

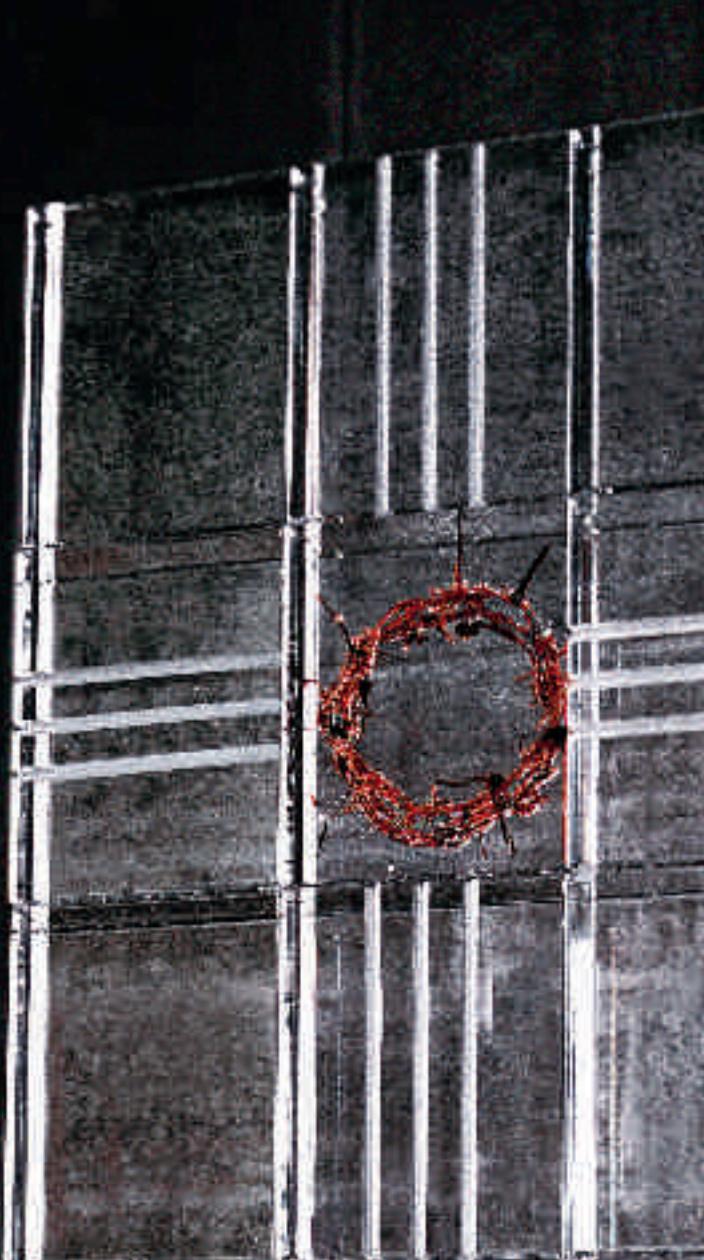
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Church of Sweden 

A PASTORAL LETTER FROM THE BISHOPS OF THE CHURCH OF SWEDEN ABOUT HIV FROM A GLOBAL PERSPECTIVE

2007

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The coat of arms on the back page is the Archbishop's.



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# Preface

SINCE THE FIRST person in Sweden was diagnosed with AIDS in the early 1980s, the Church of Sweden has adopted the same position on AIDS and HIV<sup>1</sup> as on other life-threatening illnesses. We are ready to provide pastoral care to those individuals affected, but the Church has not publicly positioned itself on issues surrounding HIV. With few exceptions, the same silence has been notable throughout Swedish society.

We, the Bishops of the Church of Sweden, wish to make our views known on HIV. We do so based on the experience gained by the Church of Sweden in its work with HIV-infected persons, and based on the experiences shared with us by other churches. We have noted that, even as the epidemic continues to grow, HIV issues receive less attention than they used to. Our intervention is now timely.

The Church of Sweden has had workers stationed in various parts of the world for more than a hundred years, and during that time our awareness that events outside our country's borders also affect us has deepened. We have learned, not least through

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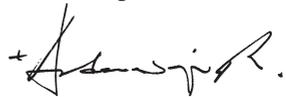
1. HIV is an abbreviation of Human Immunodeficiency Virus. AIDS is an abbreviation of Acquired Immunodeficiency Syndrome.

these workers, just how devastating HIV is, not only for the individual, but also for the whole of society and for the churches.

This Pastoral Letter is addressed to the members and workers of the Church of Sweden and to everyone who works with us for a good society where the value of every individual is respected. We especially address those who have particular social responsibilities in our own country, in other countries, and in international cooperation. In the public sector, we address those responsible for care or humanitarian aid; in the private sector, we address those who represent the pharmaceutical industry. We also address this Pastoral Letter to the parishes and leaders of the world's churches.

Our Pastoral Letter has three parts. The first part gives a picture of the HIV situation at the current time. We point out that HIV is a structural problem that affects already vulnerable groups particularly hard. We highlight value-related issues as a global problem, and we focus on the role of churches. The second part elaborates on the theological and ethical background to our assessment of the situation and takes account of the HIV experience gained by the Church of Sweden in its pastoral care. The third part presents our conclusions and recommendations.

Uppsala, Sweden, November 2007  
For the Bishops' Conference

A handwritten signature in black ink, appearing to read 'Anders Wejryd', with a small cross-like mark at the beginning of the first stroke.

Anders Wejryd, Archbishop

# I HIV – a status report

“**W**ITH THE COMING of HIV and AIDS people are starting to realise the injustices that have been there. Even injustices that have not been mentioned for many, many centuries now they are out in the light. Things that were accepted, now in the face of HIV and AIDS they make women more vulnerable.

People that are living with HIV are part of the solution and not a problem. They should be involved in decision making and given support that is needed and allowed to live their lives as normally as they can.”

*Annie Kaseketi, Zambia, pastor and member of ANERELA+<sup>2</sup>*

## **A structural problem**

HIV was identified in the early 1980s in the USA, but is thought to have spread around the world after its origin in Africa decades earlier. With almost two thirds of the world's infected, including two million children, sub-Saharan Africa remains the worst

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2. African Network of Religious Leaders Living with or Personally Affected by HIV & AIDS.

affected region. An estimated 12 million children have lost their parents to AIDS. There is no sign that the epidemic is abating.<sup>3</sup>

The spread of HIV varies considerably between continents and countries (see figure 1). The increase in the number of HIV-infected in East Asia, South America and, not least, the Baltic states and several Central Asian countries is alarming.

During the time that the virus has spread, UNAIDS has calculated that around 25 million people have died of AIDS. Statistics from 2007 indicate that there are almost 33.2 million HIV-infected worldwide, of whom about 2.5 million were diagnosed. That same year, 2.1 million people died as a consequence of the disease. However, the mortality rate from AIDS varies in different parts of the world. The number of HIV-infected in Western and Central Europe and in North America was put at 2.1 million, but access to better treatment meant that only around 32,000 people died of AIDS in these countries. In Sweden, it is thought that today around 4,000 people are living with HIV.<sup>4</sup>

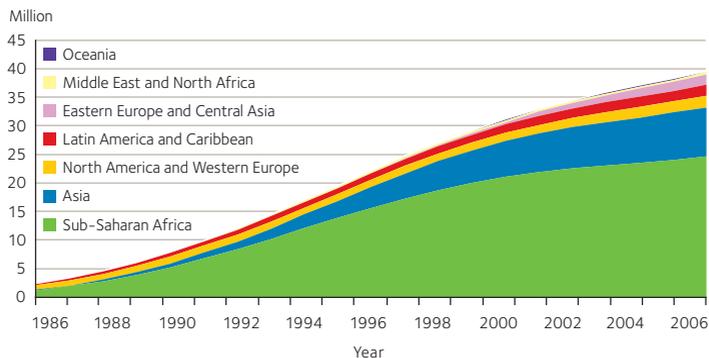
This summary confirms that HIV is spreading fastest among those whose situation is already the most difficult. Being born in the “wrong” country is clearly a health risk. Despite a large number of deaths in Africa, research to identify the virus was only funded

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3. The statistical data in this text is taken from UNAIDS reports. See resources on p 53.

4. Data from the Swedish Institute for Infectious Disease Control: [www.smittskyddsinstitutet.se/statistik/hivinfektion](http://www.smittskyddsinstitutet.se/statistik/hivinfektion)

**Figure 1. Number of people living with HIV in different parts of the world. Annual figures 1986–2006. Source: UNAIDS.**



when AIDS started affecting people in the USA and Europe in the early 1980s. HIV is thus one of the social, economic and cultural factors that affect people’s living conditions globally.

Even within various countries, the spread of HIV reflects the injustices in the society. The disease primarily affects those who are already vulnerable. This has fuelled the public image of HIV and AIDS as self-inflicted and, above all, as something that affects “the other”. In the early years, HIV and AIDS were depicted as something that affected certain high-risk groups, particularly men having sex with men, sex workers and drug users. One of the painful facts about HIV in our own country is that the virus was only taken seriously when it became known that it also reached into traditional nuclear families.

In our country, increased knowledge, more effective infection control, and, in particular, good access to antiretroviral treatment (ART), have led to the situation being viewed as less alarming today than 20 or 25 years ago. The fact that a large proportion of those found to be HIV positive were infected before immigration to Sweden may also contribute to the disease still being seen as affecting “the other”. Such attitudes are thought to have led to an underestimation of the risk of infection. In recent years, the spread of infection has increased to a level reminiscent of the situation at the start of the epidemic.

HIV is spread through bodily fluids, chiefly blood, sperm and vaginal secretions. The virus makes its way into the white blood cells that normally exert the body’s immune system. Without treatment with antiretroviral drugs, the affected blood cells gradually die. The person then develops the immune deficiency syndrome AIDS, which is characterised by infections that are normally combated by a functioning immune system. Eventually, these infections have a terminal outcome.

It has not yet been possible to produce a vaccine against HIV, but research continues. ART limits the ability of the virus to spread in the body and thus limits the risk of the infected person developing AIDS. ART can restore the immune system, but the underlying HIV infection always remains. Proper medication gradually leads to the infected person becoming symptom-free, and to an undetectable viral load. At this point, the risk of infecting someone else is practically non-existent, but the infection lies

dormant and the virus reappears if medication is stopped. For economic and infrastructural reasons, the population in many low-income countries does not currently have access to anti-retroviral treatment.

Infection is prevented primarily by practising safe sex, including the use of a condom during sexual intercourse. The most common route of infection is through unprotected sex, but the virus can also be transmitted from mother to child during pregnancy, at birth or through breast-feeding.

Time and again, established hierarchical structures between the sexes put women at a disadvantage. The number of women infected with HIV is increasing in comparison with the number of men infected. This is at least in part due to the fact that, in practice, women in many countries have no control over their own sexuality. In some countries, married women run a greater risk of becoming infected than unmarried women, since they cannot refuse to have intercourse or require their partners to use a condom. In addition, some women are forced into selling sexual services to provide for themselves and their families, putting themselves at great risk because their male customers are unwilling to use condoms.

Since the risks of HIV infection became known, infection through blood transfusion has rarely occurred in the Western world. However, in countries without the resources to ensure that blood from infected people is not used, blood transfusions do put people at risk.



A significant route of infection is intravenous drug use, when several people use the same needle. Drugs and poverty are often interlinked. Drug use in itself is always a tragedy, and widespread drug use bears witness to a society in which people lack constructive opportunities to overcome their sense of powerlessness, marginalisation and misery. Marginalisation is often bound up with exclusion for other reasons, and this is strengthened through drug use. It is, for instance, not uncommon for people with poor mental health to use drugs to alleviate both their mental problems and the hopelessness they experience. The spread of infection in a society increases with growing drug problems; this is particularly apparent in Eastern Europe today.

HIV is currently the most serious challenge in all development work. It is impossible to fight poverty unless the issue of HIV is tackled at the same time. Nor is it possible, in the long term, to handle the HIV epidemic without addressing the problem of poverty. The destructive effects of poverty and HIV reinforce one another. HIV is not just a problem for individuals; it is a structural problem at societal and global levels.

Poverty means poorer healthcare and poorer education. Many of those who live with HIV in materially poor countries are unaware of their situation and have never had the opportunity to take an HIV test. Others avoid being tested for fear of discrimination. However, where there has been access to testing, HIV medication and support groups, discrimination has been reduced and openness surrounding HIV has increased.

Few people living with HIV today have access to ART. The scope for greater investment in medication in low-income countries is limited by the costs and is made more difficult by international patent and trade regulations. The World Trade Organization (WTO) agreement regulating patent rights, known as the TRIPS Agreement (Trade-Related Aspects of Intellectual Property Rights), permits the import or manufacture of cheap pharmaceutical copies, or generic pharmaceuticals, where this is justified with regard to the public health interests of the country. Despite this possibility, many practical obstacles remain when, in line with this agreement, low-income countries try to take measures to increase access to medication.

A particular problem is the increasing number of children infected with HIV. There has not yet been any conclusive research into the correct doses for children and, above all, there are only a few, expensive, types of medication suitable for children.

Many materially poor countries lack adequate numbers of trained healthcare professionals. Active recruitment by rich countries of such professionals from low-income countries has a serious impact on the ability of low-income countries to treat HIV and operate functional healthcare systems.

Poverty cannot be successfully eradicated without the cooperation of the rich countries of the world. A small proportion of its population consumes the vast majority of the earth's resources. This imbalance is costing millions of people their lives.

Despite the lower number of people infected with HIV and

better access to treatment, the risk – and dread – of discrimination is a real problem for those who are HIV-infected in Sweden. Ignorance about HIV is widespread and causes significant problems. Not even within the health service, where knowledge and empathy should be at their greatest, can every HIV-infected person be confident of being treated professionally and respectfully.

A particular problem arises when HIV-infected asylum seekers are deported from the country. While they are in Sweden, they have access to vital medication, but this access ceases upon deportation. This clearly shows that HIV raises issues that can only be solved through international cooperation.

### **An attitude problem**

It is not only the illness itself that makes life difficult for those infected; other people's ignorance and fear are important parts of the problem. Public information initiatives, although they are necessary, can never completely eradicate these. What people only read or hear about in the media and other public contexts can be kept at a remove and the unknown is more frightening when experienced solely at a distance. Only when people are actually confronted with what they fear, can they deal with it in a constructive way.

People who are informed that they have a life-threatening illness are forced to re-evaluate their lives, but in most cases they have the support and sympathy of those around them. To avoid discrimination, many people with an HIV infection choose to keep quiet about their disease. They dare not be open about

what, for them, is a question of life and death and, thus, perpetuate a state of exclusion and perceived lack of dignity.

Often the most difficult thing to deal with is the sense of shame and guilt. HIV, more than other life-threatening illnesses, is seen as self-inflicted through morally reprehensible behaviour. This is, to a large degree, bound up with the fact that HIV is sexually transmitted. A similar level of shame is attached to other sexually transmitted diseases. To the extent that other chronic and life-threatening illnesses can be considered self-inflicted, for example, as a consequence of smoking or overeating, they are seen as tragic, but are not stigmatised to anywhere near the same extent.

Denial and silence are the virus's most powerful allies. This is true in all contexts, from the individual to the global. Many people die without ever having told anyone about their condition. Knowledge about the disease and the spread of infection that could change this situation is not getting through. It is essential for the future that the silence is broken, so that vital knowledge can be disseminated and the virus halted. This applies both in countries with large numbers of people who are HIV-infected and in our part of the world, where the virus appears to have practically disappeared from public consciousness.

People infected with HIV are brought up with the same values as those around them. When the person who *becomes* infected has already learned to despise those who *are* infected, he or she will direct that contempt towards themselves, often more mercilessly than anyone else. From an existential point of view, this

is the most destructive aspect of the lives of the HIV infected. By not telling anyone, it may be possible to avoid the judgement of others, but one can never escape one's own self-judgement. If one also believes that God is on the side of those judging, then there is no escape in life or in death.

There is, therefore, a great risk that the person infected will be unable to accept this realisation and so will remain in a state of denial that is a natural reaction to any crisis. Naturally, such denial can have devastating consequences for a partner, or partners; it also deters the infected from dealing with the situation and finding constructive ways forward.

The need for conversational support, respectful listening, empathy, pastoral care and human intimacy is as great as the need for medication, and this need is just as great for those who have and for those who do not have access to medication. Medication can prolong life, but does not necessarily make it meaningful. A meaningful life requires a restoration of humanity. This occurs in the meeting of people with people and the meeting of people with God. The restoration of humanity would be supported if the issue of HIV as a question of the value and dignity of every individual were moved up the public agenda.

### **Churches as part of both the problem and the solution**

Part of the problem is the inability of churches to handle issues of sexual ethics. Churches' silence or ill-advised recommendations have contributed to the ongoing spread of the epidemic. At the

same time, churches have been instrumental in providing information and recommendations that have resulted in effective prevention; they have also combated marginalisation and stigmatisation. The role of churches in HIV response relates not least to the issue of values. This is also the case within the churches, which, in many countries, have kept resolutely quiet about the existence of HIV – also among the churches’ members and leaders.

Health institutions run by churches have offered treatment to HIV victims for a long time and taken important social initiatives, often long before other players started their work. Today, churches are still responsible for a large proportion of the work carried out at hospitals, within various programmes for Home Based Care and within social initiatives, despite receiving a very small share of the resources allocated through international funds for HIV work.

Over the years, it has been easier for churches to accept that HIV is a problem in society than to accept that HIV is also spreading amongst church members. Through the metaphor “The Body of Christ has HIV”, churches are seeking, in a partnership between north and south, to break the silence and remind each other that HIV affects us all – that it is a matter of concern for the whole of the worldwide Church and all its members.

The phrase “Body of Christ” alludes to churches as organisms, as something more than just an organisation, and the churches’ members are described as the limbs of one body – even if they are infected with HIV. The declaration that “the Body of Christ has HIV”, therefore, highlights the need for a conscious solidarity. Churches

with large resources have a clear responsibility to listen to those who are infected and to speak for those who have been silenced.

This applies to the relations between different churches as well as to relations between people in our Swedish parishes. Unless parishes can offer a safe and welcoming environment where those who live with HIV can dare to be themselves, declarations of solidarity with HIV-infected around the world are empty words.

A church that seeks to be the body of Christ in the world must lift its gaze and look outside its own inner circle. Christ has told us where he wants to meet us and where he wants to lead us: “Truly I tell you, just as you did it to one of the least of these who are members of my family, you did it to me” (Matt 25:40). In the reversed perspective of the Kingdom of God, all social conventions are challenged: the greatest become the least and the least the greatest and in the greatest suffering the glory of God is shown most clearly.

In this context, people may want to consider the double meaning of the word “stigmatisation”. The original meaning of the Greek work *stigma* is “a brand or puncture wound”, and it is usually used to signify the “branding” of groups seen as being of less value than others. However, particularly in its plural form *stigmata*, in religious terminology the word has denoted Jesus’ wounds. These are two different meanings which should not be confused, but which can be combined in a deeper interpretation: in the experience of those stigmatised, the churches recognise the suffering that Jesus Christ took upon himself out of love for all humanity, and that he calls us to share.



## II Theological, ethical and pastoral perspectives on HIV

“**W**E WERE BORN TO make manifest the glory of God that is within us. It’s not just in some of us; it’s in everyone.”

*Nelson Mandela*

### **A Christian view of humanity**

To talk about “vulnerable groups” or about how HIV is more likely to affect “those whose situation is already difficult” in itself runs the risk of reinforcing unequal structures. Our intention in describing the situation is to emphasise where the needs are greatest and which circumstances particularly demand our attention. The analysis fails its purpose if the consequence is that certain people or groups are perceived as helpless in relation to others and dependent upon the benevolence of others. It is far too easy to take the patterns of power and marginalisation that we see around us as given, and – perhaps with the best of intentions – to become locked in roles and expectations that perpetuate these patterns.

To find ways to achieve constructive change, we need to be able to relate every given situation to a view of humanity that champions the fundamental value and dignity of all people. With such a view of humanity, we can provide a perspective on what it is to be human and sharpen our focus on actual reality.

A Christian view of humanity takes as its starting point a view of the world as created by God, who is love. The Bible speaks of the world as created by God at the beginning of time, but also about how God constantly renews our world with his Spirit. Creation is not a distant, isolated, single event. God is always with us, and this world that we live in is in a state of constant change and renewal.

At the core of the Christian view on humanity is the idea, expressed in the Bible, that mankind is created in God's image. This likeness to God means that each and every one of us has a role to play in God's ongoing creation. As humans, we can share God's love for the world and strive to make sure that the resources available to us are used to manifest God's love. We have a responsibility to maintain good relations in the world through a wholehearted commitment to life and peace, justice and sustainable development. In so doing, we constantly face new challenges and new opportunities.

Our dignity as people is thus closely linked to our ability to live in responsibility and love. However, our human reality also includes the experience of vulnerability and imperfection, disappointment and unavoidable guilt. We constantly long for a life

that is completely and utterly genuine, but over and over again we are forced to accept that we are not able to live up to our own ideals. The more clearly we see how life should be, the more aware we become of our own powerlessness.

In church terminology, our inability to live in love and responsibility is expressed in terms of sin. The Bible's story of the Creation is immediately followed by a story of human shortcoming. Like the story of Creation, it depicts an eternally ongoing process, but one where we as humanity are tempted to approach life and the world in a destructive way.

In the Bible's depiction of Jesus, we recognize a life that is complete and true, filled with love and care – but that also challenges all destruction, small-mindedness and self-absorbedness. As Christians, we also see God himself in Jesus. At our side, God in Jesus' person bears all the guilt that is ours, shares our weakness and dies our death. But more than that: Jesus goes before us into death and through the Resurrection he explodes the boundary that we thought was the definitive end of all things and paves the way to a new life.

### **Three HIV-related issues**

In this overarching perspective, the Church must interpret the questions that face us in the meeting with HIV.

Firstly, since the disease is chiefly spread through sexual relations, we must address *issues of the body and sexuality*. Our bodies are an indispensable part of our individual and social identity. All

our relations are, in some respect, physical. We cannot live a life of love and responsibility without this also including our bodies.

As such, we have an obligation to treat our lives with care and intelligence, not hurting others but also not hurting ourselves or foolishly exposing ourselves to danger. Self-destructive behaviour bears witness to broken relationships with other people, with one's own life and with God, who loves us and wishes us well. Abuse of drugs or sexual relations, is evidence that people lack the fundamental security that everyone needs in life. When such a situation is used and exploited commercially, people are systematically stripped of their most fundamental human dignity.

Sexuality was given to us in creation as God's way of constantly creating new life. Sexuality is necessary for humanity's continuation and a source of togetherness, joy and deeper love and intimacy. The sexual relationship is an expression of every person's need to relate to another person with their entire being: it is life-giving in many respects.

It is deeply tragic that a life-threatening disease such as HIV is spread through sexual relations. However, that fact adds another dimension to the responsibility that we all bear for how we deal with our sexuality and our sexual relations. Fundamental in this context – as in others – are values such as love, reciprocity, trust and equality. Trust and reciprocity are constantly put to the test in our sexual relations, which is particularly clear in situations that in various ways are marked by insecurity and marginalisation. Perceived lack of power can make it difficult to recognize one's

responsibility as a person. The scope for making responsible choices can, in practice, be extremely limited for those who live in vulnerable situations. Work to combat HIV is, therefore, largely an issue of increasing people's scope for self-determination over their lives and their bodies.

Secondly, HIV also raises *issues of solidarity and equality*, not least in terms of superiority and inferiority between the sexes. According to a Christian view of humanity, everyone – man as well as woman – is made in God's image and those who harm their fellow people deface God's image.

This also applies to the relationship between the rich and poor of the world. We have been entrusted with the world so that we may look after it in the best interests of everyone, as is God's will. From this perspective, the fact that a small part of humanity grows rich at the expense of others is indefensible. The God who created the world is a God for all people, and particularly for those who in people's eyes are poor and vulnerable.

A responsible and loving attitude in the face of the inequality that we encounter, and that we ourselves are always a part of, demands that we strive with all the means at our disposal to restore people's dignity. It is a case of combating abuse of power and marginalisation in all its forms, and the despondency born of a sense of powerlessness.

Thirdly, our HIV brings us to pose the question *what makes a meaningful life?* Every person's life is unique and meaningful because it is created by God. When we seek to deal with everything

that happens to us and everything that we face with trust in God, and in a responsible and loving way, we can find a meaning both in our own and other's lives. This is also the case in situations that push us to our limits, as when we come face to face with a life-threatening illness.

The Bible and Christian tradition offer many stories of people who have been healed through divine intervention. But there are also stories of people affected by serious illnesses, accidents or losses who still find a way to live on. This can also be seen as a work of God. These are stories of how people have found not only a way of continuing to live, but also of living a life full of meaning and importance.

### **The example of the Gospel**

At the heart of a Christian view of humanity are both the experiences that we as Christians share with all human beings and the texts given to us in the Bible. These stories contain a dynamism that, even today, functions to help us interpret life. The stories must be re-interpreted in every era, and also relate to our experiences, for example, of HIV.

The central stories are naturally those about Jesus. In Jesus Christ, God shows, in a unique and eternally unsurpassable way, his love for all people and calls upon us to follow his lead. The ultimate confirmation of the value of human life is the Gospel story of how God himself was born in human form in Jesus. In this story, our own experience as people is mirrored, and God

invites us to make the story of Jesus our own by following him on the path that leads through death to life.

There are, of course, no stories about HIV in the Bible. The closest we get are the stories about leprosy, for example, how Jesus cures ten lepers (Luke 17:11–19). Throughout the ages, leprosy has been a marginalised and stigmatised disease, just like HIV in our time. People saw those affected as unclean and banished them from social communion. The Bible shows how Jesus treats these people who are suffering and marginalised. However, there is a risk in reading the Gospels' stories of miraculous healing as if they were essentially about the disease. The Gospels are not primarily about how a person can be freed from disease, but rather who Jesus is and what God's will is with regard to human life. We discover the deeper contexts in our lives when we learn to look beyond the obvious.

In the Gospel of John, chapter 9, we find a story that is unusual in that Jesus comments on the condition with which he is faced and rejects the interpretation that everyone around him makes. His words help us not only to understand the concrete situation in the story, but also our own attitudes to illness and disability. The story starts with Jesus meeting a man who has been blind since birth.

“Rabbi, who sinned, this man or his parents, that he was born blind?” Jesus answers, “Neither this man nor his parents sinned; he was born blind so that God's works might be revealed in him.” He spreads a paste of mud and saliva over the blind man's



eyes and sends him off to wash in the pool of Siloam. The man returns from the pool able to see – and immediately comes into conflict with the religious leaders, who want to cast Jesus in an unfavourable light.

Speaking of Jesus, they say, “We know that this man is a sinner.” The cured man answers, “I do not know whether he is a sinner. One thing I do know, that though I was blind, now I see.” Later, he meets Jesus but without recognising him – after all, he has never actually seen him. Jesus asks him, “Do you believe in the Son of Man?” and he answers, “And who is he, sir? Tell me, so that I may believe in him.” When Jesus says to him “You have seen him, and the one speaking with you is he,” the man declares his faith and falls at the feet of Jesus, who says, “I came into this world for judgement so that those who do not see may see, and those who do see may become blind.”

The striking thing about this story is how Jesus rejects the assumption of his time that illness and disability are a direct consequence of someone’s sin. He turns the perspective on its head. Instead, he gives meaning to the man’s situation. Blindness and clarity of sight switch places: the blind man, who through his disability, was marginalised and so seen as a sinner, is freed from his marginalisation and becomes the one who, through his faith, sees clearly. Those who see themselves as sighted are portrayed as blind inasmuch as they fail to understand who Jesus is, despite seeing him there in front of them. The experience of the formerly blind man is contrasted with the false sense of security of the Pharisees.

As subject, his humanity restored, the congenitally blind man is even able to challenge the religious leaders of his time.

We who read the text are offered a choice between identifying with the blind man or with the Pharisees. A false sense of security can, unfortunately, appear to be an all too familiar attitude, not least in the materially secure existence that many people enjoy in a country such as Sweden. But a crisis can become a turning point that allows us to discover life's real values.

The Gospel stories seek to help us find a deeper meaning in our lives. Illness and disability can become visible reminders that we are all essentially dependent on each other and the grace of God. Vulnerability in life is something that we all share, and once we realise that, we are already on the path towards a good life, full of empathy.

### **Ethical points of departure**

HIV brings up fundamental questions about how we as people behave towards each other. HIV is sometimes referred to as “the great revealer” that forces us to talk about human behaviour and attitudes that we neither want nor dare to speak about.

We see these as questions of ethics. Like life itself, an ethical discussion cannot be stated as a simple theoretical formula nor can it be reduced to a set of principles. Stories and examples are keys when it comes to understanding the morally relevant aspects of different situations. The tangibility of the stories can give substance and clarity to the principles. In Christian ethics,

this is particularly true as regards the Gospel stories about Jesus – both what he said and what he did.

In the previous section, we gave an example of how the Bible can be used when reflecting on ethical issues. However, the Bible is not the only point of departure for Christian ethics. Like everyone else, we as Christians are required by Creation itself to be ethical in our relations with our fellow human beings. Creation is set up in such a way that we are dependent on each other. This comes into sharp focus at certain stages of our lives: we are utterly dependent when we are born, but also when we are very sick. Each and every one of us has a responsibility to meet the needs of other people when it is possible for us to do so. We may do this in our families, at work and in our local communities, but our responsibility for each other is not limited to the people who belong to the same group as we do: it applies to everyone, regardless of where we may happen to find ourselves.

When faced with other people's needs, it is often perfectly clear how we can help to make sure they are met. For instance, we do not need any biblical revelations to understand that a small child needs to be cared for. God created us with common sense and a conscience that we can use to understand how we should behave in different situations. We have a responsibility to make use of this gift to the best of our ability. This means that ethics is, to a large extent, rooted in Creation.

Ethics cannot be reduced to individual principles, but such principles can still assist us in clarifying our ethical arguments.

Starting from the Bible and Creation, we can justify two important points of departure: the principle of human value and the concept of stewardship.

Both negative and positive duties follow from the *principle of human value*. The negative duties set the limits for how we can treat other people. They state what we may not do and express a respect for the integrity of the individual. For example, none of us has the right to exploit other people for our own purposes; we should always see our relationships with other as ends and not means. The negative duties also require that we refrain from actions that can hurt or offend other people.

The positive duties, on the other hand, require us to act in the interests of other people. This means that we are obliged to actively protect the rights and well-being of others. We also have to work for the fair distribution of the planet's resources and for equality between people. As such, the principle of human value places obligations on us concerning justice and solidarity, key elements of any ethic that seeks to safeguard values such as love, respect and reciprocity.

The *concept of stewardship* is also bound up with the view of the world as God's Creation. God has entrusted us with the resources of Creation, so that we may use them in the service of others. Created in God's image, we, as humans, are able to understand how various things relate, and human ingenuity has made it possible for us to make the most of the resources of Creation. From an ethical perspective, we can highlight two cen-

tral aspects of the concept of stewardship. One relates to using the resources of Creation in order to improve human welfare and combat suffering and need, and the other relates to caring for and defending Creation, with respect for its integral value and with regard to the needs of future generations.

Scientific achievements have radically improved our ability to make use of the resources of Creation. Our lives have been made easier in so many ways through technical progress, and medical science has made it possible to conquer many illnesses. God, who is love and goodness, wants the resources of Creation to be used with responsibility and for the common good. Within The concept of stewardship, is predicated on that we, as humans, have been given freedom, at the same time as it is expected of us that we will remain faithful to the will of God.

Neither the principle of human value nor the concept of stewardship is exclusive to a Christian ethic. For instance, the idea that all people are equal lies at the heart of universally recognised human rights, and the concept of stewardship is brought into focus in the global debate on distribution issues, environmental destruction and the exploitation of non-renewable natural resources.

The principle of human value and the concept of stewardship are important points of departure as we seek a loving and responsible approach to HIV. According to the principle of human value, everyone affected has the right to receive care, loving support and medical help. This is also true for those children whose parents have died of AIDS or who are far too sick to be able

to take care of them. Respect for the value of human life also obliges each and every one of us to behave responsibly in order to prevent the spread of HIV.

The concept of stewardship can motivate us to exploit the potential of science and make major investments in research to develop medication that prevents the progress of the disease, relieves the symptoms and hopefully, in the long term, provides a permanent cure.

It has already been established that the destructive effects of HIV and poverty are mutually reinforcing, and that this especially affects women. The HIV epidemic strengthens the arguments for fighting poverty that follow from both the principle of human value and the concept of stewardship. Among other things, it is a question of, in various ways, giving everyone infected with HIV access to the medication that is currently only available to those who can pay.

Working against HIV requires the commitment of enormous resources, which clearly has to be carried out at the societal level and globally. Information initiatives are one area that requires massive investment. At the same time, it is important to realize that we as individuals must also act responsibly, and that this cannot be delegated to someone else. Every one is responsible for their sexual relations and for getting tested if they suspect they may be infected. However, we are also obliged, in our own relations, to defend everyone's value and dignity, and to combat all discrimination in the contexts in which we move.

Respect for human life demands that no vulnerable person be discriminated against. It also means that no one can primarily see themselves or any fellow human being as a victim of circumstances beyond our control, or as an object of other peoples' benevolence. Respect for the value of every person requires us to see each other as the responsible subjects of our own lives.

From the Gospel stories about Jesus, we can discern the attitudes that should inform our relations, and that these attitudes should apply to everyone, even vulnerable persons. We need to show love, empathy, care, respect and fairness. In our shared aim of combating HIV we, as good stewards, must also efficiently exploit the resources at our disposal.

### **HIV in churches' pastoral care**

People affected by HIV are a challenge for the pastoral care of churches. HIV touches on our innermost integrity, not least because it is a sexually-transmitted disease. HIV engenders strong feelings of shame and guilt, both in relation to other people and in relation to a person's own situation. This is dealt with in different ways in different cultures. Reactions of repression, denial and silence are common. Fear of the reactions they expect makes people keep quiet instead of opening up for the conversations that can be the start of a positive development.

In pastoral care there is an atmosphere of security, which means that we dare to tell more than we have before – even about matters that we have kept secret, even from ourselves.



Dealing with guilt and dealing with shame are two separate processes that should not be conflated. The root of our guilt is concrete actions, or neglecting to act the way we think we ought to have. A healthy sense of guilt can most easily be described as regret or a bad conscience.

Many of those who receive an HIV diagnosis feel that they have brought it on themselves. This feeling seems to arise, no matter how a person becomes infected. In this context, no one can avoid dealing with the issue of responsibility. Coming to terms with what has happened, who or what is responsible and how it occurred can be a long process. Part of this process involves differentiating between what is real, “healthy” guilt and what is guilt about something for which the individual is not actually responsible.

To take responsibility for what you have done or omitted to do, to acknowledge and to regret is the path to release: that is how the guilt can be dealt with, forgiven and reconciled. Pastoral care can highlight the opportunity for openness, and hopefully also for reconciliation and forgiveness, in relation to other people. But in pastoral care the question of guilt and reconciliation are also related to God. Through Jesus Christ, we have the promise of redemption for all guilt. God’s forgiveness is already there for us, ready to be given to those who ask for it. In individual pastoral care and in divine services, churches have a duty to convey this forgiveness.

When it comes to HIV, shame is often a major problem. We can cause each other pain by sending out the message of shame

to each other. However, the message only gains a foothold when the shame has an ally in our own wounded inner self. Then the shame can prevent us from reacting with healthy anger towards those people who lack respect for us.

The unhealthy shame comes from how we perceive ourselves. It has its roots in our self-image, which has been created through the experiences that life has given us. A person who has been badly treated from the start, or who has been bombarded with messages that strengthen their sense of inferiority, finds it easy to feel like a worthless failure. To then be infected with HIV creates a whole new level of shame, both from the outside and the inside. It can be difficult to differentiate between the feelings that arise out of unhealthy and healthy shame. Here we often need help from outside, from people who are experts at seeing and understanding the difference. It is a frightening and new experience to act as if the shame did not exist: to dare to say no, to stand up for our own needs or to set boundaries when others lay on us a responsibility that is not ours. It is difficult, but every time we succeed in overcoming the shame, we feel its power fade.

Having the courage to tell other people that one is infected with HIV is an effective way of overcoming the shame. The pastoral caregiver can encourage this, and can be an important ally for those who feel that they are standing alone against the entire world.

The shame cannot be removed through forgiveness. On the contrary, it is disastrous when we ask for forgiveness for some-

thing that is not our responsibility. That simply deepens the shame. In this situation, there is a need for understanding, insight, and rehabilitation – perhaps during many conversations with a gentle, empathetic and understanding spiritual caretaker, someone who takes care of us and mourns with us as the truth emerges.

Talking with other people in groups can also be a way of rectifying a destructive self-image. Honest and open exchanges with others who are wrestling with the same issues are one of the very best ways of reducing the shame. That which has been wounded in relationships needs new relationships in order to heal. New accepting and loving relationships can lessen and eliminate the shame that has built up through early destructive relationships.



# III Conclusions and recommendations

“**I** DON’T WANT my church to say, ‘I can help you to die,’ but ‘Let me help you to live!’”  
*Japé Heath, South Africa, priest and member of ANERELA+*

## Conclusions

Dealing with HIV reveals our deepest attitudes to the value and dignity of people and our fear of the unknown, not least our own mortality. Whether or not we are infected with HIV, we are forced to face up to the disease and to each other. Together, we will determine whether HIV spreads any further.

It is universally the case that HIV confronts us with questions of human dignity and of how we view humanity. The extent of the epidemic varies in different parts of the world, but the same questions of value arise everywhere: In Southern Africa, where the problems are numerically greatest, in Eastern Europe or Central and South East Asia, where the number of new cases is worryingly high – and in Sweden, despite worrying tendencies to trivialise the problem because of its relatively small scale.

The issue of HIV raises questions as to how we perceive other people and how we respect their inherent human dignity. The first and most obvious aspect of this, and the one thus far to receive most attention, deals with halting the spread of the epidemic and preventing people from dying of AIDS. Respect for the life of each individual requires that we focus on this. Considering the fact that it has long been known just how serious the situation is, it is practically incomprehensible that the global fight against HIV is not more extensive.

The second aspect has so far not received adequate attention. Insufficient resources are being put into breaking the “culture of silence” that surrounds HIV. For the person infected and for his or her family, the silence can be just as difficult to deal with as the disease itself. A global strategy for the value-related issues surrounding HIV is just as necessary as the global strategy in the epidemiological field.

In both these respects, churches have a key role to play in maintaining respect for the value of human life. A responsible and loving attitude in dealing with HIV requires that the epidemic and the risk of infection are taken extremely seriously, and that churches work together with other players to combat the spread of infection. Secondly, it also requires that those already infected be taken seriously. Dignity lies at the heart of all care and treatment. Dignity is necessary in all human contexts, not only in healthcare but also throughout society, including in churches and parishes. Churches should focus particularly on their vital role when it comes to

value-related issues surrounding HIV. Churches, organisations and agencies should be encouraged to work in close partnership, so that the resources of the churches can be put to full use.

In the history of the Church of Sweden, it should be remembered that we showed solidarity with the people of Southern Africa in their fight against apartheid. Today, we have to show the same solidarity – with them, with each other and with everyone – in the fight against HIV. In both cases, it is a matter of standing up for the inviolable value of human life. HIV is an issue of life and death in many more respects than just expected lifespan. The question is what we all have to look forward to in our lives: love, empathy and dignity or shame, isolation and humiliation?

On such issues, all the world's churches have an answer, a greeting to every person from God who is the God of life. That message is in every sense a promise of life.

As churches, we must turn away from shaming persons who are infected with HIV. In individual pastoral care, churches' workers meet people who are infected with HIV or are concerned about HIV. Our task as churches and as Christians is to act as beacons of life, hope and meaning even in difficult situations. Being diagnosed with HIV should not be trivialised, but after the severe reactions that such a diagnosis can naturally cause, it is necessary to find a constructive approach to a new situation in life. In offering pastoral care, it is essential to maintain respect for the value of each person, and to strengthen each person's will to live in responsible and loving relationships. Those who already feel powerless, value-



less and marginalised need more empathetic support to realise their opportunities and defend their human and moral integrity.

Those who regularly provide pastoral care to people should have sufficient knowledge about HIV not to be frightened of meeting infected people and their families. We in the churches should strive to express ourselves clearly on the issue of HIV and sexual relations, within pastoral care and in education and preaching. The silence that arises out of modesty must be broken if the spread of HIV is to be halted, and it is our duty to remind people just how vital it is to use condoms.

However, the importance of expressing ourselves clearly relates not only to concrete issues such as condom use or the promotion of other methods of prevention. We also need to speak positively and realistically about human sexuality, and we need to bring up fundamental, but often ignored, questions of people's ability to retain their sexual integrity. This applies not least to issues surrounding the sexual rights of women. Destructive social patterns must be challenged, even when they are part of a long tradition.

Churches are able, in various ways, to get involved in the care and treatment of HIV-infected and AIDS patients. In many countries, churches and religious organisations are by far the largest players in the healthcare sector, alongside national health services. Medication is a reality of life for the HIV-infected, and those living with HIV are, in many ways, on their own in their difficult situation. In this context, churches can provide support for the infected and his or her family.

Churches around the world have a key role to play in responding to HIV, but they have not always fully realised just how important their role is, both in terms of speaking out about the spread of infection and prevention and in terms of the underlying value-related issues. Very few players in civil society have such a great overall reach. In some countries, churches are the only movements operating from the suburbs of the cities to the most remote rural villages. Religious leaders, churches and faith-based organisations are, therefore, close to the most vulnerable groups and can promote prevention, care and treatment.

The Church of Sweden has a presence throughout the country, and its parishes reach not least a large proportion of young people. This gives the Church of Sweden opportunities to help young people gain a good understanding of what the disease means and how they can protect themselves. It also enables the Church of Sweden to take young peoples' insights and experiences into account and incorporate them into the ongoing work on issues of human dignity, determination and justice.

Added to this is the extraordinarily important role that the Church can play in the matter of shaping opinion and work on underlying values. This is true locally, nationally and globally. Churches must actively protest against active recruitment of medical staff by rich Western countries that leaves low-income countries stripped of valuable expertise. Churches must work to influence the pharmaceutical companies, so that they do not profit from the situation of poor people.

The role of churches in combating HIV is primarily to resist discrimination and stand up for people's rights and value in every way possible. We would urge all church workers and members, in conjunction with the annual World AIDS Day on 1 December, to make churches a prominent and committed force in society's manifestation against HIV, and also to raise the issues surrounding HIV prominently and forcefully in the heart of the parish. Naturally the HIV work must continue all year round, but World AIDS Day offers an opportunity to highlight the issues raised by HIV.

The Church of Sweden, together with other churches, must stand up for every person's right to care and treatment. In this context, no person or country should be seen chiefly in the light of their shortcomings, but in the light of their potential. HIV makes it possible and necessary for us to appreciate the equal value of everyone and everyone's shared vulnerability. This is the empathetic path that God himself showed by making Jesus Christ human for our sake.

## **Recommendations**

Based on the points above, the Bishops of the Church of Sweden direct the following recommendations

*To Swedish agencies and political decision-making bodies:*

- that they increase initiatives to combat all tendencies towards discrimination on the grounds of HIV
- that they put more resources into HIV information for preventive purposes, particularly among young people



- that they increase international aid to projects aimed at protecting and strengthening the sexual and reproductive health and rights of everyone.

*To UNAIDS and other international organisations tackling HIV issues:*

- that they work with NGOs to develop a global strategy regarding value-related issues surrounding HIV.

*To those responsible for healthcare resources in their country:*

- that they strive to treat every patient well and with dignity in meeting their medical, social and spiritual needs
- that they refrain from actively recruiting medical staff and thereby contributing to the draining of healthcare systems in countries with widespread HIV infection.

*To patent-holders and decision-makers in the pharmaceutical industry:*

- that they honour their human responsibilities and use their resources in ways that benefits humanity
- that they increase initiatives to develop medication suitable for children
- that they respect the World Trade Organization's TRIPS Agreement and refrain from challenging and fighting poor countries' legal right to increase access to medication through their own production or through import of generic drugs

- that they adjust the pricing of their products in relation to what is reasonable considering the needs and resources of different countries.

*To all parishes and workers in the churches:*

- that they seek to increase their knowledge of the issues surrounding HIV
- that they make the most of their opportunities to influence young people and make them aware of the risk of HIV
- that they strive to make the parish a safe and trustworthy meeting place where everyone can feel welcome, important and valued.

*To us church leaders around the world:*

- that we all, in our own contexts, contribute to an increased competency in and theological reflection on HIV-related issues
- that we work to increase knowledge about HIV and HIV prevention in our churches and set a good example by starting to talk about HIV ourselves
- that we, to save human lives, recommend that people use condoms
- that we develop pastoral expertise in our churches on the issues surrounding HIV
- that we stand up for the value of every human being, defend vulnerable groups and, in every way possible, combat discrimination.

## IV Resources

### *The Church of Sweden*

Postal address: SE-751 70 Uppsala, Sweden

Visiting address: Syslomansgatan 4, Uppsala, Sweden

Phone: +46-(0)18-16 96 00

Website: [www.svenskakyrkan.se](http://www.svenskakyrkan.se)

E-mail: [info@svenskakyrkan.se](mailto:info@svenskakyrkan.se)

### *ANERELA+*

*(African Network of Religious Leaders Living with or Personally Affected by HIV & AIDS)*

Address: 5th Floor JCC House, 27 Owl Street, Milpark,  
Johannesburg 2006, South Africa

Phone: +27 11 482 9101

Website: [www.anerela.org](http://www.anerela.org)

E-mail: [info@anerela.org](mailto:info@anerela.org)

### *INERELA+*

*(International Network of Religious Leaders Living with or Personally Affected by HIV & AIDS)*

Address: 5th Floor JCC House, 27 Owl Street, Milpark,  
Johannesburg 2006, South Africa

Phone: +27 11 482 9101

Website: [www.inerela.org](http://www.inerela.org)

*EAA*

*Ecumenical Advocacy Alliance*

Ecumenical network for international cooperation in advocacy on HIV-related issues.

Website: [www.e-alliance.ch](http://www.e-alliance.ch)

*EHAIA*

*The Ecumenical Response to HIV/AIDS in Africa*

Programme within the World Council of Churches which gives churches in Africa access to information, training, networking and support in their work with HIV in their local communities.

Website: [www.wcc-coe.org/wcc/what/mission/ehaia-e.html](http://www.wcc-coe.org/wcc/what/mission/ehaia-e.html)

*IAS*

*International AIDS Society*

International organisation for researchers working on HIV and AIDS.

IAS also organises scientific conferences and congresses.

Website: [www.ias.se](http://www.ias.se)

*Swedish Institute for Infectious Disease Control*

Central administrative agency responsible for monitoring the epidemiological situation regarding infectious diseases among the population and with promoting protection against such diseases.

Website: [www.smittskyddsinstitutet.se](http://www.smittskyddsinstitutet.se)

*UNAIDS*

*The Joint United Nations Programme on HIV/AIDS*

The website posts important documents and statistics about HIV.

Website: [www.unaids.org](http://www.unaids.org)

*WHO*

*World Health Organization*

Aims to achieve the best possible health for people everywhere. WHO leads and coordinates health work within the UN.

Website: [www.who.int/hiv/en/](http://www.who.int/hiv/en/)

## Photo credits & captions

- COVER PHOTO: ULRIKA SKÖLD. The altarpiece in Linköping Cathedral, *Golgota – Christ's Crown of Thorns* by glass artist Jan Johansson, is dedicated to all those who have been affected by HIV.
- PAGE 6 PHOTO: JIM ELFSTRÖM/IKON. Monks making candles in Östanbäck's monastery.
- PAGE 14 PHOTO: JIM ELFSTRÖM/IKON.
- PAGE 22 PHOTO: JIM ELFSTRÖM/IKON. Preparations for a "Soup Mass" at Samariterhemmet Diaconia Institution in Uppsala.
- PAGE 30 PHOTO: JIM ELFSTRÖM/IKON. Caption: Crucifix in the Church of Sweden Central Office chapel.
- PAGE 38 PHOTO: EVA PÉREZ JÄRNIL/IKON. Julio César Cruz Requenes, is HIV-infected and the director of the volunteer organisation Prosa, which works for the rights of the HIV-infected in Peru.

- PAGE 42 PHOTO: LEIF GUSTAVSSON/IKON. Athi and his mother Xoliswa Matshabane in Khayelitsha shantytown in Cape Town, South Africa. Athi is HIV-positive and a lively little boy after being given medication and treatment at Philani, one of the many clinics that the Church of Sweden supports.
- PAGE 46 PHOTO: LEIF GUSTAVSSON/IKON. Caption: Schools and teaching have always been an important part of the church's work. The Church of Sweden supports Mekane Yesus Church in Ethiopia.
- PAGE 50 PHOTO: JIM ELFSTRÖM/IKON. *Världens fest* in Västerås.