

Involving men in community home based care for HIV and AIDS toolkit: **Information Manual**



Involving men in community home based care for HIV and AIDS toolkit: pathfinder



Who is this toolkit for ?

This toolkit is for programme managers in Community Home Based Care (CHBC). It can be used to help support volunteers:

- ✓ during training of male home based care volunteers
- ✓ in planning the future of their clients
- ✓ in encouraging prevention in their community activity
- ✓ in promoting mens involvement in community home based care

CHBC is caring for those who have terminal illnesses and conditions such as AIDS in the home.

The toolkit is to encourage and guide men who take part in the care and support of family members living with HIV and AIDS. We also hope this will help programmes to include HIV prevention more in CHBC.

You can use this toolkit with experienced volunteers and new volunteers joining programmes. We hope it will be a starting point for involving men who are thinking about helping in the care of family members living with HIV and AIDS. We know this toolkit is mainly to help you bring men into home based care roles, but it can also be valuable in the training of women and young carers as well. Including all volunteers, men and women, young and the old, the methods in this toolkit will help everyone to learn and understand that men can do caring roles. Volunteers need to work together, and the families and community need to hear the same encouraging messages about men in caring roles in the home.

How to use this toolkit?

The toolkit has four parts:



This page is the *pathfinder*, which will help you know how to use the toolkit;



The *Information Manual* to make sure you have the right information for volunteers;



Eight '*How To*' cards to help you assist the volunteers using an *action learning* approach;



A *resource pack* containing leaflets, brochures, pamphlets, pictures and posters.

Whenever you see these symbols it will help you to know where you are or where to go when reading.

Getting the most out of this toolkit

1. The first part of the manual lists all the topics that it covers, and the pages you can find these topics on for easy reference.
2. The first two sections are to help you when training CHBC volunteers, building on the skills you already have, using ideas that have been seen to work with adult groups.
3. You can go through the manual from start to finish with volunteer groups, or move between sections as you need them, at your own pace. Each section can therefore be used on its own or one after the other.
4. At the end of the manual is a suggested workshop outline. Using this outline you can choose to use this toolkit to conduct a three-day workshop on “Involving men in HIV/AIDS related CHBC.”

The cards support each of the topics listed and discussed in the manual, and outline a way you can introduce the topics and work with volunteers to better understand how to involve men in community home based care. Each card explains what it is trying to do and why it is important to talk about it. The card also suggests an activity that volunteers can do in groups with advice on what you will need, how long it will take and how to get the most out of the time spent discussing these issues.

We hope the cards will help you when talking to and supporting volunteers. They give you ways to talk about men in caring roles which you can use as they are, or adapt as you need. You can put together learning and support sessions using these cards. Involving the volunteers in these topics through group work and discussion can help volunteers get a deeper understanding of the issues involved in including men in the home based care of people living with AIDS.

Much of the information here will be helpful during the sessions, in a workshop or generally in your support work with volunteers. You are encouraged to add your own items to make this toolkit your individual work pack. Posters, pictures to make copies from, examples of such documents as Wills and Memory Books are shown here and can be introduced to share with volunteers and families to help explain and plan for the future.



Involving men in community home based care for HIV and AIDS: information manual

This part of the toolkit is to provide information about involving men in the care, support and planning needed for the care of people with HIV and AIDS in the home.

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Ideas for programme managers when training

We know how challenging it can be to discuss caring roles and suggest new ways of doing things. This means that building trust, openness and honesty between yourself and the volunteers, as well as between the volunteers as a group and the volunteers and the community is very important. As programme managers you are able to support community action on HIV and AIDS issues, through raising awareness and sharing ideas with volunteers who work with families living in communities.

Community action is a form of public action that can mean the achievements of groups of people to support a cause.

How people learn

Action-based means- allowing volunteers to first share their knowledge in order to build on it, and then using new and old ideas in old and new ways.

The best way to learn, especially for adults, is to *get involved* in the learning process. Getting involved means finding out for yourself instead of just being told. Action based learning is a method, which programme managers can use to help volunteers understand important issues in a way that is best understood by them. It allows volunteers to put across these issues in a personal way, in their own words, suitable to their own situations.

Assisting men and women in the community home based care of people with AIDS is no easy task. Culture, environment, social and economic factors are different from place to place, home to home and person to person. Time spent with volunteers is often never enough, so using the time you have as best you can is important. Action based learning helps to make sure that vital information is both heard and understood. Working in groups is an important part of this approach.



A group learning approach

Working in groups does not always mean working together. Sometimes it helps to have time to do things on your own. Group work needs to be properly planned before you meet, and works better with clear direction so that you achieve what you want to learn with the group.

Group learning that you have spent time preparing for:

- Gives everyone a chance to talk to others and put ideas into their own words.
- Shows that co-operative learning can be more productive than competitive learning.
- Shows that everyone has something to bring to the discussion.
- Helps to use the differences between people - background, experience and ability- more productively.
- Develops the skills volunteers need to help run and manage self-help groups.

“We all remember much better what we have discovered and said ourselves than what others have told us” Training for Transformation Manual.

“A group never becomes a community unless it develops the habit of deep, respectful listening to one another” Training for Transformation Manual.

What type of groups should you use?

Working in twos is useful for icebreakers and the sharing of personal information, as well as trying out ideas they may want to use in their work. Working in threes is ideal for getting everyone thinking and taking part, and when introducing new ideas and views. Groups with up to six people are very useful for planning and discussing, sharing ideas and insights. Larger groups need more time and will take longer to reach decisions.

To help you work more effectively with volunteers when discussing men's involvement in CHBC use 'How To' card number 1.

Why should men be involved in community home-based care?

We have put together this toolkit especially for male volunteers because:

- Men need to be encouraged to become *partners* in the caring of family members with AIDS, including prevention, care, support and planning for the future.
- Women currently do most of the work around home-based care for people with AIDS because of their traditional role as carers in families. They deserve more *solidarity and partnership from their men folk* in providing what is essentially a family and community service for people affected by AIDS.
- Men have a lot of *influence in communities* as traditional leaders and decision makers and can provide leadership within programmes and more support to families affected by AIDS.
- If men get involved in home based care they may be in a better position to act as *role models for younger men*, show other men how to change their behaviour, protect themselves and their families against HIV and the consequences of AIDS. This shows how caring for people with AIDS can also help to prevent HIV from spreading.
- Men and women working together in a programme on HIV and AIDS are better able to *fight stigma and fear of discrimination in communities*. Men who are HIV positive have a particular contribution to make in providing hopeful examples of living positively with HIV to other men and community members.
- Some men are already involved in provision of home based care and would benefit from *support* from their peers.

What can men do?

- Men can work hand-in-hand with women to prevent HIV and to care and support People Living with HIV and AIDS (PLWHAs).
- As leaders in the community, men can help reduce stigma and discrimination against PLWHAs and their families.
- Men who are involved in home based care can be role models for other men, including helping them to be responsible in their relationships.
- Men who are HIV positive can provide good examples of living positively with HIV.
- Men can help families get the right social services.
- Men can make a difference by talking about consequences of men's behaviour and stereotypes.

The introduction of men as CHBC volunteers for people living with HIV and AIDS should not be seen as a threat to the role of women in communities. Rather we recommend encouraging men to work as partners with women in lessening the consequences of HIV and AIDS in their communities. Partnership in CHBC means helping prevent 'burn-out' or exhaustion through men's support to their wives, daughters, grandmothers, and others.



To help you discuss the challenges facing men in community home based care with volunteers go to 'How To' card number 2

Gender roles in CHBC

In most of southern Africa, men are seen traditionally as leaders and providers in their communities. However, these ideas are slowly changing, with more women getting educated and taking senior positions as politicians, directors of companies, professors and so on.

Families

In families, men are still regarded as the decision makers. There are divisions in the duties men and women have in their homes. This idea persists even though many households are headed by women, either because they have been widowed or because their husbands are working as migrant labourers and do not spend much time at home. Women will often have major decisions affecting their homes made by male relatives if their husbands are away from home. For these reasons, women usually do not have the power to ensure that they are protected. Women often become financially or materially vulnerable when their husbands are sick with AIDS, and are unsure whether they will have security if the husband dies.

Women and Children

Customary practice can mean that the husband's relatives acquire all the family's property after the husband's death, making the family dependent on the good will of their in-laws for their material well-being. There are Laws on Inheritance that families need to know. Regional organisations such as Women and Law in Southern Africa (WLSA) and Women In Law and Development in Africa (WILDAF) help women and their children to negotiate for their well being. If they choose, women can remain independent after a husband dies. Volunteers can discuss such issues with family members to reduce tension and conflict around property and care. Male volunteers especially need to support the needs of women, talking to male members of the family and arguing on behalf of women and the children, advocating for their needs and rights in general.

Because so many men have died of AIDS in our communities, there are more women living as widows with young children. The women may also be sick with HIV and need help from the community. There is a real need for planning for the future of their children with the extended family rather than waiting until after death when it may not be clear who should take responsibility for bringing up these children. Planning for the future is an important area that male volunteers can get involved in and is explained in detail later in this manual.

Projects that try to reform inheritance laws and traditional practices can make choices in the family broader.

Male volunteers

Male volunteers are in a good position to work with families, particularly when the father, the head of the household, is still alive and able to plan with his wife.

Male volunteers should have the trust and respect of the families they are supporting to be able to bring these issues up in a dignified and concerned manner.

They can help them discuss how one would like their children to be looked after in the event of death. If the volunteer has come from a faith based organisation, the first time these issues are discussed with the family could be done with another senior person from the group present [such as the priest] so that it does not appear to be for his own personal gain.

For this reason, there may be more than one volunteer visiting a family living with AIDS, each with a different purpose. A woman volunteer may attend to support the family in caring duties for the person sick with AIDS, while a man volunteer may attend to discuss pastoral and planning functions with the head of the household [whether the father or the mother]. They may negotiate meetings with the extended family to clarify issues, or to bring them into whatever decisions are taken.

Once male volunteers have become well known and respected for their contribution, they may also become accepted as persons who can teach about hygiene or protection from infection, duties usually assigned to women volunteers.

A direct approach is not always possible; volunteers need to know when to ask for help themselves and whether this would break confidentiality.



Roles for men in CHBC

As role models

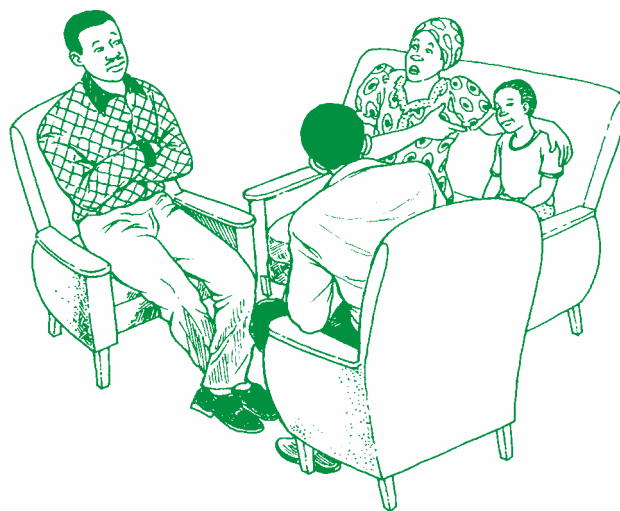
When men get involved in CHBC, they are providing models of responsible behaviour that will help other men in the community to behave in similar ways. Young men and older men are more likely to listen to, accept, discuss and share issues with other men rather than with women volunteers.

As advisors to families

Trained men volunteers will become sources of information and guidance to the families they help on issues that are discussed in this toolkit as well as general information from basic CHBC training. Examples range from advising families on the risk of tuberculosis associated with HIV and how to check for symptoms; to where to go for voluntary counselling and testing [VCT]; to the necessity of writing a will; or how to leave a memory book to help children come to terms with their parents having AIDS.



An example from a memory book can be found in the resource section of this toolkit. It helps those left behind to cope with their loss and remember loved ones.



As advocates of CHBC to their communities:

Men will succeed better in providing CHBC if they have the support and acceptance of the communities they live in. They are in a better position to mobilise community support for families living with AIDS and to identify resources for them.



To help you talk about and explore these issues on gender in community home based care use 'How To' card number 3

Challenges for male volunteers in CHBC

Due to many traditional beliefs, it is not easy for men to volunteer to do home based care in their community. Men are expected to be the main income earners for families and do not often carry out work without payment for it. In addition, the duties we usually think of as related to home based care are 'domestic' and thought of as caring and cleaning, work that is traditionally done by women.

CHBC volunteers are also family members and bring their own beliefs and ideas to their work.

Women's work?

The idea that home based care is 'women's work' is strongly reinforced by women as well as men. The domestic world is seen as women's territory. Sometimes women volunteers discourage men from carrying out caring duties for their sick wives or children, and they may take over when they come to visit instead of seeing the caring as a way a man can show love for his family. AIDS is forcing people to re-examine their roles in the family and at home. People can change, especially with examples of other respected men and women acting as role models or opinion leaders.

Real men do CHBC!

Trust and confidentiality

One important way to earn the trust and support from the community where you are volunteering is to adopt a responsible lifestyle. This is important even during the times you are not volunteering. Community members watch, listen to others and evaluate your character according to how you behave in public and private. Compassion, sincerity, honesty, commitment and hard work need to be part of your daily contact with the people in your community. You have to be a role model. If you are getting drunk at the beer hall and going off with different women for sex, you cannot advise people to act differently.

“Trust building can only be a gradual and continual process”

Training for Transformation Manual.

In southern Africa, people tend to do things for their families rather than volunteering for others that they may not know, or asking for help from outsiders. More and more faith based organisations, among others, have encouraged their members to get involved in practical and material support for communities. This is seen in times of natural disasters such as floods or cyclones where groups of people as well as companies and development agencies help support affected communities. Also, more people are volunteering now in the hope that they will also get help when it is their turn to need help.

Seeking support from communities

Getting support from key members of your community can overcome many of the difficulties for male volunteers. These key members may be men or women, but to encourage people to see the roles of men differently you will need the backing of influential men in particular such as:

- traditional leaders
- religious leaders
- community role models
- local opinion leaders
- authority figures such as headmasters and teachers
- political leaders and business personalities
- media personnel

Other ways of avoiding the misconceptions around men volunteering for CHBC could be:

- joining or starting men's support groups and any other groups which support home based care volunteering
- maintaining a role model lifestyle even during the times you are not volunteering
- helping to set up income generating projects for your clients
- making sure your time for volunteering fits in with any employment you are already engaged in
- making sure that you have another person in the room while you are with a family member even if you are the same sex, to avoid conflict around privacy and sexual contact

Trust building within the community

Volunteers' groups become more effective if they themselves have trusting and open relationships with each other.

All volunteers for CHBC have to earn the trust of the families and the communities they are working with. Because home based care is usually carried out by families who are not used to strangers coming in to the home, they may be suspicious of anyone doing this. Men may have more distrust than women, because to some extent families are used to women nurses and social service workers carrying out home care tasks. It may be difficult to understand why men do this. Families may be worried that men volunteers are actually coming to steal from them, or that they are from political parties, coming to spy on them. They may also be afraid that the women and children in the family are in danger of sexual abuse from the volunteer.



Volunteers can overcome this fear and suspicion by being particularly careful about their own behaviour and approaches to the family. They need to be trained in what is often called “professional” behaviours, where they realise that the way they present themselves reflects the reliability of the whole programme and other volunteers. Trust building exercises have to be built into all the aspects of your training programme with volunteers, particularly men.

Trust is earned before it is given.

Trust building between volunteers

When dealing with death and bereavement, volunteers working with HIV need to be sensitive and confidential with families. This confidentiality also needs to be maintained between volunteers. Programme managers must work to build trust within volunteer groups that is self sustaining.

Volunteers need to respect the autonomy and lifestyle choices of the families they support.

As programme managers and CHBC organisations, you can advise and encourage male volunteers to be thoughtful in their own behaviour with families, and:

- recommend that their first visit should be with the coordinator of the volunteer programme so that they can be properly introduced, and their roles as the volunteer made clear to the family
- to behave in a very polite and courteous manner with every member of the family they are volunteering with
- not to criticise what the family is already doing: they are there to support them not to take over
- to give them accurate information without making the family feel they are stupid
- to discuss accepting gifts of food from families with you and other volunteers. Sharing food with volunteers is often a way families can maintain their dignity but not everyone is comfortable accepting such gifts.
- to talk about and discuss such issues to help them cope and make the right decisions in each household
- never to gossip about the family to anyone - this is part of keeping their privacy and confidentiality
- not to behave in a very familiar or intimate way with any of the family members, particularly the young women in case this becomes misunderstood as sexual advances
- to make sure there is always another person in the room with them when they are discussing information or carrying out duties with women members of the family
- to always try to make arrangements for when they are to visit and not to always turn up unexpectedly
- never to take money for any duties they carry out. If they are involved with money as part of an income generating group then this must all be done carefully using receipt books and following the rules set up by the group.

Autonomy means the right for people [men and women] to do things the way they want to.

Dealing with stigma & discrimination in the community

Combating stigma and discrimination starts with each one of us as individuals - not just as home based care workers.

Stigma can be seen as beliefs that are hurtful about people from different groups or with certain characteristics. In this case, stigma is related to a person or family living with HIV. HIV has become linked with something to be ashamed of, because of the association with sex and death, and because it is thought that people must have behaved in a bad way to get infected.

Discrimination occurs when someone is treated unfairly and unjustly on the basis of their belonging to a particular group, in this case because they are HIV positive, or because someone in their family is HIV positive.

Common misconceptions

Some of the misunderstandings that increase stigma and fear about HIV are:

- wrong information about how HIV is transmitted
- social fears about death
- moral judgements about sexuality
- irresponsible media reporting on HIV and people living with HIV
- that HIV is a punishment from God for loose morals or bad behaviour
- that only sex-working, intravenous drug use and homosexuality are responsible for the spread of HIV



We are all living with HIV and AIDS, whether we are infected or affected. Live and let live!

Feelings and emotions

Stigma and discrimination make HIV positive people feel ashamed and bad about themselves, leading to depression, feelings of low self-esteem and self-worth, despair, and afraid of what others might say and do. If people are afraid to get tested then HIV negative people do not have the chance to stay negative, and HIV positive people do not get to know that they should avoid unprotected sex. Parents who are too afraid to get tested do not learn how to protect their babies from infection from parent-to-child transmission of HIV.

It is hard if you discover you have HIV in your body. It takes time and love and support from the people around you to get used to it. Yet people with HIV live

longer, have better quality lives and do not get AIDS so quickly if they are able to practice positive living and get treated for infections early through access to good health care. It has been shown that stigma can be reduced through a variety of activities including providing information and counselling, developing the skills of people living with HIV to deal with stigma, and increasing individuals contacts with people living with HIV.



This pack has info about positive living and sex, nutrition and HIV/AIDS facts.

Many people keep HIV a secret- they fear that other people, like their family and friends, will reject them. So they tell no one that they are HIV positive. They cannot talk to others about HIV and AIDS and how they feel about it.

Disclosure

It is only when we are all able to discuss HIV and AIDS openly like any other disease, that we will be able to deal with what the disease does to people, their families and communities. Because of stigma and fear of discrimination, most people living with HIV are terrified of other people finding out their HIV status. As a result they may be unable to access the good health care they need to stay fit and strong, or they may lose a job or the chance of promotion because they are unable to insist on their right to employment and promotion regardless of their HIV status. Many people do not realise that *there are laws that protect their rights to employment* even if they are HIV positive.

Domestic violence

Disclosure is not always easy to accept and reactions to disclosure can often be unsupportive or violent. Women in particular are at risk of violence from partners or other family members after disclosure and male volunteers should be aware of the possibility that violent behaviour can follow disclosure. For more information you should refer to the booklet on domestic violence referenced in the resource section of this toolkit.

Volunteers do not need to tackle disclosure in the community; what they should strive for is disclosure within the home, with volunteers and other family members.

Because of the shame associated with HIV, people have been fearful of calling the disease AIDS by its name. When someone dies of AIDS, the cause of death is given another label, tuberculosis or malaria for example. This makes the disease even more shameful, because it is so bad that it cannot be called by name. Men volunteers can help break this stigma by helping families accept that they are living with AIDS, and to make it something normal by calling it what it is, **HIV or AIDS**. They need to talk openly about why they are visiting, to provide CHBC for AIDS, and to refer to the different aspects of HIV that they can help deal with. This will involve exploring people's fears of what will happen if they reveal their HIV status.

Why should people disclose their HIV status?

- Disclosure can help people living with HIV get medical care and support services, as well as to be more confident about living positively.
- The stress of 'keeping a secret' is taken away.
- Disclosure will help families to get involved in planning for the future.
- People living with HIV will feel encouraged to be sexually responsible, and in turn protect themselves, their partner and loved ones.
- Family care givers will know to protect themselves from infection when they are caring for people sick with AIDS.
- Children will have a chance to deal with their fears about the future openly, rather than in silence.
- Other people may be more willing to give assistance to the household.

These are some general guidelines that volunteers can follow to help people disclose their HIV status:

- provide support and reassurance to clients in order to help them not to blame themselves
- discuss who would be the easiest person to begin disclosure with, their partner, parent, a brother or sister?
- if the volunteer is HIV positive he can relate his own experiences to clients and their families, helping them to discuss their concerns, fears and emotions
- volunteers can 'role play' with the client so that they can practice how to tell others about their HIV status
- volunteers can offer to be present when clients disclose to others
- prepare clients how to respond to a shocked or hostile reaction. Reassure them that over time, people close to them will learn to accept them as they are
- give lots of examples of where people have benefited from disclosure

How to help volunteers to begin addressing the challenges of Stigma and Discrimination use 'How To' card number 5

Practical support for families preparing for the future



In the resource material enclosed there are fact sheets on registering births, and deaths, getting a burial order, writing a will, children's education funds and memory books.

Volunteers need to be able to offer useful advice to families. This section looks at a number of practical ways volunteers can support families who are able to think towards the future for other household members, children and relatives.

There are many practical matters that men volunteers can advise families on to help them plan for the future. Because the heads of families are often [but not always] men, it is often more appropriate for men to discuss these issues than for women. This does not exclude women who feel confident to do this, in fact they must be encouraged. However, this is a neglected area that men can start discussing with families with the backing and support of their communities.



To help you introduce and discuss future planning with volunteers and share the information in the toolkit use 'How To' card number 6.

Social networks for men

We use the term social networks to mean the places where men meet. This can be work, family or community get-togethers.

Men volunteers will need to identify existing social networks to work with to promote CHBC in communities. Where there are no groups, they can work towards establishing some. An example of men's discussion forums adopted from the traditional southern African forum is called 'Padare' in Zimbabwe. This is based on gatherings of men where community issues are debated. Other possibilities are through workplace HBC committees, faith-based men's groups, loans clubs, peer education programmes, sports groups for young boys, and anti-AIDS clubs.

These forums could have the following functions:

- to challenge stigma and discrimination related to HIV and AIDS in their homes and communities
- to correct misconceptions and myths on sexuality and HIV and AIDS
- to reinforce positive and responsible behaviour among men, including being caring and protective towards their families, correct and consistent condom use for prevention of STIs and HIV, VCT prior to marriage or pregnancy, and prevention of parent to child transmission of HIV [PTCT]
- to encourage male involvement in CHBC

A forum is where people meet, talk and share information.

'How To' card number 7 can help you discuss social networks for men with volunteers

Men are labelled the 'breadwinners' in the home and are expected to earn something for the work they do. Volunteering may be difficult for some men, even if the interest is there. Understanding the motivations and incentive men may need to volunteer can be addressed through public recognition of their efforts, as well as their association with decision making and income generating activities [IGPs].

Many support groups for people living with HIV try to set up IGPs to help provide PLWHA's with money to buy food and treatment. Most of these groups are not successful in generating surplus income because they do not get the right financial and marketing advice on what to do. Men volunteers may be able to support families in these groups by linking them with organisations and training opportunities that can make the project work better. More importantly, these groups become a meeting point for members to avoid feeling loneliness, to come together and share ideas, give each other advice and enthusiasm, and to set up small loan schemes. Organisations such as ITDG in Zimbabwe can help support and market products. These contact details can be found in the resources section of this toolkit.





It is important that income-generating projects are sensitive to the needs of people living with HIV/AIDS. For example market gardens can include useful plants such as garlic and ginger. Labour based projects should take into account the added burden of caring tasks for those affected, and the need for those infected to rest, take any medications, visit clinics and eat well. For advice on nutrition The Center in Harare, Zimbabwe can help. AffOResT (African Farmers' Organic, Research, and Training) can assist on agriculture and nutrition. Again, the resource section of this toolkit has information on all these organisations, which you can contact directly or encourage volunteers and the families they care for to do so.

Prevention rights and responsibilities

What are the prevention links with care that especially involve male volunteers?

As men become more involved in CHBC, they will be better informed and more able to advise on aspects of prevention. As advisors and role models in families and communities, they will be respected enough to be able to advise generally on hygiene, condom use and staying faithful to partners. As part of their work in CHBC however, they have specific roles in advising families on protection from HIV.

A person's immune system is the part of the body that fights disease

Prevention : protection from infection through coming in contact with body fluids that can pass on HIV

This can happen when a carer has to clean up a family member with a lot of diarrhoea or is bleeding from sores. Family members may feel that using gloves for this work is unkind. A male volunteer can use this opportunity to explain how they can use protection simply because HIV is an infectious disease and may be spread from person to person by blood contact, especially if the carer has cuts or sores on their hands. The male volunteer needs training to balance practical help and advice and ease family fear and anxiety as well.

Prevention : protection from re-infection through sexual contact with HIV positive partners

Volunteers can also discuss with the partner of the ill person the need to protect themselves during sexual contact. The volunteer needs to understand that a person who has AIDS may have a high level of HIV in their blood [compared to when they did not have symptoms of AIDS and were only HIV positive] and is more likely to transmit HIV to a sexual partner or to a baby if they are breastfeeding or pregnant [parent to child transmission]. It has happened that women get pregnant when their husbands are already dying from AIDS, and may get a new dose of infection of HIV from him because he has a lot of the HIV virus in his body which causes the woman's immune system to become weaker.

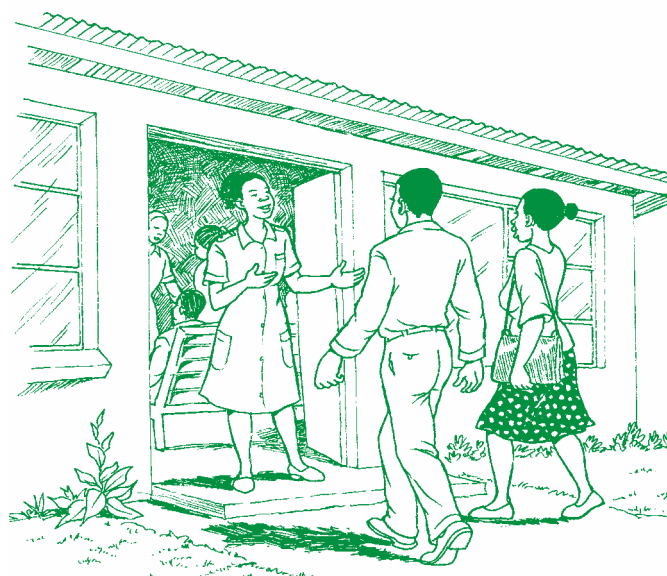
Prevention : protecting babies and children from parent to child transmission and breastfeeding



When a pregnant woman's immune system is weakened from continued unprotected sexual contact the levels of HIV in her blood increase. She is then more likely to pass the infection on to her baby during delivery or through breast-feeding. The male volunteer is in a good position to advise his male clients to use condoms, especially during the pregnancy and breast-feeding. A male volunteer can also motivate these men to support their wives and partners in getting tested after child-birth, so that they can be protected if they are still negative. If positive, there are a number of ways of protecting their babies from infection, such as giving the mother and baby Nevirapine during delivery, delivering the baby by caesarean section rather than vaginally, avoiding mixed feeding-either giving exclusive breast milk, or exclusive artificial milk but not both and so on.

Prevention : creating acceptance around HIV and supporting disclosure

By accepting HIV within a family, a male volunteer can help break down denial and stigma that prevents family members from knowing about the risks of having HIV. It also encourages them to know their status. Many families have more than one member with HIV at one time. Others become infected even though they have lived through the death of a family member, because they have not faced up to what they have to do to protect themselves. Training male volunteers about aspects of voluntary confidential counselling and testing [VCT], will help them support family members, through the male decision makers, to get tested and deal with their test results.



This toolkit contains information about the New Start Centres in Zimbabwe.



Prevention : advice and role modeling in homes and communities

Through their work with families and by acting as advisors and role models, the men volunteers will also be able to talk to and show young men in families how to take responsibility for themselves and avoid infection with HIV. Young people learn about HIV at school and know how to recognise signs and symptoms of AIDS in their family members. However, they absorb the secrecy and denial at an early stage, and feel this is something bad that's happening to their family. They may not have a sense of knowing that you can change or make a difference to your world, a belief necessary to protect themselves from infection.

Knowing how to avoid early teenage sex, or how to buy and use condoms is essential and more acceptable when discussed 'man to man'. Talking about HIV in an open way makes it less of a secret, takes away the shame and helps young people to understand ways they can protect themselves. Abstaining or using condoms becomes a way of showing love, of creating trust with your partner, rather than meaning you are HIV positive.



Prevention : support of young caregivers and young volunteers in homes and communities

Young care-givers in particular need a lot of support in protecting themselves. Because HIV is treated as something to be ashamed of, young care-givers often feel bad about themselves, and may lose respect for their parents who are sick with AIDS. When young people feel bad about themselves, they are more likely to look for attention from people outside the family to make them feel good about themselves once more. This attention often comes in the way of sex, and the young person may not have the skills or experience to negotiate for protected sex. This increases their chances of getting infected. For young men this may involve sex with sex workers. Men volunteers can work with these young male youth, to build up their sense of self worth, restore respect for their parents, and support them in protecting themselves from HIV.

To help you discuss with volunteers how prevention and care go together, use 'How To' card number 8

Men's health seeking behaviour

To help both men and women volunteers there is a need to understand men's behaviour. When it comes to health issues men often behave differently from women.

Targeting men

Men do not seek health care from clinics and hospitals to the same extent as women, mainly because men are in formal employment and do not get time off to attend clinics with their children. It is also considered women's caring role to take children and older relatives to the clinic. Men therefore do not receive the same health education on HIV as women and may not be familiar with health aspects of positive living such as nutrition and getting treated quickly if there are infections. They may not be aware of the close links between HIV and TB. Men volunteers have an important role in giving other men this basic information-especially those living with HIV-even before they need CHBC.

The TASO slogan, "Living Positively with AIDS", calls on everyone in society, infected or non-infected.



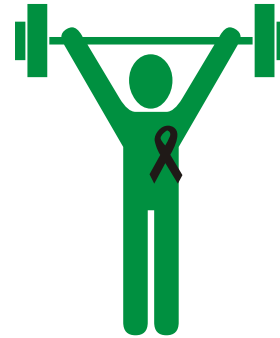
Accepting themselves

Acceptance of HIV has to come from the person living from HIV, from their families and from those around them, such as the health workers who treat them. With proper information people will not waste so much time and money going from one traditional healer to another, or from one physician to another, looking for a cure, or being treated for the wrong condition because they have not disclosed their status. People living with HIV need to work in partnership with their healers and health workers, in full knowledge of what they are dealing with, to get the right treatment quickly and without pretence. In addition, men volunteers can support their male clients to behave in accordance with positive living, encouraging them to avoid further sexually transmitted infections, avoiding alcohol and smoking, using condoms and living a healthy lifestyle.

Living positively with HIV and AIDS

Male volunteers in CHBC will need training on what is known as “positive living” for people living with HIV. This concept emphasises:

- living rather than dying with AIDS
- quality rather than the quantity of life
- a positive attitude to life



What is a positive attitude to life?

This is where people living with HIV:

- know and accept that they have the HIV virus
- understand the facts about HIV and AIDS
- are responsible in their behaviour and take steps to protect others from their infection
- take care not to expose themselves to further HIV or other sexually transmitted infections
- take special care of their physical health such as seeking treatment for illness as soon as possible and avoiding alcohol, smoking and illegal drug use
- get access to emotional support
- continue to have an enjoyable social life
- follow guidelines on good nutrition, coping with stress, balancing exercise and rest

TASO is The AIDS Support Organisation and it formally began in Uganda in 1987 through the efforts of volunteers and people living with HIV/AIDS. It was the first of its kind!

[adapted from the TASO philosophy on positive living]

We recommend that volunteers should not restrict “positive living” to members of the family that are diagnosed HIV+, but should encourage the concept among those who are providing care and support to infected people. Positive living in HIV negative people can be a tool for behaviour change. It means encouraging proper and careful steps towards prevention of HIV, through practicing safer sex.

Transmission of HIV

Volunteers and families have to know the facts about HIV transmission. They need to know that hugging and kissing is not dangerous to their children. It is very painful for mothers who know they are HIV-infected but are afraid to be close to their children, either because they are afraid they may infect them or because they feel death is going to separate them and so they start to push them away. People with HIV can get married and share the joy of love in relationships, as long as they are honest to each other in their relationships and responsible in their sexual behaviours.

Volunteering in Community Home Based Care can mean discussing sensitive family and sexual issues. Volunteers themselves need to know first about positive living and sex before they can be supportive and helpful with their clients.

Living life!

Another essential aspect of positive living is social life. TASO also led the way in showing that people with HIV should not be isolated, they have the same important role to play in social life as before. By continuing to participate fully in family events, even when they may look ill, they are accepted as people living with HIV rather than dying of AIDS. Marking life events is an important part of celebrating their victory over HIV, celebrating each day of life as a precious gift. This is another area that may be guided by men volunteers, particularly in encouraging men to take a lead role in creating this acceptance.

Involving men in CHBC does not mean ignoring women or youth; everyone at risk has the right to learn how best to protect themselves from infection.

Changing men's behaviour

Both men and women need to change their sexual behaviour. However, this will not be easy. Men (and women) are more likely to protect themselves and their partners when they are encouraged to do so by their peers. Male volunteers have a special role in helping to change the behaviour of men in the homes and communities where they work. Changes in men's behaviour - consistent use of condoms and fewer sexual partners - will have the greatest impact on the HIV epidemic. When targeting men in CHBC support and advice needs to be tailored according to different men's needs.

Positive living and sex

Many people are afraid of knowing their HIV status because they are told that being HIV positive means that they can no longer have sex.

Men volunteers have an important role in advising their clients [especially men] that people living with HIV can have healthy and active sex lives.

People living with HIV can be advised that showing love and intimacy with partners is a vital part of acceptance of each other in families living with HIV. But sexual intercourse is not the only way to be intimate.

Alternative ways of showing love include:

- ✓ hugging, touching, caressing, massage
- ✓ kissing, provided neither have open sores in their mouths
- ✓ helping your loved one in doing things
- ✓ remembering and talking about special times and events that your loved one likes
- ✓ listening to what your loved one has to say
- ✓ spending time together
- ✓ comforting and consoling each other



Non-penetrative sex can be an option, but many think it is not culturally acceptable. Men volunteers can be trained on how to advise on these methods, so that they can be done safely. Non-penetrative sex is particularly important during pregnancy and breastfeeding, so that HIV positive men do not infect or re-infect their wives during these times, so that they in turn do not infect their infants when they are born.



Practicing safe sex is very important, to prevent re-infecting oneself or infecting others. Even if both partners are HIV positive, sexual intercourse without condoms will increase the amount of the HIV virus in their bodies [the viral load] and the progression to AIDS may be faster. Therefore, PLWHAs need to use female or male condoms correctly and consistently EVERY TIME they have sex.

CHBC volunteers can help clients understand the need to discuss positive living and sex. Male volunteers in particular can help other men talk about sexual issues more openly, helping to create a more open environment in the home for women to talk more freely with men too! At the same time volunteers must make their clients aware of the risks so they can make informed and responsible choices about their sexual and reproductive lives.

Helping men negotiate with their partners about their relationships

Both men and women are at risk of becoming HIV positive. But women face a special risk when they can't talk to their partner about:

- ▶ using a condom
- ▶ having only one faithful partner

Women may be afraid that their partner will become violent towards them if they insist on using a condom, or talk to them about being faithful. As a man, you can talk to other men about using condoms and sticking to one partner. You can encourage men to be open with their partners about their HIV status and about sex. You can help men find ways to express their feelings.

Know and share the facts about condoms

- ▶ Using a condom means you care for your partner and want to protect them from any infection.
- ▶ Using a condom doesn't mean that you don't trust each other.
- ▶ Some men think that condoms take away from the pleasure of sex, you can help men decide what is more important physical pleasure or lifelong health.
- ▶ The Medicines Control Authority of Zimbabwe tests condoms in Zimbabwe - that means they are reliable and safe to use.
- ▶ Wearing a condom does not mean you are less of a man. It means you are responsible.



This toolkit contains information to help you explain proper condom use

Demonstrate how to use condoms. Find out who in the community has been trained in promoting female condoms (such as community based distributors and local family planning clinic health workers). Know where male and female condoms are sold or available for free.

Having children

Couples who are HIV positive may feel that they do not want to have a baby and need to know how to protect themselves from pregnancy through consistent use of contraception. If only one of the partners is HIV positive, having a baby means having sex without a condom. That could lead to the infection of the other partner. They may also be worried that:

- ✓ The baby will be born HIV positive
- ✓ The mother may progress from HIV to AIDS more quickly if she gets pregnant
- ✓ They won't be able to take care of the child if they get sick with AIDS
- ✓ They won't live long enough to see the child grow up

A key way of preventing babies born with HIV is by preventing unwanted pregnancies by HIV positive women. Men volunteers can encourage couples to go for family planning.



This toolkit contains an info sheet on PTCT issues that organisations and volunteers can use in their work.

Coping with pregnancy and childbirth

The most important thing is for the pregnant woman to go early for booking at the antenatal clinic, and to inform the midwife or doctor that she is HIV positive if she knows, or to get tested for HIV if she does not know. This first visit is the best time for the husband or partner to attend with her, so that the couple can be given information together, and can make decisions together. Male volunteers can encourage the man to attend the clinic together with his wife or partner. If the mother is HIV positive she can take antiretroviral medicines like Nevirapine to help prevent the baby getting HIV. This is given to the mother once during childbirth and then given to the baby before it is three days old.

Male volunteers need to know about **parent to child transmission** so they can advise couples about their decision and if they decide to have a child how to help prevent giving HIV to the baby.



Feeding an infant child

The safest way to prevent the baby from getting infected from breastfeeding is for the baby to be given artificial milk all the time without any breastfeeding at all. However, many women mix artificial feeding with breastfeeding because they may not be able to afford artificial milk [formula] or because they may be ashamed that people will think that they have HIV because they are not breastfeeding. There is more risk of HIV transmission to the baby if the mother mixes feeding like this.

Where it is uncertain whether the mother will be able to give only formula, it is better if she feeds the baby only with breastfeeding, which is safer than mixed feeding. Whichever method she uses, the mother will need a lot of support from her husband and family. You can help the family support the mother by making sure they understand why she is feeding in the way she has chosen, and only uses that method rather than mixing methods. It is much easier for the mother to give only breast-milk or only formula when she has disclosed her HIV status to her family [Eg her mother in law or her mother] so that they can support her.

If the couple decides not to have a baby, but still want to have children in their family, volunteers can suggest that they:

- ✓ help to care for other children from their family who may have been orphaned, or from a brother or sister
- ✓ become a foster parent for children in the community who have been orphaned or deserted by their parents

There is no 'HOW TO' card on this section but the resource sheets in this toolkit offer guidance you can draw on in the sessions and in your work.



We hope that this manual has given you what you need to begin supporting men's involvement in caring for families affected by AIDS. Also we hope the toolkit has helped you find out where to get more information. On the next page is a suggested outline if you choose to use this toolkit to conduct a workshop with volunteers. We hope you find this useful.

The following is an example of how you can introduce this toolkit to volunteers through a workshop.

All the How To cards can be treated as separate sessions to work through with volunteers, but there is an opportunity to link them together over three days or successively in the order they are presented. The order the topics are presented in allows each activity to support the next and so on. We hope it is useful to you!

A suggested outline for a three-day training workshop

“Involving men in Community Home Based Care (CHBC)”

Suggested course programme for CHBC volunteers

Day 1	Exploring men's involvement
09.00	Registration/arrivals
09.30	Welcome and introductions
	Domestics
	Course objectives
10.00	Ice-breakers & trust building exercise
10.45	Break
11.00	Why men?
12.30	Lunch break
13.30	Gender roles in CHBC
15.00	Break
15.30	Review of the day
16.45	Housekeeping, notices and close
Day 2	Addressing men's involvement
09.00	Recap of Day 1
09.30	Overcoming challenges facing men
10.45	Break
11.00	Stigma and discrimination in CHBC
12.30	Lunch break
13.30	Preparing for the future - practical support for families
15.30	Break
15.45	Review of the day
16.45	Housekeeping, notices and close
Day 3	Linking men's involvement in the community
09.00	Recap of day 2
09.30	Social networks for men
11.00	Break
11.30	Prevention, rights and responsibilities involving men in CHBC
13.00	Lunch break
14.00	Review of the day's topics
15.00	Break
15.30	Course summary and evaluation
16.30	Thanks, AOB and close

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