



**If not now, when?**  
HIV, drugs and prevention

# Contents



**Above:** Mourners at Kawama cemetery, Ndola, Zambia. Dozens of funerals are held every day, the burial mounds stretch to the horizon. If current infection rates continue and there is no large-scale treatment programme, up to 60 per cent of today's 15-year-olds in sub-Saharan Africa will not reach their 60th birthday

**Front cover:** Victoria and Jackson in their home in Paarl, South Africa. Both are HIV-positive and want to take antiretrovirals but cannot afford the transport costs to the clinic. Only 440,000 people are currently taking antiretrovirals worldwide, UNAIDS estimates six million need the drug therapy

**Front cover photo:** Don McCullin

<b>Executive summary</b>	<b>1</b>
<b>Chapter 1: Getting worse – the global HIV crisis</b>	<b>3</b>
<b>Chapter 2: The drugs are here already</b>	<b>8</b>
<b>Chapter 3: Turning treatment goals into reality</b>	<b>13</b>
<b>Chapter 4: Overcoming drug resistance</b>	<b>23</b>
<b>Chapter 5: Prevention and care are as essential as treatment in the response to HIV</b>	<b>28</b>
<b>Chapter 6: The battle continues – the future control of HIV</b>	<b>34</b>
<b>Recommendations</b>	<b>37</b>
<b>Notes</b>	<b>38</b>

# If not now, when? HIV, drugs and prevention

The rapid spread of HIV around the world is devastating families and whole communities, and threatening to cripple entire economies. Poverty, war, rape, stigma, discrimination, domestic violence and gender inequity are all driving forces in shaping individual epidemics. Nothing short of a concerted attack on all fronts will avert a major catastrophe.

Sub-Saharan Africa bears the brunt of the HIV pandemic, with 25 million people infected. But Asia and eastern Europe are setting new alarm bells ringing, with fast-growing epidemics that could exact an even greater toll. The time to act is now – to stabilise the epidemics in Africa and avert a major crisis in Asia.

At present, however, there are two contradictory and confusing messages in circulation regarding the HIV pandemic – both encourage inaction. The first is that the crisis is so huge, of such exceptional dimensions, that there is little or nothing that the world can usefully do. The other, more recent, is that with the introduction of antiretroviral therapy (ART) – drugs which control the HIV infection and prevent its progression to AIDS – HIV can be eradicated or at least controlled. Both these assumptions are wrong.

There is some good news. Intensive public awareness and prevention programmes have resulted in a decrease in adult HIV prevalence in some countries in sub-Saharan Africa. Government, business and religious leaders are speaking out about the need for action. The veil of stigma and discrimination, which has seriously hampered attitudes towards HIV in the past, is beginning to lift. And new injections of money are now available to support many different HIV prevention and care interventions.

The provision of ART can, and is, saving lives. But in this highly complex epidemic, drugs alone are not a panacea. At the July 2004 International AIDS Conference in Bangkok, Christian Aid set out its policy on ART in the report *Drugs Alone are not*

*Enough*.<sup>1</sup> Christian Aid unreservedly supports the provision of ART; access to ART is a human right, but while critical for prolonging the life of people living with HIV/AIDS, by itself is an inadequate response.

There are many evidence-based approaches, which have been shown to have a major impact on preventing HIV and caring for people living with HIV/AIDS. But effective action must see all these tools being deployed together. It must include both treatment of those who are infected and a wide range of proven prevention strategies to protect those who are currently uninfected. There must also be support for future research into improving existing efforts and devising new tools against HIV including funding for microbicides and vaccines.

While the current focus on increasing access to ART must continue, equal emphasis must also be given to HIV prevention. The pivotal role that poverty plays in the HIV epidemic must also be acknowledged and practical policies aimed at reducing vulnerability to HIV implemented. These must include changes to trade policy as well as those of debt relief and higher levels of aid provision by donor countries.

The substantial knowledge that already exists across all these areas must now be harnessed and made to work together. The alternative is a world whose poor people become increasingly overwhelmed by the scale and ferocity of the advancing epidemic.

For an ART programme to be truly effective:

- the overwhelming debts owed by low- and middle-income countries to wealthy nations must be cancelled and the public sector spending limits arbitrarily imposed by the International Monetary Fund must be reviewed. Only then will these countries be able to rebuild their health and social infrastructures to cope with the HIV epidemic. Zambia, for instance, has almost one million HIV-positive people but spends 30 per cent more on servicing debt than

on health. Kenya spends US\$0.76 per capita on HIV/AIDS and US\$12.92 per capita on debt repayments<sup>2</sup>

- the role of community-based groups in decision-making and funding for HIV prevention and care programmes must be enhanced. These groups know best what their communities need and how the most effective action can be taken
- a realistic and flexible approach to prevention is required. Focusing on abstinence alone is not effective
- a dramatic increase in the availability of voluntary testing, counselling and education is needed.

**Christian Aid demands that all developed countries honour their commitment, made more than 30 years ago, to contribute at least 0.7 per cent of their gross national product to development assistance. This would be a vital next step towards overcoming the poverty, hunger and inequality that helps to drive HIV epidemics.**

While Christian Aid believes that there is a real and deliverable way of curbing the spread of HIV, an examination of current initiatives shows just how far the world will have to move in both its attitudes and actions if this is to become a reality.

The World Health Organisation, together with other UN agencies and bilateral and multilateral donors, is trying to make antiretroviral drugs freely available to everyone who needs them. The initial aim is to provide ART to three million people (half the number who need them) by the end of 2005. This is known as the '3 by 5' strategy.

**Yet, just one year before the target date, only 440,000 people are receiving antiretrovirals.**

In July 2004, UNAIDS said US\$20 billion would be needed by 2007 for prevention and care in low- and middle-income countries. This would provide antiretroviral therapy to the six million people who

need it, support for 22 million orphans, voluntary HIV testing and counselling for 100 million adults, school-based HIV education for 900 million students and peer counselling for 60 million people not in school.

**The current level of global spending, however, is currently just US\$4.7 billion. In other words, it will require more than a four-fold increase in expenditure over the next two years if this target is to be reached.**

There is even the possibility that the advances that have already been made will be eroded by rich countries protecting their own interests.

The production of cheaper, high-quality generic ART is providing welcome competition to expensive brand-named drugs, helping many countries to get national treatment plans underway. This encouraging situation is severely threatened, however, by trade negotiations now taking place between countries and regions, most notably between the US and many low- and middle-income countries. There is evidence that the hugely powerful pharmaceutical lobby is using these negotiations to apply pressure in order to protect its own profits at the expense of cheap drugs for poor countries.

In order that the rights and interests of poor people and people living with HIV/AIDS are protected and advanced, Christian Aid demands that their voices be heard during any such negotiations. The needs and rights of communities must be taken into account when deciding how to spend money and what action needs to be taken against HIV/AIDS, because they will be the ones most affected by any measures taken against the epidemic.

Without such grassroots support, much of the action planned or taking place will flounder. HIV/AIDS will then continue to flourish and so devour much of the progress made over the past 100 years.

# 1 Getting worse

## The global HIV crisis

AIDS is an extraordinary kind of crisis; it is both an emergency and a long-term development issue. Despite increased funding, political commitment and progress in expanding access to HIV treatment, the AIDS epidemic continues to outpace the global response. No region of the world has been spared. The epidemic remains extremely dynamic, growing and changing character as the virus exploits new opportunities for transmission.<sup>1</sup>

UNAIDS, *Report on the Global AIDS Epidemic*, July 2004

The nightmare of HIV is still with us, and will not go away unless the world acts immediately on many fronts and on a large scale.

Every day, approximately 14,000 new infections occur worldwide, more than half of them among young people aged between 15 and 24. There are now thought to be around 38 million people on the planet infected with HIV and the figures are increasing, according to the latest estimates from UNAIDS.<sup>2</sup> Last year alone, around three million people died of AIDS.

Behind these mind-boggling numbers of the global HIV crisis lie the more revealing statistics of individual epidemics that rage in different countries, each with its own combination of driving forces and future trends. The key to fighting HIV globally is understanding each individual epidemic, seeing who is affected and why, and targeting both prevention and care at those that need it.

HIV infection is caused by the sharing of bodily fluids, including blood, semen and vaginal secretions. It can be prevented by avoiding unsafe sex and contaminated needles – using condoms, clean needles for injecting drug use, and through

screening blood products before transfusion. But once a person is infected, there is no cure. If left unchecked, HIV reproduces and mutates faster than any other known virus, and targets precisely what people need to fight off other infections – the immune system. HIV-infected individuals are thus more prone to infections that cause tuberculosis, herpes, thrush and pneumonia, and to cancers such as Kaposi's sarcoma and lymphoma. These are the symptoms of AIDS (acquired immune deficiency syndrome), which can kill if they go untreated: the more advanced the HIV virus, and the less access an HIV-positive person has to treatment for these conditions, the more likely they are to die.

### **Eating the heart out of Africa**

In sub-Saharan Africa, HIV-related illnesses are the leading cause of death. Up to 25 million people there are living with HIV, and the numbers are increasing. Life expectancy has fallen by more than ten years in many nations, down to just 29 years in the worst affected countries.<sup>3</sup>

The HIV epidemic had its origins in sub-Saharan Africa, and HIV has diversified and spread rapidly over the past five or more decades, aided by rapid

social change, poverty, famine, other diseases, gender inequity, domestic violence, political upheaval, war, rape, stigma and discrimination. The main routes by which HIV spreads are through sex between men and women, and by mothers infecting their infants during pregnancy, birth and breast-feeding.

The HIV epidemics are well established throughout sub-Saharan Africa. South Africa is the worst affected country, with around 5.6 million HIV-infected people, including 100,000 infants. Swaziland now has the highest adult prevalence of infection – at 38 per cent, after Botswana claimed to have reduced its prevalence from 38.8 per cent to 37.5 per cent.

Uganda is unusual in that the numbers of new infections have decreased from around 18 per cent to six per cent of the adult population according to official figures – although these are disputed.<sup>4</sup>

Meanwhile, in other parts of Africa, HIV epidemics are smaller, but threaten to have an increasing impact in the future. Angola, Ethiopia and Nigeria have the onerous label of ‘next-wave countries’, where there is now a critical opportunity to implement prevention methods to avert a looming crisis.<sup>5</sup>

For example, Angola has half a million people living with HIV, and a prevalence rate of less than ten per cent. It does not receive the same level of international funding as other African countries that are worse affected. Ethiopia has three million HIV-infected individuals, with the mostly rural population being threatened by a dramatic rise in infections in the future, from a current prevalence rate of around 3.7 per cent.

In Nigeria, the adult prevalence rate is between 3.6 and 5.4 per cent, which represents up to five million people living with HIV. The country’s population is set to double in the next 25 years,<sup>6</sup> and the number of children already orphaned is between a staggering one million<sup>7</sup> and 2.6 million,<sup>8</sup> and expected to rise.

### **The orphan crisis**

Alarmingly, there are now around 12 million orphans in sub-Saharan Africa who have lost one or both parents to HIV, and this number is expected to rise to 18 million over the next six years. Orphans face a higher risk of malnutrition and death, are less likely to receive an education, and more likely to suffer violence, sexual abuse, and to become vulnerable themselves to HIV infection – if they are not already HIV-positive – than children whose parents are still alive.<sup>9</sup>

### **The burden of debt repayments and structural adjustment**

Many African countries are so beset by economic difficulties – caused largely by the continuing burden of debt repayment to foreign donors – that they cannot afford to build up the health, education, welfare and administration services that are so critical to fighting HIV. Many of the countries worst affected by HIV, including Zambia, Cameroon, Malawi and Kenya, spend more on debt repayments than they receive in foreign aid, and more than they devote to healthcare.<sup>10</sup> Together with the legacy of structural adjustment programmes that imposed caps on public sector spending, the result is the continuing failure to build healthcare services and other infrastructures that are essential for mounting and sustaining an attack on HIV.

Christian Aid strongly believes that wealthy countries should cancel the debts owed by poorer nations. This would allow them to improve health and education systems, and make a significant impact on HIV.

### **Social upheaval and sexual behaviour**

The movement of both men and women from poverty-stricken rural communities to cities in search of employment is a major driving force behind the increasing HIV-infection rates in Africa. Without the traditional support of family and community, relocating and migrating workers are more likely to engage in higher-risk sexual behaviour; in particular, having more than one



Don McQuinn

Mavis, ten, with her grandmother, Margaret, 62. Mavis and her brother Aaron, 13, live in Ndola, Zambia and have lost both their parents to HIV. 'We miss our mother,' Aaron recalls. 'When she was ill, we swept the house, washed the clothes and fetched water. We liked looking after her because she was our mother.' The children still cry at night. Aaron and Mavis now live with their grandparents, Margaret and Ofeshi, 69. 'We are happy, praise the Lord,' says Margaret. 'We lost our only son and now we have the grandchildren to replace him'

sexual partner, buying and selling sex, and failing to use condoms. There is also a tendency for some men and women in Africa to have two or three concurrent sexual relationships with different partners over a period of months or even years, rather than serially monogamous relationships.<sup>11</sup>

### **Political upheaval, war and rape**

The wars that have torn apart whole societies in the Democratic Republic of Congo, Angola, Sierra Leone, Rwanda and Uganda have created conditions ripe for the spread of HIV. In Gulu, northern Uganda, for example, three-quarters of the population have abandoned their homes and livelihoods as a result of 18 years of conflict between the government and the Lord's Resistance Army. Many children have been abducted either to fight or to become sex slaves, and more than 1.6 million people now live in refugee camps. The prevalence of HIV infection is almost 12 per cent – double the official national average. The government army, the Ugandan People's Defence Force (UPDF), also plays a role in spreading HIV.

'The camps where most of our people live are a big mistake. They are the basis for the virus to spread. There is no work and the only people with money are the soldiers,' says Richard Opio of Christian Aid partner organisation ACET, based in Kitgum, Uganda. He adds: 'The worst are the UPDF mobile units. When they come to town they pay a lot – it is open day for sex.'<sup>12</sup>

### **Gender inequity, domestic violence, stigma and discrimination**

Women are especially vulnerable to HIV infection through sexual coercion – particularly of young girls by older men – domestic violence and rape.<sup>13</sup> At the same time, women are more likely than men to suffer from the consequences of HIV in their families; they usually care for the sick, and face the stigma and discrimination of being HIV-positive – being ostracised by family and friends, and deprived of property, work and power. HIV-infected

children, particularly orphans, are also highly vulnerable to discrimination.<sup>14</sup>

War only serves to amplify the suffering of women and children, as seen in the rape survivors of Rwanda, who experience not only stigmatisation, discrimination and poverty, but also have little access to basic healthcare and antiretroviral drugs.<sup>15</sup>

### **Asia's time bomb**

Asia is at a crossroads. The total number of people affected by HIV – around seven million – is less than in Africa, but has the potential to increase massively in future unless dramatic and rapid prevention measures take place. While the impact is being felt as acutely as in Africa for individual families and communities in Asia, experts predict that the worst is yet to come.<sup>16</sup>

The slowly evolving epidemics of Asia are very dangerous, because they will grow steadily and silently unless we do a better job of monitoring them and convincing decision-makers to address them effectively.<sup>17</sup>

While many of the same driving forces exist in Asia – political instability, social upheaval, poverty, social and gender inequity, stigma and discrimination, and sex with multiple partners – other lifestyle elements are important, particularly the buying and selling of sex, sex between men, and injecting drug use.

The impact of HIV on individual countries in Asia depends on both population size and the prevalence of infection. Cambodia, for example, has the highest prevalence of HIV infection in Asia – 2.6 per cent of the population are HIV-positive – but the overall number of affected adults and children is lower than in some other countries, at around 170,000. However, in India, where HIV prevalence is estimated at between 0.4 and 1.3 per cent, a population of more than one billion means that the overall number of HIV-positive people could be anywhere between 2.2 and 7.6 million, placing India on a par with South Africa.

The extent of poverty, gender imbalance, denial, stigma and discrimination that continues to pervade Indian society, however, means that the Indian epidemic could rapidly escalate, to what experts fear may be as many as 20 million by 2010. HIV is already spreading through the wider population in India – beyond those engaging in high-risk behaviours such as buying and selling sex, injecting drug use and sex between men – to women and children.<sup>18</sup>

India and other Asian countries are also noticing the impact of HIV because of increasing numbers of orphans.<sup>19</sup>

‘We are starting to see AIDS orphans...’ says Arogya Agam, a staff member of a Christian Aid partner in Tamil Nadu. ‘I was in a village just yesterday where a friend had asked me to look at an orphaned boy of seven years old. He was living with his old aunt. She lives in extreme poverty. The boy’s father had died of AIDS and the mother had been discriminated against and committed suicide, leaving the boy. The village people made me take the boy – who is sitting next to me here now eating a large quantity of rice.’<sup>20</sup>

Equally disturbing predictions hang over China’s future, where currently around 850,000 people are living with HIV. The Chinese government is now being congratulated on paying greater attention to the HIV crisis, and launching public awareness and education campaigns. Critics maintain however, that Chinese officials are still ignoring the plight of many of those already affected, particularly in rural communities, and failing to recognise the extent of high-risk behaviour that contributes to the epidemic, such as injecting drug use and sex between men.<sup>21</sup>

### **Overlapping risk behaviours**

Concern over the future of HIV in Asia also stems from the presence of overlapping risk behaviours in the same individuals. In Vietnam, for example, sex workers are also engaged in a significant level of injecting drug use. Such overlap helps to explain why a recent steep rise in HIV infection among sex

workers and their clients followed soon after a rise among injecting drug users in parts of China, Nepal, Vietnam and Indonesia.<sup>22</sup>

If such activities continue in the absence of preventive measures, such as the use of clean needles for injecting drug users and condom use, then HIV is likely to spread further among the regular sex partners, wives and children of those engaging in high-risk activities. This is already occurring in India, Vietnam and Burma.

‘When we ignore prevention among vulnerable groups we open the door for the virus to spread to women and their children,’ said Unicef director Carol Bellamy at the International AIDS Conference in Bangkok, in July 2004.

### **Eastern Europe and central Asia**

While western Europe and North America enjoy reasonable control of their HIV epidemics, as well as widescale access to antiretroviral drugs, eastern Europe and central Asia are showing alarming trends towards rapidly expanding epidemics, according to data presented by UNAIDS and the World Health Organisation at a conference in Lithuania.<sup>23</sup>

Eastern Europe and central Asia are home to 1.3 million people living with HIV. In particular, Estonia, Latvia, the Russian Federation and Ukraine have some of the world’s highest rates of new infections, driven mainly by injecting drug use, as well as by fear of stigma and discrimination. The spread of HIV through unprotected sex is now becoming increasingly common in some countries.

### **Central and South America**

Latin America has around 1.6 million people living with HIV, mostly infected as injecting drug users or men who have sex with men. In Central America, the spread of HIV is mainly through unprotected sex. Haiti, in the Caribbean, has the highest prevalence outside Africa, with 5.6 per cent of the population HIV-positive.

## 2 The drugs are here already

Greater availability of HIV treatment for the 40 million people currently infected with HIV is a humanitarian imperative that could prolong the lives of millions, restore economic productivity, and stabilise societies in some of the world's hardest-hit regions.<sup>1</sup>

Global HIV Prevention Working Group, July 2004-11-01

There are drugs that are highly effective at stopping HIV from taking its toll on the body, known as antiretrovirals (ARVs). ARV treatment, or ART, has completely transformed the face of HIV in western Europe, North America, Australia and New Zealand, reducing deaths from HIV-related illnesses by more than 70 per cent. For most HIV-positive individuals, ART has turned what was once considered an immediate death sentence into a mostly manageable condition. Some HIV-positive people receiving ART have now lived productively and healthily for more than 20 years. Most people living with HIV, however, are in developing countries. Globally, only seven per cent of people who need ART have access to it, and millions are dying needlessly.<sup>2</sup>

### **Overcoming side-effects and resistance: the era of HAART**

Treatment with the first antiretroviral, known as AZT or zidovudine, began in Europe and North America in 1987. But within two to three years it became evident that this and other early types of ART soon led to the development of drug-resistant forms of HIV if patients switched from one drug to another in succession. A first course of drugs is known as first-line; if a change in the drug regime is needed, it is called a second-line treatment.

By the mid-1990s, however, a larger selection of drugs was available, enabling three or even four drugs to be taken in combination. This was the beginning of the current era of highly active antiretroviral treatment (HAART), in which the virus

is attacked on several fronts at once to far greater effect. While side-effects and resistance still occur, these can be kept to a minimum if HAART is properly administered and monitored (see chapter 4).

### **Cheap generics bring prices crashing**

The main drawback of HAART, however, is the cost. In Europe and North America, treatment with the brand-named original drugs of multinational manufacturers can cost up to US\$15,000 or more per year – way beyond the reach of low-income developing countries where the average spending on healthcare per capita is less than US\$7 per year.

But thanks to a booming generic drug industry, particularly in India, Brazil and Thailand, cheaper copies of brand-named ART are now available to countries where multinational companies have yet to be granted patent rights – mostly in Africa, Asia and parts of Latin America. Indian manufacturers Cipla and Ranbaxy, for example, offer two-in-one and three-in-one 'fixed-dose combinations' of different ART in a single pill for less than US\$300 per year, and sometimes as little as US\$140 per year. Following deals negotiated between the William J Clinton Foundation, the World Bank, Unicef, and the Global Fund to Fight AIDS, Tuberculosis and Malaria, these treatments are now widely available to developing countries.<sup>3</sup>

Médecins Sans Frontières (MSF) has gained enormous ground providing three-in-one pills



Don McCullin

Charlie with her daughter, Khanya. Charlie cherishes every moment with her youngest child. Without ART, she would not have seen Khanya reach school age

(fixed-dose combinations) as the first choice of ART to more than 13,000 patients in 25 countries. Besides cost, fixed-dose combinations have the important advantage of being simpler to take than the brand-named originals – just one pill in the morning, and one in the evening, instead of six or more a day. Patients are more likely to take their full course of treatment, which in turn helps them to avoid the development of drug resistance (see chapter 4).<sup>4</sup>

Charlie in Cape Town, South Africa, has benefited from MSF's programme. Charlie was diagnosed HIV-positive in 1996. By 2000, she was so ill she could not get out of bed to look after her children. In May 2001, she started taking antiretroviral drugs, but suffered unpleasant side-effects. 'I had skin rashes, diarrhoea and fevers. But that did not put me off.' She switched to another drug regime, and

within months was feeling better, had put on weight, and had more energy. 'I am so much better now, I do the housework and I look after the children.'

Her daughter, Khanya, is now four, and she also has a 17-year-old son and 12-year-old twins – all are HIV-negative. 'They are all happy to see me doing so well. They remember the days when I was so ill – they thought I would die. They were so worried about their future.'

Charlie takes her drugs twice a day: once before the children go to school in the morning, and again in the evening. If she forgets, the children remind her. They have a vested interest in Charlie remaining healthy. With the encouragement of Christian Aid partner Wola Nani, a community-based HIV services organisation, Charlie now gives talks to

young people about the need to practise safer sex and how to avoid risky behaviour. She knows that her infection came from her husband, who died of an HIV-related illness in 1999. 'It is important that people know how I was infected and that I am HIV-positive. People have never behaved badly to me. As a matter of fact, they are happy to see me so healthy now.'

The World Health Organisation (WHO) endorses the use of generic fixed-dose combinations in its '3 by 5' initiative, which aims to provide three million people with ART by 2005 (see chapter 3).

The most popular three-in-one combination for starting on ART contains the drugs nevirapine, lamivudine (3TC) and stavudine (d4T). However, in the US and western Europe, the same drugs are only available as individual medications because the multinational pharmaceutical companies Glaxo Smith Kline, Bristol-Myers Squibb and Boehringer Ingelheim each hold separate patents on the drugs. For developing countries, however, these and other pharmaceutical companies – namely Roche, Merck and Abbott – are making their drugs more widely available and at lower cost through the Accelerating Access Initiative. This is a partnership with UN agencies UNAIDS, WHO, Unicef and the UN Population Fund, which now provides treatment for more than 150,000 Africans.<sup>5</sup>

At the recent AIDS conference in Bangkok in July 2004, MSF called for further reductions in the cost of ART – particularly for second-line drugs. 'Resistance to first-line ART is as inevitable in poor countries as in rich ones,' said Dr Alexandra Calmy, MSF's AIDS advisor. 'Yet with second-line treatments costing as much as US\$5,000 per patient per year in developing countries – 15 times the cost of first-line treatments – it will simply be out of reach. Unless this situation changes, per patient costs will skyrocket and people will die needlessly,' she warned (see also chapters 3 and 4).

### **Drug quality: stumbling block or excuse?**

Despite the popularity of generic ART with MSF and UN agencies, the Bush Administration's Presidential Emergency Plan for AIDS Relief (PEPFAR), which plans to spend US\$15 billion on HIV/AIDS over five years, including the provision of ART to two million people, has not yet permitted its funds to be spent on generic ART. In March 2004, PEPFAR drew criticism from activists and UN agencies alike for questioning the safety and quality of generic ART, and was accused of bowing to pressure from the US pharmaceutical industry.<sup>6</sup> PEPFAR requests that generic manufacturers submit to the scrutiny of the US Food and Drug Administration (FDA). As of September 2004, the FDA has yet to approve any generic ART.

All parties agree, however, that ART must involve acceptable quality drugs – using the right raw ingredients and manufactured to high standards. The WHO recommends both generic and brand-named original ARVs on a special list of approved drugs for the treatment of HIV, tuberculosis and malaria in particular, as part of its 'Prequalification Project'. The approved list represents the only internationally accepted set of standards for drug safety, quality and dosage, and is as good as any standards set by the US Food and Drug Administration, according to the WHO.

### **Community activists demand ART as a human right**

Community-based activists have played a major role in demanding – and achieving – access to affordable ART in developing countries, particularly in South Africa, Brazil and Thailand. The arrival of cheap generics in private clinics in developing countries served only to heighten the frustration that poor individuals were dying while life-saving drugs were available to those who could pay.

Highly vocal in South Africa and on the world stage, the community-based Treatment Action Campaign (TAC) has mounted a series of political campaigns

against the South African government for its stance on HIV, resulting finally in the government agreeing, in November 2003, to begin a national ARV treatment programme. Since then, TAC has criticised the government further for failing to obtain adequate ARV supplies; by September 2004, only 8,000 people had access to ART through the public health system.

TAC has launched a new forum to monitor the progress of the national programme, together with other non-government organisations. In September 2004 it launched a court action demanding the South African Department of Health release details of treatment targets and timetables.<sup>7</sup>

Jackson and his wife, Victoria, who live in Paarl near Cape Town are both HIV-positive. 'We have heard of antiretrovirals and want to take them,' says Jackson. But getting the drugs is another matter. Ria, their carer, says: 'In South Africa we are supposed to have access to free antiretrovirals, but it is not that easy. Just saying they are available doesn't mean that people like Victoria and Jackson can get them.'

MSF's pilot projects in Khayelitsha, a township in Cape Town, initially depended upon generic ARVs imported from Brazil's state-owned manufacturer FarManguinhos. Brazil is hailed as a glowing example of how a 'middle-income' country can mount a national response against HIV, and now has more than 130,000 patients on ART. Intense pressure from community-based groups and non-government organisations persuaded the Brazilian government to scale up treatment using locally produced generics and resist attempts by multinational pharmaceutical companies to impose patent restrictions.<sup>8</sup>

In Thailand earlier this year, two HIV-positive people won a victory over pharmaceutical company Bristol-Myers Squibb after going to court to overturn the firm's patent for the drug DDI. The patent, awarded previously by the Thai government, was preventing local generic producers from

making a cheap copy of the same DDI preparation. Their actions, supported by the Thai AIDS Access Foundation, set a precedent that now means access to such life-saving treatment is a legal right.

'This ruling had great international implications for health and human rights, confirming that patients – whose health and lives can depend on being able to afford a medicine – can be considered as damaged parties and therefore have legal standing to sue,' writes Nathan Ford, advisor to MSF's Access to Essential Medicines campaign.<sup>9</sup>

The involvement of civil society groups was essential in bringing about the legal challenge and was driven by people living with HIV.

'People living with HIV in Thailand began to educate themselves and found out that drugs could be cheaper. Having the experience of that has made them more active partners in a whole lot of issues,' MSF's medical coordinator in Thailand, David Wilson, told Christian Aid.

Wilson is disappointed, though, that such civil society activism for treatment access has so far only taken place in South Africa, Thailand and Brazil. 'It's not happening elsewhere as it should. I feel irritated and frustrated that this is not being promoted elsewhere. It's important because it mobilises society and brings together different groups – people with HIV, lawyers, pharmacists – to work together.'

Thailand's generic ARV industry is now booming and provides treatment for around 37,000 HIV-positive people, which the government hopes to expand to around 70,000 in the near future. Thailand is also offering to supply generic ARVs to neighbouring countries, including Burma.<sup>10</sup> Indeed, such is the success of the Thai Government Pharmaceutical Industry, that its former director of research and development, Krisana Kraisintu, is now assisting African companies to produce their own generic ARVs, in Tanzania, Eritrea and the

Democratic Republic of Congo.<sup>11</sup> Other African countries, including South Africa, Kenya and Ethiopia, are also pursuing their own local production of generic ARVs.<sup>12</sup>

### **Trade restrictions threaten ARV supplies**

But the current generics manufacturing boom could be severely hampered if international trade negotiations proceed. At present, developing countries can, in theory, override patent restrictions on the import or manufacture of generic ARVs, because of an amendment to World Trade Organisation (WTO) rules, known as the 2001 Doha Declaration on Trade Related Aspects of Intellectual Property Rights (TRIPS) and Public Health. The amendment allows members to issue compulsory licences that bypass patents for the sake of 'taking measures to protect public health'.<sup>13</sup>

In August 2003, a WTO ruling allowed those countries able to produce generic ARVs to manufacture drugs mainly in order to export them to countries without this capability, under compulsory licences. Previously this had been forbidden. Both these agreements followed demands from developing country governments and an international campaign.

In reality, however, the process of issuing compulsory licences is legally complex and governments may find themselves under political pressure not to follow through. Thailand, for example, is currently in trade negotiations with the US, leading to fears that restrictions may be imposed on the country's generic ARVs production that could, in turn, undermine the national HIV programme and plans to export to other countries in the region. Trade negotiations between the US and South America may have similar consequences.<sup>14</sup>

'The US government is trying to force even greater protectionist measures and make clauses for the use of compulsory licensing much more difficult

and some countries have written that out of their national law entirely,' warns Nathan Ford.

Furthermore, according to the TRIPS agreement, members of the WTO are obliged to award patents to new drugs registered after 2005 (except for 'least-developed countries' that have until 2016 to comply). In India, for example, companies such as Cipla would be barred from producing generic copies of new ARVs patented after 2005 (although they can continue producing and exporting existing ones), unless the governments of both India and the importing countries issue compulsory licences.

New drugs are important for keeping pace with HIV as second or third treatment options when initial treatment fails. If countries only have access to expensive patent-protected originator drugs, continuing and expanding ART programmes could become too expensive.

'It puts us back to where we were three or four years ago, except that there may not be the generic industry able to produce [new second-line drugs],' says Ellen t'Hoen, of MSF's Access to Essential Medicines campaign.

Last year, Cambodia became one of the newest members of the WTO, raising concerns about the impact on the future supply of generic ARVs.

'Drugs have become available in the last two years in a way that we'd never dreamed of before,' says Father James Noonan at the Mary Knoll Foundation, a Christian Aid partner providing HIV services to the community in Phnom Penh. 'They have saved hundreds of lives so far, but in Cambodia only a small percentage of those who need drugs have received them. I'm afraid now that these will not be available to the many people who need them because of logistics. The World Trade Organisation has put pressure on Cambodia to sign agreements that call into question the right to allow generic drugs to be imported in future.'

# 3 Turning treatment goals into reality

Everyone living with HIV, regardless of income, should have access to drugs, which will prolong their life, allowing them to be productive members of society and raise their children. Christian Aid believes, however, that the provision of drugs alone is not enough... Christian Aid wholly supports the goal of '3 by 5', but calls for the essential role of community-based organisations to be acknowledged in overcoming these challenges.<sup>1</sup>

Christian Aid, *Drugs Alone are not Enough*, July 2004

In 2003, the World Health Organisation (WHO) and its partner organisations declared HIV/AIDS a 'global health emergency' and launched the '3 by 5' initiative with the intention of getting three million of the most seriously ill HIV-positive people on ART by the end of 2005.<sup>2</sup> They estimated that at least six million were in such an advanced stage of disease that they needed treatment immediately. Although 3 by 5 would only reach half this number, it would be the start of an unprecedented global effort to make ART available to everyone who needs it.

Around 90 per cent of people living with HIV in developing countries are unable to afford even the most basic healthcare, let alone expensive antiretroviral drugs. Providing drugs for HIV treatment is only one part of a multi-pronged attack that has to take place for 3 by 5 to succeed and expand. Other measures are essential to prevent new infections, if treatment services are not to become overwhelmed.

## Slow progress

From the outset, the 3 by 5 campaign has faced doubts and criticism over its progress and whether or not such an ambitious target can be reached in so short a time.

'Some people have said that 3 by 5 is an inflated target, unrealistic, an impossible dream. But I find it difficult to see the value of that sort of speculation. What we do want to hear is what the obstacles are, how these barriers may be overcome, how we can work better, faster and more effectively together to reach the goal... No one ever said reaching three million people would be easy. But we knew that only a concrete, measurable, time-limited target like 3 by 5 could bring about the change needed to make WHO act with the urgency that this terrible epidemic demands', said the WHO's Dr Jim Young Kim.<sup>3</sup>

The WHO's own figures support the contention that 3 by 5 is moving painfully slowly. So far, just 440,000 people are receiving ART worldwide – less than the 500,000 milestone expected in the first six months of 3 by 5 when it began in December 2003.<sup>4</sup>

## Solutions for 3 by 5: drugs alone are not enough

If the 3 by 5 initiative is to succeed in bringing ART to more than a tiny fraction of those intended – and for the patient's entire lifetime – a host of challenges must be overcome, including the need to:

WHO region coverage	Number of people on treatment	Percentage of people on treatment	Estimated need
Africa	150,000	4%	3,840,000
Americas	220,000	54%	410,000
Europe (Eastern Europe, and central Asia)	11,000	9%	120,000
Eastern Mediterranean	4,000	4%	100,000
Southeast Asia	40,000	5%	860,000
Western Pacific	15,000	9%	170,000
All WHO regions	440,000	8%	5,500,000

Number of adults in developing countries on antiretroviral treatment by WHO region, as of June 2004

- challenge HIV-related stigma and discrimination
- increase funding for comprehensive HIV prevention and care
- enhance awareness of HIV and the benefits of ART
- provide voluntary counselling and testing
- strengthen basic healthcare infrastructure and stop the medical 'brain drain'
- reduce the cost and complexity of ART
- increase community-based support, care and counselling for people living with HIV, including for those undergoing ART, and providing nutritional support
- enhance the role of community-based groups in decision-making and funding for HIV prevention and care.

### **Challenge stigma and discrimination against people living with HIV**

HIV-positive individuals suffer appallingly because of stigma. This is the undeserved shame bestowed upon them by others through ignorance, fear of death and disease and prejudice, and is influenced by social status, gender, age, moral beliefs, religion and cultural practices. The consequences can be devastating.

For example, in Ethiopia, Tanzania and Zambia, people with HIV, particularly young people and women, are often stigmatised for their 'immoral

behaviour'. They experience physical and social isolation by family, friends and communities, and discrimination through the loss of legal rights and employment. HIV-infected children, especially orphans, are the most vulnerable to discrimination.<sup>5</sup>

It is no surprise, then, that most people who suspect they may be HIV-positive are too afraid to come forward for testing, and are consequently unable to access treatment and care.<sup>6</sup> In Asia, stigma and discrimination against people living with HIV is especially rife, and in India it is reinforced by ignorance and the caste system. Anecdotal reports tell of ostracism, discrimination and even suicide and murder when people disclose their HIV status.

Non-government and community-based organisations can play a vital role in recognising when stigma and discrimination is occurring and educating people against unacceptable behaviour.

Christian Aid partner Milan, which means 'coming together', is an HIV anti-stigma project in Karnataka, southern India. Its main objective is to integrate HIV prevention, care and support programmes, treatment and advocacy for the rights of people living with HIV/AIDS (PLHA) into a joint project run by a consortium of four organisations: a PLHA network, a sex-workers' collective, a health



Catherine is 33, and too weak to move. She has been in hospital three times since January 2004 and knows she is very ill. 'Yes, I am HIV-positive. I found out last year but I don't know how I got infected. My husband thinks he may also be ill.'

Catherine does not have access to ART and she despairs over the future of her three sons aged 14, nine and two. Of the youngest, she says: 'Kenan has no good future, he is often ill like me.'

Catherine lives at Nkwazi compound in Ndola, Zambia. One of her few sources of comfort is her carer, Edith Banda who works with the Catholic Diocese of Ndola, a Christian Aid partner. 'In Zambia we are all infected or affected. I do this work because I feel I must. But it affects me when I see a person who was once laughing, now so sick', says Edith

service provider and a coordinating body. Together, these organisations have developed a clear, shared vision for challenging HIV-related denial, stigma and discrimination in Bangalore.<sup>7</sup>

### **Increase funding for comprehensive HIV prevention and care**

According to UNAIDS, the seemingly impressive figure of US\$4.7 billion spent globally on HIV/AIDS in 2003 is woefully inadequate. In order to mount an effective response to HIV, to prevent new infections and treat and care for those living with HIV, this figure needs to at least double by 2005, and to reach a staggering US\$20 billion in annual spending by 2007.<sup>8</sup> Some of this funding will come from developing countries' own resources; the rest needs to come from debt cancellation and aid.

Zambia typifies the poverty-stricken state of most African countries, and the difficulty in trying to achieve 3 by 5 targets. Around 16 per cent of the ten million adults in Zambia is HIV-positive. To meet the goals of 3 by 5, at least 10,000 should be on treatment by now, and 100,000 would need to begin treatment by the end of 2005, according to the WHO. But presently, only a tiny proportion of those who need treatment have access to ART – a mere 3,000.

Struggling to repay debts to international creditors and hampered by IMF reforms, which limit public spending, Zambia is poor at the levels of both government and the population. In theory, the government offers free treatment to patients who are unable to contribute 40,000 kwachas (around US\$7) per month towards their treatment. But in reality, it is unable to do so, and patients require a guarantee of payment from a friend or relative before they are permitted to enter the programme.

'There's simply no money at the ministry,' says Chanda Fikansa, AIDS programme manager at the Catholic Diocese of Ndola, a Christian Aid partner. 'At the end of the day, no one can access ART through social welfare.' Situated in the Copperbelt

region of Zambia, the Diocese cares for more than 8,000 individuals living with HIV, yet none of the 7,000 who are likely to need ART are receiving it.

The WHO is working together with a number of co-sponsors, including other UN agencies, the Global Fund to Fight AIDS, Tuberculosis and Malaria, the Bush Presidential Emergency Plan for AIDS Relief (PEPFAR), the World Bank, the European Commission, other bilateral donors, governments, non-government organisations and the Gates Foundation, to provide grants and subsidies to low-income countries such as Zambia that have developed national treatment plans for HIV. These must include plans for improving healthcare infrastructure and fund disbursement, as well as for procuring and providing drugs, treatment monitoring, counselling and testing.

Zambia now has a grant from the Global Fund to Fight AIDS, Tuberculosis and Malaria, and has announced its intention to expand treatment to 10,000 people.<sup>9</sup>

### **Enhance awareness of HIV and the benefits of ART**

Astonishingly, around 90 per cent of people estimated to be infected with HIV do not know of their condition. The level of ignorance about HIV and the benefits of antiretroviral drugs is appalling, and particularly affects poor illiterate communities and women. It is no wonder, then, that fewer than seven per cent of those who need ART have access to it. Meanwhile, HIV continues to spread and kill thousands of people every day.

There is an urgent need to improve HIV awareness and education, not only among the general population but also among high-risk and often disenfranchised groups, such as men who have sex with men, sex workers and injecting drug users.

The government of China, for example, has failed to sufficiently inform and educate rural populations, so

blood transfusion operations involving the repeated use of contaminated needles has led to an HIV explosion. Infection rates are also believed to be high among vulnerable groups such as injecting drug users.<sup>10</sup> And in India, the taboo that prevents talk of sex and HIV severely hampers attempts to raise awareness about the threat of HIV infection, particularly to women.<sup>11</sup>

### **Provide voluntary counselling and testing**

A massive increase of voluntary counselling and testing is urgently needed to enable people to learn their HIV status and seek appropriate treatment and care. To identify the three million that 3 by 5 aims to treat by 2005, around 20 million people need to be identified as HIV-positive – assuming that 15 per cent of these are ill enough to require ART immediately – which in turn requires the testing of around 200 million people.<sup>12</sup>

To achieve testing on such a scale, the WHO advocates the integration of testing and counselling services into all clinical settings where people at greater risk of HIV infection are likely to be present. This would include clinics for tuberculosis, sexually transmitted diseases and injecting drug users, as well as family planning and antenatal care services.

Christian Aid's partner, the Christian Health Association of Malawi, illustrates the importance of counselling in maternity units. Located on the outskirts of Malawi's capital, Lilongwe, it runs a programme to provide antiretroviral drugs to HIV-positive mothers to prevent infection of their babies during pregnancy, delivery and after birth (known as prevention of mother-to-child transmission). Blessing Banda, a senior community care nurse at the hospital told Christian Aid that only around 15 per cent of women agreed to be tested when the programme was first set up 'because the nurses were so overworked that they did not have enough time to counsel women properly'. But after the training of four full-time counsellors from the community, women can spend as much time as

they need going over the available options. 'Now 70 per cent of women attending antenatal clinics are opting for counselling and testing, and they are very pleased with the service,' says Blessing.

Promising though this is, there is still a long way to go towards improving the uptake of counselling and testing because of the stigma suffered by HIV-positive women. Few are able to go home and tell their families that they have tested HIV-positive, or to involve their partners/husbands. 'There is need to get husbands to the clinic so that they can have counselling with their wives – but so few are willing to come,' says Blessing. The clinic is currently building a voluntary counselling and testing centre away from the busy antenatal clinics to help men feel more comfortable about attending.

### **Strengthen basic healthcare infrastructure and stop the medical 'brain drain'**

It is a frustrating irony that many of the countries worst affected by HIV lack the kind of basic healthcare infrastructure that people living in the West take for granted. Lack of funds (in part due to debt repayments), an absence of political commitment, corruption, poverty, inadequate provision of education and training, and a continual 'brain drain' of doctors and nurses to the private sector or abroad undermine the provision of decent healthcare.

For example, in Zambia, the demand for voluntary counselling and testing is far outstripping the capacity to provide it.

'Unfortunately we are facing the situation where counsellors are complaining of being overworked,' says Chanda Fikansa, AIDS programme director for Christian Aid partner the Catholic Diocese of Ndola. 'The counsellors we have are either clinical officers, nurses or doctors, who have to do the duties they are employed for, and then do counselling part-time. There are few nurses in the hospitals now because most of them have gone to work



Andrew Banda at the funeral of his sister-in-law in Kawama cemetery, Ndola, Zambia. She had two young children who will now live with Andrew

elsewhere, or have died of AIDS. Unlike in the UK, there are not so many nurses in developing countries because of the poor pay, so the government can't give us more staff.'

Andrew Banda also worries about the 'brain drain' of educated Zambians. His two eldest children plan to leave the country once they have finished university. Andrew would also like to leave to find work, but cannot because he has 'too many orphans'. His sister-in-law, Nzali has just died at the age of 25, leaving two children aged five and one-and-a-half. 'Now we have two more orphans to look after. My home is already an orphanage,' says Andrew. Ironically, Nzali had just been accepted on a pilot

programme to dispense antiretroviral drugs at the Ndola central hospital, but treatment was delayed because she was too anaemic.

Other countries face a similar toll on healthcare workers, either directly due to HIV or because of the brain drain.<sup>13</sup> In South Africa more than 15 per cent of healthcare professionals, including nurses, are believed to be HIV-positive, although data is sketchy owing to 'secrecy and silence'.<sup>14</sup> In addition, higher salaries and better working conditions elsewhere are proving irresistible. In Zambia, the public health sector has retained only 50 of 600 physicians trained between 1978 and 1999,<sup>15</sup> while doctors from South Africa account for ten per cent of Canada's hospital-based physicians and six per cent of the UK's.<sup>16</sup>

If the fight against HIV is to be sustained, it is essential that healthcare infrastructure is built up. Debt cancellation and increased aid would help provide the necessary injection of funds. If health workers are to be paid an adequate wage, making them more inclined to stay in their own countries, the IMF-imposed public spending ceilings need to be relaxed in some countries, and donors need to be more willing to fund ongoing costs, such as salaries. HIV treatment and care programmes need to be organised in such a way that they support and build national health systems rather than undermining them.

#### **Reduce the cost and complexity of ART**

The ART programmes of many developing countries use combinations of two or three drugs together in a single pill (fixed-dose combinations) as the first treatment option for HIV-positive individuals. These are cheaper generic copies of brand-named drugs and make it easier for patients to comply with treatment instructions – just one pill twice a day rather than six or more individual tablets for each drug. However, if patients need to switch to a new range of drugs because of adverse reactions, they often face a more complicated regimen of

drugs that are only available individually. Adherence to treatment becomes harder, and patients risk defaulting on their medication and developing drug-resistant HIV (see chapter 4).

According to Médecins Sans Frontières (MSF), more antiretroviral drugs need to be manufactured as generic fixed-dose combinations to ensure treatment compliance. In addition, more drugs need to be produced in a form that is palatable for children, such as a syrup.

‘Children with HIV are generally not interesting for pharmaceutical companies,’ David Wilson, the medical coordinator for MSF Belgium in Thailand, told the International AIDS Conference in Bangkok in July 2004. ‘But some generic companies are developing more child-friendly ARV treatments. International agencies need to push this issue higher up the agenda and governments will need to remove barriers to the use of generic products.’

**Increase community-based support, care and counselling for people living with HIV, including those undergoing ART, and provide nutritional support**

In the poor township of Khayelitsha in Cape Town, South Africa, Christian Aid partner Wola Nani trains community-based volunteers to provide care and support to people living with HIV, including those on ART. They are trained in drug literacy and understanding the importance of complying with drug regimens, and visit patients in their homes to check that they are taking their medications. They also learn the importance of sensitivity and discretion.

‘This is real treatment support because often an HIV-infected person might be living with their family but no one else knows about their infection,’ says Wola Nani’s director Pat Francis. ‘Sometimes the purpose of the visit is entirely secretive, with the carer posing simply as a well-wisher. When someone makes the tea the carer has a quick discrete “conversation” with the patient about their medication.’

Wola Nani works with MSF and antenatal clinics in Khayelitsha to identify patients who need help. MSF values Wola Nani’s support highly. ‘From the moment the MSF programme started in Khayelitsha in 1999 we’ve involved people who are benefiting from, and understand the benefit of, the programme,’ Pat Francis tells Christian Aid. ‘We have people who are themselves on ART or are supporting someone on ART, who go out there and talk about the experience. Wola Nani has been a strong ally, as many of the Wola Nani people are being seen in the clinics that we are running.’

The kind of support that Wola Nani provides has helped MSF to achieve treatment and care in a resource-poor setting that is as effective as anywhere in Europe or North America.<sup>17</sup>

MSF relies upon an extended network of nurses and trained community-based supporters, managed by only a minimal number of primary care physicians. A quarter of Khayelitsha’s population of 50,000 is estimated to be HIV-positive, with around 5,000 in need of treatment. By last year, the programme had treated 1,000 people, and had a two-year survival rate of 92 per cent. Globally, MSF teams are treating more than 13,000 people in 25 countries.

MSF is now establishing a new treatment project in one of South Africa’s most remote rural communities, Lusikisiki in the East Cape. Until now, a patient there who tested HIV-positive would be ‘reviled by her parents and ridiculed by her neighbours’ and left to die ‘in a shack in the weeds beyond the village’.<sup>18</sup>

The new programme encourages community-based groups of people living with HIV, their friends and families, to counsel and support others who are HIV-positive and to teach them about treatment. Community-based nurses rather than hard-pressed hospital doctors conduct tests and dispense medication.



Don MacQuillin

Cynthia lives in the poor township of Khayelitsha in South Africa. She was diagnosed as HIV-positive in 2000 at the age of 36. In September 2003, she started ART with support from Wola Nani, a community-based AIDS service organisation and Christian Aid partner. Cynthia helped the MSF clinic in Khayelitsha celebrate having 1,000 patients on ART.

'I am very glad I am on the drugs. I am much better, I have no pains or fever or headaches. I have one child of 20 who is very happy that I am on the drugs. I don't have the money to buy drugs, so I am very happy to have free drugs'

In 2000, 23-year-old Nomalunga was pleased to have received the drug AZT during the delivery of her baby to prevent HIV passing to her daughter, Zikhona – now a healthy four-year-old. But Nomalunga was underweight and feeling extremely unwell.

'I was so sick then, I thought I would die. I didn't know there were different stages in this disease and I thought once you had HIV you died very soon.'

In September 2002, Nomalunga's luck changed when she began ART. 'It was amazing; before, I was losing weight and I had meningitis too. Then I

gained weight very quickly and felt stronger. I had no side-effects, and just once had a case of shingles.'

Nomalunga was so inspired by the change in her health, and so optimistic for her own and her daughter's future that she has trained with the Red Cross as a carer. 'Sometimes when I visit a patient I remember how sick I used to be.'

Her client Andiswa, 24, says, 'Nomalunga makes a big difference in my life. It is important to me that she is also HIV-positive – she understands me.'



Don MacQuinn

Andiswa in her one-room home in Khayelitsha township, Cape Town, which she shares with her nine-year-old twins

### **Drugs without food are not enough**

Simply providing ART without tending to the other needs of people living with HIV is short-sighted and will further threaten the success of 3 by 5. Patients on ART experience an improvement in their appetites and require a nutritious diet in order to cope with the drugs' side-effects, sustain their health and become productive members of society. But poverty is a major impediment to assuring access to food.

'One of the very important components of treatment which unfortunately is not well appreciated by our donors is food,' Chanda Fikansa of the Catholic Diocese of Ndola tells Christian Aid. 'Even without AIDS most of the Zambian people are struggling to get one meal a day.' To add to Chanda's concerns, funding from international

donors for the food programme at Ndola has recently ceased in order to support long-term agricultural production instead.

In Zimbabwe, too, food is often the first priority in a home-based care and orphans-support programme. Without food, people living with HIV will not get the maximum benefit from ART. In a high-density suburb of Harare, Moses, a home-based care volunteer himself living with HIV and supervising daily tuberculosis treatment as part of an HIV programme, describes his frustrations. 'It is so hard to work like this because as people get better they get hungry but many are poor, unemployed and have no food.'

Gorden Simango from Christian Aid partner Christian Care in Harare also identifies the need for

food provision as part of an urgent, integrated response to HIV. 'In this complex crisis all our staff must be trained to understand HIV and challenge stigma in our communities,' he says. 'No care without food, no food without prevention and no prevention without care.'

In Angola, where a national programme for HIV prevention and care has been in place since the beginning of 2004, the supply of free ART has done little to alleviate the day-to-day suffering of people such as Pedro Mande. Pedro, 26, is on ART but he lives on the street. He is too weak to return to work, has no money for food, no home, and has been rejected by his family. 'If I could live in a proper house and have proper food, I would grow stronger, but with this life, without any support, I am only getting weaker,' he says.<sup>19</sup>

In tandem with food programmes, the root causes of food insecurity need to be addressed. Trade rules must be changed. Rapid and uncontrolled liberalisation of agriculture in poor countries, combined with the massive subsidies paid to farmers in rich countries, dramatically reduces the incomes of small farmers in the developing world, threatening their supply of food.

**Power to the community: enhance the role of community-based groups in decision-making and funding for HIV prevention and care programmes**

At least part of the drive towards achieving 3 by 5 owes its momentum to the people living with HIV who have campaigned hard to convince governments and bilateral donors that improving care and treatment for HIV is both possible and worthwhile, according to Richard Burzynski, director of the International Council of AIDS Service Organisations.

'It's advocacy from people living with HIV, and the science behind it that has shown how we can

do it – that it creates cost savings, keeps people productive, that we need to reach millions and need to do it progressively,' he told Christian Aid.

As a result, there has been a huge attitude shift among governments and international donors who now welcome community-based and faith-based groups at the negotiating table. They now take part in the country coordinating mechanisms, or CCMs, that the Global Fund requires countries to establish in order to apply for grants for national treatment programmes, together with non-government organisations, policymakers and other stakeholders.

Christian Aid believes that community- and faith-based organisations have a vital role to play at every level of decision-making about the treatment and care of people living with HIV.

# 4 Overcoming drug resistance

‘Perhaps the fear of the western world of being confronted with transmission of drug-resistant HIV plays too large a role... it seems inconceivable to let people die of AIDS because of preconceived risks and side effects of treatment.’<sup>1</sup>

Johannes A Bogaards and Jaap Goudsmit, *Journal of Antimicrobial Chemotherapy*, 2003

Challenging in every way, HIV is not an easy virus to treat: if patients fail to take their full dose of antiretroviral drugs, then HIV can soon develop resistance to the treatment, and patients have to switch to other, sometimes more expensive, drugs.

Resistance occurs because the concentration of a drug has fallen too low to stop the virus from growing and reproducing itself. HIV is the fastest reproducing virus known to infect people – producing billions of copies a day in the body of an infected person, given the chance. When this occurs, each ‘copy’ can contain one or more mutations, which makes each copy slightly different and potentially less vulnerable to the drug in question.

## Causes of drug resistance

Various circumstances can cause patients to miss taking their full daily dose of drugs, or abandon their treatment altogether. These include:

- being unwilling to reveal HIV status to a close friend or family member owing to stigma, making it less likely the person will adhere to medication in the long term
- failure to follow instructions
- lack of money to pay for drugs or transport to the clinics
- unregulated or irregular access caused by friends and family sending drugs from abroad, westerners smuggling drugs in, provision of drugs by pharmacists without doctors

prescribing the type and dosage

- use of poor quality or counterfeit drugs containing other ingredients that either dilute or substitute for the correct drug
- complicated drug regimens of too many pills to take each day
- lack of ‘child-friendly’ syrup-based drug formulations
- sharing pills with family and friends
- lack of emotional support to keep taking pills with unpleasant side-effects such as nausea and diarrhoea
- poor absorption into the body due to diarrhoeal diseases or vomiting
- hunger, which exacerbates nausea and vomiting
- poor healthcare infrastructure due to a brain drain of skilled staff and lack of training and funds, exacerbated by debt repayment and IMF reforms.

In cases of drug resistance, poverty, which is rife in many of the communities that are worst affected by HIV, only serves to exacerbate these circumstances. And if patients are unable to access high-quality healthcare services, the telltale sign that drug resistance may be developing – a rise in the amount of virus in their blood – may go undetected.

Christian Aid believes that only by tackling poverty can the HIV/AIDS epidemic sweeping through so many developing countries be brought successfully under control.

### Conditions ripe for resistance

Many of the circumstances leading to drug resistance already exist in Africa and other developing regions. In June 2003, Ruairi Brugha and colleagues from the London School of Hygiene and Tropical Medicine warned that uncontrolled prescribing of ARVs was taking place in Africa. And in March 2004 a 'confusing and dangerous free-for-all' occurred in Swaziland where ARVs had been introduced in an unregulated way, with pharmacists dispensing drugs without instructions on how people should take the medication, or warning of side-effects. Taxi drivers were picking up ARVs for people and getting an extra supply, then selling them onto their passengers, according to claims by the AIDS support group Swazis for Positive Living.<sup>2</sup>

Drug shortages, too, are occurring in some parts of Africa. In January 2004, the South African Treatment Action Campaign reported that at least one child defaulted on treatment when supplies of the paediatric formulation of the drug efavirenz dried up.<sup>3</sup> In Nigeria, a four-month shortage of ARVs occurred recently at many of the 25 HIV treatment centres, caused by the enrolment of too many patients and insufficient funds.<sup>4</sup> And counterfeit drugs are also circulating on the black market. In the Democratic Republic of Congo, anti-depressants and muscle relaxants are being sold as counterfeit ARV drugs, according to Médecins Sans Frontières' Access to Essential Medicines campaign.<sup>5</sup>

### Drug roll-out must proceed properly

But rather than allowing such stories to slow or halt plans to expand access to ART, most activists, doctors and scientists believe that the answer is to increase access to ART under properly-controlled circumstances.

'[The] spectre of widespread viral drug resistance... should not lead to a slowing of the pace at which these life-preserving medications are made

available to the millions in need in those countries. With proper HAART (Highly Active Antiretroviral Therapy) regimens and proper adherence, development of drug resistance is not a common event.'<sup>6</sup>

Experience in Europe, North America and Australia shows that anywhere between five and 17 per cent of patients can develop resistance to ARVs, even when being treated with a combination of three drugs together.<sup>7</sup> To prevent drug resistance, patients need ideally to take the correct dose of their drugs more than 90 per cent of the time. Resistance is three times more likely to develop when patients adhere to treatment only 80-85 per cent of the time. This creates high stakes for ART programmes in developing countries, where nothing less than extremely good adherence will do.<sup>8</sup>

### Consequences for developing countries

Very little is known about the extent of drug-resistance in developing countries, because not much monitoring has taken place. Studies in Uganda and Botswana have confirmed that when the cost of treatment causes patients to forego some of their treatment, or take only one or two ARVs rather than the recommended combination of three or four, drug resistance is more likely.<sup>9</sup> But where treatment is available together with counselling, people in developing countries have as good adherence rates as anywhere in the developed world.

Gerard, an accountant in Zambia, tells Christian Aid about his drug treatment: 'I started taking antiretrovirals in 1997. My health was very poor – I had lost so much weight. Now I am really fine. I have managed to take the drugs ever since – for seven years now. I have never missed a single day. I am one of the lucky ones because the company I work for subsidises my treatment and I have a wonderful counsellor who I can see when I need to. Also, my wife is always there to remind me to take the tablets. I feel I have been given the chance to see my kids grow up and I feel bad that so many of my



Don McCullin

A charcoal vendor in Nkwazi compound, Ndola, Zambia. Tens of thousands of people live here, surviving on a hand-to-mouth existence. They can only afford to buy tiny amounts of charcoal, which they use for cooking

friends and relatives have died because they could not get the drugs.’

Christian Aid believes that when adequate healthcare infrastructure and community support are in place, treatment adherence in developing countries is likely to be as good as, if not better than, in the West.

In Brazil, for example, where more than 125,000 HIV-infected patients have received ARVs and AIDS-related mortality has dropped by nearly 70 per cent, the prevalence of drug resistance in newly infected patients is less than seven per cent – lower than in North America and Europe. And in Senegal, a government-led ARV treatment programme praised good clinical monitoring and lab testing for results that compared very favourably with western countries.<sup>10</sup>

Médecins Sans Frontières (MSF), which has treated more than 13,000 HIV-positive patients in 25 developing countries, says that levels of drug resistance to first-line treatments are no worse than in Europe and North America. Its pilot treatment programme in Khayelitsha, South Africa, is a convincing demonstration that people from poor, uneducated backgrounds can be trusted to adhere to treatment, and that community-based peer support helps to ensure patients comply with their regimens and turn up for regular monitoring.

‘People take their drugs very seriously,’ says Marta Darder of MSF South Africa, which works together with the government programme to provide ARVs in South Africa. ‘They have normally been very sick when they start ARVs, and many people around



Don McCullin

In Paarl, South Africa, Christina, now 33, was diagnosed HIV-positive in 2003 after suffering months of illness and weight loss. She started taking ARVs in April 2004, one month before this photograph was taken, and is supported by volunteer carer Ria Booysen (left), who is also HIV-positive.

'I go to the hospital every month for check-ups. The drugs are free, and I also have free counselling. I have to take tablets in the morning and in the evening. I set my alarm so I remember to take them.'

Christina and her four children live with her sister Eunice and her children. Eunice supports them all by earning around 60 rands (£5) per day with a part-time job at a bakery.

'We are lucky to have free drugs. If we had to pay for them, Christina would not be able to take them,' Eunice told Christian Aid

them are dying or are suffering – they understand that they have to take their drugs. We don't see much sharing of drugs. That's all achieved through a lot of education about treatment and promoting people's responsibility for their drugs.'

### **Mothers at risk**

The best-studied cases of drug resistance in developing countries are those arising in some pregnant women who receive the antiretroviral

drug nevirapine to protect their babies against infection – the prevention of mother-to-child transmission of HIV. Giving a single dose of nevirapine to a mother during labour, and to her baby just after birth, is now a cheap and effective way of halving the risk of the baby becoming infected. It offers real hope to mothers in developing countries. But as with so many examples of progress in medicine, this advance has some complications.

In July 2004, at the International AIDS Conference in Bangkok, scientists presented the latest data from a study in Thailand confirming that around one-third of women develop drug-resistant forms of HIV after receiving a single dose of nevirapine to prevent mother-to-child-transmission (MTCT). Moreover, if they then need to start on ART within six months, and their treatment includes nevirapine, it is less likely to keep the level of HIV in their blood under control. Doctors do not yet know how such women will fare as treatment continues, but are sufficiently concerned to want to continue monitoring them.<sup>11</sup>

The findings gained notoriety when the South African health minister Manto Tshabalala-Msimang used them to justify her announcement that nevirapine was to be deregistered in South Africa.<sup>12</sup>

The announcement caused dismay, and re-ignited the already sensitive feelings of campaigners who had fought long and hard to persuade the South African government to pay for life-saving antiretroviral drugs, including nevirapine, through the country's public health system. More than 100,000 HIV-infected babies are born in South Africa each year.<sup>13</sup>

Since then, the South Africa Medicines Control Council has not acted on the announcement, and nevirapine has not been deregistered. Government-run clinics are proceeding as before, many using an alternative protocol involving zidovudine (AZT) to prevent MTCT. But confusion is likely in clinics operating in rural areas that can only afford to use nevirapine.

'Clinicians and nurses and the ones on the ground and the beneficiaries got very confused about that statement,' says Marta Darder. 'In many places in rural remote areas it's very hard to find any alternatives to nevirapine alone at the moment. It's a very simple intervention.'

According to the WHO, the benefits of using nevirapine to prevent MTCT outweigh the risks of drug resistance, and MTCT programmes in resource-poor settings should continue using nevirapine unless alternative drugs are available.

### **Too much talk of resistance?**

Treatment failure and drug resistance may well be important concerns, but there is also a danger that these issues are overshadowing patients' other needs, according to MSF Thailand medical coordinator, David Wilson.

In his experience in Thailand, while 80 per cent of patients adhere 'very well' to their treatment, many of the remaining 20 per cent have such overwhelming emotional or family problems that they drop out of treatment programmes. It would be better, in these cases, to focus on the need for appropriate counselling and support rather than talk about the switch to alternative drug regimens.

'Treatment failure does happen because patients can't adhere due to problems in their lives, and second-line drugs can't solve those problems. The resistance issue misses the point,' he told Christian Aid.

He asserts that community networks are best placed to look after the 20 per cent who are having emotional problems or other difficulties that prevent them from staying in treatment programmes. They can provide emotional and social support, financial assistance, food, housing and other care.

# 5 Prevention and care are as essential as treatment in the response to HIV

The danger is clear. Countries must not prioritise treatment at the expense of prevention.

Comprehensive HIV education and prevention programmes must continue to be a key element of all countries' efforts to fight the epidemic.<sup>1</sup>

Christian Aid, *Drugs Alone are not Enough*, July 2004

In the rush to increase access to ART in developing countries, it is critical not to overlook the importance of prevention – stopping new infections – and care of people living with HIV. Unfortunately, in developing countries, all three elements are sorely lacking.

A mere seven per cent of HIV-positive people who need ART currently receive it. At the same time, fewer than one in five HIV-negative people at high risk of infection have access to proven intervention measures, such as condoms, voluntary counselling and testing, treatment for sexually transmitted diseases, prevention of mother-to-child transmission of HIV, and clean needles for injecting drug users. UNAIDS estimates that making these prevention strategies available to those who need them would avert as many as 29 million of the 45 million new infections projected to occur between 2002 and 2010.

In areas where HIV infection rates are high, healthy people are more at risk of infection. They live in communities that desperately need prevention, treatment and care. In addition, without controlling HIV epidemics, antiretroviral treatment programmes will simply become overwhelmed.

Unless the incidence of HIV is sharply reduced, HIV treatment will not be able to keep pace with all those who will need therapy.<sup>2</sup>

Community and faith-based organisations are in an ideal position to support prevention, treatment and care programmes. Indeed, many such organisations have developed this role over time and provide a wide range of services to people living with HIV.

Christian Aid partner the Mary Knoll Foundation, on the edge of Cambodia's capital Phnom Penh, for example, began simply as a home-based care and HIV awareness provider.

Despite a fall in infection rates in Cambodia, after aggressive HIV awareness and condom promotion campaigns a decade or so ago, the HIV epidemic continues to make an enormous impact. 'Now we're reaping the harvest of when Cambodia had the highest infection rate in Asia – this year there will be 20,000 deaths from AIDS and there are at least 170,000 people living with HIV,' says Father James Noonan, a catholic priest who directs the Foundation's activities.

The Foundation's activities now include HIV counselling and testing. The number of people who test positive is a staggering 70 per cent – because people tend to 'wait and wait until they can't deny any longer' before seeking help. Many of these are suffering from tuberculosis and other opportunistic



Don McCullin

All too many people living with HIV have never heard of antiretroviral drugs. Ngosa, 28, lives in Ndola, Zambia and has been ill since October 2003. He has lost weight and suffers from stomach pains and swollen joints. He has agreed to take an HIV test but is too ill to go to the clinic.

'I think I have the illness because I am ill all the time – in and out, in and out,' he says. His carer from the Catholic Diocese of Ndola, Anna Banda, has seen a considerable change in a matter of months. 'He used to be very big,' she says. Ngosa used to work as a houseboy but lost his job because he was always ill. He doesn't know that there are drug treatments for HIV

infections, but they can ‘make a remarkable recovery’ with appropriate medication and care. The Foundation then assists them in pursuing new activities, life-skills training, and income-generation. Others, however, are too ill to recover from HIV infections, and are cared for in the Foundation’s 14-bed hospice.

It is the orphans of those who die from HIV-related illnesses who occupy much of Father Noonan’s attention. ‘When people are dying they say to me “I can accept that I have to die, but what will happen to my children?” They cannot die peacefully because they know that unless someone like me can take care of them, their children will be in a worse state than they are now.’

Father Noonan oversees the education and care of around 400 orphans, some of whom are also HIV-positive. ‘Their future is in education, and without that they would be totally discarded as human beings,’ he says.

The Foundation gives treatment support to adults on antiretroviral drugs, supplied by non-government organisations, such as Médecins Sans Frontières (MSF), and refers clients to them. Meanwhile, Mary Knoll outreach workers can be found at the gates of factories surrounding the Foundation, as well as in schools and youth clubs, talking and providing leaflets about the danger of HIV and the need to avoid high-risk sexual activity. ‘People are quite inquisitive, but changing behaviour is not an easy thing,’ says Noonan.

### **Prevention through ART: more than just treatment alone**

Access to ART benefits not only the HIV-positive individuals themselves but also their communities, as it encourages people to come forward for testing to find out their status. Patients with access to treatment are more motivated about the future and some even volunteer to carry out HIV awareness-raising and education work.

‘It was rare some years ago to see anyone with an HIV T-shirt but now you see that regularly,’ says Marta Darder of MSF South Africa. ‘It doesn’t mean that the problem of stigma is over because it’s a long battle, but the community is certainly getting more open and willing to talk.’

‘The best education messages that you can send out there in the community is to get someone healthy again, someone who was bedridden, dependent, who had to stop any normal activity and was just waiting to die. If you bring that person back to health and normal life then everybody understands.’

Christian Aid’s partner Wola Nani assists MSF’s work by providing community-based support to patients undergoing treatment in the poor township of Khayelitsha, Cape Town (see chapter 3).

### **More tests, please**

Scaling up HIV testing and ART is a golden opportunity for delivering prevention messages to those that might not otherwise hear them. For those whose tests prove negative, counselling can help them to avoid HIV infection and stay healthy in the future: by using condoms, reducing the number of their sexual partners, and so on.

For those who test positive for HIV, counselling can reduce the risk that they might pass HIV onto others through high-risk sexual behaviour. This is equally important for those on ART as for untreated individuals; in the West the lack of adequate counselling has in the past led to complacency among patients, who believe that they may be less infectious once on treatment, and whose sex drive returns as they start to feel healthier.<sup>3</sup>

Voluntary counselling and testing is most cost effective if focused in areas where there is a high prevalence of HIV infection, and if couples can be persuaded to volunteer for counselling and testing together.<sup>4</sup>

### **HIV prevention by treating sexually transmitted infections**

Tackling the sexually transmitted infections (STIs) that often occur in communities with high HIV infection rates is a highly effective way of reducing the risk of HIV infection. STIs, such as genital herpes, gonorrhoea and syphilis, can increase people's vulnerability to HIV infection by anywhere between two- and five-fold, by damaging the protective lining of the vagina and rectum, and enabling HIV to enter. With limited access to basic healthcare services for diagnosis and treatment, people in developing countries are especially vulnerable to the spread of STIs and hence more susceptible to HIV. And HIV-positive people are likely to experience STIs more severely. STI diagnosis and treatment services urgently need expanding to help protect people against HIV.<sup>5</sup>

### **Epidemics in reverse: condoms and clean needles work!**

Thailand, Cambodia and the Indian state of Tamil Nadu serve as reminders that spiralling epidemics can be tamed through aggressive HIV awareness and prevention measures, such as condom use among sex workers and their clients, and by reducing stigma and discrimination.

Epidemiologists predict that if other countries with smaller but no less threatening epidemics, such as Bangladesh, the Philippines, East Timor and Indonesia, follow this example they could avert a major crisis in future.<sup>6</sup> Likewise, the free distribution of clean needles can make a considerable difference in controlling HIV infection among injecting drug users.<sup>7</sup>

### **The right intervention in the right place**

Intervention needs to be tailored to those that need it most, rather than assuming the same strategies will apply to all. On the other hand, for some people, two or more strategies may be needed simultaneously. For example, a rapid rise

in infections is occurring in China, Nepal, Vietnam and Indonesia, because some of the same people engage in more than one high-risk activity – the buying or selling of sex and injecting drug use, for instance. These people need both condom promotion and clean-needle exchange in order to reduce their risk of HIV infection. The benefits would extend to their regular sex partners, wives and children.<sup>8</sup>

### **ABC together, or just A, or just C?**

An important prevention strategy is the much talked about campaign known as 'ABC', where A means abstinence, B means be faithful, and C means use a condom. It has become popular with both politicians and activists alike, and is open to misinterpretation. It also has its limitations. For example, 'being faithful' requires that *both* partners know and understand their HIV status and that *both* remain faithful.

Rather than a dogmatic interpretation, Christian Aid advocates that communities adopt a flexible approach that takes into account the full spectrum of people's circumstances and lifestyles in different cultures around the world. Christian Aid does not dictate how people should behave, or what prevention tools they should use, but instead supports local organisations and groups to use the HIV prevention methods and approaches they find most effective for their communities. The partners make condoms freely available, and offer education about HIV and sex for young people.

Some countries, however, have adopted ABC whole-heartedly. In Uganda, for example, the government attributes its success in reducing the official HIV prevalence rate from around 18 per cent in the early '90s to less than six per cent today to public education campaigns along ABC lines.

Whether or not the campaign's success is due to abstinence, faithfulness or condom use, or a combination of these, however, has been hotly debated. One group of eminent HIV authorities, including the Global Fund and the Gates

Foundation, which is supported by many scientists, attributes the success to a remarkable willingness to change sexual behaviour – in particular, to people reducing the number of their sexual partners.

‘Rather than arguing over the merits of abstinence versus condoms, it is time for the international community to unite around a balanced, evidence-based ABC approach,’ it concludes in a report to the *British Medical Journal*.<sup>9</sup> In an accompanying editorial, David Wilson of the World Bank’s Global HIV/AIDS Program wrote, ‘partner reduction is the most obvious, yet paradoxically neglected approach to the prevention of HIV’ and should be the ‘centre-piece of a unified ABC approach’.

The opposing lobby, championed in particular by religious-based groups in the US, has given the credit to sexual abstinence, and refutes the importance of condoms. This view appears to influence the policy and spending of the Bush Administration,<sup>10</sup> as illustrated by the US global AIDS coordinator Randall Tobias, who says, ‘statistics show that condoms really have not been very effective’ against HIV in Africa.<sup>11</sup>

Christian Aid believes that there is little evidence that focusing on sexual abstinence *alone* is effective, and instead advocates a flexible approach to prevention.<sup>12</sup>

### **Tuberculosis, malaria and HIV together**

The overlap between HIV infection and tuberculosis (TB) is so enormous that it is the focus of a major strategy for the control and prevention of HIV.

‘TB is too often a death sentence for people with AIDS,’ Nelson Mandela said at the International AIDS Conference in Bangkok in July 2004. ‘Today we are calling on the world to recognise that we can’t fight AIDS unless we do much more to fight TB as well.’

Tuberculosis is the leading cause of death in people who are HIV-positive, and around 14 million people

around the world are infected with both HIV and the bacteria that causes TB. In some parts of Africa, up to 75 per cent of people carry both infections, yet only one in three of them have access to TB diagnosis and treatment facilities.

HIV weakens defences against TB, so that the organism becomes ‘active’ and causes fatal lung disease in an HIV-positive person, whereas it can reside harmlessly in an HIV-negative individual. Unlike HIV infection, however, TB is curable with the appropriate medication.

The provision of TB testing and treatment to HIV-positive people in the most severely affected areas could save the lives of as many as half a million people a year.<sup>13</sup> If patients with TB are tested for HIV and placed on ART if positive, this would help them to fight off TB.<sup>14</sup>

Targeting malaria may also help to prevent the consequences of HIV. Malaria is rife in many regions with HIV epidemics, especially in Africa. Although the effects of overlap are less clear than for TB, HIV may weaken defences against malaria, and can lead to higher death rates in babies born to affected mothers. HIV transmission from mother to child also increases if mothers have malaria during pregnancy. Some experts are therefore considering providing drugs against malaria to HIV-positive pregnant women as a way of minimising the danger of the two diseases coinciding – at least during pregnancy.

### **Patients need feeding!**

Christian Aid is deeply concerned that the food shortages that prevail in many of the countries worst affected by HIV greatly increase the adverse effects of HIV.

Overwhelmingly, food shortages in sub-Saharan Africa are now HIV-related, as families and communities in rural areas become increasingly less able to tend to their crops. Trapped in a cycle of poverty and inability to generate income through

food production, many people go hungry. Malnutrition and hunger make treatment adherence more difficult as people are less able to cope with the adverse effects of being on ART, such as nausea, dizziness and fatigue (see chapter 3). Nutritional support for people living with HIV strengthens their ability to cope with treatment. It is also vital for ensuring the continuing health of people living with HIV – whether or not they are receiving antiretroviral treatment. Good nutrition strengthens people's ability to fight off infections, and so can help to counteract some of the vulnerability that HIV-positive people have to devastating illnesses.

'You cannot address emotional needs of people living with HIV without addressing the need for food. Many organisations do one or the other – but Wola Nani does both,' says Pat Francis, director of Wola Nani, a Christian Aid partner based in Khayelitsha, South Africa.

### **Life beyond ART**

Effective care of people living with HIV also involves promoting self-sufficiency, which can include a range of skills training and the provision of loans for setting up small businesses, as well as food production.

Christian Aid partners around the world support the development of life skills for people living with HIV. In Cambodia, for example, the Mary Knoll Foundation advises people living with HIV on how to establish new livelihoods, depending on their interests and skills. 'They're no longer in a state of preparing to die. They have independence again. We visit them with their families and try to get them into a frame of mind so that they can support themselves,' says Father James Noonan. The clients also form their own support groups in which they discuss their future plans with each other.

The Foundation also has an income-generating programme in which people living with HIV produce and sell patchwork quilts, table-place mats and

napkins, as well as hanging baskets for plants. In the Democratic Republic of Congo, another Christian Aid partner, Amo-Congo, provides microcredit loans to people living with HIV to start their own income-generating projects.

Marie Mbuka is HIV-positive and runs a kiosk selling food, thanks to a starting donation of US\$100 from Amo-Congo. Before life 'was miserable', she says. First she lost a child, and then her husband to HIV-related illnesses in 1997. Marie then fled with her remaining three children to Kinshasa from their home in Kasai, because her brother-in-law wanted to take the children from her.

Amo-Congo is paying for Marie's children to go to school, and helping her obtain medicines for opportunistic infections. Meanwhile, Marie is gradually building up her business, selling items such as sacks of maize. 'I am very proud of this business. Now I can even give food to my sister's family!'

# 6 The battle continues

## The future control of HIV

‘We know we have the money, we know we have the means. We can prevent and treat HIV in every country so that this epidemic does not continue to destroy so many lives unnecessarily.’<sup>1</sup>

Dr Rachel Baggaley, Head of HIV unit, Christian Aid

### The future control of HIV

The future of HIV is in our hands: we now have the tools to bring many epidemics under control, and drugs with which to treat people living with HIV.

Meanwhile, scientific research is endeavouring to improve upon them and create new ones. But if they are ever to be fully effective in confronting HIV, these tools and drugs must reach everyone who needs them.

### Prevention tomorrow: vaccines and microbicides

In future, scientists hope to produce what may ultimately be the simplest and cheapest weapons against HIV: vaccines and substances known as microbicides.

Vaccines are intended to prepare the body to fight off HIV infection, and with just a single jab, and perhaps a booster shot or two, could in theory provide years of protection, as is already possible in the case of measles and polio. Microbicides on the other hand, are gels, creams or pessaries that women will be able to insert into the vagina, or for women and men to insert into the rectum, to protect against HIV infection during or after sex.

Both have the potential to be cheap, widely available, and to make a difference in circumstances where there are obstacles to existing prevention methods – such as when women are unable to persuade male partners to use condoms. But neither vaccines nor microbicides are options today – scientists are at too early a stage with their development, and too vexed with scientific and

logistical hurdles, to even be able to predict when such tools may become reality, particularly in developing countries.

For the time being, HIV prevention must focus instead on putting the tools we already have to proper use, and deploying them on a far wider scale than happens now.

### Prevention today

Some of the many existing prevention tools that we know work and which need further promotion include:

- **HIV awareness and education and life skills programmes** that alert and inform people about the danger of HIV infection are essential for bringing about change in sexual behaviour. They particularly need to target young people, given that the majority of new infections are occurring in those aged between 15 and 24
- **condoms** to prevent infection passing from men to women, women to men, and men to men, need to be made more widely available and promoted more vigorously to young people and general populations. In many parts of the world, cultural taboo, ‘machismo’ attitudes, reluctance and ignorance all play their part in stopping condoms being used for safer sex. Many organisations are now actively attempting to overcome these obstacles in order to promote condom use
- **voluntary counselling and testing** needs to be expanded if it is to reach some of the 90 per cent of people estimated to be infected with HIV

but who do not know their status. Clinics providing antenatal services, treatment for HIV, tuberculosis and sexually transmitted diseases, are all potential 'entry points' for HIV counselling and testing that need to be promoted for this purpose. Spouses, partners and family members of patients attending these services in areas of high HIV prevalence also need to be encouraged to take an HIV test. This happens already in the 'MTCT-plus' programmes being piloted in some African countries and in Thailand, in which the partners of pregnant women attending antenatal clinics are encouraged to seek HIV testing and treatment

- **clean needles** exchanged for used ones are effective in preventing HIV infection in injecting drug users. In too many areas, these are either not promoted, or are made available only as small-scale projects reaching out to just a minority of the people who need them
- **drug treatment to prevent mother-to-child transmission of HIV** needs to be made available to all HIV-positive mothers during pregnancy and delivery, and to their babies after birth. Ongoing studies of different ARV combinations aim to make prevention of mother-to-child transmission more effective and reduce current problems with drug resistance. Over the next two to five years, the results of new research will also indicate how to make breast-feeding safer in situations where mothers are unable to switch to giving their babies formula milk. Possibilities include the prolonged use of antiretroviral drugs during breast-feeding, and/or the injection of antibodies for the baby to stop HIV from gaining a foothold.

### **Value for money: the cost effectiveness of prevention**

With so many possible HIV prevention strategies to consider, and the paucity of funds for public spending in low- and middle-income countries, how can governments decide which strategy to fund? Even if a particular strategy is deemed cost

effective, it may not be affordable if it has to be provided to large numbers of people.

An analysis of interventions in Africa suggests that blood safety measures, condom distribution and treatment of sexually transmitted infections are the cheapest and most cost effective ways to avoid new infections. The use of nevirapine to prevent infection of babies by their mothers and drugs to combat tuberculosis are also cost effective, though more expensive.

The introduction of ART for those who are already infected may help reduce the size of epidemics through encouraging people to undergo counselling and testing, and adopting less risky behaviour. But more research is needed before the precise cost effectiveness of prevention through ART can be determined.<sup>2</sup>

### **All prevention strategies together**

When it comes to the value of life and the importance of human rights, however, Christian Aid believes that there is more to decision making about prevention strategies than cost effectiveness alone. More funds for the introduction of all available prevention strategies are critical to ensuring an adequate response to HIV.

UNAIDS recommends that in order to expand access to the full range of effective HIV prevention and treatment strategies, total spending on HIV must increase from US\$4.7 billion in 2003 to US\$20 billion by 2007.

### **Treatment and care for people living with HIV**

A vital part of coping with the HIV crisis is ensuring the proper treatment and care for those who are already infected with HIV – 38 million people are infected around the world, and an additional 14,000 new infections occur daily. To do so over many decades will require an unprecedented level of international commitment

and cooperation. The WHO's 3 by 5 initiative is making good but slow progress towards providing ART for free to at least some of those who desperately need it.

In order for 3 by 5 to succeed, a whole raft of improvements must take place. Firstly, more ARVs need to be made available and affordable to millions of people, and steady supplies need to be assured – remembering that once started, ART is for life.

More research is needed to produce new alternative drugs to overcome adverse side-effects and drug resistance, and manufacturing capacity needs to be expanded to meet present and future demand for drugs – both generic and brand-named originals.

Community and faith-based organisations, whose work underpins much of the success of HIV prevention and care, must wield greater influence in national and international decision making, to make sure that the needs and priorities of people living with HIV are met. They must also put pressure on governments to enact new legislation to ensure steady supplies of affordable drugs, either locally produced or imported.

Funds must be made available through the cancellation of debt repayments and larger donations from wealthy nations, so as to tackle entrenched problems such as poverty and lack of basic healthcare infrastructure.

Only by maintaining a broad attack on HIV, with many prevention, treatment and care strategies, can we hope to thwart a virus that has been with us for so little time, and yet has the potential to cause so much destruction.

# Recommendations

## **To the donor countries, member countries of the G8 and of the European Union:**

Increase funding for HIV prevention, care, treatment and support to an absolute minimum of US\$12 billion annually by 2005 and US\$20 billion by 2007.

Ensure that resources are not diverted from prevention to treatment; both must be increased.

Provide adequate financing to ensure ART is free at the point of use.

Give developing countries enough support to enable them to reach the international target of treating three million people with ART by the end of 2005.

Ensure prices of medicines continue to fall, by:

- supporting countries to use their right under TRIPS to override patents in the interests of public health, and refraining from bilateral trade deals which undermine this right
- working with the pharmaceutical industry to keep prices at a minimum for all developing countries.

Tackle poverty and HIV by:

- changing trade rules to ensure that poor-country governments can choose the best solutions to end poverty, and avoid policies that could worsen their HIV epidemics. These will not always be free trade policies
- cancelling in full the debts of the worlds' poorest countries
- providing 0.7 per cent of national income in international aid.

Some of these new funds would be used to improve health and education systems, which are vital for an effective HIV response.

Ensure the International Monetary Fund, in particular, reviews arbitrary public sector spending limits imposed on poor countries which prevent them from taking full advantage of resources available to them.

Dialogue between donor and recipient governments on HIV should be governed by a mutual commitment to human rights, and particularly the rights of women, orphans and other vulnerable children.

## **To developing country governments:**

Make HIV prevention, care and treatment a priority.

Ensure ART is free for people who need it.

Make ART treatment programmes safe and effective through community support by:

- providing basic information about ART
- combating stigma and discrimination, especially by supporting groups of people living with HIV
- facilitating equity of access
- supporting HIV counselling and testing
- providing long-term emotional, nutritional and financial support for people on ART, and providing care for the carers themselves.

Prioritise the development of health services, in particular improving the skills of staff and paying sufficient salaries to retain them.

Plan ART programmes that aim to contribute to improving the general health system rather than operating in isolation.

Ensure HIV is fully integrated into poverty reduction strategies.

Enact new legislation to prevent stigma and discrimination against people living with HIV/AIDS, eliminate gender inequality in access to education and employment, and protect women and vulnerable children against domestic violence and abuse.

# Notes

## Executive summary

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## 1. Getting worse – the global HIV/AIDS crisis

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## **6. The battle continues**

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Girls playing basketball in Nkwazi compound, Ndola, Zambia. Women in the hardest-hit countries are especially vulnerable to HIV as they face economic, legal and cultural disadvantages. In sub-Saharan Africa 57 per cent of adults infected are women and 75 per cent of young people infected are women and girls

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