



■ Caring for carers



*Managing stress in those who care
for people with HIV and AIDS*



Joint United Nations Programme on HIV/AIDS

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Sinosizo Home-based Care
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CARING FOR CARERS

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who care for people with HIV and AIDS

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1. Executive summary

The strains on those caring for people with HIV/AIDS are enormous. And as the epidemic matures, overwhelming the capacity of the health services in many countries to cope, they are being borne increasingly by lay carers within families and communities. These people are a precious resource. The quality of care they provide and their ability to do so over a sustained period depend on the protection of their own well-being and morale. But although this is well recognized in principle, care for the carers is rarely given the priority it deserves, and “burnout” is a serious problem. So what should care programmes for people with HIV and AIDS be doing to minimize stress and burnout?

To look for answers to this question, a consultant for UNAIDS visited AIDS Support Organizations (ASOs) in Uganda and South Africa to interview a range of people including: managers and supervisors of care teams; carers on the staff of ASOs; community volunteers; primary carers within families; and individuals with expertise in this field. The objectives were to:

- identify who the carers are within the family and at community level;
- identify the stressors – causes of stress – associated with their care-giving roles;
- draw lessons from the field in how to manage stress and minimize burnout in these settings; and
- recommend strategies to safeguard the health of carers at family and community levels.

Who are the carers?

At the family level, the burden of care is borne predominantly by women and girls. However, AIDS is challenging traditional attitudes, and men are increasingly willing to take on the physical care of sick partners and family members. The least-acknowledged carers within the home are children. When one parent dies in a nuclear family there is often no one else to look after the other parent who falls sick. Nobody knows how many children in Uganda and South Africa are acting as primary carers, but it will become increasingly common as the epidemic matures simply because AIDS targets the parent generation.

The backbone of community care programmes for people with AIDS are volunteers. Some are “informal” volunteers – friends or neighbours who care for sick people they know out of a sense of love or duty. Or they are people, such as members of a church, who give time to community service. But huge numbers of people working for AIDS care programmes are

“formal” volunteers, recruited, trained and supervised by the organizations for whom they work on an agreed basis.

Most of the AIDS organizations visited have only a small complement of care professionals on their staff. These employees may work directly with clients and families themselves, but their main responsibility is to recruit, train and support volunteer carers in the community.

The most widely consulted health practitioners throughout Africa are traditional healers. However, there is little official recognition of their importance within communities, and traditional healers are, by and large, caring for people with HIV/AIDS without training or support from non-governmental organizations or the statutory health services.

The causes of stress

Much of the stress experienced by carers is in the nature of the work itself – the fact that they are dealing with an incurable condition that kills largely young people, causes terrible suffering and is heavily stigmatized. But stress may also be caused by organizational factors – the way a care programme is designed and managed. The most commonly reported causes of stress among carers working with AIDS programmes include:

- financial hardship;
- oppressive workloads;
- secrecy and fear of disclosure among people with HIV or AIDS;
- over-involvement with people with HIV or AIDS and their families;
- personal identification with the suffering of people with AIDS;
- the unmet needs of children;
- lack of an effective voice in decisions that affect them and their work;
- inadequate support, supervision and recognition of their work;
- inadequate training, skills and preparation for the work;
- lack of clarity about what the caregiver is expected to do;
- lack of referral mechanisms; and
- lack of medication and health care materials.

In addition to many of these causes of stress, family-level carers may suffer from:

- isolation, insecurity and fear for the future;
- the effect of HIV and AIDS on personal relationships and family dynamics; and
- difficulty in communicating with children.

Management of stress and burnout

The report looks at personal coping mechanisms before going on to describe the strategies used by AIDS organizations to deal with stress and burnout among staff and volunteer carers. Lessons and observations from the field include the following:

- A first requirement in supporting carers working with people with HIV or AIDS is to acknowledge formally the fact that their work is inherently stressful, and that feelings of distress are legitimate and not signs of personal weakness or lack of professionalism.
- Carers at all levels need to be relieved of the burden of responsibility for things they cannot help.
- Stress and burnout are complex phenomena with multiple causes and multiple manifestations. Thus no single, time-limited activity will ever be the solution.
- Knowledge is empowering – it gives people confidence, control and choices in life, and it has lasting value. Thus training (including regular refresher courses) plays a central role in the management of stress and burnout among carers.
- For the sake of their morale and self-confidence, carers at every level need to know that their work is recognized and valued.
- Relieving poverty is a top priority. Income-generation schemes are much needed and much valued by AIDS-affected families and communities to relieve the stress of poverty.
- To relieve the anxieties of dependence and insecurity, there needs to be greater constancy of support from donors.
- Stress management is a necessity, not a luxury, for AIDS care programmes. Effective measures for managing stress include:
 - realistic work targets, clear job descriptions and good referral mechanisms;
 - regular time off that is respected;
 - health care provision and paid sick leave;
 - team work and regular meetings to discuss issues and share problems;
 - dispersal of the emotional burden by assigning different people to care for a client;
 - the appointment of a carers' counsellor; and
 - an effective voice for carers in decisions that affect them.
- National governments need to look carefully at how existing laws and policies affect the operation of AIDS care programmes, and how they might be modified to make the work of carers easier and more secure.

2. Introduction

Latisa, manager of an AIDS care programme in Soweto, South Africa, tells a story that haunts her about her work in the township. She had gone to the home of a single mother with three boys aged 10, 7 and 5. “The mother was terribly ill. She had sores all over her body that were oozing pus,” recalls Latisa. “The woman had nobody to care for her but the boys, and they were bathing their mother and trying to cope with everything themselves. The 10-year-old asked Latisa: ‘how do I cook for my mother?’ He was trying to do all that needed doing, but he didn’t know how. When I left that home I was crying; I couldn’t keep my mind on the road ahead.”

Gladys, a volunteer in a rural area of South Africa, says she was unprepared for all the social problems she finds in the homes she visits: “I thought I was going to give health care, but then you find there’s no food in the house, the whole family is hungry, there’s no money coming in, and you feel you can do so little.” And in Uganda, Christine, a counsellor on the staff of an AIDS organization who is herself HIV-positive, tells of her anxiety at being unable to reach her targets, as she is often too weak to handle the scooter she has been given to visit her clients. She feels guilty at having to lean on her colleagues, but cannot face the idea of retirement: “I have children to support – who will pay their school fees if I give up? And how will I manage without medical care?” she asks.

The strains on those caring for people with HIV infection and AIDS are enormous and wide ranging. And as the epidemic spreads and matures, overwhelming the capacity of the health and social services in many countries to cope, they are being borne increasingly by lay carers within families and communities. These people – pioneers of the home care movement, front-line workers in the efforts to stop AIDS and to contain the damage it does to their societies – are a precious resource. The quality of care they provide and their ability to do so over a sustained period depend on the protection of their own well-being and morale.

The purpose of this report is to draw attention to the needs of carers and to what can be done to support them more effectively. It will focus on those involved in home and community-level care. And it will draw on the first-hand experience of individuals and AIDS organizations in Uganda, which was one of the earliest countries to be affected by AIDS and to respond with imagination, and South Africa, where the virus is spreading faster than almost anywhere else on earth. The report is intended for all those with an interest in the care of people with HIV and AIDS, but especially for those with direct responsibility for providing care or managing carers, for policy-making in this field, or for supporting AIDS programmes.

Please note: some of the names in this report have been changed in the interests of confidentiality.

3. Uganda and South Africa: two faces of the epidemic

AIDS in Uganda

Uganda at a glance

Total population:	20 million
Population urbanized:	13.2%
Infant mortality rate:	86 per 1000 live births
Child mortality rate:	137 per 1000
Life expectancy at birth:	39.6 years
GDP per capita:	\$602
Population living in absolute poverty (below \$1 per day):	50%
Adult literacy rate:	64%

Source:
*Human Development
Report 1999, UNDP.*

Some of the earliest cases of AIDS in Africa were identified in 1982 in the fishing communities living along the shores of Lake Victoria in Uganda's Rakai District. Since then the virus has spread throughout the country, affecting rich and poor, urban and rural people alike. The great majority of infections are transmitted through heterosexual intercourse. However, babies who have contracted the virus from their infected mothers before or during birth or through breastfeeding account for about one in five of all new infections.

At their peak in the early 1990s, HIV infection rates above 30% were regularly recorded at sentinel surveillance sites. These rates have been declining steadily over recent years – especially among women aged 15-19 years – and behavioural surveys suggest that youngsters are postponing their sexual debut, that people are having fewer sex partners and that they are using condoms more regularly. However, no one could say the sting has been drawn from Uganda's AIDS epidemic. Still today around 13% of the adult population is HIV infected, with three times as many women as men below the age of 25 being HIV positive. And, as the epidemic matures, the burden of sickness is growing daily. Each year thousands of infected people develop AIDS, which is the number one cause of death among adults and the fourth most important cause of death among children under five years of age.

Virtually no family remains untouched by the epidemic. Almost everyone is caring for a sick relative, looking after the orphaned children of brothers, sisters, sons or daughters, or helping to support relatives who have lost their breadwinners and no longer have any money coming into the home. How to make ends meet – to pay the rent, keep children in school and food on the table, and find the money for drugs and treatment – is the main preoccupation of families, as AIDS quickly impoverishes even relatively well-off households and pushes those already battling to survive over the edge into destitution.

Access to government health services in Uganda is extremely limited, with 88% of the population living more than 10 kilometres away from a health facility of any kind¹, and many clinics and health posts lacking trained personnel and short of the most basic medical supplies and drugs.

¹Source: 1995 *Uganda Demographic and Health Survey*, Claverton, MD, USA, 1996.

Typically, more than half of all hospital beds are occupied by AIDS patients, and many terminally ill people are turned away by chronically overstretched institutions. In response to the growing crisis, a mass of organizations has emerged to fill the gaps in care and prevention. Today, some 1050 non-governmental and community-based organizations across the country are working in the AIDS field. They are the pioneers of home-based care for people with HIV and AIDS, which has recruited thousands of community-level volunteers and trained them to deliver a variety of services from basic preventive health care and first aid to practical advice and emotional support. The volunteers are supported by the staff of these organizations with a wide range of professional skills, including especially counselling and nursing.

These organizations, backed by a government that has shown singular courage in acknowledging the nature and extent of the epidemic facing Uganda, have managed largely to overcome the despair and hopelessness that gripped communities early in the epidemic. When World Vision first went into Rakai in 1989, recalls a staff member, people knew so little about AIDS, except that it was a killer and they felt helpless in the face of it. "When you visited houses you would find people had died: there were dead bodies and hopeless relatives not knowing what to do, full of fear and hurt and shame, weeping over the dead bodies. We would weep with them." Today people understand that a diagnosis of HIV infection is not an automatic death sentence and that they can live for extended periods if they take care of themselves. With luck and positive thinking there is time to plan for the future. Whereas coffin-making was the growth industry a few years ago, with carpentry workshops powdered with sawdust all along the road to Rakai, today brick-making has taken off too, since providing a secure house for their families, with brick walls and tin roof to replace the high-maintenance mud and thatch, is a high priority for infected people. Everywhere, straw-topped brick kilns puffing like dragons send plumes of smoke rising among the banana palms in rural plantations.

However, the home-based care movement and all that it has achieved is today threatened by weakened commitment from donors that has pulled the carpet from under some of the most-valued enterprises, and threatened the morale of all organizations working in the field. This insecurity is just another cause of anxiety to people already carrying almost intolerable burdens. The staff and volunteers of AIDS organizations get no respite. Almost no one can shut the door on the problems and the pain of AIDS at the end of the working day, for most of the carers, like so many other Ugandans, go home to families bowed by disease, loss of loved ones and financial struggles of their own.

AIDS in South Africa

South Africa at a glance

Total population:	38.8 million
Population urbanized:	49.7%
Infant mortality rate:	49 per 1000 live births
Child mortality rate:	65 per 1000
Life expectancy at birth:	54.7 years
GDP per capita:	\$2336
Population living in absolute poverty (below \$1 per day):	23.7%
Adult literacy rate:	84%

Source:
*Human Development
Report 1999, UNDP.*

Perhaps partly because of South Africa's isolation during the apartheid era, the AIDS epidemic was much slower to take off there than in other countries of the subcontinent. The first cases of AIDS appeared among gay white men in 1983. It was not until the early 1990s that the virus gained a strong foothold in the heterosexual community and began to spread like a bush fire. Today, South Africa has one of the fastest-growing HIV epidemics in the world, with around 1600 people becoming newly infected every day, and nearly 4 million believed to be infected by the end of 1998.

On the basis of results from anonymous testing at antenatal clinics, the South African Department of Health estimates that nationally around 23% of pregnant women were HIV-positive by the end of 1998. But the spread of the virus is very uneven. KwaZulu/Natal – with its major sea ports, busy trucking routes, large population of migrant workers and history of social and political turmoil – has consistently shown the highest prevalence of HIV. The rate for this province, based on antenatal clinic statistics, was estimated to be around 32.5% at the end of 1998, while HIV prevalence in the least-affected province, the Western Cape, was estimated to be around 5%. Nearly everywhere else in the country, at least one adult in five was believed to be infected at the end of 1998.

To a great extent it is the secrecy surrounding AIDS that has allowed the virus to spread so rampantly. "For too long we have closed our eyes as a nation, hoping the truth was not so real," said Thabo Mbeki, then deputy president, in an address to the nation in 1998. "At times we did not know that we were burying people who had died from AIDS. At other times we knew, but chose to remain silent."

More than a year has passed since Mbeki's speech, yet little has changed. So great are the stigma and fear surrounding AIDS today that in many places home care programmes are carrying out the work of treating and comforting terminally ill patients and their families without anyone ever mentioning the word AIDS. The case of Gugu Dlamini, a young Zulu woman who was beaten to death in her local *shebeen* (drinking house) by an angry mob after coming out in public as an HIV-positive person on World AIDS Day 1998, was reported around the world. But it was not an exceptional incident: stories of infected women, children and men being left to die in dark corners, abandoned by their families, or physically abused, are common, and make it hard to break the silence.

Nevertheless, more and more people in South Africa are finding the courage to speak out and show compassion for people with AIDS, as they themselves become infected or witness the suffering and death of people they love. Support groups of people with HIV and home-based care programmes are springing up in South Africa just as they have done elsewhere in Africa as the epidemic advances and reality can simply no longer be ignored.



A mother of three, with support from the South Coast Hospice, lovingly cares for her husband in Port Shepstone, South Africa.

4. Who are the carers?

A diagnosis of HIV infection is always profoundly shocking. Feelings of fear, anger and despair, and thoughts of suicide, are common in the hours and weeks that follow. Where do people turn for comfort and guidance at such times? And who is most likely to care for them when they become too sick to look after themselves? This chapter will look at who the carers are, focusing predominantly on those outside the formal health services. It will look, too, at what motivates them to do this kind of work, how they are recruited and trained, and at the kind of tasks they perform.

Often the different roles of caregivers are interchangeable and the demarcation lines between levels of care blurred. In areas badly affected by HIV and AIDS, many who work as counsellors or nurses with non-governmental organizations, or as trained community volunteers, are also caring for someone at home who has AIDS. Some who work as professional or volunteer carers are themselves HIV infected and registered as clients of AIDS organizations from which they receive care.

Carers in the family

Lucy looked after her daughter-in-law and then her two sons when they were terminally ill with AIDS, and now she is helping to care for her little orphaned granddaughter who is HIV infected. In the same city, 18-year-old Grace, one of a large family of children, is caring for her mother who is bedridden and blinded by Kaposi's sarcoma that spread across her face within days of her noticing a small dark patch on her nose. Though no one in Uganda or South Africa has systematically documented who is doing the caring at family level, it is clear to those working in the field that the burden of care is borne predominantly by women and girls. Typically a woman or girl child will find herself in the position of caregiver as a matter of course, of cultural expectation. And though many women are proud of their nurturing role and consider it natural, their subordinate status means there is likely to be little discussion within the family in assigning this responsibility, and little thought given to the personal sacrifices it will demand of females.

"If a husband is ill, it is invariably the wife who looks after him, but if the wife is ill it's her children, or her sisters or mother who care for her, while the husband focuses on earning money to support them all," says Jovah, who works as a counsellor for The AIDS Support Organization (TASO) in Uganda. "Men are almost never the primary carers in the home." Evelyn Kezwa, a nursing sister responsible for counselling HIV-positive mothers at an antenatal clinic in South Africa, says: "Men still aren't coming along very

well as carers." Many people in South Africa's townships today live in nuclear families far from their relatives. Often a mother will leave her home in a distant rural village to come and care for her daughter. "Elderly mothers are finding themselves drawn into a role they just never imagined."

But AIDS is beginning to challenge traditional attitudes, and men, especially those who are infected themselves or who have worked with AIDS organizations and are knowledgeable and skilled, are increasingly willing to take on the physical care of sick partners and family members. "We have seen both extremes in the behaviour of men here in Soweto," says Mark Ottenweller, local director of Hope Worldwide. "Some have looked after sick partners or relatives magnificently; some have abandoned infected wives or thrown them out of the home." In KwaZulu/Natal, South Africa's worst-affected province, "it's not at all unusual to find men as primary carers," says Liz Towell, director of the Sinosizo Home-Based Care Programme, which has an extensive database on AIDS-affected families. "But most times they get tired of the job, or have to go back to work, so then they'll call their mothers from the farm. But that's only when things get bad – otherwise they just get on with it."

The least-acknowledged carers within the home are children. When one parent dies in a nuclear family there is often no one else but the children to look after the other parent who falls sick. This will be the case most especially in places where the intense stigma and shame of AIDS make people fearful of disclosing their infection. Many children are left to cope with terrifying conditions and witness the suffering of the person they most love and depend on in the world, without skills or knowledge and often without anyone ever having talked to them directly about what is happening. Nobody knows how many children in Uganda and South Africa are acting as primary carers, but it will become increasingly common as the epidemic matures simply because AIDS targets the parent generation. Anecdotal evidence from elsewhere in Africa suggests that it is often very young children, 8 to 11-year-olds, who are caring for sick parents, since older children tend to leave home to find work or seek survival on the streets as family poverty deepens.

Volunteer carers

Volunteers are the backbone of community care programmes for people with HIV and AIDS. Some are what could be called "informal" volunteers – friends or neighbours who step in to care for sick people they know, out of a sense of love or duty towards them. Or they are people, such as members of a church, who regularly commit some of their time to community service. But huge numbers of people working for AIDS care programmes are "formal" volunteers,

recruited, trained and supervised by the organizations for which they work on an agreed basis. The organizations look for people who are:

- good listeners;
- non-judgemental and respectful of others;
- trustworthy and able to keep a secret;
- able to get on easily with people;
- sympathetic;
- self-confident; and
- committed.

Whereas most organizations stipulate that volunteers must be literate because they are required to keep records, Sinosiso, which works in some of the poorest and most disadvantaged rural communities in South Africa, has consciously developed a training programme and working practices that do not require the ability to read and write. "We have 'scribes' – at least one person in each group of volunteers who's literate and who sits down with the others and writes their reports for them," says Liz Towell. In her programme, information on home care – how to recognize conditions and what to do to prevent or treat them – is presented in simple drawings on cards that the volunteers keep for reference.

What motivates volunteers?

A sense of religious duty is the most frequently stated reason for taking on voluntary work, and seems to be what sustains people in the toughest times. While religious commitment is seen as a strength – and many care programmes are themselves church based – people with a desire to evangelize are not generally considered suitable as volunteers. Broad-mindedness, tolerance and acceptance of diversity are especially important in caring for people with AIDS.

Simple compassion for others who are suffering is a common motivation for volunteering. "In Africa there's a strong sense of community and a rich tradition of doing good work – reaching out to your neighbour or sick friend," says South African psychologist Pierre Brouard. Very many people are motivated, too, by personal experience of AIDS in family or friends. They may have painful memories of the helplessness they felt without knowledge or skills when AIDS came into their own lives, and what they learn as volunteers is both hugely empowering and a source of pride. Alternatively, people who volunteer may simply want to join the effort to control a disease that is laying waste to their societies, and they cannot bear to sit by.

Large numbers of volunteers are HIV positive themselves and have become involved in caring for others through joining support groups of people living with HIV/AIDS. The backbone of Hope Worldwide's care

programme in South Africa is their support group members – people who have come together following a positive test for HIV, and part of whose strategy for survival and “positive living” is to keep active, be useful and find purpose in life.

Self-interest is also frequently part of the picture, even if it is not the main driving force for volunteering. Said Christopher, a volunteer in one of Uganda’s worst-affected districts: “I hope that when I get that problem myself someone will help me because I have helped them.” In his village there are few homesteads without graves marked with rough crosses among the coffee and cassava bushes. Many remember the days when people died, often with little dignity, in homes where no one knew what to do, and bodies were sometimes interred without ceremony by fearful and traumatized relatives.

Some people volunteer in the hope of promotion to paid employment with the organization. Others are attracted by the incentives offered by volunteer programmes, such as preferential access to income-generating schemes and skills training, or perhaps food handouts. In Uganda, voluntary work in the community has, for a number of people, been a stepping stone towards positions in local government. “We encourage them to stand for local council elections because we feel political office will give them a wider platform to use the skills and knowledge they’ve learnt,” says a World Vision staff member responsible for supervising volunteers.

“I think people’s motives for becoming caregivers are complex – we all do it for some reason of our own to start off with,” says Pierre Brouard. “I guess I’m involved in this work because I lost a parent when I was very young. I’m a gay man, so it’s been very real for me, this disease. AIDS work helps me process all kinds of personal issues to do with mortality and spirituality, so there are very good selfish reasons why I do it. I also feel a sense of responsibility, a social connectedness, a concern for people who are victimized, because as a gay person I’ve experienced stigma and discrimination myself.”

What are volunteers trained to do?

Volunteers are trained to provide a wide range of services. The community volunteers with TASO and World Vision in Uganda are trained to counsel clients and their families, which essentially means listening to their concerns, giving comfort and information, and exploring the options they have for dealing with various problems. They work closely with the local health services, acting as links between people in their homes and the clinic or hospital which may be many kilometres away. They collect drugs for bedridden patients, and will, if necessary, try to encourage a nurse or doctor to go out to treat a patient at home. Very often volunteers accompany people with AIDS to the health unit to help them communicate

with staff. Some are concerned that clinic staff may lack specialist knowledge about AIDS or skill in handling nervous and distressed patients.



Home care volunteer with client in Kampala, Uganda.

Community volunteers with the South African programmes provide much the same services. In both countries, overstretched staff in the health services are, generally speaking, grateful for the work volunteers do that lightens their own workload and augments their skills. In Uganda, for example, government health professionals are deployed only to subcounty level, which means the most peripheral health teams each cover a population of about 30 000. Most programmes make a point of introducing volunteers to local clinics and establishing strong working relationships between them from the start. World Vision encourages mutual respect by involving local health personnel in their volunteer training programmes. Sinosizo's volunteers are members of the regional health forum, which gives them status and support. And Hope Worldwide worked with the health services, developing specialist skills in AIDS care, before they started their community programme.

Typically, volunteers working with AIDS care programmes are trained to recognize health problems, and to know which conditions they can treat themselves and how to do so, and which need referring to someone with greater skills. Sinosizo's volunteers in KwaZulu/Natal learn practical hands-on care, which means, for example, mouth care, how to perform a bed bath and how to prevent or treat pressure sores. Immediately following training,

they must demonstrate these skills with families in front of their supervisors to show that they are competent themselves and that they are able to pass the skills on successfully to the primary carers in the home. The objective is to empower families to do their own caring as far as possible.

Some community volunteers are trained to supervise the treatment of tuberculosis. Some are given specialist skills in bereavement counselling. And in Uganda, World Vision has added a component on communicating with children to their training curriculum, recognizing the huge unmet needs



A Ugandan mother and her children who lost their father to AIDS.

of children, and the fact that more and more of them are being left with the responsibility of caring for sick relatives. Sinosizo, too, is developing, with the Psychology Department and Child and Family Centre at the University of Natal, a training package for its volunteers on the needs of children. And as the caseload of AIDS patients rises in this most heavily affected province, the programme is giving its keenest and most competent volunteers specialist skills such as terminal care and pain management.

Clarifying the relationship between the AIDS organization and the volunteers, and what each can expect from the other, is crucially important for

the success of a programme and the morale of everyone involved. This is usually addressed in training. Sinosizo starts its training course with a one-day seminar on the meaning of volunteering, which is an opportunity for those who are really looking for paid employment or are not truly committed to drop out before resources have been spent on them. Life Line, whose focus is on specialist counselling rather than home nursing skills, devotes a great deal of training time to "personal growth" in which trainees are helped to discover their own strengths, to deal with troubling issues in their own lives, explore their attitudes and build self-confidence.

A clear understanding of their own limitations, and what they are and are not expected to do, is crucial in volunteers, says Mark Ottenweller of Hope Worldwide. In his organization, this issue is addressed in training, and thereafter there are usually regular discussions between volunteers and programme staff about what needs doing in their areas and how to divide the workload. By and large, organizations choose to avoid drawing up formal contracts with volunteers because they want to encourage a sense of community ownership of the volunteer programme, rather than giving the impression that the volunteers are unpaid employees of the organization.

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What do volunteer carers do?

The community-level volunteers who work with AIDS care programmes provide a wide range of services, often combining both care and prevention. These typically include:

- emotional and spiritual support for people with HIV or AIDS, and their families wherever possible;
- psychosocial counselling to help clients resolve personal problems;
- practical advice about nutrition, hygiene, and preventive health care;
- basic nursing care to bedridden patients, and/or passing on such skills to primary carers within the home;
- help with domestic chores;
- liaison between the health and welfare services and patients in the community;
- supervision of tuberculosis treatment;
- peer counselling;
- community mobilization against AIDS;
- public information and education; and
- condom distribution.

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Extra helping hands

In addition to the support group members who are central to its home care programme, Hope Worldwide in Soweto uses the services of volunteers attached to the Johannesburg-based Church of Christ, who number around 2000. Everyone who offers time to the organization is given basic information and education about HIV and AIDS. But a select group of about 150 volunteers who want to be more involved have been trained to do basic counselling so that they can give emotional support to people with AIDS in their homes or in hospital. The casual volunteers are called upon to do such things as prepare the ground for the vegetable gardens for support group members, or to mend the leaking roof of an AIDS-affected family living in a shack. A core group of specially committed church volunteers is used for the most demanding cases. If a family is nursing a terminally ill patient they will draw up a rota among themselves so that someone goes every day to help with the household chores – cooking, cleaning, washing bedclothes and perhaps bathing the sick person.



A hospital nurse visiting a home care patient in Kampala, Uganda.

Staff carers

Most of the AIDS organizations visited have only a small complement of care professionals – typically counsellors and nurses – on their staff. These employees may occasionally work directly with clients and families, but their main responsibility is to recruit, train and support volunteer carers in the community. TASO, however, employs large numbers of counsellors who are equally responsible for providing care themselves and for looking after teams of volunteers in the community. In addition to the counsellors, the TASO centres each employ a number of health professionals who give medical care to clients.

Very much the same things seem to motivate those applying for jobs with an AIDS care programme as those who volunteer their services. The most frequently stated motivations include:

- personal experience of AIDS that left painful memories of helplessness and fuelled a desire for knowledge and skills;
- personal experience that encouraged a commitment to join the struggle against the epidemic;
- compassion for the sick and suffering; and
- a desire to serve others, often stated in terms of religious calling or duty.

Staff members may be recruited from amongst the volunteers working with a programme. But, since 1989, TASO has advertised for counsellors,

looking for people with compassion, resilience, patience and quick minds, preferably with a background in social science, education or health. An evaluation of the programme in 1998 suggested that it would be most cost-effective to recruit people with nursing qualifications as counsellors so that the same person could provide medical and psychosocial care.

TASO's training for its professional counsellors starts with a three-day exercise in self-reflection. "This is our opportunity to evaluate a person thoroughly. We can observe their attitudes, beliefs and values, and help them change where necessary," says training officer Hannington Nkayivu. Inappropriate traits include religious fundamentalism or bigotry, a tendency to be judgmental or moralistic, personal prejudices such as lack of respect for women or certain types of people, and inability to relate to children. "A counsellor must be prepared and able to treat everyone as an equal, whoever they are, and they must have respect for all ages and both genders," he says. After the initial exercise, the training course teaches the facts about HIV and AIDS, and develops skills in counselling and general communication.

However, the curriculum is due for a change. "TASO started counselling in a crisis," explains Sophia Mukasa Monico, TASO's director. "At that time nobody knew anything about HIV. But when a client comes to a counsellor today they know nearly everything about it, so what they want is not information but help with developing a coping strategy. We are looking at ways of addressing that." TASO also intends adding a module on "communicating with children" to the training curriculum as counsellors and clients have become increasingly aware of the unmet needs of children.

At present, each of TASO's counsellors is assigned to a zone and is responsible for all the clients living in that zone. They see their clients at the TASO Centre on clinic days, when they come for medical care as well. On non-clinic days the counsellors go on home visits to check that people who have missed appointments at the Centre are all right, or they accompany nurses and medical assistants visiting bedridden clients as part of a home care team. In addition to these duties, the counsellors are expected to mobilize communities and set up a number of new volunteer programmes each year, as well as giving ongoing support to volunteer programmes already established in their zones. Some counsellors are trained in aromatherapy, and offer this service to clients as well.

Most non-governmental organizations (NGOs) caring for people with HIV and AIDS work closely with staff from government clinics. In South Africa, Hope Worldwide's support groups are based in local clinics, and rely on the nursing staff to provide medical care – at home if necessary and if resources permit – when they reach the limits of their own skills. Similar arrangements are common in other care programmes in Uganda and South Africa. Frequently, however, government health staff in these countries lack specialist knowledge and relationship skills in dealing with

people with AIDS because these are not part of their training curriculum. In an effort to fill this gap, TASO runs AIDS Care Orientation Workshops for government health workers to supplement their basic training.

Traditional healers

In her book about her family's struggle with AIDS², Noerine Kaleeba, the founder of TASO, speaks of the frantic search for a local cure when her husband Chris became bedridden. She had the use of a car at the time, and she says: "If I heard that there was a healer in a particular part of Uganda I would drive there and come back with a bottle or jerrycan of preparation. I would go from place to place as people heard of effective healers and preparations. Relatives were bringing medicines by the jerrycan too, and soon there were medicines for wrapping, medicines for sniffing, medicines for drinking, and so on... Chris took all these remedies faithfully alongside the medicines he had been given (in the hospital)."

Traditional healers are the most widely used health practitioners throughout Africa, and the great majority of people with AIDS consult them at some time or another. Yet there has been little official recognition of their importance within communities or commitment to informing and educating them about HIV and AIDS. "All along training has stopped where the road ends. At last this training is reaching beyond the road, where the real rural people live," commented a traditional healer

in South Africa, where the AIDS Foundation, in collaboration with traditional healers in KwaZulu/Natal, has developed a training curriculum and recently started running workshops with them. Its objectives are to:

- increase the impact of AIDS prevention, education and management; and
- help trained traditional healers to be accepted within the mainstream health system.

In Uganda in the early 1990s, an expert in sexually transmitted infections based at Kampala's Mulago Hospital, and some colleagues, set up an organization called Traditional and Modern Practitioners Together against AIDS (THETA), which has carried out research into the effectiveness of traditional herbal medicines and run training programmes. By the end of 1999, some 205 traditional healers from Kampala and several rural districts had been through the programme. In both countries training covers biological aspects of the disease, modes of HIV transmission, prevention,

²Kaleeba N, with Ray S and Willmore B. *We miss you all. Noerine Kaleeba: AIDS in the family*. Zimbabwe, Women and AIDS Support Network (WASN) Book Project, 1991.



Dr Conrad Tsiane,
a traditional healer
in South Africa.

infection control and counselling issues, as well as addressing the relationship between the modern and traditional health services, and referral issues.

Despite these initiatives, traditional healers are, by and large, caring for people with HIV infection and AIDS without any support from non-governmental organizations or the statutory health services, and must cope with the stresses of the role and the problem of burnout in their own way.

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A traditional healer speaks

Conrad Tsiane, once a schoolteacher, has worked as a traditional healer since 1989. He is a man of influence, whose reputation as a healer saw him elected mayor of Moutse District, a sprawling underdeveloped rural area north of Johannesburg. Today, his large brick house stands in well-tended gardens in a landscape of small shabby homes and subsistence plots strung out along a network of sand roads. Behind the house are consulting rooms, offices, a dispensary for herbal remedies, as well as accommodation for students who attend his school of traditional medicine. Dr Tsiane first heard of AIDS at a conference he attended in Zambia in the early 1990s. But it was not until 1994 that he became aware of the disease in his own community.

"I started to see people who were getting slim, having headaches, a running stomach, a lot of symptoms. At that time people were very shy to tell me they were HIV positive. But I could see that these people were not like others who came to me with 'rough coughing', ordinary TB. They were so dry; their hair was so fluffy. Some were getting leaner and leaner. Others would have big spots which could not be healed. I checked with my bones and they would talk the same language. I realized that when the bones are in this fashion, the person has 'bad blood'. I was worried that I could maybe touch someone and have that very disease myself without knowing.

"At that time I felt it is not enough to be a traditional doctor, to know about herbs, and not to supplement this knowledge with something else. So I read a lot of books, and I attended a few courses where they spoke about AIDS and HIV. I learned that with HIV you can die of so many diseases because you are no longer strong – the soldiers of your body are eaten up by the virus.

"I don't test blood, so when I see someone who is giving me that fright and I talk bones and see this is someone with HIV, I refer that patient to conventional doctors. Today I have friends who are medical doctors. But at first it was very, very tough, because when I referred patients to them they would say: Ooh Tsiane, he's taken a lot of money, and now he's sent us people who are dying!

"But we are not in competition. We all want the best for our patients, so we must supplement one another. Here we are faced with a mammoth disease, which cannot be addressed by traditional healers alone, or anybody alone, which needs everyone to cooperate. I can be an asset because I am seeing people with HIV and AIDS day in day

out. They come to talk to me. I comfort them, and when they leave this house they are happy. They feel loved.

“There are traditional healers who say they can cure AIDS, and I feel bad about that. Because you can never cure what you don’t understand. My ancestors didn’t know about AIDS; this is definitely a new disease. So I say: let there be workshops where traditional doctors can be taught not to deceive people. Let there be workshops where we can learn about AIDS – because when hospitals send people away, we are left to care for them; we are left to counsel them; we are left to talk to them in a polite manner. But we have no resources to do it all, no support, and we are suffering.”

5. Stress and burnout among carers

What are the symptoms?

Burnout is not an “event” but a process in which everyday stresses and anxieties that are not addressed gradually undermine the carer’s mental and physical health, so that eventually caregiving and personal relationships suffer. As a medical condition burnout has no clear definition, but as a psychological condition it has been well defined³ and is increasingly recognized by people in the caring professions. Managers and staff of the AIDS care programmes visited in Uganda and South Africa have identified some common features.

“Staff who are not coping will begin to be less punctual in coming to work or keeping appointments,” says Tom Kityo, manager of one of TASO’s centres in Kampala. The records they keep may show that they are regularly failing to meet their targets or to see the clients assigned to them. Their reports may be handed in late and of poor quality. And they may become withdrawn from their colleagues and less interested in, and sensitive to, their clients.

Pierre Brouard, who works as a counsellor’s counsellor in South Africa, says that chronic stress caused by the emotional burden of caring for people with HIV and AIDS typically manifests itself as either over-involvement or under-involvement on the part of the caregiver. “Over-involvement is a kind of flooding response where you get so emotionally connected that you lose all perspective and burn out very quickly. Under-involvement, on the other hand, is a withdrawn, unemotional, disconnected way of working with people. Some of the counsellors get almost brutal, tough, because they get ‘compassion fatigue’. I think both are very real dangers with an epidemic of this nature.

“Stress may also manifest itself in physical symptoms such as sleeplessness, lethargy, feelings of restlessness and loss of concentration, and perhaps even shaking or tremors, and bowel disturbances,” says Pierre Brouard. “Behavioural problems, such as irrationality, mood swings and depression, are common too.”

Anne Finnegan, director of the Rustenburg branch of Life Line in South Africa, says that a counsellor may suddenly develop an antipathy for either telephone work or face-to-face counselling. “Loss of confidence with some

³See: Miller D. *Dying to Care? Work, Stress, and Burnout in HIV/AIDS*, London, Routledge, 2000.

aspect of the work usually tells us something is wrong – there is a problem the counsellor hasn't dealt with in their own life." Mark Ottenweller of Hope Worldwide comments that lack of initiative and enthusiasm, excessive fatigue, frustration, anger, quarrelsomeness and a tendency to complain are commonly observed signs of stress, and things he has trained his supervisors to look out for and address before they cause illness.

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Signs of stress

Stress among caregivers in the field of HIV and AIDS manifests itself in a wide range of signs and symptoms, psychological, behavioural and physical. Typically, they include:

- loss of interest in and commitment to work;
- loss of punctuality and neglect of duties;
- feelings of inadequacy, helplessness and guilt;
- loss of confidence and self-esteem;
- a tendency to withdraw – both from clients and from colleagues;
- loss of sensitivity in dealing with clients;
- loss of quality in performance of work;
- irritability;
- difficulty getting on with people;
- tearfulness;
- loss of concentration;
- sleeplessness;
- excessive fatigue;
- depression; and
- bowel disturbance.

Many of these feelings are not of themselves unhealthy, but they become so if they are neglected or suppressed and allowed to accumulate.

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Talking of their personal experiences of stress, one counsellor in Uganda commented that she regularly gets to the pitch where her "brain feels so overloaded" that she cannot cope with another demand made on her, no matter how trivial. Another said that she found developing personal relationships outside her work very hard because she had so little emotional energy left. She would like to get married but did not feel the prospects

were good. A counsellor working with HIV-positive mothers and babies commented: "Some people take so much from you that you feel you're going backwards rather than forwards." And a community health nurse in Soweto said that a year of working in a sexually transmitted diseases (STD) and AIDS clinic almost completely destroyed her interest in sex.

Though volunteer workers may drop out of an AIDS care programme if stress becomes too great, the drop-out rate is not a good indicator of the levels of stress among staff members simply because, in poor countries, salaried employment is at a premium. Often there is a balance to be struck between stress and economic survival.

Many of the symptoms of stress identified among people working for AIDS care programmes mirror exactly those experienced by primary carers looking after people with HIV and AIDS in their own homes and families. But, for those at home, such symptoms are less likely to be recognized and acknowledged, and they are more likely to be isolated with their problems, without easy access to anyone who can help them find solutions or relief.

What are the causes?

Much of the stress experienced by carers is in the nature of the work itself – the fact that they are dealing with an incurable condition that kills largely young people and that causes terrible suffering. Furthermore, it is a condition that stigmatizes not only infected individuals but very often uninfected people working in the field too. This is known as "secondary stigma" and it can have a powerful effect on the caregiver's status with family, friends and the public at large. But stress may also be caused by organizational factors – the way a care programme is designed and managed.

Matters of poverty

A survey by Hope Worldwide among its support group members found that food was their single most pressing need. This came as little surprise, for there is a great deal of evidence that financial hardship is one of the foremost causes of stress to carers. AIDS is often concentrated among the very poor. But even those families who are not already on the margins of survival are swiftly reduced to poverty when the breadwinners are struck down by disease, or forced to give up paid employment or work in the family fields to care for a sick partner or relative.

Elizabeth lives in a neat, comfortable house in Soweto. There is TV and a modern, upholstered three-piece suite in the living room, a glass coffee table with books and a pot plant, and, outside, a neatly-tended garden. But Elizabeth's daughter Betty – a nursing assistant whose wages supported

herself, her mother and her two teenage sons – is bedridden with AIDS and suddenly there is no money coming into the home. Elizabeth says there is no food in the house. The boys have stopped asking for bread when they come in from school because they know there is none. And when Betty needs drugs, Elizabeth must first go out to find washing or ironing to do in the neighbourhood, and use what she earns to take the minibus taxi to hospital, to buy the drugs and catch the taxi home.

Josephine, living in a tiny, sweltering shack made of corrugated iron sheets on the treeless plains of Hammanskraal to the north of Pretoria, has always been poor. But now that she is too weak to look for work, the family is starving. Josephine, sitting at home in the shack she shares with seven others, is so hungry that she regularly loses her temper with her children. And given a bag of apples by the nurse from the home care team who comes to visit, she can hardly bear to share the fruit with her children.

For carers from outside, having to witness day in and day out the struggle of families to meet their most basic needs – for food, rent, medical care, clothes, kids' schooling – can be extremely stressful. "The messages of TASO about living positively, eating well, looking after your health, can seem cruel when people are struggling to bring in any food to the home," says senior training officer, Hannington Nkayivu. "But in training our counsellors we stress that they must recognize their limitations and make it very clear to their clients that they cannot do everything. Nevertheless, counsellors do feel the strain of expectations because the needs are so great." The director of a home-based care programme in South Africa asks: "What good does it do to bring pain killers when you find that the caregiver in the household doesn't have the strength to roll the patient over because she is starving?"

The stress is often compounded by the fact that the carers themselves are in a similar position. "It is hard to look after our own families when we're not earning even a cent for this work," said a volunteer in KwaZulu/Natal. "We go to see hungry people and we are hungry too." It is common for volunteer and staff carers alike to spend all day in the field visiting clients without anything to eat or drink, because AIDS care programmes on tight budgets rarely give allowances for refreshments. Besides demoralizing hunger, volunteers frequently cite lack of money for transport to visit sick clients, or to fetch and pay for drugs, or buy paper and pens for record-keeping, or rubber gloves for handling sick patients, as a principal cause of stress because it undermines their ability to do their work and makes them feel inadequate. Sometimes their own families are resentful of the fact that they are working hard for no money. And, in a number of programmes, volunteers admit that partners have walked out on them, or that they themselves have had to leave home because of intense disapproval over their volunteer work.

Making ends meet is often a preoccupation for employees of care programmes, too. In Uganda, wages generally are so low that even professionally qualified people like doctors, nurses, teachers and university professors have to do more than one job, or find other ways of supplementing their income, to earn enough to support their families.

Besides the preoccupation with personal hardship, the dependence of AIDS programmes on their donors is a constant background source of stress to many carers. Staff at all levels are often acutely aware of the insecurity of funding – and therefore of their own jobs – because they see organizations working in the same field flounder from time to time as donors change their focus or philosophies, or simply lose commitment.

And when a donor pulls out for whatever reason, a whole tapestry of activities, hopes and expectations unravels. Lucy Nsubuga is coordinator of an AIDS organization staffed by HIV-positive people in Uganda that recently lost the support of its principal donor with very little warning. There is too little money to continue operating, yet Mrs Nsubuga cannot give up hope and dismiss her staff. “They thought they were useful



Mpho Sebanyoni, the founder of Moretele Sunrise Hospice, cheers up a grandmother who shares her pension with and cares for her grandchildren, orphaned by AIDS. The family lives in Temba, South Africa.

when they went out to the people, shared their life experience and counselled them. People identified with them. Now they are sitting at home,” she says. “Sometimes they can come to do proposal writing or to review our training materials, but it’s difficult when you don’t know what’s going to happen. And most of the time we are redundant, because most of our work is in going to the field with people with HIV or AIDS. Also, it causes problems in the family. Husbands or wives ask: if you’re not getting a salary, why are you going to work? What’s the point? But if they stop coming, people will think they’ve resigned. So, they’re puzzled and very much demoralized.”

AIDS care programmes are at the mercy, too, of government policy-makers who can change the rules for donating to non-governmental organizations. In Uganda, for example, food handouts have been the mainstay of many carer support programmes. News that the government was considering imposing tax on food aid from abroad led recently to the drying-up of free food supplies to one of the most widely respected home-based care programmes in Uganda, and the undermining of its activities and staff morale. Furthermore, as of late 1999, NGOs were concerned that new rules being considered by the government would mean that donor funds could no longer be paid direct to individual organizations, but must be channelled through government structures.

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Alan's story: caring for others gives new meaning to life; given enough support, everyone has something to offer

Alan was an armaments fitter with the South African Defence Force for 27 years, and worked also as a volunteer paramedic with the fire brigade. He became an alcoholic and his life disintegrated around him, until he ended up living rough on the streets. In 1994 he went to live at The Ark in Durban, and the following year was trained to work in the centre's clinic. Today he is a senior member of the health team that runs The Ark's 77-bed hospice for people with AIDS.

"I was just a normal resident here for about a year, then I decided I'd taken enough from the world; it was time to give something back. And I tell you, I've never enjoyed life so much. Today, I feel I've got something to get up for; somebody to look after that I know needs my help.

"I started my training with basic first aid, then I did advanced first aid, then I learned a bit about psychiatry and pharmacology. And of course there's stress management – how to deal with anger... loss... We do a lot of things because we are in a very stressful situation – and to cope is incredibly hard. Over the last couple of years, the problem of AIDS has been growing here and the demand for care increases by the month.

"Caring for terminally ill people is terribly distressing if you take it personally. I try to distance myself – that's my coping mechanism. When someone is very sick I begin to see them as a 'patient', and it makes it easier. Last year we had about 69 deaths, and I can't get emotionally involved with 69 deaths! I've had enough of my own with my wife, my sister-in-law and my brother-in-law all going in one six-month period. There are times when stress does overwhelm me. But you get through it; you bounce back again. I've got a closed place where I go and sit on my own and do my own mourning – let's put it that way."

Besides caring for terminally ill people and the regular experience of death, Alan says there is much that is stressful in the health team's own circumstances. "You know, we get no financial reward – no pay whatsoever. I smoke, for instance, but I never know where the next packet of cigarettes will come from. I have faith enough to believe I'll get what I need, and I've lived like that for five years. But having just a bit of money to spend would be one little stress less. You wouldn't have to worry: how am I going to do this tomorrow? How am I going to do that? I don't have money, and that's the way it is. But there are times you just want to get out and go to a movie, or have a hamburger in town, or something like that. But instead of doing that, you end up working. In other words you're loading yourself the whole time."

When Alan is feeling stressed, is there anyone he can talk to for comfort and guidance? "Yes, Pastor Shirley and I counsel each other. That's an immense relief. Very few people from outside can understand what we go through. People think we're hard, you know? But all the time inside we're very soft. We have to put up a front, but we hurt just as hard as anybody else. The only way you can relieve your feelings is to sit down and discuss things. So we talk. And we drink a lot of tea."

Too much work, too little time

“There’s so much to do and so little time to do it.” “Time is very squeezed.” “If you’re not careful, this job can take over your whole life.” These comments from TASO staff in Uganda underline a root cause of stress in AIDS care programmes everywhere – overwork. The pressure to overwork may come from outside, when carers are set what they consider daunting targets by their managers or supervisors. A common feeling among staff members of care programmes is that pressure to achieve certain targets or population coverage comes primarily from donors, and failure to achieve them may cause the donors to withdraw support for the programme. Lack of control over the process of target-setting compounds the anxiety for carers.

Alternatively, pressure to overwork comes from inside – from individuals failing to recognize what is feasible and do-able in the face of overwhelming need, and pushing themselves beyond their own limits. Staff in several programmes admitted they regularly feel unable to take their annual leave because there is too much to be done. Though some programmes insist on staff taking the time off they are allowed, in others their sacrifice is gratefully accepted by their supervisors.



A grandmother (in woollen hat) looks after children left behind by an AIDS death.

However, cutting back on vital rest and recreation time is not always a matter of personal choice. In Uganda, TASO used to hold regular retreats for counsellors and health teams which were greatly appreciated as an acknowledgement of the toughness of their work as well as an opportunity to recharge batteries. But these have been suspended for the time being as an unjustifiable expense. “It’s a fact that outside donors are not really concerned with staff welfare matters – they are more interested in how many clients can be reached for the amount of money they give,” commented a senior staff member.

Some carers say that the regular training courses they are offered by their programmes can be a double-edged sword. While they greatly appreciate the opportunities to upgrade their skills, it can mean they find themselves with additional tasks and responsibilities to fit into their working day. The job descriptions that staff members are given at the start of their contracts usually offer little protection. A counsellor with one programme commented, smiling: “Our job description is very open. It even states at the end of the prescribed duties: ‘...and any other tasks that may be necessary!’”

Volunteers, too, feel the pressure of expectations from their communities. One of the most common requests from volunteers at meetings, said a supervisor from World Vision, is how to manage their time effectively so that they don't become overwhelmed. "They tell us: 'People come and ask for my help even when I'm digging my fields'. Or 'My neighbours knock on my door at any hour of the night'."

At the family level, caring for a sick person can leave little or no time for anything else – for paid work or food production, or for school if the carer is a child – and it is this that pushes families over the edge into destitution.

The question of disclosure

"Our survey last year revealed that about half our support group members had disclosed their HIV status to their families, about half had not – that raises serious problems," said Mark Ottenweller.

The issue of disclosure is especially problematic in South Africa because the stigma surrounding HIV and AIDS is still so strong that infected individuals risk serious discrimination or even physical harm if they reveal their serostatus. Moreover, there is a tendency to apportion blame: AIDS is known by many people as "the woman's disease" – a tendency encouraged by the fact that HIV infection rates found at antenatal clinics are used as prime indicators of the scale of the epidemic and are frequently quoted, and the fact that most families only find out HIV is among them when a young woman becomes pregnant and goes for health care. But even in Uganda, where stigma is no longer so strong, infected people still find it hard to tell family and friends that they are HIV positive. "You come out at your own risk," comments one young woman who works as a counsellor in Uganda. "It's not easy living with HIV. (Once you have revealed your status) you are never treated the same again. You are always someone with the virus first and foremost."

The failure to disclose their status makes the task of caring for people with AIDS very hard. A wife or husband looking after a sick partner, or a mother caring for a son or daughter who is wasting away before her eyes or persecuted by a secret he or she will not share, may suspect the problem is AIDS. But these family carers will be handicapped by uncertainty and inability to seek information and help openly. Or they may have no suspicion, and be left to care as best they can with a situation they do not understand. AIDS is an isolating disease anyway; secrecy makes it doubly so, and compounds feelings of helplessness and despair in primary carers.

For carers coming into the family from outside, the burdens of secrecy are equally heavy. Unless a client has confided in a family member, the

visiting caregiver cannot easily pass on knowledge or health care skills to anyone else and must carry responsibility alone. "If I go to a house and find that no one knows, the person is all alone with the secret, I think to myself 'I'm too far away to help you', and I worry too much about them," says Catherine, an AIDS care worker in Soweto. Jovah, a counsellor with TASO in Uganda, says: "If we get consent from the client, we prepare the family for what to expect and for the eventual end." But if the client has not told anyone, the home care team can do nothing to make death easier for the family.

Secrecy and widespread fear of disclosure means that carers sometimes have to operate under false pretences. Either the word AIDS remains a strict taboo with patients and carers alike, as in a home-based care programme in the South African mining town of Carletonville where volunteers take over the care of terminally ill patients when the hospital can do no more for them. Between March and July 1998, the programme buried 40 people, most of them very young women, without anyone acknowledging openly the disease they were dealing with. In KwaZulu/Natal the Sinosizo programme, wishing to avoid being handicapped by the stigma of AIDS, has taken pains to be associated with others in need of home-based care as well, such as elderly people and cancer patients.

The issue of disclosing to children is particularly stress-laden for all concerned – sick parents, carers within the home and those coming in from outside. In neither South Africa nor Uganda is there a tradition of talking with children as equals and on an intimate basis. But carers have become increasingly aware of the suffering of children, who are too often hovering in the shadows of a sick room, seeing and hearing everything but never addressed directly. "We have this huge problem with children being excluded from the counselling all over the place. And some of them are so badly traumatized," says Liz Towell of Sinosizo. "Of course bereavement is part of life and they have to go through all that. But we've seen a lot of complicated grief, prolonged grief, and those are things that are not all right. Some of the children become mute with emotional trauma. We try to do the best we can, but it's not good enough."

Another particularly distressing aspect of secrecy for carers is when they discover belatedly that one of their own colleagues has been living with HIV for a long time without telling anyone. The person begins to fall sick and the secret is revealed. Typically colleagues react with feelings of hurt that he or she was not able to trust them, and feelings of sadness and inadequacy because they, whose special expertise is in giving comfort and support, were not asked for help.

Commenting on why someone trained to care for people with AIDS, and therefore to be at ease with the disease, might be unable to disclose infection in themselves, psychologist Pierre Brouard said: "There's anxiety about disclosure because one of the things disclosure does is to take away

a certain sense of control. 'I don't have control over who you subsequently tell, or how you see me. You may see me now as a diseased person, a dying person, a sick person.' And that perception change can be very difficult." A person who has become used to being a source of strength to others can find it specially hard to reveal their own vulnerability. Furthermore, they may have feelings of failure that they have been unable to practise in their own lives what they advise their clients.

Too close for comfort

In a country where almost no family is unaffected by AIDS, it is extremely difficult for carers to achieve professional detachment from their clients, or from the job itself. For most people it is not even possible to shut the door on AIDS at the end of the working day because they go home to care for relatives or friends, or children whose parents have died. The tendency to find themselves becoming over-involved is very real and the risks of stress and burnout as a consequence are high.

"When you work with a client you build up trust and closeness, and soon you begin to love them and they begin to love you. The relationship goes beyond the professional boundaries," comments Hannington Nkayivu. "You get so close to a person, and then seeing them die in the end is very distressing." In Uganda, he explains, setting professional boundaries is specially difficult since the extended family system means that a person is rarely a stranger in a village or community. "From your name people can see what clan you are from, and there is always someone to whom you are related by clan."

The pressure to become over-involved comes also from the intense neediness of infected people who tend to be isolated with their fears and suffering, without many people to turn to. "Lay carers, especially, can feel easily manipulated by clients – that it's their job to take a patient to a clinic if they can't get there themselves, or give them a bus fare if they haven't got the money, or find a sandwich for a hungry person," says Pierre Brouard. "When you're faced with those real issues it's difficult to resist, to walk away from people."

Sometimes, the stress of over-involvement comes from the caregiver developing expectations of the client, and feeling a sense of personal failure or disappointment when advice is not heeded. For example, several carers admitted finding it hard to cope with the news that an HIV-positive woman whom they had been counselling had become pregnant, putting the health of herself, her partner and her unborn baby at risk.

Carers interviewed identified a number of other common stresses associated with over-involvement. These include:

- inability to be there for their clients when they need them;

- inability to meet even the most pressing needs, such as the need for food or drink;
- feelings of inadequacy and sometimes guilt when they can do no more to help a person;
- feelings of loss and sadness at the death of a client; and
- lasting anxieties about the family members left behind, especially children.

For carers who are themselves HIV positive, stress is a risk not only of getting too close to clients but of personal identification with a client's illness and impending death. Lucky Mazibuko is an HIV-positive man who writes a weekly column in a popular South African newspaper to try to dispel the silence and myths surrounding AIDS. After seeing a man who was dying of AIDS, whose eyes looked huge in his emaciated frame, Mazibuko commented: "I could see myself in that man's battered body."

For the HIV-positive person, caring for someone else with the disease can be like looking into a mirror, says Catherine, a member of Hope Worldwide's support groups in Soweto. "When I see other people with AIDS, I think to myself: am I going to be like that? It's so frightening." At the family level, says TASO's director Sophia Mukasa-Monico, it is not uncommon for an infected wife or husband looking after a terminally ill partner to give up hope. "They say: after all, I'm going to go through the same thing, and who's going to look after me when my time comes?"

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Christine's story: As a counsellor, being HIV positive herself is a strength and a burden

Christine is a stylish young woman who wears her neatly plaited hair gathered back into a ribbon. She has an open, generous face, and smiles easily. But her smile is a kind of protection. When she isn't talking to someone her face is serious and a little sad; as soon as she is approached it is transformed by the smile – as if Christine is pulling a curtain across her deepest feelings.

She tested positive for HIV in 1990 soon after her husband died, and has been a client and then a counsellor with TASO since 1991. It had been a very difficult time for her, nursing her husband. Her mother-in-law was hostile, accusing Christine of bewitching her son. "It was a very painful experience. I had two small daughters aged 5 and 1 at the time, and my parents-in-law denied them any rights, saying that as girls they couldn't be heirs. Girls have a very bad status in our society. My husband hadn't written a will, so I had no legal way of fighting for their rights. We didn't have a house of our own, but my husband's family took all our personal possessions – beds, chairs, cupboards, household utensils, and even our 15 cows. They just wanted me and the children to go away. I expected them to be fair to me, just to be human and kind. But they thought I'd killed their son and that I should bear my punishment."

When Christine's husband died she didn't know what had been wrong with him. But when she saw something about AIDS on television she realized his symptoms fitted the picture. So she went for an HIV test. She was devastated when she found she was HIV positive because she had been faithful to her husband, whom she had known since her school days. "At first I wanted to kill myself. I could see no reason to go on living. After all that I'd suffered – the stigma, the discovery that my husband had been unfaithful to me, the cruelty of his family towards me and the girls. What was the point?" But counselling from TASO brought her comfort and gave her the will and the reason to live.

Is it specially hard for someone who is HIV positive to work with sick clients and to confront what might be their own future suffering? "Now I'm getting weak, and yes, I do get frightened. You never get used to sickness. I've seen so many good friends die. It is frightening. But you just learn to take one day at a time. I am open with my clients about my status. When you're still strong your clients feel encouraged at seeing you like that. You're a source of strength to them. But for yourself there's no way of avoiding being worried about what the future holds."

The organizational environment

A common cause of stress in the working environment, rather than in the work itself, is lack of communication between carers and their managers. Often, people say, the channels of communication exist, but they are not effective: their voices are either not heard or not heeded. Sometimes people feel they are given inadequate time to consider a policy issue before they have to comment, and decisions are made, simply because other business crowds it out until the deadline looms. Sometimes they give considered and strongly held opinions that are not represented in the decisions that are finally taken, and they are not given feedback or an explanation. A common feeling, in Uganda particularly, is that carers lack any voice at the level of the donors, where they believe their work targets are being set without real understanding of what their work entails.

Volunteers working out in the community are particularly vulnerable to feelings of isolation and powerlessness in their work. A related issue is that of adequate training and preparation for the work carers are expected to do. "If your carers are not equipped to help people on many levels, you're sending them out into a minefield and they're going to get hurt," says Mark Ottenweller. "We concentrate on giving our people as broad a training and as much support as we can because they're our biggest resource."

Counsellors working in centres rather than out in the field identified lack of adequate space to see clients in privacy as a source of stress. Administrative requirements, such as keeping records and writing reports, can also cause stress if there is nowhere to which they can retreat to write them, or not enough time allocated in their working schedule. Under such conditions, maintaining morale is an uphill struggle.

Whether working in the community or in an institution, carers need to know there is someone they can turn to for guidance with a difficult case or just to confirm that they are doing things right, says Desiree, an AIDS counsellor with Life Line in South Africa. Carers also need to feel they have the authority to do what needs doing if they feel competent. Before joining Life Line, Desiree was working in a similar capacity at a hospital run by a mining house, but was extremely frustrated. "At the hospital I always felt I wanted to learn and do more, and we were very much controlled," she recalls. "I think it's important to give a person responsibility for making their own decisions, and a chance to show initiative."

The degree of authority and responsibility a carer is given depends to a great extent on their status within the organization. This also affects the relative power they will have in decision-making and the priority given to their own needs. Herein lies a paradox. In both Uganda and South Africa, counsellors appear to be greatly respected by their clients and to have a high status within the community. Yet they are often relatively powerless within the organizations for which they work.

"There are indeed many settings where the counsellor is valued but the actual *counselling* – in the sense of a professional set of skills that require expertise and training – is undervalued in some way," says Pierre Brouard. "I think defining a clear area of competence is a real difficulty with this work. It's almost as if there's a sense that 'anybody can do it' – anybody who's in a relationship with a patient or client can do it. No way does it have the same status as doing a clinical examination." Lack of recognition and professional status are, he believes, root causes of why counsellors' own needs for care and support are too often given low priority within organizations.

Family affairs – the challenge to personal relationships

AIDS can have a dramatic effect on personal relationships and the balance of power within families, which is a cause of stress to primary carers as well as to people offering assistance from outside the family. While the infected person is cast into a whirlpool of emotions and struggles to adjust to life with the virus, other family members are forced to confront the implications of the diagnosis for themselves. Perhaps it means that a partner has been unfaithful, in which case the other partner may feel anger, betrayal and fear that they too are infected. Perhaps parents are forced to recognize that a son or daughter in whom they invested great hopes is going to die without fulfilling them, and may be leaving grandchildren to be cared for as well. Or perhaps a child is faced with the loss of one parent and fears that the other parent might be infected too.

Jackie, a mother of three children in Uganda who is HIV positive, remembers caring for her sick husband while coping with intense feelings

of betrayal. "I just hoped at the time I found out we were both positive that he'd be strong enough to receive my anger," she says. "But he was already very weak and needed my help. So I didn't have anybody to vent my anger on – I just had to be the simple wife and look after him. Sometimes I would look at him who was so vulnerable and realize that my anger would be a waste of time; it would be adding pain to the physical pain he was having. So I think I forgave him somehow." Jackie's feelings settled into deep depression after her husband died. For two years she was unable to return to the village to visit his grave.



A home-care visit to a South African family whose mother is living with AIDS.

Many carers describe the difficulty, and sometimes personal pain, of looking after sick relatives who are moody, uncooperative and even hostile at finding themselves so vulnerable and dependent. But as a counsellor with TASO and an HIV-positive woman whose own health is deteriorating, Christine sees the picture from both sides. "Being a patient can be hard," she comments. "I feel hurt sometimes when people show concern. You can be angry at being weak. And when you get very sick you can get disgusted with yourself and stop feeling there's any reason to care for yourself any more. I think it's important to help carers to understand the range of feelings of the patient, to advise them not to force care on a patient if they don't want it – especially when the end is coming. You must accept when the end is there."

Christine nursed her husband when he was terminally ill with AIDS and remembers him being in such pain that he wept. "I didn't know a man could cry like that and I was shocked," she says. "And I was fearful – I realized he was in pain and I didn't know what to do. He was rude to all of us at the end, because he was fearful. When you're heading for death you're heading for the unknown, and it is frightening."

However, it is not always the sick person who is uncooperative and hostile. Latisa Mabe, coordinator of Hope Worldwide's programme in Soweto, says that relatives often believe a positive HIV test means imminent death, and they may withdraw from the infected person and neglect their needs until they have understood what it is they are really facing. "I have been into homes where the husband just sat there and motioned to another room when we visited, saying: 'she's in there'. And you'd find a very sick woman just waiting for us to come and help her," she says. Alternatively, families may become fatalistic. TASO's director, Sophia Mukasa Monico, says that the attitude that a sick relative is not worth spending time and money on because they are going to die anyway is not uncommon.

Carers often need help and support in understanding and learning to deal with their own feelings as well as those of the sick person, commented a World Vision staff member.

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What are the causes of stress and burnout?

Some of the most commonly reported causes of stress and burnout among staff and volunteers working with AIDS care programmes are:

- financial hardship;
- stigma associated with HIV and AIDS;
- secrecy and fear of disclosure among people with AIDS;
- oppressive workloads;
- over-involvement with people with AIDS and their families;
- personal identification with the suffering of people with AIDS;
- fear of infection;
- the fact that AIDS is incurable;
- unmet needs of children;
- lack of space and privacy in work environment;
- lack of an effective voice in decisions that affect them and their work;
- too little autonomy or responsibility;
- lack of scope for initiative;
- inadequate support and supervision;
- inadequate training, skills and preparation for the work;
- lack of clarity about what the caregiver is expected to do;
- lack of referral mechanisms;
- lack of medication and health care materials;
- lack of recognition for their work; and
- lack of mutual respect or liking between caregiver and client.

Many items on this list are causes of stress to carers at the family level also. In addition, they might suffer from:

- isolation;
- the effect of HIV and AIDS on personal relationships and family dynamics;
- insecurity and fear for the future;
- difficulty in communicating with children; and
- difficulty in facing bereavement.

6. Managing stress and burnout: what are the options?

Personal coping mechanisms

Religious faith is a powerful source of comfort to many people in Uganda and South Africa. "I talk to God, pray or read my Bible," is often the first thing a caregiver will mention when asked how they cope personally with the stress of their work. But there is a wide range of other coping strategies that carers employ too. "I make a point of not talking about AIDS when I get home in the evening," said one lone mother who works for a care programme. Another sets aside one day a week which she devotes entirely to her family. One South African remarked: "I always tell clients I'll do my best but that I can't do more than that. There are so many limitations out there that you have to find a way of not letting things get you down. Anyway, we know what it is to have needs and not get what we want – our background (in the apartheid era) has taught us not to have too high expectations."

An elderly woman described how, when nursing her two sons with AIDS, she learnt to anticipate stressful events and to plan ahead. She kept a suitcase packed with fresh clothes and bed sheets in case her sons developed uncontrollable diarrhoea and there would be no time to search for things needed to keep them clean and preserve their dignity. A counsellor in Uganda remarked that, if she is feeling overwhelmed, she will explain to a client politely that she cannot see them at that time and make another appointment. "If someone has a grievance we sit down and talk it through immediately," said the supervisor of a care team in South Africa. "If necessary we say sorry to each other, if we've caused hurt or upset, then we start all over again. It's an African tradition to talk things through – to sort out problems in the *kholla* or the *indaba*."

It is just these kind of strategies that Pierre Brouard tries to encourage in his training courses for counsellors. "I often say to trainees that the needs out there are like a hole in a bucket," he says. "You can be pouring all your compassion and work into the bucket and it'll just go on pouring out. That's not to make them feel helpless or useless, but to make them have a certain sense of perspective – that if you stop pouring for 10 minutes it's not going to make a difference. A central message in our stress management sessions is that, to an extent, you have to take responsibility for yourselves. You can't wait for someone else to come and say to you: stop and take a break."

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A psychologist speaks

Pierre Brouard has worked in the AIDS field since the mid-1980s. Recently he was appointed by an AIDS programme at Soweto's busy Chris Hani Baragwanath Hospital to offer supervision, support and training to the staff on a two-weekly basis. He also trains counsellors for a variety of different programmes within and outside the health sector. Management of stress is a theme that runs throughout his courses because, he explains, knowing how to preserve themselves is crucial for people to remain effective and committed over the long term.

"I constantly stress to my trainees: you're not God; you can't solve all the problems; you cannot prevent every infection; you cannot save the world. Give yourselves permission not to be perfect.

"In my training sessions we look at a variety of things for coping with stress on a daily basis. We look at things like diet, exercise, getting enough rest and sleep, nurturing oneself a bit. We talk about strategies to have time out. And we look at possible support mechanisms in the trainees' own lives – someone they can talk to like a spouse or partner. I suggest that carers should have variety and take breaks from HIV work. And we discuss the idea of getting involved in other work, such as activism, which can channel anger and frustration and helplessness."

Visualization – where people close their eyes and imagine a scene of beauty and tranquillity into which they project themselves – is a relaxation technique that can work for some, says Pierre Brouard. Another is to take what he calls "worry breaks", in which the person allows themselves 10 minutes at a set time each day to sit down and worry about everything that is bothering them. "There's a sense of deferring worry until the time you allow yourself to indulge it and then putting it away again," he says. "These are mind-control strategies which people can use. And I encourage them to talk and to listen to each other. I know from my own experience that just talking things out, even if they aren't resolved, can be very healing. Group support can be very powerful because counsellors realize that other people are struggling with the same things and there's a sense of shared endeavour and mutual concern.

"Sometimes I talk about little physical things people can do, such as breathing exercises. When we're stressed we tend to breathe more shallowly, so deep breathing can actually be powerful. It releases hormones which are more calming. Also, we talk about things like walking around outside; going to stand in the sun for a few minutes. We tend to forget about little things like that when we're in a stressful situation. We don't feel we have the right to say to a patient: 'I'll see you in five minutes, rather than right now', and then just go out and watch a bird sitting on the wall, or bask in the sun for a few minutes. But that can be a tremendous break."

AIDS care programme strategies to deal with stress

Though they share some common features, the programmes visited have a variety of approaches to dealing with stress and burnout among their staff and volunteer carers. This section will look at them in context, focusing on those that are most imaginative and most likely to be applicable elsewhere.

The AIDS Support Organization (TASO)

TASO gives high priority to the salaries of counsellors in drawing up its budget. At present they are paid about twice as much as government employees with commensurate qualifications. Counselling is one of the most demanding jobs a carer can do and, besides showing them that they are valued, TASO is keen to relieve counsellors of the stress of having to look for secondary sources of income to support their families. Paying unusually high salaries is also a way of ensuring that people in whom TASO has invested valuable time and effort in training are not easily lured away by other employers.

Income-generating activities for its clients are also considered an important strategy for relieving the stress of families impoverished by AIDS. But TASO has had mixed results. "Our clients tend to be among the very poorest people in Uganda," explains Sophia Mukasa Monico. "And when you give money to anyone who's very poor, the first thing they do is take care of their basic needs. You can't think of generating income when you actually don't have anything to start off with."

After evaluating the situation, the organization has decided to hive off this important activity to a separate organization, "TASO 2", which can give it the undivided attention it needs. And it intends changing the paradigm from one in which making profit is the objective to one in which "making a difference" – simply improving the standard of living within the home – is the goal. This means, for example, that a family may be helped through skills training and perhaps a grant to increase food production on their land so that they can eat twice instead of once a day. But training and loans will also be available to people wanting to start small business enterprises. "We intend working with groups so that they can help each other and take collective responsibility for repaying the loans," explains Sophia Mukasa Monico. "We want to involve clients' family members too, so that when a client dies the family's source of income won't collapse."

For its staff carers TASO has instituted a number of measures to minimize stress and the risk of burnout. The organization has developed a culture of talking and sharing problems, in regular and frequent meetings between care teams and their supervisors, in workshops which bring

management and staff together to discuss policy issues, and in fostering the feeling that TASO is a “family”. Respect for the principle of confidentiality between staff members as much as between staff and clients means that people can feel safe in admitting stress and seeking help, even if some do still find it hard to show vulnerability. During their initial training, counsellors are encouraged to identify someone among their peers as a personal counsellor.

Members of staff who are sick continue to receive their salaries when they are unable to work, and will receive a further year's salary if they resign voluntarily because of ill health. TASO's director intends to introduce a policy whereby at least two children of a sick staff member are supported through school and even university.

Another new idea for stress management is meditation. A teacher of meditation will shortly be joining TASO as a volunteer for six months, to observe the work of the carers and devise a programme of training them in meditation, which Sophia Mukasa Monico hopes will become a routine part of the working day.

Mildmay International

The Mildmay Centre sits behind impressive gates on a hillside on the outskirts of Kampala. A series of low brick buildings connected by covered walkways through bright gardens, Mildmay was opened in September 1998 as a referral centre to which severely ill patients can be sent by other institutions or programmes which can do no more to help them. It is a centre of excellence in palliative care, particularly the management of pain, which it offers on an outpatient basis. But, besides providing hands-on care, the Mildmay Centre's chief function is as a resource for training others in the care of people with AIDS, offering advanced nursing and specialist skills, like pain management, that are rare but much needed in Uganda at this stage of the epidemic. “We are committed to expanding care, and to expanding the capacity to care effectively,” explains the director of clinical services, Dr Catherine Sozi. Both TASO and World Vision regularly take advantage of its training courses.

The Centre runs “carers’ workshops” once a month at which its multidisciplinary team – representing medicine, nursing, child care, physiotherapy, occupational therapy, dietary advice, counselling and spiritual care – addresses any issue carers want to raise. “We find that what most carers want is advice on how to deal with what they call ‘difficult’ patients – the patient who doesn't seem to appreciate what they're doing for them; the patient who is in distress and they don't know what to do; the patient with wounds; the patient who doesn't eat. And many are scared of dealing with the inevitable – which is facing end-of-life issues. So the workshops give them a forum,” explains Dr. Sozi.

In conjunction with the Ministry of Health, Mildmay has taken its “carers’ workshops” to suburban and slum areas of Kampala, and has recently started running them in rural areas, too. Recognizing the special and neglected needs of children, Mildmay runs separate workshops for different categories of people looking after children with HIV and AIDS – that is, one for health professionals, and one each for mothers and fathers. “We are planning to run workshops for schoolteachers, too,” says Dr. Sozi. “They have told us: we have these children, they look so small, they’re off sick the whole time and we don’t know how to communicate with them.”

Mildmay is at the forefront of teaching people how to communicate with children, both infected and affected. Christine, who has two young daughters, attended one of the Centre’s “Positive Mothers” training courses and says it dramatically improved her relationship with her children, bringing them all very close. “I used to be rough with the children – ordering them to do this and that, and telling them to be quiet and stop asking questions. I didn’t want to tell them about my HIV status,” she admits. “But I learnt at Mildmay that children need to know the truth, and that they need kindness and encouragement to talk. I learnt that they get depressed if they’re left out, and that they get angry and resentful and then they are uncooperative because they’re unhappy. In our training we were given the skills for communicating with our kids.” Christine has, in turn, run workshops at her own TASO centre to pass on the skills she learnt at Mildmay.

To address the issue of stress among its own staff – who care for some of the most desperately ill AIDS patients, many of them children, at the end of their lives – Mildmay has engaged the services of an independent therapist from the institute of psychology at Makerere University to offer them individual counselling. She attends the centre once a fortnight. Mildmay’s practice of working as an interdisciplinary team is itself an effective way of protecting staff from undue stress because it spreads the burden of care and responsibility.

Aware of the heavy demands of the Centre’s work, Dr. Sozi believes in the value of taking time off and has established a culture of respect for weekends and annual leave – no one is allowed to give up their free time lightly. Staff have their health and medical expenses covered, and these benefits are extended to up to four blood-related children, too.

World Vision

World Vision is well established in Uganda, carrying out a broad range of development activities in 21 districts at present. The organization started working with AIDS-affected communities in 1989 and, aware of the uniquely stressful nature of caring for people with HIV and AIDS, it has developed a wide range of support mechanisms for carers at all levels. Primary carers are offered counselling, and basic training in health care.

The organization also makes them aware of the range of resources available and how to access them. And it offers them income-generating activities to help them cope financially. Income-generation projects usually involve groups of people working together. "These have a value beyond simply helping people cope financially," explains Robinah Babiryé. "Doing some activity as a group affords people the opportunity to talk and give each other mutual support. It can have a real impact on their emotions."

Support for its volunteers is given especially high priority by World Vision. To maintain their morale, the organization tries to show its appreciation of their work as often as possible. It makes a point of acknowledging their presence and contribution and formally introducing them at every community gathering. It recognizes, too, that volunteers' daily responsibilities often leave them little time for working their *shambas*, and that, as with primary carers, loss of food production and the struggle to feed their families cause great anxiety. World Vision therefore brought in an agriculturalist to find ways of increasing the volunteers' skills in farming so that they could produce food more efficiently and with less effort. It offered an extra day's training at the end of their seminars, and was surprised at how ready people were to spend the extra time. Today World Vision has a system of "model farmers" whereby a few people, specially trained and using their own *shambas* as demonstration plots, act as a resource for training others in the community – especially families impoverished by AIDS – who want to learn how to increase the yield from their land.

Recognizing the importance of knowledge and skills to self-respect, social status and confidence, World Vision devotes a large part of its budget to training activities, including refresher courses for volunteers and staff, and upgrading of skills. It also believes in flexibility and giving people as much scope for initiative as possible. "In World Vision, if you can defend your position and convince them of your point of view, you are allowed to do things your way," says Gladys Rukidi. "And if you need something from them, they will cooperate if they have the money to do so."

World Vision is aware of the risk of burnout in its staff, and regular retreats in which they are able to get away completely from their normal work environment and spend time in structured bible study and prayer, or simply relaxing and having fun, are one answer to this. The retreats foster a family spirit in which people can talk freely and share their problems – a spirit that is encouraged by the policy of using first names for everyone at all times, and no titles, says Robinah Babiryé. Retreats are a tradition in TASO too, but, to the regret of many counsellors, they have recently been suspended in some centres because they are considered an unjustifiable expense.

With HIV so widespread in Uganda, the possibility of infection among staff members is high. To minimize anxiety about the cost of falling ill, World Vision has a policy of reimbursing health care fees of up to 30 000

shillings (approx. US\$ 21) a month for each staff member. "When it became clear that some sick people were needing more than this to cover their expenses and others were never using their allowances," said Robinah Babirye, "the staff had a meeting at which they agreed to pool the allowance. This way, there is more money for those who need it most."



The clinic at Freedom Park near Rustenburg, South Africa, where Life Line has trained AIDS counsellors.

Life Line

Life Line South Africa, inspired by a similar organization in Australia, was established in 1968 as a counselling service for people facing some kind of personal problem or crisis. As HIV infection has taken off in South Africa, Life Line's counsellors are finding themselves increasingly involved in helping people affected by the epidemic. Today, as well as doing telephone and face-to-face counselling, Life Line trains community volunteers who work in a variety of settings, such as clinics and schools. Their skills are widely acclaimed, and Life Line is frequently called upon to train counsellors for other organizations, too.

Training starts with a "personal growth" course lasting 8-10 weeks. This is followed by an equally long course in communication skills and counselling, in which the issue of stress and how to cope with it is given special attention. "We impress upon counsellors the importance of looking after themselves, pointing out that if they allow themselves to get sick or

burnt out they will be unable to help anyone," explains Anne Finnegan, director of one of Life Line's branches.

She describes an exercise called "Life is a Choice" used during training to bring home this truth. Working in groups of 7-10 people, trainees are asked to imagine themselves going on a special trip. They build a picture together of the destination and how they are travelling there, imagining themselves on a coach, a train, a boat or a plane. Then the facilitator informs the group that their chosen transport has crashed and all but three people have been killed. Each person in the group is asked to imagine he or she is one of the survivors and to argue their case before the others. Finally, everyone is asked to vote on who should survive and is given three pieces of paper to write down their individual choices before reading them out to the group. "Only very rarely does someone vote for himself or herself with one of the three votes," comments Anne Finnegan. "Of course most people feel that it would be selfish to vote for themselves, and that selflessness and sacrifice are absolute virtues. But in the discussion afterwards they are made aware of the fact that you have to be strong and healthy – and alive – to be able to help others," explains Finnegan. "Then we bring the focus back to HIV and ask: how can you take care of another person if you don't take care of yourself?"

Once they are working in the field, the relationship with their supervisors is of critical importance in maintaining their health and morale, says Anne Finnegan. Counsellors working within Life Line are required to fill in a debriefing form after every session with a client. The forms do not record the names of the clients, nor detailed descriptions of their stories, since their primary purpose is to allow supervisors to monitor the counsellors' performance and state of mind. Counsellors are asked about their own emotional state at the end of a session, and where they felt they were most effective and most ineffective in their performance. "Entries such as 'I felt exhausted – this session was not in my diary' or 'I am unhappy about how fast time goes' are good indications of the strains of the job," comments Anne Finnegan. "We try to make sure counsellors don't get to the state of burnout. We look after each other at Life Line before we look after the community, because if we don't we can't look after the community."

Hope Worldwide

"Rather than a single trauma that you have to work through, the traumas our people deal with are more like waves of the ocean that keep rolling in to shore," comments Mark Ottenweller, the director of Hope Worldwide. "With the constant stresses on our counsellors, it's very important that we provide ongoing support and supervision so that they won't be overwhelmed."

“The key to minimizing stress and preventing burnout,” says Ottenweller, “is to disperse the emotional burden”. Hope ensures that no single caregiver is left sitting for a long time with a sick or dying person by drawing in a large circle of people to do the caring. These may include members of the immediate family, the extended family, the support group or church volunteers. And in order to protect his staff from the full impact of the epidemic as much as possible, Dr. Ottenweller makes sure there is variety in their duties so they do not get bored or too deeply involved in any one activity.

Another key to minimizing stress on carers at all levels is to create a broadly supportive environment. This means networking, identifying and accessing local resources of all sorts, and creating mutually beneficial partnerships with others in the community. Hope’s programme in Soweto is centred on community health clinics, which provide accommodation for the support group activities, land for their vegetable gardens and medication, while Hope provides condoms, food, counselling and support to people with HIV and AIDS in the area served by the clinic. The organization has enlisted support from local food retailers who donate food near the end of its shelf-life to the programme for its AIDS-affected families. And it has tapped into the volunteer network of one of the biggest local churches, whose members assist Hope’s support groups in caring for sick individuals and families when needed.

Hope’s staff also keep themselves up to date with information regarding health, social welfare and legal issues. “When I visit a family at home,” explains one of the coordinators, “I sit down with them and discuss all the resources available to them and give contact names and telephone numbers if possible. I talk to them about where to go with legal problems like discrimination against an infected person, and what their rights are under welfare and human rights legislation. And I advise them on how to apply for the benefits they’re entitled to.”

Hope also helps organize income-generating projects for its support groups. Like TASO and others, it recognizes that these are much needed but hard to establish successfully, so the organization seeks expert advice, as necessary, on running small businesses and marketing. “Income generation takes patience and persistence to develop,” says Mark Ottenweller. The vegetable gardens planted in the clinic grounds are supposed to bring in a little income, but yields are unpredictable and they mostly just supplement the diets of support group members.

The vegetable gardens are one answer to the need for food, which came top of the list in a recent support group survey. “The surveys, conducted annually together with an evaluation of Hope’s services, are important for monitoring the welfare and performance of carers,” says Mark Ottenweller. “You have to have constant input from your clients, your

community and your coordinators to figure out what your problems are and where people are experiencing difficulties.”

Sinosizo

Sinosizo means “We Help” in the Zulu language. The home-based care programme started in the early 1990s under the auspices of the Catholic Archdiocese of Durban, but it is not church affiliated. “We have a spiritual dimension in that people are dying, people are frightened, people are coming to terms with their own being, and so they need spiritual support, and that’s clear,” explains the director, Liz Towell. “But it doesn’t have to be Catholic, or any denomination; it doesn’t have to be church at all.”



Caring for a bedridden patient at home in South Africa.

Sinosizo’s basic objective is to empower the communities with which it works to care for their own people with AIDS. The function of its four staff members, who are all professional nurses with specialist skills in palliative care, is to train and supervise the teams of volunteers working at community level.

For volunteers to be effective they must have credibility, authority and status in the community. It is Sinosizo’s policy, therefore, that none of its supervisors wear uniforms that might identify them as professional nurses. Liz Towell explains: “If you put a nurse in a uniform in the community, the volunteer will have no status at all. Instantly! The family will say: ‘We want the nurse back’. So there is nothing to distinguish our supervisors as nurses. And when they’re in the field with the volunteers they aren’t allowed to give hands-on care themselves – their job is to supervise.”

The supervisor’s job is also to introduce volunteers to staff at the local clinic and to encourage good working relationships. “These are crucial to the success of home-based care for AIDS patients, but establishing mutual respect is not always easy – it can be fraught with suspicion, insecurities and turf rivalry. Here the supervisor’s professional qualifications and rank are important,” says Liz Towell. Whereas a volunteer with little formal education might have great difficulty approaching or gaining the acceptance of health staff, the supervisor will automatically be recognized and respected as an equal. And having her support always in the background gives confidence to volunteers.

However, developing self-reliance in its volunteer teams is important to Sinosizo, since many of them work in remote areas beyond the reach of good roads and telephones, and the supervisors are few. Volunteers generally work in pairs, when doing their home visits. This is firstly a matter

of security: the townships and rural villages of KwaZulu/Natal have been rocked by sporadic political violence over recent years. But working in pairs also means that volunteers give each other moral support and share the emotional burden of care. Besides encouraging strong bonds with the team, the key to self-reliance and self-confidence, says Liz Towell, is to let things develop in their own time and to resist the pressure from funders to set inflexible timetables for the achievement of targets. "If you rush volunteers, the programme will fail," she says. "If you let things happen in Africa Time, they will actually work well."

Sinosizo's core funder, Caritas, has taken a close interest in the programme and spent time with staff in the field. "They see every area we work in; they see the terrain that people are walking up and down; they see the level of education our volunteers have; they have a chance to speak to whoever they want. So they leave with a nice clear vision, and as a result it has made life so much easier for us, it really has."

Record-keeping is an important activity at Sinosizo, and literate volunteers who wish are given a two-day training course. Liz Towell has a record card for every patient, which she enters onto a computerized database and which includes details of dependants; support systems, if any; whether there are children at risk of being orphaned; the patient's financial situation; who is looking after them as primary carer; as well as details of their medical condition. "At all times I can look and see exactly where the patients are, who's looking after them and how many patients each volunteer has, how many deaths they have experienced and how many orphaned children they have in their area," she says. "For me it's a monitoring tool, to make sure we aren't overloading anybody emotionally. It also helps to have the statistics so that you can see where the growth areas are and where you might need to recruit more volunteers. You wouldn't necessarily know if you didn't have a database."

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Without constant commitment even good schemes will fail: South Africa's mentoring programme for counsellors

There are no records of the number of people involved in counselling in South Africa, nor of the drop-out rate, but there is a wealth of anecdotal evidence that counselling is an unstable profession. Experience shows that burnout and the decision to quit are often the result of lack of support once a trained counsellor gets out into the field. The HIV/AIDS Directorate in South Africa's Department of Health decided, therefore, to set up a mentoring programme.

Mentors, explained Themabela Kwitshana who devised the programme, are people with counselling skills and long experience themselves who look after counsellors working on the front line. They are different from supervisors in that their responsibility is the welfare of the counsellors, not the quality or style of their work. "Supervisors often take on this role

too, but there can be a conflict of interests, so that a counsellor may feel that her job will be on the line if she admits to the supervisor that she's struggling or has done something wrong," said Ms Kwitshana. "However with a mentor the counsellor should have absolute trust and know she can discuss any of her professional problems without feeling she's threatening her position." In addition, the job of a mentor is to be an advocate for counsellors' rights at every level, from the government to the organizations and institutions for which they work.

The programme was conceived in 1995, and the initial plan was to train people put forward by the provincial administrations, who would then employ them to support the counsellors in all organizations throughout the province. It was piloted successfully in KwaZulu/Natal, where four mentors were trained and subsequently provided support to a total of 900 counsellors across the province who came together regularly in small groups at a time, at local hospitals nearest to their places of work. They would spend a few hours with the mentor, going over cases, discussing work-related issues and problems, and perhaps having an expert give a talk on some relevant topic.

In KwaZulu/Natal the mentors were paid by the province but were seconded to the local non-governmental AIDS Training and Information Centres (ATICs), which had good contacts in the field. It was an inexpensive programme because of using hospital premises, said Ms Kwitshana. But it collapsed very suddenly when the budget for paying the mentors ran out after a year and their contracts were terminated. It was a bitter blow to all who had invested so much hope and energy in the programme – and especially so since it was just about to be launched nationally.

"But I don't give up," commented Ms Kwitshana. "I try to understand why progress is slow, and see if there are ways round the obstacles." Today she is working on the idea of bypassing local government and training mentors to work directly for a whole range of organizations. The new programme will offer training to people who are already working as nurses or counsellors or are in some other relevant profession, and who are therefore already receiving a salary from the hospital or NGO for which they work. She is aware of the danger that they might not have time to devote to another task, or to be able to keep up the commitment. But this is the best way at present of continuing with a programme which has already proved its worth, and Ms Kwitshana says she will address problems if and when they arise.

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The Ark: caring for South Africa's "shadow people"

The Ark is a barracks of a place standing among elegant but derelict colonial buildings in Durban's old dockland area. Once a hostel for stevedores, it is now a shelter for destitute people and home to a thousand men, women and children at any time. These are South Africa's "shadow people", says Alan, a resident who came to The Ark five years ago as an alcoholic who had lost his family, his friends and his job. "There are so many homeless people out there, it's unreal. But they're not seen. People walk past us and they don't care."

Two years ago The Ark opened a hospice for terminally ill AIDS patients, and today the 77 beds in seven small wards are mostly full. Care is given by residents of the Ark who have been rehabilitated and trained by Shirley Pretorius, who runs the shelter's general clinic. A pastor of the independent church that founded The Ark in the early 1980s, she believes no one is beyond having something to give to society. And when AIDS began to manifest itself more and more strongly among the people who came in for shelter, Pastor Shirley, a registered nurse with specialist psychiatric qualifications, looked no further than the corridors and crowded dormitories of the hostel for people who could help her look after them.

"In 1998 the hospitals were becoming overwhelmed with terminally ill patients. People with AIDS were being discharged; many were too sick to get home, often to distant rural villages; others were being rejected by their families, and they were ending up on the streets," Pastor Shirley explains. *"We had a meeting at The Ark and we decided this was a 'gap' that needed filling. It goes against our Christian beliefs that anyone should have to die in the gutter without dignity. So it was given to me to set up the unit."*

The Ark's clinic is now a registered primary health care unit. Pastor Shirley has six people, trained by herself, to help her run the clinic and the hospice. *"My six core members move from bay to bay in shifts throughout the day and night. In each bay I have a monitor, who lives with the patients and is there to give help where it's needed. The staff check every morning that everyone's bathed and dressed and clean. And if someone has an accident or a bed needs to be changed inbetween times, the monitor comes and calls the staff members on duty."*

As well as basic health and nursing care, the clinic staff are trained in counselling of people with HIV and AIDS. Many patients have been rejected by their families, so reconciliation is one of the major objectives of counselling. *"When somebody reaches the point of dying, it gives them great peace of mind if they have been reconciled with their families,"* comments Pastor Shirley. *"We have several people who are 'outside patients' – they just come in once or twice a week for medication and extra feeding. But they've gone home to their families when they thought they never would. Once the families have understood the problem, the fact that they're not going to catch AIDS from nursing, then they've wanted the patient home. And as a result they've been prepared to be trained. What usually happens is that the patient selects a family member who comes in, does two to three weeks' training, and then we send them home with the patient."*

Recognizing that many of her staff have struggled mightily with their own personal problems, Pastor Shirley spends a great deal of time with them looking at stress and how to manage it. *"I find the more you involve people in the decision-making that's relevant to them, the more they feel they've got control of what they're doing and their lives,"* she says. *"If a problem arises in a sick bay – and we do get some very, very difficult patients – I'll get the monitors and the staff for that particular bay and say: 'Right, what are the problems? We're going to brainstorm. Write down everything you can think of to solve those problems, and we'll see if they're practical. And if they are, we'll do them'. I find that because they feel they're in control of the situation, the stress level goes down."*

Besides involving everyone concerned in the decisions about how the AIDS units are run, Pastor Shirley frequently starts the day with a short training session on stress

management. "We deal with anger, we deal with shame, we deal with guilt. And we deal with 'getting tired of trying to measure up'," she says. "This is a course I've put together, for people who are constantly feeling they've got to achieve someone else's standard because they don't feel good enough. We deal with all those types of things together."

7. Conclusions and lessons learned

Caring for the carers of people with AIDS is not only a humanitarian imperative, it is a social and economic necessity, for no country in Africa has yet seen the worst of the AIDS epidemic or experienced the full pressure on its health and social services. And no country can afford to squander the skills and commitment of the carers of today, for they must be the carers of tomorrow, too, and the inspiration and role models for new generations of carers. As the brief case studies in the previous chapter show, caring for carers requires action on several fronts at the same time. Managing stress and preventing burnout requires:

- strengthening the capacity of the individual carer to cope with the duties and responsibilities of the role;
- ensuring that the working conditions, practices and policies of care programmes offer a supportive environment to carers and are not causes of stress in themselves; and
- advocating for national policies and laws that are sensitive to the needs of carers.

This section is intended to highlight lessons and observations from the field that have broad relevance and that lend themselves to being adopted elsewhere.

The work of carers is inherently stressful

A first requirement in supporting carers working in the field of AIDS is to acknowledge formally the fact that their work is inherently stressful, and that feelings of distress are a legitimate reaction to their experiences, rather than signs of personal weakness or lack of professionalism. Bottled-up feelings lead almost inevitably to burnout, and carers need to feel confident and free to express doubts and distress and to seek timely help without fear of affecting their jobs or reputations. They will only do so if acknowledgement of the stressful nature of the epidemic is part of the culture of the organization or institution for which they work.

Carers should be relieved of responsibility for things they cannot help

Carers at all levels need to be relieved of the burden of responsibility for things they cannot help. The message that “bad things happen and it’s not your fault” should be a litany of home-based care programmes. This is particularly important to child carers, since they are most vulnerable to feelings of guilt about suffering they cannot relieve.

Burnout is a process not an event

Stress and burnout are complex phenomena with multiple causes and multiple manifestations. Thus no single, time-limited activity will ever be the solution. For AIDS programmes, managing stress among carers requires a broad-based, sensitive and continuous response, of which good support and supervision are essential elements.

More systematic research is needed into stress management

The management and mitigation of stress are difficult to get right unless one has a clear picture of the problems. More systematic studies of stress among carers at all levels and in all settings are therefore needed, and more formal documentation of the different strategies used to cope with stress, how well they work, what they cost, and their effects on the quality of care as well as on the morale and commitment of carers. Furthermore, ideas for carer support need to be shared between people working in this field, and the lessons of experience widely disseminated.

Knowledge has lasting value

Knowledge is empowering – it gives people confidence, control and choices in life, and it has lasting value. Thus training plays a central role in the management of stress and burnout among carers. Besides imparting the knowledge and skills needed to care for a person with HIV or AIDS, the training of carers should deal directly with the issues of stress and burnout. It should encourage self-reflection and self-knowledge and look at personal coping mechanisms. Another important issue is how to manage one's time effectively and how to recognize and accept one's own limitations.

Ongoing training – both regular refresher courses as well as training in new skills – is important for maintaining confidence and morale. When planning refresher or advanced training courses, programmes should try, as far as possible, to fill the gaps in knowledge and skills that carers themselves identify.

It is important to know your work is respected

For the sake of their morale and self-confidence, carers at every level need to know that their work is recognized and valued. Words of praise or thanks are important, and some programmes understand this and make

a habit of acknowledging and thanking people. Where volunteers are the first line of support to family carers, and perhaps doing much of the hands-on care themselves, they should be given the credit by their communities. Programmes should take great care to ensure that the staff members who train and supervise them, and who may be professionally qualified health workers, do not undermine the authority or status of these front-line workers.

Volunteers are likely to have greater self-respect, more realistic expectations and deeper satisfaction from their work if they have a sense



Home-care nurse and volunteer with a client in Kampala, Uganda.

of ownership of their community programmes, rather than seeing themselves as unpaid employees at the bottom of the hierarchy of the organizations with which they work. The relationship between the volunteers and the organization should be clarified at the time of recruitment and training. And because members of the public are not always clear about the status of volunteers and what they can expect from them, the message that they “belong” to the community rather than to the NGO should be

put across at every opportunity in public gatherings.

Relieving poverty is a top priority

Income-generation schemes are much needed and much valued by AIDS-affected families and communities to relieve the stress of poverty. However they are not easy to get right. Experience shows that necessity, commitment and enthusiasm are not enough to make small businesses successful: people need skills training as well as loans, and their enterprises need careful planning and management, and usually more attention to marketing, than is typically the case. Bringing in expertise to help with income-generation schemes is a sound idea.

Where food handouts are part of the strategy for relieving hunger, programmes should try to obtain supplies from sources as close to the community as possible, rather than from international food aid organizations. Not only will this involve less red tape, but local businesses are more likely to be reliable partners over the long term. Moreover, their direct involvement in the fight against AIDS will help to challenge denial and ignorance of the epidemic locally and to dispel stigma.

Donors need to be more dependable, and more committed to staff welfare

Because of the nature of their work – caring for people with incurable conditions and many needs – AIDS programmes have limited scope for self-reliance. Thus the preoccupation of donors with “sustainability” is a constant source of anxiety, and the pressure to demonstrate effectiveness too often means that staff welfare measures get pushed aside in the interests of population coverage.

To relieve the anxieties of dependence and insecurity, there needs to be greater constancy of support from donors. Furthermore, donors cannot afford to focus narrowly on population coverage issues alone. Unless they look more sympathetically on issues of staff welfare, they will be falling into the classic trap of so many development aid donors in the past – that of purchasing vehicles for development projects but making no allowance for fuel or maintenance! There is much to be gained on both sides by donors visiting programmes on their own home territories, going into the field with carers and seeing for themselves what their work entails.

Stress management is a necessity not a luxury

Stress management is not a luxury: burnout is a very real threat to people who spend their time with the sick, the dying and the grieving, and watching the struggle of families to survive. Thus staff welfare should be a high priority for all AIDS programmes. Effective measures for managing stress include:

- setting realistic targets for work;
- regular time off that is respected;
- annual retreats for carers;
- health care provision and paid sick leave;
- team work and regular meetings to discuss issues and share problems;
- the appointment of a carers’ counsellor; and
- an effective voice for carers in decisions that affect them.

Having good policies and mechanisms in place is only the first step, however; it is important to see that they do not get pushed aside by pressures of work and lack of money. Maintaining staff welfare requires constant commitment and the political will to see that it remains a priority. The value of having strong and sensitive managers, aware of their responsibility for the health and well-being of their staff, cannot be overstated.

Dispersing the emotional burden minimizes stress

An effective way of minimizing the stress of working in the AIDS field is to assign several people to the care of a client where appropriate, so that no one carer has to shoulder the responsibility or the emotional burden alone. This is difficult to arrange, however, if a client is fearful of disclosure. Helping clients identify someone with whom they can safely share their diagnosis is an important part of counselling, and an important element in creating a coping family situation as well as in dispersing the burden of care. However, the dangers of being identified as HIV positive are very real in some settings, and disclosure is an extremely sensitive issue that requires careful handling. Clients must never feel coerced into revealing their status.

Rather than sending in carers from outside, AIDS programmes should encourage and empower communities to do their own caring as much as possible. Not only does this approach help to disperse the burden of care, but it also helps to dispel stigma and prejudice by bringing home to people the reality of the epidemic – the fact that it is not just a problem for other people “out there”, but is in their own midst, affecting friends and neighbours and perhaps their own relatives.

Prejudice, discrimination and stigma need constant challenging

A powerful lesson from experience is that the battle against prejudice and stigma is never conclusively won. The association of AIDS with grim suffering, death and behaviours that people everywhere find difficult to talk about, and to accept, means that the stigma of AIDS needs to be constantly challenged.

Clear job descriptions and good referral mechanisms are important

Carers need a clear understanding of their duties and the limits of their responsibility for any client. They also need to know who or where they can refer clients to when their condition calls for greater expertise or they are unable to manage the situation alone. Good communication and referral mechanisms within AIDS care programmes are therefore essential. And programmes should aim to strengthen their own foundations and create a supportive environment for carers at every level through networking and partnerships with other organizations and individuals with something relevant to offer.

For carers at home, being made aware of the resources available locally and other sources of support is a great comfort.

Independent evaluation offers a fresh perspective

Independent evaluation of programmes at regular intervals is important for a number of reasons, not least because it gives everyone working for the programme a fresh perspective on their daily activities. By putting services, working practices and relationships under the spotlight, it can identify problem areas and suggest alternative ways of doing things that might not be obvious to the people involved. Several programmes spoke with enthusiasm about the exercise, saying that it allowed them to refocus their activities and to change things that were not working as well as they should. One director said that independent evaluation had given her programme a new lease of life – she and her colleagues seemed to be caught in a downward spiral of overwork and inadequate resources, and were on the point of giving up when the evaluation team analysed what they were doing and showed them how they could restore the balance.

Governments need to review laws and policies to facilitate care

Government policies and laws can create a supportive environment for the care of people with HIV and AIDS, or they can be obstructive. Of particular significance are laws and policies regarding:

- HIV testing;
- access to drugs;
- the prevention of mother-to-child transmission;
- the human rights of people with HIV infection and AIDS;
- the status of traditional healers;
- the disbursement of donor funds and food aid; and
- the inheritance rights of widows and children.

Governments need to look carefully at how existing laws and policies affect the operation of AIDS care programmes, and how they might be modified to make the work of carers easier and more secure.

8. Afterword

When it comes to caring for people with HIV and AIDS, the richest resource a country has is, without question, the compassion of its people. As these examples from Uganda and South Africa show, the level of funding is not the most important predictor of the quality of care. It is an extraordinary fact that some of the most effective programmes are found in the poorest communities, where care is delivered by people who not only earn nothing for their services but risk sliding deeper into poverty themselves because of the time they devote to this cause. Even for staff members of AIDS care organizations, the pay they receive is almost never the motivating factor for getting involved in this field – like the volunteers, it is most often the desire to help others who are suffering.

Drawing attention to the rich pool of compassion that sustains the care effort in so many places is by no means to downplay the importance of money – nor the pressing need for a much greater allocation of funds, nationally and internationally, to the care of people with AIDS. It is simply to highlight a resource that is too often taken for granted, and to underline the case made by this report: that carers deserve greater recognition for their extraordinary and selfless contribution to the battle against AIDS, and that concern for their well-being should have the highest priority.

The Joint United Nations Programme on HIV/AIDS (UNAIDS) is the leading advocate for global action on HIV/AIDS. It brings together seven UN agencies in a common effort to fight the epidemic: the United Nations Children's Fund (UNICEF), the United Nations Development Programme (UNDP), the United Nations Population Fund (UNFPA), the United Nations International Drug Control Programme (UNDCP), the United Nations Educational, Scientific and Cultural Organization (UNESCO), the World Health Organization (WHO) and the World Bank.

UNAIDS both mobilizes the responses to the epidemic of its seven cosponsoring organizations and supplements these efforts with special initiatives. Its purpose is to lead and assist an expansion of the international response to HIV on all fronts: medical, public health, social, economic, cultural, political and human rights. UNAIDS works with a broad range of partners – governmental and NGO, business, scientific and lay – to share knowledge, skills and best practice across boundaries.



Joint United Nations Programme on HIV/AIDS

UNAIDS

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