African Palliative Care Association

Palliative care for women living with HIV

Basic Information for women in communities
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FOREWORD

The Joint United Nations Programme on HIV/AIDS (UNAIDS, 2011) estimated that at the end of 2010 there were 34 million adults worldwide living with HIV and AIDS out of which 70% are in Africa and 50% are women. The AIDS epidemic has had a unique impact on women, which has been made worse by their role within society and their biological vulnerability to HIV infection. Generally women are at a greater risk of heterosexual transmission of HIV and are twice as likely to become infected with HIV through unprotected heterosexual intercourse than men. UNAIDS (2012) estimates that women account for 58% of people living with HIV in sub-Saharan Africa and in most countries less than 50% of young women have comprehensive and correct knowledge about HIV. In most cultures, women are less likely to be able to negotiate condom use and are more likely to be subjected to non-consensual sex. More importantly, women’s childbearing role means that they have to deal with issues such as mother-to-child transmission of HIV. The responsibility for caring for AIDS patients and orphans is also an issue that has a greater effect on women.

Sometimes, women infected by HIV do not access proper care due to their various responsibilities. There are a number of things that can be done in order to reduce the burden of the epidemic among women. These could include providing access to anti-retroviral therapy (ART), palliative care and promoting and protecting women’s human rights, increasing education and awareness among women and encouraging the development of new preventative technologies.

More generally though for patients with HIV infection, studies have shown that pain is present throughout the disease trajectory. At least 80% of those with advanced disease experience moderate to severe pain. In addition patients on anti-retroviral therapy (ART) experience chronic symptoms such as fatigue, anorexia, nausea and vomiting. Consequently, the World Health Organization (WHO) has identified palliative care as an essential component of comprehensive HIV care not only to address pain but also to deal with the burdensome symptoms which people living with HIV experience as well as other spiritual, social and psychological issues. It is therefore important to pay attention to the benefits of palliative care for patients with HIV disease in improving their quality of life and addressing adherence issues and other complex psychosocial issues faced by patients living with HIV.

This monograph therefore discusses some of the benefits of palliative care for women living with HIV and AIDS and provides some case studies of real women who have had experience of palliative care. This information is intended to help women living with HIV, their families and others in the community who support them to understand their illness and to help address some of the questions they might have with regard to the illness and how they can get help. It is acknowledged that individual situations might require specific information other than what is provided here in this document. We hope that women living with HIV and AIDS, community members and health professionals working with them will find this a useful resource in addressing complex questions in a simple and straightforward manner.

Dr. Emmanuel Luyirika
Executive Director
African Palliative Care Association (APCA)
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## ACROYNMS

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ART</td>
<td>Anti-retroviral Therapy</td>
</tr>
<tr>
<td>IUD</td>
<td>Intra Uterine Device</td>
</tr>
<tr>
<td>PID</td>
<td>Pelvic Inflammatory Disease</td>
</tr>
<tr>
<td>PLHIV</td>
<td>People Living with HIV</td>
</tr>
<tr>
<td>PMTCT</td>
<td>Prevention of Mother- to- Child Transmission</td>
</tr>
<tr>
<td>SAfAIDS</td>
<td>Southern Africa HIV &amp; AIDS Information Dissemination Service</td>
</tr>
<tr>
<td>STIs</td>
<td>Sexually Transmitted Infections</td>
</tr>
<tr>
<td>TB</td>
<td>Tuberculosis</td>
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<tr>
<td>UNAIDS</td>
<td>United Nations Programme on HIV/AIDS</td>
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<tr>
<td>WLHIV</td>
<td>Women Living with HIV</td>
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Palliative Care for Positive Living

INTRODUCTION

The information in this booklet is intended to help women living with Human Immunodeficiency Virus (HIV) and others in the community who support them. Individual situations might require specific information other than what is provided here. This document provides a good start towards understanding the role of palliative care for women living with HIV (WLHIV), their families, caregivers and health professionals.

You can use this information:

- As an individual to make good decisions;
- During information sharing within a support group;
- While providing health services to give take home messages; and
- As an advocacy tool to help others support quality care for WLHIV.
HIV stands for Human Immunodeficiency Virus. It is a virus that destroys the body’s defence system. It is spread through three main ways:

1. Body fluids from having sex without a condom (unprotected sex);
2. Getting in contact with HIV-infected blood when the skin has cuts or injury with instruments such as needles and blades which are contaminated with infected blood; and
3. From mother to baby through pregnancy, childbirth or breast feeding.

The only way anyone can be sure she has HIV is to get tested for HIV by a health-care worker trained in the use of the testing kits. There is no other way to know for sure apart from being tested. HIV can be treated with medicine known as ART (Anti-retroviral Therapy) that makes the virus stop growing and multiplying in the body even though the virus does not completely go out of the body; HIV cannot be cured. These medicines are not a cure but if taken correctly they help people to live a better and normal life. In view of this, these medicines are very important and they must be taken as prescribed without missing any doses. If someone stops taking the medicines, the virus starts growing and multiplying again and this may lead to development of resistance to the medicines and the deterioration of the person’s health.

2.1 What can I do if I have HIV?

Once you know you have HIV, you can keep healthy and prevent spreading it to others by:

1. Ensuring that you visit a medical doctor who treats HIV;
2. Taking your antiretroviral medicines as prescribed by the health professionals;
3. Avoiding other opportunistic illnesses by:
   - Observing good hygiene;
   - Using an insecticide-treated mosquito net to avoid malaria;
   - Using Cotrimoxazole to prevent opportunistic infections;
   - Practicing healthy habits such as eating good healthy foods and drinking fully boiled water;
   - Only having safe sex, using a condom, and having one partner; and
   - Having any infections treated immediately, particularly sexually transmitted infections (STIs).
Women with HIV have the same sexual and reproductive health needs and experiences as other women. However, some effects of HIV and ART medicines can create problems unique to WLHIV. For all women, it is helpful to know the various stages of the life cycle as summarised in Table One below.

**Table One: Life cycle of a Woman**

<table>
<thead>
<tr>
<th>Life cycle stage</th>
<th>Usual features of the stage</th>
<th>Specific effects of HIV on girls and women</th>
<th>ARV effects and what to do</th>
</tr>
</thead>
</table>
| **Teenage (12-15 years)** | Rapid body growth and change in body features  
Menstrual periods start, may be irregular till much later in teens | Rate of growth may be stunted, damaged immune system may cause hormonal imbalance and menstrual changes – irregular periods or unusually heavy or light periods or no periods at all. Being prone to depression. | Changes in body weight with different fat distribution  
Missing periods or heavy flow |
| **Child bearing age (15-49 years)** | Sexually active reproductive system matures.  
• Menstruation is normal and regular, although individual patterns vary and may include emotional and physical discomfort  
• Sexual activity depends on lifestyle, availability of partners and marriage  
• Possibly miscarriages or therapeutic abortion  
• Possibly unwanted pregnancies  
• Possibly STIs  
• Variations in libido between individuals, time and context. | In addition to the above, hormonal imbalance.  
Some women have reduced sexual desire immediately after learning about their HIV positive status. This may go back to normal after acceptance of their status. | There might be changes in the menstrual flow, but ART medicines should continue to be taken even if there is no sexual activity. The health worker needs to be informed about unusual changes. |
<table>
<thead>
<tr>
<th>Life cycle stage</th>
<th>Usual features of the stage</th>
<th>Specific effects of HIV on girls and women</th>
<th>ARV effects and what to do</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child bearing age (15-49 years)</td>
<td>Contraceptive use</td>
<td>Depending on what contraceptive method is used, the menstrual cycle may be affected. For example periods may be heavier, longer and sporadic. Some contraceptive methods such as the IUD may increase the risk of infections. Some reproductive health problems are made worse by HIV infection if not properly treated e.g. Pelvic Inflammatory Disease (PID) which is an infection of the womb (uterus) and Fallopian tubes and can lead to infertility.</td>
<td>Discuss with your doctor about taking a contraceptive method that suits your situation, especially if you are taking hormonal contraception and ART. Note that hormonal contraceptives and contraceptive devices do not prevent HIV transmission, and should therefore be used in conjunction with a barrier contraceptive (female and male condoms) for greater protection.</td>
</tr>
<tr>
<td></td>
<td>Pregnancy</td>
<td>There is a risk of transmitting HIV from an HIV positive mother to her child during pregnancy, childbirth and breast-feeding. The risk is significantly reduced by PMTCT methods that include taking medicines during and after pregnancy and delivery.</td>
<td>Inform your doctor about the pregnancy as soon as you suspect you could be pregnant but do not stop taking your medicines. Other ART medicines may be taken to prevent mother to child transmission of HIV (PMTCT). Make use of this service and seek advice from your doctor.</td>
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<td></td>
<td>Breastfeeding</td>
<td>The World Health Organization advises that mothers who are HIV-infected should exclusively breastfeed their infants for the first 6 months of life, introducing appropriate complementary foods thereafter, and continue breastfeeding for the first 12 months of life. Breastfeeding should then only stop once a nutritionally adequate and safe diet without breast milk can be provided. It has been clearly shown that when anti-retrovirals are taken through the pregnancy and breastfeeding stage, there is a greatly reduced HIV transmission rate. Some women who have the means may opt not to breastfeed at all. However, this is costly and can put the baby at risk of death because of inadequate or inappropriate feeding or improper hygiene.</td>
<td>Breast feeding women can safely take ART medicines. There must however be 100 percent adherence to taking the drugs correctly, otherwise there is a risk that the baby will become infected with HIV or resistant to the medication. There needs to be good support for mothers to help them adhere to an extended drug regimen as well as keeping to 6 months of exclusive breastfeeding.</td>
</tr>
<tr>
<td>Life cycle stage</td>
<td>Usual features of the stage</td>
<td>Specific effects of HIV on girls and women</td>
<td>ARV effects and what to do</td>
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</tbody>
</table>
| **Midlife** (45-55 years) | Menopause  
Symptoms of menopause may include:  
- Less frequent menstrual periods which eventually stop  
- Dry vagina  
- Hot flushes  
- Lack of sexual desire  
- Increased frequency of passing urine  
- Sleep disorders  
- Osteoporosis (weakening of the bones)  
- Depression and mood changes  
- Aging skin which may become dry and/or spotty | HIV may lead to early menopause and make usual menopausal symptoms appear worse. | Menopause and some ART medicines may contribute to weakening of the bones (osteoeroporosis). |

Adapted from *HIV and AIDS Treatment Literacy Toolkit for Women, SAfAIDS*
4 What is palliative care?

DEFINITION OF PALLIATIVE CARE

Palliative care helps people with a life limiting illness to live better through helping with pain, symptoms, worrying about life, death and other problems that come with serious illness. Think of palliative care as your friend who helps you along the way in good and not so good times. Palliative care can help you and your family from the early days of learning about HIV – through years of healthy living. Although antiretroviral treatment can help you to live healthier for longer, when the treatment runs out, palliative care can continue to ensure that you have the best possible quality of life. For those who do not respond to treatment and continue to get very ill, this is when the palliative care team can help you to have quality care, assist your family and prepare for the end of life.

4.1 Where is palliative care provided?

Palliative care can be provided at home, in the hospital, by a hospice service and at the clinic.

4.2 Who provides palliative care?

Palliative care is given by a team of people with different skills who are there to support you. You may not need all the team members at the same time but they are there should you need them. The team may include a doctor, social worker, community caregiver, spiritual leader, physiotherapist, nurse, counsellor and volunteer. Sometimes it is not possible to have such a big team but by connecting you to other service providers in the community, different needs can be met. See figure below

4.3 Who provides palliative care in your country?

There are many palliative care providers across Africa. To get information on where these services can be found in your country, please contact the African Palliative Care Association who will be able to help you.
### 4.4 What can palliative care do for women with HIV?

Palliative care benefits women living with HIV plus their families by providing the best possible quality of life. Palliative care does not prolong life but supports the individual and the family with physical, social, spiritual and psychological concerns during the illness and in bereavement. Furthermore, palliative care for HIV not only enhances quality of life and reduces depression but has a survival benefit. The table below shows how the palliative care team can help.

**Table Two: Palliative care team members, what they do and why they do it**

<table>
<thead>
<tr>
<th>Team Members</th>
<th>What they do (some examples)</th>
<th>Why they do it</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Clinic staff – Nurses, Doctors, Pharmacists, clinical officers and other health professionals</strong></td>
<td>Assess you regularly</td>
<td>• To get a full picture of your condition</td>
</tr>
<tr>
<td></td>
<td>Prescribe medications</td>
<td>• To treat or prevent infections, relieve symptoms and pain</td>
</tr>
<tr>
<td></td>
<td>Refer or link you to other services for holistic care</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Diagnose (find out) what is wrong</td>
<td>• To let you know what is wrong with you</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• To suggest what to do to feel better and avoid problems.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• To discuss any information you might need to know with regard to your illness</td>
</tr>
<tr>
<td></td>
<td>Give sexual reproductive health information on family planning, PMTCT, cervical cancer screening</td>
<td>• To be able to plan or prevent pregnancies</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• To prevent cervical cancer</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• To eliminate mother to child transmission of HIV</td>
</tr>
<tr>
<td></td>
<td>Give ART and prevent mother to child transmission of HIV (PMTCT)</td>
<td>• To prevent HIV infection passing to your child and to reduce HIV infection in your body</td>
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<tr>
<td></td>
<td></td>
<td>• Improve quality of life and reduce the risk of death</td>
</tr>
<tr>
<td><strong>Social Workers/ Counsellors</strong></td>
<td>Assess you regularly and help you to talk about your problems</td>
<td>• To get a full picture of your situation and to help you express emotions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• To help you find solutions to your problems and/or get help</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• To talk about your family situation and any concerns with regard to children, partners or wider family</td>
</tr>
<tr>
<td></td>
<td>Support you to make and implement informed decisions</td>
<td>• To help you get accurate information and use it to make and implement decisions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• To help you own your decisions and take responsibility for your actions</td>
</tr>
</tbody>
</table>
### Spiritual Counsellors

<table>
<thead>
<tr>
<th>Task</th>
<th>Support</th>
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</thead>
</table>
| Talk with you/visit you and your family | • To help with worries you may have about spirituality/God, life, death, bereavement  
• To help you understand how the illness has impacted on your beliefs |
| Support your spiritual needs            | • To practice your faith as you wish which may involve praying and/or other rituals. |

### Caregivers

<table>
<thead>
<tr>
<th>Task</th>
<th>Support</th>
</tr>
</thead>
</table>
| Visit you and your family at home when you feel ill, take you to the clinic for review | • To help with basic nursing and other support  
• Support you to adhere to your medications |
| Show your family how to give care       | • To help you and your family to know what to do so you can be well taken care of at home and know when to get other help |

### Support Groups

<table>
<thead>
<tr>
<th>Task</th>
<th>Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meet and encourage each other</td>
<td>• To share with others and encourage living long and healthy lives</td>
</tr>
</tbody>
</table>

### Community Leaders

<table>
<thead>
<tr>
<th>Task</th>
<th>Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Speak to community members to make them aware of needs of PLHIV</td>
<td>• To create understanding and helpful attitudes and actions from community members</td>
</tr>
</tbody>
</table>

### All team members

<table>
<thead>
<tr>
<th>Task</th>
<th>Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Link you to the help you need</td>
<td>• To make sure your needs are taken care of in the best possible way</td>
</tr>
</tbody>
</table>
Women with HIV may need palliative care at various times in their lives as told by these women who met each other at the local clinic. The names of these women have been changed to protect their identity. Their stories are told to show how you too can benefit from palliative care.

**CASE STUDY ONE**

**MARTHA**

Martha, a 43 year old widow told us “I came to the clinic because I was having a bad cough for a long time. When they tested me for TB they also tested me for HIV. I found out I have both. I was shocked when they told me. From the TB medicine I have had problems with feeling sick and having a skin rash. They changed my medicine and told me to make sure I eat before I take it. The palliative care visitor also helps me to understand the importance of keeping things clean, drinking safe water and eating a healthy (balanced) diet.

One year later

Martha’s community caregiver, Shirley shares

“I enjoyed helping Martha. At first she was very scared as she did not really understand her illness and was afraid that she would die and leave her children alone. We would meet once a week at first and we would discuss her fears and concerns as well as immediate disease related problems. As we continued meeting and addressing her concerns, Martha started to live a fuller life and was no longer afraid. Martha’s key concerns were; her children, her God, the problems she had with her medications, some pain that she was experiencing in her lower limbs and she had also not accepted her diagnosis thinking that she was bewitched. We had many opportunities to address all her concerns through our palliative care team and we also linked her to a local community care worker who helped when she was very weak. Although her immediate concerns, pain and symptoms were addressed, we found that she had developed a serious cancer that is often found with people with HIV called Kaposi Sarcoma. By the time this was discovered it could not be treated and she died after one year. Before she died we helped her with medicine for pain, the loan of a wheelchair so she could go outside and she also wrote a will so her children who live far away knew what she wanted. Through palliative care she was able to be at peace in all ways before she died. We talked about her life and how she felt a need to talk with her pastor. He came often too as part of our team. After she died, the children were counselled by the social worker. They learned that it is ok to share their sadness with others. It will take time for them to feel better but it helps that Martha died peacefully. I miss her, she was a lovely woman.”

Key messages from Martha’s story:

- You do not need to be in pain – there are medicines that will help take pain away.
- Ask questions about your health, your body, your future.
- It helps to share your problems with others

Remember to ask your Palliative care provider:

- What are the signs of TB?
- Can I be tested for TB?
- What are the signs of Kaposi Sarcoma?
- How can I be diagnosed for it?
- What is the right way to take my ARTs?
- Where are other resources that can help me?
Palliative care for women living with HIV

**CASE STUDY TWO**

**PATRICIA**

“I am Patricia. I met Martha at the clinic when I went for my check-ups while pregnant (pre-natal check-ups). I am 23 years old and pregnant for the first time. I found out I am HIV+ at the same time I found out I was pregnant. I was so upset. But the counsellor suggested I bring my partner, Freddy, the baby’s father to also be tested. But he refused. After disclosing I am HIV+ to him he left and I haven’t seen him for 3 months. Naturally I became very sad. But the clinic sister helped me to meet with a palliative care social worker who helped me to understand that my baby may not get HIV if I get help through PMTCT (prevention of mother-to-child transmission). This is when they will give me medicine that helps prevent HIV from me to my baby. He also helped me to think about family planning so I will be better prepared in the future. Because of palliative care I am no longer sad or lonely – I now go to a support group and we all are good friends.”

**Later**

Barnabas Patricia’s social worker has this to say; “Patricia delivered a very healthy baby boy and through the HIV test for babies we know he is HIV negative. She gave him only breast milk for the first six months and he is growing bigger every day. She takes her ARVs correctly and keeps clinic appointments. Patricia is using the pill for birth control and she will be taking a sewing course through a support group I suggested she join. Patricia is also beginning to be closer to her family members who are helpful to her – she no longer feels ashamed. I also managed to track down Freddy and after counselling him, he is supportive to Patricia again. She is proud of being a “positive” good mother.”

**Key messages from Patricia’s story**

- Plan your pregnancy
- Contact the prevention of mother to child transmission services (PMTCT) when you are pregnant
- Only give breast milk to your baby for the first 6 months
- Use barrier method of contraception to avoid further unwanted pregnancies and limit cross transmission of HIV

**Remember to ask your palliative care provider:**

- When can my baby be tested for HIV?
- When is the best time for me to become pregnant?
- What family planning is available and safe for me?
- Where would be the safest place to have my baby?
- How can I keep my baby healthy?
CASE STUDY THREE

RUDO

“Hi, my name is Rudo. I am now 18 years old and I was born with HIV because my mother was HIV infected. When I was five years old, my mother became very ill and eventually died even though she was taking ARVs. I remember that time very well. During my mother’s illness I was told about the HIV that my mother had. My aunties showed me how to wash my hands so I could help to look after her. As I grew older my aunts told me that I also carried the virus that my mother had, because it had passed to me when she was giving birth to me.

As I grew up, my family encouraged me to eat plenty of healthy foods like fresh maize, fruit, vegetables, fish or meat, eggs and beans. They asked me not to eat much sugar and said I should drink lots of clean/boiled water.

About 5 years ago, my aunt took me to the clinic because I was having diarrhoea and didn’t want to eat. The nurse took my blood and talked to us about ART. She explained that it was a good idea to start this medication because I had a lot of virus in my blood. I was told that I would need to take this medication every day for the rest of my life. I had to really think about something so serious and worried about what my friends and teachers might think if they saw me taking tablets. The nurse helped me by listening and introduced me to a caregiver, Anna, who is part of the palliative care team. Anna visited me and gave me information about how I could live well, and about a youth group for people like me. I have been taking ART now for five years. I am healthy and now live a normal life as an 18 year old woman that my mother would be so proud of.

Boys are now interested in me but I’m worried about my HIV status. There is one special boy I like and he wants to have sex. I know that this virus can be passed to another person that way and I am very scared. I have told Anna and she helped me realise that the only way we can deal with this is to talk honestly with each other, and then decide what we want to do. I also know that using a condom can help to stop the virus spreading so I know that will be important for me whenever I decide to begin a sexual relationship.”

Key Messages from Rudo’s Story:
- Eat nutritious food to stay healthy
- Practice safe sex
- ART is for life!
- Avoid infecting others
- Share your concerns with others who can help you

Remember to ask your palliative care provider:
- When is the best time to start taking ART?
- What happens if you stop taking ART?
- What do I need to do differently now that I take ART?
- What should I watch out for after starting ART?
JOYCE

“My name is Joyce and I am 32 years old. I am sad when I tell you my story. My husband had many women but he convinced me to have 3 children before he left me. I don’t even know where he is now and he sends no money. When I became ill and I realised how many women he was with I decided to have an HIV test and it was positive. I didn’t want to live but I had my 3 children and had to feed them. They are now aged 8 years, 5 years and 3 years. A few weeks ago, I started having a smelly discharge and went to the clinic. A health worker said I had an infection called thrush. Since I seem to be getting more and more infections the nurse at the clinic recommended I have a CD4 and viral load test. These tests showed I could benefit from taking some medicines. The nurse at the clinic told me about ART and how these pills can make me live a long life. She told me how important it is to take them every day at the same time and to never miss a day. Even when I feel unwell I make sure I take my pills. Sometimes my children ask me if I am going to die and I don’t know what to say to them. I am also scared sometimes that I can die, and sometimes I cry. When I cry my children also cry. There is a caregiver who comes to visit me who has been trained in something called palliative care, and she helps me a lot with these difficult things that come with living with a life-limiting illness. I thought the kids were too young to talk to but I have realised that they all understand what is happening in their lives according to their ages. I once told them not to worry but they kept asking me different questions about my pills, whether they could catch this illness from me, and what was going to happen to them if I died, so I now just try and answer their questions. My caregiver also checks whether the ART is making me feel sick, or if I have pains in my legs as some people do not do well on these tablets. I hope I can keep taking them like this with no problems.”

Key messages from Joyce’s Story:

- ART is for life and needs to be taken every day
- Involve your family and let them understand what is happening
- If you have side effects from ART, they can be managed or you can be put on other combinations that do not cause them
- If you have pain ask for pain medication

You can ask your palliative care provider:

- At what age should children be tested for HIV?
- Do I have to inform children about my HIV status?
- What can be done if children are HIV positive?
- How can my pain be controlled?
PALLIATIVE CARE ROAD
HIV Positive    Treatment (ART, TB) STI

Ongoing Counselling, Treatment for: Symptoms, Infections and, Side Effects Pain Management, Disclosure Support, Healthy Living (nutrition, exercise, hygiene) Home Nursing Care, Linking up

Adherence Support
Family Planning
Support Groups
Clinic Check-ups

End of Life Care
Bereavement Counselling
Spiritual Support

PMTCT
Post-Natal Care
Breastfeeding

Pre-Natal Care

End of Life Care
Bereavement

Social Support
Family Counselling
Emotional Support

Motherhood Lane

RUDO
Adolescent Crescent
Youth Group
Sexual Debut
Safe sex

MARTHA
Widow Walk

JOYCE

JOYCE

PMTCT

End of Life Care
Bereavement

PREGNANCY CIRCLE

PATRICIA
Pregnancy Circle

 мате

End of Life Care
Bereavement

Support Groups

Clinic Check-ups
SOURCES OF INFORMATION


ABOUT APCA

The African Palliative Care Association (APCA) is a non-profit-making pan-African membership-based organisation, which was provisionally established in November 2002 and formally established in Arusha, Tanzania, in June 2004.Acknowledging the genesis of modern palliative care within the United Kingdom, APCA strives to adapt it to African traditions, beliefs, cultures and settings, all of which vary between and within communities and countries on the continent. As such, APCA being a recognised regional voice for palliative care in Africa works in collaboration with its members and partners to seek African solutions to African problems.

APCA’s vision is to ensure access to palliative care for all in need across Africa, while its mission is to ensure that palliative care is widely understood, underpinned by evidence, and integrated into all health systems, to reduce pain and suffering across Africa. APCA’s broad objectives are to:

- Strengthen health systems through the development and implementation of an information strategy to enhance the understanding of palliative care among all stakeholders
- Provide leadership and coordination for the integration of palliative care into health policies, education programmes and health services in Africa
- Develop an evidence base for palliative care in Africa
- Ensure good governance, efficient management practices and competent human resources to provide for institutional sustainability
- Position palliative care in the wider global health debate in order to access a wider array of stakeholders and to develop strategic collaborative partnerships
- Diversify the financial resources base to meet APCA’s current funding requirements and to ensure the organisation’s future sustainability.

APCA works to build effective linkages between all our key stakeholders, including: patients, their families and communities; carers (both family and volunteers); health care providers and educators; African governments, policy makers and decision-makers; its constituent members (both individuals and organisations); national palliative care associations, hospices and palliative care organisations; academic institutions; the media; governmental and non-governmental donors (both within and outside the continent), and the general public, in a network of national, regional and international partnerships.

The development of a core curriculum for palliative care is one of the strategies through which palliative care can be integrated in existing pre service and post service health education programmes. This is instrumental in ensuring that palliative care is integrated into the wider health systems across the African continent.

www.africanpalliativecare.org
ABOUT OSISA

The Open Society Initiative for Southern Africa (OSISA) is a growing African institution committed to deepening democracy, protecting human rights and enhancing good governance in the region. OSISA’s vision is to promote and sustain the ideals, values, institutions and practices of open society, with the aim of establishing vibrant and tolerant southern African democracies in which people, free from material and other deprivation, understand their rights and responsibilities and participate actively in all spheres of life.

In pursuance of this vision, OSISA’s mission is to initiate and support programmes working towards open society ideals, and to advocate for these ideals in southern Africa. This approach involves looking beyond immediate symptoms, in order to address the deeper problems - focusing on changing underlying policy, legislation and practice, rather than on short-term welfarist interventions. Given the enormity of the needs and challenges in the region it operates in - and acknowledging that it cannot possibly meet all of these needs - OSISA, where appropriate, supports advocacy work by its partners in the respective countries, or joins partners in advocacy on shared objectives and goals.

In other situations, OSISA directly initiates and leads in advocacy interventions, along the key thematic programmes that guide its work. OSISA also intervenes through the facilitation of new and innovative initiatives and partnerships, through capacity-building initiatives as well as through grantmaking.

Established in 1997, OSISA works in 10 southern Africa countries: Angola, Botswana, DRC, Lesotho, Malawi, Mozambique, Namibia, Swaziland, Zambia and Zimbabwe. OSISA works differently in each of these 10 countries, according to local conditions. OSISA is part of a network of autonomous Open Society Foundations, established by George Soros, located in Eastern and Central Europe, the former Soviet Union, Africa, Latin America, the Caribbean, the Middle East, Southeast Asia and the US.