Guidelines for establishing community-led Antiretroviral Treatment through a Human Capacity Development approach

The Salvation Army International Headquarters
Health Services
Issued April 2005
Guidelines for establishing community-led Antiretroviral Therapy Through a Human Capacity Development approach

PREFACE

The following guidelines have been developed by a working group of practitioners drawn from clinics, hospitals, congregations and communities. They are intended for use by practitioners from the congregation, community, clinic, and other partners in local responses which are incorporating ART.

The content is organized according to what people need to know and do. It is not filled with subtitles for issues such as prevention, youth vulnerability, nor for stigma and the context of response. All these issues are included, within the knowledge and behaviour framework, as part of integrated response.

20 years of experience in community response has shown that communities do not organize in compartmentalized ways, unless organizations and funding pushes them to do so. The normal response is integrated, and ‘systems thinking’ comes more or less naturally, as all of life is understood to be interrelated. The guidelines are based on an interrelated view of life, as strength for response.

The expectation is that people in ordinary life can be treatment supporters and monitors, within the context of their ongoing concerns about prevention and quality of life.

Many more people can be reached with treatment as the local community and congregation become directly involved.
CONTENTS

Preface 1
Acronyms 3
Background 4
Community/Corps/Clinic Partnership 7
Circle of Health Care 9
Drugs Procurement and Administration 13
Training and Learning ART/HCD 16
Documentation/Measurement 17
Our response 20
  + Persons Living with HIV 21
  + The Affected Family 22
  + The Neighbourhood 23
  + The Corps/Congregation 25
  + The Clinic 27
ACRONYMS

ART  Antiretroviral Treatment
ARV  Antiretroviral
CCCP  Congregation Communities/Clinics Partnership
CCPT  Community Care and Prevention Teams
CPT  Care and Prevention Team
CHART  Community Helper for ART
CORPS  A Salvation church congregation
HCD  Human Capacity Development
IGA  Income Generating Activities
PLWHA  People Living with HIV/AIDS
SALT  Support/Stimulation, Appreciation/Accompaniment,
      Learning Transfer of experience and response
TFT  Territorial Facilitation Team
TS  Treatment Supporter
TSA  The Salvation Army
Health care can be greatly expanded and influenced by the involvement of local family members and people from the community. With a minimum of training, communities can confidently and competently undertake health care relating to HIV/AIDS including distributing, administering, observing, monitoring and referring in relation to ART.

The Salvation Army has been involved over the past 20 years with communities responding to HIV and AIDS. The strength and capacity of communities has been demonstrated in many ways including, for example, the way that conflict is resolved in local culture. Reconciliation is an indicator of the fact that God comes near to people in the midst of the epidemic. Such experience is a reminder of the foundation to all our health and healing work. The availability of ART is an opportunity, for health and healing, for thousands of people who are living with HIV and are in touch with The Salvation Army across the world.

Since January 2004 Salvation Army facilitation teams in Africa, India, Asia/Pacific and Latin America have been carrying out research on how best to develop community-led ART in both rich and poor countries. The results include:

+ Seven countries in Africa noted their readiness to act as ‘practice demonstrations’ in June 2004. There are others, including India, China and Haiti.
+ Some already have access to ‘free’ ART through government channels (Zambia, South Africa, DRC, Haiti for example).
+ It is understood that involvement by the local community is needed and should be at the centre of the process.
+ Partnerships (CCCPs) between congregations, communities and clinics will be the key successful community leadership.
+ Support from health services is vital in order to shape a continuum of care, consistent with government guidelines. Community involvement is vital in order to help expand response and access to ART.
+ Monitoring and support accountability is reflected in the guidelines that follow, from hospital and clinic to community, to family and person living with HIV. Documentation at each level will build shared accountability and will enable professional monitoring.
+ The Salvation Army experience of stimulating home and neighbourhood responses in the context of confidential sharing is a strong foundation to offer practice demonstrations of the integration of ART.
Community-led ART can be scaled up through CCCPs (corps [congregation], community and clinic partnerships), and through strategic development of country (territorial) facilitation teams (TFTs). Country facilitation teams will not only help practice demonstrations become competent and share their experience, but will focus on learning from local action and experience through SALT activity (support, stimulation, appreciation, accompaniment, learning, and transfer of experience and response), and through networking, partnership development and development of experience in project writing.

The following principles are declared in order to affirm and build on existing strengths:

The Salvation Army remains committed to Human Capacity Development (HCD) for response to HIV within and by local community, with or without ART.

+ ART is seen as a complementary therapy to help those infected to live better quality life and continue to be productive members of society.
+ ART is to be integrated into the broader response, and not to stand alone as a response.
+ ART is not to take the place of the facilitation of HCD.

HCD for response to HIV includes the capacity to:

+ act for change, response for change and transfer, response from a community to another community;
+ cope with the impact of HIV/AIDS;
+ care for those who are infected and affected and link care to prevention;
+ with ART, form a channel for the distribution, monitoring and documentation of ART within local communities.

The Salvation Army remains committed to a role of participation, stimulation and facilitation of community developed, owned, and monitored responses to HIV/AIDS, and to other issues important to the community.

The Salvation Army remains committed to promoting community-to-community transfer of the vision, skills and process for response to HIV/AIDS, including ART where appropriate.
With an understanding of human capacity development (HCD) for response, the need for a participatory approach and facilitation team development, and learning from local action and experience, we are confident that ART can be an integral part of the HIV/AIDS responses of The Salvation Army. Together, with links between countries and continents, The Salvation Army experience can be shared with partners and organisations so that active learning and expansion of access can happen.

**The Guidelines** which follow, have two major components.

+ First, particular guidelines are offered for each of the following:
  + The CCCP partnership
  + Circle of health care
  + Drug management - procurement and administration
  + Training and learning for ART and HCD
  + Documentation and measurement - ART and HCD

+ Second is a listing of what must be known and what should be done, or the role, from the perspective of each participant, including the person living with HIV, his or her family, the neighbourhood or community, the corps or congregation, and the local clinic. The lists are each organised into four categories. Together they can describe 'our response':
  + Health Care
  + Drug Management
  + Documentation
  + Partnerships
Community/COrps/Clinic Partnerships (CCCP)

Hospital

Clinic far away from Neighbourhood

Clinic near to Neighbourhood

Church/Corps

Family (including ART)

Community/Neighbourhood
COMMUNITY, CORPS (CHURCH), CLINIC PARTNERSHIP - CCCP

Partnership will need to be built and maintained, especially between the Community (neighbourhood, including families), the corps (congregation) and the Clinic (CCCP). Each has a specific role to play, but none can achieve equitable, sustainable, effective and reliable provision of ART for people with HIV without the collaboration and co-operation of the others.

The key shared beliefs of this partnership are:

+ The partnership promotes the concept and practice of Human Capacity Development for response: essential parts of this are home-based care and community counselling.
+ All potential partners have the mandate to recognise and initiate a partnership development: partnerships are built on the basis that each partner has its own unique role and contribution, which is of equal value to the roles and contributions of other partners.
+ As well as unique roles, partners have different strengths. These need to be clearly and openly identified, and should develop within the partnership.
+ Transparency is essential: no partnership should be created to further the interests of any one partner, and the enhancement of quality of life for people with HIV should be the aim and vision of all partners.
+ The objective of the partnerships is to make care, voluntary testing and counselling, and ART accessible at community level and available on a just and equitable basis to all who need it.
+ One purpose of the partnership is to ensure that people on treatment are referred, when they need it, quickly and efficiently. Referral links must be clearly established.
+ While partners may appear to have defined roles, these may need to adapt in response to learning from local experience. For example, where a clinic is far from the community, the corps may need to develop a health post, and offer testing and counselling. Flexibility in approach is needed to use available capacity and strengths, and this may mean a change in traditional roles.
Role of Family
- Primary care and support
  - ARVs safe keeping and storage
  - Administration of ART
  - Encourage adherence
  - Observe side effects
  - Documentation

‘When one of our family members is sick, we all sit down to discuss how we can help’ (family member of a person with HIV, Zambia)

‘A 9 year old boy is under ART. The community response has been energising in such a way that the community encourages the young boy to go to school. As a result he feels integrated into the community since he is allowed to socialise with kids of his generation.’ (Congo)

‘A 45 year old man is undergoing ART at the “Centre de Traitement Ambulataire”. He is given social support and accompaniment by his wife as well as by the community...He received home based care from the Salvation Army health professionals and the community. This has allowed him to resume his job three days a week. This is partly due to the positive attitude shown by his wife and the community.’ (Congo, Kinshasa)

Role of the person living with HIV
- Adherence and self-care
- Note side effects
- Live responsibly
- Stimulate response in others

‘When I found out that I was HIV positive, I encouraged the rest of my family to go for VCT.’ (Man living with HIV Chikambola September 2004)

‘Since I started ART, I feel a lot better and I have encouraged 17 people in the last three weeks to go for VCT.’ (man on ART from Chikambola September 2004)
The Salvation Army (China) supports communities to carry out health education and care, and peer education and harm reduction in Henan and Longchuan. ART is available to 500 community members through the National and Provincial Government since March/April 2003.

**Role of Corps/Congregation**

- Secondary care and support
  - Participate in the CCCP.
  - Corps/congregation facilitation team to stimulate response in partnership with Community Care and Prevention Teams (CCPT).
  - Stock and distribute and monitor ARVs where the clinic is too far away.
  - Accompany people with HIV in maintaining treatment and prevention through home based care.
  - Participate in community conversation and transfer.

"The corps is a house of mercy, confidentiality and trust."
(Chikambola community, Zambia)

**Role of neighbourhood**

- Secondary care and support
  - Participate in the CCCP.
  - Care and Prevention Teams (CPTs), home-based care support for adherence and prevention.
  - Supporting and advocating for community-based voluntary counselling and testing.
  - Support documentation.
  - Ongoing community conversation for dealing with issues arising, and updating information about ART.
  - Transfer of concepts and action to other issues and communities.

"In this community we care for our sick and look for transport. We want the medicine at our clinic here so that people can easily access them."
(Village Headman, Zambia 2004)

The Salvation Army (China) supports communities to carry out health education and care, and peer education and harm reduction in Henan and Longchuan. ART is available to 500 community members through the National and Provincial Government since March/April 2003.

"In our work in the village, some villagers have been taking the ARVs for a few months. We found they were very confused with the use, effects and complications of it."
In response The Salvation Army team invited people living with HIV and taking the same treatment from Beijing to come to the village to share their experience, and the project team went to each village commune to listen to the villagers on ART and encourage them to share experiences and support each other.

'We found one woman [who] shared that she had had a strong reaction, but she persisted for three months and gained full strength. We asked her to share more of her experience, and she continues to do this in the village'.

Refer to web sources
To explore Regional and National training courses relating to ART e.g. for Africa:
- Salvation Army Mission: Chikankata, Zambia: sathq@coppernet.zm@NET
- RATN: www.ratn.org
- Health Services Ministries Africa: Afro AIDS information portal: Afroaidsinfo.org

For the other regions refer to the Ministry of Health websites.

Agencies:
- UNAIDS: www.unaids.org
- WHO: www.who.int
- AIDS Competence Programme: www.unitar.org/acp
- Global Fund: www.theglobalfund.org

Treatment Websites:
- AIDSmap (NAM website): www.aidsmap.com
- Treatment action campaign: www.tac.org.za

Development and HIV
- Soul Beat Africa: www.comminit.com/Africa index
- HIV Site: www.changeproject.org/technical/hivaids/index

Training
- Mildmay International: www.mildmay.org.uk

The Salvation Army
www.salvationarmy.org/health
Drugs Procurement, Administration

Hospital
Storage at Pharmacy

Community
Clinic
Corps/Church
Storage at Clinic or Corps

PLWHA Family
Storage at Home

CPT
Treatment Supporter
DRUG MANAGEMENT - PROCUREMENT AND ADMINISTRATION

Role of person on ART
+ Have a secure place to store drugs - eg a cupboard with a lock.
+ Have a means of accurate timing to take drugs - sunrise and sunset if this is regular, a watch, clock or radio.
+ Have ‘treatment supporter’ - friend or relative - who will monitor drug adherence.

Role of family
+ Family member trained in monitoring and administration of ARVs (Treatment Supporter [TS]).
+ Family member able to collect ARVs if patient cannot collect them.
+ Support/supervision of drug taking and monitoring adherence to treatment schedule.

Role of neighbourhood/community
+ Know where to obtain ARVs.
+ Ensure there is a ‘treatment supporter’ to offer support and encouragement to the person on ART.
+ Ensure that there are community members trained and motivated to link between the clinic and treatment support (a Community Helper for ART (CHART)).
+ Encourage adherence, especially when the person on treatment gets physically well and returns to normal activities.
Role of clinic/hospital
+ Obtain ARVs from referral hospital, central drug authority or drug manufacturer, according to country regulations.
+ Ensure there are trained persons to prescribe/dispense drugs.
+ Ensure adequate stocks (for at least four months): review stock and patients quarterly.
+ Train Care and Prevention Teams (CPTs) and corps members to distribute ARVs as required to people living in the community, and to encourage treatment supporter.
+ Establish and maintain link with referral hospital/drug information centre for assistance and information regarding ART.

Role of congregation/corps/church
+ Can be a place for storing ARVs for stable PLWHA already receiving ART when the clinic or hospital is too far away, or too expensive to reach regularly.
+ Provide a trained person with responsibility for distribution and storage of drugs.
+ Monitor adherence through a pill count system, and follow up when the person on treatment does not collect drugs, or cannot adhere to the treatment schedule.
The Human Capacity Development (HCD) approach is built on an understanding that communities, organisations, institutions, families and individuals can learn together from what they are already doing and what they have already experienced. In particular, organisations and institutions need systematically to build into their work a process of learning from local experience and action in order to build on community strength and work effectively with communities.

The guidelines that arise from this are:

1. Training should be under the control of the community (ie the partners acting together). Training should be done through invitation from the community rather than by imposition from external organisations.

2. Everyone in the CCCP should have the opportunity to take part in the training together, so that all partners have the same basic knowledge and roles are clarified with representation of all partners. This may happen by representation of neighbourhood, corps/church, and clinic and followed with the responsibility to feed back to the rest of the group.

3. Community members who are on ART should be invited to participate in any training to share their experience and learn with others.

4. Part of the training is to note how the CCCP is developed, including the responsibility agreed, actions to be implemented, and desirable results in terms of:
   - improve drugs access;
   - improved counselling and testing access;
   - number of neighbours/villages participating in CCCP.

Principles:

- Communities have the capacity to monitor, document and distribute ART. This is already happening effectively and safely.
- In order to achieve this, trust between the various partners is essential. Therefore the same information and knowledge must be shared between all partners if the provision of ART is to be safe and effective. The process must be transparent and open.
- The person on ART must always be at the centre of the circle of health care (see page 9).
### Person living with HIV

Together with treatment supporter will document when and where ARVs are taken.

Will notify treatment supporter of illnesses, symptoms - together they will note and share with the referral base.

### Affected Family

A responsible member of the family will be noted as treatment supporter with the responsibility of encouraging the treatment schedule, nutritious food intake and exercise, with support from the rest of the family.

The treatment supporter will note the collection of medications for patient if they are unable to go themselves: time and location of handover to PLWHA, and storage location in home.

Whether the PLWHA is improving or not and in what way.

### Neighbourhood/corps/congregation

Register of CHARTS-community members trained in drug storage and handling, documentation and monitoring.

Source of drugs.

Drug storage and dispensing procedure.

Register of those who are accessing treatment in the community.

Record of referral for clinic attention.

Counselling occurring for families as well as persons with HIV.

### Clinic

Training of CHART.

How many people have been tested and qualify for ART.

How many are currently on ART.

Referrals between clinic, community, family for follow-up/support.

Laboratory tests in support of ART.

Supply of ART.

Storage and distribution of ART.
<table>
<thead>
<tr>
<th>Person living with HIV (cont’d)</th>
<th>Affected Family (cont’d)</th>
<th>Neighbourhood/corps/congregation (cont’d)</th>
<th>Clinic (cont’d)</th>
</tr>
</thead>
</table>
| Treatment supporter will note family interactions that enhance care and prevention and involvement of family in community counselling. | Will note family to family transfer of response (eg, uptake of testing, ART, care and prevention). | The process record of community counselling, including:  
- issues of stigma, care and prevention;  
- community and family concerns related to ART and testing (clinic should be informed of such concerns);  
IGAs.  
Community-to-community transfer of vision and response.  
Self-assessment tool for AIDS Competence used every six months and shared with other communities. | Informed consent of the patient to undergo ART.  
ART regime/combinations and side effects.  
Adherence levels.  
Side effects noted.  
Opportunistic infections. Schedule for follow-up and periodic assessment (in partnership with the community).  
Referral to secondary and tertiary centres. |
OUR RESPONSE

+ Persons Living with HIV
+ The Affected Family
+ The Neighbourhood
+ The Corps/Congregation
+ The Clinic
PERSON LIVING WITH HIV

What do we need to know:

Health care
- I can live with HIV
- Who needs drugs, and why not everyone is eligible for ART
- Treatment should lead to a longer, more active life
- Success means absolute adherence to the treatment schedule
- Treatment is for life
- ART is not a cure, and the person with HIV can still share the virus so must continue to practice safe sex and prevention
- How drugs work in the body, drug resistance and side-effects
- Good nutrition, exercise, avoiding alcohol and substance abuse are all still important for health
- Where to go for help with symptoms
- The community/neighborhood will help and support me.

Drug management
- Cost and frequency of medication.
- How to store ARVs safely in the home
- Where to collect supplies of drugs and who should do this if I am unable

Documentation (together with family)
- Adherence to the treatment schedule
- Pattern of nutritious food intake and exercise
- Effects (both positive and negative) of the drugs
- How many conversations with others to encourage testing and treatment

Partnership (for individual, with neighborhood and family)
- As health improves, return to an active ‘normal’ lifestyle and return to work
- As treatment continues, allow and support monitoring by treatment supporter and clinic/hospital
- Encourage family members and others to go for testing and treatment
- Link with local groups for care and support
- Participate as part of home-visiting team to others
- Be willing to share experiences through community conversations

What do we need to do (role):

Health care
- Collaborate with the treatment support in my family
- Consult the clinic before taking any other medicines
- Live positively, in nutrition, exercise, and prevention

Drug management
- Take drugs regularly, adhere to treatment schedule
- Ensure accurate ways of timing doses

Documentation (together with family)
- Adherence to the treatment schedule
- Pattern of nutritious food intake and exercise
- Effects (both positive and negative) of the drugs
- How many conversations with others to encourage testing and treatment

Partnership (for individual, with neighborhood and family)
- As health improves, return to an active ‘normal’ lifestyle and return to work
- As treatment continues, allow and support monitoring by treatment supporter and clinic/hospital
- Encourage family members and others to go for testing and treatment
- Link with local groups for care and support
- Participate as part of home-visiting team to others
- Be willing to share experiences through community conversations
## THE AFFECTED FAMILY

### What do we need to know:

<table>
<thead>
<tr>
<th>Health care</th>
<th>Drug management</th>
</tr>
</thead>
<tbody>
<tr>
<td>+ About HIV, the status and the illness of the family member affected, and include him/her in the family.</td>
<td>+ Cost and frequency of medication.</td>
</tr>
<tr>
<td>+ Who needs drugs, and why not everyone is eligible for ART.</td>
<td>+ How to store ARVs safely in the home.</td>
</tr>
<tr>
<td>+ Treatment will lead to a longer, more active life.</td>
<td>+ Where to collect supplies of drugs and who should do this if the person with HIV is unable.</td>
</tr>
<tr>
<td>+ Success means absolute adherence</td>
<td>+ Good nutrition, exercise, avoiding alcohol and substance abuse are all still important for health.</td>
</tr>
<tr>
<td>+ Treatment is for life</td>
<td>+ How to tell whether or not the person with HIV is improving.</td>
</tr>
<tr>
<td>+ It is not a cure, and the person is still able to share the virus, so safe sex and prevention is still necessary.</td>
<td>+ How to support psychologically and spiritually.</td>
</tr>
<tr>
<td>+ How drugs work in the body, drug resistance, and side effects</td>
<td>+ Our own HIV status (not necessary to know, but helpful).</td>
</tr>
<tr>
<td>+ Good nutrition, exercise, avoiding alcohol and substance abuse are all still important for health.</td>
<td>+ What do we need to do (role):</td>
</tr>
<tr>
<td>+ How to tell whether or not the person with HIV is improving</td>
<td>+ Health care</td>
</tr>
<tr>
<td>+ How to support psychologically and spiritually</td>
<td>+ Ensure that a responsible member of the family supports the person with HIV to take drugs and live positively, including psychological and spiritual support.</td>
</tr>
<tr>
<td>+ Our own HIV status (not necessary to know, but helpful)</td>
<td>+ Be aware of whether the person is improving or not, and take action to seek further help when necessary.</td>
</tr>
<tr>
<td>+ What do we need to do (role):</td>
<td>+ Live positively as a family with a lifestyle which will prevent the transmission of HIV, and encourage the person with HIV to continue with prevention measures.</td>
</tr>
</tbody>
</table>

### Drug management

- Cost and frequency of medication
- How to store ARVs safely in the home
- Where to collect supplies of drugs and who should do this if the person with HIV is unable.

### Documentation (together with PLWHA)

- Is noting my experience in order to help myself and others

### Partnership (with person with HIV, neighbourhood)

- Realise ART is a cost and be prepared to allocate part of the family budget towards this
- Where, when and how to encourage others to go for voluntary counselling and testing

---

### What do we need to do (role):

<table>
<thead>
<tr>
<th>Health care</th>
</tr>
</thead>
<tbody>
<tr>
<td>+ Ensure that a responsible member of the family supports the person with HIV to take drugs and live positively, including psychological and spiritual support.</td>
</tr>
<tr>
<td>+ Be aware of whether the person is improving or not, and take action to seek further help when necessary.</td>
</tr>
<tr>
<td>+ Live positively as a family with a lifestyle which will prevent the transmission of HIV, and encourage the person with HIV to continue with prevention measures.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Drug management</th>
</tr>
</thead>
<tbody>
<tr>
<td>+ Ensure that drugs are collected regularly and kept safely.</td>
</tr>
<tr>
<td>+ Directly observe drug treatment as per treatment schedule.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Documentation (together with PLWHA)</th>
</tr>
</thead>
<tbody>
<tr>
<td>+ Who is collecting medications for patient if they are unable to go themselves.</td>
</tr>
<tr>
<td>+ Adherence to treatment schedule and follow-up appointments.</td>
</tr>
<tr>
<td>+ Pattern of nutritious food intake and exercise.</td>
</tr>
<tr>
<td>+ Is the person improving or not, and how, noting any side-effects.</td>
</tr>
<tr>
<td>+ Family response in terms of participation in care and in decisions for prevention.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Partnership (with person with HIV, neighbourhood)</th>
</tr>
</thead>
<tbody>
<tr>
<td>+ Allocate part of family budget to financial support for the ARV</td>
</tr>
<tr>
<td>+ Transport to health facility and support for monitoring</td>
</tr>
<tr>
<td>+ Encourage each other to go for testing and treatment</td>
</tr>
<tr>
<td>+ Share stories and learning with other families</td>
</tr>
<tr>
<td>+ Participate as part of home-visiting team to others</td>
</tr>
<tr>
<td>+ Be willing to share experiences through community conversations</td>
</tr>
</tbody>
</table>
### THE NEIGHBOURHOOD

#### What do we need to know:

**Health care**
- Who needs drugs, and why not everyone is eligible for ART
- Treatment will lead to a longer, more active life
- Success means absolute adherence
- Treatment is for life
- It is not a cure, and the person is still able to share the virus, so safe sex and prevention are still necessary.
- How drugs work in the body, drug resistance, and side effects
- Good nutrition, exercise, avoiding alcohol and substance abuse are all still important for health
- Interaction of ART with traditional and herbal medicines
- The signs of response to ART or failure to respond
- When immediate medical attention is needed

**Drug management**
- Cost and frequency of medication
- Know how drugs must be stored, how the drug distribution system works

**Documentation**
- Is noting our experience in order to help ourselves and others

**Partnership**
- CCCP is possible, and can be initiated by the neighbourhood
- What we are responsible for within the partnership
- We can learn from our own experience, and share this with other communities, by visiting or hosting

#### What do we need to do (role):

**Health care**
- Encourage those who are HIV positive to go for testing and possible treatment
- Be a treatment supporter to a person living with HIV or AIDS and supervise drug taking
- Help the person with HIV to return to work and a productive life
- Refer people to medical care where necessary, and support them, eg with transport, to access this care
- Address issues, such as stigma, through community conversations and home visits
- Continue to work for prevention, especially among youth, through the influence of care
- Encourage each other to be tested

**Drug management**
- Maintain community drug storage, handling, documentation and monitoring of drug supplies (through the CCCP)
- Determine who can be trained as community-based helpers in drug storage, handling, documentation, monitoring and treatment support

**Documentation (responsibility of CCCP)**
- Lessons we are learning and sharing with others
- Transfer to other neighbourhoods
- Community counselling process, including:
  - Concerns/issues emerging within the community as a result of ART
  - Changes happening in relation to care and prevention
  - Community and family action in responding to ART
<table>
<thead>
<tr>
<th>What do we need to do (role):</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Partnership</strong></td>
</tr>
<tr>
<td>✤ Initiate and nurture development of CCCP</td>
</tr>
<tr>
<td>✤ Guardianship role for vulnerable people, young children, orphans, pregnant women including responsibility for the provision of ART</td>
</tr>
<tr>
<td>✤ Community meetings including village headmen on ART and HIV. Seek other partners to help with access to ART and testing</td>
</tr>
<tr>
<td>✤ Learn from and share experiences with other neighbourhoods. Transfer experience to other communities (community to community transfer)</td>
</tr>
</tbody>
</table>

**THE NEIGHBOURHOOD (cont’d)**

What do we need to know:

- THE NEIGHBOURHOOD (cont’d)
THE CORPS/CONGREGATION

What do we need to do (role):

Health care (together with the neighbourhood)

- Encourage those who are HIV positive to go for testing and possible treatment
- Be a treatment supporter to a person living with HIV or AIDS and supervise drug taking
- Help the person with HIV to return to work and a productive life
- Refer people to medical care where necessary, and support them, eg with transport, to access this care
- Continue to work for prevention, especially among youth, through the influence of care
- Encourage each other to be tested
- Help to develop a clear referral system between clinic, community and family for follow-up
- Support people and families living with HIV, including spiritual support
- Counsel families and individuals
- Stimulate and support community counselling in the wider community, where issues can be addressed

Drug management

- Be available as a base, storage and distribution centre for ARVs
- Store and dispense ARVs for people already on treatment if the community is far from a clinic (supervised by the clinic or the hospital)
- Help to set up a system to follow drug adherence
- Ensure that relevant corps/church members are competent

Drug management

- Cost and frequency of medication
- Know how drugs must be stored; how the drug distribution system works

Documentation

- Is noting our experience in order to help ourselves and others

What do we need to know:

Health care

- Who needs drugs, and why not everyone is eligible for ART
- Treatment will lead to a longer, more active life
- Success means absolute adherence
- Treatment is for life
- It is not a cure, and the person is still able to share the virus, so safe sex and prevention is still necessary.
- How drugs work in the body, drug resistance, and side effects
- Good nutrition, exercise, avoiding alcohol and substance abuse are all still important for health
- Interaction of ART with traditional and herbal medicines
- The signs of response to ART or failure to respond
- When immediate medical attention is needed, when to refer
- Cost and frequency of medication
- Know how drugs must be stored
- Who will be responsible for stock keeping and dispensing
- How to monitor adherence to treatment

Drug management

- Cost and frequency of medication
- Know how drugs must be stored, how the drug distribution system works

Documentation

- Is noting our experience in order to help ourselves and others
What do we need to do (role):

- Support people on treatment to ensure strict adherence to treatment schedule
- Follow-up if someone does not return for supplies of drugs
- Documentation (together with the neighbourhood)
  - Community concerns related to ART and testing, as part of the CCCP
  - The following are for the CPT or the corps, whoever is doing direct follow up in the home:
    - Number of people going for treatment
    - Number of home visits to patients and families
    - Number of young people accessing ART
    - Interactions with drugs and herbal/traditional remedies
    - Signs of response/failure to respond
    - Counselling for family as well as person with AIDS

Partnership

- The corps should ensure equal opportunity and access to everyone regardless of faith, gender, age etc
- Address issues of stigma through community conversations and home visits
- Initiate and nurture the development of CCCP
- Respond to CCCP invitation to distribute ART when there is no clinic nearby
- Stimulate corps-to-corps (congregation) transfer of learning and action

What do we need to know:

Partnership

- CCCP is possible, and can be initiated by the neighbourhood
- What we are responsible for within the partnership
- We can learn from our own experience, and share this with other communities, by visiting or hosting

THE CORPS/CONGREGATION (cont’d)
THE CLINIC

What do we need to know:

**Health care**
- Who needs drugs, and why not everyone is eligible for ART
- Treatment will lead to a longer, more active life
- Success means absolute adherence
- Treatment is for life
- It is not a cure, and the person is still able to share the virus, so safe sex and prevention is still necessary.
- How drugs work in the body, drug resistance, and side effects
- Good nutrition, exercise, avoiding alcohol and substance abuse are all still important for health
- Interaction of ART with traditional and herbal medicines
- The signs of response to ART or failure to respond
- The economic status of the person with HIV
- How to do clinical and basic lab assessment of patients for ART
- How to advise the person with HIV, family and the community
- How to diagnose and manage complications of ART
- How to identify and manage opportunistic infections
- When to refer

**Drug management**
- ART components, classes
- How to store and manage drug supplies
- Cost and frequency of medication
- Who will be responsible for stock keeping and dispensing

What do we need to do (role):

**Health care**
- Consider available treatment options and choose the most appropriate for the patient
- Explain everything to the person with AIDS and the family, including side-effects and adverse reactions
- Prepare schedule for follow-up and periodic assessment in addition to monitoring in the community
- Be equipped to identify and manage opportunistic infections and advise the person with AIDS, family and community accordingly
- Give information about nutrition, exercise and a healthy lifestyle
- Welcome groups, couples, and families for testing and treatment
- Integrate treatment into home care
- Follow-up clients in their homes
- Visit the chronically ill
- Support the development of follow-up skills within the CCCP

**Drug management**
- Help to set up a system to follow drug adherence by the person with HIV
- Be the base, storage and distribution centre for ARV in partnership with the community and congregation
- Follow up if someone does not return for supplies of drugs
### THE CLINIC (cont’d)

**What do we need to do (role):**

<table>
<thead>
<tr>
<th>Documentation</th>
</tr>
</thead>
<tbody>
<tr>
<td>+ Know how to keep statistics and records of ART and other records relating to HIV. How many are currently on ART?</td>
</tr>
<tr>
<td>+ Develop referral system between clinic, community, family for follow-up/support.</td>
</tr>
<tr>
<td>+ How many people have been tested and qualify for ART and how many are currently on ART?</td>
</tr>
<tr>
<td>+ Adherence levels and treatment responses.</td>
</tr>
<tr>
<td>+ Record of referrals to tertiary care.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Partnership</th>
</tr>
</thead>
<tbody>
<tr>
<td>+ Help to establish a referral system between clinic, community and family for follow-up support, with all partners taking part.</td>
</tr>
<tr>
<td>+ Develop partnership with tertiary referral centre.</td>
</tr>
<tr>
<td>+ Make links with other clinics distributing ARVs.</td>
</tr>
<tr>
<td>+ Involve well wishers and explore multiple sources where possible, to ensure uninterrupted supply of ARV drugs.</td>
</tr>
<tr>
<td>+ Hold sensitisation meetings.</td>
</tr>
<tr>
<td>+ Carry out programme to programme visits for learning from the experience of others, and sharing experience as it develops.</td>
</tr>
</tbody>
</table>

**What do we need to know:**

| + How to monitor adherence to treatment (Reference: WHO). |
| + Where to get drugs; how to find the drugs which have less severe side effects and are cheaper. |
| + Who can be trained at community level to distribute ARVs. |

**Documentation**

| + Is noting our experience in order to help ourselves and others. |
| + Clinic role is to link documentation by the partners in the CCCP. |

**Partnership**

| + Partnership with community and congregation is most direct for distribution of drugs and for ongoing care and prevention. |
| + Which clinics or hospitals nearby are distributing ARVs. |
| + Where tests are available that the clinic does not have. |