

The beginning of the end of AIDS?

by David Deakin



Chris Boyd/Tearfund

The number of children being infected with HIV in Malawi has gone down rapidly in recent years.

Many of us can remember the situation with HIV and AIDS over a decade ago. New infections were still rising, especially among young people. Deaths from AIDS-related diseases were increasing rapidly, eventually peaking in 2005. Stigma was a huge problem for most people living with HIV. There were more than 15 million children orphaned by AIDS. As well as having a devastating impact on families, these issues were also damaging many countries' economies.

What was the church's reaction to this crisis? Unfortunately, at that time the church was often perceived to be part of the problem. Many congregations were still in denial that their members were dying from AIDS, and some believed that AIDS was a judgement from God.

Yet the last decade has seen amazing progress in the response to HIV and AIDS. The rate of HIV infections and deaths is slowing down, and world leaders are now

trying to end the AIDS epidemic by 2030. What has caused this transformation?

The world wakes up

Antiretroviral therapy (ART) has been available since the 1990s, but at first it was incredibly expensive, costing more than 10,000 USD each year for one person. Campaigns such as the Treatment Action Campaign (TAC) of South Africa were

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very successful in making ART much more affordable (see page 22 for more details).

The next important breakthrough was in July 2005 when the leaders of eight high-income countries (known as the G8) met at Gleneagles, Scotland. Influenced by a powerful advocacy campaign, the leaders agreed to work towards universal access to HIV prevention, treatment, care and support. They also made commitments to provide funding to achieve this goal.

After this meeting, the number of people receiving ART steadily increased. In 2005, fewer than 2 million people were receiving effective treatment. By March 2015, this number had grown to 15 million.

As a result of effective treatment, HIV-positive people are now living longer. The disease is no longer considered to be a 'death sentence', but instead has become a manageable long-term illness. With good

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treatment, HIV-positive people can now have a similar lifespan to people who do not have HIV.

Steps forward in prevention

When people first started trying to prevent the spread of HIV, the ABC approach was popular (**a**bstain from sexual activity, **b**e faithful, use a **c**ondom). However, this way of thinking was too narrow. The organisation INERELA+ developed the SAVE approach (Safer practices, Access to treatment, Voluntary counselling and testing, and Empowerment) to be more holistic, while still including the ABC principles (see page 19 for more details).

In 2007 a new prevention method was recommended by UNAIDS and the World Health Organization (WHO) – voluntary male circumcision. This reduces the risk to men of contracting HIV through heterosexual intercourse (although it only partially lowers the risk, so other methods of protection must also be used). Between 2007 and 2013, around 6 million men were newly circumcised in 14 countries in East and Southern Africa with a high prevalence of HIV.

Further progress in treatment

It was well known that ART could save lives. But in 2011, an important piece of research showed that effective ART could also help to prevent the transmission of HIV from one person to another. This is because ART can reduce the amount of HIV present in a person's body (known as their 'viral load'), to the point where it

cannot be detected in a blood test. When a person's viral load is this low, their risk of transmitting HIV to another person is greatly reduced (though they should still take other precautions).

Another development in HIV prevention was pre-exposure prophylaxis (PrEP). This is a special type of daily medication that can help to prevent people from becoming infected with HIV. It is intended for those who are at high risk of exposure to HIV (such as sex workers or people who inject drugs). Other protection methods must also be used, as it is not 100 per cent effective in preventing HIV from being passed on.

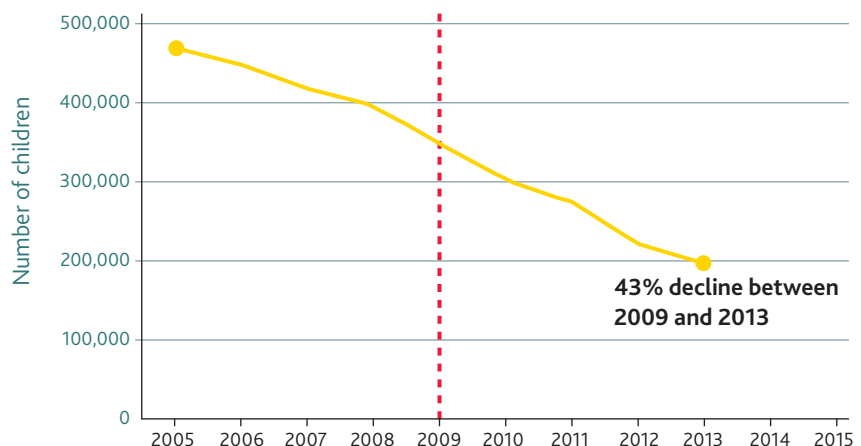
Preventing mother-to-child transmission

There has been great progress in preventing mother-to-child transmission of HIV. In 2011 the 'Global Plan' was launched, which aimed to stop children becoming infected with HIV and to protect the health of mothers. Without any health care interventions, a pregnant woman who is living with HIV has up to a 45 per cent chance of passing HIV on to her baby. However, with proper treatment, this risk can be reduced to below 5 per cent. In 2013 WHO recommended that all pregnant and breastfeeding women with HIV should be provided with ART.

The Global Plan focused on the 22 countries with the highest number of pregnant women living with HIV. Between 2009 and 2013 there was a remarkable 43 per cent decrease in the number of new HIV cases in children in 21 of these countries.

Number of new HIV infections among children, 2005-2013, in 21 Global Plan countries

Source: UNAIDS 2013 estimates



Future challenges

World leaders have set an ambitious goal of ending AIDS by 2030. At present there are still more than a million AIDS-related deaths a year, so dramatically reducing this figure in the next 15 years will be a huge challenge. There are currently more than 36 million people living with HIV, and all of these will need access to treatment. UNAIDS has set the target that, by 2020, 90 per cent of people will know their HIV status, 90 per cent of those living with HIV will be treated, and 90 per cent of those treated should have a viral load so low that it cannot be detected in a blood test.

There are many challenges to achieving this. One priority is making it easier to carry out viral load testing (measuring the amount of HIV in someone's blood to check, for example, how well their ART is working). Currently these tests are usually processed in a laboratory, requiring time and special equipment. It is much quicker and simpler if viral load testing can be carried out at the same time and place as a person's health care appointment. This is called point-of-care testing. Organisations such as UNITAID are working to make these tests more affordable and widely available to health care services.

Another challenge is helping people to access second- and third-line ART. When someone begins ART, the combination of medicines they are given is called 'first-line' therapy. However, if their strain of HIV becomes resistant to the medication, or if they experience bad side effects, they will need to change to a different combination of medicines. This is called 'second-line' or 'third-line' therapy. In many countries, first-line ART is now available at an affordable price, but second- and third-line medicines cost much more. This is because some pharmaceutical companies have patents for these medicines, meaning that other manufacturers are not allowed to produce them. Advocacy initiatives that overturn pharmaceutical patents will become even more important in the coming years.

Perhaps the ultimate challenge is the development of a vaccine against HIV.

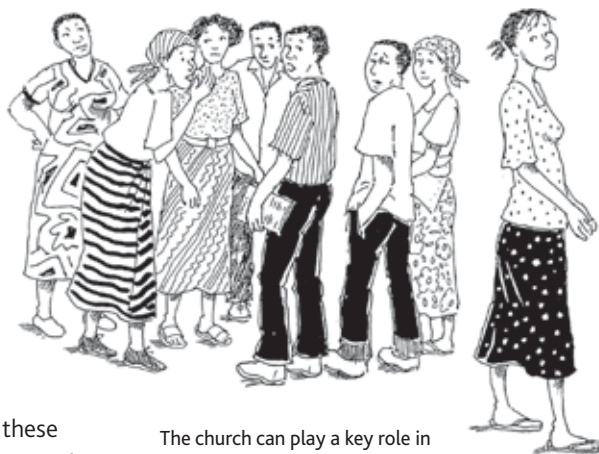


Illustration: Petra Röhr-Rouendaal, 'Where there is no artist' (second edition)

The church can play a key role in challenging stigma and discrimination.

Scientists have not yet been able to achieve this, but research is ongoing.

No one left behind

As progress is made in prevention and treatment, another challenge is ensuring that vulnerable groups of people are not left behind. People who often find it harder to access treatment include children, sex workers, men who have sex with men, injecting drug users and people with disabilities. Sometimes people living with HIV are also suffering from other illnesses (for example, TB and Hepatitis C), and these diseases need to be dealt with better. Although stigma around HIV has reduced, there is still a huge amount of stigma against many of these groups of people. This is an area where the church could play a much greater role in the future, if it is courageous enough.

A unique opportunity

There has been dramatic progress over the last ten years in addressing the huge challenges posed by HIV. The outlook now is so much more positive. But with more than a million people still dying every year because of AIDS, the task is as urgent as ever.

More than 30 years since HIV was identified, the global AIDS response is at a crossroads. We can invest now to end AIDS by 2030, or we can simply maintain the current efforts and potentially miss this unique opportunity. Let's pray and act to ensure that AIDS is beaten for good.

David Deakin is Tearfund's HIV Team Leader.

EDITORIAL



Zoe Burden

Warm greetings to all our readers around the world. My name is Zoe, and I've temporarily joined the *Footsteps* editorial team while Helen Gaw is on maternity leave (and I'm delighted to let you know that Helen gave birth to a healthy baby girl in April).

This edition focuses on HIV, celebrating the progress made so far and highlighting innovative ideas for meeting future challenges. At *Footsteps* we have covered HIV in several previous editions, starting with *Footsteps 6* in 1991. So much has changed since then. Advances in the quality and availability of treatment mean that HIV has gone from being a 'death sentence' to a manageable condition (pages 1 to 3). HIV prevention has expanded to include more than just sexual behaviour (page 19). There have been massive steps forward in preventing mother-to-child transmission (pages 8 and 9). Great work has been done on tackling stigma and discrimination, and brave individuals within the church have played an important role in this (pages 16–17). Much has been achieved, but there is much still to do if we are to achieve the goal of ending the AIDS epidemic by 2030.

It has been exciting to see the new innovations in responding to HIV and AIDS, such as the Alongsiders movement in Cambodia (page 5) and the Freedom Programme's work in Egypt (page 18). In this edition we are experimenting with an innovation of our own – expanding *Footsteps* to include eight extra pages. We would love to hear your views on whether this is helpful. Please email us at publications@tearfund.org with your thoughts, or write to us at the address on page 2. We love to hear from you!

As you read this edition, I hope you will feel as encouraged as I do by the progress made so far, and that it will inspire us all to be part of God's solution to HIV in the years ahead.

Zoe

HIV: myths and realities

Inaccurate information can add to the fear and stigma that surround HIV. It can also increase people's risk of transmitting or becoming infected with the virus. Here are some common myths about HIV, followed by explanations of why the reality is different.

MYTH 1:
'HIV and AIDS are the same thing.'

REALITY: HIV is a virus that attacks people's immune system. HIV can lead to AIDS, but not everyone with HIV has AIDS. When HIV weakens the immune system so much that the body becomes infected with a number of different infections and diseases, we call this condition AIDS. However, with antiretroviral therapy (ART), you can prevent HIV from developing into AIDS.

MYTH 2:
'If you have HIV, you will die soon.'

REALITY: In the 1980s, the death rate from AIDS was very high. But now, with properly managed ART, HIV does not have to lead to AIDS. With ART, HIV-positive people can live long, productive and healthy lives.



MYTH 3:
'You can only get HIV through risky sexual behaviour.'

REALITY: Although HIV can be transmitted through unprotected sex, there are other ways of contracting the virus.

HIV can only be transmitted in the following ways:

- having unprotected sex (anal, vaginal or, less commonly, oral) with someone who is HIV-positive
- using non-sterile needles or blades that have been used on someone living with HIV – for example, when injecting drugs
- from mother to child during pregnancy, childbirth or breastfeeding
- through HIV-infected blood transfusions or blood products (check that the blood has been tested for HIV).

MYTH 4:
'You can get HIV through kissing, hugging, sharing cups, sharing toilets or being bitten by mosquitoes.'

REALITY: HIV has to get inside another person to cause infection. It is not transmitted through the air or water, and does not survive for long outside the human body. Saliva, sweat and tears do not contain enough HIV to infect another person. HIV is not spread through hugging, sneezing, coughing, sharing toilets, sharing clothes, holding or shaking hands, sharing food and drink, or being bitten by a mosquito. Unless both partners have open sores or cuts in their mouths, there is no risk of HIV transmission from kissing.

MYTH 5:
'There is no need to use a condom during sexual intercourse if both partners already have HIV.'

REALITY: There is more than one kind of HIV, and it is possible to be re-infected with another type of the virus. Even if both partners are living with HIV, they should make sure they protect themselves from re-infection by always using a condom and using it correctly. A health worker can

provide advice on how to do this (see also 'Useful websites' on page 14).

MYTH 6:
'If someone who is on ART feels better, they can stop taking their medication.'

REALITY: It is very important for people living with HIV to continue taking their medication even when they are feeling well. If they stop their ART, the amount of HIV in their bodies will increase again. The gap in treatment can also give the virus a chance to become resistant to the medicine, making it harder to treat.

MYTH 7:
'HIV can be cured with traditional medicines, or through having sex with a virgin.'

REALITY: These ideas are untrue and dangerous. There is currently no cure for HIV, but with ART it can be managed and controlled so that people can live healthy, productive lives.

Words used in this issue

Antiretroviral (ARV) medication is special medicine that slows down the development of HIV into AIDS. A combination of ARVs is used in antiretroviral therapy (see below).

Antiretroviral therapy (ART) uses a combination of special medicines (usually three or more) to slow down or prevent the development of HIV into AIDS.

Palliative care is care that is given when little can be done to make the patient healthy again. This might involve reducing pain and making the patient comfortable.

Patent means a licence giving exclusive permission to make, use or sell an invention (such as a medicine).

Sterile means completely free from all germs.

Viral load is the amount of HIV present in someone's body.

Coming alongside vulnerable children



Hanna Tzou, Alongsiders

After Chenda was orphaned at the age of eight, she was mentored by a young woman from her church. Now aged 18, Chenda has become an Alongsider mentor herself to Vary, whose mother also died.

In 2013 there were 17.8 million children around the world who had been orphaned as a result of AIDS, losing one or both parents.

Children orphaned by AIDS

Children orphaned by AIDS are vulnerable to a wide range of problems. Firstly, they will have to deal with the emotional pain of the death of a parent. In addition, the household's income is likely to decrease, which could result in children lacking physical necessities such as food, shelter and health care. These children might have to take on additional responsibilities in the home. They may also face stigma from people who associate them with AIDS.

The Alongsiders approach

How can we help children who have been orphaned by AIDS? One innovative approach has been developed by the organisation Alongsiders. Although Alongsiders started in response to AIDS, it has now expanded to work with any children in the local community who are vulnerable, marginalised and alone. Alongsiders trains young people to be mentors (known as 'Alongsiders') to love and encourage a 'little brother or sister' – a vulnerable child in the same community who would benefit from support.

Alongsider mentors are usually aged between about 16 and 35. People who want to become mentors need a recommendation from their pastor, and the church is advised to check that they are suitable to work with children.

How Alongsiders grew

In 2000 the founder of Alongsiders, Craig Greenfield, started an orphan care movement in the slums of Phnom Penh, Cambodia, empowering and supporting communities to look after their own orphans.

However, Craig and his wife felt frustrated that they could only help a small number of children. They realised that hiring more paid staff was not the answer. Instead, Craig set up a volunteer movement of young Cambodian Christians who could reach thousands of children all across the country. Today, hundreds of young Christians mentor one vulnerable child each in their own communities, and the movement has spread into seven provinces of Cambodia.

Most of the first group of 'little brothers and sisters' are now in their early 20s. Many have become leaders in their churches and communities, and a large number of them have gone on to become Alongsider mentors themselves.

In 2013 Alongsiders set up similar movements in Indonesia and India. They now want to expand into Asia, Africa and beyond, and are eager to partner with church networks and denominations.

What do Alongsider mentors do?

Alongsider mentors visit their 'little brothers and sisters' at least once a week. Most spend two or three hours together.

- They eat together.
- The Alongsider mentors provide help with homework and reading and writing.
- Some read the Bible together.
- They work through the Alongsiders curriculum together, learning about practical and spiritual topics presented in a fun, comic book format.
- Some of the Alongsider mentors have chosen to take their 'little brothers and sisters' to buy school supplies using their own money.
- Most of the Alongsider mentors help their 'little brothers and sisters' with hygiene and cleanliness – for example, helping them wash their clothes.
- Where appropriate, mentors will support their 'little brother or sister' to take any medicines they need. For children living with HIV, this would include their ART medication.
- All the Alongsider mentors pray for their 'little brothers and sisters' in their personal prayer times, and some pray for them when they are together.
- Once a year they attend an Alongsiders camp together.

With thanks to Craig Greenfield.

Write to info@alongsiders.org if your denomination would like to partner with Alongsiders to start a similar movement. Alternatively, you can write to Alongsiders at PO Box 2475, Phnom Penh, Cambodia.

➤ Ideas for using this article

- In a group, discuss what you think works well about the Alongsiders approach.
- Discuss how your church or community can support vulnerable children, such as those who have been orphaned as a result of AIDS or who are experiencing other difficulties.

Health tips for living positively with HIV

by Elijah Ogeda

If you are living with HIV, you need to take good care of yourself and follow extra precautions to protect your health and immune system. By keeping your body as healthy as possible, you can help it to fight off viruses and other types of infections.

People living with HIV need to incorporate healthy habits into their lifestyle. Following these eight tips can help.

1. Practise safer sex

Following safer sexual practices is essential. Make sure you understand how HIV is transmitted to reduce the risk of passing it on to others. Always use condoms and make sure you put them on correctly. This not only helps to avoid the spread of HIV, but will also help to protect both you and your partner against other sexually transmitted infections (STIs).

2. Get tested for other sexually transmitted infections

If you have an STI in addition to HIV, you may be more likely to transmit both HIV and your STI to someone else. Some STIs can also worsen HIV and make it progress more rapidly. HIV can make some STIs more difficult to treat, so you need to seek medical help for an STI as soon as possible. Getting tested is

essential because many STIs do not cause any symptoms – without testing, you may not even realise that you have one.

3. Prevent infections and illnesses

Since HIV makes your immune system less effective, you become more vulnerable to all the viruses, bacteria and germs that you are exposed to. Wash your hands frequently to help prevent diseases, and make sure that all of your vaccinations are up to date.

4. Follow your doctor's instructions about your medication

It is very important to take your HIV medication exactly as prescribed by your doctor. Missing even one day of antiretroviral therapy (ART) can give the virus an opportunity to become resistant to the medicines, making them ineffective. Always have your medication with you so that if you are away from home, you will not miss a dose.

5. Eat a healthy, balanced diet

If your body is well nourished, it will be better able to cope with HIV and fight infections. Try to eat a variety of foods every day, including plenty of fruit and vegetables. If you are living with HIV you will need ten per cent more calories than someone who is not HIV-positive, and up to 30 per cent more if you are recovering from an illness. Ask your

health worker for advice about the best diet for your situation.

6. Stop smoking and avoid drug or alcohol abuse

Giving up cigarettes is beneficial for anyone. Stopping smoking will help you to feel better and live a healthier life, and will greatly reduce your risk of serious problems such as heart disease, cancer and stroke.

Alcohol and drug abuse is damaging to your health and can increase feelings of depression. Try to avoid any form of illegal drugs.

7. Manage physical and emotional health problems

Everyone's experience of living with HIV is different. Some people may experience depression or feelings of anxiety and stress. These can worsen any physical pain associated with HIV. Keeping stress, depression and pain under control can help improve your physical and emotional health. See a mental health professional if you feel you are experiencing depression, and be sure to mention whether you are taking medication for HIV.

8. Exercise your mind and body

Physical and mental exercise can keep your mind and body strong. Regular physical exercise, such as walking, cycling, running or swimming, keeps you physically fit and can lessen stress and depression. Physical exercise helps the immune system as well. Allow your body to recharge each night with enough sleep. Mental exercise, such as doing a daily crossword puzzle or playing brain-challenging games, can improve your memory and concentration.

Many people feel powerless when they are diagnosed with HIV, but this is not the case. By following the tips above, you can take control and live a healthy, active life.

Elijah Ogeda is a Footsteps reader from Kenya.



It is important for people living with HIV to eat a healthy, balanced diet.

Healing and antiretroviral therapy (ART)

Adapted from Hand in hand: Bible studies to transform our response to HIV, edited by Isabel Carter and Maggie Sandilands

Read 2 Kings 5:1-15

This story focuses on some really important 'big' people – Naaman (a great army commander), the King of Aram and the King of Israel. However, it is the humble people, the servants, who see and understand God at work and who are used to transform Naaman's understanding. God's prophet Elisha doesn't provide the miraculous cure Naaman expects. Rather, Naaman has to humble himself and accept a simple and practical healing in which he has to participate.

God's miraculous provision

The discovery of antiretroviral therapy (ART) has removed the 'death sentence' which was formerly associated with HIV and AIDS. It is possible to be returned to good physical health, through both treatment and prayer, while HIV remains in our body.

Healing is different from a cure. There is currently no known cure for HIV. However, God's miracles occur in different ways for different people. We have prayed for God to help doctors find a way to treat HIV infection. ART is God's miraculous

provision, now available to many. All healing comes from God, and the God who is behind scientific discoveries is the same God behind spiritual healing.

How should we respond?

It is good to pray for healing for people with HIV while encouraging them to benefit fully from medical services. However, it is false and dangerous to tell people to have faith that God will cure them and that taking ART shows a lack of faith.

Those of us knowing or suspecting that we have HIV must take full responsibility not to pass it on to others. Those of us who do not have HIV must take full responsibility not to get it. As a church we need to pray with people and also encourage those of us living with HIV to obtain and continue with ART (even when we feel better). In the end, God heals all of us through death, ending suffering on earth and bringing us to eternal life with him.

For more information on Hand in hand: Bible studies to transform our response to HIV, see the Resources section on page 14.



Illustration: Amy Levene

Discussion questions

- *What kind of healing was Naaman expecting from the prophet Elisha? Why was Naaman at first unwilling to follow Elisha's advice?*
- *How did Naaman's servants help him?*
- *Are there people among us like the people in the story? Who encourages people to go for testing and treatment? Who helps people to continue taking their ART?*
- *What kinds of treatment and healing has God provided for those of us living with HIV? Why is it important to continue with treatment and prayer even when we feel better?*
- *What does God want us, as his church, to do to promote health and healing for those of us living with HIV?*

'ARV treatment is God's mercy to me!'

Vladimir grew up in a poor family in Russia, and started using drugs at a young age. Through using non-sterile injecting equipment, he contracted HIV.

Ten years later, Vladimir's life was dramatically different. He had encountered God powerfully in his life, and had received emotional and practical support from a Tearfund partner. All this had helped him to break free from drug addiction. He even started leading a church project reaching out to other drugs users.

Vladimir's faith in God was strong. However, he believed that God would show him mercy by curing him of HIV. He therefore rejected the advice of his friends and doctors to start taking antiretroviral medications (ARVs). Instead, he waited expectantly on the Lord.

One day Vladimir attended a workshop run by Tearfund's partner organisation Pure View. He heard new facts about the human immune system and learnt more about the way ARVs work. This led to a revelation for Vladimir.

'I understood that ARV treatment is God's mercy to me!' he says. 'This is his plan to provide us with the ability to control HIV so we can live and serve him. When I realised this amazing plan, I cried, and thanked God for the hope that I have had from him, but did not want to believe in.'

Making an impact:

Tearfund's work on HIV

by David Deakin

Tearfund has been responding to HIV through local partner organisations since 1991. In 2006 Tearfund launched an ambitious ten-year plan to stop the spread of HIV and reverse the impact of AIDS in all of the communities where its partners were working. In particular, it aimed to change the church from being part of the problem to becoming part of the solution.

This strategy has been effective and has achieved some great results. For example:

- In Ethiopia and Malawi, a network of churches worked together to change inaccurate knowledge, unhelpful attitudes and risky behaviours relating to HIV and sexuality.
- Tearfund's partners in Russia have helped injecting drug users (IDUs) to protect themselves against HIV and to recover from drug addiction.
- Tearfund produced the *Think livelihoods!* toolkit to help people living with HIV to develop sustainable livelihoods (see the Resources page for more details).
- Tearfund's church-based partners helped to improve palliative care for people living with HIV. This included helping people to access pain relief medication and providing spiritual and psychological support to individuals and their families.

These achievements have shown that real progress can be made through mobilising churches and communities.

Protecting children from HIV

One of Tearfund's main priorities was preventing parent-to-child transmission of HIV. However, it soon became clear that even if HIV transmission was prevented, the mother or baby could die during pregnancy or in the first year after the birth.

Tearfund therefore developed an approach called IMPACT (Improving Parent and

Child Outcomes). IMPACT aimed not only to prevent parents passing HIV on to their children, but also to help reduce death and disease among mothers and babies. The IMPACT framework covers everything from family planning, through pregnancy and birth, to six months after the baby is born.

One of the main innovations of the IMPACT approach is a scheme called 'Mother Buddies'. Mother Buddies are trained volunteers who visit vulnerable pregnant women eight times, during pregnancy, after birth and up to six months after delivery. The Mother Buddies are equipped with a smartphone and software that guides them through the key questions to ask in each of the eight visits. The phones also store helpful training and spiritual resources, and allow the Mother Buddies to collect data on the women they care for.

Inspiring results

So far, Tearfund has introduced the IMPACT programme in Malawi, Nigeria, DRC and Tanzania. Results from Malawi have already shown significant improvements for women supported by Mother Buddies compared to women who have not had this help. For example:

- There was a 38 per cent increase in the number of pregnant women attending four antenatal care visits (as recommended by the World Health Organization).

- The number of men accompanying their female partners to antenatal care appointments went up by 28 per cent.
- The number of women going for counselling about family planning increased by 34 per cent. Similarly, the number of women using modern contraceptive methods went up by 22 per cent.
- Women supported by Mother Buddies had better standards of nutrition, and were 40 per cent more likely to have three meals a day.
- The Mother Buddies project also benefited the wider community. By the end of the project, more children were being tested for HIV and more HIV-positive people were using antiretroviral therapy (ART).
- The community's knowledge about parent-to-child transmission of HIV also increased. Clinic results showed that the rate of mother-to-child transmission of HIV had more than halved by the end of the project.

These are just some of the results indicating the amazing impact that Mother Buddies are having.

David Deakin is Tearfund's HIV Team Leader.

For more information on Mother Buddies, please contact David on davidgdeakin@gmail.com or write to his colleague Veena O'Sullivan on veena.osullivan@tearfund.org

Chris Boyd/Tearfund



Mother Buddies are transforming communities in Malawi.

Baby Edward is born HIV-free

Deborah is from a southern region in Malawi, where one in seven people is living with HIV. In 2007, after her health started to deteriorate rapidly, Deborah was tested for HIV. She was found to be HIV-positive and was advised to start treatment straight away.

When she found out she was pregnant in 2012, Deborah had many concerns about the future of her child. She did not want to pass HIV on to her baby. Thankfully, Deborah was introduced to a Mother Buddy called Emma. Emma is also HIV-positive, and has given birth to four HIV-free children. Emma visited

Deborah during and after her pregnancy, providing practical advice, emotional support and counselling to Deborah and her husband.

'My Mother Buddy reminds me about collecting the treatment,' says Deborah. 'We can ask lots of questions that we would otherwise be scared to ask.' Emma also encouraged Deborah to give birth in the local clinic rather than at home, making a healthy delivery much more likely. Happily, Deborah's baby Edward was born HIV-free. 'I was so happy and excited about the results,' says Deborah.

Emma is an inspiring role model in her community. However, her own story is a

painful one. When she first discovered she was living with HIV, her husband refused to be tested and abandoned her. But Emma uses even this sad experience to help the women she supports. 'The first thing I do is share my story,' she says. 'Then they are reassured and can trust me.'

The Mother Buddies are having an amazing impact in this community in Malawi. 'The most rewarding thing is the happiness and appreciation of the mothers who have not lost their babies,' says Emma. 'When I hear these stories I feel so proud.'

Top ten tips from a Mother Buddy

by David Deakin

Below are ten of the most important pieces of advice that a Mother Buddy might give to a pregnant woman she is supporting.

- 1 Make sure you have at least four antenatal care visits with a trained health worker during your pregnancy. 
- 2 Give birth in a clinic or hospital, attended by a professional health worker (a doctor, midwife or nurse). 
- 3 Make sure that you get tested for HIV. If the results show that you are HIV-positive, ensure that you receive antiretroviral therapy (ART).
- 4 If you have a male partner, encourage him to attend antenatal care appointments with you and be tested for HIV and syphilis. If the results show he is HIV-positive or has syphilis, he should start treatment. 
- 5 Make sure you have a birth plan, including an emergency birth plan. (You can find more information about birth plans in *Footsteps 91: Maternal Health*.)
- 6 Eat a healthy, balanced diet during your pregnancy. 
- 7 If you live in an area with a risk of malaria, sleep under an insecticide-treated mosquito net. This is because catching malaria during pregnancy can damage your baby's health, as well as your own. (However, it is important to know that HIV is not spread by mosquitoes.) 
- 8 Make sure you receive counselling on all aspects of family planning. This may be available at your local health clinic.
- 9 Follow the right guidelines about breastfeeding, with support from your Mother Buddy. Also, make sure your baby gets the vaccinations he or she needs. 
- 10 If there is a chance that your baby might have been exposed to HIV (for example, if you are living with HIV yourself), make sure he or she is tested for HIV at six weeks of age. If the results show that your child is HIV-positive, he or she should start on ART immediately. 

Breastfeeding and HIV

Breast milk is the perfect food for babies. It provides important nutrients and strengthens their immune system. Breastfeeding helps to protect babies from malnutrition and diseases such as diarrhoea and pneumonia, which can be fatal.

Unfortunately, there is a risk that HIV can be passed from mother to child during breastfeeding. However, with the right actions, that risk can be lowered to less than five per cent.

Should women living with HIV breastfeed?

The decision about whether or not HIV-positive mothers should breastfeed their babies is a complicated one. According to the World Health Organization (WHO), a country's health authorities should decide whether to advise women living with HIV to breastfeed or not.

The health authorities will make this decision based on the local situation, considering factors such as the main health risks in that region. For example, some areas do not have a good supply of clean water and reliable sanitation, meaning the risk of diarrhoea is high. In these regions, it might be more dangerous for the baby's health if it is **not** breastfed by its HIV-positive mother.

There are only two options the authorities should decide between:

EITHER

Mothers living with HIV should not breastfeed at all, but use other sources of nutrition for the baby (known as 'replacement feeding').

OR

Mothers living with HIV should **exclusively** breastfeed their baby for the first six months (see box). The mothers should receive antiretroviral therapy (ART) and the baby should be given ARV medication.

The option that is **never** recommended for HIV-positive mothers during the first six months after birth is 'mixed feeding'. This is using a combination of breastfeeding and other types of food and drink. Other

food and drink (such as porridge, cows' or goats' milk, or even water) can damage the lining of the baby's digestive system during this period, making it easier for HIV from breast milk to infect the baby.

You can ask your health worker for more information about whether breastfeeding is advised for women living with HIV in your region.

How to reduce the risks

ART FOR MOTHERS

All women living with HIV should receive ART during their pregnancy and while they are breastfeeding. This greatly lowers the risk of the mother passing HIV on to her baby. It is very important that the mother takes her ART regularly, exactly as prescribed by the doctor.

Countries have different policies about how long they will continue providing ART for mothers living with HIV.

- Some countries will provide the mother with ART for the rest of her life.
- Other countries will supply the mother with ART until one week after she stops breastfeeding. They will then only continue to provide ART if HIV has damaged her health to a certain level.

ARV MEDICATION FOR BABIES

- If a mother living with HIV is breastfeeding her HIV-negative baby, the baby should be given ARV medication for the first six weeks.
- If an HIV-positive mother is not breastfeeding, the baby should still be given ARV medication for four to six weeks after birth. (If at any point, after testing, the baby is found to be HIV-positive, it should start on ART immediately.)



Illustration: Petra Rohr-Rouendaal, *Where there is no artist* (second edition)

Breastfeeding advice for women living with HIV

The following advice applies only in countries and regions where the health authorities recommend breastfeeding to women living with HIV.

EXCLUSIVE BREASTFEEDING FOR SIX MONTHS

For the first six months after birth, the baby should only be fed with breast milk. It should not be given any other types of food or drink.

FROM SIX MONTHS ONWARDS

- After the first six months, the mother can start giving the baby other food and drink as well as breast milk.
- The mother should carry on breastfeeding until the baby is 12 months old. She should only stop breastfeeding when the baby can get enough food and nutrition without breast milk.

This article is based on the World Health Organization's Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection, 2013.

This article is accurate at the time of printing in August 2015. However, advice on breastfeeding can change over time, so please check with your health worker to make sure that the information in this article is still correct.

Designing a programme? Think HIV!

by Shannon Thomson

The response to HIV is changing. We are moving from programmes specifically tackling HIV to responses that include HIV but also address other issues. Some people refer to this as 'HIV mainstreaming'.

What is mainstreaming?

HIV mainstreaming just means thinking about HIV in all of our development responses. It means seeing people living with HIV as a unique group within any community programme, whether it is dealing with food security, livelihoods, WASH (water, sanitation and hygiene) or another sector.

Mainstreaming means understanding that people living with HIV have additional needs to the wider community. These needs may not be met unless we specifically address them. By mainstreaming HIV, we not only improve our response for people living with HIV, but we also avoid damaging the results of development programmes by ignoring this special group.

More than 36 million people worldwide were living with HIV at the end of 2014. In sub-Saharan Africa, nearly 1 in 20 people are HIV-positive. If you are a development professional working in a community, it is very likely that you are working with people living with HIV.

Practical ideas for HIV mainstreaming

Consider these suggestions for ways to integrate HIV more meaningfully into your work.

- 1. Programme design** Have you consulted with groups of people living with HIV to understand any specific needs they may have within the programme?
- 2. Monitoring and evaluation** Have you included HIV-specific indicators in your monitoring and evaluation framework? (You can find examples of

indicators on page 27 of the Trócaire resource listed below.)

- 3. Organisational capacity** Does your organisation have a workplace HIV policy? Are your staff trained to understand issues related to HIV? Do you have access to additional technical support on HIV if needed?
- 4. Inclusion** Have you considered marginalised groups? People living with HIV can often be marginalised in general, but there are also specific groups of people living with HIV who are even more severely affected by stigma. These groups include sex workers, injecting drug users, men who have sex with men, migrant workers and the LGBT (lesbian, gay, bisexual and transgender) community.
- 5. Basic needs** How are people meeting their basic needs (housing, education, health care and food security)? Do people living with HIV have any specific needs that frequently are not being met?
- 6. Understanding vulnerability** Does the community you are working with understand what makes a person vulnerable to HIV infection? How confident are people to address these vulnerabilities themselves?
- 7. HIV services** What services are available for people living with HIV? How can you develop ways of referring people to these services?

Understanding the issues

It is important for development workers to have a good understanding of HIV and related issues in order to mainstream them effectively.



Richard Hanson Tearfund

People living with HIV have an increased risk of acquiring diarrhoeal disease from unsafe water and sanitation.

DID YOU KNOW...?

- Adults living with HIV need ten per cent more calories than people who are not HIV-positive, just to sustain their bodies while taking ART.
- HIV stigma can be strong enough to affect a person's livelihood. In some communities, people will refuse to buy items in the marketplace from someone living with HIV.
- A person living with HIV is up to six times more likely to suffer from diarrhoeal diseases if they do not have access to safe water and sanitation.
- In some regions, women who experience violence from an intimate partner are 1.5 times more likely to acquire HIV than women who do not suffer partner violence.

HIV mainstreaming resources

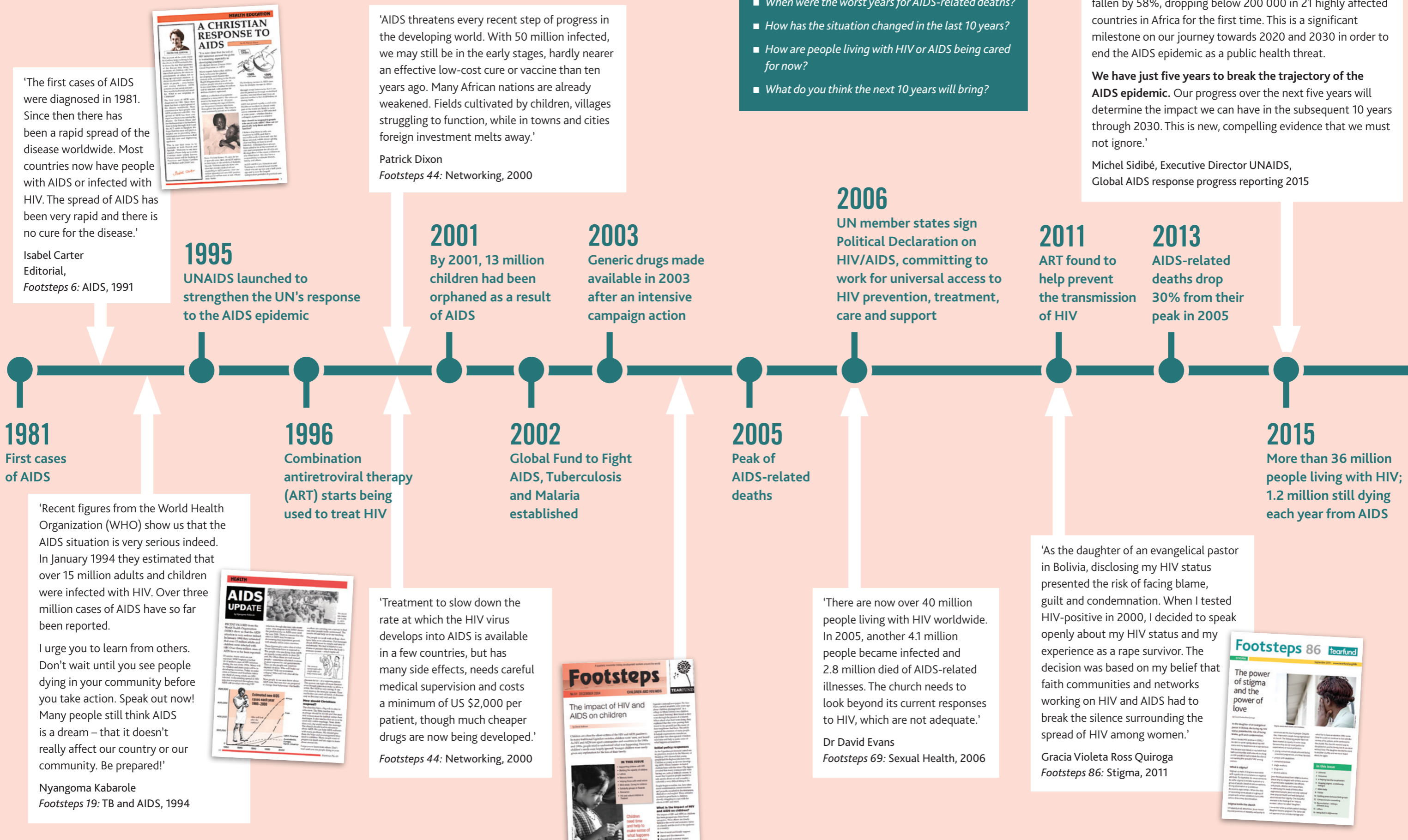
- Visit www.stopaids.org.uk to download useful factsheets on HIV and WASH, HIV and livelihoods, and HIV and violence against women (click on 'Our work', then 'Information exchange', then 'Factsheets'). Available in English only.
- Visit www.trocaire.org and type 'HIV mainstreaming' in the search box to download Trócaire's *HIV mainstreaming resource pack*. Available in English only.

Shannon Thomson is the Projects Officer for Tearfund's HIV Unit.

HIV and AIDS: the story so far...

compiled by Alice Keen

Statistics from various sources including UNAIDS, the Global Fund and WHO



'The first cases of AIDS were diagnosed in 1981. Since then there has been a rapid spread of the disease worldwide. Most countries now have people with AIDS or infected with HIV. The spread of AIDS has been very rapid and there is no cure for the disease.'

Isabel Carter
Editorial,
Footsteps 6: AIDS, 1991



'AIDS threatens every recent step of progress in the developing world. With 50 million infected, we may still be in the early stages, hardly nearer an effective low-cost cure or vaccine than ten years ago. Many African nations are already weakened. Fields cultivated by children, villages struggling to function, while in towns and cities foreign investment melts away.'

Patrick Dixon
Footsteps 44: Networking, 2000

- Questions for group discussion**
- When was the first case of HIV in your community?
 - When were the worst years for AIDS-related deaths?
 - How has the situation changed in the last 10 years?
 - How are people living with HIV or AIDS being cared for now?
 - What do you think the next 10 years will bring?

'Since 2001, new HIV infections have fallen by 38%. Even better news is that new infections among children have fallen by 58%, dropping below 200 000 in 21 highly affected countries in Africa for the first time. This is a significant milestone on our journey towards 2020 and 2030 in order to end the AIDS epidemic as a public health threat.'

We have just five years to break the trajectory of the AIDS epidemic. Our progress over the next five years will determine the impact we can have in the subsequent 10 years through 2030. This is new, compelling evidence that we must not ignore.'

Michel Sidibé, Executive Director UNAIDS,
Global AIDS response progress reporting 2015

1981
First cases of AIDS

'Recent figures from the World Health Organization (WHO) show us that the AIDS situation is very serious indeed. In January 1994 they estimated that over 15 million adults and children were infected with HIV. Over three million cases of AIDS have so far been reported.'

I urge you to learn from others. Don't wait until you see people dying in your community before you take action. Speak out now! Many people still think AIDS is a dream – that it doesn't really affect our country or our community. Be prepared!'

Nyangoma Kabarole
Footsteps 19: TB and AIDS, 1994



1995
UNAIDS launched to strengthen the UN's response to the AIDS epidemic

1996
Combination antiretroviral therapy (ART) starts being used to treat HIV

'Treatment to slow down the rate at which the HIV virus develops into AIDS is available in a few countries, but has many side effects, needs careful medical supervision and costs a minimum of US \$2,000 per patient, though much cheaper drugs are now being developed.'

Footsteps 44: Networking, 2000

2001
By 2001, 13 million children had been orphaned as a result of AIDS

2002
Global Fund to Fight AIDS, Tuberculosis and Malaria established



2003
Generic drugs made available in 2003 after an intensive campaign action

2005
Peak of AIDS-related deaths

'There are now over 40 million people living with HIV worldwide. In 2005, another 4.1 million people became infected and 2.8 million died of AIDS-related illnesses. The church needs to look beyond its current responses to HIV, which are not adequate.'

Dr David Evans
Footsteps 69: Sexual Health, 2006

2006
UN member states sign Political Declaration on HIV/AIDS, committing to work for universal access to HIV prevention, treatment, care and support

2011
ART found to help prevent the transmission of HIV

'As the daughter of an evangelical pastor in Bolivia, disclosing my HIV status presented the risk of facing blame, guilt and condemnation. When I tested HIV-positive in 2000, I decided to speak openly about my HIV status and my experience as a rape survivor. The decision was based on my belief that faith communities and networks working on HIV and AIDS had to break the silence surrounding the spread of HIV among women.'

Gracia Violeta Ross Quiroga
Footsteps 86: Stigma, 2011



2013
AIDS-related deaths drop 30% from their peak in 2005

2015
More than 36 million people living with HIV; 1.2 million still dying each year from AIDS

TILZ website www.tearfund.org/tilz Tearfund's international publications can be downloaded **free of charge** from our website. Search for any topic to help in your work.



Previous *Footsteps*

Visit www.tearfund.org/footsteps to download previous editions of *Footsteps* that include material on HIV and AIDS.

- *Footsteps 91* Maternal health
- *Footsteps 86* Stigma
- *Footsteps 61* Children and HIV
- *Footsteps 44* Networking: HIV and AIDS

Please note that, because the global HIV situation changes so quickly, some information and statistics will now be out of date.

Guardians of our children's health toolkit

This training kit, produced by Tearfund, explains how men and women can reduce the risk of transmitting HIV to their children. It particularly focuses on strengthening men in their roles as guardians of the health of their families. The toolkit has a biblical perspective, but can be adapted for use with other community groups. The manual contains interactive group activities.



The soft bag toolkit contains: activity manual including handouts, *Positive health* information book, 10 picture cards, 16 activity cards, 2 packs of condoms and a plastic penis for demonstrating correct condom use. The complete toolkit costs £25 including postage. You can order a kit

by emailing publications@tearfund.org or writing to us at the address on page 2.

Alternatively, download the *Guardians of our children's health* activity manual in English or French free of charge at www.tearfund.org/gooch

Umoja: HIV and your community

By Veena O'Sullivan, Bill Crooks and Jackie Mouradian

This is a guide about HIV for people who have been trained as Umoja facilitators. Umoja is a process that helps churches to work together with their local communities to bring about positive change.

The guide will help the church to work with the community to prevent the spread of HIV and reduce its impact. It is recommended for use in churches and communities who have already completed at least one cycle of Umoja.

Printed copies cost £5 and are available in English and French. See the box below for details of how to order. Alternatively, visit www.tearfund.org/umojaguides and scroll down to the bottom of the page to download the manual free of charge in English, French, Portuguese or Nepali.

Think livelihoods! toolkit

By Kara Greenblott, Isabel Carter and Debora Randall

HIV can have a damaging effect on people's livelihoods. This is a facilitator's manual for helping people and communities affected by HIV to think about how to improve their livelihoods. It can be used by churches and other organisations working with people living

Useful websites

www.avert.org

Includes helpful information on HIV transmission, prevention, treatment and support.

www.avert.org/condom-use-types-sizes.htm

Step-by-step guide on how to use a condom correctly.

www.unaids.org

Information from the Joint United Nations Programme on HIV and AIDS, including goals, reports and news stories.

www.who.int/hiv

The World Health Organization's website on HIV and AIDS, containing fact sheets, reports and news stories.

www.tearfund.org/hivresources

Details of Tearfund's response to HIV.

with HIV. The toolkit contains case studies, training exercises and biblical reflections.

Visit www.tearfund.org/livelihoods to download the *Think livelihoods!* toolkit free of charge in English, French, Portuguese and Kiswahili. Contact us by post or email to order a printed copy in English (costing £6).

Hand in hand: Bible studies to transform our response to HIV

Edited by Isabel Carter and Maggie Sandilands

This booklet contains 23 Bible studies covering a range of issues relating to HIV, including stigma, forgiveness, gender, bereavement, healthy marriages, and understanding disease and suffering. Each Bible study includes helpful notes for facilitators. The studies can be adapted to use as sermons.

Visit www.tearfund.org/churchandhiv to download *Hand in hand* free of charge in English, French and Nepali. Printed copies cost £6 and are available in English and

ORDERING PRINTED COPIES FROM TEARFUND

If you have a credit or debit card and good internet access, you can order printed copies of *Umoja: HIV and your community* and *Hand in hand: Bible studies to transform our response to HIV* by visiting www.tearfund.org/publications. If you have any difficulties, email publications@tearfund.org and we will be pleased to help. One copy may be available free of charge to organisations or individuals who are unable to pay.

Please write to: The Editor, Footsteps, 100 Church Road, Teddington, TW11 8QE, UK
Email: publications@tearfund.org

French. See the box on page 14 for details of how to order.

Reveal toolkit

Reveal is a collection of tools (activities, games, guidance and Bible studies) for people working directly with local communities or churches. The tools explore hidden issues that people do not often talk about openly, such as HIV, conflict and violence against women.

Visit www.tearfund.org/reveal to download these materials free of charge. The toolkit is currently available in English, but other translations are planned for the future.

SAVE toolkit (second edition)

By Clare Mead,
Vanessa Michael and
JP Mokgethi-Heath



This booklet is a practical guide to the SAVE approach to HIV prevention (Safer practices, Access to treatment, Voluntary counselling and testing, and Empowerment). It contains notes for facilitators and exercises for group training sessions.

Please note, the *SAVE toolkit* does not take any specific religion's perspective on issues relating to human sexuality.

Download the *SAVE toolkit* free of charge at www.inerela.org/resources/save-toolkit (you can download the first edition in French from this web page, and click through to download the second edition in English). To obtain a printed copy of the English second edition or French first edition, email info@inerela.org or write to INERELA+, Corner Rabie and 4th Avenue North, Fontainebleau – Randburg, 2032 – South Africa. The toolkit costs approximately £15.50, plus £2.50 for delivery; INERELA+ will advise you on payment methods.

Are people with disabilities being overlooked?

When a project caters for people who are vulnerable, disabled people are not always included. In Zambia we have programmes for orphans and vulnerable children. Very few, if any, of these programmes have disability issues as one of the key aspects of their work.

Disabled children continue being sidelined. They have no access to education, training, rehabilitation services and even employment opportunities when they are grown, particularly in rural areas. The programmes are biased towards HIV- and AIDS-related concerns.

How is the situation in other countries? I would like to hear the comments of other people on my observation.

Bosswell Mboози

Chikankata College of Biomedical Sciences, Private Bag S2, Chikankata, Zambia

Using *Footsteps* as a teaching aid in Cuba

I have been receiving *Footsteps* for many years, and it has had a big impact. Through *Footsteps* I have been able to teach my medical students about different cultures outside of Cuba. I am

a doctor and medical professor, and have used examples from the magazine in my classes – for example, number 61 from 2005 which talked about the impact of HIV and AIDS on children. Also, we have used it in community work with young people, and in my church we have enjoyed the articles about health and sexuality. We use and show the drawings and photos in some classes.

A *Footsteps* reader from Cuba

Healthy eating

Healthy eating has been a great concern in our community. It was not being adhered to, but it is now embraced by community members. *Footsteps* issue 87 of January 2012 addressed the topic, and has reduced health problems in pregnant mothers and people with diabetes.

Our community is more concerned with their health than ever before. They now eat plenty of fruit, vegetables and wholegrain cereals and legumes. Smoking and alcohol use has now reduced drastically. Thank you for your good and informative magazine, which has supported our community health training workshops.

J. B. Cheruyyot

Wheritage Community Health Association, Kenya

We are planning a special celebratory edition for the 100th issue of *Footsteps*, and need your help! We would love to hear which article from the previous 98 editions of *Footsteps* has been the most helpful for you and why. Please write to us at publications@tearfund.org or at the address above.



Fighting stigma together

Reverend Canon Professor Gideon B. Byamugisha is an ordained priest in the Anglican Church of Uganda. In 1992, he became the first African religious leader openly to declare his HIV-positive status. He is the founder of the African Network of Religious Leaders Living with or Personally Affected by HIV and AIDS (ANERELA+), now an international organisation (INERELA+) working in 48 countries. Currently, Canon Gideon serves as Executive Director of the Friends of Canon Gideon Foundation.

Canon Gideon has won many prestigious awards for his work tackling stigma against people living with HIV and AIDS. We asked him to share some of his experience and knowledge with *Footsteps* readers.

What made you decide to disclose your HIV-positive status in 1992?

Three things influenced my decision to disclose. First, I wanted people to pray very specific prayers for my care, treatment and future. Second, I did not want to lead a life of 'double identity', being one thing in public and something else in private. Third, I wanted to break down some of the myths about HIV transmission, especially those myths that always associated HIV with sexual immorality. I wanted to help both the local community and their leaders to know that someone's HIV status will reveal very little about their morality,

their spirituality or their ability to be a religious leader.

How did people respond after you disclosed that you were HIV-positive? Were you personally affected by stigma?

Different people reacted differently. Some welcomed my public disclosure, saying that God would use me to help overcome the silence, stigma and discrimination that were very common then.

Some significant others were not happy with the disclosure, saying that I was damaging the image of the church. Others in this group wrongly feared I was going to transmit HIV to them while sharing the Holy Communion cup or while baptising their children. Some individuals actually asked my archdeacon and bishop to withdraw me from church ministry.

Sometimes people said to me, 'You have told us you are HIV-positive. Have you ever repented about it?' That is stigma, connecting my HIV status with immorality. People asked me, 'How did you get HIV?' That is also a stigmatising question; it implies that people want to know whether you were 'innocent' or 'guilty'.

I am so lucky and blessed that individual friends, family members, faith communities, congregations, leaders and agencies have supported me through it all. Today, there are fewer people who are not supportive of my disclosure.

What are the different types of stigma affecting people living with HIV?

The stigma around HIV comes from several sources.

- Firstly, some people fear that HIV-positive people are 'contagious'. They

think that you can get HIV if you eat with someone who is HIV-positive or shake their hand.

- Secondly, people sometimes think that being HIV-positive means you are going to die soon. Because of this, they deny you resources and opportunities. They think, 'Why should we waste food on someone who is going to die? Why should we take them to school?'
- Thirdly, stigma comes from linking HIV with immorality or deviance. People associate HIV with sexual immorality and with marginalised groups such as injecting drug users.
- There is also a fourth kind of stigma within the church. Some people think that if you are living with HIV, you do not have enough faith for miraculous healing. They tell you to throw away your ART medicines, because you should have more faith in miracles.

All these types of stigma have seriously held back progress in stopping HIV transmission and deaths from AIDS, despite the great advances in HIV prevention and treatment.

What are some of the negative effects of stigma for people living with HIV?

Stigma leads to paralysing shame that damages the self-esteem and self-confidence of people living with HIV. It can also affect their family members and community.

Stigma often makes people afraid to be tested for HIV. Others who do get tested are too fearful to collect their test results. Many others are scared to disclose their HIV status to the people who need to know, such as their partners or health workers.

Stigma means that people living with HIV are blamed, ridiculed, shamed and discriminated against. Instead, we need to support them and empower them so that they can have better life chances and healthier outcomes. This will also help to prevent the spread of HIV, as people who know and accept their status are more



Sandra Nabukalu

Reverend Canon Professor Gideon B. Byamugisha was the first African religious leader openly to declare his HIV-positive status.

likely to choose safer practices, such as taking ART medication.

What practical things can people do to eliminate stigma in their communities and churches?

Churches and communities can identify the sources of stigma and fix them one by one.

- If people are afraid of acquiring HIV from shaking our hands, what should church and community members do? Hug, shake hands with and care for people living with HIV. Then other people will learn from this, and say, 'Hey – so you can hug someone who is HIV-positive!'
- If people are afraid that HIV always leads to an early death, church members can bring people who have been living with HIV for a long time to speak to the congregation. This will communicate the message, 'This man has been HIV-positive for 20 years, but he is now a Member of Parliament, or a bishop in his church. So don't abandon your loved ones who are HIV-positive, because with love, support and treatment, they can live long, productive lives in their community.'
- Churches and communities should teach that AIDS is not a punishment from God. They should spread the message that HIV is not necessarily acquired in ways that are 'sinful'. There are many 'sexual saints' who are HIV-positive and many 'sexual sinners' who are HIV-negative.
- Communities and churches should make clear plans for reducing stigma and helping people living with HIV to get

the support and treatment they need. Organisations and churches will need policies, strategic plans, partnerships, budgets, youth training initiatives, communication strategies and prayers.

If you could say one thing to Footsteps readers, what would it be?

God has given us enough information and science to stop the AIDS epidemic. We must work together to give people the knowledge, skills, attitudes and supportive policies that they need. Then we can accompany each other on this journey to end new HIV infections and the stigma that surrounds them.

Visit www.focagifo.net for more information about the Friends of Canon Gideon Foundation.

Awakening the church in Honduras

by Norman Molina

The Atlantic coast of Honduras is home to an ethnic group called the Garifuna. They have their own language and a rich tradition of dance and music. Sadly, HIV is five times as common among the Garifuna people as it is in the rest of Honduras.

In the Garifuna communities, most people living with HIV keep their condition a secret because of stigma and discrimination. They are afraid of being asked to leave their jobs. Families often treat people living with HIV as outcasts, and people call them rude names.

AMIGA Garifuna is an organisation working in the Garifuna communities, training pastors and community leaders about HIV prevention and how to tackle stigma. Xiomara Guzman is a leader in both her church and community who has been taking part in the training offered by AMIGA. She can already see the difference that AMIGA's support has made in her life, the church

and the wider community. 'I have been able to develop a good set of skills and knowledge, allowing me to talk to people and support families living with HIV now,' says Xiomara.

Xiomara explains that churches used to either ignore HIV or condemn the problem. But now things have started to change. 'As churches we are waking up to a new approach,' says Xiomara. 'We are responding with compassion, patience and love. Churches are providing counselling and guidance to people living with HIV. People's mentality is changing, and self-esteem is being restored.'

AMIGA believes that publicly acknowledging HIV will help to reduce stigma and, ultimately, will help to



Deiby Amaya AMIGA

Xiomara Guzman is reaching out to people living with HIV and AIDS in her church and community.

prevent HIV. But the challenge is far from over. There are still some risk factors that contribute to the high levels of HIV, such as poverty, abuse, gender inequality, and lack of access to education and health care. However, the church embracing its role to show Jesus' love in both word and deed is a hopeful start.

Norman Molina is the Project Officer for Tearfund's Central America office.

Reducing the risks for injecting drug users



A health worker carries out an HIV test at a drug rehabilitation centre.

Injecting drug users (IDUs) are one of the groups most at risk of HIV infection. The Freedom Programme is an organisation working to prevent the spread of HIV among IDUs in Egypt.

Although a relatively low proportion of Egypt's population is HIV-positive, the percentage of IDUs who are living with HIV is much higher. If IDUs use non-sterile needles and syringes that have previously been used by someone who is HIV-positive, they are at very high risk of HIV infection.

The ethics of harm reduction

Some people might feel uncomfortable at the thought of providing IDUs with sterile needles and syringes. People might wonder: Are we enabling people's unhealthy behaviour? Is it ethical to provide this kind of help? Might it actually increase drug abuse?

However, many years of research have shown that providing sterile needles and syringes effectively reduces the spread of HIV among IDUs. A World Health Organization (WHO) report has found that these programmes do not increase injecting drug use.

It may take people many months or years to break free from drug addiction and other harmful behaviour. In the meantime, we can protect people from the dangers that they may find themselves in.

The Freedom Programme

The Freedom Programme was started in 1989 and is now one of the largest drug rehabilitation programmes in the Arab world. They run 28 drug rehabilitation centres across Egypt, as well as an outreach and drop-in centre. They also offer training for people working with those suffering from addictions, and these courses include information on HIV prevention.

A holistic approach

The Freedom Programme runs a range of holistic activities to help prevent HIV among people who inject drugs:

- Outreach teams, made up of a social worker and two ex-IDUs, build relationships with IDUs in the community. They provide IDUs with education about dangerous behaviours and how to protect themselves better.
- The outreach workers refer any IDUs who want to stop using drugs to rehabilitation centres, where they can go through a 12-step rehabilitation programme.
- Freedom's workers provide IDUs with condoms and training on how to use

them, helping them to adopt safer sexual practices.

- The Freedom Programme provides IDUs with sterile needles and syringes. This is to prevent them from contracting HIV by using injecting equipment that has been used by other people. It is part of an approach called 'harm reduction' (see box).
- Counselling is provided for IDUs before and after they take an HIV test to help them deal with the result.
- Advocacy workshops are held for IDUs, teaching them about their rights and training them in advocacy skills.
- The Freedom Programme advocates at a national level for better prevention of substance abuse and HIV, campaigning for the better treatment of marginalised groups.

What works well?

The Freedom Programme has found that several approaches are particularly effective in its work with IDUs.

- Having ex-IDUs on the outreach teams provides current IDUs with powerful role models, bringing an inspiring message of hope and transformation. The ex-IDUs are given full training, and supporting others helps to increase their own sense of self-worth.
- It is vital to build caring and respectful relationships with IDUs, who have often been stigmatised by society. Outreach workers offer a year of follow-up support for the people they are helping. Freedom staff aim to make their rehabilitation centres feel like home.
- Support groups for people living with HIV are very successful, and Freedom refers HIV-positive IDUs to these.
- The Freedom Programme's good reputation means that its leaders are often asked to speak about drug abuse and HIV in the media, particularly on television. This helps to spread Freedom's advocacy messages.
- The Freedom Programme has also arranged meetings between key decision-makers, religious leaders and people living with HIV to advocate for their rights.

From ABC to SAVE

When organisations began trying to prevent the spread of HIV, they often encouraged people to follow an approach called ABC (**ab**stain from sexual activity, **b**e faithful, use a **c**ondom).

However, over time people began to realise that there were some problems with this approach:

- It was too narrow. HIV can also be transmitted in non-sexual ways (such as from mother to child or through injecting drugs using non-sterile equipment).
- It did not mention the importance of treatment.
- It could stigmatise people living with HIV, suggesting that they had failed in abstinence, faithfulness or condom use.
- It suggested that individuals alone were responsible for preventing HIV, instead of showing that families, communities and governments had a part to play.

To address these issues, the organisation ANERELA+ (African Network of Religious Leaders Living with or Personally Affected by HIV and AIDS) developed an approach to HIV prevention called SAVE (Safer practices, Access to treatment, Voluntary counselling and testing, and Empowerment). The SAVE approach includes the ABC principles, but also brings in other things that are important in preventing HIV.

Safer practices

It is important to follow safer practices to prevent the transmission of HIV. Safer practices can include:

- choosing to abstain from sexual activity, if you feel that this is the right option for you
- always using a condom and putting it on correctly (see Resources page for more details)
- being faithful to your sexual partner
- preventing mother-to-child transmission of HIV (see pages 8 and 9 of this edition for more details)
- using sterile needles if you inject drugs
- for men, choosing to be circumcised
- making sure that blood transfusions have been tested for HIV
- for those living with HIV, taking anti-retroviral therapy (ART) to help reduce the risk of transmitting HIV to others.

Access to treatment

Everyone who is living with HIV should have access to treatment. This includes ART, which allows people living with HIV to live longer, healthier lives. People living with HIV will also need access to treatment

for other infections they might catch, such as TB or pneumonia. They will require good nutrition and clean water to make sure that their treatment is effective. It is important for them to have regular blood tests to monitor how well their ART is working.

Voluntary counselling and testing (VCT)

Regular testing and counselling should be available so that everyone can know their HIV status. If people know they are HIV-positive, they can access treatment and take steps to live a healthy life. They can also make sure they don't pass HIV on to others. People who know that they do not have HIV can take steps to remain that way.

Counselling is essential for people who are going to have an HIV test. They will need counselling before the test to prepare them for the results, and after the test to help them deal with the outcome (whether or not they are HIV-positive). HIV testing and counselling should always be confidential and should be carried out by a trained counsellor.

Empowerment

Empowerment means helping people to take control of their own lives. Empowering people through education and advocacy is an important part of all work on HIV. It is essential to defend the rights of people living with HIV so that they can access the services and support they need. Empowerment includes ending the stigma and discrimination that can make people afraid to go for HIV testing and treatment.

ANERELA+ has now become the international organisation INERELA+. INERELA+ has produced the SAVE toolkit containing training materials on the SAVE approach. You can find out more in the Resources section on page 15.

Illustration: Petra Röhr-Rouendaal, Where there is no artist (second edition)



It is important to learn how to use a condom correctly to help prevent the spread of HIV.

➔ Ideas for using this article

- Discuss whether all the aspects of the SAVE approach are being put into practice in your community.
- If any aspects are missing or are not being done well, discuss what your church or community can do to introduce or improve them.

ACTIVITY: HIV counselling and testing



WHY USE THIS ACTIVITY?

This activity explains what VCT (voluntary counselling and HIV testing) is. It helps people to think about the issues involved in going for VCT themselves, and encourages them to do so.



WHO IS THIS ACTIVITY FOR?

The activity is designed to be used with small church and community groups (ideally around 10–30 people). Please be aware that this is a sensitive subject and that it may bring up strong feelings in the participants.



YOU WILL NEED

- plain paper
- scissors



TIME TAKEN

30–40 minutes for the activity itself, in addition to the time needed for preparation.

PREPARING FOR THE ACTIVITY

- Cut up enough small pieces of paper so that the people taking part in the activity have one each. Make half of them in the shape of a square and the other half in the shape of a triangle. Fold all of the pieces and put them in a box, bag or bowl.
- Find out what VCT facilities are available locally, and what procedures they use for counselling and testing for HIV. If possible, obtain leaflets about the services they offer to give to your participants. You could also try to arrange for a counsellor from a local VCT centre to come and talk about VCT and the services they offer. They may even be able to provide a counselling and testing service immediately after the session.
- Get tested yourself, if you have not already! When learning about VCT, participants often ask the facilitator: 'Have you been for VCT yourself?' If you can honestly say: 'Yes, I have', and talk about it based on your own personal experience, it will add credibility and impact to the session.

How to run this activity

STEP 1

Discuss HIV testing issues and concerns

Clarify that an HIV test is the only way of knowing for sure whether or not you have the virus in your body.

ASK:

- What happens during VCT?
- What do you need to think about before having the test?
- How would it feel if your test result was HIV-negative?

- How would it feel if your test result was HIV-positive?
- Who would you tell and how might they react?
- Who among you would decide not to go for a test?

Get everybody to stand together in the middle of the room. Ask those who say they would not go for a test to take a step back. Those who would go for a test should move forward, so the two groups are separate.

Illustration: Petra Röhr-Rouendaal, 'Where there is no artist' (second edition)



Voluntary counselling and testing is an important part of the SAVE approach to HIV prevention.

STEP 2 Imagine going for VCT

Get participants to imagine going through the VCT process, describing it using your own words:

EXPLAIN: 'I would like you to relax and imagine you are now going for VCT. You go for pre-test counselling, and then give a blood sample. The blood sample is tested and you are coming for the results. Your counsellor invites you into the counselling room and asks you to sit down. The counsellor asks if you still want to know your result.'

ASK: 'Is there is anybody who does not want to know their result?' Ask them to put up their hand.

If anyone puts their hand up, ask them to move to join the group at the back who chose not to go for VCT.

STEP 3 Give 'test results'

Get each participant who says they want their test result to pick one of the folded pieces of paper.

EXPLAIN: 'Imagine the piece of paper you have picked represents your test result. Open it up. It is in the shape of either a square or a triangle. One means that your test result is HIV-positive, the other that your test result is HIV-negative. How would you feel if I told you that a square means an HIV-negative result, and a triangle means an HIV-positive result?'

The 'window period'

There are different types of HIV test, which look for different signs of HIV being present in the body. After a person gets infected with HIV, it takes time for some of these signs to develop. Because of this, test results may give a 'false negative' for up to six months. A false negative is when a test result says that a person is not HIV-positive even though they actually are.

The amount of time it takes for signs of HIV to show up in tests is called the 'window period'. The length of the window period will depend on the person's body and the type of test that is used. Your health worker

Going for voluntary counselling and HIV testing (VCT)

Why go for voluntary counselling and HIV testing (VCT)?

- If you are aware that you are living with HIV, there are many things you can do to stay healthy, live a long life and still achieve your goals and dreams.
- If you know you are living with HIV, you can enjoy sex while ensuring that you protect yourself from re-infection and protect others from getting infected.
- If you are expecting a child and know that you are HIV-positive, there are many things you can do to minimise the chance of HIV being transmitted to the child.

How does VCT work?

Before going for an HIV test, either alone or with your partner, you spend time with a counsellor. The counsellor will help you

think about your issues and concerns, and will ask you questions like:

- What will you do if the test shows you are living with HIV?
- What will you do if the test shows no sign of HIV?
- Are you sure that you want to go ahead with the test?

The counsellor will meet you again when you get the test result. He or she will help you think through the implications of your HIV test result and plan what to do next.

These discussions are confidential. The doctor and professional counsellor should not tell anyone else about your test result or anything that you have said. Sharing the result is up to you.

ASK: 'Those whose test result is negative, how do you feel? Those whose test result is positive, how do you feel? What would you do next? Who would you tell?'

Then ask how people would feel if the results were reversed – that is, if a square meant an HIV-positive result and a triangle meant HIV-negative.

Include in the discussion those who 'decided not to go for a test', or who did not get their result.

ASK: 'How do you feel now about not knowing your HIV status?'

STEP 4 Discuss where testing is offered

Find out from participants whether they know where VCT is available in their area. Discuss what options might be available for participants to access VCT. Give participants the name, location, opening times and cost of VCT centres. Try also to provide details of centres in other towns outside the area, for people who want to be sure of confidentiality.

STEP 5 VCT counsellor presents information, answers questions and – if available – offers testing (optional)

If you have a counsellor or representative from a local centre offering VCT, ask them to describe the services offered and answer questions from participants. If mobile HIV testing and counselling services have been arranged, they can also explain how participants can use these services.

Adapted from the Guardians of our children's health (GOOCH) toolkit. See Resources page for more details.

Speaking out about HIV

by Melissa Lawson and Shannon Thomson



Courtesy of the Treatment Action Campaign

South Africa's Treatment Action Campaign has made HIV treatment much more affordable.

We have come a long way in HIV advocacy since the very first cases of AIDS in the early 1980s. Campaigning at community, national and international level has transformed HIV treatment, prevention, care and support.

We have had a number of big wins (such as those in South Africa – see below), but the fight is not yet over. The agreements at the international and national levels do not always result in real changes at the community level, particularly in rural and hard-to-reach areas. People living with HIV still face huge challenges in accessing the services and treatment they need to live healthy lives.

Many people living with HIV still face:

- Lack of other medicines that they may require in addition to ART (such as antibiotics to combat infections)
- Stigma and discrimination from health workers
- Lack of HIV test kits in their communities.

CASE STUDY The Treatment Action Campaign, South Africa

Back in 1998, the Treatment Action Campaign (TAC) was set up in South Africa. At that time, South African political leaders were in denial about the realities of HIV and AIDS, and gave out a number of misleading and inaccurate statements about the virus. Treatment was difficult to access and incredibly expensive, even for people living in more developed countries. TAC was set up to respond to this situation, made up of people who were living with or affected by HIV.

In 2002, TAC launched a campaign for affordable treatment, putting pressure on pharmaceutical companies to allow cheaper generic (non-branded) medicines into the market. In 2003 they won, and this success transformed the HIV response. Treatment was first made more accessible for people living on lower incomes and was later made free through government and donor partnerships. The TAC campaign not only influenced South Africa and access to treatment there, but had a global effect.

So what can be done?

Local-level advocacy is vital for influencing government decisions about HIV response and for ensuring that communities can access the services they need. This advocacy can be done at the community, district, provincial or national level. Here are a few tips to begin advocating for improved HIV services in your community:

1. FIND OUT WHAT YOUR COMMUNITY IS ENTITLED TO

The first step is to understand what HIV services you are entitled to within your country. Most countries affected by HIV have a national AIDS authority, which produces plans for their HIV response and policies on how to handle issues related to HIV. These documents can be accessed through your national AIDS authority's website, or through representatives of your district, province or state. If the information is hard to understand, seek advice from churches, non-governmental organisations (NGOs) or officials for your district or province.

2. CHECK WHETHER YOUR COMMUNITY IS RECEIVING THE SERVICES YOU HAVE BEEN PROMISED

Once you know what you are entitled to, you can check whether your community is receiving all the services that should be in place. By talking to people living with HIV in the community, you can understand what is happening at your local health centres. Are people being discriminated against because of their HIV status? Are the drugs they need available when they need them? For people who want to be tested for HIV, is there a supply of test kits at the health centre?

3. IDENTIFY WHAT NEEDS TO CHANGE

Once you have the information on what services you are entitled to, and have assessed how this compares to the reality at the community level, you can identify what needs to change. Does a policy need to be put into practice – for example, is your local health centre failing to provide a legally required

service? Or does a policy need to be changed?

4. ADVOCATE TO LOCAL OFFICIALS

After you have decided what needs to change, you need to identify who has the power to bring about this change. The first person to approach at a local level would usually be a local government representative. In some places this is the Village Development Committee. In other places there might be representatives for dealing with health issues, such as a Village Health Committee. Outline your concerns to them – share what you know about the government's commitment to HIV services and the gaps you see in your community, and propose solutions to them. Seek a way forward together.

5. TAKE THE ISSUE HIGHER

If your local government does not respond, you might want to raise the issue at a higher level. You may have a District Health Management Team or a team of representatives who work on health at a higher level than the Village Development Committee. There might even be committees responsible for particular aspects of the HIV response. Find these representatives and take your concerns to them. Be clear about what you are asking for and what you want them to do.

CASE STUDY Advocating for food in Mozambique

Many people in Mozambique are living in poverty and do not have a reliable source of food. Natural disasters, such as flooding, make the problem worse. The lack of food security particularly affects people living with HIV.

This was an issue that worried Rede Cristã, a network of Christian NGOs and churches in Mozambique. Over several years, members of Rede Cristã developed relationships with officials in all the departments of the Mozambique government that were involved with HIV. Together, they helped to draft a law setting out the rights of people living with HIV to adequate food supplies and levels of nutrition.

After the law was passed, Rede Cristã worked closely with their church members

to make sure it was put into practice. They did this in several ways:

- They made sure that people with HIV knew about the law.
- They inspired local churches to take more responsibility in caring for people affected by HIV.
- They encouraged good relationships to be formed between local authority officials and members of churches and communities affected by HIV.

Adapted from the second edition of Tearfund's Advocacy toolkit (ROOTS 1 and 2) by Joanna Watson.

Visit www.tearfund.org/advocacytoolkit to download the Advocacy toolkit free of charge. You can order a printed copy (costing £20) by following the instructions at the bottom of the Resources section on page 14.

6. WORK WITH OTHERS

Working together with others (such as other communities, NGOs or community groups) can help to put pressure on decision-makers to bring about the changes needed. Consider whom you can work with to advocate for change.

If you see things in your community that you think are not right, such as a lack of drugs, a shortage of test kits or people being discriminated against because of

their HIV status, speak out! Together we can ensure that all people living with HIV have access to quality health care, dignity, support and the life-saving treatments they need.

Melissa Lawson is Tearfund's Policy Officer for East and Southern Africa. Shannon Thomson is the Projects Officer for Tearfund's HIV Unit.

For further information and ideas, visit www.tearfund.org/whyadvocate and download Tearfund's booklet Why advocate on HIV? The booklet is available in English, French, Portuguese and Spanish.



How I remember to take my ARVs

For those of us living with HIV, taking our antiretroviral medication (ARVs) regularly every day is one of the most important things we can do to stay healthy. We must keep taking our ARVs even when we feel better. If we stop taking them, in time we will become sick again – and worse, the virus may have a chance to become resistant to the medication. However, remembering to take our medication can sometimes be a challenge!

Footsteps asked people living with HIV around the world to share their top tips on how they remember to take their ARVs.

Ade, Nigeria

'I have been on ARVs for nine years now. I have set the alarm on my phone to remind me at 07:00 and 19:00. This is when I usually take my medication.'



Treasure, DRC

'Taking ARVs has become like my daily food. I take them twice a day: every morning before brushing my teeth and after meals in the evening. I put the medicines in the living room next to the TV so they are visible.'

Sarita, India

'I remember to take my ARVs by ticking the date in my calendar, which is hung on my kitchen wall, when I have taken them for the day.'

Dorcas, Nigeria

'I keep my medicines in the bathroom. I take them as I brush my teeth; it reminds me daily.'



Lionel, DRC

'In the morning after brushing my teeth, I take my medication straight away. As I am part of a couple, if one of us does not see the other take their medicine, we remind the other person.'

Raj, India

'Every day before I go to my shop I drink a glass of water, and after I return home I repeat this. This habit of drinking water was there since I started the business. After I began to take ARVs, I added them to my habit of drinking water as a reminder.'



Stella, Nigeria

'I use a pill box to remind me.'

Nimith, Cambodia

'I set my alarm to remind me. My grandchildren remind me, and my children bring the medicine for me when it is time to take it.'



Anu, India

'Rojamma [a church care giver] reminds me daily to take my ARVs. She is my neighbour. Even if she is not around, she gives me a call to remind me.'

Alphonse, DRC

'Taking this medicine has become like my ID card: every time I go out I have a supply in my pocket.'

(Please note, this method is only suitable for medication that does not need to be kept refrigerated.)

Gabriel, Nigeria

'The thought of going for lab tests and being told by health care providers that I am doing well has greatly inspired me to take my ARVs daily for six years now.'

Names have been changed to protect identities.

Reflection: How 'my lady' took her ARVs

by Virginia Lockett



I will never forget staying with 'my lady' in Cambodia on my first trip with Tearfund. She changed my life forever. I called her 'my lady' because I struggled to say her name in Khmer. But 'my lady' is a title of respect and communicates so much about her.

'My lady' was living with HIV. She had contracted HIV from her husband, who had died some years before. She showed me his photograph, in a frame that was lovingly decorated with paper flowers.

Every night 'my lady' had a ritual. In front of that photograph, by the light of a bare lightbulb in her bamboo hut, she opened her Khmer Bible and read aloud a passage. Then, very carefully, she took her ARVs. When she had taken the medication she paused silently, bowed her head and prayed.

It seemed to me that I had witnessed redemption – life in the midst of death. By bringing Jesus into her daily ARV routine, 'my lady' reminded herself of the truth that she was not alone. Her faith and trust were in Christ, who has saved her and goes on saving her day by day.

Virginia Lockett is an ordained vicar and is Director of Tearfund's UK Churches team.