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HOME-BASED CARE



HOME-BASED CARE

Why Can't the Clinics and Hospitals Care for All HIV and AIDS People?

Increasingly, particularly in Africa today, home care for PWAs (people with AIDS) is a necessity not a choice.

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Why Home-Based Care?

- **Hospitals, clinics, and medical caregivers are finding that they cannot cope with the magnitude of the needs of people living with AIDS (PLWAs).** In some areas of Sub-Saharan Africa, as much as 70% of hospital and clinic care is already occupied by HIV/AIDS-related illnesses. This can leave little room for those with other treatable and desperate illnesses. Clinics and hospitals find themselves having to turn away those with HIV infection and AIDS-related illnesses. This brings extreme hardship to the persons with AIDS, and also brings much frustration to their family members. Home-based care is essential for every church group to incorporate into its ministry.
- **As much as one-half of public expenditures for health care in Africa could be spent in costs for AIDS care.** Compassionate care for those HIV-infected who are moving into full-blown AIDS is an essential part of community education in the new millennium (year 2000 onwards). It is an excellent opportunity for Christians in the church to show the love of Jesus Christ in a practical way.
- **It is a low-cost option avoiding financial drain on the country and community.** One does not have to be professionally trained in healthcare to adequately assist the AIDS patient. A simple, common-sense approach to caring for a person who is sick with AIDS can prolong his/her quality of life and bring much consolation to family members. It also is the more cost-effective for the majority of people living in Africa who neither have medical facilities available to them, nor expensive medicines, nor access to professional help. This is where home-based care meets the need.
- **The nature of AIDS as an illness.** There is no medical cure for AIDS. Most problems faced by PWAs can be dealt with at home very well. Often, the medical profession can provide back-up when the home caregiver needs help, by lending information in a supportive role.
- **Financial considerations.** Long and repeated stays in clinics and hospitals are not within reach of many in the African community. Extensive stays and expensive medicines can put a tremendous burden on the extended family, unnecessarily so. Money to care for a person living with AIDS is best spent by providing compassionate home care, costing little. Money should then be reserved to provide support for the children who will be left behind, for good food for the family, including the person with AIDS.
- **A caring, loving environment is best given by family members of the PWA.** Most sick people would rather be at home than in the hospital. PWAs need the support of family and friends more than anyone else in their time of need. Keeping persons with AIDS at home and lovingly caring for them is perfectly adequate and possible once the family realise that it is not dangerous to provide home care for family members living with AIDS.

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Traditional African Lifestyle Included Caring for Members of the Family Who Were Sick and Dying

This tradition needs to be encouraged and strengthened. A negative aspect of “western” medicine is that it relies upon taking sick people to hospitals only for treatment and care. This can make people feel that care given at home is not sufficient or proper. Sometimes the FEAR of AIDS has caused families to leave family members uncared for because of myths surrounding AIDS. Such fear is unfounded and every effort should be made to alleviate that fear. Caring for AIDS sufferers at home is not risky for the caregivers and needs to be supported from the Christian community.

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The Bible Encourages Strong Family and Community Involvement in the Care of the Sick and Needy

- Jesus is our example of this as we read in the Bible that He cared for and healed the sick and afflicted. Jesus reached out to sick people; so should we.

”God anointed Jesus of Nazareth with the Holy Spirit and with power, who went about doing good and healing all who were oppressed by the devil, for God was with Him” (Acts 10:38).

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- Christians are encouraged to cheerfully help those who are in need, which definitely includes people living with AIDS.

“Be joyful in hope, patient in affliction, faithful in prayer. Share with God’s people who are in need. Practice hospitality” (Romans 12:12-13).

- Jesus condemned the Pharisees for avoiding their responsibility of caring for their parents (Matthew 15:3-6). Jesus commends caring for the sick as a form of ministering to Him (Matthew 25:34-40).
- Jesus also tells us (James 1:27) that the Christianity God wants is for His people to care for orphans and widows. Jesus then goes on to say that being a Christian without the practical outworking of faith is dead, it is of no profit (James 2:14-17).
- The New Testament Bible church set aside men to help with the needs of those who had no means of helping themselves, to provide care for the sick (Acts 6:1-3).
- Caring for the sick, including PWAs, is clearly in line with God’s will for Christians and the Christian Church (James 5:13-15).

The Caregiver

Caring for someone in a long-term illness can be very demanding and sometimes even discouraging. Friends and family members giving care to the PWA also need mental, emotional, and spiritual support due to the demands that come with caring for a person with AIDS.

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Caregivers can be assisted in the following ways:

- Give them time off away from the ill person, so they can attend to their own affairs.
- If a family member, allow them to openly share the emotions they experience in seeing their loved one become so sick.
- Help them to maintain a positive attitude. Continually caring for and being with a terminally ill person can sometimes be depressing. Friends of caregivers must help each other to be positive in their outlook.

The Aim of Home-Based Care

- To allow Persons With AIDS (PWAs) to stay at home with their loved ones and not go into a clinic or hospital care, which is less personal for them
- To encourage and empower the family to confidently care for the PWA and to keep the PWA as comfortable as possible
- To care for the PWA physically and medically, but also to give quality of life mentally, emotionally, and spiritually in the security of the family
- To allow family members and friends to come to terms with their loved one having AIDS without fear, shame, and denial. They should spend quality time with the person with AIDS.

Spiritual Counsel for the PWA

Just like anyone else, the person with AIDS needs to know Jesus Christ, God's Son, as his/her personal Saviour. Caregivers who are Christians can help non-Christian PWAs by leading them to Jesus Christ. First, this is done by demonstrating the love of Christ in one's own life. Second, this is done by sharing with the PWA God's love for him or her through Jesus Christ. Here are some important steps that the Christian caregiver can share with the PWA so he/she feels the assurance of salvation:

➡ FACT 60

- **Know that God loves the PWA just as he or she is:**

Romans 5:8 says *"But God demonstrates his own love for us in this: while we were still sinners, Christ died for us."*

➡ FACT 52

- **Every person including the PWA must admit he or she is a sinner and needs to be forgiven; ask Jesus Christ to come into your life and to forgive you of your sins:**

1 John 1:9 *"If we claim to be without sin, we deceive ourselves and the truth is not in us. If we confess our sins, he (Jesus Christ) is faithful and just and will forgive us our sins and cleanse us from all unrighteousness."*

➡ FACT 61

- **Believe that Jesus Christ is the ONLY Saviour of mankind:**

John 14:6 *"Jesus answered, 'I am the way the truth and the life. No one comes to the Father (to God) except through me (through Jesus Christ).'"*

➡ FACT 62

- **Call upon Jesus Christ to be your personal Saviour and Lord:**

Romans 10:13 *"Everyone who calls on the name of the Lord will be saved."*

➡ FACT 63

- **To call on the name of Jesus is to receive Him, by faith, into your life and to live for Him every single day of your life:**

John 1:12 *“But as many as received Him, to them He gave the right to become children of God, to those who believe in His name.”*

- **Now is the day of salvation, do not wait until another day:**

2 Corinthians 6:2 *“Behold, now is the accepted time; behold, now is the day of salvation.”*

- **The Christian caregiver can lead the PWA in a prayer something like this:**
“Thank you, God, for Your love for me. Thank you Jesus, for dying on the cross for me. I admit that I am a sinner and I confess all my sins to You. Please forgive me and make me clean with Your blood that was shed for me. Come into my life now, as my Saviour and my Lord. I will live for you for the rest of my life. Amen.”

➔ FACT 64

Everyone with AIDS Should Have Home-Based Care Available to Them

How sad it is to see people with AIDS suffer alone, be rejected, and not have anyone to help them with the process of dying. Often families quarrel, war, and divide because the pain of having a loved one sick with AIDS was too much to bear. Each one of us makes plans for marriage, raising children, building the future, employment, etc. How strange it is for most of us to have to look death in the face and deal with it by relating it to our lives. Yet, death is part of living.

Obviously, the PWA is the main recipient of home-based care. PWAs often go through ups and downs of AIDS-related illnesses; they may recover for a while before contracting another infection or illness. At some point, unless they receive healing from God, a PWA will become sick and not get better and move into the end stages of the illness. This last stage can last days, weeks, or even months, and will differ with each person. They will, however, need compassionate care from loving friends until death.

Areas of helping a PWA would be:

- Housework, gardening, farming
- Obtaining and preparation of food for the family
- Transportation, communication to friends
- Extended family members and children
- Financial assistance
- Preparation emotionally for a terminal illness and the dying process
- Good counsel regarding eternal destiny if the sick person is not a born-again Christian
- Good counsel regarding the care and finances of the family after death

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Some Practical Tips That the Caregiver Needs to Know

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1. Prevent the spread of infections and protect the caregiver.

- **Care in dealing with blood and/or body fluids of the HIV-infected and PWA:**
 A person’s intact skin is a perfect barrier and will prevent the virus entering one’s body. Only if there is a cut or an open sore can the HIV virus penetrate one’s

body. It is important that those caring for PWAs are careful in handling any blood, diarrhoea, vomit (particularly if there could be a little blood in them), or the discharge from wounds or body sores. If any blood or body fluids from the PWA gets on your skin, it is advisable to wash it off as soon as possible with soap and water. Always wash hands after any handling of soiled bed sheets or clothing. If the PWA is passing blood, wear surgical gloves whilst caring for them.

• **Dealing with open wounds or sores:**

- Always cover open wounds of both the caregiver and the PWA with a plaster, bandage to cloth to remove the risk of the virus being passed on to the caregiver.
- If the caregiver handles bloodstained sheets or clothing, it is a good idea to cover hands with rubber gloves. Even a plastic bag over the hands is better than nothing.
- Hold the unstained part with your covered hand and wash off any blood or diarrhoea with water until it is gone.
- The soiled items may be washed with soap and water and put out in the sun to dry.
- Cleanse with a solution given below to kill the virus if fresh blood is present on clothing or surfaces:

1 part bleach to 10 parts of water
(DO NOT USE BLEACH ON THE SKIN)

- Keep clothing, bedding, and surroundings clean...this helps the PWA to remain as protected from additional germs as possible, and also prevents unnecessary skin problems and sores. It also minimises the number of flies in the house.

Remember, HIV/AIDS is NOT usually spread casually. It is most often spread through the body fluids during sex. Common sense, cleanliness, and precaution must be exercised if the caregiver must handle fresh blood or body fluids while caring for the PWA. You do not have to worry about sharing toilet seats, sharing cooking utensils, and living in the same house with a PWA. These do not make you susceptible to the disease.

Lifestyle Changes Necessary for the PWA to Live with Quality of Life for a Longer Period

- **Addictive behaviours** must go (smoking, alcohol, drugs, etc.). These should not be part of the lifestyle of an HIV-positive person or PWA.
- **Sexual expression** for an HIV-positive person with an HIV-positive spouse should still be protected as much as possible during sex with the use of a **condom**. Condoms are not 100% effective, but they will help the couple to lessen the chances of cross-infecting one another with a different strain of the virus, or reinfecting the partner with more of the virus. Unprotected sex (without a condom) by married couples could increase their viral loads. Alternatively, couples where either one or both of them are HIV-infected may choose **non-genital (private part)** forms of expressing their love to one another in order to minimise cross infection.
- **Rest and naps** should be taken often during the day, particularly when periods of weakness are felt. The PWA should get eight hours of sleep at night.
- **Healthy diet** is essential for an HIV positive or PWA in order to preserve quality of life. **Frequent** (5-7) nutritious small **meals each day** are better than 2 or 3 large meals. These should include the following: fresh **fruits** either uncooked or lightly cooked, beans, lentils, **dairy** products such as milk and cheese, fresh cooked or

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uncooked **vegetables** particularly green beans/spinach/carrots/beet roots/sweet potato, etc. Once the PWA has difficulty digesting food, it is better to avoid raw vegetables and cook them soft, since raw vegetables are hard to digest. As the PWA becomes more ill and is unable to digest as well, softer **meats** and **fish**, or **boiled chicken**, is good. Mealie is good to eat along with vegetables and fruit. However, mealie alone is a **starch** and needs to be balanced with other starches such as porridge, bread, potato, banana, etc. When the PWA finds it difficult to digest, then mash and soft cook the food. **Fluids** are very important and the PWA should drink plenty of boiled clean water each day. Juices can also be squeezed for good nutrition. Drinking fluid is especially important for all those with diarrhoea, and liquids should be sipped very often. **Vitamin supplements**, if available in pill or powder form, are good for the PWA.

- **All symptoms** the PWA feels in the body should be treated and cared for early. Do not wait hoping they will go away by themselves. Some common symptoms are: coughing, mouth sores or thrush, swollen glands, skin rashes, and diarrhoea, etc.
- **Exercise** keeping the body limbs moving is essential to prevent the PWA from bedsores, if confined to bed. PWAs need to get out of bed and walk for short distances several times every day, even if they do not feel like it. As long as the PWA can possibly take steps, he/she should frequently get out of bed for short times. Sitting up in a chair also helps circulation in the body. When the PWA gets to the point where physically he is too sick to get out of bed, the caregiver should help him/her to exercise each arm, the wrist, the fingers, the legs, the feet, and the neck by moving them gently back and forth several times per day.
- **Environment** of fresh air and sunlight are good. Shaded areas are best to keep cool. Smoke-filled places should be avoided in order to prevent breathing problems.
- **A healthy mental state** is very important for any sick person, including the PWA. Concentrate on living rather than dying. Think of things that are positive and optimistic rather than of things negative and pessimistic. For as long as possible, the PWA should continue to work or to find something he/she is able to do, even if it is just for short periods of time. This increases his/her sense of well-being and usefulness.
- **Relationships with friends and family** are very important to a person with a terminal illness. Friends and family should visit the PWA very often. Long periods alone without friends can lead to depression and despair.
- **Spiritual wholeness** is probably the single, most important area to keep healthy. This is ONLY done through a personal relationship daily with the Lord Jesus Christ. As the PWA thinks about how precious and special he/she is before God and that God has his entire life under control, it will be easier to keep things in perspective. A daily Bible reading and prayer time is essential for the PWA, as well as for all Christians. For a PWA unable to read to himself/herself, the caregiver can read the Bible to him/her each morning. Churches ministering to PWAs could greatly assist by making sure the PWA and family have a Bible in their own language.

Symptoms and Care

Fevers:

- Drink plenty of water/liquids (minimum of two litres per day).
- Remove unnecessary clothing/blankets.
- Ventilate; open windows; give fresh air.



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- Bathe/wash with cool water and a wet cloth. Use a basin with cool (not cold and not hot) water and cloth. Use a bathtub if possible and have PWA soak in cool, clean water. Cover the PWA with a cloth on the forehead, the armpits, and on the insides of the thighs. Re-soak every 2-3 minutes until fever and sweating stop. Continue to bathe until the fever becomes normal. Put on a fan if possible, however, do not allow the PWA to be exposed to cold winds on the body.

Diarrhoea:

- Drink plenty of fluids (tea, unsweetened fruit juice, soup, lots of clean water).
- Rehydration drink for the PWA who is having difficulty keeping fluids in the body:
 - 1 litre boiled water
 - 8 teaspoons full of sugar
 - ½ teaspoon full of salt

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Mix the above together. Allow the PWA to sip this mixture every few minutes. Even a simple mouthful helps. Try to do this often before the tongue becomes dry, the eyes sunken, and the skin becomes dry and tight.

- Wash the anus skin (in the bottom) and buttocks after every stool (watery body waste from the bottom) and apply Vaseline or a hygienic cream to protect the skin.
- Continue to eat solid foods for as long as possible (porridge, rice, banana, potato, etc.). If unable to eat solids, make a broth soup with a few mashed soft vegies.
- If anal area is raw, sit in a warm salt bath (handful of salt) 3-4 times a day.

Tiredness & Weakness:

- Make activities easier.
- Get enough rest.
- Give assistance where necessary.
- Give bed-ridden patient gentle arm/leg movement several times a day. Turn from one side to back, and to other side several times a day to prevent bedsores.
- Keep person clean and dry.
- Assist person when walking or provide a walking stick.

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Sore Mouth and Throat:

- Rinse mouth with warm salt water (1 glass water & 1 tsp. salt) and spit out.
- For white patches in mouth suck lemon or eat some pineapple.
- Eat soft, mashed food.
- Apply gentian violet solution to sores on lips and mouth.
- Suck ripe piece of tomato for thrush and mouth hygiene.
- Eat bland rather than spicy food.
- Use straw for liquids and soup.
- Cold food, drink, or ice helps numb mouth and relieves discomfort.

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Skin Problems:

- Encourage not to scratch any sore/lesion. Relieve itching by cooling skin with water or by fanning it. Apply lotion like Calamine.
- Draw boils/abscesses by applying a piece of sliced onion over the site and by cleansing them with salt water.
- Keep skin dry and clean.
- For open sores:
 - Wash with clean water and soap.

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Apply gentian violet or antiseptic.

Cover with dressing/clean cloth that has been washed and dried in the sun.

- For dry skin:
 - Avoid soaps and detergent.
 - Use bath oils and skin creams (but avoid artificial perfumes).
- For shingles:
 - Keep sores dry.
 - Apply Calamine twice each day to relieve itch.
 - Mild pain can be relieved by paracetamol.

Pain:

- Take medication as prescribed at regular intervals. Be sure to follow instructions as to whether medicines are to be taken “with” or “without” food.
- Change positions frequently in bed.
- Raise any swollen parts on pillows.
- Use oil/lotion to gently massage sore muscles.
- Talk with the person, help keep a healthy mind.
- Be quiet and gentle in the presence of a sick person. Do not talk negatively. Allow the PWAs to talk about things as they are able to deal with them (e.g. future, death, dying, etc). However, do not keep secrets from the PWAs who show they want to know their own condition and their own daily progress.

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Cough, difficulty in breathing:

- Raise person’s head and upper body on pillow. Raise head of bed on blocks.
- Do not allow too many visitors in the room at one time.
- Keep room with fresh air...no smoking, cooking smoke, lamps, stoves or fires near the bed.
- Sit with persons having difficulty in breathing. It can be very frightening to them.
- Home remedy of cough mixture:
 - Piece of sliced onion (it will form a little syrup drawn by pouring sugar over it) and drink it.

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Confusion & Dementia

- Provide support.
- Keep dangerous objects out of the way.
- Avoid leaving the person unattended.
- Keep medicines out of patient’s way. In short, caregivers must care for the person who is suffering from confusion as they would a small child in order to keep the PWA with this problem from hurting himself/herself.

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TB...Tuberculosis:

- TB is very common among PWAs, although a person with TB is not always HIV infected.
- Medications given in a clinic and by a medical doctor will cure TB and make it non-infectious if taken properly. However, the medicines will only alleviate the TB and will not touch the HIV-infected person’s immune deficiency or AIDS.
- It is **extremely important** that TB medicines be taken **exactly** as the medical doctor prescribes and **exactly for the number of days** the doctor indicates. Missing days of TB medicine is very serious and can make the disease even worse for the PWA.

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- Avoid spreading the TB germ to other family members. The TB germ is easily contracted, whereas the HIV virus is not easily contracted, except by sex. The TB germ is passed through the air while coughing. Therefore, have the TB-infected person cough into a piece of cloth or toilet tissue. The toilet tissues should immediately be discarded into a plastic bag that is tied up every time. The cloth the TB-infected person coughs into should be washed every day with soap and water and put in the sun to dry.
- Washing and sunlight kill the TB germ.
- Good ventilation is very important in the house and in the room where the infected person is staying. Someone with TB infection should stay in an open room (not behind curtains) with the door and windows open to the outside air.

Pregnancy and HIV/AIDS



- If possible, a woman should be tested for HIV infection before she gets pregnant if there is any chance she, or her husband, have been exposed to the virus.
- A baby born to a mother who is HIV positive or who has AIDS has about a 30-50% chance of contracting HIV from the mother.
- It is very important to treat the baby born to an HIV-infected mother as **healthy and normal**.
- All babies born to HIV-positive mothers will test HIV positive at first, even if they are not really positive. There is NO WAY (not even with the routine HIV blood test) to know whether the baby has the HIV virus or not until about 12-18-months-old. Some babies will ONLY have the mother's antibodies for HIV and will not actually have the virus. Others will have the HIV virus. At some point in the baby's first couple of years of life, the baby will take on its own immune antibodies and only then will the true HIV status of the baby be known. That is why it is important for HIV-positive mothers to be encouraged about their babies, and not be tempted to discard them out of fear.
- Although there is some risk of an HIV-positive mother passing the virus to her baby in her breast milk, breastfeeding is still vitally important to the new baby, as this will protect the infant from other infections such as diarrhoea. (Diarrhoea is the #1 cause of infant death worldwide.)
- Immunisations are very important to protect the baby from various diseases. Mothers should have their babies immunised at the proper time.
- Any infections in both the mother and baby, before and after birth, should be treated promptly.
- In some cases, there is a combination therapy that can be given to the HIV-positive mother to treat the unborn baby, and this lessens the chances of the baby becoming infected. However, in Africa these medicines are rarely available and are generally too expensive for people to afford. This usually is not an option for the knowing HIV-infected mother to have available.

TO PATIENT

CONSCIOUS

Confidentiality

Avoid gossip or disclosing condition of patient to other people

Records

Diagnosis upon advice of the physician if the patient wants to know

Privacy

Bed pan, urinal and washing private

Noise
Spiritual help
Preparation for death and dying
Assisting with family matters
Treatment

parts of patient using a sheet
Cheerful atmosphere but not noisy
If receptive and with sensitivity
As patient is ready to talk about it
With consent
With dignity and as you would want
to be treated

TO PATIENT

Assume
Do not assume

Care

Positioning

UNCONSCIOUS

Pain
Deafness (some can be) but often the
unconscious person hears much
more than you think
With dignity, assuring best comfort
and hygiene
Move frequently. Carefully exercise
limbs if you can, particularly if
unconsciousness is prolonged or
in-and-out

CAREGIVER

Care skills

Integrity

Appearance

Love/Compassion

Balance

CHARACTER & APPEARANCE

Routines with the PWA should be
regularity of feeding times,
bathing, medicines, drinking
liquid, visitors, etc.
Be reliable. Do not make promises
you cannot carry out. Be godly.
Be clean and tidy yourself. Be
cheerful. Avoid wearing jewellery
that can cause injury to the PWA
whilst you are working with
them
Treat patient as you would want to
be treated
Balance your own life. Allow time
for yourself and family, as well as
the PWA. Do not become
obsessive and wear yourself out

TO FAMILY

Empathy
Honesty
Integrity
Confidentiality
Assistance for preparation for their loved one in the dying stages

DEATH AND DYING

Emotional support
Confidentiality

Protect valuables
Spiritual and religious matters

Last arrangements

Listening and comforting
Sharing information only
with those concerned
Give to next-of-kin
Share the gospel of Jesus
Christ if they are open to
receive it
Cooperating with family
members, if asked

1 Corinthians 13 is the LOVE chapter. It best describes the kind of love the caregiver should give to the PWA and his/her family members.

DO UNTO OTHERS AS YOU WOULD HAVE THEM DO UNTO YOU.