

18

HOME-BASED CARE

Key points:

1. Home-based care is an important part of the health care system.
2. Home-based care provides care for people in their homes.
3. Home-based care helps people living with HIV/AIDS return to being healthy and independent.

Many South Africans have the experience of caring for sick relatives, family and friends in the home. There are also many organisations working together with the Department of Health who train lay people from communities to be home-based carers. Home-based carers fill an important part in the health care system, which is struggling to cope

with high number of people who need care. This situation is made worse by the HIV/AIDS epidemic. Home-based care means that people can be taken care of outside of hospitals. With those who are living with HIV/AIDS, home-based care aims to support people as they return to being healthy and independent after starting ARVs.





ABOUT THIS CHAPTER

The aim of this chapter is to have a good understanding of what home-based care is.

This chapter covers the following topics:

- What is home-based care?
- Home-based care for people living with HIV and AIDS
- Who provides home-based care?
- The role of the home-based carer
- What is a care plan?
- Home-based care and medication
- Precautions
- Practical advice on providing home-based care
- What is needed in a home-based care kit?
- Challenges



Hello everyone. In this chapter we are going to talk about home-based care. Many of you may already have experience caring for a loved one in the home. Others of you may belong to community or church organisations which provide care for people who are living with HIV and AIDS. Home-based care is not only for people living with HIV. Let's learn more.



WORKBOOK NOTES

Home based care
allows us to care for
sick people in
their homes

What is home-based care?

Episode 18, Chapter 1



Home-based care (HBC) is the provision of basic nursing care to people in their own homes. Home-based care is about providing physical, mental, social, emotional and spiritual care to people. People who may need home-based care are those who have strokes, people living with HIV/AIDS, elderly people, people who are mentally challenged, and those who are terminally ill. When someone is 'terminally ill' it means that they are dying. Home-based care is built on 3 principles:

1. Working with the district health system.
2. Referral system between local clinic and the home-based care organisation.
3. Training members of the local community.

Here are some words and terms that are often used when talking about home-based care.

Primary caregiver

A primary caregiver is often a family member who lives with the sick person and looks after them. A friend or neighbour can also be a primary caregiver when the sick person does not live with their families. A primary caregiver is not trained but will be given lots of information by the home-based carer on how to take care of the ill person in the home.

Home-based care helps people to return to good health and to be able to care for themselves again.

Home-based carer

A home-based carer is someone who is trained to care for ill people in their homes and to educate the primary caregiver on how to care for the sick person. There are a number of organisations who train and support home-based carers in collaboration with the provincial Department of Health.

Client

When talking about the sick person they are providing care for, home-based care organisations call them a client. This shows the kind of professional relationship that the home-based carers have with the people they are caring for. In this chapter, the words client and 'sick/ill person' will be used.

Nursing co-ordinator

The nursing co-ordinator works at the home-based care organisation and oversees the work that the home-based carers do. The nursing co-ordinator is trained as a professional nurse and assesses clients and helps develop a care plan together with the home-based carer and the client.



Here we can see 2 home-based carers changing a wound dressing.



Xoliswa Mtwetafa is the Khayelitsha nursing co-ordinator at the Caring Network.



DISCUSSION POINTS

In a group talk about the following questions and see if you can answer them.

1. What kinds of care does home-based care give?

Home-based care is about providing physical, mental, social, emotional and spiritual care to people.

2. What kinds of people might need home-based care?

People who may need home-based care are those who have strokes, people living with HIV/AIDS, elderly people, people who are mentally challenged and those who are terminally ill.

3. Who do home-based care organisations work with using a referral system?

Home-based care organisations work together with the Department of Health. Clients are referred from clinics and hospitals to home-based care organisations.

4. Who is the primary caregiver?

A primary caregiver is often a family member or someone the sick person lives with. The primary caregiver takes care of the sick person when the home-based carer is not there.

5. Who is the client?

When talking about home-based care, the client is the sick person who is being cared for by a home-based carer and a primary caregiver.



WORKBOOK NOTES

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Multiple horizontal dashed lines for writing notes.

Home-based care provides physical, mental, social, emotional & spiritual care to people

Who provides home-based care?

In South Africa most home-based care services are provided by non-profit organisations, which are supported by provincial government. For example, provincial government may provide the medical supplies that are needed for the first aid kits for the carers. The organisations work closely with the public health care services. For example, if a person needs ongoing care at home after being discharged from hospital, they are referred to a home-based care organisation in the area where they live.

This referral system from the clinic to the home-based care organisation also works the other way round. For example, a home-based carer may be approached by a neighbour or family member who says that they know someone who needs home-based care. The carer will then refer this person to the local clinic so that a medical doctor or sister can assess their health and fill in a medical card for them. A home-based carer cannot start caring for someone without the referral from the local clinic, and/or a professional nursing assessment by the NGO co-ordinator.

A nursing co-ordinator from the home-based care NGO, who is also a nursing sister, will assess the needs of the person in their home together with a carer. The co-ordinator and the carer will also develop a care plan together with the person who is receiving the care and their primary carer who usually lives with them. It is very important to educate and inform the primary caregiver, because they are the person who spends the most time with the person who is ill. The primary carer must be able to tell the home-based carer when she comes to visit everything that has happened since the last visit. For example, if the sick person vomited during the night, it is important that the primary caregiver pass on this information to the home-based carer.



The Caring Network in Khayelitsha is a home-based care NGO.



Nozipho Matyeni is the Programme Manager of The Caring Network in Khayelitsha.



DISCUSSION POINTS

In a group talk about the following questions and see if you can answer them.

1. What is palliative care and how is it different to home-based care?

Palliative care is caring for people who have incurable diseases and who are dying. Now that we have better access to ARVs, we prefer to call it home-based care because people are getting better and returning to being healthy and independent.

2. Is home-based care only for very sick people?

No. Home-based care can also include check-up visits where a carer will still visit her client, but not as regularly, to make sure they are still well. Some home-based carers are also treatment supporters for people who take ARVs.

The Role of the Home-Based Carer

It is important to understand that a home-based carer does not replace the primary caregiver in the home. The primary caregiver is someone who lives with the person who is ill. In some cases, if someone lives alone, the primary caregiver can be a neighbour. The main role of the home-based carer is to support and educate the primary carer and the rest of the family so that the best possible care can be taken of the person who is ill. Home-based carers help the sick person and their family members to take care of themselves independently. Remember that the home-based carer is not with the sick person all the time and so it is important to educate the primary caregiver and family so that they know what to do if the home-based carer is not there.



One of the most important roles of a home-based carer is to educate the client and their family.

Educating means that the home-based carer needs to ask questions and listen. In this way the home-based carer will be able to learn what the primary caregiver already knows and will be able to give more information. After giving new information it is always a good idea for the home-based carer to discuss everything with the primary caregiver to make sure that they understand what they have been told. The home-based carer should also show the primary caregiver how to do things, such as give a bed bath. It is also useful for the primary caregiver to do something while the home-based carer is there so that they can make sure that it is being done correctly. When the primary caregiver and the client are educated it makes them feel more confident and they will also be able to recognise possible danger signs when a visit to the clinic might be needed. It also makes the primary caregiver less afraid and less dependent on the home-based carer.



DISCUSSION POINTS

In a group talk about the following questions and see if you can answer them.

1. What is the main role of the home-based carer?

The home-based carer supports and educates the primary care giver and the rest of the family so that the best care can be taken of the sick person when the home-based carer is not there.

2. Why is it important to educate the primary caregiver and the family of the sick person?

It is important to educate the primary care giver and the rest of the family so that they are better able to take care of the sick person when the home-based carer is not there. It also means that they will have better knowledge about health and illness and be able to take better care of themselves in the future.

3. Why is education about caring for the sick person good for the primary carer?

Education makes the primary carer more confident and able to do things even when the home-based carer is not there.



WORKBOOK NOTES

What is a care plan?

Episode 18, Chapter 2



A care plan describes the type of care that is needed and the aims of what the home-based carer wants to achieve. A care plan also places the patient into different categories depending on how much care they need.

- The client is able to live without assistance and the carer visits once or twice per month.
- The client is ill but able to take care of themselves and the carer visits 1-2 times per week.
- The client is bedridden and needs daily visits by the carer.

In cases where the client has a treatable illness, the aim is to care and support the client until their health has improved so much that they are able to take care of themselves independently. With HIV positive people who start ARVs the aim is the same. For example, someone may have some opportunistic infections and their CD4 count may be very low when they start ARVs. They will need a lot of care and support to begin with, but as their health improves and as the primary caregiver learns how to care and support them, they may only need a visit by the home-based carer once or twice per month.

Home-based care and medication

Home-based carers do not hand out or give medicine. A client must receive the medication they need from their local clinic, day hospital or pharmacy. A carer can help a client to get their medication. For example, if a client is able to walk, the home-based carer can accompany them to the clinic or day hospital and make sure that their clinic folder is ready and that they are seen to quickly. This means that they do not have to wait for hours and can return home with their medication. If the client is bed ridden, then the primary care giver needs to get the medication from the clinic or day hospital.

A home-based carer can help a person remember to take their medication and in some cases a home-based carer may even be a treatment supporter or 'treatment buddy' for someone who is taking ARVs. We have already learnt about ways to make sure that ARVs are taken at the right time every day in the chapter on ARVs and Adults.



DISCUSSION POINTS

In a group talk about the following questions and see if you can answer them.

1. What is a care plan?

A care plan is a written record of the kind of care a person needs, as well as the aims of the home-based carer for the person they are caring for. A care plan also decided how often a client might need to be visited by the home-based carer.

2. Why do you think a care plan helps takes care of a sick person?

A care plan keeps a record of how the sick person is being treated and looked after. It also explains how the home-based carer plans to take care of the sick person and how to get them back to a state of good health and able to live an independent life.

3. Can home-based carers give medication to clients?

No, a home-based carer cannot give medication to clients.

4. How can a home-based carer help a client get their medication?

A home-based carer can help their client get their medications by accompanying them to the clinic and preparing their folder so that they can be seen quickly and return home.

Practical advice on providing home-based care

Episode 18, Chapter 4



As we have already said, all people being cared for at home should be first assessed and treated by a local clinic or hospital. Once a care programme is decided on, the home-based carer together with the primary caregiver can care for the person at home. We will now talk about some of the common conditions or symptoms and how to treat them in a home environment. This information is for primary caregivers. Remember that if the sick person's condition gets worse and for more serious problems, you must tell the home-based carer. The home-based carer will then tell the co-ordinator from the local home-based care NGO who will come and assess the situation. A visit to the clinic or day hospital may be needed.

As a primary caregiver, you live with the person who is sick and so you know more about their health than the home-based carer who is not there all the time. It is important to tell the home-based carer if the ill person hasn't been eating, or if they have vomited and so on. It is important to talk to the home-based carer and tell them everything that has happened since their last visit.



Use surgical gloves when cleaning spills of blood and other bodily fluids.

Precautions

The risk of becoming infected with HIV from caring for an HIV positive person is very low (approximately 0.3%) but it is important that you take some basic steps that are better for the carer and the sick person. The World Health Organisation provides what they call 'universal precautions' for home-based carers. Here is a list of some of the precautions:

- Clean up spills of blood and other bodily fluids with diluted bleach.
- Use gloves when touching body fluids. If you don't have gloves you can use plastic shopping bags to cover your hands, but make sure there are no holes in the bags.
- After cleaning wounds or body fluids using cotton wool or toilet paper, burn the cotton wool or toilet paper or put it in a plastic bag and tie it up before putting it in the bin.
- If needles are used to give the person injections, make sure that the needles are taken back to a health care centre such as the local clinic so that they can be properly thrown away. Don't throw a needle into the rubbish.
- Separate stained or soiled clothes and bedding from other laundry and wash separately. First rinse thoroughly with running water to get most of the stain out. Then soak in diluted bleach or boil before washing with soap.
- Make sure that any wounds or sores on your own body are covered.
- Wash your hands as much as possible to protect you and to protect the sick person. You don't want to pass on any infections to them. Wash your hands before and after care, before and after going to the toilet, before preparing food and before giving food or water to the sick person.

If you are accidentally exposed to blood or bodily fluids:

- Wash the place that was exposed with lots of running water.
- Then wash with soap and water. If there is bleeding, allow the site to bleed a bit.
- Use of antiseptic (such as bleach) is not recommended because it is caustic and burns the skin. But if there is no water, antiseptic can be used.
- Go to the local clinic and consult a health worker. They will know how to manage the exposure and if need be give you post-exposure prophylactic (PEP).



SKIN PROBLEMS

The following skin problems are often experienced by people living with HIV and AIDS:

- Rashes or itchy skin
- Painful sores on the skin
- Very dry skin
- Slow healing of wounds and cuts
- Boils and abscesses

Cleaning the skin often with mild soap and water and keeping it dry will prevent most common skin problems.

Very dry skin

Try not to use soap and other detergents. Instead use bath oils and skin creams. Vaseline, glycerine and vegetable and plant oils can be just as effective as more expensive oils and creams. Aqueous cream is cheap and very good.

Rashes and itchy skin

Itchy skin can be caused by infections because the immune system is weak. It can also be a reaction to medication the person is taking. To help the itching, cool the skin. Try to keep the person cool and don't use hot water on the skin when washing. Try not to scratch the skin because this causes more itching and sometimes opens the skin and causes infections. Cold black tea (no milk or sugar) can help soothe itching by rinsing the skin with it. Itchy skin can also be a new opportunistic infection or side-effect of ARVs. If the itching does not go away in a few days, and if it spreads to other parts of the body, such as the eyes, tell the home-based carer. If the person has painful sores, boils and abscesses you will also need to tell the home-based carer. These could be a drug side-effect or an allergic reaction, especially if the person is taking ARVs. The sick person might need to visit the clinic and see a doctor. Remember: never stop ARVs without telling the home-based carer. As soon as a person has any kind of side-effect, talk to the home-based carer or clinic. Most side-effects only last 2 weeks and then go away.

Wounds

If a wound is uninfected wash it with clean water and rinse it with water mixed with a little bit of salt. The salt water should taste like tears and will help prevent infections. With people living with HIV/AIDS wounds may take more time to heal because their immune system is weak. If the wound is infected (swollen, red, painful and has pus) and if there is a fever, tell the home-based carer and you might need to visit the clinic.



Remember to always wash your hands before and after caring for someone who is sick.



Keeping the skin clean and dry is very important. Remember to use a mild soap for washing.



Wounds can take a long time to heal if someone is living with HIV.

Bed sores

If a person is so ill that they are in bed all the time, they can get bed sores. Bed sores are also sometimes called pressure sores because they form at places in the body that touch the bed and where there is pressure. Bed sores are difficult to treat and so it is very important to prevent them. Preventing bed sores is one of the most important things a primary carer can do. Here are some of the ways you can prevent bed sores:

- If possible, help the person to sit in a chair for a little bit each day before going back to bed.
- Change the position of the sick person in bed every 2 hours. Lift the person to change how they are lying in bed. Do not drag them because this can break their skin.
- Encourage the person to move his or her body in bed whenever they can. The more a person moves, the less chance they have of developing bed sores.
- Look for damaged skin (change of colour) on the back, shoulders and hips every day.
- Put extra soft material, such as a cotton towel, under the sick person.
- A little Talcum powder on the skin can also help keep the skin dry.
- Keep the bedding clean and remove all wet clothes and bedding.

If bedsores do develop, show the home-based carer as soon as possible. You can care for small bed sores by:

- Cleaning gently with salt water and allowing to dry.
- For bedsores that are not deep, leave the wound open to the air so that it can dry.
- If there is pain, you might need pain killers like Paracetamol or Aspirin (Panado or Disprin).
- Keep changing the position of the person.

If the sores or pain get worse or become infected (red, swollen, pus) tell the home-based carer as soon as possible. The client may need to be referred to a clinic. The home-based carer and the nursing co-ordinator from the NGO will probably need to assess the client and then made a decision about referral. The client may need to seek more expert care.

**DISCUSSION POINTS**

In a group talk about the following questions and see if you can answer them.

1. Why can people with HIV and AIDS often have itchy skin and rashes?

HIV positive people can get itchy skin and rashes because their immune systems are weak.

2. What helps soothe itchy skin?

Keeping the skin cool and bathing the skin with cold black tea (no milk and sugar) can help make itchy skin less irritated and sore. Aqueous cream and other creams keep the skin moisturised and also help stop itching.

3. What are some of the ways you can help prevent bed sores?

You can encourage the person to try and spend some time sitting or walking slowly around the house. If the person is too sick to leave bed, you can move them every 2 hours so that they do not get bed sores.

Preventing pain in muscles and joints

If someone is lying in bed all the time, they can get stiff joints and sore muscles. Encourage the person to move in bed or if possible get out of bed and try move around the house. Massage the person with petroleum jelly or oil. You can also encourage exercise twice a day and help with movement of ankles, knees, hips, wrists, elbows, shoulders and neck. If the sick person can walk at all, they should try to walk a bit or stand on their legs every day to maintain the strength they have. This will also improve circulation and stretch out their legs, which are often bent when in bed.

Here is some advice on how to help a sick person exercise their joints and arms and legs:

- Hold the arm or leg above and below the joint while moving it. Support as much of its weight as possible as you move it.
- Bend, straighten and move joints gently and slowly.
- Exercise the wrists: Bend wrists gently and slowly without causing pain. Repeat the exercise a few times.
- Exercise the elbows: Gently move the forearm up and down while the top of the arm is resting on the bed. Repeat the exercise a few times.
- Exercise the shoulders: Gently lift the arm up and bring the hand above and behind the head. Move the arm from side to side. Repeat the exercise a few times.
- Exercise the knees: Gently bring the knee up and to the side. Then replace it on the bed. Repeat the exercise a few times.

At all times, let the sick person do as much as they can by themselves.



Help the person out of bed and seat them on a chair. If they can walk on their own, encourage them to walk around the house.



WORKBOOK NOTES

Nausea and vomiting

If the patient or sick person feels like vomiting:

- Find locally available foods that cause less nausea.
- Give small quantities of simple, bland food such as boiled potatoes, mielie meal porridge (pap), samp and beans or rice.
- Give drinks such as water, diluted fruit juice or tea and encourage the person to drink slowly and more frequently. Avoid coffee and sweet, fizzy drinks. Very sweet drinks will irritate the stomach and can cause diarrhoea.

Some ARVs can cause nausea and it is better to take medication with food. Most ARVs can be taken with food at meal times, except for ddl which should be taken on an empty stomach. Check with the home-based carer so you know whether or not the person can take their ARVs with meals.

Remember that if someone is vomiting or has bad diarrhoea, their body cannot absorb or take in any medication they are swallowing. This means that they will not benefit from the medication. For this reason it is important to try and stop vomiting and diarrhoea as quickly as possible. Vomiting and diarrhoea also easily make a person dehydrated and weak because they are losing liquid and food that the body needs. This is why it is so important to make sure the sick person drinks as much liquid as possible.

Tell the home-based carer if the sick person has:

- Nausea for more than 2 weeks
- Dry tongue
- Vomiting for more than 1 day
- Passing little urine
- Abdominal pain or yellow eyes



DISCUSSION POINTS

In a group talk about the following questions and see if you can answer them.

1. If someone feels like vomiting and doesn't want to eat what can you do to help prevent them from getting too weak?

If someone is nauseous and doesn't want to eat, give drinks such as diluted fruit juice or tea, as well as plenty of water. Also try bland, simple food that isn't spicy or rich.

2. What can you do to help stop nausea from ARVs?

Most ARVs (except ddl) are better taken with food to stop nausea and other side-effects.

Diarrhoea

Diarrhoea dehydrates a person very quickly. This means that they lose a lot of liquid that should be in their bodies. Our bodies need a lot of water to be healthy and work properly. When someone has diarrhoea it is important to make sure that a person drinks liquids often and in small amounts. Apart from water the sick person can drink soups, thin porridge and oral rehydration solution (ORS).

You can get packets of oral rehydration at the clinic, or you can mix your own. Mix 1 litre of boiled water together with 1 teaspoon salt and 8 teaspoons sugar. Stir until the sugar and salt have dissolved and then cool. If possible keep the mixture in a fridge. Many people find it easier to drink if it is chilled. If the mixture is older than 24 hours, rather mix a new mixture before giving it to the sick person. If the person is not dehydrated but is experiencing bad diarrhoea, it is a good idea to give them oral rehydration solution, but only use half a teaspoon of salt when you make it and not the normal 1 teaspoon full.

Encourage the person to eat small amounts frequently. They should not eat raw food such as fruit and uncooked vegetables. Avoid very sweet drinks, alcohol and coffee.

Remember that diarrhoea could be the sign of a new opportunistic infection. It could also be the result of taking some ARVs. If it is caused by ARVs it usually improves in a few weeks. Talk to the home-based carer.

You should go to the clinic if any of the following happens:

- Blood in the stool
- Diarrhoea lasting for more than 5 days
- If the sick person becomes even weaker
- If there is broken skin around the rectal area.

Diarrhoea can cause dehydration - drink small amounts of fluid often to prevent dehydration

DISCUSSION POINTS

In a group talk about the following questions and see if you can answer them.

1. Why can vomiting and diarrhoea be dangerous for someone who is sick?

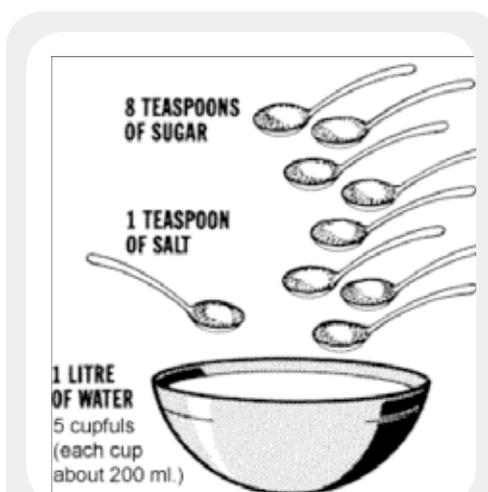
Vomiting and diarrhoea can be dangerous because a sick person can become dehydrated and they are also unable to absorb medication and nutrients which means they cannot benefit from the medicine and feel weak.

2. What is oral rehydration solution made of?

Oral rehydration solution is made from 1 litre of water, 1 teaspoon salt and 8 teaspoons sugar.



Picture of official mixture of oral rehydration therapy available at clinics and pharmacies.



Home mixture of oral rehydration solution.



If someone has diarrhoea they should not eat raw fruit and vegetables.



WORKBOOK NOTES

Fever

When someone has a fever or very high body temperature it usually means that the body is fighting an infection. In people living with HIV/AIDS fever often comes and goes. If the person is on ARVs, fever can be a sign of immune reconstitution syndrome (IRIS). It could also be the sign of an opportunistic infection. Tell the home-based carer if the person who is ill has a fever.

You can lower a fever by taking off extra clothes and blankets. You can cool the person down by wiping them down with a wet cloth dipped in cold water. If there is pain, you can give the person Paracetamol (Panado), but make sure not to give more than 8 tablets per day.

The sick person should go to the local clinic if:

- It is possible that they could have malaria or if you live in a high risk area of malaria.
- The fever stays for longer than 7 days.
- There is also a cough, weight loss, stiff neck, yellow eyes or diarrhoea.
- The sick person is pregnant or recently had a baby.



You can also lower a fever by wiping the person with a wet cloth dipped in cold water.



DISCUSSION POINTS

In a group talk about the following questions and see if you can answer them.

1. What does it mean when someone has a fever?

When someone has a fever it usually means that their body is fighting an infection.

2. How can you lower a fever?

You can lower a fever by taking off extra blankets and clothes and cool the person by wiping their body with a wet cloth dipped in cold water.

Headache

Headaches are common when someone has a fever. A massage of the scalp can help to relax the person and take away the pain. If the headache is more serious, you can give Paracetamol (Panado) – 2 tablets (500 mg per tablet) every four hours. You can also give Aspirin (Disprin) (500mg per tablet) or Ibuprofen (400 mg per tablet) at night. Remember not to give a person more than 8 Paracetamol tablets a day. Also remember to tell the home-based carer if you are giving the sick person any medication.

Tell the home-based carer if:

- The headache persists more than 24 hours, even when taking painkillers or medication
- They have problems seeing or vision is blurred
- They vomit
- They have a problem talking or slur when they talk
- Pain in the neck and/or stiff neck
- Weakness in one side of the body
- Change in behaviour or attention

Managing pain

Pain is common and can be relieved. It is important to try and control pain and stop it from getting very bad. One of the first things you can do is to try and find out what is causing the pain. This will help find out a way of making it go away. It is important to try and find out if the pain is a side-effect of medication or the beginning of a new opportunistic infection.

You can ask the sick person:

1. Where is the pain?
2. What makes the pain worse or better?
3. What does the pain feel like? Can you feel it all the time or does it come and go? Is there shooting pain?
4. Is there an emotional, psychological or spiritual side to the pain?

Talk to the home-based carer about the sick person's pain and help them to describe it to the carer. Apart from pain killers there are other things that you can do to reduce and control pain.

You can try:

- Emotional support by talking to the person and listening to them.
- Touching, stroking and holding the person so that they feel loved and safe.
- Playing the radio on a station they enjoy or switching the TV on.
- Prayer and visits from a spiritual leader such as the local priest or member of the church.

If pain is extreme and serious, a visit to the clinic is probably needed so tell your home-based carer as soon as possible.



Headaches are common when someone has a fever.



DISCUSSION POINTS

In a group talk about the following questions and see if you can answer them.

1. Why does it help to try and find out what causes the pain?

If you know where the pain is coming from, it can help you make it go away.

2. What else can you do to help relieve pain apart from giving painkillers?

You can give the sick person emotional support and talk and listen to them. You can also stroke or hold the person. Playing their favourite radio station can help, as well as a visit from a spiritual leader if the sick person asks.

Trouble sleeping, worries and fears

Sometimes a sick person can struggle to sleep. This could be because of emotional and psychological reasons, or it could be because of physical reasons. If the person is on ARVs, Efavirenz can cause trouble sleeping. It is important that people know that most side effects go away after 2 to 3 weeks. Don't stop taking the ARVs, but speak to the home-based carer or tell the doctor who prescribed the ARVs as soon as possible.

For trouble sleeping, have a comforting drink at night. Warm milk, chamomile tea or weak, milky tea can make people feel sleepy and help them fall asleep. Avoid strong tea, coffee or very sweet drinks late at night.

If the person you are caring for has worries and fears, encourage them to speak to a person they can trust. This could be a family member, a friend, the neighbour or yourself. If the sick person is feeling very sad, depressed, cannot sleep or has no interest in their life, speak to the home-based carer.



Getting enough sleep is an important part of healing.

Speaking to someone you trust can help manage your worries and fears

DISCUSSION POINTS

In a group talk about the following questions and see if you can answer them.

1. Which ARV is known to cause trouble sleeping and bad dreams?

Some people who take Efavirenz have the side-effects of struggling to sleep and having bad dreams.

2. What drinks should you avoid if you are having trouble sleeping?

You should avoid strong tea, coffee and very sweet drinks late at night if you struggle to fall asleep.

WORKBOOK NOTES

CHALLENGES FOR PRIMARY CARE GIVERS

Emotional stress

Caring for someone who is close to you or a family member is emotionally demanding. As a primary caregiver you live with the sick person and are there most of the time which means that you are often without support when the sick person's condition gets worse in the middle of the night. It is important to share everything with the home-based carer so that you do not feel alone. Also make sure that you make some time for things you enjoy and that make you happy, like watching your favourite TV programme, talking with friends, listening to music or going to church.

Financial worries

Often a primary caregiver does not work because they are taking care of the sick person in the home. This might mean that the household is short of money and there are financial worries. Speak to the home-based carer about grants and food parcels.

Inadequate knowledge

It is important to make sure that the home-based carer educates the primary carer and the rest of the family about how to take care of the person who is sick. As a primary caregiver try and be at the house when the home-based carer visits so that you can learn as much as possible and ask questions.

Uncertainty about the future of the health of sick person

Sometimes, as a primary caregiver you might not know what is going to happen to the sick person you are looking after. You may not know how quickly they will get well and how long you will have to look after them for. Talk to the home-based carer about your worries.

CHALLENGES FOR THE CLIENT

Social isolation

When you are sick in bed or need to spend a lot of time at home getting better, you can often feel lonely and isolated. Try and keep your spirits up by listening to the radio or watching TV. Ask a neighbour to come round once or twice a week if they can. Talk to the home-based carer about other ways of not feeling lonely.

Emotions such as rejection, anger and grieving

When you are sick you might also feel angry or sad about your illness and your ill health. Talk about the way you feel with the home-based carer or your primary carer if you can. You might also feel rejected by loved ones, especially if they are not caring for you or if they do not come to visit. You might also want to talk to someone from your church or a counsellor.

Financial worries

When you are very sick you cannot work. You may have even lost your job when you became very ill. This means that you might be worried about money and how you are going to live while you try and get better. Talk to the home-based carer about grants and food parcels and other social services.

Fear or mistrust of the primary caregivers

If you don't trust the person or people that are looking after you at home, talk to the home-based carer. Remember that the primary caregiver is given a lot of information by the home-based carer on how to care for you.



WORKBOOK NOTES



MULTIPLE CHOICE QUESTIONS

Name :

Circle the correct answer for each question. You can only choose 1 answer for each question.

1. Which of the following statements is true?

- a) Home-based care is only for people living with HIV.
- b) Home-based care is providing care for people in their homes.
- c) Home-based care is second class care.
- d) Home-based care is providing medicine for people in their homes.

2. Home-based care happens in:

- a) Hospitals
- b) Clinics
- c) Homes
- d) Day hospitals

3. A primary caregiver is:

- a) The only person to look after the sick person.
- b) Someone the sick person lives with who is looking after them.
- c) Always a family member.
- d) Someone from the clinic who looks after the sick person.

4. A home-based carer is supposed to:

- a) Do everything in the house like cleaning and washing.
- b) Educate the primary caregiver and family about how to care for the sick person.
- c) Stay overnight when a person is very sick.
- d) Be available on their cell phone any time of day or night.

5. If you are caring for someone who is sick you must wash your hands because:

- a) It is very dangerous work.
- b) You don't want to infect them and get infections from them.
- c) Your hands mustn't be sweaty.
- d) You are a guest in their house.

6. Which is of the following is not a challenge for a primary caregiver?

- a) Financial worries
- b) Emotional stress
- c) Not having enough knowledge
- d) Not knowing the person you are caring for

7. If someone has bad diarrhoea:

- a) You must give them strong coffee
- b) You must make them drink salt water
- c) You must give them oral rehydration solution
- d) You must give them spicy food

8. If someone is so sick that they need to stay in bed all the time you must look for:

- a) Cracked heels
- b) Bed sores
- c) Long toenails
- d) Flea bites

9. If your family does not have enough food and is struggling financially you should speak to:

- a) A clinic sister
- b) A neighbour
- c) A social worker
- d) A priest

10. Which thing is a home-based carer not able to do for a sick person?

- a) Dress wounds
- b) Give a bed bath
- c) Give medicine
- d) Talk and listen



WORKBOOK NOTES

A large area for writing notes, consisting of 20 horizontal dashed orange lines on a light gray background.