The Truth About AIDS

Caring for church members is one thing, but what about those with AIDS who are part of the wider community? They may be dying in the most terrible conditions. Are we able to sit back and ignore their plight? Incidentally their needs are largely the same and the ten point guide in the previous chapter gives a good foundation for action.

As soon as you talk about getting involved in some churches you can sense a problem. Some say it is far more important to deal with the root of the problem by preaching the gospel and seeing lives changed. However, the teaching of Jesus makes it clear that both need to go together. Evangelical churches emphasise the need to preach the gospel. However, it could be said that evangelism without love is an obscenity to God, because a gospel message without love is a gross denial of what God is like. Love will always go further than words to meet practical needs. As Christians, we are called to love people as an expression of God's love---not as a means of manipulating them into joining the church. We love because people are worth it, made in the image of God.

The church pioneered many aspects of medical care that we take for granted today. Almost all of the first hospitals and associated caring agencies in many countries were started by Christians. Medical care was spread all over the world by a small army of dedicated men and women who often died abroad of the very illnesses they went out to fight. Their living conditions were dire and primitive in Africa, Asia, South America or China.

A missionary tradition

These men and women were driven by an overwhelming compassion for those in other nations, many of whom they felt were often without care and without hope. For them, bringing treatment for leprosy, malaria, tuberculosis or smallpox was bringing the practical love of God. As a result of that work, churches in South America, Africa and Asia are the fastest growing in the world, at a rate enormously faster than the birth rate. These countries are now sending missionaries to Europe, the United Kingdom and the United States.

I cannot find a closer parallel to leprosy a century ago than AIDS today. Now is the time for the church to climb off the fence, to stop taking pot-shots at the tip of the iceberg---the bit they see (erroneously) in the West as consisting entirely of promiscuous homosexual men and drug addicts---and to start considering the whole picture: the millions of men and women dying worldwide, and those dying on our doorstep. God calls us to accept all people and extend his love to them, regardless of whether or not we agree with what they do.

Public involvement

Church leaders and their congregations need to be visibly involved; not just seen to be caring for their own. They need to be quoted in the local press, on local radio, and down on record in the national media as declaring a commitment to get involved. The message is that we care about what is happening and want to make a difference.

Leaders especially need to come forward and to be examples---filmed talking to people with AIDS, holding their hands, receiving communion with them, or giving them a hug. At the end of the day, actions like these are things that really encourage others. Fears are not dispelled by words alone, but by seeing that people are not afraid. If church leaders cannot do this, our efforts to mobilise a congregation will become hollow.

Community support

Is it practical to set up a small community support group to help those outside the `family' of the church? How could we go about it? What about those who cannot be cared for at home? Could we use a church building to provide some sort of residential care or hospice for those who cannot manage at home?

Experience has shown that these things are possible in a wide variety of community settings, whether in a country like the UK or one like Uganda. The approach may vary greatly according to the local situation, but the overriding principles of compassionate care remain the same.

Everyone cares for their friends

Jesus said that caring for our friends, or members of our own social networks, is something that everybody does: it is a great sign of his kingdom. He said that true love is to care for those who are not members of our own family; people we would not associate with; people we do not like and might not be naturally drawn to. In fact Jesus went even further and told us that we were to love our enemies, those who want to stab us in the back, those who run us down, those who hate us, those who undermine us, those who attack us, those who are against us.

If this is the test of true love, then we can never be content to care just for our own. The test of true love will be our willingness to care for others in our community and for children left behind, without any hidden agenda or additional motive other than that which drove the Good Samaritan.

Jesus wants us to care as the natural response of our nature to the need of those around us. He wants us to care because he cares and we are channels of that care. As people come into contact with us, and feel our touch, our love, our compassion, they are coming into contact with something of Jesus himself.

As we have seen in a previous chapter, this is a mystery. As we enter a room we carry his presence into the place. I remember as a junior doctor, working in a busy hospital, I came into

contact with a great number of staff. Once or twice I came home and talked to Sheila my wife about a particular nurse on one of the wards who seemed to radiate something I had come to recognise in the past.

She had never said anything, neither did she wear some kind of badge or symbol. I remember after some months, with slight embarrassment, I asked her if by any chance she was a Christian. Of course the answer was that she loved the Lord very much. It showed. She carried the aroma of Christ with her. You can smell believers as they walk into the room!

So our calling then is not to shut up the love of God in some kind of Christian ghetto just caring for each other, but to allow that love to be expressed through caring for others.

Isn't care the responsibility of the government?

Some say that it is the responsibility of the government to care, not the church. I believe it is the responsibility of both. One of the primary responsibilities of government is to spread wealth and resources by collecting taxes and providing services and benefits, whether in education, health care, road building or other ways.

The balance between individual, group and government responsibility is a political question, but one thing is clear. As Christians we are called to be a nation's conscience, responding to need ourselves, and also encouraging a compassionate government response.

Where possible, I believe it is entirely right and proper that the government contributes to or provides some or all of the running costs of church-based care and prevention programmes, so long as the running of those programmes remains within the church and there is not a loss of control. We need to be careful that Christian initiatives do not become mere extensions of government or international agencies. That is why we need such a clear vision about what God is calling us to do. Without that we will be rapidly swept off course by someone else's vision, politics or priorities.

The issue is care for people, closely linked to social justice and basic human rights. If I am

healthy, well fed and have a high standard of living, then the teaching of Jesus is that my `neighbour' has an expectation perhaps that he or she will not starve or be deprived of the basic necessities of life. The church is one vehicle for provision; voluntary agencies and government departments are others. All can work together to get the job done.

Partnership between church and funding agencies can impose useful disciplines. It can help us think through what we are doing, as well as encourage us to measure our effectiveness and to plan strategically.

In many developing countries, the government depends on international aid, often channelled through Christian agencies, with projects overseen jointly by the donor and national government. These arrangements are often very successful, because governments are able to tap into an established network of Christian medical missions that have been providing first-class care and prevention programmes in the country for decades.

The test of unconditional love

The test of unconditional love is twofold when it comes to AIDS. First, does it matter to you how someone came to be infected, or why someone's parents have died? Will that knowledge alter the way you see that person or the way that person is treated? Many people feel it is easier to care for an orphan or a dying baby than for an adult who is ill. That is certainly the situation in Romania. Everyone wants to help AIDS babies, and the care of adults or prevention can almost be ignored. But is that the way of Jesus? Our love is unconditional because it is the same expressed to all, regardless of how they have come to be ill.

Is our love always the same?

The second practical test of unconditional love is perhaps even more important and is this: two people are dying with AIDS, and one has indicated he or she would like to become a Christian. Does this person get better care than the other? If so, then our care has become conditional. This is a real challenge to us and should cause us to consider how we think and respond to a variety of situations in the church.

Some may react here by pointing out that there is a sense in which God's love is full of conditions---this is the basis of God's judgement. Perhaps Chapter 8 needs reading again to see the whole thing in balance.

Community care or caring for our own?

If the care has become conditional in subtle ways on whether the person shows signs of wanting to join our church, then the programme needs redefining. It is not really community care at all, but just an extension of church life. That may be fine to you, but other agencies may be extremely reluctant to ask you to help, unless it is to care for those who already have a strong Christian faith.

Building on what we have

The advantage of home care is that you do not need a building, or even a formal office, in order to begin. You can start by resourcing the work from within the existing structures and facilities of the church. Indeed, it is possible to provide very effective AIDS care through general care programmes, so long as people are adequately trained, and those with AIDS locally are willing to receive help from a non-specialist agency. As we have seen, in most countries of the world the church has a huge established caring network, and a long track record of delivering high-quality care. There may be other care programmes running already which can be extended or adapted to help those with AIDS. There are no blueprints for success. You will need to adapt lessons others have learned to your own situation.

Care at home is fine as far as it goes, but what do you do when care at home is impossible? What about hospices?

Caring in a hospice

Even if we set up a community programme, there may be people we are caring for who cannot manage at home. For a variety of reasons they may need to be cared for in a hospital or a hospice. Many churches have access to buildings, or may consider buying one. How can we

tell if this is a sensible way forward, and how can we make sure the project will be successful?

Why hospices are setting the pace

Over the years, I have talked to a number of people who were set on starting some kind of hospice or in-patient unit for those with AIDS, whether in a country like Uganda or in the UK. What exactly is a hospice? The hospice movement has grown enormously over the last twenty-five years, having had its origins in the UK earlier this century.

It is aimed at providing a place where those with terminal illnesses can find peace and security in a specialist environment with a particular expertise in symptom control. Hospices are usually separate from hospitals, are often independently funded, and seek to provide emotional and spiritual support, as well as practical care.

The hospice philosophy spread fast from the 1970s onwards in the UK at first and then elsewhere because traditional medicine seemed obsessed with cure and had little time for the incurable. At the same time, those with symptoms such as pain were often very badly treated. Hi-tech medicine has sometimes lost touch with the needs of people. Thus the drive to build these hospices often came from relatives of loved ones who had died badly.

When AIDS became more and more evident, most of those who were ill in many countries were treated at first by specialists in either sexually-transmitted diseases or chest problems, neither of whom had much experience of looking after the dying.

The aim is to help people die well by caring for them as whole people, physically, emotionally, socially and spiritually. The unit of care is not just the person who is dying, but also the family, or the group of people around that person.

However we do need to be 100% certain that a dedicated unit for HIV really is the most appropriate solution, keeping in mind facilities available for other conditions in the country. It may be a very poor use of resources to have a well fitted out specialist AIDS unit in a city where general medical and surgical facilities are extremely limited. In that situation a separate

AIDS facility is a luxury that cannot be afforded and is likely to be a magnet for many with a huge variety of other conditions. On the other hand, centres of excellence can provide a wide range of services supporting other hospitals and clinics as well as training of large numbers of health care workers.

There is a real need for expert advice. For example, you may have access to a property, but after all the costs of conversion you may still not have the building which is practical. It may be better to build something from scratch.

Forming a ten-year vision

You will need a steering group or committee prepared to see the vision through and sustain it. You need long-range plans and vision---for at least ten years. It may take you three of those years to get from agreeing the plan to being able to welcome your first patient. It is all too easy to go bankrupt with a beautiful building. Most people like to see something for their money, so they give to capital projects and are less happy to support staff salaries. Other approaches can be considered. For example, there may be a need for something more like a halfway house between what you would expect in a hospice and what could be provided at home.

One common solution has been to adapt an institution that was built for another reason, and is now redundant - for example a centre for leprosy or for those crippled by polio.

AIDS orphans---how have churches responded?

Whenever we care for young people who are dying, we find children swept up in the process. Churches have responded in many creative ways, depending on the local situation. I remember visiting a Ugandan village where many adults had died. At first there were just a few orphans, but numbers had grown rapidly. In Africa, a child who has lost even one parent is likely to be in big trouble, because the family may already have been living at a subsistence level. To lose both parents is usually a disaster, especially if the family is large with maybe six or more dependants.

There were 400 orphans in the village, so what should be done? Many grandparents were spending their time trying to help bring the children up. The children had no source of income, no one to pay their modest school fees, so they had dropped out of school. Nearby was a village that had been closed by the government. The generation of parents had been wiped out. Only grandparents and children were left, and the village could not survive.

It is easy to march in and build orphanages as residential institutions providing love, education and care, but this may not be the best answer. There may be a simpler approach. Attending to one area of need may release the community to provide the rest.

If school fees can be found, the problem can be greatly eased. It is a tragedy that the local schools, which may offer an excellent education, may be half-empty because AIDS orphans are dropping out. It can be unfortunate to educate them separately as this may reinforce the separation and stigma. It can also be a mistake to house them separately. Isolation from village community life may make integration more difficult later on as adults. They may have difficulty finding husbands or wives as they do not belong. Institutions can never provide the same experience of home as a family.

Sponsorship in families

For these reasons, an effective way to help in a country like Uganda can be to provide school fees. Often this is all that is needed. The children are then back in class with their friends. They are supervised and may even be fed in the middle of the day. Sleeping accommodation at home is often far less of a problem and in some countries in Africa the food supply may be adequate and inexpensive. Families usually grow most of their own.

Sponsorship in homes means that hundreds of orphans can be cared for individually in as normal an environment as possible. It is low cost with few extra staff needed. The staff role becomes that of a community visitor, advising, monitoring, supporting and encouraging. Sponsorship schemes are funded by a number of different relief and development agencies, such as TEAR Fund, in partnership with local churches and national agencies.

Every country and community is different and we need to be very careful about transporting models that seem to work from one place to another. It may be that with very little outside help,

local people are able to set up a school of their own. I have seen very inspiring examples of what can be done with almost nothing by villagers with faith, determination and vision. But there is more to survival than school. Many children with no parents need to be taught how to grow food, repair their homes and sell their produce.

Orphanages may be needed

Although we have seen that community placements can offer good provision at low cost in some countries, it may not always be possible. If the network of extended families and village resources is totally overwhelmed, then institutional help may be the only alternative. The principles of running such places are the same as for any other orphanage project. It is good not to separate those who are orphans because of AIDS from those orphaned by other events such as war, tuberculosis, accidents or malaria. In practice it's hard to separate children out on this basis in any case. Orphans are orphans and in many cases of younger children they may not even be certain of what killed mother and father.

The scale of the problem defies comprehension. In many areas at the moment, nine- or ten-year-old children are acting as Mum and Dad to younger brothers and sisters, often after nursing their own parents until they died. The children have to collect firewood and water, cook their own food---and grow it---supervise young ones and repair their homes. They have nothing.

Just a very little help can make all the difference. One project in Eastern Uganda has been helping children rebuild their huts, so at least they have somewhere safe and dry to sleep at night. The workers also give out food and other essential items.

Income-generation projects

There are often situations in developing countries where a small amount of capital and training can equip people to become self-sufficient. Small micro-loans can make all the difference - for example to buy a bicycle so that charcoal can be carried from the field beside the house up onto the main road and down into the main city. It's not only orphans who are growing up and need to provide for themselves. Older women who have been bereaved or who are otherwise vulnerable may have no means of survival, shelter or subsistence except through sex. In some

countries the women may be seen as commercial sex workers; in others they may be seen as bar girls, or `kept women'.

In Uganda there are thousands of women without family support or jobs. Many survive through the gifts of a number of men who stay with them regularly when in town. AIDS campaigns are useless to those who will starve without providing sex. A small cottage industry can enable a number of women to find a new life, with new freedom, dignity and control over their own lives---lives free from the constant fear of exposure to HIV. For example, in one area a group of women were given pigs and other livestock to breed and sell, as well as to feed themselves and their families. These issues are also important in countries like Thailand. One project has set up a needlework industry for former sex workers.

As in every area of this terrible epidemic, it is easy to feel totally overwhelmed. Where do you start? How do you begin to tackle such a vast, global, growing problem? The answer is to start somewhere.

As has often been said, *you cannot change the whole world, but you can change someone's world somewhere.*

If as a result of your help an adult with AIDS is able to die at home, free of pain and at peace; if a family recently orphaned are taken into a home and cared for together until they grow up; if as a result of an AIDS lesson five young people are still alive in ten years' time who would otherwise have died of AIDS, then you have indeed made a big difference. Just think what 100, 1,000 or 10,000 people could do together. Even more so, the whole church across your country, across the continent, across the world.

Jesus did not heal all the sickness in the world. He came and touched the lives of those around him, giving hope and purpose to a suffering world. As we ask God to show us who our neighbour is, his answer could involve us in the lives of those in another continent, or in the lives of those who live next door.

Some are called to give care in practical ways. Others are neither called nor gifted to set up or be involved in projects, build hospices or start agencies. However, there are so many other ways to be supportive: prayer, financial help, encouragement---to name but a few.

Prevention is even more important than care - if you think about the future

Whenever we begin caring for those with AIDS, we are faced with a terrible thought. Here are a growing number of people dying of a very unpleasant and incurable disease, yet every day many more are becoming infected, becoming ill, dying or becoming orphans. If we cannot cure it and the virus is spreading so fast, then we must urgently do all we can to prevent further tragedy and destruction.

Our greatest moral challenge is to spend as much time, energy and finances on saving lives as on caring for those affected by HIV. You can give all the care in the world and not beat AIDS - you will be busier every year. You can spend all your efforts on prevention and maybe, just maybe, all the care programmes will have to close down because there is nothing left for them to do. There is a middle way: we fight the disease, and care for those affected. Both should go hand in hand. But what is actually happening in almost every church-related programme across the world is neglect of prevention in favour of care. This is a route to future disaster. Churches talk about both, but their actual SPEND on prevention is usually tiny compared to care / orphan support / income generation and so on.

But prevention is difficult. It's easier in some ways to set up a care programme. What is our message? Can Christians agree? We need to decide what to tell our children, since they are in the frontline of danger, and we need to tell them in a way that is most likely to help them see the risks and change their behaviour. School is an ideal place to start, but what do we say and will our message actually change behaviour?

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