates for the service. Support from outside organisations helped the team at Lalitpur to purchase a vehicle for regular community visits and to develop a small in-patient unit.

- What were the elements needed to get this service started?
- How were the local community involved in developing services?
- Plan a drama, story or song that would help you to publicise the message of palliative care.

"Do small things with great love."

Mother Theresa

Story 6. Scaling up existing services

Visiting, teaching and mentorship played a key role in scaling up palliative care service provision in hospitals through the Evangelical Lutheran Church in Tanzania. Supervisory visits from an established palliative care team included:

- Attending staff devotions,
- Running teaching sessions,
- Home visits working alongside the local team,
- Meeting hospital and church leadership.

Partners of the programme included PEPFAR, FHSSA, APCA, the National Cancer Centre, TPCA and national teaching hospitals. (See the acronyms at the end of this handbook.)

"Being unwanted, unloved and uncared for, forgotten by everybody, I think that is a much greater hunger, a much greater poverty than the person who has nothing to eat."

Mother Theresa

Story 7. Creating space for grace

A group of churches had been working together for a number of years. The group, based in Zimbabwe, was in need of review. Infighting, greed, squabbles and poor leadership had left it morally and financially bankrupt. The leadership, including a number of senior bishops, met to see if a new start was possible. The planning process was led by a new General Secretary, supported by a group of praying women in the community. Over a period of a few days, following review of issues such as God's vision for the group and the historical roots of the organisation, there was a powerful time of prayer and repentance after the morning devotions. The facilitators felt that this marked a spiritual breakthrough, and described the turn-around as 'nothing short of miraculous'.

- What were the problems in this church-based organisation?
- What brought about change?
- Is your organisation in need of critical review?
- What might it take to breathe new life into your organisation?

"The best time to plant a tree was twenty years ago. The second best time is now."

Chinese Proverb

Story 8. Spiritual care teams

The Tanzania Episcopal Conference (TEC) initiated a four-month clinical pastoral education course at Buganda Medical Centre in 1984. Kilimanjaro Christian Medical Centre found funding to support a pastor to complete this training before taking up a full-time post alongside the palliative care team in this large teaching hospital.

- What do you think spiritual care for patients with incurable disease is all about?
- How is spiritual care given to sick people where you are?
- Are any training schemes for spiritual care providers available locally?
- Can your church organisation, diocese or pastorate identify someone to support or train spiritual care providers at your local clinic or hospital?

"My soul is overwhelmed with sorrow to the point of death. Stay here and keep watch with me."

Matthew 26:38

Story 9. Sharing the blessings

Grace was a volunteer for a church-based programme in Tanzania. She had to be creative to visit so many sick people, and so she met them as a group once a week. She visited in their homes any who could not attend the group. She would spend an average of 15 hours a week with her clients, providing physical care, spiritual, social and emotional support. The palliative care training contributed to her confidence in discussing difficult issues like pain and dying with families and palliative care clients. When asked what motivates her, Grace 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."

- What care was Grace able to provide?
- How was she being helped to provide the care?
- What differences had she seen?
- How do you feel about discussing difficult issues with people who are ill?
- How could you develop your confidence in this area? (You may want to refer to "Discussing difficult things" in section 4.)
- How do you feel about receiving from the people you are helping?

"Blessed are those who mourn for they shall be comforted."

Matthew 5:4

Story 10. Everyone wins working together

Palliative care volunteers in Tanzania initiated a savings and loans group. As a result the volunteers are raising pigs and poultry. Others take loans when they are trying to set up small businesses or when they have their own funeral expenses to meet. These groups can provide economic support as well as emotional support, and the scheme may help them to continue to volunteer to care for clients. Nursing staff provide monthly updates and education when the group meets together.

- How do these volunteer groups work?
- What are they able to provide for members?
- Is this something you could start or support in your local church community?
- What would you need to get it started?

Volunteer drop-out is a real issue. There are different ways that volunteers may be encouraged to continue in their key role. Funding can provide a small stipend, a bicycle or a raincoat for when the rains come. Encourage volunteers to work together to come up with a group initiative – perhaps sharing a kitchen or medicinal garden, or developing a small business enterprise together.

"Rejoice with those who rejoice, mourn with those who mourn."

Romans 12:15

Story 11. Celebrating life

In Malawi at the end of the year the home-based care volunteers meet for a party. They hire a local hall and a band and arrange some simple food that everyone can share. Members of the palliative care team from the local clinic are invited to celebrate together with the volunteers and small gifts are given to each of the volunteers.

- What do you think are the benefits of such an event?
- Is there any kind of similar gathering that is organised for those providing palliative care in your area?
- Who might you need to involve to get something like this going?

“There is a time to be born and a time to die, a time for sorrow and a time for laughter.”

Ecclesiastes 3:2

Story 12. Creative response in the city

Twenty years ago a new church was started in an urban area. They moved into premises with spare accommodation to rent out. This opportunity has developed into a hostel ministry providing rooms for those living in remote areas who need somewhere to stay while they visit specialist doctors and nurses in the city hospitals. More recently a purpose-built site has been developed with rooms for more than 150 people.

- In what way is this church serving sick people?
- Are you a city-based church or group?
- Are people from remote rural areas in need of accommodation so that they can get help (e.g. cancer treatment, palliative care or radiotherapy) at the specialist teaching hospitals?
- How could you adapt the ideas from this church to your local setting?

> "It always seems impossible until it is done."
>
> Nelson Mandela

Story 13. Taking church to the hospitals

At Christmas a church choir visited a palliative care clinic at a local hospital to sing to waiting patients. This was an encouragement to the staff at the hospital and to the patients who were waiting to be seen.

- Are there people in your church gifted with singing, music, dance, drama or crafts?
- Could you visit your local hospital to do a performance or put on an event to encourage staff and patients at Christmas or another time?
- How could such an event help with your palliative care programme?

"We love because he first loved us."

1 John 4:19

Story 14. Providing pain relief

Carers in Tanzania struggled to provide pain relief for their patients. This was identified as their number one need. Meetings were held with funding partners, the church health board, diocesan church leaders, health personnel and diocesan home-based care coordinators. A doctor at Bugando Medical Centre began to prescribe morphine for patients needing palliative care offered under the Christian Council of Tanzania's National Health and HIV/ AIDS programme.

- Do your patients get the pain relief they need? (You may want to refer to Why pain relief matters in section 1.)
- Morphine is the drug of choice for severe pain in cancer; it is cheap and recommended by international authorities for medical use. How could you get morphine if you have sick people with severe pain?
- What steps do you need to take to improve the availability of pain medication?
- Who might you need to involve in this process? (Think of a pharmacist, national regulatory bodies such as the police, prescribing personnel and other authorities.)

"If you want to go fast go alone, if you want to go far go together."

African Proverb

Story 15. Meeting basic needs

Staff on the Lalitpur palliative care team in India expressed that sometimes it was difficult to meet all the needs that the patients had. "It can be difficult. Sometimes they expect us to provide a new bathroom, or give other hand-outs." On the other hand the patients also expressed their thanks to the team for their visits, the medicines they gave and the fact that their patient could sleep comfortably with the treatment given.

Poverty is a daily reality in our communities. A large World Health Organisation study on palliative care needs in Africa[2] identified that as well as pain relief, provision of food and lack of money are pressing needs for many patients and families living at home. Our own daily needs and the needs of sick patients and families we care for can sometimes seem overwhelming.

- Make a list of needs that you hear about when you visit sick people.
- How do you help meet the needs of your patients?
- What gaps are there?
- Who else can you involve to help you to meet the needs of your patients?
- What can you do when the needs seem to be overwhelming?

Does the sick person have food and shelter? They may well not take medicines if these basic needs are not seen to. Families are the starting point for identifying support. It is important to meet senior members of the extended family to find out how much they know about the needs of the sick person and how much support they can offer. Traditional authorities and social workers may also help. Despite all this, it can be difficult to meet the needs of some sick people (and families!). Sometimes they are very demanding. Try to help them identify what their main concern is. Discuss this with your team and decide on the best approach.

People's stories

Grace's story: When cancer medicine stops

Grace is in her early twenties. She has a two-year-old child and lives with her mum, dad and four brothers and sisters. She has had cancer for four years. She has been receiving medicine for cancer for over a year but now the family has run out of money, for both the drugs and even for the transport to hospital. The doctors have told her that the medicine is no longer working and she should go home to the village.

- What help do you think she and her family might need at this time?
- Make a list of physical, emotional, social, mental and spiritual challenges that Grace and her family could be facing. (This is called a holistic problem list.)
- How could you find out more about the beliefs of Grace and her family?
- If Grace was a sick person in your community, how would you respond?

Godfrey's story: Pastoral care in hospital

Godfrey is 25. He has TB and HIV as well as cancer. When he leaves hospital he drinks with his friends, steals money from his family and stops taking his medication. As time goes by he gets sicker. When he next comes to the hospital he asks the palliative care team to arrange for the pastor to come and pray with him.

- How would you approach spiritual care for this young man?
- How do you think Jesus may react to his predicament?
- How can we help him to draw closer to God through his problems?
- Could your church provide contacts for local hospitals to use when patients request prayer ministry?

Godfrey reported that he belonged to the Presbyterian church. At the hospital, five days before he died, he requested prayer. When asked what he wanted prayer for he said he wanted to be forgiven. We were able to share the good news that Jesus had died for him and that he could be forgiven. We then prayed with him, asking God to forgive him.

Blessings' story: Children need care too

Blessings is 5 years old. After being unwell at home with a swelling in his face he went to the hospital where his mum was told that he needed to get cancer drugs. The palliative care team at the hospital were able to assess his problems and controlled his pain using oral morphine. After receiving treatment at hospital, Blessings went home. He was well for some months but then he started to have more pain and a bad taste in his mouth.

- Discuss your experiences of looking after children with long term illnesses.
- If Blessings lived in your community, do you know where he would need to go to get morphine and other medicines? How could you find out?
- How could your church support Blessings' mother and her other children?

It's not only adults with progressive incurable diseases who need palliative care. Children need the same approach, including help to reduce their pain and to understand what is happening to them. We must find and involve the main carer (usually the mother) at all stages of the illness.

Peter's story: Healing the heart

Peter is a 58-year-old man who is an elder in his church. He has recently been told that he has an HIV-related cancer. During discussions he is asked if there are any spiritual issues that you can help with. He says he is scared. He explains that his wife died of an AIDS-related illness 8 years ago. He says, "I don't know if I can be forgiven for what I have done. My wife died because I was sleeping with other women. She was a good lady and all the family miss her. I feel very bad."

- What issues does this story raise?
- Why might Peter be scared?
- Discuss how you would respond to Peter's story and what help you could offer.

"Praise be to the God and father of our Lord Jesus Christ, the Father of compassion and the God of all comfort, who comforts us in all our troubles, so that we can comfort those in any trouble with the comfort we ourselves have received from God."

2 Corinthians 1:3-4

4

Resources for action

This section includes the following:

i. Making an action plan

As a church group, pastor or health board, use this simple tool to note down your current situation, what you would like to do and steps to get you there.

ii. Bible study

Psalm 38 helps us to consider the range of physical, mental, social and spiritual suffering that people feel during difficult times. This study, based on the psalm, considers ways that we can bring hope and accompany sick people on their difficult journey with incurable illness. It can be used by individuals or in a group.

iii. Discussing difficult things

Most of us find it uncomfortable to discuss sensitive issues affecting those who are living with an incurable condition. However pastors, church leaders and those in our congregations with some counselling experience or training should have skills to help people to express their concerns in a supportive environment. ASK – ASK – TELL, ASK – ASK – PLAN gives a structure for such conversations. It was originally designed for the 'breaking bad news' interview but may be applicable in a variety of settings. This section includes some practice role-plays.

iv. Organising pain relief

Management of pain is a key foundation in palliative care. Learn more about why this is so important.

i. Making an action plan[24,25]

Assign someone the task of recording the following information:

1. Date of meeting
2. People present
3. Church roles or which ministry area they represent
4. Answers to the questions below (a to g)
5. Completed goal planning tool (h)
6. Date of next meeting

Answer the following questions. You may wish to refer to your answers from section 3 and the examples provided below in italics.

a) What are you doing at the moment to help people with incurable illnesses?

(e.g.prayer for sick church members, visiting, home-based care, clinic facilities)

-
-
-

b) List below anything else you would like to do – these are your goals

(e.g. offer prayer/food/transport to clinic to all people with progressive incurable illnesses in our area; starting day care in church building once a week)

-
-
-

c) List steps that are required to help you achieve each goal.

GOAL :

- Step 1 :
- Step 2 :
- Step 3 :
- Step 4 :
- Step 5 :

Example

GOAL : Offer prayer to all with progressive incurable diseases in your area.

- Step 1 : Discuss with Pastor/church leadership
- Step 2 : Meet local/traditional authorities to explain plans
- Step 3 : Meet together as a team to discuss who will work in which area.
- Step 4 : Meet local clinic staff to ask them to provide referrals of suitable people who would like prayer.
- Step 5 : After 3 months, review progress.

d) What resources do you have to make a start?

(People, practical skills and space as well as financial resources)

-
-
-

e) What resources might you need? Where might you get these resources?

(E.g., people, time, space, permission, training courses, money)

-
-
-
-
-
-

f) Who else do you need to involve in your planning?

-
-
-

g) Who will take responsibility for completion of tasks?

(E.g. board of deacons, elders, pastor, ladies' ministry leader.)

h) As a group, draw up and complete this table as much as you can.

The planning tool on the next page is designed to be photocopied or copied out onto a large sheet of paper/blackboard.

Goal				
	Details of the steps above	To be completed by (date)	Who is responsible (write names below)	General comments/ resources needed
Step 1				
Step 2				
Step 3				
Step 4				
Step 5 Review Meeting*				

*Use this meeting to discuss how far you have got towards achieving your goal.

ii. Bible study[26]

Bring to mind someone (perhaps a family member or someone in your community) who was suffering from an incurable disease.

Reflection: What do you remember of that? How did that experience make you feel?

Read Psalm 38

[1] Lord, do not rebuke me in your anger
or discipline me in your wrath.
[2] Your arrows have pierced me,
and your hand has come down on me.
[3] Because of your wrath there is no health in my body;
there is no soundness in my bones because of my sin.
[4] My guilt has overwhelmed me
like a burden too heavy to bear.

[5] My wounds fester and are loathsome
because of my sinful folly.
[6] I am bowed down and brought very low;
all day long I go about mourning.
[7] My back is filled with searing pain;
there is no health in my body.
[8] I am feeble and utterly crushed;
I groan in anguish of heart.

[9] All my longings lie open before you, Lord;
my sighing is not hidden from you.
[10] My heart pounds, my strength fails me;
even the light has gone from my eyes.
[11] My friends and companions avoid me because of my wounds;
my neighbors stay far away.
[12] Those who want to kill me set their traps,
those who would harm me talk of my ruin;
all day long they scheme and lie.

[13] I am like the deaf, who cannot hear,
like the mute, who cannot speak;
[14] I have become like one who does not hear,
whose mouth can offer no reply.
[15] Lord, I wait for you;
you will answer, Lord my God.
[16] For I said, "Do not let them gloat

or exalt themselves over me
when my feet slip."

[17] *For I am about to fall,*
and my pain is ever with me.
[18] *I confess my iniquity;*
I am troubled by my sin.
[19] *Many have become my enemies without cause;*
those who hate me without reason are numerous.
[20] *Those who repay my good with evil*
lodge accusations against me,
though I seek only to do what is good.

[21] *Lord, do not forsake me;*
do not be far from me, my God.
[22] *Come quickly to help me,*
my Lord and my Savior.

Though this psalm is not specifically referenced to someone suffering with an incurable disease, the level of physical, moral, social and emotional torment expressed reflect some of the experiences and feelings expressed by those living with long term illness, including the problem of severe pain.

Read the psalm again, this time noting the different areas of life which are affected for the writer. His final plea is that the Lord should not forsake him, but should come quickly to help him (v 21-22).

Palliative care seeks to address pain – physical, emotional, social and spiritual – and other symptoms for those with progressive incurable diseases. It requires the involvement of many different individuals, starting with the sick person, and including health workers and others, and working closely with family members. Traditional authorities (chiefs) and spiritual leaders play an important role in the identification of services at community level when our team is trying to find carers for a sick person discharged from hospital.

Finding hope...

Dame Cicely Saunders, the founder of the modern hospice palliative care movement, said: 'You matter because you are you, you matter until the last moment of your life and we will do all that we can to help you to live until you die.'

Read 1 Corinthians 15:19-22, 2 Timothy 1:10

[19]If only for this life we have hope in Christ, we are of all people most to be pitied.

[20] But Christ has indeed been raised from the dead, the firstfruits of those who have fallen asleep. [21] For since death came through a man, the resurrection of the dead comes also through a man. [22] For as in Adam all die, so in Christ all will be made alive.

1 Corinthians 15:19-21

but it has now been revealed through the appearing of our Savior, Christ Jesus, who has destroyed death and has brought life and immortality to light through the gospel.

2 Timothy 1:10

Many of us find it hard to spend time with those who are living with an incurable condition. Maybe we feel we don't have much to offer. Maybe it brings our mortality too clearly into focus.

Christians have a lot to offer people (of all faiths and none) who are struggling with incurable disease. We know a clear hope beyond the here and now, the firm promise of eternal life with God. We may or may not have the chance to share this hope with those who suffer, but it can help us to support those in need, leading us towards rather than away from them.

Read Mark 14: 38

Watch and pray so that you will not fall into temptation. The spirit is willing, but the flesh is weak.

Mark 14:38

In his hour of greatest need in the garden of Gethsemane, Jesus asked his disciples to watch and pray. For many people, watching ('being present with') and praying can be ways for us to show love and bring hope, dispelling the clouds of despair and depression which can accompany a failing body. Jesus' love never fails, and continues even beyond the grave.

iii. Discussing difficult things

Reflect on the manner in which Jesus prepared himself during his final days on earth: Jesus spoke truthfully to his closest friends about the fact that he was going to die, though they were unwilling to grasp the warnings he gave them (Matthew 16:21, John 24:6, 7).

When we visit people we spend time chatting, catching up with news, sharing jokes and opinions, providing company, friendship and distraction. However, from time to time we need to be able to talk to sick people and their families about more sensitive topics. This resource is designed to help guide us through such conversations, giving us a structure that we can practise and think through in advance. It is important that we can tell the truth to people, when they are ready and in a way that they can understand, giving them the chance to ask questions, in order to clarify issues which are troubling them. Most people like to have information when offered. Others do not and there is no need to force information on people if they don't want it. We may prefer to give information to family members but we must be guided by the wishes of the sick person in terms of who is given information about their illness. We have a duty to maintain confidentiality (i.e. not to share personal information without permission from the individual concerned), otherwise sick people and their families

cannot trust us or share things which really matter to them.

Beliefs about talking about serious illness and death vary between different societies. Some feel that this may speed up the process of decline, removing all sense of hope. These topics are sensitive and need to be handled with care. People often remember very clearly what was said to them around a time of crisis, whether it was helpful or not! This does not mean that we should avoid discussing difficult things, since giving false hope helps no one. People are often aware when they are approaching the end, and it only adds to their anxiety and sense of isolation if there is no one they can discuss this with.

This teaching guide is designed for use by pastors and church leaders who are looked to by their congregation as a reliable, compassionate source of information.

An outline of a simple structure for discussing difficult issues can be found on the next page.

Useful topics for discussion include:

- How do they feel about what's wrong?
- What do they know about their illness?
- What are their expectations and plans for the future?
- Is there anything they would like to do, say or prepare before they die?

ASK – ASK – TELL, ASK – ASK – PLAN

ASK

Ask yourself...

- Is this the right place?
- Am I the right person?
- Do I have time?
- Is my mobile phone switched off?
- Do I have any urgent engagements to attend to?

ASK

Ask the person/people you are with...

- What do they understand about what is wrong with them?
- Would they like to know more?
- Would they like someone else to be with them?

TELL

Tell the person (or people, depending on the request of the person with the illness)...

- in simple language, what is wrong.
- Be brief, clear and honest, leaving room for hope.

Then wait...
and observe any response...
Allow time for silence.

ASK

Ask the person...

- Do they understand what you have just told them?

(Explain any technical words such as HIV or cancer which may be unfamiliar or may bring confusion.)

ASK

Ask the person...

- Do they have any questions?
- What is their main concern?

PLAN

Plan with the person...

- What is the plan from now?
- How can we address their main concerns? Who will see them and when?

Role-play 1

Harriet is 45. She is a widow with 6 children, the youngest of whom has just finished primary school. She has been ill for 5 years with breast cancer. Three years ago she had an operation but now the swelling has come back in her breast and is affecting her right arm. She has been sent home from the teaching hospital in the capital city where they said they could not do any more unless she goes to the neighbouring country for treatment, which will cost more than one year's savings. When she came home, your home-based care team referred her to the palliative care nurse at the local clinic. He assessed her pain and Harriet is now taking morphine to control her pain. Harriet is finding it difficult to spend more than two or three hours out of bed and her arm is useless. She is worried that the growth is getting bigger. Her neighbour has suggested that Harriet should sell her cattle to raise money so that the witchdoctor can come.

You are the pastor visiting Harriet at home as part of the prayer support team. Just before you leave, Harriet quietly asks you, "Pastor, how do you think I can be helped with this problem? What do you think I should do?"

- As a group go through the ASK-ASK-TELL, ASK-ASK-PLAN outline.
- Role-play the conversation between Harriet and the pastor.
- Discuss how this went and give feedback on ways it might have been improved.
- Make up a scenario from your own experience for another role-play.

Role-play 2

You are called to the home of Elijah Banda, a 68-year-old man who has been an elder in the church for the past 24 years. He has recently been nursing his wife Ellen who has been sick for some 12 years following a stroke. Her son and daughter are visiting because she has been less well for the past week with breathing difficulties. As you enter the house, her son Peter takes you to one side. "My mother has just passed away. My father doesn't seem to realise it's finally over. Please can you help us to tell him?"

- As a group, go through the ASK-ASK-TELL, ASK-ASK-PLAN outline.
- Role-play the conversation between Elijah, the pastor and his son.
- Discuss how this went and give feedback on ways it might have been improved.
- Make up a scenario from your own experience for another role-play.

5

References, contacts and tools

References

All bible quotations are taken from the New International Version, International Bible Society 2004 unless otherwise stated.

Section 1

1. Adapted from Palliative care: a field guide for community home based care volunteers. Anna Anderson 2008
2. http://www.who.int/cancer/palliative/definition/en/
3. http://www.who.int/hiv/pub/imai/genericpalliative care082004.pdf
4. Foley K.M., Wagner J.L., Joranson D.E., Gelband H.. Pain Control for People with Cancer and AIDS. Disease Control Priorities in Developing Countries. 2nd ed. New York: Oxford University Press; 2006. p. 981–94
http://www.gapri.org/sites/default/files/private/Fact%20 sheet_0.pdf
http://www.gapri.org/understand-problem
5. http://www.painpolicy.wisc.edu/sites/www.painpolicy.wisc.edu/files/lancet1.pdf3. I was sick and you cared for me : a church-based response to palliative care in Tanzania, Tearfund 2011, from http://www.ipcrc.net/pdfs/i-was-sick-and-you-cared-for-me_%20A-church-based-response-to-palliative-care-in-Tanzania.pdf
4. Integrating Palliative care into HIV services: a practical toolkit for implementers : available from www.fhi.org
5. Ecumenical Initiative for HIV and AIDS in Africa http://www.oikoumene.org/en/programmes/justice-diakonia-and-responsibility-for-creation/hivaids-initiative-in-africa-ehaia.html
6. Strategies for Hope publications: http://www.stratshope.org/index.htm
7. Spiritual Care recommendations for people receiving palliative care in Sub-Saharan Africa, Kings College London: available from http://www.csi.kcl.ac.uk/spiritualcare.html
8. Faith untapped: why churches can play a crucial role in tackling HIV and AIDS in Africa, Tearfund: http://www.anglicanhealth.org/Resources/PDF/AHNresources/

Faithandhealthcare/Faithuntapped,WhyChurchesCanPlaya CrucialRoleinTacklingHIVandAIDSinAfrica
9. Linda L Emanuel, S. Lawrence Librach; Palliative Care: Core Skills and clinical competencies. Saunders, Elsevier 2007

Section 2

10. Living Prayer, Robert Benson, Doctors life support 2. ICMDA 2002
11. J.R. Woodward (http://jrwoodward.net/2013/03/easter-prayers/)
12. Our Greatest Gift: A meditation on dying and caring. Henri J.M. Nouwen. Hodder and Stoughton 2002

Section 3

13. Church involvement in Palliative care in Zambia. D Satela http://www.iasociety.org/Abstracts/A200716025.aspx
14. Audacity to Love: The Story of Hospice Africa. Dr Anne Merriman 2010
15. Getting Started ; Guidelines and suggestions for those starting a hospice/palliative care service 2ndedn: http://hospicecare.com/uploads/2011/9/IAHPC_Getting_Started_2nd_ed.pdf
16. Evangelical Lutheran Church of Tanzania Palliative care report 2008 http://health.elct.org/projects/Pallitative%20Care%20Annual%20report%202008.pdf
17. Creating Space for Grace, God's Power in Organisational Change. Rick James. Swedish Mission Council 2004
18. http://www.bugandomedicalcentre.go.tz/training.htm
19. Information from Christian Outreach Centre, Darwin, used with kind permission.
20. A Community Health Approach to Palliative Care for HIV/AIDS and Cancer Patients, World Health Organisation: http://www.who.int/hiv/pub/prev_care/en/palliative.pdf

Section 4

24. Tearfund International Learning Zone (TILZ) has a number of useful planning resources e.g. http://tilz.tearfund.org/Churches/Church+mobilisation/Issue-focused+church+mobilisation.htm
25. Detailed outline of church-based HIV planning process which may be adapted for palliative care: http://hivaids.anglicancom munion.org/resources/docs/guide.pdf
26. First published in Footsteps 87, January 2012. Tearfund International Learning Zone
http://tilz.tearfund.org/Publications/Footsteps+81-90/Foot steps+87/

Other useful contacts and tools:

Publications

Palliative care toolkit - a training manual and guide to provision of palliative care in low resource settings:
http://www.helpthehospices.org.uk/about-us/international/what-we-do-internationally/education-and-training/palliative-care-toolkit/

Ecumenical Initiative for HIV and AIDS in Africa:
http://www.oikoumene.org/en/programmes/justice-diakonia-and-responsibility-for-creation/hivaids-initiative-in-africa-ehaia.html

Strategies for Hope publications:
http://www.stratshope.org/index.htm

Mainstreaming HIV and AIDS in theological education: experiences and explorations (http://www.oikoumene.org/fileadmin/files/wcc-main/documents/p4/ehaia/Mainstreaming_HIV_and_AIDS_in_Theological_Education.pdf)

HIV, Health and your community: a guide for action. Reuben Granich and Johnathan Mermin. 2001

Beating Pain. A pocket guide for pain management in Africa. African Palliative Care Association. 2010.

Websites

APCA: African Palliative Care Association:
http://www.africanpalliativecare.org/

FHSSA: Foundation for Hospices in Sub-Saharan Africa, which offers opportunities for links and support with US-based hospice programmes:
http://www.fhssa.org/i4a/pages/index.cfm?pageid=1

Palliative Care Works: a group of people experienced in international palliative care training who can support and facilitate training events on request:
http://www.palliativecareworks.org/

Acronyms

AIDS: Acquired Immunodeficiency Syndrome
APCA: African Palliative Care Association
ARV: Antiretroviral
FHSSA: Foundation for Hospices in Sub-Saharan Africa
HAART: Highly Active Antiretroviral Treatment
HIV: Human Immunodeficiency Virus
PEPFAR: U.S. President's Emergency Plan for AIDS Relief
TB: Tuberculosis
TPCA: Tanzania Palliative Care Association

About EMMS International

EMMSInternational
Health for Today, Hope for Tomorrow

EMMS International is a Christian international healthcare charity founded in 1841. EMMS International works with partners in India, Malawi and Nepal to improve health and healthcare, and facilitates respite for people in Scotland with serious illnesses.

EMMS International operates three programmes: Palliative Care, Maternal and Child Health, and Addressing Disease and Disability.

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"This handbook is a wonderful guide to how we can communicate Christ's tender compassion and care, which circumstances cannot diminish, to those who are coming to the end of their lives.

"In clear, tangible, down-to-earth, ways, it assists church communities, leaders and members to understand more about palliative care, and how we can best contribute. It helps us review what we are currently doing and provides resources so that we may be more effectively engaged."

Most Rev Thabo Makgoba,
Archbishop of Capetown

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