

**Key Psychological Tips For
Living Confidently With
HIV...**

WHY A PSYCHOLOGICAL APPROACH TO HIV

Many people who are HIV positive have discovered ways of having a life that feels worth living in spite of HIV infection. For some this may have not been easy while others may still be trying. There are always individual differences in the experiences of people living with a chronic condition, but there are also many commonalities.

There are many new psychological challenges associated with HIV now that treatment is available. As it has changed from a terminal illness to a chronic condition, HIV+ individuals need to negotiate a whole range of issues due to the new meanings related to being HIV+. Particular skills are therefore required in order to live with HIV. To feel able to face the future with confidence, engage in healthy lifestyles, meaningful activities, relationships, and enlist social supports will help in negotiating HIV.

HIV has been in the public consciousness now for over two decades. However, despite the increasing length of time we have known about HIV, the fact that its treatment has improved immensely over this time and that more people are infected, it continues to remain controversial. As a result, there are many extra challenges to living with HIV, which can be positive or negative. The stigma and secrecy of being HIV+ can impair individuals' abilities to communicate their needs around living with the condition. Psychological aspects of HIV therefore need to be more openly discussed in order to make the experience more visible, enhance people's understanding and improve people's coping with the condition.

Psychological issues will always accompany HIV, but they will change over time. As a result, HIV+ people will increasingly have to find different ways to successfully adapt to and negotiate the issues they will come across in the future.

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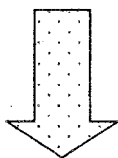
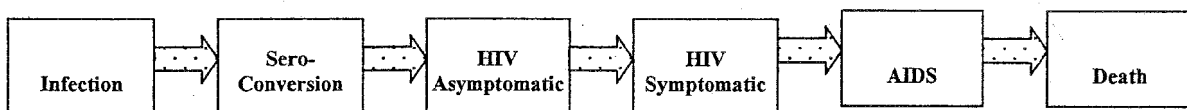
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HIV is renowned for the emotional reactions that it produces. The fact that people believed (and some may still do), that you could catch it from someone by sharing cutlery or the toilet just illustrates the extent of misunderstanding. So, the better your knowledge about your condition, the better your ability to negotiate the issues that you confront.

Tip (1) Understand what HIV is and what it isn't and how to live with it. Do accept that your life is different since your HIV diagnosis, but the extent to how different it can be, depends on how you deal with it. With treatment, HIV is a chronic condition, not a terminal illness.

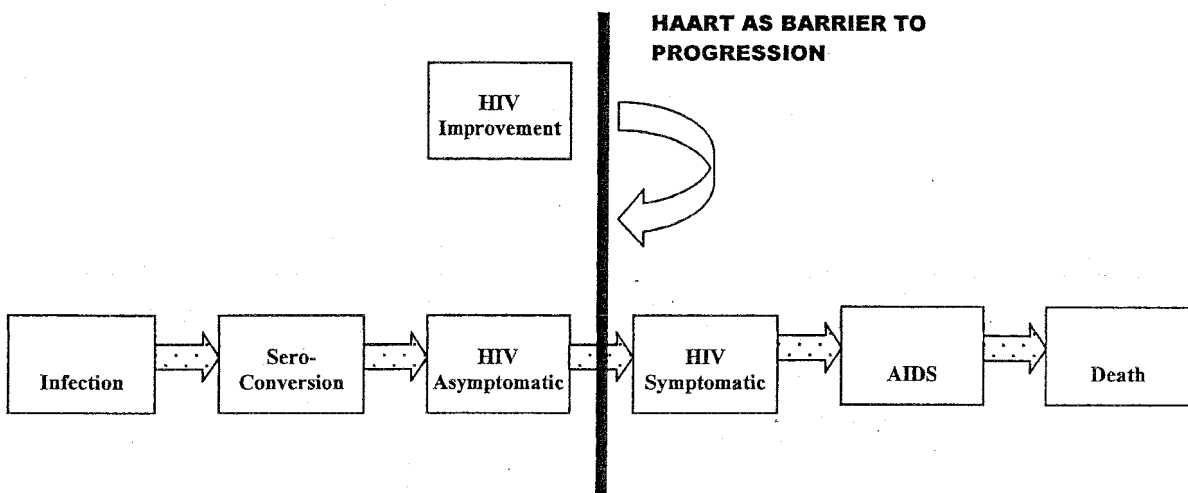
HIV as a TERMINAL ILLNESS

A person diagnosed HIV+ in the late 1980's to early 1990's would know that death was largely inevitable. HIV during this time, led to AIDS, which was a terminal illness. Only health consequences could be medically managed, such as infections resulting from low immunity.



HIV as a CHRONIC CONDITION

A person diagnosed HIV+ in the late 1990's and after (to the present day), now knows that death is not necessarily inevitable because of HIV antiretroviral drugs. HIV is now a chronic condition, which can be managed instead of progressing to AIDS and thus prolonging life considerably. For many persons a normal life expectancy is possible.



Tip (2) Engage in a healthy lifestyle and manage stress and negotiate your health system. Monitor and manage your stress as follows:

WHAT IS STRESS?

The stress response of the body is rather like an airplane about to take off. Virtually all systems (i.e. the heart and blood vessels, the immune system, the lungs, the digestive system, the sensory organs and brain) are modified to meet the perceived danger.

People can experience either external or internal stressors. External stressors include adverse physical conditions (such as pain or hot or cold temperatures) or stressful psychological environments (such as poor working conditions or abusive relationships). Internal stressors can also be physical (infestations, inflammation) or psychological. An example of an internal psychological stressor is intense worry about a harmful event that may or may not occur.

ACUTE OR CHRONIC STRESS

Acute stress is the reaction to an immediate threat, commonly known as the fight or flight response. The threat can be any situation that is experienced, even subconsciously or falsely, as a danger. Common acute stressors include: noise; crowding; isolation; hunger; danger; infection; and, imagining a threat or remembering a dangerous event. Under most circumstances, once the acute threat has passed, the response becomes inactivated and levels of stress hormones return to normal, a condition called the 'relaxation response'.

Chronic stress is the long-term reaction to stressors. As modern life poses ongoing stressful situations that are not short-lived, the stress then becomes chronic. Common chronic stressors include: ongoing highly pressured work; long-term relationship problems; ongoing health problems; loneliness; and persistent financial worries.

NEGATIVE EFFECTS OF STRESS

In the modern world, the stress response can be an asset for raising levels of performance during critical events such as sports activity, an important meeting, or in situations of actual danger or crisis. If stress becomes persistent and low-level, however, all parts of the body's stress apparatus (i.e. the brain, heart, lungs, vessels and muscles) become chronically over- or under-activated. This may produce physical or psychological damage over time. Stress-related conditions that are most likely to produce negative effects include the following:

- An accumulation of persistent stressful situations, particularly those that a person cannot easily control (i.e. high pressured work plus an unhappy relationship).

- Persistent stress following a severe acute response to a traumatic event (i.e. an automobile accident, an assault).
- An inefficient or insufficient relaxation response.
- The psychological dynamic in which stress diminishes quality of life by reducing feelings of pleasure and accomplishment, which can threaten relationships.
- The immune response is blunted by chronic stress, which increases the risk for infections.

STEP (1): IDENTIFYING SOURCES OF STRESS

- It is useful to start the process of stress reduction with a diary that keeps an informal inventory of daily activities and events. This task does not have to be done in great detail. A few words accompanying a time and date will usually be enough to serve as a reminder of the particular event/activity.
- Then note activities that put a strain on energy and time, trigger anger or anxiety, or precipitate a negative physical response (i.e. sour stomach or headache).
- Also note positive experiences, such as those that are mentally or physically refreshing or produce a sense of accomplishment.
- After a week or two, try to identify two or three events or activities that have been significantly upsetting or overwhelming.

STEP (2): QUESTIONING THE SOURCES OF STRESS

- Then ask yourself the following questions.
- Do these stressful activities meet your own goals or someone else's?
- Have you taken on tasks that are or are not reasonably accomplishable?
- Which tasks are in your control and which aren't?
- Can you change any?

STEP (3): RESTRUCTURING PRIORITIES

- The next step is to attempt to shift the balance from stress-producing to stress-reducing activities. Eliminating stress is rarely practical or feasible, but there are many ways to reduce its impact.
- Re-prioritise activities in life that are unhelpful.
- Make time for recreation and breaks.
- Replace unnecessary time consuming chores with pleasurable or interesting activities.
- Get help from someone to plan your time.

Tip (3) Seek social support where necessary – why do some things on your own when there are many good people, agencies and services eager to assist?

Alice

Alice is aged 37 years has been HIV+ for two years. When Alice visits the hospital for her three monthly blood test for Viral Load and CD₄ Counts, she becomes fearful shortly before the date. As she has not disclosed her HIV status to anyone, it adds to her anxieties, as she feels secretive. When at the hospital, Alice is filled with fear as she sees hospitals as places where people are ill. She is feeling frustrated about being HIV+. When with her Doctor, she doesn't say much or ask any questions. Alice is also very isolated but she has not told anyone. She leaves the hospital. The whole experience was difficult for Alice.

Sam

Sam is aged 37 years has been HIV+ for two years. When Sam visits the hospital for his three monthly blood test for Viral Load and CD₄ Counts, he does so in a relatively calm way. He has disclosed his HIV status to some close friends and has discussed his feelings with them about being HIV+. When at the hospital, Sam chats with the staff. He is feeling supported about being HIV+. When with his Doctor, he explains the concerns he has. In discussion with the Doctor, Sam receives a referral to a service he needs. He leaves the hospital. The whole experience was helpful for Sam.

Which of the above two cases do you think will be more aware of and in control of their network of care? Clearly Sam is more in control and because of this, achieves more. Alice has many adjustment concerns, which get in the way of her functioning and relating – even at the hospital.

Tip (4) Disclose HIV where appropriate with pride and communicate your HIV status where appropriate so that you can receive the right support from the right people.

MOTIVES FOR KEEPING SECRETS!

Keeping secret about one's HIV status is probably a very common phenomenon for many HIV+ people. You cannot tell if someone is HIV+ just by looking at them therefore its presence remains hidden. The following four reasons account for why people may not want to disclose their HIV status to others:

(1) TACT

To save the listener embarrassment.

(2) RELATIONAL STABILITY

When the HIV infected person wishes to avoid perceived conflict.

(3) PSYCHOLOGICAL COMPENSATION

In order to present a favourable social image

(4) POWER DEFERENCE

In order not to feel dependent on acceptance from others or inferior

The psychological motives for keeping secrets are clearly protective. However, if they are used, they need to be used with clear reason as to why. It is important not to be ashamed keeping your HIV secret from some people. After all it is your business. Disclosure is important though, especially to close people. One's reasons for disclosure need to be very clear.

The following highlight why HIV disclosure is important:

- **DISCLOSURE** is easier in the long run as it takes more personal effort to inhibit emotional disclosure than to disclose
- **DISCLOSURE** helps with adaptation to illness by helping with processing of disturbing emotions, and problem solving
- **DISCLOSURE** facilitates access to treatment
- **DISCLOSURE** facilitates access to practical and emotional help in the long term
- **DISCLOSURE** helps overcome loneliness

- **DISCLOSURE** helps overcome feelings that you are the only one with the condition, or fears of stigma
- **DISCLOSURE** helps to change attitudes in those around you
- **DISCLOSURE** enhances the fact that HIV is a global phenomenon as it can affect anyone who ever they are and where ever they are in the world.

How Self-Accepting Are You?

- Identify negative feelings about HIV.
- Explore possible reasons behind those feelings (personal and cultural values, stigma, fear of other's reactions).
- Evaluate positive and negative impact of those feelings on quality of life (to enhance motivation to develop a different approach).
- Challenge general beliefs about HIV.
- Distinguish beliefs about HIV from personal worth.
- Understand how disclosed HIV affects social interaction.
- Practice self talk that is more self-enhancing and powerful, and therefore less helpless, self-blaming, self-attacking.

AVOIDING AND OVERCOMING LONELINESS

If you do decide to do it alone, or end up not disclosing, one of the consequences may be loneliness. This can result in feeling cut off and depressed. The following tips may help you in dealing with it.

(1) Recognise your thinking distortions.

When your mood is low there is a tendency for your thinking to become distorted (all-or-nothing, exaggerated etc.). Note the following common thoughts associated with loneliness and identify thinking distortions: *"I have no friends."* *"No one likes or loves me."* *"What good am I to anybody?"* *"Nobody understands me."* *"I need to be loved."*

(2) Stop comparing yourself with others.

Again look out for thinking distortions. *"Everyone is busier and happier than me."* *"Everybody else has fulfilling relationships."* You have an idealised fantasy about other people's lives, which means that there is no way your own life will match up.

3) Recognise the vicious spiral of low mood.

Notice how it can lead to you withdrawing from other people because of your fear of hurt and rejection. Turn this process around and start approaching others rather than avoiding. Plan activities that increase your social contacts. Contact people you know and like. Talk to neighbours. Develop a hobby.

4) Recognise the difference between being alone and loneliness.

Don't equate alone with loneliness. Learn to enjoy doing things and caring for yourself on your own. Cook yourself a nice meal, play your favourite music, read a good book. The more you can feel at home with yourself – not looking around for others all the time – the more confident a person you will become.

5) Plan a variety of activities to do on your own.

Examples include going to an art gallery or walk in the park. Use your imagination. Before you carry out the activity draw up a chart and rate how satisfying you think it will be on a scale of 0-100 (0= no satisfaction, 100= enormous satisfaction). Then after you have carried out the activity, rate the actual satisfaction.

6) List some advantages of being alone.

It is important to appreciate the value of 'time alone'. Starting with, "*It provides an opportunity to explore how I really feel and think.*" "*It allows me to develop personal strength.*"

Tip (5) Have the choice to have safe sexual relationships but remember *disclosure* and *safe sex*.

WHY SEXUAL PROBLEMS ARISE

Sex is a natural function like digestion – and like digestion, can be upset by a whole variety of problems, usually not involving physical factors.

We all except that faulty eating, feeling rushed, stressed, anxious or in a bad mood can lead to complaints like loss of appetite, indigestion, diarrhoea or constipation even though the body is basically healthy. We also know that if we eat normally and in a relaxed way, our digestive system works naturally and we enjoy our food.

In a similar way, if sex is allowed to happen naturally and in a relaxed way our bodies will respond normally without any conscious effort on our part.

Sexual problems are extremely common. Around forty percent of the adult population will experience sexual problems at some point in their lives. It is also known that the prevalence of sexual problems amongst people living with HIV is higher than in the general population. This is unsurprising given that sexual behaviour is determined by a host of biological and psychological influences that can be adversely affected by HIV, a chronic condition.

Sexual Communication Principles

ONE Aim to communicate with each other as two adults

TWO Teach yourself to 'self-assert' and 'self-protect'

THREE Remember that you are entitled to your own feelings and you should be allowed to express them freely

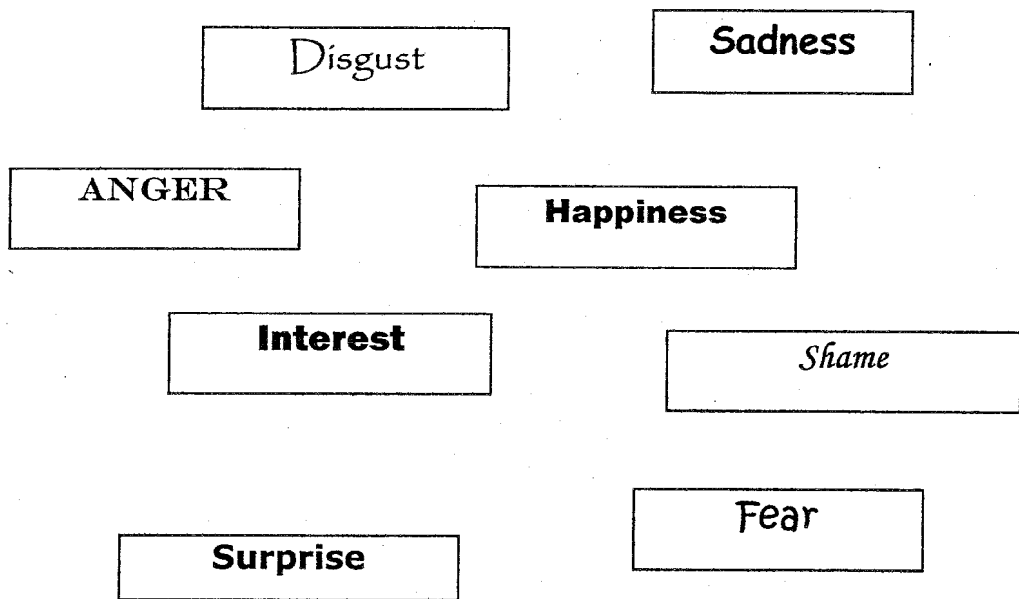
FOUR Keep negotiating what you want especially on occasions when you want something different

FIVE Use praise and encouragement. Work hard at noticing and commenting on the good things your partner does

Tip (6) Recognise, accept and manage your emotions in relation to HIV. You will feel stressed, depressed, anxious and other negative emotions at times. That is part of adjusting to HIV – but remember that these bad feelings can be changed.

EIGHT PRIMARY HUMAN EMOTIONS

They are eight primary human emotions that appear to have a biological or innate basis: happiness, fear, sadness, anger, disgust, shame, surprise, and interest. There are other emotions known as secondary emotions that are learnt and are usually combinations of primary emotions.



Chris wakes up one morning, and the sun is shining. Because happiness does not exist this makes no difference. He goes for a walk in the park and bumps into a friend who he has not seen for a long time. As surprise does not exist, the meeting is not appreciated. The shop attendant is rude to him but as anger does not exist he does not think anything of it. Finally, while crossing the road he notices a car speeding towards him. As fear does not exist, he fails to move out of the way in time.

Life would be pretty meaningless without emotions. It would be reduced to a kind of zombie like existence. Furthermore, throughout history, emotions have helped people to do good things, for example, Martin Luther King's anger at the injustice of racism in the USA in the 1960s motivated him to protest.

EMOTIONS ARE ADAPTIVE

Emotions are usually adaptive and have a range of uses. They can do the following:

- ❑ *Communicate to people about their surroundings. They are signs that something has happened. They communicate to people what is important in their lives (and what is not).*
- ❑ *Communicate to others.*
- ❑ *Motivate people.*
- ❑ *Prepare people to act.*
- ❑ *Help people to act "automatically" saving time in critical situations without having to think everything through.*

Anxiety and Depression Symptoms

ANXIETY	DEPRESSION
PSYCHOLOGICAL SYMPTOMS	
<ul style="list-style-type: none">• Scanning the environment for possible sources of danger.• Fearful thoughts.• Loss of confidence.• Feeling inadequate.• Difficulty concentrating and focusing.	<ul style="list-style-type: none">• Diminished ability to think or concentrate.• Loss of sex drive.• Loss of confidence or self-esteem.• Recurrent thoughts of death or suicide.• Feelings of hopelessness.• Increased criticisms of self and feelings of guilt.
BEHAVIOURAL SYMPTOMS	
<ul style="list-style-type: none">• Panic.• Avoidance of situations.• Restlessness.	<ul style="list-style-type: none">• Decreased motivation.• Avoidance.• Slowing down.
PHYSIOLOGICAL SYMPTOMS	
<ul style="list-style-type: none">• Increased heart rate.• Increased faintness and/or dizziness.• Increased startle reaction.• Decrease in appetite.	<ul style="list-style-type: none">• Waking in the morning 2 hours or more before the usual time or other sleep disturbances.• Depression worse in the morning.• Feeling more easily tired.• Increase or decrease in appetite.
EMOTIONAL SYMPTOMS	
<ul style="list-style-type: none">• Worry.• Feelings of sadness and uneasiness	<ul style="list-style-type: none">• Loss of interest or pleasure in activities that are normally pleasurable.• Lack of emotional reactions to events or activities that normally produce an emotional response

ANXIETY AND DEPRESSION SELF-HELP

It can be seen that there are many symptoms. Some are physical and some are psychological. The key to managing these is to think of a particular symptom that bothers you the most and which you wish to resolve and then chose a particular strategy that is the most appropriate. For example, a person experiencing uncomfortable thoughts in relation to HIV could attempt to challenge them and find alternatives or problem solve these concerns. A person feeling tense will benefit from relaxation. What follows are a range of symptom-based techniques aimed at symptom-reduction.

(1) RELAXATION

Useful for physiological symptoms and to help calm the flow of distressing thoughts, which keep coming into your mind.

- Focus on a pleasurable image, lie down, try to relax and focus on your breathing (physiological).
- Focus on calm, pleasant memories and fantasies (imagery).

(2) DISTRACTION

Useful for when distressing thoughts keep coming into your mind.

- Focus on an object and describe it in as much detail as possible.
- Mental exercises (i.e. count from 1000 in 7's).
- Focus on pleasant memories and fantasies.

(3) GRADED EXPOSURE

Useful for when an event, situation or experience is avoided due to fear.

- Chose a manageable aspect of a feared event and face it being aware of how you feel and what you are doing that helped you get through it.
- Repeat exposure to an event until it does not create anxiety, then work on a more anxiety provoking aspect of that event or other events and face it.

(4) SCHEDULING ACTIVITIES

Useful for when motivation is low and it feels too difficult to do anything.

- Plan each day or week ahead.
- Get a member of your family or friend to help you think of activities.

(5) PROBLEM-SOLVING

Useful for breaking tasks into smaller and more manageable parts.

- Think of the problem and list steps needed to reach the goal, which will help address the problem.
- Reward yourself for each step or goal that you have achieved.

(6) CHALLENGING DISTRESSING THOUGHTS

Useful for lessening the strength of distressing thinking patterns.

- Identify the distressing thoughts you are having.
- Question thoughts and look for evidence for and against them.

(7) ENLIST SUPPORT

Useful to prevent isolation and increase a sense of being supported by others.

- Find someone you trust and talk to them about your concerns.
- Maintain social contacts such as friendships, family.
- Attend groups to meet people who may be in a similar situation as you.

Tip (7) Problem solve dilemmas that occur in your life and think of small steps that you can take to achieve your desired goals. Don't stop doing things, plan them carefully.

WHAT IS PROBLEM-SOLVING

Problem-solving:

- It identifies problems as causes of distress.
- It helps individuals look at the resources they possess for approaching their problems. It teaches a systematic method of overcoming current problems.
- It enhances a sense of control over problems.
- It equips individuals in a preventative manner, with a method for tackling future problems.

THE SIX STEPS OF PROBLEM-SOLVING

If you follow the six instructions, you will find that problem-solving really makes things seem less overwhelming and more manageable.

STEP 1. WHAT IS THE PROBLEM?

Identify and define clearly what the problem is. What do you worry about? What gets you down? What would you rather be doing without? What do you need help with? Examples of HIV-related problem areas are listed:

Possible Problem Areas

POSSIBLE PROBLEM AREAS
1. Relationship with partner or finding a partner
2. Relationship with family
3. Ability to negotiate health care system
4. Disclosure of HIV to significant others
5. Employment/studies/hobbies
6. Finances
7. Housing
8. Legal
9. Social isolation and relationships with friends
10. Use of alcohol or drugs
11. Psychiatric or psychological health
12. Physical health
13. Sexual adjustment
14. Bereavement and impending loss

STEP 2. LIST ALL POSSIBLE SOLUTIONS – EVEN BAD ONES

Think of as many ways as you can that could address the problem. At this point it doesn't matter if some are not so good as solutions, the point is that you think of as many solutions as you can. You never know that the more you think the more you will find!

STEP 3. LIST THE ADVANTAGES AND DISADVANTAGES OF EACH SOLUTION

There will always be good or bad aspects to addressing problems with particular solutions. The point here is to think reflexively about what will be good and bad for you.

STEP 4. CHOOSE THE BEST SOLUTION OR COMBINATION OF SOLUTIONS

Decide on which option/s are realistic and unrealistic.

STEP 5. PLAN HOW TO CARRY IT OUT

Choose the option that is both most rewarding and feasible. Prepare and plan strategies for the accomplishment of the chosen option. Plan how to carry it out.

STEP 6. TAKE ACTION AND PRAISE ALL EFFORTS

Whatever you do, be proud of what you are doing!

PROBLEM-SOLVING AND HIV

Why is problem solving especially good for HIV? Well, it is simple really. Problem-solving is good because it is helpful in negotiating the many issues that evolve in HIV which can at times for some individuals be overwhelming. Due to the range of constantly evolving needs, services changes, treatments and so on individuals can often feel overwhelmed with the issues that they need to negotiate. Problem-solving just helps to divide tasks and break them down so that they are achievable.

The following list illustrates the issues in HIV that may need problem-solving. Some individuals experience many or few, all the time or some times:

- Disclosing HIV to family or friends
- Negotiating whether to work or study
- Coping with health problems
- Enjoying an appropriate sex life
- Managing to take HIV medicines without trouble
- Coping with mood problems
- Communicating effectively with medical staff

Bob

Bob was diagnosed HIV+ a month ago. The only people he has talked to about HIV are the staff at the hospital. He has started to feel very lonely and wants someone he trusts in his life to know so that he can get informal support. He realises that he needs to disclose his HIV+ status to someone.

The following completed problem-solving exercise sheet shows how Bob has, at this point in his life and at this stage in his awareness of HIV, problem-solved disclosure.

PROBLEM SOLVING

HIV Disclosure Example

Step 1. What is the problem?

I have not told anyone about my HIV+ diagnosis

I feel that I should at least tell some people who are close to me. Who should I tell, how should I tell? Should I tell?

I am scared to tell anyone because of how they may react to me!

Step 2. List all possible solutions – even bad ones

(i) I can just tell my best friend

(ii) I can tell all my friends

(iii) I can just tell my mother

(iv) I can tell all of my family

(v) I can tell my neighbour

(vi) I can tell my children

Step 3. List advantages and disadvantages of each solution

(i) My best friend – I've told him other problems, surely he will understand me

(ii) All my friends – what is the point of that, it is not the world's business!

(iii) My mother – well I am very close to her, I want her to know the whole me

(iv) All of my family – well many of them I don't see very often and I actually don't like Uncle John

(v) My neighbour – well I get on with her but is it really her business?

(vi) My children – they are too young to understand. Maybe in the future.

Step 4. Choose the best solution or combination of solutions

(i) My best friend – I've told him other serious problems, surely he will understand me

(iii) My mother – well I am very close to her, I want her to know the whole me

Step 5. Plan how to carry it out

I will always remember that whatever people say about me being HIV+, I know that there is nothing wrong with me. I will tell my best friend when we are out together next week. We often like to go to that quiet bar to talk. I have helped him at times so he should help me now. I actually feel safe about telling him because he talked about someone who was HIV+ and didn't say anything bad about them.

I will tell my mother the next time we are alone when I visit her at her house. My mother has always told me she will stand by me. I have to tell her and when I do I will try to remain calm and answer her questions. I will be prepared for her to be a bit shocked at first.

Step 6. Take action and praise all efforts

Tip (8) **Keep making future plans** as life needs direction and only you can create that within your own life. HIV should not stop you from living well, healthily and happily!!!

THE PAST AND THE PRESENT

Before any planning, it is important to reflect upon where you feel your life is now. Did you put your life on hold since your HIV diagnosis? What changes happened when you learned of your HIV diagnosis? Now is the time to evaluate those, think about the positive changes you would like to make and set about with a plan of action.

Some of these questions about your past might be helpful to understand what changes you made when diagnosed and would now like to alter:

- *Has my life changed much since being diagnosed HIV+?*
- *What did my ambitions used to be?*
- *Have I changed my plans because of being diagnosed with HIV?*
- *Why have I changed my future plans because of HIV?*
- *Do I feel that being HIV has stopped some of my plans from occurring?*
- *Has HIV made me want more out of my life?*

Before acting, think about now, the present and these questions:

- *What am I doing with my life now that I am living with HIV?*
- *What ambitions do I now have?*
- *What ambitions would I like to cultivate?*
- *Where would I like to see myself in the future?*
- *What would I like to be doing five or ten years from now?*

Some Final Key Tips To Living Confidently With HIV.....

Understand HIV and how to live with it. Do accept that your life is different since your HIV diagnosis, but the extent to how different it can be, depends on how you deal with it.

Engage in a healthy lifestyle and negotiate your health system.

Seek social support where necessary – why do some things on your own when there are many good people, agencies and services eager to assist?

Disclose HIV where appropriate with pride and communicate your HIV status where appropriate so that you can receive the right support from the right people.

Have the choice to have safe sexual relationships but remember disclosure and safe sex.

Recognise, accept and manage your emotions in relation to HIV.

Problem solve dilemmas and think of small steps that you can take to achieve your desired goals.

Keep making future plans as life needs direction and only you can create that within your own life.