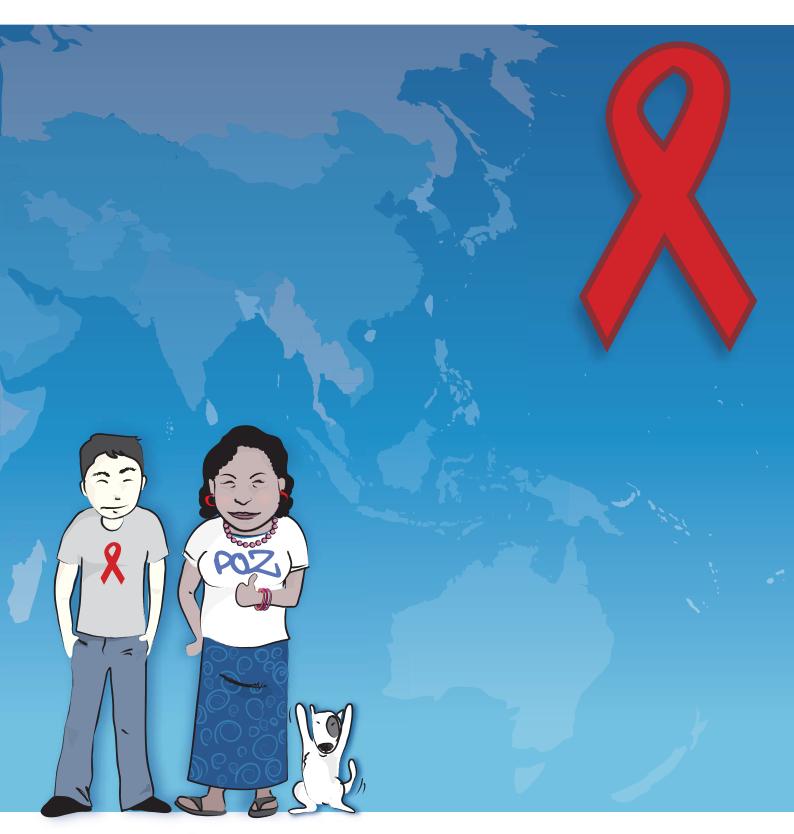
Asia Pacific Participant's Manual and Training Resource on Basic HIV Counselling Skills







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First Edition, 2005.

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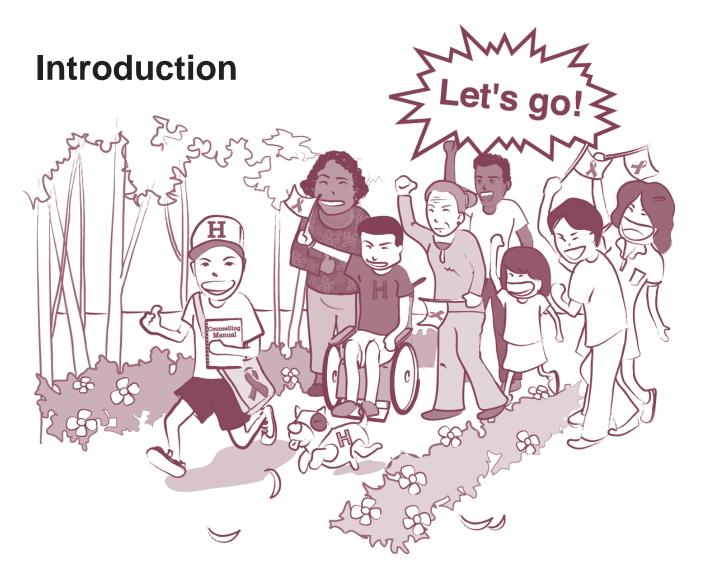
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Background to the Manual

This Manual was commissioned by the Australian Red Cross Asian Regional Office (Bangkok) in response to a need that was identified in the field by several key personnel working within the Australian Red Cross, and Red Cross Red Crescent National Societies in the Asia Pacific Region.

The need identified is for assistance in providing counselling support, for volunteers and community people associated with the Red Cross Red Crescent Movement in this Region, or other support people, whose clients are HIV positive or affected by HIV, and who do not themselves have a professional counselling background or qualification. Some of these people may well be HIV positive themselves, and be acting in what can be described as a peer support role.

This Manual is designed to take the skill levels beyond providing basic HIV information to clients and active listening, to the point where they can provide more psychological and emotional support and care to assist those living with HIV, and others affected by it.

As part of this process it is recognised that some people living with HIV/AIDS (PLWHA), including those who work for Red Cross Red Crescent Movement, offer a unique and valuable ability to

provide such psychological and emotional support and counselling interventions from a peer based perspective to other PLWHA. This Manual will assist such people to develop their skills in this area.

APN+ (Asia Pacific Network of People Living with HIV/AIDS) was commissioned to write the Manual and engaged four principal authors through NAPWA Australia who have extensive experience working with HIV positive groups and people in Asia Pacific. Input has been received from many people in the region, including other members of APN+ and people working in the HIV sector who have direct in-country experience of what is required to support their own work.

The Asia Pacific Region is enormous both in geographic size, and in its cultural, religious and ethnic diversity. This Manual covers the key issues applicable to all people in the Region. But it is recognised that in its application there will need to be modifications in the way counselling support is provided. This will be provided through a training process where participants will have the opportunity to think about how the principles will apply and be implemented in their own communities.

Using the Manual

In the Manual counselling skills are understood as those skills that focus on relationship building and communication between two or more people where one person attempts to offer support to others by assisting them to explore, understand and when possible, resolve any emotional or mental distress they are experiencing.

The Manual is divided into chapters, each dealing with an aspect of counselling support. This has been kept simple and contains the key points that are important to remember.

In most cases the Manual will be introduced by facilitators through a series of training programs. They will use the Facilitator's Counselling Skills Manual, which follows the format of the Participant's Manual, but includes activities and discussion points to assist participants in the training to understand and learn the material. Participants are expected to use the Participant's Manual both during the training and as a reference afterwards.

Participants will be expected to have the Participant's Manual available during the training.

The Future

The Manual is a dynamic document. The resource has already been trialled in 2004 at workshops in Papua New Guinea and China, and at a regional TOT (training of trainers) in Thailand, and revisions have been made based on the experiences gained in using the Manual. Feedback has also been incorporated from a wide variety of individuals and organisations from across the world. We anticipate that the Manual will continue to be revised and future versions produced, possibly in other languages and formats.

Note:	

SECTION 1:

What Is Counselling?



SECTION 1: What Is Counselling

Counselling is a way of helping people to explore, clarify and resolve difficulties they are experiencing. The goal of counselling is always to help the person being counselled to discover their own ways of managing their situations. Counselling is based on the idea that the counsellor is to support but not direct, is to help but not take control, to encourage but not to give advice.

It is important to remember that there are many ways to help others. Not all of them include the use of counselling skills. It is important to be clear on what counselling is not.

Counselling is NOT:

Education
Advice giving
Networking
Political organising
Social support
Skills Training

This is only a partial list of the many other ways to support people other than through counselling. These are all important jobs for the HIV support worker. The counselling skills taught in this manual are primarily for use when counselling. People may find them useful when doing other jobs as well.

Note:	

Note:	

SECTION 2:

Exploring Values



SECTION 2: Exploring Values

What Are Values?

- Beliefs
- Ideas
- Feelings
- Principles
- Judgments

They are everything that we hold most precious to ourselves.

Our values help us know what we hold as good or bad, worthwhile or worthless and important or unimportant.

Our values guide our actions and decisions.

Our values affect how we relate to other people.

Our values shape our attitudes to others and ourselves.

Where Do Our Values Come From?

Values are usually shared and come from:

Our society and culture (including our language, national, local and sub cultures);

Our religion;

Our families, friends and community;

Our schooling;

Our cultural traditions.

Some values we hold are personal - they grow out of our own life experiences.

Counselling and Values

Being aware of our own values can help us accept the diversity of values held by others.

Why are values so important?

- If HIV support workers are unaware of their own values they may impose their values on their clients without even knowing they are doing so. When this occurs clients can feel that they are neither respected nor valued.
- When support workers are not aware of their own values they may be tempted to examine their own values when they should be supporting their clients. This can leave clients feeling ignored and unsupported.
- When support workers are unaware of their values they can end up in a "values conflict" with their clients.
- We can identify a values conflict when a client acts, thinks or feels in a way that makes us react with strong emotions like fear, anxiety, anger or disgust.
- If support workers are not aware of their values they may try to force their client to act, think or feel the way that the counsellor thinks they should.
- Support workers may even end up in a disagreement or an argument with their clients.

What can HIV support workers do to make sure their values don't get in the way of providing counselling support to their clients?

- Become aware of your personal values.
- Recognise and accept that your values are different to your clients' values.
- Remain non-judgmental! Put your values to one side as you attempt to see the world from your client's point of view, "as if" you were looking at the world from their mind.

Counselling Values

All relationships, personal, cultural and political, are lived out in the context of our values. This is also true for counselling. The relationship that support workers form with their clients will be the way they express counselling's values.

Many researchers have tried to find out what it is about counselling skills that helps the clients. One of the most important findings is that a positive working relationship between the counsellor and client makes the difference.

There are two important values that support workers need to demonstrate to their clients if our counselling is to be effective in helping our clients.

Unconditional Positive Regard

Unconditional positive regard is the foundation of all counselling relationships.

Unconditional positive regard can be understood as the non-judgmental acceptance of and a fundamental respect for our clients as human beings.

Unconditional positive regard is about the way we see or understand the worth of our clients.

To hold unconditional positive regard for someone does not mean agreeing with him or her. It means not judging them or imposing your beliefs on them if you do disagree with them. Instead, we show our respect by helping people explore and understand their own feelings, thoughts and behaviours and the consequences of these for themselves and others.

Values must be shown to our client. How do we show unconditional positive regard?

- Demonstrate respect for the client by declining to take any advantage or make any personal gain from the relationship. This includes accepting financial, emotional and sexual favours.
- Be with and for the client. Use all of your time with the client to address their issues and concerns, not your own.
- Assume the best from your client. Even if we cannot see how their behaviour is good for themselves or others, understand that they are doing the best they can with the life they are living.

Empathy

To be empathetic is to see the world "as if" you were the client so that you begin to understand what the world looks like for and to them. This is different from sympathy, which is acknowledging how another feels without necessarily sharing the emotion of how the other person feels. It is also different from feeling sorry for someone, which is about an emotional reaction in the support worker and not about understanding the client's feelings.

Empathy is often misunderstood as being the same thing as "active listening". Active listening is an important communication skill, and is about demonstrating that you are interested in and listening to what the person says. If we are empathetic we can show our empathy with the use of active listening. But they are not the same thing. The value of empathy is found in our commitment to:

- Understand our clients from their personal point of view;
- Understand each of our clients within the entire context of their lives.

The most important way to show our empathy is in accepting our clients' differences. To do this we must become aware of our own difficulties with differences in other people. Once we are aware of differences that we have with our clients and how these differences affect us, we can become very sensitive to how these differences affect our counselling support.

Geldard and Geldard (2001) explain empathy in a counselling relationship in the following way.

"The counsellor should see the client as someone who is walking along a path. Some times the client may walk off the path, into the trees, over the rocks where they fall over, they may walk through valleys, across streams, and explore dangerous areas. Sometimes they may walk in circles and end up at the point they started at. A counsellor usually will neither follow from behind nor lead them from in front (although at times we may have to follow or lead). Most of the time a counsellor will just walk alongside, exploring those things that a client chooses to explore, being warm, open, friendly, concerned, caring and real."

This way trust develops between our client and ourselves, and we can experience the world in almost the same way that our client does. As counsellors we travel *with* our clients, matching them and walking beside them.

Note:	

SECTION 3:

Basic Counselling Skills



SECTION 3: Basic Counselling Skills

The Purpose of Counselling

There are many reasons to use basic counselling skills. A few of the main ones are listed here.

- To provide emotional support to clients in distress.
- To empower clients and assist them to bring change to their social environment.
- To help clients to deal more effectively with their emotions, thoughts and/or their behaviours.
- To help clients identify the best solution to their problems.
- To help clients make informed choices by providing and facilitating access to accurate and appropriate information.
- To provide emotional and psychological safety to clients in times of crisis.

Types of Counselling

- 1. Crisis
- 2. Supportive
- 3. Educational

Crisis Intervention

A crisis can be understood as an event or situation where a person feels that they do not have the ability to cope or the support that they need.

The five steps to crisis support are:

- 1. Define the problem.
- 2. Ensure the client's safety.
- 3. Provide support.
- 4. Make plans.
- 5. Observe the client.

The skills taught in this manual focus on supportive and educational counselling.

Supportive Counselling Skills

Inviting the Client to Talk (Paying Attention)

To begin to understand the client's point of view it is important that we gather all the information that they are communicating to us.

The first type of communication that counsellors can notice is non-verbal communication. This includes your client's body language. What does the client's body language tell you about their emotions and their health?

We also need to listen to their speech. Both the words they use and their tone of voice.

Really listening to a client draws their story out. When we really listen we can begin to learn the details of the client's:

- Experiences;
- Emotional state;
- Fears or worries:
- Their understanding of their situation;
- Concerns they have;
- Their values;
- Goals they have;
- Help/support they want.

As well as listening it is important, if the client is to develop trust in the support worker, that they know that they are being listened to and understood.

There are three ways to communicate that we are listening to them and understand.

1. Our Body Language

HIV support workers must ask themselves: "What is my body language communicating to this client; is it communicating that I am listening and I care?"

2. Non-verbal Language and Minimal Responses

The use of non-verbal responses and minimal responses, such as nodding and smiling, are important because they let the client know we are listening without having to interrupt their story.

3. Active Listening

There are two parts to active listening, reflecting the content of what they said (paraphrasing) and reflecting the feelings behind what they said.

<u>Reflecting Content.</u> Say back to the client in a clear brief way what they told you. The important thing is to capture the basic message of what they said.

<u>Reflecting Feelings</u>. To reflect feelings can be very difficult. Some clients may not want to share their feelings and may keep them hidden. Allow them to keep their feelings private if they don't want to share them with you. When clients do share feelings, to reflect those feelings to them, first identify the client's feelings and then share the underlining emotion by naming it.

4. Clarifying the Problem or Concern

There are a number of counselling skills that can help clients clarify and make sense of their problems or concerns. These skills include the use of questions and providing feedback statements.

5. Use of Open Questions

There are many ways to ask questions. Most often in counselling the question that are asked will start with:

- What?
- How?
- Who?
- When?
- · Where?

All of these questions can help the clients to clarify for themselves what is happening for them. They encourage them to talk. When asked an open question the client may provide much more information that will allow the HIV support worker to understand how they can best support them.

'Why' Questions

It is recommended that counsellors *not* use "Why?". Counselling questions that begin with 'why' are often difficult to answer.

'Why' questions can also lead to defensiveness if the client interprets it as being judgmental.

Defensiveness can lower the level of trust that the client has for the counsellor.

Closed Questions

Closed questions usually lead to a short answer such as yes or no. This means that closed questions do not encourage a client to discuss, reflect on or clarify their situation.

Closed questions are fine when we need to get some specific information (like how old are you).

Examples of Open and Closed Questions

Why Question: "Why do you treat your wife that way?"

Closed Question: Do you love your wife?

Open Question: How do you feel about your wife?

Circular Questions

With a circular question you ask the client how someone else they know might feel or think or what someone else they know might believe. By asking this type of question the client may begin to discuss their own feelings, thoughts or attitudes by clarifying if they agree or not with this other person.

Circular questions can also help a person begin to see other approaches to their situation by considering what it looks like from another's point of view.

Example of a Circular Question: "I wonder how your children will feel when they find out about your diagnosis?" or "Name one person who knows you well and feels positively about you. How might they help you in this situation?"

Feedback Statement

A feedback statement helps a client know that you have noticed something while they were speaking. For example:

- It seems too hard for you to make a decision right now;
- You seem to be having difficulty talking about this;
- You seem unsure;
- You say everything is going well, but your voice sounds sad and your face looks sad.

Feedback statements can be useful to help people become more aware of what is happening for them. They can allow the client to decide how and if they are going to continue talking about an issue.

6. Normalisation

Clients often have strong uncomfortable emotional reactions. They can feel more anxious because they believe the strong feeling that they are experiencing as wrong or weak. Normalising can often reduce this anxiety.

We must be cautious not to normalise irresponsible behaviours, while remaining non-judgemental.

We can normalise an experience simply by giving the client the basic information, that whatever they are feeling or going though is a normal human response. Clients often need to be reassured that the way they are responding is the same way many other people respond.

7. Doing Nothing May Be the Best Alternative

Sometimes the best thing is not to try to do anything. When clients are very sad, or upset or overwhelmed, the best response may be to simply be with them. Don't think it is your job to fix things or to make everything change. Sometimes the best help you can be is to just sit quietly with your client.

Note:	

Note:	

SECTION 4:

Skills That Help Find Solutions



SECTION 4: Skills That Help Find Solutions

There are many ways that HIV support workers can provide support and care to clients. Discussed below are a few of the more basic counselling skills that can be useful in helping your clients.

Help the Client Find Their Own Solutions

Counselling should not only focus on problems and concerns but also on client's strengths, problem solving and solutions.

Examples of Solution Focused Questions

- What do you have to do to achieve that?
- What would be the first step?
- What would be the next step?
- · What help do you need to achieve that?

Explore Alternatives

Often the only solution that clients can see is one that is not attainable. It can be very helpful to get clients to think about alternatives. Questions that can help include:

- Have you thought of any other ways to accomplish that?
- Do you know anyone who has solved a similar problem in a different way?
- How would (name of a significant other) solve this problem?

Support workers may also be able to help clients think of alternatives to problems by sharing ways they have solved a similar problem, or how another person they know or another client solved a similar problem.

Giving Information and Providing Education

Giving accurate information is one of the most important roles for someone supporting people with HIV. When information is given it is important to consider the following points:

The time and place must be right.

Make sure the information is in language that the client can understand.

Take the time to give all the information requested.

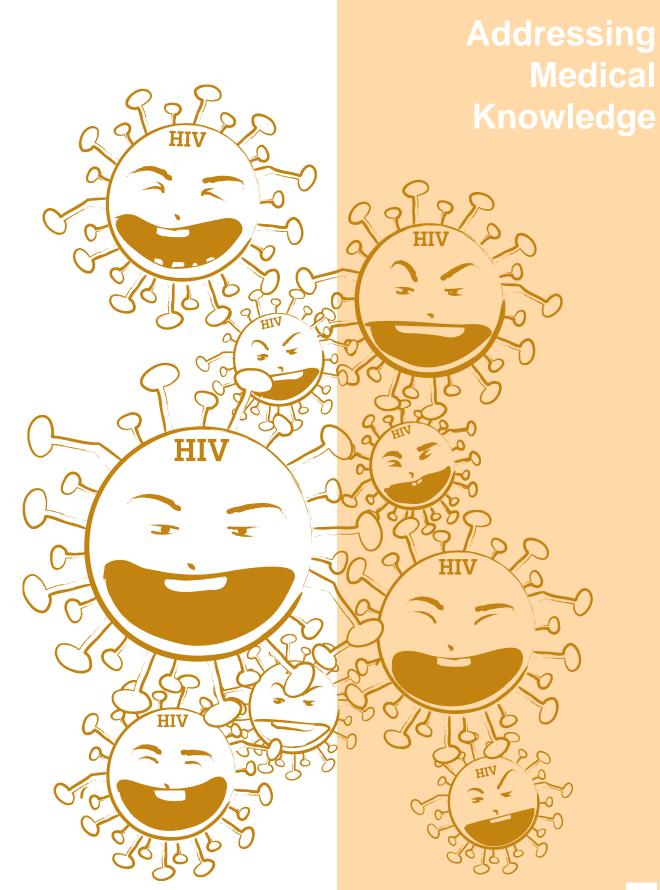
Don't give information like a lecture.

Give the information more than once.

People have different health beliefs.

Note:	

SECTION 5:



SECTION 5: Addressing Medical Knowledge

Addressing Medical Knowledge

What Is HIV?

- · HIV stands for Human Immunodeficiency Virus.
- HIV is a virus; it needs to get into human cells to be able to live and multiply.

Transmission

- HIV maybe present in semen, blood, vaginal fluid and breast milk.
- Transmission is by an exchange of these body fluids. HIV can be transmitted through:
 - unprotected sex (sex without a condom);
 - from mother to child (during pregnancy, birth or via breastfeeding;
 - sharing needles and other activities where there is an exchange of body fluids and equipment is not cleaned appropriately, such as tattooing and health procedures where the skin surface is broken.
- It is not passed on through touching, kissing, mosquitoes, sharing cups or plates, clothes or blankets.

How HIV Affects the Body

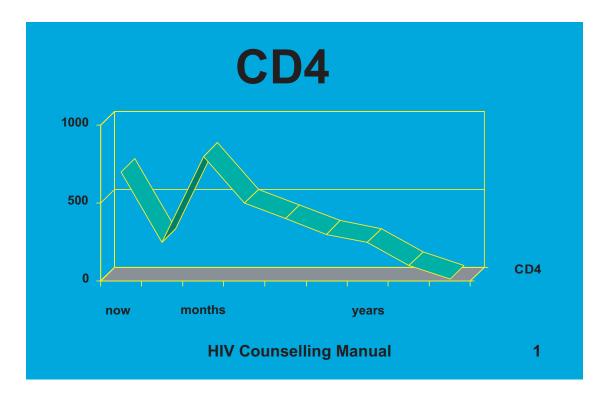
- HIV attacks the immune system, which fights off infections and keeps you well.
- HIV targets and destroys cells in the immune system. The main cells infected by HIV are called CD4 (or T4 cells), which are a type of white blood cell that plays a major role in the immune system.
- When you are infected with HIV, the immune system makes antibodies to fight the virus. The immune system cannot kill all the HIV because it continues to reproduce very rapidly.
- When your immune system is weakened it is known as being immuno-surpressed or immunocompromised.
- AIDS stands for Acquired Immuno-Deficiency Syndrome. AIDS is not a disease in itself but a stage of HIV related illnesses.

Natural History of Progression

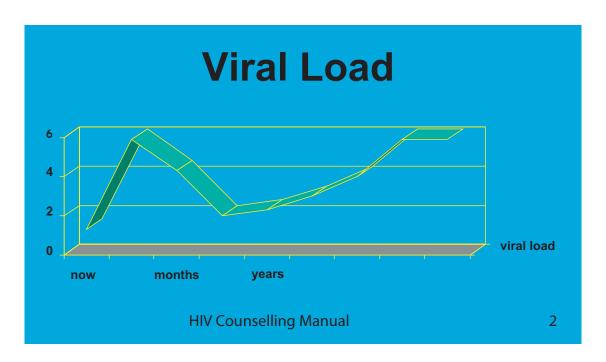
- Stage 1- Primary infection
 When a person first becomes infected with HIV.
- Stage 2- Asymptomatic infection
 For a number of years following HIV infection a person will usually remain well and symptom free.
- Stage 3- Symptomatic illness
 People start to experience symptoms of disease.
- Stage 4- Advanced disease
 By this stage HIV will have done great damage to the immune system and to the body's ability to cope with illness and infections.

Viral Load

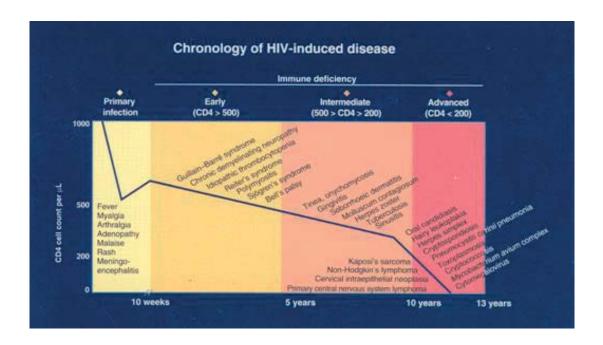
- Viral load is the amount of virus present in a cubic millilitre of blood. It is measured by a blood test that calculates the number of copies of HIV circulating in you blood.
- Knowing how much HIV is present is an indicator of how active the virus is and the risk of future damage to the immune system.



The typical progression of changes in CD4 (T Cell) counts without treatment



Typical viral load changes over time without treatment



Examples of clinical conditions a HIV positive person may experience as their CD4 cell count reduces and the effectiveness of the immune system decreases.

Source :Stewart GJ. The Challenge: Clinical diagnosis of HIV. Could it be HIV? 2nd edition 1994; 4-7 © 1994 reproduced with permission.

- If viral load testing is available, it is normally done:
 - After initial HIV diagnosis
 - Before starting or changing treatments
 - To regularly monitor the effect of HIV treatments
 - Shortly after starting treatments (to monitor if medications are working)
 - During or prior to pregnancy
 - If a person's health status has changed (this should be assessed by a doctor)

CD4 (T Cell) Count

- The CD4 test is a measure of how your immune system is working. People with a healthy immune system usually have a CD4 cell count of between 500 and 1350.
- A general guide to CD4 cell count is:
 - Between 500 and 1350 is the normal range;
 - Between 500 and 350 indicates little risk of developing an opportunistic infection;
 - Between 200 and 350 indicates some immune damage;
 - Less than 200 indicates great risk of developing HIV-related opportunistic infections or AIDS defining illnesses.

Types of ARVs

There are four types or classes of Anti-Retrovirals (ARVs). These drugs help stop HIV reproducing at different sites in the blood cell. By blocking replication of HIV, the cell cannot be infected. Each type blocks HIV in a different way:

- 1. Nucleoside reverse transcriptase inhibitors (NRTIs), also known as "nukes".
- 2. Non-nucleoside reverse transcriptase inhibitors (NNRTIs) also keep HIV from infecting cells.
- 3. Protease inhibitors
- 4. Combination HIV therapies

Adherence

- Taking ARVs at about the same time every day may sometimes not be so easy.
- It is very important to take the drugs as prescribed, because the HIV may become resistant if there are not enough of the drugs in the person's body. Once drug resistance happens, that drug will no longer be effective for that person.

Opportunistic Infections (OIs)

- Ols are infections (bacteria, viruses, fungus, etc.) that most people have been exposed to at some point in their lives, but are usually suppressed by a healthy immune system.
- Some Ols can cause serious illness or be fatal.
- There are effective treatments available for most Ols.
- Some examples of Ols are:
 - TB (tuberculosis) Crypto (cryptosporidiosis)
 - Meningitis Thrush (candidiasis),
 - Herpes CMV (Cytomegalovirus)
 - MAC (mycobacterium avium complex)
 - PCP (pneumocystis carinii pneumonia)
 - Toxo (toxoplasmosis)

Sexually Transmitted Infections (STI)

STI is an infection that is passed on through close body contact or sex.

- Some symptoms of STIs are discharge, smell, itchiness and pain.
- If a person is HIV positive they need to be advised to take extra care to protect themselves from STIs. If they contract an STI, and HIV has damaged the immune system, it may take longer for the STI to clear.
- Having an STI increases the HIV viral load in semen, vaginal fluids and blood. This may
 increase the chance of passing on HIV to an HIV negative person if they have unprotected
 sex or share needles.
- Without treatment, STIs may not go away, although symptoms may disappear. The person infected may remain infectious to others and/or may have damaging long-term health effects.

TB Co-infection

- Tuberculosis (TB) is an infection caused by a bacterium. It usually affects the lungs but can also affect other organs in the body.
- HIV weakens the immune system and makes the person more susceptible to TB.
- TB can make the HIV multiply faster and make the HIV disease worse.
- It is important for people with HIV to prevent and treat TB.

HIV and Hepatitis C (HCV) Co-infection

HCV is a viral infection of the liver. It is most commonly transmitted by sharing needles and other injecting equipment or receiving infected blood products. It seems unlikely to be transmitted sexually.

- HIV can increase the speed of HCV disease progression
- HCV can increase the speed of HIV disease progression
- Most people with HCV are unaware they have this disease. It can be diagnosed by a blood test.

Pregnancy

Every woman has the right to produce children. Being HIV positive is no exception. It is important to be aware of the risks of the pregnancy and know the choices an HIV positive woman has. Many issues need to be considered.

Maternal Health

• Obstetric management will be similar to that of women uninfected or of unknown HIV status.

HIV Testing

- HIV testing in pregnancy has a number of benefits in terms of prevention and care of the mother and child, but this should be balanced against possible risks of stigmatisation, discrimination and violence.
- To reduce negative consequences, testing must be voluntary and be done with clear explanation and pre and post HIV test discussion (see Section 6).
- A healthy lifestyle should be maintained or improved. Particular attention should be paid to nutrition and hygiene. All women should try to eat nutritious meals.
- The woman's level of knowledge concerning HIV and its potential risks to the unborn child may need to be discussed.
- Pregnancy should not make HIV worse, unless the woman has an AIDS related condition.
 During pregnancy the immune system is a bit weaker, but this is true for all pregnant women.
 If the woman is unwell with advanced HIV infection there may be increased risk of going into early labour. There is also an increased risk of passing on HIV to the baby.

Transmission

- HIV may be transmitted from mother to infant at any time during the pregnancy, during labour or as a result of breastfeeding.
- This type of transmission is known as mother to child transmission or vertical transmission.
- Other factors may increase the risks that the virus will be passed on to the baby including:
 - Mothers low T cell count (low immune status);
 - Mother's high viral load;
 - Illicit drug use during pregnancy;
 - If the mother has an AIDS defining illness;
 - Breastfeeding:
 - If the mother has an STI;
 - Mother's poor nutritional status;
 - Mother's general health status.

Antiretroviral Medications (ARV)

- Use of ARVs during pregnancy should be considered for two reasons, the health of the mother and reduction of risk of transmission.
- Taking ARVs during pregnancy may reduce the woman's viral load. Reducing viral load in the mother may reduce the likelihood of transmission of HIV to the baby.

Post Partum Care (After Baby Is Born)

Care of the mother is the same as that for all women. HIV positive women may have increased
risk of complications including chest and urinary tract infections and wound infections. This
may be due to the health status prior to birth.

Breastfeeding

- Breastfeeding has been shown to transmit the HIV virus to the baby.
- Increased risk occurs if nipples are cracked, if there is mastitis, a breast abscess, or if the child has sores in its mouth.
- WHO recommends breastfeeding for six months, with immediate weaning, if no breastfeeding
 alternative (such as no access to infant milk formula and/or clean water) is possible. (Immediate
 weaning is important as mixed feeding (breast milk and formula/solid food) can cause damage
 to the baby's gut lining, which can be sites of infection.)

Table 1. Estimated risk and timing of mother-to-child transmission of HIV, when ARVs are not used

Timing	No breastfeeding	Transmission rate (%) Breastfeeding through 6 months	Breastfeeding through 18 to 24 months
During pregnancy	5 to 10	5 to 10	5 to 10
During labour	10 to 20	10 to 20	10 to 20
Through			
breastfeeding		2 to 10	2 to 10
Early(first 2 months)			
Late(after 2 months)		1 to 5	5 to 10
Overall	15 to 30	25 to 35	30 to 45

Source: De Cock KM et al. JAMA, 2000, 283;1175-82. Copyright 2000, American Medical Association. All Rights reserved.

Other medications for the baby

 Consideration of the infant immunisation programs available locally for such diseases as measles should be recommended to the mother.

Recreational Drugs and Pregnancy

- The greatest effect a drug can have on the baby is at conception and in the first three months. Stopping recreational drug use at this time can have its greatest positive effect.
- Newborn babies may experience withdrawal from recreational drugs a mother has been taking.

Nutrition

Getting the right food is important for HIV positive people. It helps build up the body and give it energy. That in turn helps fight off infections. HIV positive people should be encouraged to eat, even when they do not feel hungry. They may be better off eating more frequent but smaller meals or a healthy snack.

When solid food is hard to eat, it can be made into a liquid form. A balanced diet is best, eating food from each of the following three groups at every meal if possible:

- Body building foods (protein) like peas, beans, mung beans, peanuts, eggs, meat, fish, chicken and milk;
- Energy giving foods (carbohydrates) such as rice, noodles, potatoes, bread, banana and coconut cream.;
- Foods that protect the body from infections (vitamins): all (well washed) uncooked fruits and vegetables, fruit juices coconut cream and milk.

Alcohol is not healthy to drink, especially in large quantities. Juices are much better. It is important to make sure that the water supply is as clean as possible. People with advanced HIV infection should consider filtering and/or boiling water before drinking it or drinking only a reputable brand of bottled water..

Exercise

Staying fit and undertaking moderate exercise is important to overall health. A brisk walk for half an hour three times a week is a very good form of exercise. Just keeping active going about day-to-day business is also good. The rule is to exercise your body without putting it under too much stress.

Note:	

SECTION 6:

Voluntary HIV Test Discussion



SECTION 6: Voluntary HIV Test Discussion

Voluntary HIV counselling, testing and referral is an important strategy in HIV/AIDS prevention and care. Individuals presenting for testing should be provided with information about the ways HIV is transmitted and can be prevented and about the meaning of HIV test results. It may enhance the positive person's ability to increase their access to medical, and social services. Guidelines for pre and post-test counselling should be followed in voluntary test discussion as far as possible in relation to local circumstances.

Pre-test Discussion

Establish a friendly rapport with your client (Use of body language, use of formal and casual speech, non-judgmental attitude, and client awareness).

Set up a private safe comfortable environment.

Explain privacy and confidentiality (Who will see the results beside the client i.e. laboratory technicians, nurses, doctors).

Explore client knowledge:

- Difference between HIV and AIDS
- Transmission and risk factors
- Positive result
- Negative result

Window period (the period between infection and the ability of a test to recognise a positive result). Clarify any misinformation the client has.

Establish the client's reason for asking for an HIV test:

- Discuss risk behaviours

Help the client plan for both negative and positive results:

- Assess clients support network (who can they tell)
- Provide information of where counselling and support is available.

Get (informed) consent from the client for the HIV (and any other) test.

Inform them how long it will take for results to become available and how to get them.

Ask the client to repeat the key information to ensure that they understand. Invite the client to ask any questions they may have.

Tara's Story

Tara is a pregnant women aged 20 requesting an HIV test. She appears to be anxious regarding HIV and pregnancy. Tara recently found out that her husband used to inject drugs/ has had many sexual partners.

What are the indicators of risk for Tara? (High, low, no risk.)

Ram's Story

Ram is a 35-year-old truck driver he is married with three children. He has casual sex with many sex workers. Over the last few months he has noticed some weight loss and chest problems. His doctor advised him to do an HIV test but Ram is scared and has not gone back to his doctor. He asks your advice on what he should do.

Post-test Discussion

Negative Result

Discuss what a negative result means, including the window period.

Recheck client's knowledge of HIV transmission and clarify any misinterpretations.

Assist the client to maintain or adopt behaviours to minimise future risk practices, including negotiating safer sex, safer drug use including harm reduction strategies.

Give the client printed information and condoms to take with them if required (ensure that the information provided is clear and understandable by the client, i.e. appropriate level of detail and language).

Invite the client to ask any questions

Invite the client for a repeat test or further support and counselling

Positive Result

Always discuss what a positive result means, including the difference between HIV and AIDS, reassure the person they can live well with HIV.

Allow time for the client to express their feelings:

- Listen:
- Assess person's reaction. If the client is distressed offer gentle support or seek expert assistance as necessary;
- Discuss support networks.

Provide the client with HIV information, including medical information, medical services, HIV positive peer support services, and written information about HIV.

Assist the client to adopt behaviours to minimise exposure of HIV and STIs to themselves and others, including negotiating safer sex, safer drug use, provide safer sex information and condoms.

Offer an appointment for support, additional information and follow up within the month.

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SECTION 7:

Disclosure



SECTION 7: Disclosure

Who to tell? Who not to tell? When to tell? When not to tell?

A person might choose to tell some or all of these people:

- Other HIV positive people
- Family (wife/husband/partner, parents, children, brothers and sisters)
- Friends
- Public, village, the community
- Only people outside your own area

Some of these are easier than others. Which are easiest? Can you limit who you would tell?

- Disclosing an HIV positive status can be difficult.
- Shame, fear, rejection or guilt are some of the emotions that a person may feel in the disclosure process.
- Some questions to think about before disclosing are.
- Some people with HIV choose not to tell anyone. We must respect everyone's right to make their own decision.
- Know the advantages and disadvantages of disclosure.
 Making a list and weighing up the pros and cons can be useful.
- It is important that individuals think through who they want to tell, how they will say it, and when.
- It is OK to say to someone, "I would like to tell you something important. Before I do I need
 you to promise me that you will not discuss this information with anyone else without my
 permission".
- Having some printed information or an information telephone number to give to close persons after a disclosure can be helpful
- CONFIDENTIALITY must be assured and that means by everyone, including counsellors.

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SECTION 8:

Stigma



SECTION 8: Stigma

Introduction

Stigma is attributing someone or a group as being 'dangerous', 'bad' or 'powerless'. Stigma can result in a person or a group of people feeling un-pure, tainted, unacceptable and without the same value as other human beings. It can also lead to self-harm.

Fear

The basis of much stigma is fear. HIV generates fear in these ways:

- The fear of death, both the person with HIV and those who live and work with them may be confronted with the fear of death. If we are afraid to think about our own mortality we may be tempted to turn away from people with life threatening illnesses like HIV/AIDS.
- The fear of catching HIV due to ignorance of how it is transmitted.

Shame

- Shame is the reaction to being negatively evaluated. It is a response to a person's very basic sense of self and identity.
- Shame has been connected to HIV because it can be transmitted through sex and illegal drug
 use. Because sex and illegal drug use are often taboo subjects and filled with negative moral
 judgements, people living with HIV are often criticised or feel ashamed.

Powerlessness

• Powerlessness can result from both the fear and shame associated with HIV/AIDS.

Opposing Stigma

Fear

- Make yourself aware of what fears you may have about your own mortality. Let your client talk about their fears of death if they want to.
- · Make sure you have the facts about HIV.
- · Combat fear with realistic hope.

Shame

- Make yourself aware of your own values about sex and drug use. Never respond to others with abuse, blame or other negative evaluations.
- Ensure your client knows that you value them and consider them a person of worth.
- Combat shame with solidarity and respect

Powerlessness

- Be aware of the language you use.
- Support your client in acknowledging and accessing their basic rights and needs.
- · Combat disempowerment through empowerment.

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SECTION 9:

Living With HIV



SECTION 9: Living With HIV

HIV support workers work with clients of all ages and because of this it is important to be aware of the many changes and stages throughout a client's life. All life stages bring challenges, learning and concerns regardless of a person's HIV status.

The life cycle is made up of a number of developmental stages. These five stages are

- Infancy
- Childhood
- Young adulthood
- Adulthood
- Older age

As HIV support workers, you need to be open, flexible and listen to what issues the client is expressing as being of concern to them. For some, their HIV positive status may be the most important issue in their life. For others, different issues may be worrying them more.

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SECTION 10:

Being an HIV Support Worker



SECTION 10: Being an HIV Support Worker

Being a HIV Support Worker

To be an effective HIV support worker we need to be honest to ourselves in owning our feelings. When a client talks or acts in a particular way, we can at times have an emotional response.

The HIV support worker also needs to be aware of any feelings the client has towards the worker, such as anger, insecurity, afraid to be rejected, too high expectations and dependence. You may need to address these issues if they are having a negative impact on the client-worker relationship.

What Is Identification?

In a client–worker relationship, emotional issues or problems in a client's life may be similar or close to some of the worker's personal issues. This is called identification.

Identification can be used to foster a deep understanding of the client's situation from the volunteer and be a useful and important part of the relationship.

Identification can become a problem for the worker–client relationship if the worker has not come to some form of acceptance, resolution or understanding in his or her own life. This is called over-identification.

The Role of Supervision

Supervision has three main roles

- To encourage and support the worker in reviewing their work with each client;
- To provide emotional support and debriefing;
- To provide professional development and education.

Being a HIV Support Worker Role-play

This role-play has 4 parts to it. There are 3 main characters in this role-play.

The "actors" are: the manager (boss), the support worker and the client. The group gives suggestions of how to deal with each situation at the end of each scene. They can ask questions of the "actors".

Scene One

The client comes to see the support worker. S/he asks the worker for some money to get a bus to a medical appointment and also for food. The support worker tells her/him they do not usually give out any money, but will check with the boss. The boss says they have a little left over from some fundraising that the support workers can give the client, but that they must tell the clients this is the only time they can do it. The support worker tells the client this and gives him/her a food voucher. The client goes away happy.

Scene Two

A few weeks later the client comes back to see the support worker and once again asks for money. The support worker tells him/her there is no money. The client starts to cry and tells the support workers that they have no food for their children. The support worker feels bad for him/her and gives a small amount of money from his/her own pocket. The client goes away happy, but the support worker feels frustrated by this meeting.

Scene Three

The support worker and others who work at the agency have noticed that many people come and ask them for money. The support worker feels they need to find a solution to this problem. S/he goes to the boss to talk about this and about how they feel when people ask them for money and they cannot help.

The boss is a bit angry and says" I'm very busy write me a memo"

The support worker leaves the boss' office. S/he feels that they do not have any support from the boss.

Scene Four

Some weeks later the same client comes and asks the support worker for money again. The support worker feels guilty. S/he tells the client there is no money. The client starts to get angry with the support worker and yells at him/her, saying they are sick and need help and no one cares and that the support worker should give some of their personal money because at least s/he has a job. The support worker gets angry and asks the client to leave. The client starts to cry but the support worker tells her/him to go. The support worker now feels angry but also very upset.

Taking Care of Yourself

It is very important to look after yourself as an HIV support worker. Your own well-being is just as important as that of your client. Remember that if you don't look after yourself you will not be able to effectively support your clients.

A number of things can happen when we don't look after our own emotional health. These may include:

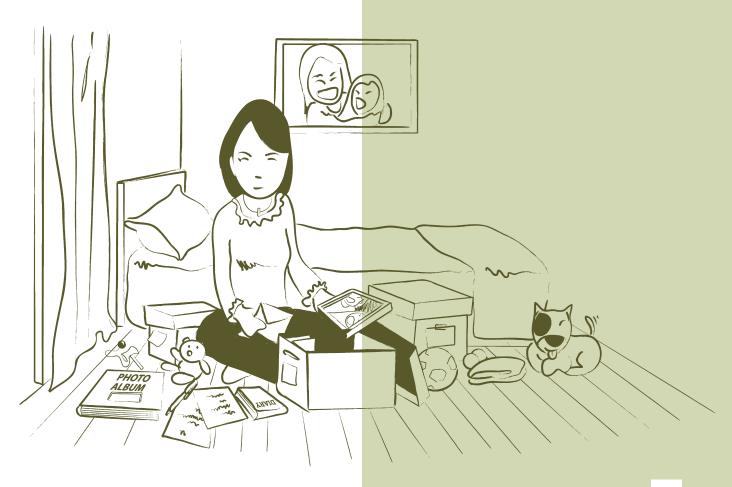
- · Physical and emotional tiredness;
- · Headaches;
- · Back and neck pain;
- Negative attitudes toward the clients you work with;
- Feeling that the work you do is not worthwhile;
- Anger and frustration;
- · Apathy.

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SECTION 11:

Saying Goodbye



SECTION 11: Saying Goodbye

Grief

What Is Grief?

Grief is a normal, natural process following a loss. The best way to help someone who is grieving is to 'be there' for them, providing support.

Grief tends to be experienced in waves, triggered predictably by new losses or unpredictably by seemingly trivial events.

Grief does not have a schedule, individuals progress through the grief process at different speeds. It can take two years or more for a person to go through the grieving process.

Common Physical Reactions:

- numbness:
- tightness in throat or chest;
- forgetfulness and difficulty concentrating;
- shortness of breath;
- sensitivity to loud noises;
- changes in sleeping patterns;
- loss of appetite;
- agitation and restlessness that will improve over time.

How Long Does Grief Last?

- · Grief may last a lifetime;
- The person who continues to express grief needs support;
- The grief process is never complete.

Children

When a parent or both parents die, children are often left in a very vulnerable situation. It is far better for them if there is an alternative to being institutionalised in an orphanage or left to fend for themselves on the street. If a child is likely to be orphaned, try to find out if there are relatives (grandparents, or aunts and uncles) who will willingly care for the child or children and treat them as their own. There may be a wider community in the village or town of which they are a part, who would like the children to stay with them.

These are some considerations:

- It is always better for siblings not to be separated whenever that is possible, whatever happens to them.
- It is better if these arrangements are made before the parent dies, as a commitment made personally is often more binding.
- It is extremely important that the children are able to go to or remain in school, and that their future is not compromised more than it already will be.

Caring for Children

For parents of young children one of the most frightening questions about their death is what will happen to their children when they die.

Questions that the person with HIV may be asking are:

- Who will look after them?
- Will they remember me?
- What will become of them when I die?

Grief and Children

Many people are concerned about answering their grieving children's questions in the "right" way and saying the "right" things, so that the children won't suffer. There are often no correct or satisfactory answers. An adult needs to help children to feel safe amidst the overwhelming feelings and chaos that can be grief.

Infants and Toddlers

While children up to three years old are too young to know the real meaning of death, the impact of death is signalled to them by changes in their environment.

What you do rather than what you say is important for a child this age. Hugging and cuddling can be reassuring.

Four to Six Year Olds

Children this age have a limited and literal understanding of death. They do not understand that death is permanent.

Because their thinking is very literal and bodily-orientated death can be explained this way: e.g. "Daddy's heart has stopped beating and no one can make it start again. He won't be able to move or talk anymore".

Seven to Eleven Year Olds

Children of this age express themselves well, especially feelings of anger, sadness and happiness. They have begun to understand concepts of truth, time, space and death. They become fearful of death because for the first time they realise it is real.

Some of their questions may indicate fears of their own death. They may feel a person's death is punishment for their improper behaviour, for being naughty.

Free expression of grief should be encouraged and that they need to be told they did not cause the death.

Twelve to Seventeen Year Olds

To the emotionally healthy adolescent, death can be foreign – it is something they do not want to talk about.

After the loss of an important relationship the adolescent's self-centred values may cause them great fear, guilt, anxiety and anger.

They often have strong relationships with peers so nurturing these groups can be important.

Create a Book Together – Leave a Story

Whether a child loses one or both parents (or a sibling), especially if they are young, they need to keep alive the 'feeling' of those people. What sort of people were they? What were they like? It is important to leave a history of their parent or sibling who died. The time to start doing this is when they are still alive.

Making the End Comfortable

At some point a person with HIV may no longer be able to fight off infections and illnesses and may not have access to medication that can help them. The person may be coming to the end of their life.

They may start to talk about or in some other way get ready for death. At this time you may need to be willing to discuss their death with them and/or their family and friends.

The person may have many things they are worried about and it may be helpful to talk about these things and possibly help them

Issues that may arise include:

- What will happen to their possessions, particularly land;
- Funeral arrangements;
- They may be worried about what will happen to their family and their children.

Spirituality may be important to the person who is dying. They may need to express their feelings to you or to a religious person.

Like so many other concerns death and dying must be dealt with in culturally appropriate ways according to national, religious, and local customs. Some individuals may have unique requirements at this time.

Respond to the dying person's emotions. Listen to the person. Do not interrupt while they are talking, they may be making some important decisions and need the opportunity to talk with you about what they are thinking and feeling.

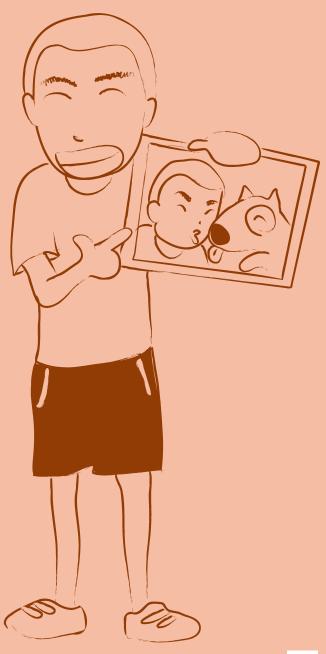
Listen to yourself. Be aware of your own emotions at this time.

You may feel emotionally involved with your client. It is important to recognise that you are human and reflect (remember to respect your client's confidentiality when doing this) on your feelings and share them with another person, your supervisor, a colleague, a friend or a loved one.

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SECTION 12:

Positive Stories



Asia Pacific Participant's Manual and Training Resource on Basic HIV Counselling Skills

SECTION 12: Positive Stories

A diagnosis of HIV is interpreted by many as a death sentence and a fairly immediate one at that, but that is not the case.

There are many people who have lived full and productive lives with HIV for over twenty years. A few of these people have never taken ARVs.

What is the secret? At this stage we do not really know:

- Maintaining general health is a factor;
- · Reducing stress is another factor;
- Healthy eating is important;
- Many people believe strongly that maintaining a positive outlook on life helps;
- There are others who say that having a caring and supportive environment also contributes.

In the last few years a tremendous amount of progress has been made in several areas. Firstly we understand much more about the virus itself. We also have much better methods of controlling opportunistic infections.

Governments are more prepared than ever before to confront the problem of HIV/AIDS.

Slowly, far too slowly maybe, ARVs and other treatments are being made available to a much larger number of people.

Work continues on development of vaccines. Trials are underway.

Positive Stories

To start with having HIV was a frightening experience for me. I thought my life had come to an end and there was nothing to look forward to. But I found other people living with HIV. We started to help and support each other. I met new people, in many cases people I would not normally have formed friendships with. I have learned so much about life, and I believe I am a better person as a result. (MJ, Female, 34 years old))

I have been living with HIV for twenty-three years. I have had a few problems, but for the most part I can't complain. Why have I managed to survive for so long? I don't know. People say that I am a fighter. I am not so sure about that. Maybe I have just been lucky. It always surprises me how many others have lived over twenty years with HIV. I know at least six others. (JR, Male, 59 years old)

I suppose when we are young we never think we are going to get sick and maybe die. Having HIV makes you face the fact that everyone will die one day. The experience has caused me to change the way I look at things. I think it has actually changed the way I think for the better. I am a better person now. (RT, Female, 28 years old)

Having HIV is an experience I would not wish on anyone. But out of every bad situation comes some good. I have learned new skills, I have put something back into the community, and I feel good about that. (SD, Male, 36 years old)

Note:	

Useful Websites and Contacts:

Useful Websites and Contacts:

- 1. redcross@nat.redcross.org.au ARC (Australian Red Cross): www.redcross.org.au
- 2. secretariat@ifrc.org IFRC (International Federation of Red Cross and Red Crescent): www.ifrc.org
- 3. info@apnplus.org APN+ (Asia Pacific Network of PLWHA): www.gnpplus.net/regions/asiapac.
- 4. infognp@gnpplus.net GNP+ (Global Network of PLWHA): www.gnpplus.net
- 5. admin@napwa.org.au NAPWA (National Association of PLWHA, Australia): www.napwa.org.au
- 6. mail@afao.org.au AFAO (Australian Federation of AIDS Organisations): www.afao.org.au
- 7. halc@halc.org.au HALC (HIV/AIDS Legal Centre, Australia): www.halc.org.au
- 8. unaids@unaids.org UNAIDS (Joint United Nations Programme on HIV/AIDS): www.unaids.org
- 9. info@nam.org.uk AIDSMAP (Treating HIV & AIDS A Training Toolkit): www.aidsmap.com
- 10. hiv-aids@who.int WHO (World Health Organisation): www.who.int/hiv
- 11. UNDP (United Nations Development Programme): www.youandaids.org
- 12. Asia Pacific PLWHA Resource Centre: www.plwha.org

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APPENDIX:

Palliative Care

APPENDIX: Palliative Care

Palliative care is directed at providing relief to a terminally ill person through symptom management. The goal is not to cure but to provide comfort and maintain the highest possible quality of life for as long as life remains.

Quality of life should be considered when a person is making decisions concerning care near the end of life. It considers the physical, functional, emotional, social and spiritual aspects of a person's life.

Assessing a person's need considering quality of life may be beneficial to the individual and those caring for them. The person who is ill will appreciate having the chance to discuss these issues with you and this will show the person that you have an interest in their well being that goes beyond their disease.

Pain

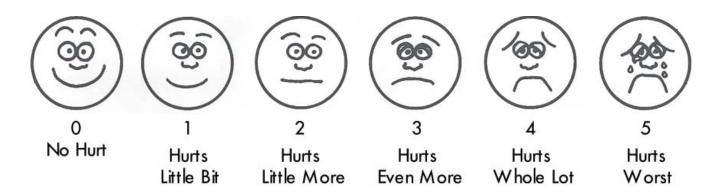
Minimising the pain a person is experiencing is essential. Using both analgesics and complementary care can relieve pain. When used properly analgesics can provide much relief to the person. The key to pain management is through assessment and monitoring the person's pain. The caregiver can record the person's pain by asking them regularly to describe it. This record should include:

- A pain rating (1 to 10, 1 being least pain 10 being worst pain);
- Duration of pain;
- Type of pain (e.g. sharp, burning, throbbing, shooting);
- Drugs used to help pain;
- Any side effects from drugs;
- How long the drugs works.

When a person starts taking pain medication they need to be monitored to see if the dose is adequate or too much. As pain is individual, so too should pain assessment be, using the above scale regularly to monitor a person's pain and whether the pain medications are useful.

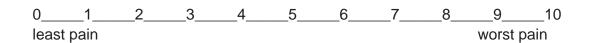
Morphine is a good analgesic for end of life or cancer pain. It is often used in conjunction with a non-narcotic drug such as paracetamol. It should be used regularly i.e. every four hours rather than when the dying person asks for it. Often caregivers assume the person is not in pain because they don't seem to be or they are not complaining, but regular pain relief should still be given as pain experience is very subjective. Those who have had a history of drug use should not be denied pain medication but may need increased doses. Using a pain assessment would assist in monitoring this person. If a person endures pain for too long it will take the pain medication longer to work because of increased severity of the pain. Other symptoms can arise out of this unnecessary pain such as increased anxiety, which can lead to nausea and then a decrease of appetite. Physical agents are often used with analgesia. Massage benefits the person by increasing circulation, and reducing pain. It also provides soothing effects that can help the person to relax both physically and mentally. Applying a gentle heat or cooling to tissues can also help relieve muscle spasm and pain. Appropriate positioning and movement of inactive patients can alleviate pain and prevent complications associated with inactivity such as pressure ulcers and contractures.

Figure One: Wong - Baker FACES Pain Rating Scale (visual pain assessment chart)



Wong-Baker FACES Pain Rating Scale from Hockenberry MJ, Wilson D, Winkelstein ML: <u>Wong's Essentials of Pediatric Nursing</u>, ed.7, St Louis, 2005, p.1259. Used with permission. Copyright, Mosby.

Figure Two: Linear Scale Pain Chart



The above charts can be useful tools to assess what a person's pain experience is like for them. These can all be used to assess the initial pain experience and also to assess pain medications. Ask the person before and 20 minutes after they have had pain relief to assess if the pain medication is having an affect.

For some people such as children, the elderly or someone who does not speak your language, using Figure One (FACES) may be helpful. Explain to the person that each face is for a person who feels happy because he has no pain (hurt) or sad becasue he has some or lot of pain.

Face 0: is very happy because they do not hurt at all; Face 1: hurts just a little bit; Face 2:hurts a little more; Face 3: hurts even more; Face 4: hurts a whole lot; Face 5:hurts as much as you can imagine, although you do not have to be crying to feel this bad. Ask the person to choose the face that best describes how they are feeling.

Using Figure Two, a linear scale, may be useful where 0 is least pain and 10 the worst pain. Ask the person to tell/show you their pain experience.

Cultural Aspects of Pain Management

The meaning and expression of pain are influenced by people's cultural background. Pain is not only a physiological response to tissue damage but also includes emotional and behavioural responses based on the person's past experience and perceptions of pain. But not everyone from a specific cultural background will conform to a set of expected behaviours. Do beware of categorising the person. Each person and their experience must be treated as individual.

Pressure Ulcers

Pressure ulcers are a major problem in end of life care. Poor attention to skin care will result in pain, odour, swelling, reduced quality of life and increased demands of caregivers. Skin can with stand pressure on one area for up to 60 minutes before damage starts. Pressure ulcers result from ischaemia (lack of oxygen to tissue) and are seen particularly at pressure points – heels, sacrum and elbows. Factors, which influence ulcers, are limited mobility, age related change to skin, malnutrition, friction and moisture.

Care of Ulcers

Persons with ulcers should be turned regularly if bed bound, or left sitting in a chair, at least every two hours. Skin should be protected from friction, moisture and shearing (tearing). If there is a break in the skin a dressing will need to be applied with regular changing as needed. If the ulcer becomes infected, antibiotics may be needed.

Mouth Care

The person may already have some mouth disease such as thrush or mouth ulcers, which may be painful. Treat with pain medications where needed, but keeping the mouth clean and moist will promote healing and reduce discomfort. Regularly clean the mouth with water, or water with a small amount of salt added. If the person is unable to help, use a small piece of clean cloth or a swab to cleanse the mouth gently. This may be done every 2 to 4 hours and after food or drink.

Confusion

Sometimes a person may become confused when they are dying or because of conditions in their brains such as toxoplasmosis or cancers like lymphoma. They may become confused about time or place, or the identity of loved ones. They may become restless trying to move about often, and they may see things that are not there, or they may pull at clothing or bed linen. Gently remind the person of place and time and the people who are with them. If the person becomes agitated, the caregiver must try to remain calm and reassuring, and seek assistance if necessary. If this

behaviour has been going on for some time it may be necessary to have a rotation of caregivers so that one person does not become too tired. Caregivers need support and the opportunity to have rest and time out.

Hygiene

A regular wash of the body will keep infections low and keep the person comfortable. If the person is experiencing a high temperature this may need to be done more regularly. If the person becomes soiled by loss of bladder and bowel control it is necessary to clean them straight away so that pressure sores do not develop, and to provide the person with dignity. Keep the person as clean and dry as possible.

Dyspnoea

Difficulty in breathing should be assessed for cause. Is it due to an episode of anxiety, severe pain, constipation or urinary retention or is the person close to death? Re-postponing the person may help such as sitting up higher on pillows, or increasing air movement by opening a window or using a fan. If the person has access to oxygen, administer it, or if they are having intravenous (IV) fluids decreasing the amount or discontinuing may help. Treating the dyspnoea with some drugs may help by drying up secretions, reducing anxiety or helping a cough.

Note:	



Asian Regional Office

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