The Truth About AIDS

How are you going to care for people with HIV in your church, especially when people in churches may still be worried about things like the communion cup? How are you going to look after church members dying at home?

Exploding myths

Priority number one must be to get educated. Church leaders need to be up to date and well informed. Books, conferences and visiting speakers are all ways to achieve this. Even a ten-minute presentation as part of a Sunday service can be long enough to bring home the impact of AIDS, if done by someone with personal experience of the illness, possibly from an organisation working in the field as a Christian agency.

Church congregations need clear information about risks, the communion cup and about social contact. They also need clear teaching on some of the ethical issues involved. Teaching needs to be given about God's accepting love, as well as his standards, emphasising the need to care unconditionally, challenging prejudice and judgementalism (see Chapter 8).

Caring for church members

We tend to think of AIDS as something out there rather than a problem within, yet AIDS is also marching into the church. Any growing church which is seeing people come into faith, with lifestyles changing and lives transformed, is likely to find imported HIV sooner or later.

Infection usually survives conversion

It is sobering to think how many of your congregation have come into faith in the last ten years. Conversion or a rediscovery of faith can happen gradually or suddenly, but infection always remains, barring God's intervention in a miracle of healing.

AIDS time bomb in the church

As we have seen, someone who joined a church in 2003 may have been unknowingly infected in the mid 1990s. The person may still be perfectly fit and well today. In a few years' time the person may be a recognised leader with many responsibilities. One day the person may come to you looking obviously unwell after having been afflicted with various medical problems for some time. Now he's tested positive for HIV.

This scenario has already become a very common scenario in many African nations. The pastoral implications are huge when you have a congregation which has mushroomed from maybe 500 to 5,000 in five years and you realise that up to a fifth of your adult members could be carrying the virus.

AIDS in the church office

It is a huge step for someone to tell you they have HIV or AIDS. In many cases it means revealing intensely personal things about the past; things which have been prayed over and forgotten years ago. This is in addition to the shock of coming to terms with a future death from AIDS. It often seems particularly tragic when someone who has made a fresh start has to pay such a very personal and public price for what happened so long ago.

Such tragedies can tear churches apart, with people asking over and over again why God has not chosen to heal the person after the greater miracle of life-changing conversion.

Can you keep a secret?

Once someone in your church has told you they have HIV or AIDS, a journey has started which will probably have a profound effect on you and the church over many years. Confidentiality is important. As we have seen already, we live in harsh times when it comes to AIDS. Violence, discrimination, verbal abuse and hostility are common reactions in many nations from an intolerant minority; common enough to create an atmosphere of tension and fear if the diagnosis becomes known.

A diagnosis of AIDS or HIV infection is sensitive information which may need to be kept strictly confidential for a long time. You may be able to create a supportive environment in the church. However, churches are by their nature public groups meeting in public places. Anyone can turn up to meetings and new people join. You cannot be certain how one or two on the edge of things might react, especially those who perhaps have not been Christians very long or who have deep personal problems of their own.

People with AIDS may leave your church

I remember talking recently to a mother with a young child. She told me that she had moved 100 miles away from her church after the news that she had HIV gradually spread. She said the church had been caring. She had felt accepted and cared for by the leaders and supported by her home group which met in someone's house during the week.

Unfortunately, once her situation became widely known in the church, she began to notice a change. She felt people were avoiding her. No one wanted to have her child to play any more. No one wanted to share the communion cup with her. She felt isolated, insecure, rejected and afraid. After a few weeks she left. I am pleased to say she is now happily settled elsewhere.

Her story made me think. The same could so easily have happened in my own church or in any church for that matter. Much of the supposed rejection could have been her own hypersensitivity and insecurity, but it is quite likely that one or two may have made inappropriate comments, or behaved in a hurtful and unkind way.

For these reasons we need to address the issue of who is told before the event, rather than working out a policy an hour after realising someone has HIV. Do all the leaders need to know at this stage? What about their spouses? If one person in the church knows, will others be told---`just for prayer, of course'?

Big leaks can start slowly

News may leak gradually before an explosion occurs. Take the situation of four senior leaders who know, each confiding in one other person over the next six months. Each of the new four also confide in one other, while the four leaders also tell two or three others. The result is that in just twelve months at least fourteen to sixteen people already know. After the second year the number knowing has grown to twenty, and by the third year to twenty-five.

One day a conversation is overheard by someone else who very likely tells another ten in as many days. By the end of the month people at work have found out and are saying they will refuse to co-operate unless the person is laid off. The result could be loss of job, loss of income, public humiliation and a big question mark: Does every other person in the church know?

Now is the time to prepare

Churches for whom all these things are quite new and unfamiliar need to prepare now, before someone turns out to have HIV. Perhaps someone in your church is already infected, but he or she---or you---has yet to find out. Sometimes I am asked to speak to a church because the leaders are now aware of someone with HIV who is becoming unwell. They realise people are going to guess soon and they want help now, so when people find out there will not be any panic. It would have been better to have visited the year before.

It can be hard to know when to widen the network of those who are aware of the situation. The timing and occasion are best determined by the person with HIV. The process becomes easier if one or two new people are told at a time, before involving larger groups. Often the person with HIV feels anxious about possible reactions. As each person is found to be accepting, warm and encouraging, it helps to overcome the big lie which says that people will reject once they know.

This fear of being known is a curse because it robs and destroys friendship. Whenever someone lives under the shadow of discovery, there will always be deep insecurity. It is only as we find people still love us despite our failings that we begin to see and feel what the love of God is like.

Openness can bring release

The more open we can be, the more AIDS becomes normalised as a part of our suffering world, and in turn the easier it is for others to be open in the future. More importantly, the more open we are, the easier it is to organise help. So in general it makes sense to be as open as possible, given all the constraints of the local situation and culture, and all the cautions above.

One rule of thumb if you are unsure how to proceed is is to operate on a need-to-know basis. And as illness develops, the need to know becomes gradually greater for a larger circle of people.

Practical care at home

The needs of those with AIDS living in the community are in many ways exactly the same as the needs of those with other kinds of illness. There is always the need for friendship, but often the greatest needs are practical. It is easy for barriers to form and for people to feel a burden, unable to ask for help. On the other hand, wanting to help can make us feel awkward and embarrassed, not knowing what to say or do.

Here is a brief outline of ten practical steps that any church can take to support a church member, most of which also apply in many ways to caring for others in the community. This is not a definitive guide. Many of the basic principles of care are valid in different cultural and economic situations, but other aspects require adaptation.

The greatest help is often the simplest: things that anyone can do, whether they live in Manhattan apartment in New York, or in a house of corrugated iron and plastic on a rubbish tip in Brazil. It doesn't cost money to be kind.

1. ´Show you still care

Someone with HIV is likely to feel especially vulnerable after telling you the news, or just after knowing someone else has told you. What will the next meeting be like? Will there be a smile, a hug or an awkward turning away? People may say it does not make any difference, but is that really true, or are they just pretending? Surely I am a liability, an embarrassment, a burden on the church? Go out of your way to express appreciation, acceptance, love, care and support in those first critical days.

Learn about the illness so you are well informed and can help others later on who may be struggling with ignorance.

2. ´Maintain friendship

Try to maintain as much normal life as possible. The person who has HIV will probably want to carry on as usual rather than be dragged down by thinking about the illness all day long. Be sensitive to changing physical needs, moods and feelings about the future. It is perfectly normal for people to swing from optimism to pessimism, from grand plans to the depths of despair, from acceptance of the situation to denial.

This is just part of the process of adjustment to grief and loss. Often we think of grief as an emotion triggered by the death of someone we love. However, grief is a process of adjustment triggered by losses of any kind. As we have seen in earlier chapters, the losses for someone dying with AIDS are numerous and often devastating. Loss of health; loss of memory, sight, physical comfort, sleep, control over one's body; loss of future plans, ambitions, hopes and dreams; loss of friends, family, job, physical attractiveness, energy; loss of independence and freedom; loss of future; loss of life on earth. It is no surprise, then, to find people oscillating between denial, anger, sadness and acceptance, or with mixtures of all four. AIDS can be a heavy burden to carry.

3. ´Listen to the questions

The Psalms are full of heart cries towards God. Why is this happening to me? What is God doing? This seems so unfair. Questions and statements like these are cries of pain and anguish which need a listening ear rather than a trite reply. The person may just want you to sit and listen while feelings are expressed. There are no simple answers to human suffering, as Job's friends discovered.

Anger can often be directed at others such as members of the family, neighbours, friends, doctors, nurses, volunteers and members of the church. Anger and sadness are closely linked. They can both be a part of the process of grieving for a life that has been unexpectedly shortened. The anger may be directed at you too. It is important not to take such rejection too personally, and to continue to offer friendship.

Sometimes anger can become a test of friendship. You may be on trial yourself. Is your love great enough to keep coming back? In the meantime, while offering continued support, there may be another who is better placed to maintain the closest links.

4. ´Open your home

Be ready to offer a meal, a place to stay or sit quietly during the day. Often a change of environment can help not only the person who is unwell, but also the other carers. Many with AIDS have no real homes or families. Many have been effectively orphaned by their condition, or by previous circumstances. Many are living on their own, or with friends, in situations where dying at home may be difficult, or impossible. As we open up a network of homes and relationships, we are offering new choices to people who may feel they have none.

5. ´Draw others in

In our desire to preserve confidentiality, to care and to protect, it is easy for intense relationships to develop, and to reach a situation where `lock up' occurs. It is easy as a carer to convince yourself that no one understands the person better than you, and that you alone have an `inside track' on the situation. You want to be involved in all decisions; to be present at every discussion. It is easy to have mixed feelings about others becoming involved. Yet that very intensity can become more than the relationship can bear when illness develops.

As the situation unfolds, it is wise to draw others in. As a church leader myself, I feel it is vitally important that at least one member of the church leadership is closely involved, providing pastoral support to the person and to the carers, spotting signs of pressure or difficulty and helping to find ways through.

At every stage you will need the backing of the person concerned to involve others in this. If this is constantly blocked at every turn, you may have some hard talking to do. I have seen many situations break down at home, with people landing up in hospital simply because no one was willing to think seriously about the future.

6. ´Seek expert help

At some stage or other you are going to need expert help. It is all very well providing emotional support as a friend, but when events unfold you may need extra professional advice and support either from a clinic or from a community service. It may be that there is no local service available in which case even telephone advice can be helpful.

Community care varies from country to country, but the trend in many places is towards caring for people in the community. Neither the richest nor the poorest nations can afford to keep people with AIDS in hospital when they do not need acute medical care.

As we have seen in Chapter 1, anxiety can produce many of the symptoms of early HIV illness, and as in other areas of medicine it is possible for people to convince themselves and others that they have HIV when there is no evidence of this. Because medical confidentiality is so strict in many nations, it is only possible for health care professionals to obtain confirmation of diagnosis after written permission from the person concerned, and even then it can be difficult. However, such confirmation is important . Fraud and deception are not unknown, in order to get extra attention or material help.

7. ´Be ready for the long haul

Both those with HIV and those who care for them can be bewildered by rapid changes in the illness. One week there may be such a marked deterioration that they assume the end must be near, while the next week things may be back to their usual state. AIDS is a disease of ups and downs. People can be close to death, yet recover with prompt treatment, and be home again. People with AIDS are living longer in many countries with improved treatment, as we have already seen. Therefore it is wise to plan for a level of support that may need to be sustained for a long time.

People often ask me when the end will come. The answer is that no one knows, although we can often be certain about one thing: death is not here yet. With onset of new symptoms it is natural for everyone to become anxious. I often say to people that although it is true they are going to die of this illness, barring a miracle or a sudden new discovery, it is also true that they are not dying at this moment. We can often look back and see that maybe over the last few days things have actually improved a little.

One of my greatest joys has been seeing people begin to make realistic plans again: a last holiday, a project to complete, friends to see, a place to visit. Our aim is to redeem time; to give back dignity, freedom and choice. That is why expert care is so important. When it comes to practical care, nothing is more rewarding to me than something as simple and important as being able to give someone their first good night's sleep in months, so that the following day can be enjoyed.

8. ´Fear of death can be worse than death itself

Remember that the process of dying can be far more worrying to people than death itself, particularly if the person is sustained by the hope of eternal life. Common worries can include losing control over bowels or bladder, becoming mentally feeble with loss of memory, becoming disabled and confined to a wheelchair, losing hair as a result of chemotherapy for cancers, having to be washed and dressed by another.

Other worries can include the fear of uncontrolled symptoms of pain, breathlessness or other kinds. Finally, there is also the fear of losing control, of others marching in as strength fades, and of the wrong decisions being made.

The way to deal with these fears is to address them, and to try to discover what lies behind them. I remember someone asking me one day whether he would suffocate to death. There was real fear in his eyes as he gripped my arm waiting for the reply. Before answering, it occurred to me to ask why he was asking the question and, even more importantly, why he asked today when I was visiting so regularly.

The answer tumbled out that he had woken in a terrible fright the previous night in the middle of a nightmare. He had seen himself lowered into the ground in a coffin while still alive. Despite his shouts and his hammering on the sides of the box, they had covered him with earth. He had suffocated to death.

We were then able to talk about the dream, and I was also able to promise him first that he would not suffer from feelings of suffocation if he developed a pneumonia, and secondly that death when it did come would be certain. No one would suddenly whisk him away. He could remain in the house for some time. As a result of the conversation he felt at peace and the fear never returned. It is an important principle to find out what lies behind a question before wading in with an insensitive and immediate response.

9. ´Support the carers too

Sometimes all the attention can naturally fall on the one who is ill, ignoring those giving most of the support. Sometimes partners, children, other family and friends can unexpectedly run out of steam. Things can become too much, juggling job, other responsibilities and the needs of someone with AIDS. An effective early warning system is vitally important. Often it's the case that very young children are having to do most of the day to day caring.

Those doing all the work need to know they too have someone who is special to them, watching out for their own needs, stepping in with practical help, sharing the load, providing a shoulder to cry on, and being a friend in times of trouble. The greatest help is often practical. You could spend an hour a day counselling a carer who is near breaking point when the time would be better spent sitting in the home for a morning or an afternoon so the carer can go out. Perhaps you can take the person who is unwell out for the day, or have the person to stay for a night or two, possibly longer.

Do not wait for people to shout for help, as they will often tell you much too late. Keep in touch regularly, even when things seem to be going very well. Time can fly by. Write a note to yourself in the diary when you are going to telephone next or drop round again.

Be honest about your own needs, to yourself and to others. You are a special person too in God's eyes. He loves you too. Allow yourself to be vulnerable. Let the right people see when you too are feeling the strain and are hurting inside---obviously you need to be careful not to share too widely, nor to dump your own emotional needs on someone who is ill, or on the main carer. Maybe you will encourage someone when they see that you are human too. Be ready to say no, to draw the line, to have recovery time of your own. That is why it is a good idea to involve a few others. You never know just when you will need their support.

10. ´Be ready to help around the clock at the end

You will need to be well-organised if the person wishes to die at home. It is likely that the last day or two, or even longer, will be quite harrowing. There may be a need for a continuous presence in the home, in addition to professionals coming in and out. You may need to identify a few sensible friends who would be willing to help on a rota basis, and who are acceptable to the person who is ill. The main need is likely to be for the sort of help that a caring relative would provide, to help in various practical ways.

On the whole, the care approach is the same as would be taken locally for any illness, whether you are living in Kampala or Bangkok or San Francisco. The only thing you need to take extra care about is exposure of skin to body secretions. Spillages of blood or other secretions should be wiped up wearing a pair of gloves. The easiest thing to do is mop up using disposable paper towels, and then to soak the area for two or three minutes with a freshly-made solution of one part bleach to nine parts water. The area can then be cleaned in the normal way (see Chapter 5).

Gloves are not needed at other times. As we have seen, intact skin is an excellent barrier to HIV. Even if there is some skin contact with secretions, infection is most unlikely to occur unless the skin is damaged. It is wise to cover cuts with a waterproof plaster before going into the home.

Although this may all seem rather daunting, it is most unlikely that you will be managing on your own. In many countries you will find community nurses and other health care workers are also providing support and advice. In other places, churches have found themselves having to develop their own community services because there is nothing available in their area.

When the moment of death comes, those in the home can feel uncertain as to what to do. There is no need for great activity when someone dies. The normal cultural rituals can be observed, remembering that secretions from the body will still be infectious. There may be one or two who need to be contacted, and would like to be able to say goodbye before the person is taken out of the home.

I want to look now at extending our care from our own church to the wider community. Should we? Can we?

The Truth About AIDS