

Theme 4

Care and Support

Theme 4 is about care and support for people infected with and affected by HIV and Aids. Together we will visit homes, clinics and hospitals and learn how to make a contribution to the lives and health of people with HIV infection or Aids. We will also look at the difficult circumstances of children made vulnerable by HIV and Aids – and how to take care of YOU, the caregiver.

The following issues will be discussed:

- What does developing a home-based care programme entail?
- What is the best way to care for orphans and other children made vulnerable by Aids?
- What are the infection control measures that should be applied in all care settings to prevent the spread of HIV and other infectious organisms?
- How do I care for a patient with HIV infection and Aids in the various care situations (e.g. home-based care, hospital care, clinic care)?
- How do I take care of myself as a caregiver?



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Learning Unit 17: Community and home based care

**CARE TRACK
ONLY**



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Introduction

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Imagine you have a serious chronic disease. Who would you prefer to care for you if you could no longer take care of yourself? Would you prefer to be admitted to a hospital or hospice, or to be cared for in your own home by your loved ones, supported by a community health care team?



Home-based care has become a practical solution in a time when hospitals are often overburdened by the huge demand placed on them, particularly by the Aids epidemic. In this learning unit we will discover what home-based care is, as well as how to develop and implement an integrated home-based care service for your community.

Key Questions

Use the following questions as pointers to ensure that you retain your focus on the important issues in this learning unit:

- What is the background to home-based care?
- What is involved in planning and implementing an integrated home-based care programme?
 - Who is the home-based care team?
 - What is the role of volunteers, and how are they selected?
 - How should an integrated home-based care programme be planned?
 - What services should be offered by an integrated home-based care programme?
 - How can home-based caregivers be trained?

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Key concepts

Please pay special attention to the following concepts:

<u>Integrated home-based care model</u>	<u>Professional caregiver</u>
<u>Primary (or informal) caregiver</u>	<u>Volunteer worker</u>
<u>Community caregiver</u>	

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Background to home-based care

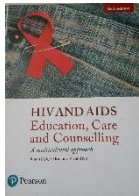
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What is **home-based** care, why is it important and what are its implications for individuals specifically and for the health care system in general? You will find the answers to these questions in your prescribed book.

Note: In this learning unit we will simply refer to “home-based care” for short, but remember that we usually talk about an integrated community and home based care (CHBC) model.



Study



Prescribed book: pp. 510-518

Introduction: Read how Aids has “forced” us to implement home-based care programmes to assist families and communities to look after their own sick members. Do you personally know anyone who receives home-based care in your community?

Section 17.1: Definition of community- and home-based care. After reading this section, write down your understanding of the meaning of home-based care in your journal. Are you aware of any home-based care programmes in your community? If so, write down the name of the agency that provides this service.

Section 17.2: The goal and functions of community- and homebased care programmes. Jot down the main goal of home-based care. Now name four important functions of home-based care programmes. You may need this information one day when you are part of a team that needs to develop a new home-based care programme for your community. Name ten types of services delivered as part of a community and home based programme.

Section 17.3: Advantages of community- and home-based care. This section gives 17 reasons why home- based care is preferable to hospital care. Think of at least three more reasons to add to this section.

Section 17.4: Potential problems with community- and home-based care. We mention five drawbacks of home-based care in this section. If you can think of any other potential problems, add them here.

Section 17.5: Models of community- and home-based care. In this section you will learn why the integrated home-based care model is preferable to the single-service or the informal home-based care programmes. Make sure that you know what each one of these models entails. Look at figure 17.1 in your prescribed book to see what an integrated home-based care model looks like. Describe the CHBC model followed in South Africa.

You are now familiar with the concept of an *integrated* home-based care model, which means that the patient and family are supported by a *network* of services. I am sure I can hear someone asking: “But where do I get a reference list with resources and services available to the people in my community?” Although reference lists are available in some bigger centres, most of the time it is up to us to develop our own reference lists that are relevant for the community we live in.

The next activity will assist you in developing your own service reference list for your community.

ACTIVITY 17.1: A RESOURCE AND SERVICE REFERENCE GUIDE FOR YOUR COMMUNITY

Draw up a reference guide in the form of a table, listing all the resources and services available in your community to people living with HIV infection. Go to [Activity 17.1](#)

Feedback: I hope this reference guide will help you in future if you have to refer someone to a specific service.

Now that you know what an integrated community home-based care programme entails, it is time to talk about the development and implementation of such a programme.

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Planning and implementing

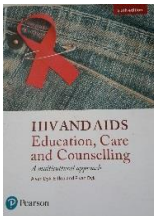
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To plan and implement an integrated home-based care programme, you need to do your homework first. You have to get a clear picture of who you want on your home-based care team, how you plan to select and train volunteers and other caregivers, what services you want to offer, and exactly how you intend setting up your home-based care programme.



While reading through your prescribed book, keep your own community in mind and make notes of how you would apply each one of the principles under discussion if you had to develop and implement a home-based care programme for your community.

Study



Prescribed book: pp. 518-527

Section 17.6: The community- and home-based care team. Note that the home-based care team consists of core as well as support team members. Apart from the patient and the family, identify people in your community who can fulfil the role of core and support team members.

Section 17.7: Volunteers in community- and home-based care. Home-based care can almost not exist without the help of volunteers. But can everyone with the urge to be a volunteer be accepted into a home-based care programme?

Go to this YouTube video <http://goo.gl/y6Kgfs> to see a home-based care volunteer at work. **Section 17.8: Using children in community- and home-based care.**

Section 17.9: Developing an integrated community- and home-based care programme. Although professional and volunteer caregivers are the backbone of home-based care, an integrated comprehensive home-based care programme needs much more to be a success. Make sure that you know and understand all the points that should be taken into consideration in developing a home-based care programme that will assist the community for which it is meant. Think of your own community:

- Who would you talk to about developing a home-based care programme?
- Who would be on the management team?
- Who would take responsibility for a community Aids awareness programme?
- How would you advertise your services so that the community knew about them?
- Who would assist in writing the policy, procedures and training programmes for the home-based care service? How would you evaluate the efficiency of the service?

Section 17.10: Implementation of a CHBC programme. Any home-based care programme should start with an exploration of the needs of its clients. The services rendered should then be tailored to fit the community needs. After



reading this section, do the following:

- Make a list of all the needs that should be taken into account when a home-based care programme is developed.
- Now think of your own community and identify any needs that are unique to it and add them to your list.

Section 17.11: Training community- and home-based caregivers. It is important that home-based caregivers be trained properly to empower them to offer a helpful service, to experience work satisfaction and to prevent occupational stress and burnout. After reading this section, do the following:

- List the points that should be included in a good training programme for home-based caregivers.
- Think of the needs in your own community and how they impact on volunteer training. Adjust your training programme by adding these additional points.
- Read what should be included in a home-care kit for home-based caregivers in your prescribed book.

Watch this YouTube video <http://goo.gl/VUzEg7> on training home-based care volunteers in Africa.



Requirements for a volunteer

A friend of mine (who is a social worker) was very unhappy because a well-known NGO did not want to use her services as a volunteer. She has a very busy life as a full-time social worker with three children still at school. She decided to volunteer after she lost her husband and she felt that volunteering would help her to do something useful for other people in need and that it would also help her to get over her husband's death. She was prepared to give the NGO at least two hours per month of her valuable time. She accused the NGO of being ungrateful and being "beggars who do not realise that they cannot be choosers". Can the



NGO be blamed for not wanting to make use of her services? The points under "Selection and management of volunteer workers" will help you to form an opinion on the NGO's "rejection" of her help.

It is not easy to be a volunteer, and you will also read about the problems and frustrations often experienced by volunteers.

The following activities will help you to get some practical experience with home-based care programmes and volunteer work:

ACTIVITY 17.2: EVALUATE A HOME-BASED CARE PROGRAMME AND VOLUNTEER YOUR SERVICES

Get hands-on experience with a home-based care programme in your community by going to [Activity 17.2](#). This activity will also give you the opportunity to evaluate your own suitability as a volunteer, and who knows? Maybe you can also volunteer your services.

Feedback: I said somewhere at the beginning of this study guide that this course will strive to be **different** from any other courses that you will do at university. If you are the same person at the end of the course, I have failed in my objective to make a shift in the way you look at your community and Aids. I want you to “get your hands dirty”; to be an activist and to fight for people who cannot talk for themselves. And you don’t have to take part in Aids rallies to be an Aids activist – it can also be in the way you talk about people who are HIV positive to your friends and colleagues. And you will really feel this shift in attitude if you volunteer your services to an organisation which needs it.

Read the chapters entitled “Kate Marrandi” and “Nomvalo” in the *Three-letter plague*. These two chapters tell the story of Kate Marrandi, a community health worker who does community home-based care in Nomvalo village. It tells the story of an extraordinary woman who tirelessly walks the maze of pedestrian paths in Nomvalo to get to the sick. This is how the author, Jonny Steinberg, remembers Kate:

An image of Kate Marrandi filled my mind. Her rucksack on her back, her nose keenly tuned to the scent of illness, she knocks on every second or third door in the village. She is invited in, and sits in the family living room speaking softly and paging through her ledger. She coaxes the sick into a taxi to visit Dr Hermann.

“How much does the government pay you to be a community health worker?” I asked.

“Five hundred rand per month. So that we can buy soap to be clean when we visit the people.”

It was the first hint of irony I had encountered since meeting her, although her face remained so deadpan it was impossible to tell what she thought of her remark.

You are now finished with this learning unit. Click on [Assessment](#) to do some self-assessment questions.

Assessment

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Study reflection

After completing Learning Unit 17 (Home-and community-based care), you should have acquired the following knowledge and understanding and be able to:

- do some self-reflection about your own abilities of what you can offer your community.
- offer your services as a volunteer to an NGO that works in the HIV and Aids field (but only if your self-reflection leads you in that direction).
- assist your community leaders in developing and implementing an integrated community home-based care programme.
- critically discuss the role of volunteers in a home-based care programme.
- offer basic training for volunteer home-based caregivers.

Self-Assessment 17



Now is the time to pause briefly and to assess whether you have acquired the necessary knowledge and skills. Click on [Self-Assessment 17](#) to do a few questions on this learning unit.

You are now finished with the assessment. The next learning unit in the Care Track is Learning Unit 19.

APPENDICES

- Activities
- Self-assessments
- Glossary

ACTIVITY 17.1 - A RESOURCE AND SERVICE REFERENCE GUIDE FOR YOUR COMMUNITY

Draw up a reference guide in the form of a table, listing all the resources and services available in your community to people living with HIV infection. Use the integrated community home-based care model in your prescribed book (figure 17.1) to give you some ideas of possible available services (e.g. hospitals, crisis centres, doctors, counsellors, and social workers in your community). Use the telephone directory or the internet to search for services. If your town does not offer a specific service, who does? Is it close enough for patients to travel there? Visit or phone some of the services on your list to get a personal account of what they offer. Use the following headings for your table (and add to them if you can think of more).

Reference guide of Aids organisations

Name of organisation	Service provided	Contact person	Physical address	Telephone no.	Office hours	Fees

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ACTIVITY 17.2 - EVALUATE A HOME-BASED CARE PROGRAMME AND VOLUNTEER YOUR SERVICES

1. Phone your local hospice and find out if they offer a home-based care programme in your community. Make an appointment with the manager of the programme and ask him or her to talk to you about the programme. Use the information in the prescribed book (sections 17.1 to 17.10) to make a checklist to indicate what a good integrated home-based care programme should look like. Also use the information to prepare some questions that you would like to ask during the interview. Some of the questions you might ask are listed below:

- What services do you offer?
- Who is part of your home-based care team?
- What are your selection criteria for volunteer workers?
- What training do you offer volunteer workers?
- What do you expect from your volunteers in terms of work ethics?
- How was your home-based care programme developed?
- What problems do you encounter with the home-based care programme, if any?
- Do you have a reference guide that your caregivers can use to refer patients if necessary?
- What services do you offer to the patient's family and loved ones, if any?
- What advice would you offer someone who plans to start a home-based care programme?

After the interview, use your checklist to evaluate the home-based care programme. For example, is it truly an integrated comprehensive home-based care programme? Did they include the community leaders and members when they developed the programme? Do they select their caregivers and train them properly?

2. Evaluate your own suitability as a volunteer. Make a list of your strengths, knowledge and skills and reflect on what you can offer to lighten the burden of primary and home-based caregivers. Be critical and honest and also list the factors or characteristics that might hinder you from being a good volunteer. Use the list of factors in the section "Selection and management of volunteer workers" in your prescribed book to assist you in your self-evaluation as a volunteer. Keep the bigger picture in mind and remember that patients need more than nursing care. They need volunteers to read to them, to do shopping, to care for their animals or plants, to take children to school and to help the children with their homework.

3. If you feel that you have the experience, skills, willingness, time, commitment and dedication to volunteer your services to lighten the burden of caregivers, contact an organisation (e.g. a hospice, NGO, or faith-based organisation (FBO)) close to you and volunteer your services. Keep a diary of your experiences and concentrate on your feelings. Ask yourself the following questions:

- How does volunteering make me feel about myself?
- What am I learning about myself?
- How has volunteering changed me as a person?

SELF-ASSESSMENT 17

Question 1

Is the following statement true or false? Home- and community-based care is preferable to hospital care because it promotes a holistic approach to care.

Question 2

What is the definition of home-and community-based care?

Question 3

Complete the following sentence: Two of the important factors to be considered when selecting volunteers are and

Question 4

What are the four important functions of home-based care?

Question 5

Who are the primary caregivers according to the home- and community-based care module? They are mostly:

1. Family or friends caring for patients.
2. Professionals or volunteers trained in community-based care.
3. Non-government organisations assisting in the community.
4. Faith-based organisations giving support to people living with HIV and Aids.

[\[FEEDBACK\]](#)

FEEDBACK 17

Feedback Question 1

The statement is true. Home- and community-based care is preferable to hospital care because it promotes a holistic approach to care.

Feedback Question 2

Home-and community-based care is comprehensive health and social services offered by primary and community caregivers in the home and community.

Question 3

Two of the important factors to be considered when selecting volunteers are motivation and availability.

Question 4

The four important functions of home based care are:

- To empower the community and the family to cope effectively.
- To educate the community about the prevention of HIV transmission.
- To support family members in their caregiving roles.
- To reduce the social and personal impact of HIV.

Question 5

Primary caregivers are mostly family or friends caring for patients. (Alternative 1 is correct).

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Integrated home-based care model

A model that links all the service providers with patients and their families in a continuum of care.

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Primary (or informal) caregiver

A family member or friend caring for a patient – usually the patient’s mother, grandmother, partner, friend or a foster or adoptive parent.

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Community caregiver

A person from the community trained to help the primary caregiver with direct care and support of the patients. Community caregivers may be professional caregivers or volunteers.

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Professional caregiver

A professionally-trained caregiver such as a nurse, community health or TB worker, social worker, medical doctor, psychologist or counsellor, pharmacist, physiotherapist or occupational therapist.

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Volunteer worker

A community member offering his or her services without any remuneration and of his or her own free will. Volunteers are trained to do their jobs and usually offer support services such as residential care, respite care services, pastoral care, legal aid and advice and transport services.

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