



Comprehensive HIV prevention,  
treatment, care and support

Good practice examples from India

## **Imprint**

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# Comprehensive HIV prevention, treatment, care and support – Good practice examples from India

Nina Urwanzoff, Ellen Schmitt and Piet Reijer

MISEREOR

## Dedication

This publication is dedicated to Sr Dr Mary Prashanti, who died on 3 January 2013. She was a great inspiration for us in preparing this publication. She will be remembered by all who knew her, especially her patients from the Assisi Dermatological Centre and Hospital.

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## Foreword

Every country in the world is facing a more or less severe threat of HIV. Individuals, families, communities and societies are affected in various ways. The HIV epidemic reduces development achievements, diminishes opportunities for future development, and makes people poorer. A major pillar of Misereor’s work, and that of its partners, is to reduce poverty and assist the poor and marginalized in Africa, Latin America and Asia.

India has the third-largest number of people living with HIV in the world. Misereor supports Indian partner organisations engaged in development work and in health care services. Without health there is no development, and without development there is no health. Misereor aims to strengthen partner organisations to deliver good-quality health services where the need is biggest. We hope that the examples of good practices in this publication will help strengthen the work of our partner organisations. We also hope the publication will motivate others to adjust their current work practices and to support collaboration and dialog between non-government and government organisations.

The Catholic Health Association of India (CHAI) is an important partner for Misereor. It has worked with Misereor for several decades in the provision of health care services, and Misereor has supported its work to address the HIV epidemic in India since 1994. Over the years Misereor has assisted CHAI to develop a variety of activities in the fields of HIV prevention, care and support of people living with HIV, and to mitigate the effects of HIV.

The continuous support and solidarity by religious leaders within India, Germany and worldwide in response to the challenge of the HIV epidemic are indispensable.

This publication describes good practice examples of three community care centres in comprehensive HIV prevention, treatment, care and support. All three centres are active in rural areas, but many of their patients come from towns and cities. All three centres follow a community-oriented approach. Representatives of the three centres were actively involved in this documentation.

We hope that you will find this publication informative and helpful in your work and that it will assist people living with HIV to improve their health and living conditions.

Dr Martin Bröckelmann-Simon

*Managing Director Misereor, International Cooperation*

*Meeting of outreach workers who are members of a self-help group*





## Preface

This book is based on a study to analyse and document good practices in HIV prevention, treatment, care and support in India, and to share the findings with others. It is intended for Misereor's partners in India and other countries, and the public in Germany and elsewhere. We hope the document will help share experiences in this field, and support learning and discussion with related projects and programmes.

We used various methods to gather the information in this book. It is based on interviews with individual staff of the three community care centres, staff from government facilities, and with people living with HIV. We held focus-group discussions with people living with HIV. We also collected and analysed data and studied the relevant literature.

The document gives an overview of the HIV epidemic in India and efforts to organise HIV prevention, and treatment, care and support for people living with HIV, focusing on centres that provide medical and community care. It then highlights the work of three community care centres (two in Andhra Pradesh and one in Tamil Nadu) which are members of the Catholic Health Association of India and supported by Misereor. For each of these centres, it describes the history and current activities, illustrated by stories of the centre's staff and the patients who benefit from their services. The document concludes by identifying some key aspects that have led to the centres' success.



*Director of Jeevan Jyothi Hospice and Community Care Centre, in the nearby village*

## Acknowledgements

The editorial team thanks everybody involved in the realisation of this publication. We are especially grateful for the support we received from the former director of CHAI, Fr Sebastian and his staff, the directors Sr Anastasia, Sr Dr Prashanti Mary and Sr Lucy and the personnel of the three community care centres for sharing their experiences, the time they have dedicated and their infinite patience to organise our stay. We are particularly grateful for the willingness and openness of people living with HIV to share their experiences. Without them this document would not

be so rich in stories that describe their reality to live with the infection in difficult circumstances.

Last but not least, our thanks go to Paul Mundy for editing and assistance in formulating the text into a language that is easy to understand for readers who are not familiar with medical terms, to Michael Klinkebiel for the layout and creative design, and to Annegret Schroif and MVG Medienproduktion for the printing,

Nina Urwanzoff, Ellen Schmitt, Piet Reijer

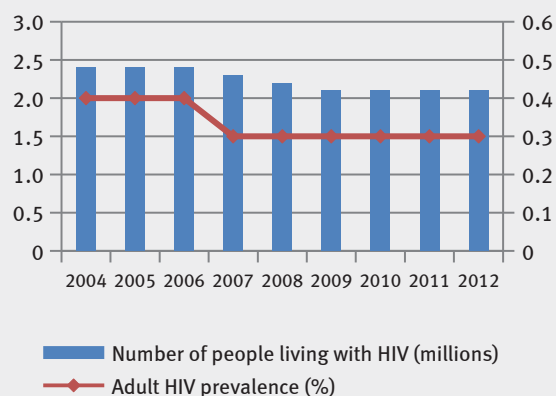
# Introduction

At the end of 2012, 35.3 million people around the world were living with HIV, the virus that causes AIDS. In India, the first HIV infection was discovered in 1986 in Chennai. The HIV epidemic is one of the country’s most serious public health problems. The epidemic in India is now slowly declining: from a total of 2.73 million infected people in 2002 to about 2.1 million in 2012.

Although only 0.3% of adults aged 15 to 49 are thought to be infected, India’s huge population means that it has the third-largest number of people living with HIV in the world, after South Africa and Nigeria. The infection affects a broad range of people: women aged 15 and older account for 35.7% of the numbers infected (in 2012), and another 3.5% are children (in 2009). The majority are men.

**Figure 1**

Trends of estimated adult HIV prevalence and estimated number of people living with HIV, 2004–12



Source: UNAIDS (2013)

Indian society is highly diverse. Some people are rich, but the majority are poor or very poor. The population has a huge range of social and ethnic backgrounds. There are many languages and cultures, and relations between men and women vary widely. This diversity makes it a challenge to respond effectively to HIV and AIDS.

The spread of the virus is linked to many underlying factors, including poverty, migration and mobility, gender inequality, social disadvantages, drug consumption, limited access to education, lack of information and awareness, a poor health-care system, inadequate access to health services, and changes in lifestyle, norms and values. All these influence individuals’ sexual behaviour.

India’s HIV epidemic is still concentrated among

populations who are most at risk. Sex work is a major factor. It is based not only in brothels but increasingly also on the street or at home. A large number of female sex workers come from rural areas, where poverty and a lack of economic opportunities force both men and women to migrate to the cities. Such migrants are unlikely to have benefited from any HIV prevention programmes because these interventions are mostly urban-centred. That makes the migrants vulnerable to HIV infection.

The important drivers of the HIV epidemic in India are sex work and injecting drug use. Men who buy sex have mostly unprotected sexual intercourse and this is the single most powerful driving force in the epidemic. As more than 90% of HIV-positive women acquire the infection from their husbands, they are at increased risk not because of their own sexual behaviour, but because they are partners of men in a high-risk group: clients of female sex workers, men who have sex with other men, or injecting drug users. Young people are also vulnerable to HIV infection. Many of them lack knowledge and access to information, and are exposed to sexually transmitted diseases.

There are now less stigma and discrimination concerning HIV than before, but they are still an issue. Some health-care providers refuse to treat people living with HIV. Children who are infected (or whose parents are) face stigma and discrimination at school, and they may drop out of school. Afraid of losing their jobs HIV-positive workers may try to keep their status secret.

Why this stigma and discrimination? Reasons include a lack of information about the virus and AIDS, associated myths and misconceptions, and the “shameful” topic of sex, which is closely associated with HIV. HIV is more common in female sex workers, men who have sex with men, and injecting drug users. The stigma associated with these population groups gets attached to HIV too.

These problems hinder access to information, prevention measures, testing and treatment opportunities. That makes it important to fight stigma and discrimination and to dispel myths and misconceptions associated with HIV and AIDS. Health workers play an important role in this fight.

Topics of sexuality and sexual relations – and HIV infection is closely linked to these – are taboo in Indian society. Spouses find it difficult to talk openly about these issues; so too do parents and children, and people with medical staff. Because most health workers are women, it is hard for them to talk to men about HIV and safer sex. Plus, in general, men have a poor health-seeking behaviour.



The status of women is changing only slowly, and inequalities between women and men still exist. Various factors make women vulnerable to HIV infection.

- **Exposure through partners.** They may be exposed to the virus because their male intimate partners have unprotected paid sex, have unsafe male-to-male sex, or inject drugs.
- **Socio-economic conditions.** Women face tough social and economic conditions, especially in rural areas. They tend to be dependent on men and have little power to negotiate (e.g., for safer sex). They have less education than men, limited access to information and little power to make decisions. They have little control over money, and their mobility is restricted. That makes it difficult for them to access HIV prevention, treatment and care services.
- **Young marriage.** Many girls marry young, so are not prepared for sexual relations. Marriage with older men put them at greater risk of infection because the men may already have had other sexual partners.
- **Violence.** Violence, abuse and rape expose women and girls to HIV and other sexually transmitted infections. Trafficking puts them into exploitative and dangerous situations, where they are subject to physical and sexual abuse as well as infection.

- **Lack of rights.** Women lack equal rights when it comes to inheritance of assets and resources. Sometimes women living with HIV are blamed and rejected by the family.
- **Women's responsibilities.** In addition to their many other duties, women are typically responsible for taking care of children and the sick.

The health of Indians has improved since independence, especially in the last 20–30 years. In 1970, 202 of every 1,000 children did not live to see their fifth birthday; by 2010, 63 failed to do so. Infant mortality rates have fallen too: from 190 per 1,000 live births to 48 in the same period (Table 1).

Despite this progress, over 40% of Indian children are undernourished, and more than two-fifths of the population lives in absolute poverty. Large numbers of people have no access to safe drinking water, adequate housing and health care services. Half the population defecates in the open. There are marked differences in the health status of different states and between rural and urban areas. State-of-the-art, high-tech private health facilities are found in the large towns. The prices for procedures such as heart surgery, orthopaedics and transplantations are much lower in India than in North America and Europe, attracting many patients from these regions. At the same time, rural areas in the poorer states of India lack even the most basic services.

**Table 1**

Population statistics for India, 1970–2010

	1970	1990	2000	2010
Total population (millions)	550	850	1,100	1,200
Under-5 mortality rate	202	116	94	63
Infant mortality rate	190	83	68	48
Life expectancy at birth (years)	49	58	61	65 (2009)
Immunization coverage measles (1 year)		56	54	70 (2009)
Maternal mortality ratio	1,700	570	390	230 (2008)
Crude birth rate	38	32	26	22 (2009)
Crude death rate	16	11	9	8 (2009)
Gross domestic product per capita (\$)	110	374	450	1,375

	1970	1990-1999	2000-2007
Adult literacy rate (%)	34	48	66

Data Sources:

Health: World Health Organization; [www.who.int/healthinfo/statistics/mortality/en/](http://www.who.int/healthinfo/statistics/mortality/en/)

Population: International Monetary Fund; <http://tinyurl.com/8fnu4c9>

Gross domestic product: <http://data.worldbank.org/indicator/NY.GDP.PCAP.CD?page=6>

## Regional distribution of HIV

Six high-prevalence states account for over two-thirds of the HIV cases in India (Figure 2). There were 156 category “A” districts in 2007, where over 1% of the women attending antenatal clinics were HIV-positive. (In 2009 this number had fallen to 108 districts.) The distribution of cases is changing continuously: while in high-prevalence states fewer women who attend the clinics are now HIV-positive; numbers rising in some states with low and moderate prevalence, including Gujarat, Rajasthan, Orissa, Uttar Pradesh, Bihar and West Bengal.

In Tamil Nadu, a large state in southern India, HIV prevalence has fallen markedly. Of women attending antenatal clinics, 1.59% were found to be HIV-positive in 2000; this proportion fell to 0.36% in 2006. Of almost 700,000 pregnant women tested between April and December 2010, only 0.13% were positive. Tamil Nadu is no longer considered a high-prevalence state.

Similar trends have been seen in Andhra Pradesh, the state to Tamil Nadu’s north. The Andhra Pradesh State AIDS Control Society reported that in 2010 the prevalence among pregnant women was less than 1% for the first time. The highest prevalence was recorded in the coastal districts, with Kadappa the highest at 2.25%, followed by Karimnagar (1.25%), East Godavari (1.25%), Guntur (1.08%) and Krishna (1.0%).

**Figure 2**

States in India with high and rising HIV prevalence



**Table 2**

Population statistics for India, Andhra Pradesh and Tamil Nadu, 2009

	India	Andhra Pradesh	Tamil Nadu
Population (2011, rounded figures)	1,200 million	85 million	72 million
Annual population growth (2001–11)	1.60%	1.10%	1.50%
Female literacy (7 and above)	74%	68%	80%
Sex ratio (female/1000 male)	940	992	995
Sex ratio (0–6 years) (female/1000 male)	914	943	946
Crude birth rate	22.5	18.3	16.3
Crude death rate	7.3	7.6	7.6
Infant mortality	50	49	28
Under 5 mortality	64	52	33
Maternal mortality (2007–9)	212	134	97
Total fertility rate	2.6	1.9	1.7

Source: Ministry of Health and Family Welfare (2011)

# Organising treatment, care and support

In 1992, India's National AIDS Control Organisation was founded and the first National AIDS Control Programme (1992–99) was launched. Its objective was to control the spread of HIV by expanding the infrastructure of blood banks and treatment of sexually transmitted infections, to start a sentinel surveillance system, and to prevent transmission by creating awareness.

The programme's second phase (1999–2006) included a component of "care and support" for HIV-infected persons. It includes standard precautions to prevent cross-contamination and cross-infection among health workers, between health workers and patients, and among patients.

**Antiretroviral therapy centres (ART centres).** In April 2004, eight government hospitals in six high-prevalence states started providing antiretroviral therapy for eligible people living with HIV. This programme has since been scaled up, both in terms of treatment facilities and the number of beneficiaries. Most therapy centres are located in medical colleges and government-run district hospitals. In December 2010 there were 292 fully functional centres. About 300 centres are needed, based on the demand for antiretrovirals. Table 3 gives details of the antiretroviral therapy centres in Andhra Pradesh and Tamil Nadu.

**Centres of excellence.** The HIV epidemic has over the past decade become more complex. It requires operational research, effective health-delivery systems, and a trained and motivated workforce. Medical institutions have to be able to deliver high-quality care, treatment and support. Complex treatment schedules and patient management require constant training and upgrading of providers' skills. The third National AIDS Control Programme (2007–12) established centres of excellence to facilitate the provision of tertiary-level specialist care and treatment. By 2010, ten such centres were functioning.

**Link antiretroviral therapy centres (Link ART centres).** A study revealed that distance, travel time and costs were the main reasons for patients not regularly attending antiretroviral therapy services. To bring these services closer to the beneficiaries, it was decided to set up "Link antiretroviral therapy centres". These are located mainly at counselling and testing centres in district or sub-district hospitals, and are linked to an antiretroviral therapy centre

nearby. Some 550 such link centres have been established and were running by December 2010.

**Community care centres.** These have a mandate to provide a comprehensive package of care, support and treatment services. They are run by non-government organizations but are linked to the government's antiretroviral therapy centres. The first such centres were started in 2001/2 in Andhra Pradesh, where they were named "care and support centres". They ensure that people living with HIV receive:

- Counselling for antiretroviral treatment preparedness and drug adherence, nutrition and prevention
- Treatment of opportunistic infections
- Referral and outreach services for visits of patients in their homes
- Psycho-social support
- Visits if they miss an appointment to make sure they get antiretrovirals on time.

In 2010, 255 community care centres were fully functional. Most are in the high-prevalence states.

**Regional paediatric centres.** All the antiretroviral therapy centres serve children. In addition, seven regional paediatric centres serve as centres of excellence for paediatric care, including the management of complicated opportunistic infections, training and research. These centres have various roles and responsibilities in caring for and supporting infected children, including specialised laboratory services and counselling on adherence and nutrition. They also provide technical support to the other antiretroviral therapy centres in paediatric care.

**Table 3**

Antiretroviral therapy centres in Andhra Pradesh and Tamil Nadu

Andhra Pradesh	Tamil Nadu
38 centres treating...	40 centres treating...
• 79,009 adults	• 45,179 adults
• 4,050 children	• 2,776 children
• 83,059 people in total	• 47,955 people in total

Date: December 2010  
Source: NACO (2010a) p. 62

## History of HIV services

Access to treatment, care and support in the high-prevalence states has improved a lot in the last ten years, especially after 2006/8, when many antiretroviral therapy and community care centres were opened. In the low-prevalence states, access is still unsatisfactory. In some states people living with HIV have to travel more than 150 km to reach a centre.

Access to services in the high-prevalence states was very poor in the 1990s and early 2000s. There were very few places in India where one could be tested voluntarily. Health facilities tested certain groups of patients for HIV without their consent (for example, before an operation), and often sent away anyone who was found to be HIV-positive. A UNAIDS study (2001) of discrimination, stigma and denial found that there was no place in the community at that time for people living with HIV. They were discriminated against at all layers of society: in their families, communities, places of work and health services. The study concludes:

*“In contrast, Catholic church-run hospitals and a few other private hospitals in this same city (Bangalore) had opened all their treatment facilities to patients with HIV and AIDS. Indeed, Catholic hospitals were in the unusual position of having a written policy on AIDS that clearly stipulated the provision of unconditional care to patients with HIV. Small private clinics, on the other hand, as was pointed out by doctors at different hospitals and by HIV-positive patients, sometimes denied care and treatment” (UNAIDS 2001).*

The Catholic Health Association of India (CHAI) was one of the first organisations in India that recognised the need for action. It developed a policy on HIV/AIDS in 1994. With financial support from Misereor (the development agency of the German Catholic Bishops’ Conference), and technical support from the Medical Mission Institute (based in Würzburg, Germany), CHAI started training staff from its member institutions from all over India in various aspects of HIV management. These health workers were often the only people in their regions to offer care and support.

## A start in Andhra Pradesh

In 2001, the Andhra Pradesh State AIDS Control Society started establishing care and support centres. It asked non-governmental and faith-based organisations to make space and staff available. It approached in particular CHAI member institutions that had extra bed capacity. Most of these were former tuberculosis sanatoriums and leprosy wards. CHAI members established seven care and support centres in 2002, and CHAI trained their staff on

the medical management of HIV/AIDS, the provision of counselling services, and documentation and advocacy. This was the first time in India that people living with HIV were recruited to provide counselling services and were trained in counselling. These centres offered care and support for both in- and out-patients, covering medical, nursing and psychological aspects. From 2004 onwards, the services of six centres were expanded with support from Misereor, and they added outreach activities such as active case-finding, awareness creation and education, and home visits. These six centres offered comprehensive services, excepting only antiretroviral therapy. For several years, these centres were the only facilities in a wide area that offered services for people living with HIV. Patients would come from as far as 100 km away.

After the Indian government began setting up antiretroviral therapy centres and link antiretroviral therapy centres, the CHAI care and support centres were renamed “community care centres”. They continue to play an important role and work closely with the antiretroviral therapy services.

## Expansion to other states

After the start in Andhra Pradesh, the concept was introduced in other states in the following years. The Catholic Bishops’ Conference of India started supporting 45 community care centres in high- and medium-prevalence states with financial assistance from the Global Fund to fight AIDS, Tuberculosis and Malaria. Most of these do not have a community component like that in the six centres in Andhra Pradesh.

**Figure 3**

Services (including outreach activities) provided by community care centres



Source: CHAI (2005)

**Box 1****Objectives of community care centres**

Under the national programme, a community care centre is a place with facilities for outpatient and inpatient treatment where a person living with HIV receives the following services:

**Inpatients**

All patients started on antiretroviral therapy will be sent to the community care centre for a minimum of 5 days of inpatient care:

- Medical monitoring for side effects and tolerance to antiretroviral therapy regimen and/or stabilisation of opportunistic infections as initiated.
- Verification of patient address.
- Follow-up home-visits to ensure home care and to monitor well-being and treatment adherence.
- Preparing family and/or spouse for acceptance of test status of person living with HIV, counselling for supervised administration of drugs, home based care etc.
- Psychosocial and counselling support on treatment adherence, patient education, nutrition counselling, positive prevention, reproductive health counselling for HIV-positive women and couples etc.
- In case of requiring stay for over five days, discharge of the patient would be determined by the treating physician.

**Treatment of opportunistic infections**

Following assessment at the antiretroviral therapy centre, people living with HIV who do not require antiretroviral therapy, will be followed up for pre- antiretroviral therapy care such as routine regular monitoring of CD4 testing and other medical concerns. The people living with HIV will also receive psychosocial support and counselling, treatment literacy, positive prevention, etc.

**Referrals to:**

- Integrated counselling and testing centres for confirmation of HIV status in patients with unconfirmed or unknown status, spouses and family members of people living with HIV, etc.
- Prevention of parent-to-child transmission for care of HIV-positive pregnant women.
- Paediatric HIV services/antiretroviral therapy centre for children living with HIV/AIDS for routine check-up.
- Monitoring including growth, immunization, prevention and care of opportunistic infections, assessment for antiretroviral therapy initiation, etc.
- Antiretroviral therapy centre for the CD4 test and other laboratory investigations and if required, initiation of antiretroviral therapy at the antiretroviral therapy centres.

- Medical facilities for specialised services as required.
- Directly observed therapy, short course for treatment for tuberculosis.
- Other services as required, e.g. welfare-legal services, harm-reduction programmes for injecting drug users, peer support networks, etc.

**Outpatient facility for:**

- Consultation of illnesses related to HIV infection.
- Treatment of opportunistic infections.
- Counselling for adherence and home-based care.

**Home based care**

- Outreach facility for people living with HIV who required home care or additional psychosocial support.
- Counselling for home-based care.

Some community care centres may also serve as a Link antiretroviral therapy centre for patients on antiretroviral therapy. These community care centres have to be accredited by National AIDS Control Organization.

A community care centre may also provide integrated counselling and testing centre service as per the Integrated Counselling and Testing Centre Operational Guidelines of NACO.

The integrated counselling and testing centre will offer HIV testing to

- Spouses and children of people living with HIV
- High risk groups
- Clients reporting to the community care centres with tuberculosis
- Any client referred to the centre
- Direct walk-in clients seeking an HIV test

The community care centre will provide the range of prevention of parent-to-child transmission services:

- Pregnant women referred to the community care centres
- Spouses of people living with HIV
- Positive pregnant women.

**Directly observed therapy, short-course facility**

In the absence of a nearby directly observed therapy, short-course centre or based on the client load requiring tuberculosis treatment, the community care centre can function as a directly observed therapy, short-course centre, or serve as a drug dispensing centre for tuberculosis patients following the criteria set by the Revised National Tuberculosis Control Programme.

**Risk reduction**

- All people living with HIV should be counselled for risk reduction.

*Source: Modified from NACO (2007a)*

The community care centres have been a successful and effective response to the HIV epidemic. Many people living with HIV have found their way to the centres and have become regular visitors. The introduction of antiretroviral therapy has given a second chance in life for many. The community care centres help their clients to access antiretroviral therapy, and assist them in adhering to the therapy.

### The community care centre concept

First known as “care and support centres”, the community care centres were renamed following guidelines from the National AIDS Control Organisation. They

*“...were intended to function as a bridge between hospital and home care. Hence, [community care centres] were envisaged as stand-alone short-stay homes for [people living with HIV]. These were not linked to other activities of the programme.” (NACO 2010b, p. 1).*

The main tasks of the community care centres were

*“...to provide treatment for minor opportunistic infections and provide psychosocial support through sustained counselling.” (NACO 2010b, p. 1).*

In 2007, the original concept of stand-alone centres was replaced by the following:

*“The [community care centre] needs to be transformed from a stand-alone short-stay home to playing a critical role in enabling [people living with HIV] to access [antiretroviral therapy] as well as providing monitoring, follow-up, counselling support to those who are initiated on [antiretroviral therapy], positive prevention, drug adherence, nutrition counselling etc. The monitoring of [people living with HIV] who do not require [antiretroviral therapy] yet (pre-ART care) will also be a critical function that needs to be carried out by the [community care centre]” (NACO 2007c, p. 7).*

The original concept of the care and support centres, developed in 2002, has moved into a more integrated support mechanism, combining various aspects of care. The arrival of antiretroviral therapy in 2004 has induced these changes. Everyone who gets antiretroviral therapy for the first time is supposed to stay in a community care centre for at least the first five days of the treatment.

## Three community care centres

**Figure 4**

Location of the three community care centres in southern India



The following sections show the impact of community care centres on the lives of people living with HIV and their families. They describe two centres in Andhra Pradesh and one in Tamil Nadu:

- **The Assisi Hospital and Dermatological Centre** in Krishna District, Andhra Pradesh
- **Snehasadan Community Care Centre**, also in Krishna District.
- **Jeevan Jyothi Hospice**, in Tamil Nadu.

All three are CHAI member institutions, and members of their staff were among the first to be trained by CHAI in HIV management, long before the government started with a coordinated effort to assist people living with HIV. The three community care centres have different backgrounds and daily operations. Nevertheless, their activities are similar.



## Assisi Hospital and Dermatological Centre

The Assisi Hospital and Dermatological Centre was established in 1985 as a general hospital specialising in leprosy treatment and control. Community-based rehabilitation for leprosy patients was (and still is) an integral part of its services, although new leprosy cases are now rare. It still serves as a general hospital for local people and a dermatological centre for a large part of the district. It is managed by the Assisi Sisters of Mary Immaculate.

Krishna District is one of the high HIV prevalence areas in Andhra Pradesh. In 2002, CHAI asked the Assisi hospital to collaborate with the Andhra Pradesh State AIDS Control Society and become a care and support centre. Assisi already welcomed people living with HIV, and CHAI had trained some of the staff in HIV management. CHAI continued to do this, and later trained outreach workers, too. From 2004 to 2009 it provided financial support for the hospital's outreach activities through a Misereor grant. The trainees included counsellors who were trained in the local language. In recent years, the Andhra Pradesh State AIDS Control Society has provided more and more training and staff supervision. In 2008 the name "care and support centre" was changed to "community care centre" in accordance with national policy.

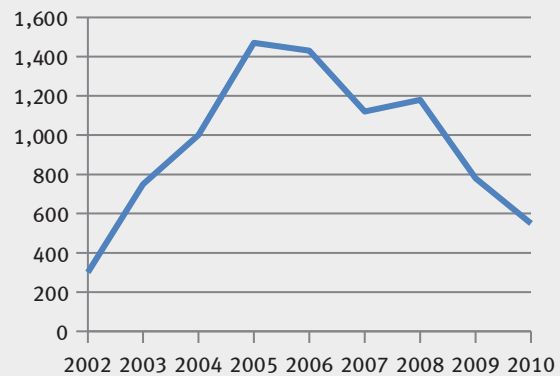
For many years, Assisi was the only facility in the district that welcomed people living with HIV. Patients also came from other districts and even from the large towns of Guntur and Vijayawada (both some 70 kilometres away), which had no suitable facilities. Assisi identified more than 2,000 people living with HIV in the two years after it became a care and support centre.

Figure 5. Assisi hospital entrance



Figure 6

Newly identified HIV infected persons at Assisi hospital, 2002–10



After 2005 the annual number of newly identified HIV infected persons dropped (Figure 6). This may be due to two causes: it may reflect a decline in HIV incidence observed in southern India from 2004/5 onwards, or it may also be a result of improvements in service provision elsewhere.

But despite the fall in new registrations, the centre's workload is declining only slowly (Table 4).

The centre has registered over 8,500 people living with HIV (2011).

The medical college in Guntur was one of the first anti-retroviral therapy centres in Andhra Pradesh (April 2004). Assisi used to send people living with HIV there to start antiretroviral therapy. But then the doctors in Guntur asked Assisi not to send any more patients as they did not have enough medicine.

**Table 4**

**Patients at the Assisi clinic, 2008–10**

	2008	2009	2010
<b>New patients with HIV registered at the outpatient department</b>			
On antiretroviral therapy	55	64	143
Not on antiretroviral therapy	931	904	493
<b>Patients with HIV re-attending at the outpatient department</b>			
On antiretroviral therapy	3,285	5,526	6,386
Not on antiretroviral therapy	12,829	12,791	9,391
<b>New patients with HIV admitted</b>			
On antiretroviral therapy	65	132	112
Not on antiretroviral therapy	332	321	228
<b>Patients with HIV re-admitted</b>			
On antiretroviral therapy	137	283	469
Not on antiretroviral therapy	226	145	230

The sisters at Assisi realized that antiretroviral therapy had positive effects, and knew there was a long queue of people in need. So they started to look for support, and began antiretroviral therapy on a small scale with 30 patients. The centre negotiated a reduced price for the drugs with pharmaceutical companies in India. Only a few patients could afford to pay for the treatment; others paid part of the cost, while the very poor were treated for free. The number of patients requiring antiretrovirals steadily increased, even after the general hospital in Vijayawada started providing therapy. The capacity at Guntur and Vijayawada was still too low, and many people who had been referred there did not start the therapy. Many of them died as a result.

The Assisi hospital approached Misereor for support, and in 2008 a pilot programme started to provide antiretrovirals to those who could not get therapy from government facilities. It offered therapy for 151 people; it is still treating 130 of them. It also installed a CD4 counter (CD4 cells are the managers of the immune system: if the CD4 count falls below a certain level, it is time to consider antiretroviral treatment).

In the last few years, the larger hospitals' capacity for antiretroviral therapy has increased, and a link antiretroviral therapy centre has been established in Machilipatnam, a small town about 12 kilometres from Assisi. This rise in capacity means that Assisi now refers all new patients to the government centres.

The Misereor-funded programme showed the health authorities that adequate antiretroviral therapy care could

be offered outside highly specialised centres. Although Assisi provides a relatively small number of people with antiretrovirals, the community care centre still plays an important role in the treatment of many. It provides regular counselling and support for people who get their antiretrovirals from Machilipatnam or Vijayawada, and treats opportunistic infections and other HIV-related conditions.

*Figure 7. Sr Dr Prashanti Mary, head of the Assisi Hospital, during a consultation*

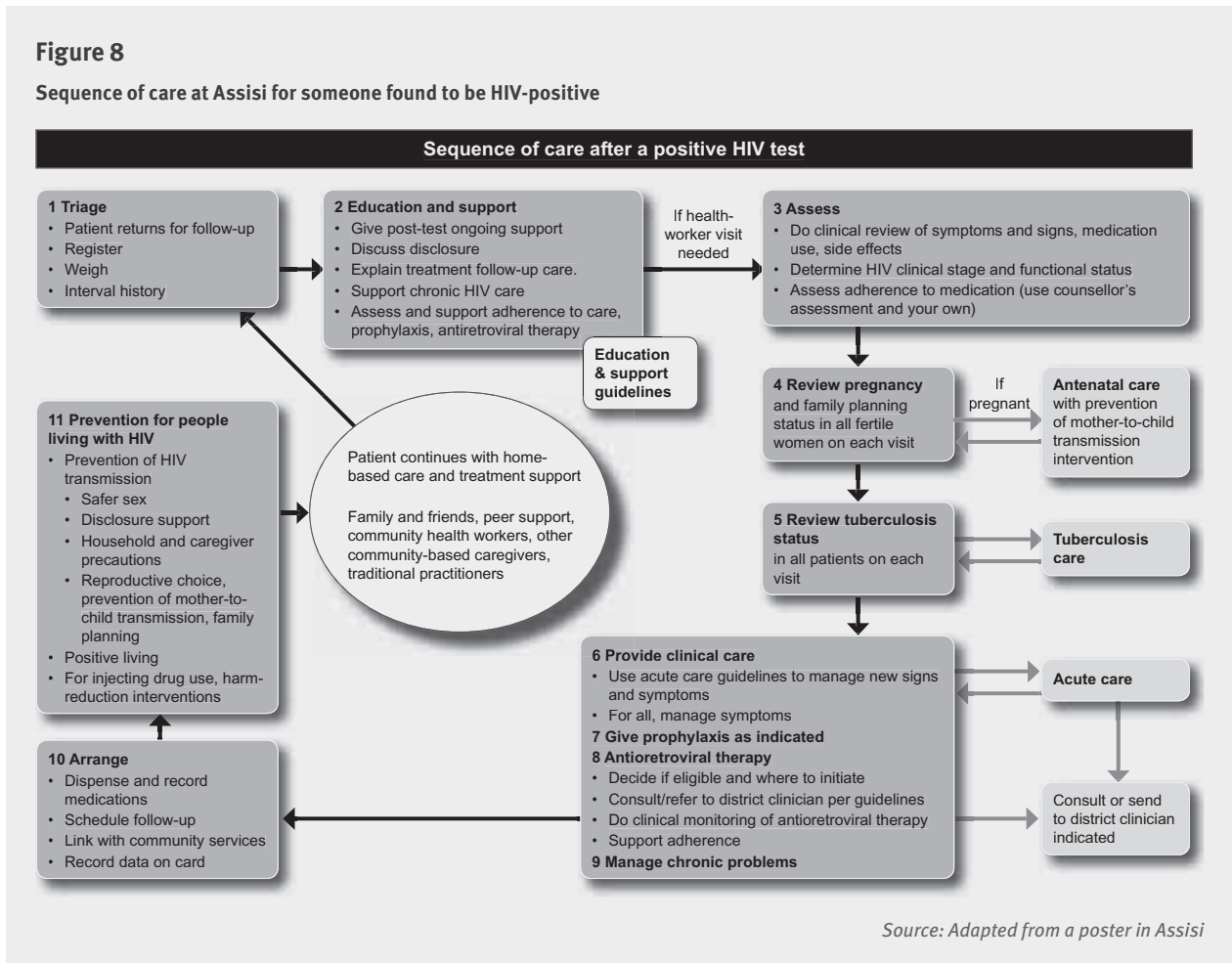


**Services**

Figure 8 shows the procedure followed by the Assisi hospital if someone is found to be HIV-positive.

Assisi offers a combination of medical, psychosocial and welfare support. Before antiretroviral therapy was introduced, the main medical intervention was treating

opportunistic infections. Patients could be admitted for up to 15 days, and sometimes more if necessary. People on antiretroviral therapy suffer less from opportunistic infections.



**Box 2**

**The shock of finding out**

Mr Saya was shocked when he went to donate blood in 2005, and his blood was refused. That was when he discovered that he was HIV-positive. Extremely worried, he continued to work as a sales representative for agricultural products. Then his health got worse, and he had to give up his job.

He went to the hospital in Machilipatnam, where he was diagnosed with tuberculosis. His treatment brought him to Assisi, which he had heard about several years

before when staff had gone around the villages to tell residents about HIV.

Now 32, Mr Saya says that the counselling at Assisi has helped him a lot. After a few sessions he understood his condition better, and finally he told his family about it. They were shocked at first, but now fully accept him. He has told many people that he is HIV-positive. The doctor at Assisi has referred him to the antiretroviral therapy centre.

Mr Saya has visited various HIV facilities in recent years. He says Assisi is by far the best. The staff are always welcoming, he says: the service is very good and he is always supported.

**Box 3**

**Love unites two Assisi outreach workers**

Bhaskara and Richa have known Assisi since 2002. Both say that they would no longer be alive without the hospital.

Bhaskara used to work as an electrician, but stopped in 2002 as he was not feeling well. He went to Machilipatnam Hospital, where a test showed that he was HIV-positive. He was afraid of coming to the Assisi hospital, so went instead to a private health clinic. He lives nearby Assisi and he was afraid that people would know that he was HIV-infected. The private clinic put him on antiretroviral therapy without any further examination, but he had to stop after 3 months because he had no more money.

His village neighbours suspected that he was infected and wanted him to move out. It was all very stressful for his father, who ended in hospital with a stroke. His sister wanted to marry, but could not find a husband because of his condition.

Desperate, Bhaskara decided to end his life. He bought some poison, but before he took it, he went to see the parish priest, who talked with him and contacted the Assisi hospital. There, Bhaskara was put on supportive medication and was offered counselling.

Bhaskara became Assisi's first outreach worker, and later was trained as counsellor. He became very open about his condition. In the village he says: "I am HIV-positive. What is your problem with that?" He says that people living with HIV are now much better accepted than when he found out his status. His family supports

him fully. A few months ago he restarted antiretroviral therapy, and he is feeling fine.

Richa, Bhaskara's wife, is also from nearby. She was trained as a teacher and got married to her first husband when she was 18. She got pregnant, but her husband was sickly and went to Kerala for treatment. She was also not well and in 2002 tested positive for HIV. Her husband died in 2004, and her brother moved her out of the house. In despair, she went to Assisi, where she was welcomed and could stay for some time. She was trained as a counsellor and joined the hospital's prevention of parent-to-child transmission programme.

Richa's family life has changed a lot over the years. Her son is now 10 ten years old and lives with the parents of her late husband. In Assisi she worked with Bhaskara, and they fell in love. They got married in 2008, and have a child. She is now on antiretroviral therapy and her health is fine.

In the years since they heard that they were HIV-positive, many things have changed. In the past, many people committed suicide, but this is rare nowadays. Villagers' attitudes have changed a lot. The work of the Andhra Pradesh State AIDS Control Society is visible, but the Assisi hospital has made a special impact. Due to its support, Bhaskara and Richa now have a future again.





Assisi's outreach activities include home visits, sensitization of the community, awareness creation and formation of support groups to strengthen the position of people living with HIV.

Counselling is one of the Assisi community care centre's main activities. The counselling unit provides counselling as well as psychosocial services to patients and their families. The unit has a well-functioning network with the government and non-government organizations. It is managed by a full-time counsellor and four HIV-positive outreach workers. They are a client-friendly team. All five staff are properly trained and are confident in their work. The unit has standalone premises near the hospital, making it possible for people to come for counselling without having to go into the hospital. It records hundreds of contacts each year. Most counselling sessions are done there, but outreach workers also meet people living with HIV and their families in the community.

The centre keeps a list of HIV-positive people who want to get married. This has resulted in eleven marriages of HIV-positive couples so far. Other organisations have similar initiatives.

#### Box 4

##### Kiran gets hope from counselling

Kiran has come to the Assisi counselling unit for a "friendly visit" and to pick up the preventive medication co-trimoxazole and vitamins.

He found out he was HIV-positive two years ago when he was diagnosed at the government hospital, which referred him to the Assisi counselling unit.

Kiran was very depressed at the time. The first time he came to the Assisi hospital he did not know where to go, and he ended in the dining hall where an awareness and anti-discrimination film was being shown. That gave him some hope. The counsellor explained during his first meeting what HIV was, and he was offered continuous psychosocial counselling. The counselling gave him information, confidence and trust in life again. He finds that the Assisi community care centre explains things in a loving and understanding way, and he says that he can express his doubts openly.

He earns around 10,000 rupees a month by making jewellery: enough to live on. He is 28 years old, and lives with his parents. He has told them that he is HIV-positive, and they support him. Since learning about his HIV status, he has abstained from sex. But he is in good shape, and is looking for an HIV-positive woman to marry.

## Monitoring adherence and counselling

The counsellor checks whether patients come regularly to their appointments, counts their pills to see whether they have taken the medication as prescribed, and discusses the drug intake. If the person has not been adhering to the treatment correctly, the counsellor tries to find out why, then offers advice. If the patients do not come on time to collect their medicines, an outreach worker visits them at home. The government antiretroviral therapy centres also inform Assisi if someone misses an appointment.

## Support

The centre runs self-help groups of infected and affected people. There are 10 such "mutual support groups", each with 10 members. The majority of the members are women; they meet regularly at the Assisi centre because of fear and discrimination in their communities. The members share experiences and discuss their situations and needs: nutrition, hygiene, savings and loans. They appreciate such sharing and come regularly to the meetings.

The centre also provides livelihood support, in particular to widows. A microcredit scheme (a revolving fund) helps them to support themselves and their families.

The centre gives temporary welfare support to poor and needy patients. Children in need can get books, uniforms and other items for their schooling. The hospital's outreach workers provide palliative care to few patients at home. Patients may be in this serious condition if, for example their drugs have not been effective or have serious side-effects. Patients may also need such care if they stop taking the treatment or cannot afford to come to the centres for antiretroviral therapy.

## Outreach workers

The outreach workers are HIV-positive. This is important as they can share their personal experience with the patients and encourage them not to give up. Their outreach work earns them respect in the community and has given them self-confidence.

Assisi has two groups of outreach workers. Two men and two women work in the counselling unit, do home visits, monitor adherence and counsel patients. Another 16 women work in a programme to prevent parent-to-child transmission of the virus. Some have been doing this job for five years. They have been trained by CHAI, the Andhra Pradesh State AIDS Control Society, and other organisations. They tell

people about HIV and AIDS, how the virus is transmitted and how to protect themselves. They also raise awareness on hygiene, nutrition, sexually transmitted infections, and government schemes.

#### Box 5

##### **“I didn’t dare to leave the house”**

“I didn’t dare to leave the house because of shame and fear and the rejection of the community,” says one of Assisi’s outreach workers. “After the continuous counselling at Assisi and with the employment as outreach worker, I can maintain my family and have gained self-confidence.”

Several of her colleagues have similar experiences. Most are widows: their husbands died of AIDS and they have to take care of their children alone. The children of two of the staff stay with their fathers’ parents during the holidays. One widow says her mother-in-law came to see her grandchild for the first time only after 10 years.

One of the outreach workers has no contact with her two children. After her husband’s death, his family took them away. She misses them, but she consoles herself with the thought that she may be ill one day and not be able to care for them.

The in-laws often say that the wife has infected the husband. But the outreach workers say that it is the women who suffer most.

Only one outreach worker said that her late husband’s family wanted her to stay with the children, and that they take good care of her. All the others had to leave their husband’s house and return to their own families. Their parents are supportive. It helps that the women earn income as outreach workers, so do not depend economically on their parents.

Each outreach worker in the prevention of parent-to-child-transmission programme covers several villages with up to 8,000 residents. They collect the data on all pregnant women and tell them about the HIV test and how it can benefit their unborn children. They also assist at antenatal care camps, which are organised by the government hospital.

In this region, a woman traditionally leaves her husband’s house when she is 7 months pregnant. She goes to stay with her parents until 3–4 months after the birth. Assisi links such women to an outreach worker near where she will give birth to ensure regular follow-up.

Usually, an outreach worker accompanies an HIV-positive pregnant woman to a hospital or clinic to make sure that she gets adequate attention and care. It is rare nowadays for doctors or nurses to be unwilling to do a delivery or caesarean, but this often happened in the past. If they

refuse to cooperate, the outreach worker tries to get them to do their job, or goes with the patient to another hospital. The outreach worker may have to help deliver the baby. If the health staff do not give adequate assistance, the outreach worker asks the coordinator of the transmission-prevention programme to intervene. Refusing service can be reported, and along with improved knowledge about HIV, the health staff’s behaviour towards people living with HIV has improved.

The counsellors also motivate pregnant women (especially those who are HIV-positive) to persuade their husbands to come in for testing. If one or both partners are positive, the centre offers individual or joint counselling. It can be a challenge to work with “discordant” couples (where only one partner is HIV-positive).

Approaching patients in their homes can be difficult. The outreach worker may arrive at a house, only to find that the address or phone number is wrong. Some people are afraid that their neighbours will learn their HIV status through the home visits. The outreach workers may have to come up with explanations for their visits: they may say they are from the dermatological centre, or that they work for a loan scheme.

The outreach workers are highly motivated. They want to help others who are in the same situation as themselves. They have a lot of empathy and have gained in confidence and self-esteem. They have learned from their training, the supervision by the project coordinator, and their work experience.

The outreach workers have multifaceted tasks. Two examples:

- Teachers in a school did not want an HIV-positive child

*Outpatients department at Assisi Hospital*





**Box 6****Sacked as a health worker; a new life in HIV outreach**

From 1996 to 2005, Neena worked as a multipurpose health worker in a private hospital. She got married in 2000, but six months later her husband died. The doctor told her that her husband was HIV-positive. Neena was tested and found to be HIV-negative. She did not know what HIV and AIDS were.

She was very active in her work and was popular among her colleagues. But after four years, she had fever and diarrhoea, and she was admitted in the hospital where she worked. Another HIV test showed she was HIV-positive. The hospital administrator asked her to stop the job she liked so much. She went to stay with her parents for two years.

In 2007 she attended a meeting of an HIV-positive network, where she met her new husband. He is also HIV-positive. "I am HIV positive", she says, "and I should avoid that others get infected".

Both families are supportive. Her parents, her brother and sister know that she is HIV-positive but her sister- and brother-in-law do not. "They would not understand, and would not send their children to me," she says.

Since 2007 she has worked as outreach worker for Assisi. She appreciates very much the work the sisters and staff are doing for people living with HIV. In 2007 she started to take antiretroviral therapy. Her husband is also on this therapy.

to attend their classes. The Assisi programme coordinator and two outreach workers went to the school and met them. They explained how HIV is transmitted, and helped them understand the child's rights. The teachers agreed to let the child study along with other children.

- When an employer found out that one of his workers was infected, he terminated his contract. The Assisi sisters and an outreach worker went to see the employer and explained what HIV is. That convinced the employer to reinstate the worker.

**Collaboration with government health institutions**

Close collaboration between Assisi and government health institutions is important. It usually works well, but sometimes challenges are encountered (Box 7).

The work of the hospital head and clinician Sr Dr Prashanti Mary goes beyond treating hospital patients. She also lobbies for patients' rights to treatment and other assistance:

*"Antiretroviral therapy is a wonder drug. It changes the life of people for the better. Less people die and they can go for their work. But this means also that they understand and follow the importance and conditions for a life-long treatment."*

The Assisi hospital's and the community care centre's strength is the comprehensiveness of the care they offer: counselling, life skills, welfare, medical, etc. This total care concept is not found in the government facilities. For instance, if someone fails to turn up for treatment, Assisi starts looking for him or her within two days; the government facilities do so only after 2–3 weeks. Over 95% of Assisi's patients who receive antiretroviral therapy directly from Assisi stick to their antiretroviral therapy (this is known as "adherence"). Assisi also provides additional support and preventive medication such as co-trimoxazole (an antibiotic) and multivitamins and is able to treat some opportunistic infections.

Sr Dr Prashanti Mary says that the Andhra Pradesh State AIDS Control Society does not provide Assisi with enough support for palliative care. She is also worried about the long-run financial sustainability of providing care because of continuous threats to funding in Andhra Pradesh and India as a whole.

**Box 7****Challenging the doctor**

A mother with her four-year-old son comes to the Assisi hospital for a consultation every month. The boy looked much younger and smaller than children of the same age. Nearly every time the boy has an infection: pneumonia, bronchitis, diarrhoea. The mother and her husband are HIV-positive and they take antiretroviral treatment. Two of their children have already died, and the mother is frightened of losing her son. Luckily the fourth child, a girl, is not infected.

Sr Dr Prashanti Mary sent the mother several times to the antiretroviral therapy centre with a letter recommending that the boy start with antiretroviral treatment. "As per the CD4 count the treatment is not necessary" was the doctor's standard reply, not taking into account that laboratory results are not the only criteria for starting therapy: physical signs and symptoms must be considered too.

So Sr Dr Prashanti Mary empowered the mother. On her next visit to the therapy centre, the mother challenged the doctor: she said he would be responsible if her son died. Now the boy is on antiretroviral therapy, and his condition has improved enormously.

## St. Ann’s Snehasadan Community Care Centre

Snehasadan (“Home of Love”) is the community care centre in Nunna, Krishna District, Andhra Pradesh. This centre is run by the Sisters of St. Ann of Luzern. The Nunna Health Centre, as it was formerly known, started about 30 years ago as a centre to train student nurses from St. Ann’s Hospital in Vijayawada in community health. Later it functioned as a small local hospital and sanatorium for tuberculosis patients. The sisters who manage Snehasadan also run St. Ann’s Hospital, a large, private, not-for-profit hospital with approximately 300 beds.

From 1996 onwards, St. Ann’s Hospital noticed a steady increase in the number of terminally ill people with HIV. The hospital found it difficult to give these people continuous care and support on an inpatient basis. Private nursing homes in the region refused to admit these patients, so the congregation decided to convert the Nunna Health Centre into a care and support centre for HIV-related terminally ill patients. The centre was renamed “Snehasadan”. It became operational in February 2002 and has 20 beds available where patients can stay for up to 15 days.

Today, Snehasadan is one of the regional centres collaborating with the National AIDS Control Organisation (NACO). In 2010 it received an award from this national organisation for its performance.



Figure 9. St. Ann’s Snehasadan

Like the other two community care centres described in this chapter, Snehasadan follows the guidelines set by the National AIDS Control Organisation (NACO 2007a). In addition to the services listed in Box 1, Snehasadan also offers:

- Psychological support to people living with HIV, their relatives and friends
- Awareness creation in the community about HIV and AIDS, prevention and treatment

- A women’s empowerment programme
  - Nutrition education
  - Advocacy against stigma and discrimination.
- Snehasadan has a staff of only 11 people, including four Catholic nuns (who work as nurses), a doctor and three outreach workers (who are all HIV-positive). The outpatient department is the busiest part of the centre and is open five days a week.

Staff members were first trained by CHAI with financial support from Misereor, but later the Andhra Pradesh AIDS Control Society took over this responsibility. The Society covers most of the salaries and running costs, and the congregation covers some supplementary costs.

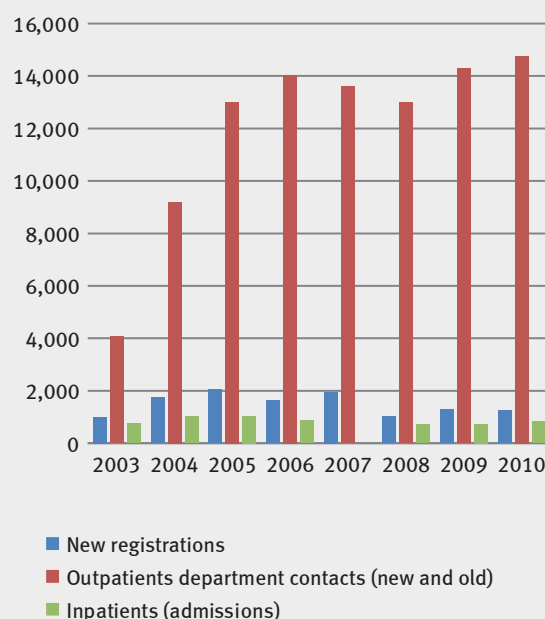
### Workload

Over 12,000 people living with HIV have been registered at Snehasadan. Some have died, and others have moved away, but many come regularly to the centre. Snehasadan currently registers 3–5 new patients a day, and 70 to 90 outpatients visit the centre each day. The number of new registrations has fallen in the last couple of years.

Snehasadan has registered 298 HIV-positive children. So far 38 have started antiretroviral therapy.

Figure 10

Patients at Snehasadan, 2003–10



Many patients who come to Snehasadan are referred by an antiretroviral therapy centre for counselling and follow-up of their medication. Patients who have just started antiretroviral therapy are admitted for at least five days.

### Outreach workers

The antiretroviral therapy centres provide antiretrovirals and follow this up with patients, but Snehasadan also plays an important role by providing additional drugs such as co-trimoxazole, treatment for opportunistic infections, and supportive medication.

Snehasadan traces people who do not continue their medication. The antiretroviral therapy centre sends a list of patients who have not come for follow-up, and a Snehasadan outreach worker visits them at home. The Snehasadan outreach workers name the following as the main reasons for people not attending the antiretroviral therapy centre at the right time:

- At work (patients are scared to ask or cannot get permission to go for medical services)
- No money for transport
- Antiretroviral therapy centre is too far away
- Fear to be seen at the antiretroviral therapy centre (fear of stigmatisation)
- Treatment at a private clinic
- Side-effects of antiretroviral therapy
- No improvement of the health condition despite the medication
- Away from home for prolonged periods of time (e.g., because of work as a lorry driver)
- Migratory work (seasonal workers who leave the area after the end of a contract, or people who look for work elsewhere)
- Rejected or abandoned by the family.

The outreach workers organize awareness campaigns on HIV at the community level, for youth groups in the church, and in schools.

People admitted as inpatients get antiretroviral treatment along with nutritious food. Once they start their antiretroviral therapy, they stay at Snehasadan for at least 5 days, depending on their physical condition. The centre provides very poor patients with food supplements (oil, wheat, dal (dried pulses or lentils), millet and rice) and nutrition support (vitamins, folic acid, vitamin B-complex and calcium). Some of the food items are supplied by Catholic Relief Services (CRS). Local people also provide food items and clothes.

### Counselling

The Snehasadan counsellor started work at the centre in 2005. She recalls that the stigma was high at first. This is slowly declining, she says, but it remains a challenge with every new patient.

Counselling in various forms is an important component of Snehasadan's work. It is provided to everyone referred to the centre, and is offered to their partners, family and guardians. Counselling services are also available on demand, as part of Snehasadan's voluntary counselling and testing activity. The centre devotes specific attention to counselling of couples where only one partner is HIV-positive (in the jargon, such couples are known as "discordant"). Such couples are quite common, and counselling them is a challenge. The counselling covers living together, safer sex practices, creating empathy, and not blaming the partner who is HIV-positive. Despite these efforts, the relationship may break.

The National AIDS Control Organisation keeps Snehasadan staff informed about new guidelines for treatment and counselling. The latter includes behaviour-change communication and safer-sex practices. People living with HIV also receive counselling before they start antiretroviral therapy. This includes three or four sessions on the effects of antiretroviral therapy, the importance of drug adherence, the risks of stopping the treatment, and potential side-effects and what to do in case they occur.

Snehasadan links HIV-positive people to networks of others who are living with HIV. These networks may then form support groups. Like the Assisi centre, Snehasadan has drawn up lists of single men and women who are HIV-infected and enable people who are interested to get in touch with one another. A few marriages have already taken place as a result.

The counsellor needs to know about her clients' living circumstances. A good number are long-distance drivers. Often away from home, they engage in sexual relationships when they are on the road, and may drink alcohol. Another group are field workers, who often work seasonally for landlords; others include construction workers, cooks and vendors. Further populations at risk of HIV infection are youth (from injecting drugs), transgendered individuals, men who have sex with men, and women (most of whom get infected through their husbands). If a woman's husband dies, she suffers: she gets poorer but still has to take care of her children. If she rents a house and the owner finds out she is HIV-positive, she may be told to leave. The patients of Snehasadan are often widows with two to three children.

People living with HIV rarely inform their employer about their status because they are scared of losing their jobs. This makes it difficult for them to come during office hours, so counsellors have to be flexible in making appointments.

The counsellor's task depends on keeping various records up to date: the outpatient register and follow-up register, the inpatient register, individual health records, the master register for new patients, a list for pre-antiretroviral therapy referrals (for referring people for CD4 testing), and the outreach register for following up patients who fail to continue their treatment. The counsellor is supported by the three female outreach workers who visit the patients at home and advise them on the importance of taking the medicines.

## Medical service

The medical service at Snehasadan provides the following inpatient and outpatient care:

- Diagnosis and treatment of opportunistic infections
- Monitoring of people before antiretroviral therapy and after they start it
- Maintaining patients records
- Ensuring that infection control practices are in place at the centre
- Ensuring that post-exposure prophylaxis and adherence to standard precautions to prevent cross-contamination and cross-infection are provided.

### Box 8

#### “Now we feel that we are somebody!”

All three of Snehasadan's outreach workers are HIV-positive. “We thought we are dying, but now we feel that we are somebody. We like to inspire other people and we are proud of this institution. After coming here to the centre our life is meaningful,” they say.

Two of the outreach workers started work in 2005 after attending training by the Andhra Pradesh AIDS Control Society in Hyderabad. At the time they worked on preventing parent-to-child transmission. Their third colleague joined them in 2008. Since then their tasks have grown. They now also raise awareness about HIV, AIDS, sexually transmitted infections and tuberculosis in the surrounding villages, among pregnant women, and in schools. They use a behavioural change communication approach in their work with various groups: men and women in the villages, sex workers, truck drivers, and men who have sex with men. They also provide basic counselling. If someone wants voluntary counselling and testing, the outreach workers refer them to the appropriate organisation.

If parents of other children do not accept HIV-positive children in a classroom, the outreach workers go to the school to talk to them. Luckily there are no such problems with the teachers.

The programme has led to visible improvements and less stigma. In the past clients did not want to talk with their partners about their HIV-positive status. This still sometimes happens even now, but counselling of couples and families have improved the situation. People are now more ready to accept a family member with HIV.

The situation of women is still difficult. At the beginning they were afraid to go out of the house. Now, and then, women are blamed as “the one who has brought the virus into the house” – even though it is often their husbands who have infected them. Sometimes the wife is sent

home to her family while the husband's family takes care of him. This is because sons are considered to be more important than daughters (or daughters-in-law). If the husband dies, his family may take the property away from his widow and children. In such cases, the outreach workers intervene and ask the family to stop. If this does not work, they invite a lawyer from a legal centre to intervene.

The outreach workers visit the homes of an average ten clients a day, or 160–170 a month. If they find a client with disease symptoms, they refer them to the appropriate centre. They sometimes accompany a client to the centre for a check-up. During a home visit to the sick, the outreach workers explain safety precautions and how to take care of patients, how to maintain hygiene (e.g., disposing of rubbish) and how to handle cuts and wounds of someone who is HIV-positive.

The outreach workers face various challenges. They are given the patients' addresses by the antiretroviral therapy centres. But some people do not like being visited at home, as they do not want their families to know they are HIV-positive. They deny being the person in question. So for the first contact, the outreach worker might say that an insurance company has sent her. Only after she finds the right person she gives the real reason of the visit.

The outreach workers put their clients in touch with support groups, organisations that offer loans to people living with HIV, or groups that provide nutritional support and medicines.

“We were not aware of many things and now we know more,” say the outreach workers. They use their small salaries to educate their children. “Our children have a better future now,” they say.



The **outpatient service** receives an average of 5–7 old and new patients per day. Each one is registered and a health record for him or her is created. Every 6 months, the patients are referred to the government hospital to check their CD4 counts. They also are provided with supplementary vitamins and folic acid.

Antiretroviral therapy has led to fewer people dying of AIDS.

The **inpatient service** has around 15 to 20 patients per month, and its beds are practically always full.

When someone starts antiretroviral therapy, he or she stays in a community care centre for at least 5 days of inpatient care, in accordance with the National AIDS Control Organisation guidelines. The centre does the following:

- It verifies the patient's address
- It monitors any side-effects and the patient's tolerance to the therapy, and stabilizes any opportunistic infections
- It counsels the patient on continuing to take the drugs (adherence)
- It provides counselling to families on accepting the patient

#### Box 9

##### And what about our children?

Sunita (28) and Amar (33) have been married for 10 years. They have two children: a 10-year-old boy and an 8-year-old girl. They live 70 km from the Snehasadan centre.

Amar completed 10th class in school, while Sunita is illiterate. They both worked as coolies until they got sick. But now they have no work, and no property. They live with Sunita's parents. Their immediate family has accepted the fact that they are HIV-positive. The grandparents take care of the children. Sunita and Amar feel ashamed because of the HIV infection, and they keep it a secret. They have not informed the villagers about their condition because they are afraid of being rejected.

Four years ago they fell ill. They went to the hospital and were tested for HIV. They were both HIV-positive. Neither had heard about HIV or AIDS before, so they knew nothing about it.

Now they are on antiretroviral therapy. Both come to the centre regularly. Amar is currently in hospital because he is dizzy and nauseous: side-effects from the drugs he is taking.

The couple say they are treated well and are taken care of at the centre. They share their experiences with people in a similar condition who are also staying there. Their main concern is the future of their children.

- It prepares for home visits after the patient is discharged.

Some patients come to Snehasadan because of opportunistic infections and secondary effects of the treatment – for example if they have fever, diarrhoea or dizziness. They may also come for observation when the medication has been changed at the antiretroviral treatment centre. Most patients come with their spouse, mother or guardian. The National AIDS Control Organisation supports the hospitalization costs. Local and international non-governmental organisations and the Congregation of St. Ann of Luzern (the order to which the nuns belong) cover the costs of food.

#### Box 10

##### Feeling at ease

Seven years ago, Sunil (now 42) and his wife got tested for HIV at a private hospital. Both tested positive. They paid INR 3,000 for the tests, but could not afford to pay for treatment. So they went to a public hospital for help.

Both developed AIDS, and have been on treatment for the last 2 years. They were ashamed at first. The antiretroviral therapy centre gave them treatment and sent them to Snehasadan. There, they get periodic care and counselling. They knew little about the disease before, but have learned what they know from the counsellor and other staff.

Only one other person knows about their status and helps them. Afraid of discrimination, they hide their status in the community. Neither has any work at the moment, so a brother supports them. Their two adolescent children are staying with them.

The couple say that the antiretroviral therapy centre not only gives them the medicines; Snehasadan provides counselling, care and food. Snehasadan is a “friendly institution”, says Sunil, and he feels at ease there.

*Outreach workers updating files*



**Box 11****Rejected by her husband's family**

Tulasi is a female outreach worker. Born in 1969, she has two brothers and a sister. Her father was a labourer; he has died, and the family is poor.

Tulasi failed her final school exams at the age of 18. She stayed at home for a year, then got married in 1991 to a truck driver. The couple had two children: a girl (now aged 18) and a boy (16). Her husband was tested HIV-positive in 2003, and he died at Snehasadan in 2006.

In 2004, after her husband was found to be HIV-positive, Tulasi also tested positive. She felt well at the time and had no complaints. She was tested in the general hospital in Vijayawada, but her follow-up counselling was done in Snehasadan.

After the couple found out their HIV status, they informed their families. Her own family reacted with understanding, but her husband's relatives rejected her. Since her husband died, they have shown no interest in her or her children's wellbeing.

Physically, Tulasi is doing very well. She has a high (i.e., normal) CD4 count, and has no complaints at all. Her children know her status and have no problem with it.

Snehasadan has played an important role in her life. She feels at home here. She appreciates what the centre has meant for her husband. She joined the centre's prevention of parent-to-child transmission programme in 2005. Now she works as an outreach worker. Her income is not very high, but the sisters also support her children's education. Both are doing very well at school.

Although health-wise she is doing well, she fears that she will not be able to help her children through their education.

many of whom had been rejected by their families and the community. Care, medical and otherwise, was hard to find.

So the congregation of the Presentation Sisters of the Blessed Virgin Mary decided to open a community care centre for people living with HIV to offer good-quality care and rehabilitation. Jeevan Jyothi Hospice started in August 2003 with 24 beds and a unit for up to 12 children. It now has 42 beds and functions as a small local hospital. Local people can come as outpatients, and for people living with HIV it functions as a community care centre. The idea of a hospice – i.e., a place for the terminally ill to get palliative care and support during their last days of life – has been replaced largely by the community care centre concept.

The director, Sr Anastasia was one of the first people to be trained in AIDS management by CHAI. At that time the work was mainly home-based care. By 2004, the Tamil Nadu State AIDS Control Society provided funds for the beds as well as staff salaries, nutrition, medicines and patients' travel costs. Jeevan Jyothi has affiliated programmes to support orphans and vulnerable children, as well as outreach for people living with HIV. Awareness on HIV and AIDS is raised among adults and young people in different parts of the city of Theni and the surrounding district.

Jeevan Jyothi has 35 staff, some of whom are HIV-positive.

The community health project, and later Jeevan Jyothi, both received assistance from Misereor. This support was mainly for outreach work, to treat opportunistic infections, to bring patients to and from the antiretroviral therapy centre, and to pay for supporting drugs such as co-trimoxazole.

## Jeevan Jyothi Hospice

Jeevan Jyothi Hospice is a community care centre in the south of Tamil Nadu, near the town of Theni. The Presentation Sisters of the Blessed Virgin Mary founded the Holy Redeemer Hospital in 1933 in Theni. This hospital has grown over the years to a facility with 85 beds and well-equipped maternity, medical and paediatric departments.

In 1985, the hospital opened a community health unit. The staff of this unit went into local slums and rural areas to serve people there. At first they concentrated on prevention, health promotion and social mobilisation, for example through women's self-help groups. But they started to see more and more people living with HIV in the community,

Figure 11. Jeevan Jyothi Hospice





## Collaboration

Jeevan Jyothi works with various organisations. Someone generally gets tested for HIV at the government-run medical college or at other institutions such as the 16 integrated counselling and testing centres in Theni. These refer anyone found to be HIV-positive to the antiretroviral therapy centre, and from there they are referred to Jeevan Jyothi for counselling. Sometimes field workers or other people living with HIV identify new patients.

The Tamil Nadu State AIDS Control Society requires that cases be reported using no less than 10 registers. There is even a register on the number and type of counselling sessions. The Society says that of all the centres, Jeevan Jyothi is the best in terms of reporting: it has twice been awarded an A grade. This is one reason the Society supports the running costs of 20 beds at Jeevan Jyothi.

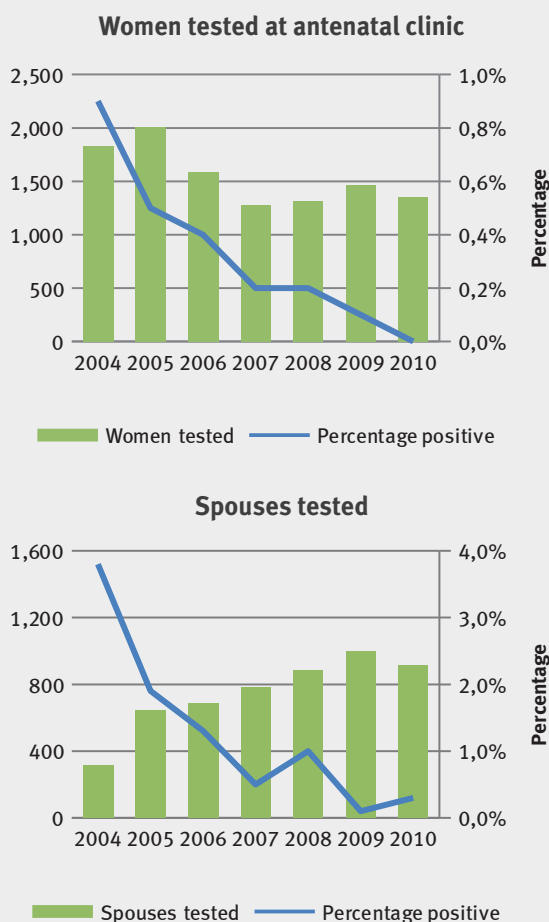
The state government does not recognise Jeevan Jyothi as an integrated counselling and testing centre. But its parent institution, the Holy Redeemer Hospital in Theni, is recognised as such. HIV tests done at the hospital show that the incidence and prevalence of HIV infection is decreasing.

Among pregnant women who visited the hospital's antenatal clinic, for example, 17 out of 1,834 (0.9%) tested positive in 2004, while in 2010 none did so (Figure 12). In the same period, the percentage of spouses who were HIV-positive fell from 3.8% in 2004 to 0.3% in 2010. It can be difficult to persuade a woman's husband or partner to have a test done, but things are improving: in 2004, only 315 spouses came in for testing, while in 2010, 915 did so.

The centre also tests patients referred by the hospital, as

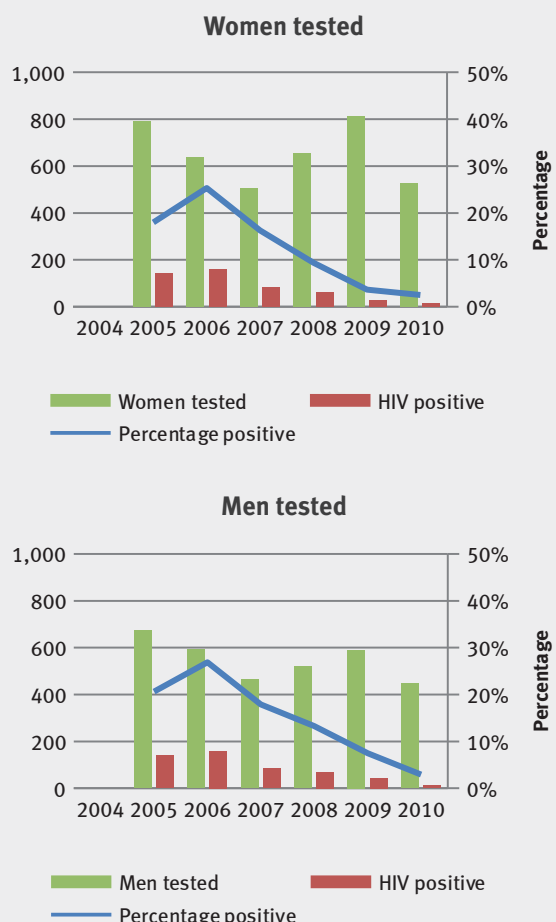
**Figure 12**

Results of testing pregnant women and their spouses attending the antenatal clinic, Holy Redeemer Hospital, Theni, 2004-11



**Figure 13**

Results of testing people coming for voluntary testing at the Integrated Testing and Counselling Centre, Holy Redeemer Hospital, Theni, 2004-11



well as individuals who come forward spontaneously. This data here are not representative of the general public, but the decline in prevalence of the years is striking (Figure 13).

While one cannot draw definite conclusions from these data, they suggest that the number of new cases of HIV infection is going down rapidly in the area. The managers of the Jeevan Jyothi centre say the same thing: the centre's workload is not yet decreasing, but most of the people come for antiretroviral therapy supervision, and fewer new patients are seen. The number of cases with opportunistic infections is also going down.

## Counselling

Jeevan Jyothi's trained male counsellor provides counselling to adults on all prevention measures, including information on safer sex. He has about 12 to 15 counselling sessions per day. The clients are satisfied, reflecting the quality of the counselling. The counsellor looks closely at each client's circumstances and his or her level of understanding, and advises them accordingly. Proper attention, the right tone, and the way to make people understand are important. It is necessary to assess the clients' knowledge first even if they have come from another specialised centre. The counsellor then structures the session according to what the client knows and needs.

There are different types and steps of counselling: covering basic counselling, dealing with other issues desired by the clients, handling administrative matters (settlement of bills etc.), counselling concerning stigma and discrimination, and referring the client to governmental or non-governmental institutions for support. The counsellor also refers clients to the HIV-positive network. Legal problems crop up, including land and property problems, stigma and discrimination. Property conflicts may occur if the husband dies and his relatives send his widow back to her family. Sometimes the woman is referred to a legal aid

*Inpatients at Theni Community Care Centre*



unit or a lawyer to get her property back. The counsellor also assists clients to get supportive measures such as a widow's pension and food rations for the family, or training on how to save money.

The counsellor says that the most important thing is to build the clients' self-confidence. However:

*"Sometimes, even I get depressed and in the night I think of clients and how I can help them. All the energy goes to them so I cannot talk much when I am out of the office."*

Despite these strains, the counsellor says he is satisfied in his work to help others to live in spite of the hardship they are going through.

More and more of Jeevan Jyothi's clients are on anti-retroviral therapy. But not everyone adheres properly to the treatment. There are different reasons for this: forgetfulness, heavy workload, a false sense of security due to a lack of symptoms, alcohol consumption, the feeling that others are dying despite medication, the side-effects of the drugs, or the lack anyone in the family to supervise taking the drugs.

### Box 12

#### What will the neighbours say?

The Jeevan Jyothi outreach workers say their task can be a challenge. At first, people living with HIV do not want to be visited at home. They fear that their neighbours may come to know their status. They are afraid that people will think their children are also HIV-positive, so will not be able to find someone to marry. And there are other risks: one HIV-positive couple took a bus to the centre. The driver told their landlord where they had been. The owner told them to get out of the house.

The outreach workers may have to visit new clients several times to convince them that home visits are necessary. They tell the neighbours (and clients) that they come for a social welfare scheme, a bank or for loan, or they say they are relatives. Caution is vital: neighbours are very curious and observant. After the outreach worker has established the clients' trust and confidence, they take them to see other people who are also HIV-positive for mutual support. Villagers often know if someone is HIV-positive, but they generally do not spread such information. At the same time, the person with HIV may think nobody knows. Even nowadays people are rarely open about their status.

Experiences differ. One female outreach worker has been on antiretroviral therapy for 4 years and is open about this. Her neighbours know her status, and she mixes freely with other people.

Before someone starts on antiretrovirals, several counselling sessions are necessary to prepare him or her to take the medication regularly and on time. Someone else – perhaps the person’s mother or another relative – should also come for counselling. This preparation takes time, but reduces the risk of the person stopping the treatment.

## Outreach work

The outreach workers support the counsellor; they visit patients at home and count the pills, etc. to see if the patients take their medicines properly. The outreach workers are HIV-positive themselves, and this work enhances their self-confidence.

## Inpatients

People living with HIV are admitted to the Jeevan Jyothi centre for treatment of opportunistic infections, and for observation when they start taking antiretroviral therapy. More or less equal numbers of women and men are admitted. The antiretroviral drugs are prescribed by an antiretroviral therapy centre, but patients can get them from Jeevan Jyothi while they are admitted there. After a few days of treatment, they usually feel better. Patients stay for at least 5 days when they first go on the antiretroviral therapy; some stay up to a month, though the government pays for only 5–6 days.

After they are discharged, the patients often come back (or telephone) for counselling or medication.

At first sight, it seems that the workload of the centre changed little in the last 5 years (Table 5). But the number of patients who have died at the centre has fallen, and fewer children are now found to be HIV-positive. On average, 10 inpatients a month are treated for tuberculosis, with the treatment paid for by the government.

### Box 13

#### “Nowadays most know that it is possible to stay alive”

“In the beginning, people thought that we are also HIV-positive because we work here,” says one of the nurses at Jeevan Jyothi. “But now they know that this is not necessarily the case. It was difficult because nobody was interested to marry someone of the personnel. In the past people feared but now they think it is important to help the society and the awareness is also better nowadays.”

“Even five years ago, patients were scared to come to the centre because they feared that they would die here. Nowadays most know that it is possible to stay alive. The others still think of dying if they would come here. Earlier it was somehow a secret disease and people have committed suicide. But now people are more open even in the place they live. A lot of lives have been saved compared to five years back. People living with HIV have hope and think of marriage. In such cases we refer them to the positive network which has a list of people living with HIV willing to marry.”

“Continuously fewer patients come with very low CD4 counts, such as 30 or 40.”

**Table 5**

Patients with HIV at Jeevan Jyothi (2006–11)

	2006/7	2007/8	2008/9	2009/10 <sup>1</sup>	2010/11 <sup>1</sup>
New people living with HIV identified	492	511	522	528	450
New patients with HIV admitted	410	438	416	424	257
Patients with HIV readmitted	393	345	354	482	394
Deaths among people admitted	70	57	32	47	29
Deaths at home	60	50	64	81	53
Infected children	82	49	66	49	11
Children admitted	35	45	46	45	25
Deaths among children	3	3	4	4	3

<sup>1</sup>April–December 2010 (9 month) only

**Box 14**

**Three HIV patients, three problems**

One patient at Jeevan Jyothi is bleeding continuously. She needs an operation urgently. She came to the centre because a hospital did not admit her: the doctors there feared for their own safety if they operated on her. The centre staff are trying to find a gynaecologist who is willing to do the operation.

A woman in intensive care unit is terminally ill. She was on antiretroviral therapy, and six months ago she had a CD4 cell count of 720, which is almost normal.

But of unclear reasons she was still afraid, and she stopped taking the medicines. Now it is too late: Further treatment is no longer effective.

A third patient was admitted with her 2-month-old baby, which has rashes and may be HIV-positive. Her family has rejected her because she married someone from a different caste. Without their support, she wanted to give her baby away.

**Box 15**

**Jeson and the tea shop**

Jeson and his wife, both of whom are HIV-positive, run a small tea shop in their small village. He comes from a poor family: his father also used to run a tea shop, and Jeson was the only child and never went to school. He started work when he was 10, and got married when he was 18. Now 45 years old, he and his wife have two sons, aged 18 and 16.

Jeson used to work on a coconut farm: it was a backbreaking job. But several years ago he fell ill and came to stay with a relative in Theni. He got tested, and discovered he was HIV-positive. His wife had a test too: also positive.

His elderly parents have accepted this situation, and they are looking after the couple's two boys. An uncle helped them start the tea shop.

Jeson's wife is on antiretroviral therapy. She is doing well on the medication and is very precise in taking the drugs and coming to appointments on time. Jeson says she is a role model.

But that is also a reason he is not yet on treatment: he feels he cannot be as good as her. He is afraid that the doctor will be angry if he is a day late for his appointment.

Discrimination is not an issue: Jeson talks freely about his HIV status. Most of the neighbours know that the couple are both infected, but he says they do not avoid their tea shop. They are related to many of the villagers, and there is a strong community feeling: a bond that is stronger than the fear of HIV.

Tomorrow Jeson is going to the medical college. After a lot of pressure from his wife, he has finally found the courage to go there. He says his wife will help to keep taking the antiretroviral drugs if he needs to take them.

Antiretroviral treatment has changed the lives of people living with HIV. But other things are just as important: psychosocial support, counselling, support by family members and friends, the will to live, and sufficient nutritious food. A comprehensive treatment addresses all these components.

**Box 16**

**How Jeevan Jyothi is helping Padma**

Padma worked for many years as an assistant nurse in a private health practice. She got married in 1998, and has a 12-year-old daughter. In 2001, her husband had a fever and died. He had tested positive for HIV, but the hospital refused to treat him: the nurses were afraid of contracting HIV themselves.

After her husband died, Padma moved in with his parents (both her own parents had already passed away). That was not easy. Her father-in-law is still upset about his son's death, but luckily does not blame her. The relationship between Padma and her in-laws is slowly improving, partly because her daughter is their only grandchild.

About a year ago she became ill. She lost a lot of weight and was coughing a lot. She was put on antiretroviral therapy, but this was stopped when it was discovered that she also had tuberculosis. She is not very well, and she hopes that the antiretroviral therapy can be started soon again as it was improving her condition.

Padma speaks very positively about Jeevan Jyothi. People in Madurai (about 70 km away) advised her to come there. Before that, she had spent a lot of money on all kinds of treatments. But at Jeevan Jyothi she finds good treatment, good food and a lot of support. She does not see the centre as a place for people living with HIV only; everybody is welcome.

## Support groups

Several support groups are attached to the Jeevan Jyothi centre. A member of one of these, a woman in her mid-30s, says that her husband died of AIDS some time back. They were of different castes and had married without their families' consent. Neither family supports her and her three children now, so she has to manage by herself.

The support groups have various objectives: savings, bringing people together, enabling them to share problems and find solutions, and learning from each other. The members gain confidence, and being together helps them overcome difficulties. Sometimes their families discourage them, saying "Your life is at risk. Why do you struggle such a lot for your children?" But the main aim of the group members is for their children to grow up in the same way as other children.

## Collaboration with government health institutions

The local antiretroviral therapy centre (the medical college in Theni) works with 16 non-governmental organisations, including Jeevan Jyothi and another community care centre.

### Box 17

#### An antiretroviral therapy support group

This group meets once a month. Almost all the members are working. The Jeevan Jyothi staff members tell them about nutritious food, hygiene, and the importance of regular medical check-ups, treatment and taking their tablets on time. The members encourage each other to take their medicine promptly. Their children also sometimes remind them to do so.

One man said he was ill for a long time and went to various doctors. He spent nearly INR 200,000 (€5,000) on consultations. Finally he got tested for HIV in a government hospital. He has been on antiretroviral therapy for the last 3 years. He cannot talk with his boss about the infection because he is afraid he will get the sack.

Nevertheless, things have improved. Ten years ago, people were afraid even to touch the body of a person who might have died of an HIV-related disease.

Another man said he would like to be a member of an HIV/AIDS support group, but he has no time to come to the meetings because of his job. His boss simply would not understand or give him time off.

Among all the community care centres in Tamil Nadu, Jeevan Jyothi has twice received an "A" classification – the highest possible.

### Box 18

#### Doctors' praise

The medical college in Theni, one of the 42 antiretroviral therapy centres in Tamil Nadu, starts people off on antiretroviral treatment. It also monitors the patients. The patients choose which of the two community care centres they would like to go to. They are admitted for 14 days to observe any reactions to the antiretroviral drugs: this is a requirement in the Tamil Nadu State AIDS Control Society guidelines. The college handles any serious cases itself.

The college's antiretroviral therapy centre had registered 6,124 HIV-infected individuals in March 2011; of these, 1,889 had started taking antiretrovirals. Thirty patients were eligible for second-line therapy, which is available only at centres of excellence. Four of the college's patients were receiving this treatment in such a centre in Chennai, the state capital. The patients have to stay there for 6 months for observation, but many eligible people cannot leave their families and homes for such a long period.

Every day an outreach worker from Jeevan Jyothi accompanies patients to the medical college to visit the doctor there. Partly as a result of this assistance, over 90% of the Jeevan Jyothi patients stick to their therapy. The staff check the adherence by counting the number of pills they have left, and listening to what the patients say. If someone misses an appointment, the college staff call them two days later to remind them. If the patient still does not arrive, the community care centre is informed and an outreach worker goes to visit them at home. In some cases, family members are allowed to collect the drugs, but the patient him- or herself has to come at least every 2 months. The college has trained outreach workers how to manage opportunistic infections.

The doctors realise that there are problems in the collaboration between the two types of centres, the antiretroviral therapy centre and community care centre. But, says one, "I am very proud to say that we have a good collaboration with Jeevan Jyothi and the other community care centre."



## Conclusions

In this publication we follow the UNAIDS concept of “best practices” (UNAIDS 2000):

*“For UNAIDS, Best Practice means accumulating and applying knowledge about what is working and not working in different situations and contexts. In other words, it is both the lessons learned and the continuing process of learning, feedback, reflection, and analysis (what works, how and why, and so forth).”*

Our analysis of the three community care centres has identified some key aspects for success. We discuss these below.

### Strategies

The three community care centres follow a strategy that is based on a holistic rights-based approach to health, community participation and involvement of people living with HIV. All three centres cooperate closely with the Catholic Health Association of India (CHAI) and the State AIDS Control Societies. They follow national and regional guidelines and policies, but also take into account the centres’ own principles and backgrounds. They ensure quality by employing well-trained staff and exposing them to contin-

uous training and supervision. Although the basic idea is to provide health care to people living with HIV, they also incorporate intersectoral links, such as to legal services or education. Finally, the three centres serve anyone living with HIV, without discriminating on the basis of gender, religion, caste, ethnic background or sexual orientation.

### Achievements

The three centres provide high-quality comprehensive HIV prevention, treatment, care and support in a non-discriminatory way. This achievement is the result of the wide-ranging strategies they have adopted (see above). The centres have adjusted their activities over time: the introduction of antiretroviral therapy has changed the scope of their work. All three counsel people to continue their therapy (this is called “adherence counselling”), provide home visits, and support those on therapy. This has led to very good adherence rates: over 95% in the case of the Assisi centre. The three centres provide HIV preventive measures in and outside the facility.

The centres’ strategy makes patients feel at ease, and they have great trust in the centres. The patients know that

*Pharmacy at St. Ann’s Snehasadan Community Care Centre*





everything possible is done, and that their confidentiality is safeguarded.

The patients also greatly appreciate the livelihood support that the centres offer both the people living with HIV and their relatives. The centres' work is strengthened by involving not only people living with HIV, but also the community, patient-support groups and other organisations.

Because the three centres are embedded in the government structures (and in the Catholic Health Association of India), their work is recognised. This also forms the basis of their sustainability into the future. The awards that the three centres have received from the government are a sign of appreciation for their work.

The reduction of stigma and discrimination in the local communities is an important development. This is at least partly attributable to the centres' work. The decline in desperation and self-stigma, which used to cause many people to attempt suicide, is largely a result of the centres' intensive counselling and their open and non-discriminative approach.

The three centres' work is ethically and religiously in line with the teaching of the Catholic Church. Their work is also in line with the UNAIDS guidelines.

## Lessons

Faith-based organisations are important contributors to the response to HIV, especially through their unique and close position within communities. Often these communities are among the less privileged, for example in remote rural areas or slums, where public services are scarce. The three centres work for the poor and disadvantaged. Their collaboration with the government improves the sustainability of their work and has led to their recognition.

Memoranda of understanding are a prerequisite that support cooperation among various organizations and ensure that policies and guidelines are implemented. The memoranda regulate activities and make it possible for public and private institutions to share costs.

The three centres employ many people who are living with HIV as counsellors, outreach workers and peer educators. Their meaningful involvement has a big impact. They are highly committed as they see themselves in the same position as the person who seeks or needs assistance. They have empathy with those in difficult situations and are able to share their own experiences. They regain their confidence and self-esteem and know their work is important.

Community participation and community involvement, e.g. through peer education, support groups, and awareness training in schools, contribute to the reduction of stigma and



*Children at Theni Hospital*

discrimination. At the same time the community participation and involvement has led to behaviour change and sharing of information and mutual support has been increased.

By providing services at low cost or for free, the centres ensure they are accessible to the poor and disadvantaged in the society.

The introduction of antiretroviral therapy has dramatically changed the outcome of HIV infection. The need for palliative care is decreasing, but at the same time the need for economic empowerment of people living with HIV and the affected families is becoming more important. The three centres have been able to change their scope of their work. It is important that they continue to network and collaborate with others in this field.

## Challenges

The main challenge for the three centres is sustainability. The centres have adequate infrastructure, but their reliance on external financial support is a risk for their future. Their good collaboration with government structures guarantees their financial sustainability to a certain extent, but not in full, and certainly not on the long run.

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## MISEREOR – The German Catholic Bishops’ Organization for Development Cooperation

Misereor was founded by the German Catholic Bishops’ Conference in 1958 as an overseas development agency “against hunger and disease in the world”. It cooperates with partner organizations in Africa, Asia and Latin America, whose work it supports. Since its foundation, more than 98,000 projects have been funded and carried out.

Misereor’s mandate is:

- to fight the causes of hunger and disease,
- to support the poor in their efforts to lead a life of human dignity,
- to promote justice, freedom, reconciliation and peace in the world.

### The three pillars of Misereor’s work

#### 1. Support for partner organizations in the South

Misereor supports self-help among the poor in order to help improve their living conditions in a sustainable way and to enable the underprivileged to claim their civil, social, cultural and economic rights. Misereor’s partners are organizations working with people in distress, irrespective of ethnic back-ground, gender, creed or nationality.

#### 2. Spiritual renewal

Misereor calls upon Catholics, and everyone else in Germany, to open their eyes to poverty and injustice in this world, to see the world as the poorest of the poor and the oppressed see it, and to empathise with them as Jesus did: “Misereor super turbam” – “I suffer with the people“ (Mk 8:2). The annual Lenten Campaign organized by Misereor

invites Catholic communities and other interested people to help, share with the poor, and undergo a process of spiritual renewal through solidarity and community with the poor. It also calls for a commitment to ensure the responsible development of our own society in order to create “One World” which is more just and where people can live in peace.

#### 3. Lobbying, advocacy and campaigning

Hunger, poverty and injustice cannot be overcome by development cooperation alone. The underlying root causes also have to be addressed. That is why Misereor’s activities include lobbying and advocacy work and campaigning in Germany and at the international level on various topics such as climate change, world trade, debt relief, HIV/AIDS, intellectual property rights, “fair play” in the toy industry, etc.

### Funding

Misereor’s financial resources are threefold:

- donations from German Catholics, in particular through the annual Misereor Lenten Campaign, and other private donations,
- funds allocated from German diocesan budgets through the Association of German Dioceses, and
- public funds provided by the Federal Republic of Germany and the European Union.

For further information, please visit our website [www.misereor.org](http://www.misereor.org).



*Ihre Spende kommt an!*

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