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Original Contributions

Stability and Inactivation of HTLV-III/LAV Under
Clinical and Laboratory Environments

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The stability of human T-cell lymphotropic virus type III/lymphadenopathy-associated virus (HTLV-III/LAV) under environmental conditions encountered in a clinical or laboratory setting and its inactivation by commonly used chemical disinfectants were investigated. Under our experimental conditions using a highly concentrated viral preparation, virus with an initial titer of approximately $7 \log_{10}$ tissue culture infectious dose (TCID₅₀) per milliliter can be recovered for more than a week from an aqueous environment held at room temperature (23 to 27 °C) or at 36 to 37 °C. Virus titer is reduced at a rate of approximately $1 \log_{10}$ TCID₅₀ per 20 minutes held at 54 to 56 °C. Dried and held at room temperature, HTLV-III/LAV is infectivity for more than three days with a reduction of approximately $1 \log_{10}$ TCID₅₀ per nine hours. Viral infectivity is undetectable and reduced to $7 \log_{10}$ TCID₅₀ within one minute with 0.5% sodium hypochlorite, alcohol, or 0.5% nonidet-P40, and within ten minutes with 0.08% primary ammonium chloride or with a 1:1 mixture of acetone-alcohol. These results help provide a rational basis to prevent the accidental spread of HTLV-III/LAV in the laboratory or clinical setting.

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Human T-cell lymphotropic virus type III/lymphadenopathy-associated virus (HTLV-III/LAV), the etiologic agent of the acquired immunodeficiency syndrome (AIDS) and AIDS-related complex,^{1,2} infects helper/inducer (OKT4+/Leu 3a+) T lympho-

cytes and possibly other cell types with a direct cytopathic effect and/or with indirect effects on cells involved in cellular and humoral immunity, as noted in the literature³⁻¹¹ and our personal observations. The HTLV-III/LAV is transmitted primarily by sexual contact and through blood or blood products in vivo, and will infect fresh human helper/inducer T lymphocytes, as well as established T- and B-lymphoid and monocytoid cell lines in vitro^{2,9,10,12} (unpublished data, S.Z.S. and P.D.M., 1985). In view of the serious consequence of HTLV-III/LAV infection, its stability under

clinical and laboratory conditions and its inactivation by commonly utilized inactivating agents and disinfectants are of tremendous importance to health care workers and laboratory personnel.

Here, the results of testing the stability of HTLV-III/LAV under various experimental conditions are reported. The test system utilized different HTLV-III/LAV isolates to infect fresh human peripheral blood mononuclear cells and, in some instances, an established T-cell line, H9.² Cell cultures were propagated for more than a month to facilitate the detection of low quantities of virus.

These and similar studies should lead to a more complete understanding of the stability of HTLV-III/LAV and to the development of rational procedures to limit its accidental spread in the laboratory or clinical setting.

METHODS
HTLV-III Viruses

Isolate HTLV-III (TM) was obtained from the culture supernatant of normal peripheral blood mononuclear cells infected with virus isolated from a patient with AIDS.¹³ The virus stock contained approximately 10^6 total virus particles per milliliter by electron microscopy count. The HTLV-III (H9) was obtained from the culture supernatant of H9 cells infected by multiple isolates of virus² and was concen-

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T-Cell Lymphotropic Virus Type III—Resnick et al 1887

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trated $\times 1,000$ by banding in sucrose. The H9 virus stock had a total virus particle count of 10^6 to 10^7 /mL. Using the Reed and Muench method¹¹ for calculation of the tissue culture infectious dose (TCID₅₀) of virus, virus stock HTLV-III (TM) contained an infectious titer of approximately $7 \log_{10}$ TCID₅₀/mL and the $\times 1,000$ concentrated HTLV-III (H9) approximately $10 \log_{10}$ TCID₅₀/mL. Filtered (cell-free) TM and H9 stocks were stored at -100°C until used.

Preparation of Peripheral Blood Mononuclear Cells and H9 Cells

Peripheral blood mononuclear cells (PBMCs) were obtained by leukopheresis of healthy adults and banding by Ficoll-Hypaque gradient centrifugation. These mononuclear cells were incubated in growth medium (RPMI 1640, with 20% heat-inactivated fetal calf serum and 0.25 mg/mL of glutamine) containing 5 mg/L of phytohemagglutinin for 48 hours at 37°C in a 5% carbon dioxide atmosphere. They were then washed with phosphate-buffered saline (PBS) and refed with growth medium containing 10% purified interleukin-2,¹² as previously described.¹³ The established T-cell line H9⁹ was maintained in growth medium until used.

Infectivity Assays

Virus-containing supernatant fluids were thawed and diluted with 50% human plasma before use for experimental procedures. After the indicated treatment, sequential dilutions of the treated virus or untreated control virus were prepared in PBS and 1.0 mL of each dilution was used to infect fresh PBMCs or the T-cell line H9.⁹

For infection, target cells were seeded at a concentration of 10^6 /mL and exposed to diethylaminoethyl dextran (25 mg/L) for 20 minutes at 37°C . Cells were then rinsed twice with PBS, pelleted, and 5 to 6×10^6 cells exposed to 1 mL of treated or untreated HTLV-III for 90 minutes at 37°C . After infection, cells were resuspended in fresh growth medium supplemented with 10% interleukin-2 and carried in triplicate cultures maintained at 0.5 to 1×10^6 cells per milliliter at 37°C in humidified air containing 5% carbon dioxide. Viral TCID₅₀ was determined as described previously.¹⁴ With some reagents or conditions, HTLV-III-infected H9 cells were exposed for the indicated times, rinsed, and 5×10^6 cells cocultivated with 5×10^6 uninfected H9 cells.

Monitoring Infectivity

Media changes were performed at three- to four-day intervals, and the viable cell concentration was adjusted to 0.5 to 1×10^6 cells per milliliter. To determine infected

cell cultures, cells were monitored for characteristic cytopathic effect by light microscopy of Wright-Giemsa-stained cells and supernatant fluids were assayed for particle-associated reverse transcriptase activity, as previously described, using Mg^{++} as divalent cation, oligo dT-poly(rA) or oligo dG-poly(rC) as primer-template representing viral polymerase activity, and oligo dT-poly(dA) as primer-template representing cellular polymerase activity.¹⁴ Results are expressed as counts per minute of methyl-tritiated-deoxythymidine triphosphate (16 to 18 Ci/mmol) incorporated per 10^6 of culture fluid concentrated 17-fold. Cell cultures were monitored for a minimum of a month.

Temperature Conditions

One milliliter of each dilution of HTLV-III (TM) was exposed to the following temperatures and time periods: room temperature (23 to 27°C) for 2, 3, 4, 6, 11, and 15 days; 36 to 37°C for 2, 3, 4, 6, 11, and 15 days; and 54 to 56°C for 30 minutes and 1, 3, and 5 hours. Virus suspended in 50% human plasma was placed in closed tubes and incubated in a regulated water bath. After incubation at the specified temperatures and time periods, infectivity assays were performed to detect infectious virus and to determine the TCID₅₀. Samples were also tested directly for residual reverse transcriptase activity.

Drying Conditions

One-milliliter aliquots of each dilution of HTLV-III (TM) were spread in 30×50 -mm culture plates and allowed to dry completely at 23 to 27°C (approximately 45 minutes). When fully dried, samples were covered and incubated at room temperature for 3, 6, 24, 72, and 168 hours. After the specified incubation period, samples were reconstituted in 1 mL of serum-free media and tested for residual reverse transcriptase activity and infectious virus.

Chemical Disinfectants/Inactivators

Chemicals were obtained from commercial sources: a combination of quaternary ammonium chlorides, octyl-decyl-dimethyl ammonium chloride (1.536%), dioctyl-dimethyl ammonium chloride (0.768%), *N*-docyl-dimethyl ammonium chloride (0.768%), and alkyl-dimethyl benzyl ammonium chloride (12.288%), totaling 15% quaternary ammonium chlorides; alcohol; sodium hypochlorite; nonionic detergent P40 (Nonidet-P40); and alcohol and acetone. These were used at recommended concentrations to treat HTLV-III (H9) supplemented with 50% human plasma or HTLV-III-infected H9 cells for various times at room temperature (23 to 27°C). Infectivity assays were performed begin-

ning with a dilution of treatment containing a nontoxic concentration of chemical, ie, one that did not interfere with cell growth and viability and replication. The concentrations of chemical used to treat HTLV-III (H9) were as follows: quaternary ammonium chloride diluted 3 g/3.8 L of water (a final concentration of 0.08%); sodium hypochlorite diluted 1:10 in water (0.5% final concentration); nonidet-P40 diluted to 0.5% in isotonic buffer; alcohol diluted to 50% in water; and methyl alcohol and acetone mixed in equal proportions (1:1).

RESULTS

Serial dilutions of virus stock were tested in an infectivity assay to titrate the amount of infectious virus present. A delay in the appearance of detectable reverse transcriptase activity and, in some instances, a reduction in the level of recovery activity correlated with the decreasing concentrations of virus used in infection (Fig 1, top). The titers of HTLV-III (TM) was calculated to be approximately $7 \log_{10}$ TCID₅₀/mL. A similar pattern was obtained with $\times 1,000$ concentrate of HTLV-III, and the titer was determined to be approximately $10 \log_{10}$ TCID₅₀/mL (not shown). The relative sensitivity of reverse transcriptase assay and infectivity assay for HTLV-III are reflected in Fig 1, top. Undiluted supernatant fluids contained detectable reverse transcriptase activity (at time 0), infected virus was detected at higher dilutions (10^{-1} through 10^{-4}). This emphasizes the need to continue cell culture for an adequate time period to ensure detection of low levels of virus for infection.

To test the effect of some frequently encountered clinical and laboratory conditions on the infectivity of HTLV-III (TM), virus diluted in media supplemented with 50% human plasma was dried (Figs 1, bottom, and 2, top) and incubated at 23 to 27°C , or incubated in an aqueous state at one of several different temperatures: room temperature (23 to 27°C) (Table 1), 36 to 37°C (Table 1), and 54 to 56°C (Fig 1, bottom). Various periods of time. In an aqueous state, complete inactivation of virus (approximately $7 \log_{10}$ TCID₅₀) required between three and seven hours with an inactivation rate of approximately nine hours per log reduction.

tion of treated toxic concentrations that did not impair viability and concentrations of HTLV-III (H9) were ammonium chloride water (a final concentration of 0.5% sodium hypochlorite) or 0.5% final concentration of alcohol diluted to 70% (alcohol and ammonium chloride portions (1:1).

RESULTS

of virus stocks in infectivity assay to normal human mononuclear leukocytes. Infectious virus was detected in the appearance of reverse transcriptase activity. In some instances, a low level of recovery was observed with the detection of virus used in the assay. The titer was calculated to be 10^6 TCID₅₀/mL. A log reduction in TCID₅₀ per 20 minutes (Figs 1, bottom, and 2, bottom) of HTLV-III (H9) was determined to be 10^6 TCID₅₀/mL. After one hour, 6 log₁₀ TCID₅₀ or more sensitivity of the assay was not detectable. In contrast, no residual reverse transcriptase activity was detected in virus preparations after exposure to 30 minutes at 54 to 56 °C (time 0 points in Fig 1, bottom).

This emphasizes the importance of cell cultures in the period to ensure the levels of virus of some frequent laboratory infections. Infectivity of virus diluted with 50% bleach (Figs 1, center) and 23 °C in an aqueous solution at different temperatures (23 to 37 °C) (Table 1, bottom). In a dried state, HTLV-III to 0.5% nonidet-P40 resulted in inactivation of virus (reduction of infectivity ≥ 8 log₁₀ TCID₅₀) within one minute. A combination of

titer (Fig 2, bottom). A low level of residual reverse transcriptase activity could be detected in the dried preparations only through the 24-hour incubation period at room temperature (Fig 1, center). Infectious, cell-associated virus in a dried state was detected in a dried preparation of infected cells (5×10^5 cells) after 24 hours, but not after three days (Table 1).

Exposing virus to different temperatures resulted in a reduction of infectious virus corresponding to increasing times of incubation and decreasing temperatures. Complete inactivation of 7 log₁₀ TCID₅₀ or more of infectious virus was seen between 10 and 15 days of exposure at 36 to 37 °C (Table 1). Infectious virus was still detected after 15 days at room temperature (23 to 27 °C) (Table 1). Heating virus in 1 mL of medium containing 50% human plasma at 54 to 56 °C resulted in a reduction of virus titer at a rate of approximately 1 log reduction in TCID₅₀ per 20 minutes (Figs 1, bottom, and 2, bottom). The infectious virus titer was reduced approximately 3 log₁₀ TCID₅₀ after one hour, 6 log₁₀ TCID₅₀ or more within three hours, and after five hours no infectious virus (≥ 7 log₁₀ TCID₅₀ reduction) was detectable.

Several commonly used chemical disinfectants were also tested for their ability to inactivate HTLV-III (H9) at room temperature (23 to 27 °C). Sodium hypochlorite at a 0.5% concentration (common household bleach in 10% concentration in water) and alcohol at a 70% concentration inactivated infectious virus below detectable levels within one minute (a reduction of ≥ 7 log₁₀ TCID₅₀). Quaternary ammonium chlorides at a concentration of 0.08% reduced virus titers to below detectable levels in less than ten minutes. Since nonionic detergents are routinely used for the preparation of viral proteins, the effect of nonidet-P40 on viral infectivity was also tested. Exposure of HTLV-III to 0.5% nonidet-P40 resulted in inactivation of virus (reduction of infectivity ≥ 8 log₁₀ TCID₅₀) within one minute. A combination of

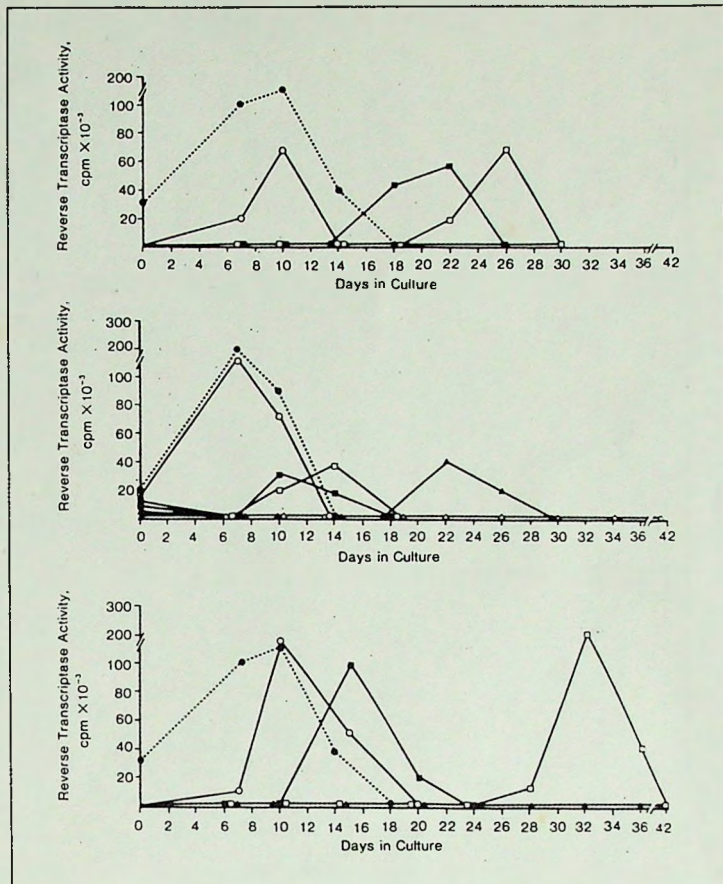


Fig 1 — Effect of sequential dilutions of untreated human T-cell lymphotropic virus type III (HTLV-III) (TM) (top) and exposure of undiluted HTLV-III (TM) to dried state (center) or 54 to 56 °C (bottom) on infectivity of normal human mononuclear leukocytes. Mononuclear cells from normal donors were prepared and infected with sequential dilutions of untreated or treated HTLV-III as described in "Methods" section. Top, Solid circles indicate undiluted; open circles, 10⁻² dilution; solid squares, 10⁻⁴ dilution; and open squares, 10⁻⁶ dilution. Dilution of 10⁻⁸ yielded no detectable virus through 42 days in cell culture (not shown). Center, Solid circles indicate control; open circles, three hours; solid squares, six hours; open squares, 24 hours; solid triangles, 72 hours; and open triangles, 168 hours. Bottom, Solid circles indicate control; open circles, 0.5 hour; solid squares, one hour; open squares, three hours; and solid triangles, five hours.

Table 1 — Stability of Human T-Cell Lymphotropic Virus Type III (HTLV-III) After Exposure to Environmental Conditions*

Day	Cell Free		Cell Associated† (Drying [30 °C])
	23-27 °C (Room Temperature)	37 °C	
1	+	+	+
3	+	+	—
5	+	+	—
11	+	+	—
15	+	—	—

*After exposure of HTLV-III (TM) (titer of approximately 7 log₁₀ tissue culture infectious dose) to an indicated condition for the specified time period, infectivity assays were performed as described in the "Methods" section. Plus sign indicates that infectious virus was detected; minus sign, no infectious virus detected.

†One milliliter containing 5 × 10⁵ HTLV-III-infected H9 cells was dried; after the specified time period, cells were reconstituted in 1 mL of serumless media, cocultivated with 5 × 10⁵ normal peripheral blood mononuclear cells, and monitored for infectious virus as described in the "Methods" section.

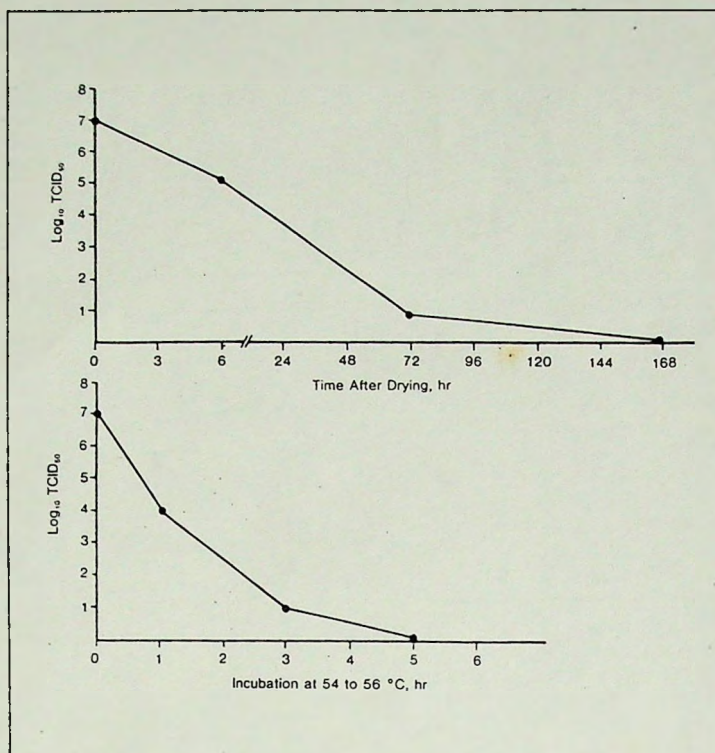


Fig 2.—Effect of storing of human T-cell lymphotropic virus type III (HTLV-III) (TM) in dried state at room temperature (24 to 27 °C) (top) and in aqueous solution at 54 to 56 °C (bottom) on titer of infectious virus. Mononuclear cells from normal donors were prepared and infected with sequential dilutions of HTLV-III (TM) preparations that were exposed to dried state and at 54 to 56 °C for variable periods of time as described in "Methods" section. Log₁₀ tissue culture infectious dose (TCID₅₀) was calculated using Reed Muench method. Standard deviation was calculated to be $\pm 0.513 \log_{10} \text{TCID}_{50}$.

Table 2 — Stability of Human T-Cell Lymphotropic Virus Type III (HTLV-III) (H9) After Exposure to Chemical Disinfectants

Chemical*	Final Concentration†	Exposure Time, min	Infectivity After Exposure, Log ₁₀ TCID ₅₀ ‡
Untreated virus (control)			+ 10.5
NP-40*	0.5%	1, 5, 10, 15	- <2.5
Sodium hypochlorite	0.5%	1, 5	- <3.5
Alcohol	70%	1, 5	- <3.5
Quaternary Ammonium chloride	0.08%	1	+ >4.5
		10	- <3.5
Alcohol-acetone	1:1	20	- —4

*Chemicals and viruses are described in "Methods" section.

†Virus preparations were mixed with the indicated final concentration of chemical and incubated for the specified times at room temperature (23 to 27 °C).

‡Time of exposure of the virus to the chemical.

§Infectivity assays were performed at a final dilution that avoided toxic effects on the cells, as described in the "Methods" section. Infectivity is expressed as log₁₀ tissue culture infectious dose (TCID₅₀) per milliliter of virus treated with the chemical disinfectants. Plus sign indicates virus detected; minus sign, no virus detected.

||Five $\times 10^5$ HTLV-III-infected H9 cells were fixed and air dried after the specified time period. Cells were reconstituted in 1 mL of serumless media, cocultivated with 5×10^5 normal peripheral blood mononuclear cells, and monitored for infectious virus as described in the "Methods" section.

alcohol and acetone at concentrations routinely used to fix cells being for viral proteins also reducing number of cells liberating virus to below detectable level. Virus was detected in H9 infected H9 cells treated for 48 hours with a 1:1 mixture of acetone (Table 2). In contrast, virus can be recovered from fewer than 100 infected H9 cells using the same cocultivation procedure (data not shown).

COMMENT

Human T-cell lymphotropic virus type III/lymphadenopathy-associated virus, in the presence of human immunodeficiency virus, was exposed to several environmental conditions encountered in natural, clinical, or laboratory settings. It should be emphasized that the concentration of virus used for experimental studies (7 to 10 log₁₀ viral activity) was many orders of magnitude above those concentrations encountered from patient specimens. However, it is important not to ignore any potential implications regarding possible transmission of virus by contaminated needles, syringes or in clinical situations involving contact with patient or body fluids.

Infectious cell-free virus recovered from dried material up to three days at room temperature and in an aqueous environment. Infectious virus survived longer than 11 days at room temperature (27 °C) and 11 days at 36 °C. Even under the more rigorous conditions commonly used to inactivate complement (54 to 56 °C), infectious virus was detected after hours of exposure. The approximate rate of HTLV-III inactivation observed, about 1 log₁₀TCID₅₀/20 minutes, is much slower than previously reported, ie, inactivation of HTLV-LAV after 30 minutes¹⁷ or within minutes^{18,19} at 54 to 56 °C.

It is not known why an approximate tenfold difference in the approximate rate of inactivation at 54 to 56 °C was found. It appears that the rate of inactivation determined herein closely approximates that reported for 50 °C in a previous report.¹⁷ Our data emphasize the necessity of taking into account initial virus concentration and the effect of different exper-

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From: "TEX 32" <texthirtytwo@hotmail.com>
To: <hiv@phmovement.org>
Sent: Thursday, May 20, 2004 10:03 AM
Subject: Treating HIV and AIDS using the Dr. Harold D. Foster Concept

Hello

I got an email sent to me asking me to share information about the work of Dr. Harold D. Foster on the treatment of HIV and AIDS. I think you may be very interested in it.

Dr. Harold Foster has apparently developed a safe, simple to administer and low cost approach to help people with HIV and AIDS. Dr. Foster's approach addresses the extreme nutritional deficiencies found in people with AIDS by applying the concept of "total deficiency targeting". Dr. Foster's approach apparently helps people with HIV and AIDS overcome competition from the HIV virus for specific essential minerals and amino acids in their bodies.

Dr. Foster's approach is consistent with treatment regimes promoted by Dr. Tshabalala-Msimang, South Africa's Minister of Health, a physician and obstetrician, and with the general principles of the VITAGRANT program operated by the Clinical Directors Network, Inc. in New York. Details on the research that supports Dr. Foster's treatment concept can be found at www.lookforhelp.com.

Dr. Foster has been committed to helping people with HIV and AIDS recover and resume productive lives. He has been responsible for providing advice on the formulation of products presently undergoing clinical trials in Africa. Preliminary reports from Botswana, Kenya and South Africa apparently indicate a recovery rate exceeding 90%.

I believe Dr. Foster has been providing products at his own expense to people with HIV or AIDS in Kenya and South Africa. Dr. Foster's approach appears to work quickly without the unfortunate and unpleasant side-effects of many antiretroviral drugs. Dr. Foster has apparently developed products suitable for children, both those with HIV and those who are most susceptible to contracting it.

Dr. Foster is a very accomplished academic and researcher, with over 235 books and articles published.

Dr. Foster's journal articles, including, "Why HIV 1 has Diffused So Much More Rapidly in Sub-Saharan Africa Than in North America", Medical Hypotheses, Vol. 60(4), pp. 611-614, 2003, and "How HIV-1 causes AIDS: implications for prevention and treatment", Medical Hypotheses, Vol. 62(4), pp. 549-53, 2004, are available at the National Library of Medicine MEDLINE/PubMed websites, www.nlm.nih.gov or www.pubmed.com. If you search PubMed for "Foster HD" you will see that the abstracts for the Medical Hypotheses HIV/AIDS papers are available online.

The January/February 2004, and March/April 2004 issues of Nexus Magazine also contain recent articles written by Dr. Foster about the treatment of AIDS. These articles are available at www.nexusmagazine.com/articles/aids.selenium.html and www.nexusmagazine.com/articles/aids.selenium2.html.

If one is interested, copies of Dr. Foster's book, "What really causes AIDS", published by Trafford Press, are available free at www.hdfoster.com/WhatReallyCausesAIDS.pdf.

A complete list of his publications is available at www.hdfoster.com.

Interest in Dr. Foster's work has been growing. On March 23, 2004, Dr. Foster was a special guest for over one hour on Radio786 in Cape Town, South Africa. On April 1, 2004, he was a special guest on Paltalk Radio in New York, when two hours were dedicated to caller questions on his research and treatment approach for HIV and AIDS. Earlier this month, Dr. Foster was apparently presented with its "Doctor of the Year" award by the International Society for Orthomolecular Medicine at its 33rd Annual International Conference in Vancouver, Canada.

If you are interested, Dr. Foster can be reached by telephone at the University of Victoria, in Canada, at (area code 250) 721-7331, or by email at fosterhd@fosterlabs.com.

Sincerely,

Tex Tardy

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HIV

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Sent: Sunday, May 23, 2004 11:41 PM
Subject: 700 PLWA in Panama Face 'Death by Bureaucracy'

If you wish to be removed from this list, send an e-mail to rsstern@racsa.co.cr.

Complete silence from UNAIDS, PAHO:

700 PLWA in Panama Face 'Death by Bureaucracy'

By Richard Stern and Guillermo Murillo
 Agua Buena Human Rights Association*

Unbelievable as it seems, 700 People Living with HIV/AIDS (PLWA) in Panama have been without their anti-retroviral treatment for over two months due to bureaucratic "errors."

Most of these 700 people receive ARVs through the Panamanian Ministry of Health at one major inner city hospital and come from the country's working classes, and informal labor force, and are therefore among the nation's most impoverished people.

1100 employed middle and upper class PLWA who receive treatment through the government run but semi-autonomous "Social Health Institute," continue to receive their treatment. Like many Latin American countries Panama has a divided health care system, with the poorest people generally receiving little or no health care through the Health Ministries.

This past April, two Panamanian NGO's, Genesis and PRORINSIDA sent letters to Health Minister Fernando Garcia demanding the end to interruptions of ARV therapy, which succeeded in immediately ending a brief treatment interruption for those who receive medications from the Social Health Institute, but has had no impact on the care and treatment of those who must rely on the Health Ministry.

In total, 1,823 PLWA receive ARV therapy in Panama, through both segments of the divided Health care system.

Dr. Gladis Guerrero, National AIDS program director acknowledged that because of "human error," the Health Ministry program failed to carry out purchases to insure continued treatment access for those who receive their ARV's

through its programs. The result has been a complete halt to treatment for these 700 people. Agua Buena spoke with Dr. Guerrero on May 21st.

Dr. Guerrero would not say when the problem was expected to be resolved, only that she hoped that it would be "as soon as possible."

Just six months ago, during the third Central American AIDS Conference held among Panama City's five star hotels and skyscrapers, the country was praised by officials from UNAIDS, PAHO, and WHO for its efforts to combat the epidemic. But now that the limelight has shifted elsewhere, the Panamanian government seems to have found a way to save some money at the expense of the country's poorest people who have little impact on government policies and face overwhelming social and economic obstacles. Meanwhile not a word of protest or concern has come from these same International Agencies of Cooperation who are busy espousing new programs at innumerable press conferences.

Although both government and international officials are aware of the danger of resistant strains of AIDS, not to mention the inevitable deterioration and eventual death of those affected, there has been virtually no public outcry other than the fruitless gestures by the Panamanian NGOs.

50 other Panamanians with advanced AIDS who also receive their health care from the Health Ministry have completed the onerous bureaucratic procedures in order to qualify to begin anti-retroviral therapy but many of them have already died while waiting for medications that have never arrived.

Dr. Peter Piot, Director General of UNAIDS, and Dra. Mirta Roses Periago, Director of PAHO,** should step forward and condemn this blatant human rights abuse that violates all of the best practices developed by the various UN Agencies with respect to the epidemic, and also singles out as its victims the most defenseless members of Panamanian society.

Although failure to place individuals on anti-retroviral therapy should be condemned, in our opinion it is even more horrible to start PLWA on treatment and then interrupt this treatment for a period of months, which will inevitably lead to death for some, and constitutes a serious public health problem for all concerned. If UNAIDS and PAHO continue to maintain "neutrality" around such blatant abuses they lose their moral credibility and become accomplices in this very worst example of abuse by indifferent authorities against a class of totally marginalized individuals.

**PAHO is the Pan American Health Organization, responsible for implementation of the WHO "3 x 5" program in Latin America.

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(Agua Buena wishes to recognize Javier Rozette of Fundacion Genesis for his support in compiling this information)

community health cell

From: "AIDS Health News" <aids_health_news@yahoo.com>
 To: <shiv@phmovement.org>
 Sent: Tuesday, December 14, 2004 12:53 AM
 Subject: Article: Disease theory more innovative, says MD

Disease theory more innovative, says MD

Grania Litwin
 Times Colonist

Friday, December 10, 2004

An American specialist who has treated AIDS patients for two decades believes the controversial theory advanced by UVic professor Dr. Harold Foster has merit.

"I think the combination of nutrients he has come up with addresses the Achilles heel of the immune system, when it is infected with HIV," says Dr. Brad Parks, a medical doctor and neurologist who treats AIDS patients in the Seattle area and specialized in immunity disorders.

"I used to get 40 or 50 active AIDS patients coming to see me each year, but I haven't for the last couple of years." Parks says he's not getting the calls because he directs patients to Foster's Web site, where they can print out his book for free and use the information in it to buy their own supplements or nutrient-rich foods.

"I say, call me if you have any questions, but they don't. Clinically, these people get well," Parks said.

Parks adds the theory about these supplements is not complex or controversial. "It's just innovative," and word of it is spreading through the AIDS community.

"No one else is promoting it because there is no patent substance here, no exorbitant mark-up, no payoff in millions. Harry has put everything out there, without any hook, because he is tremendously generous."

Victoria respirologist Dr. Jim Sparling, who has been to Africa a dozen times and is well aware of the AIDS pandemic, is also investigating Foster's theory.

The director of Victoria's TB Clinic at the Jubilee Hospital, is involved in a small trial at a hospital in Kampala, Uganda, where three UBC students are tracking 40 patients taking the supplements.

"So far the information is anecdotal, but patients do feel better and some

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have gained weight."

As a mainstream doctor, what does he think of the theory?

"Either Harry Foster is totally off-the-wall crazy, or brilliant, I do know he is very interesting, enthusiastic and passionate."

Sparling adds the fact that AIDS patients in Africa and everywhere have increasingly low levels of selenium is important and has never been properly studies, "though it has been known for 15 years."

"Hepatitis B is also associated with a selenium dependent enzyme system, and 350 million people are infected with it in Asia.

"These are opportunistic infections, and I am very concerned both as a doctor and a human."

There have been 11,510 reported cases of HIV in B.C. during the past 20 years and 3,730 cases of AIDS., according to the B.C. Centre for Disease Control.

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chc

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 Subject: Deadly Bureaucracy: Dominican Republic Retreats from "3 x 5" commitments. Lowers ARV Access Goals

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13 September, 2004

Deadly Bureaucracy:

Dominican Republic Retreats from "3 x 5" commitments. Lowers ARV Access Goals

Eugene Schiff ^{PHD}
 Santo Domingo,

The two of us held tightly to the moto-taxi driver and handrail as the rusty old bike sputtered along the dirt road leading to a middle class neighborhood on the outskirts of Higüey, an agricultural town in the easternmost corner of the Dominican Republic. We paid 40 pesos, about a dollar, and the moto zipped away.

Irene Ramirez*, an HIV+ mother, leader and activist from the nearby city of La Romana and I were soon met by Alejandra Sanchez. Alejandra greeted us, and welcomed us into her home. She prepared plastic chairs, and begged us to please sit down.

Alejandra* is the founder of a support group consisting of forty individuals, mostly of women living with HIV or AIDS in Higüey. She related that of these forty, only she and another woman were currently receiving antiretroviral (ARV) therapy. Both were paying for the therapy and their own tests and doctors fees out of pocket, without any assistance. Alejandra confessed she was periodically obligated to buy her medicines on the black market from another person living with AIDS* who offered their own treatment to her at reduced prices.

Still, even the minimal package of generic ARVs, vitamin supplements, expensive lab tests needed to monitor viral load and CD4+ counts, and transport to the clinic is too costly for the vast majority of people living with AIDS in the Dominican Republic to pay for themselves. Economic security for people living with AIDS is further challenged by the fact that employers in the area, including resort hotel owners and factories in special Free Trade Zones, regularly break the law nominally protecting people living with AIDS here. They routinely fire workers found to be HIV+ and require an HIV test before hiring new employees. Most of the HIV+ men and women I have met here are poor and unemployed, which they

attribute in significant part to workplace and employer discrimination. This forces some into less regulated commercial sex work.

Even more seriously, Alejandra stressed that she personally knew 15 to 20 of the others, many highly sensitized and longtime members of the group, who already showed signs of AIDS defining illnesses, such as wasting and weight-loss, and some had been hospitalized for opportunistic infections. Urgently needing but without access to ARV treatment, many of them might not live more than six months to a year without these medicines.

Nationally, there are an estimated 88,000 people living with HIV/AIDS in the Dominican Republic, according to the 2004 UNAIDS report. At least ten thousand people living with AIDS currently need antiretroviral treatment. Yet barely 600 (6%) receive medicines in publicly funded treatment centers. Of the 9,400+ others who need treatment now, and 80,000+ others who may need it in the future, most have incomplete or no access to antiretroviral treatment, medicines for opportunistic infections, or lab tests physicians use to place patients on ARVs at the appropriate time and monitor progress.

Many blame the lack of significant political will and the previous administration's notorious ineffectiveness for the current situation. Expectations for scaling up treatment access here have been lowered repeatedly, from the goal of 2000 people on ARVs by the end of 2003 to 1500 in 2004 and now to 1000. There are some doubts if there will even be 1000 people enrolled in the National Program by the end of 2004. These expectations run counter to the WHO's well publicized "3 x 5" plan designed to dramatically increase numbers of PLWA who have ARV access by 2005.

However, there are also numerous other institutions with tremendous resources, capacity, and influence--all of which must do much more, as they have committed to working for scaling up treatment here. For example, the Clinton Foundation secured and provides the cheapest available medicines from generic manufacturers, which are now distributed in at least 12 sites throughout the country. Columbia University has provided technical assistance in areas like establishing national guidelines, training health workers, and looking at adverse effects for patients on ARVs. In press releases, websites, and bulletins both Columbia and the Clinton Foundation regularly promote their respective institution's programs and commitments. Unfortunately neither publicly disseminates candid, accurate and up to date information about the real needs and lack of progress to date as widely in similar media channels.

USAID, which is one of the main donors for HIV/AIDS programs here, sponsors a diverse range of projects--upgrading clinics, training youths and counselors for prevention and education campaigns, and collaborating with religious groups, among other efforts while providing \$35 million dollars for HIV/AIDS over 5 years. USAID also finances an NGO called Conecta, which coordinates and provides technical and financial support to NGOs and government health programs.

Conecta has assumed temporary financial responsibility for certain lab procedures like CD4+ and viral load tests for a limited number of people living with AIDS registered in the National Program. However, the agency pays well above the market rates, approaching nearly \$100 per CD4+ test and even more for the viral load. In contrast, CD4 tests cost from \$5 to \$30 in most countries in the region. With excuses of "limited funds," and need for greater control, the tedious bureaucracy associated with obtaining these tests has also created severe bottlenecks and waiting lists that reduce timely access to the tests throughout the country.

Often unable to pay out of pocket for the same test, which would ensure them speedier results, many people living with AIDS find themselves returning numerous times to centers in order to be placed on a waiting list and again to find out when they will be allowed to can take the CD4+ test and then to again to obtain the results.

Many lose patience as result, some never return, while others switch sites and enroll elsewhere to take the test again. Worse still, many people living with AIDS are hospitalized and near death (if even then) before they can be authorized to take this test and obtain results indicating they must start ARV treatment. Guidelines provided by the World Health Organization for "resource poor countries" suggest beginning ARV treatment in symptomatic HIV+ individuals, without waiting for CD4 test results. Still, government programs, international donors, lab facilities, and companies supplying reagents and equipment for such tests must reinforce their commitments to people living with AIDS and assure that these tests are widely available to those who need them, not simply a luxury purchased by those who can afford it.

The pharmaceutical companies also exercise great influence. Indian companies like CIPLA, entered into special agreements with the Clinton Foundation providing their cheapest prices for their generic medicines, which most of 600 people enrolled in the national program currently receive. This same price should also be unequivocally offered to the National AIDS Commission (COPRESIDA) for ARV purchases with money from the Global Fund. Also, serious concerns about bio-equivalence and recent WHO disqualifications of certain CIPLA and other generics need to be addressed in order to prevent confusion and assure patients and physicians (who often have little choice in the matter) of the safety and quality of generic antiretroviral medicines in the future. The Brazilian Government has also offered to donate stocks its own generic medicines and provide complete ARV therapy here for 100 pregnant women who are HIV+.

Certain manufacturers of patented medicines, like Merck, have committed to reduce the price for ARV medicines, like its Stocrin (Efavirenz) a drug commonly used in first line ARV cocktails, and are providing the lowest available prices they offer globally both to the Clinton Foundation and nationally here in the Dominican Republic. Still, doctors report that efavirenz is part of one of the preferred first line treatment combinations but that it hasn't always been widely available

Other companies (including Pfizer, Abbott, and Roche) either refuse to include the Dominican Republic in special access programs or continue charging prices which make their essential medicines and lab products all but out of reach for inclusion in public health budgets even for the relatively limited numbers of patients who might need such treatments.

For example, a group of nuns that manage the Casa Rosada, a well known orphanage has provided ARV medicines and cares for children living with AIDS in Santo Domingo, offered documentation to Agua Buena that prices in Dominican Pesos of Abbott's Kaletra, even with a special discount offered by a local distributor, have doubled over the past year. The government coordinating unit (UCAM) has incorporated 11 new children at the Casa Rosada into the national program and provided them with generic ARVs medicines, but has stated that it cannot assume the cost of the remaining 22 children who started with different therapeutic regimes, primarily due to the high costs of brand-name drugs, including Kaletra.

The nuns at the Casa Rosada, a religious charity, says that private donations have decreased recently, and the entire program is in jeopardy as they can barely afford the escalating cost of ARV therapy for the 22 children initially covered, which has risen to over \$60,000 dollars per year just for the medicines for these children alone. Despite the national economic crisis and treatment needs like those at the Casa Rosada and elsewhere, Abbott refuses to include the Dominican Republic in its Access to HIV Care Program, which would free up new resources for scaling up treatment access by providing lower prices for Kaletra and other ARV medicines.

Another highly profitable pharmaceutical company, Gilead, has performed clinical trials that have helped in evaluating and approving its popular new drug Viread here in Santo Domingo for the past four years. Still, despite promoting its commitment to company's philanthropic global access programs, Gilead won't include the Dominican Republic in the list of countries eligible for its access program for Viread (tenofovir), and reportedly doesn't even market this drug in the country.

Additionally agencies like UNAIDS, UNICEF, UNFPA, UNDP, GTZ, PAHO/WHO, the Spanish Cooperation, resources from the Catholic Church and private sector, a \$25 million dollar loan from the World Bank for HIV/AIDS several years ago, and the Dominican government's own public health sector budget have established several important programs, but disastrously, these agencies have been unable to coordinate better access to treatment. UNAIDS and PAHO have special mandates to support the WHO 3 x 5 program, but their impact in the Dominican Republic has been negligible.

The Global Fund proposal, which would provide over \$40 million during a five year period, was approved here in January 2003, with the objective of quickly increasing resources available for the purchase of ARV treatment. Yet in September 2004, over 20 months later, none of this money has been received for treatment and no ARVs have been purchased. Bureaucratic procedures and internal conflicts between the Global Fund, different agencies and COPRESIDA, the Principal Recipient, have resulted in delays and the deaths of thousands.

The combined result of all of these agencies and resources is dismal and insufficient--a national program that has not been able to provide more than 600 people with ARV treatment to date. Extraordinary measures must be taken in order for these institutions to move forward with the appropriate dynamism and ambition needed to empower local actors and overcome current crisis. For the sake of thousands more people living with AIDS here and their families and children--medicines, lab tests, counseling, and appropriate social services must be made swiftly available. A month or year or two from now will be too late.

(*Names changed to respect the confidentiality of individuals in provincial cities mentioned above)

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HIV Counselling Series No. 5



**Counselling Guidelines
on Survival Skills for
People Living with HIV**



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Counselling Guidelines on Survival Skills for People Living with HIV

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Foreword

This is the fifth publication in a series of guidelines for counselling people who are infected with HIV, who are concerned about being infected with HIV, or who are living with or caring for people with AIDS. Each booklet offers practical guidance on specific counselling issues. The publications are designed for use by volunteer counsellors, non-professional counsellors, and professional counsellors who do not have extensive experience of counselling in the context of HIV.

The guidelines are the result of workshops organised under the SAT Programme's "School Without Walls" bringing together professional counsellors, people living with HIV, staff of AIDS Service Organisations, and people working in the field addressed by the publication. Production of this booklet on survival skills for people living with HIV was facilitated by The Centre, a self-help group of people living with HIV in Harare, Zimbabwe. Editorial and design assistance was provided by the Southern Africa AIDS Information Dissemination Service (SAfAIDS), a regional organisation based in Harare specialising in AIDS information management and dissemination. The booklet reflects the unique experience of the group of counsellors and activists that met in the workshop facilitated by The Centre.

To date, the SAT Programme has published counselling guidelines in English and Portuguese on the following subjects:

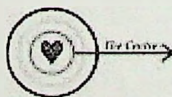
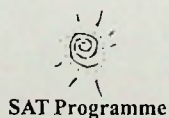
Number 1: Disclosure of HIV Status

Number 2: Child Sexual Abuse

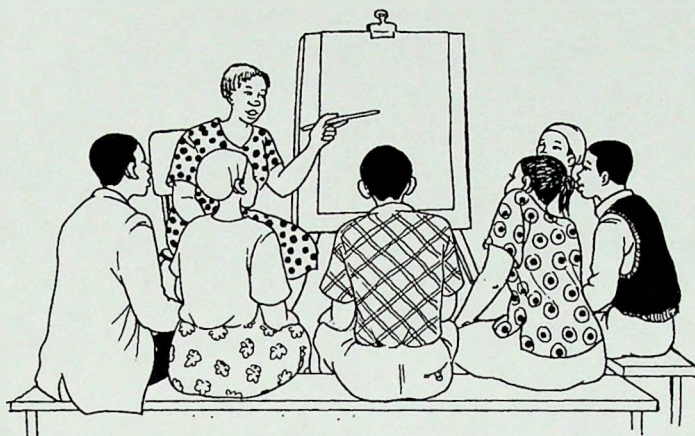
Number 3: Palliative Care and Bereavement

Number 4: Domestic Violence

The SAT Programme is a project of the Canadian International Development Agency delivered by the Canadian Public Health Association. It has been at the forefront in supporting the community response to AIDS in Southern Africa since 1991. "The School Without Walls" is an initiative of the SAT Programme to validate, promote, and diffuse the unique Southern African experience and expertise in responding to HIV. The SAT Programme is profoundly grateful to the volunteers and professionals who have made this publication possible and who are supporting SAT in the preparation of further publications.



SAFAIDS



Counselling guidelines on survival skills for people living with HIV

Creating these guidelines

These guidelines are based on the experiences and advice of people from across Southern Africa who have extensive experience in counselling people living with HIV or AIDS. The guidelines were produced by the SAT Programme in collaboration with The Centre and with editorial support from the Southern Africa AIDS Information Dissemination Service (SAfAIDS). The Canadian International Development Agency funded the publication. Cartoons were drawn by Joel Chikware.

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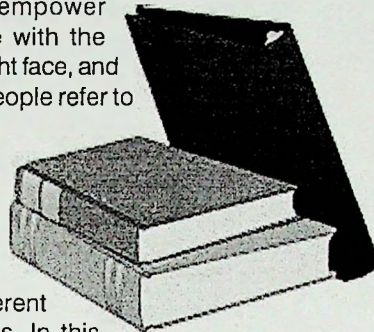
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Definition of terms

Survival skills are skills that empower persons living with HIV to cope with the difficulties and challenges they might face, and to live a long, fulfilling life. Some people refer to such skills as *positive living skills*.

Client is used to refer to the person who is being counselled.

PLWHA is an abbreviation for "person living with HIV or AIDS". The abbreviation is used with different meanings in different publications. In this booklet, it refers to a client who is HIV positive.



Support groups are groups of people who are facing similar challenges and who decided to meet regularly to share experiences and to help each other. Sometimes such groups are referred to as *self-help groups*.

Opportunistic infections are infections that are particularly common or particularly severe in people whose immune system has been weakened by AIDS. The most common opportunistic infection is tuberculosis.

Disclosure means telling others that you are HIV positive. Disclosure can also be involuntary when this information is revealed by someone else without your approval or knowledge.

Anti-retroviral drugs or **ARVs** are a group of medicines that are capable of slowing down the progression of HIV infection to AIDS. These medicines do not cure AIDS, but if taken daily for the rest of your life, they may prevent the progression from HIV infection to AIDS.

Introduction

Talking about survival skills is a vital part of HIV counselling. It helps people understand that their life is not over because a laboratory test has found that they are infected with HIV. They can still live fulfilling lives, and they are still in control of their own quality of life. Survival skills should be discussed in all counselling sessions, including in sessions with clients who are unaware of their HIV status and are considering being tested. Knowing about survival skills helps people accept a positive HIV test result because it reinforces the message that this result does not mean the end of their life. Everybody needs to understand that being HIV positive is not an immediate death sentence. Following the positive living practices described in this booklet helps people living with HIV to stay healthy and to live a longer life.



Preparing for a counselling session

Counsellors need to prepare for counselling sessions. Each counselling session differs depending on the needs of clients and on the issues and concerns they bring to the session. There are, however, several things you can do to prepare yourself:

- ⌘ Find out as much information as possible about HIV, AIDS, and related subjects. This information should be accurate (from a reliable and recognised source) and up-to-date.
- ⌘ Make yourself familiar with the skills needed to prolong life and the behaviours that speed up the progression of AIDS.
- ⌘ Inform yourself about other counsellors, groups, and organisations you can refer your client to for further help and support, especially on issues where you feel that you lack expertise and experience.
- ⌘ If you know other people dealing with similar problems for your client, explore your client's interest in meeting these people to help in the formation of support or self-help groups.
- ⌘ Decide on the length of the counselling session beforehand and advise your client.
- ⌘ Have a positive attitude; your personal gloom will not help anybody.

**HOPE
Is
VITAL**

Pre-test counselling

Begin to discuss survival skills with your clients as early as possible, preferably during pre-test counselling. Most people going for an HIV test are already thinking about how a positive test result may affect their life. Knowing beforehand that there are survival strategies can ease the tension. If the test does turn out to be positive, the knowledge that there is something one can do to stay healthy will help your client cope with receiving the result.

Some issues you should be aware of when you are counselling a person who intends to have an HIV test:

- ✂ Determine the reasons why the client has decided to have an HIV test. Sometimes people are pressured or coerced into having a test by another person such as a doctor, counsellor, or partner. It is important that the client, and nobody else, decides to have a test. Taking an HIV test is a big step and the client needs to be aware of the advantages and disadvantages. The test should not be done without the client's full and genuine consent.
- ✂ Give the client accurate and up-to-date information about HIV and AIDS, and correct any misconceptions the client might have. Give your client time to express any worries or fears, and address them before the test is taken.
- ✂ Stress the confidentiality of counselling and testing. It is important that the client understands that both the discussion and the results of the test will be confidential, and that nobody else will be told about them without the client's permission.
- ✂ If your client thinks that he or she might be HIV positive, you should explore the reasons. Help your client assess the risks and the effects of HIV in preparation for the results.
- ✂ Whenever possible, help your client identify a support person – a relative or a friend – to provide company when going for the test results and for post-test counselling.
- ✂ Tell your client about support groups and explore the possibility that he or she may join such a group if the HIV test is positive. This

is particularly important if you sense during the interview that the client does not have a strong social support network.

- ✘ If the client has a stable sexual partner, you should explain the advantages of getting tested and getting results with the partner. Explore the difficulties and possible consequences of disclosing the test result to the partner. Try to encourage the client to bring his or her partner to a pre-test counselling session.
- ✘ Prepare your client for both a positive and a negative HIV test result. In preparation for a negative result explore with your client how to reduce his or her personal risk for HIV infection. In preparation for a positive result introduce the subjects of survival skills and positive living that will be covered in much greater detail during post-test counselling.

Testimony 1: pre-test counselling

Very few people come for pre-testing of their own free will. Doctors or relatives usually send them. Others get tested to join a pension or health care insurance plan, or a training programme such as entry to the police force. At their first visit, clients are usually very anxious. As counsellors, we give them as much information as possible. We discuss what HIV is, what it does, how it can be controlled and how one can manage it. We stress the importance of having a positive mind. After talking to us people usually want to go ahead with the test.

"We stress the importance of having a positive mind."

Post-test counselling

Survival skills are a very important subject of post-test counselling. When people find out that they are HIV positive they often feel as if their world has fallen apart and that there is no point in living any longer. Post-test counselling should help people develop coping mechanisms for dealing with their HIV status, and to realise that life is not over just because of the result of a laboratory test.

Some issues you should be aware of when you are counselling persons who have returned for their HIV test result:

- ✘ Assure yourself that the client is ready to receive the result. You can assume that most people who have returned to the testing centre want to know their test result, but you should still ask. If you sense some hesitation, talk about the reasons. Your client may not be here out of his or her own free will. Discuss the advantages and disadvantages of knowing one's HIV status. Do not give the results until you are sure your client is ready to receive them.
- ✘ Assure your client again that the result of the HIV test and the discussions of the counselling session are confidential and will not be disclosed to anyone without his or her explicit permission.
- ✘ If and when the client is ready, give the test result.

If you have just given a positive HIV test result to a client:

- ✘ Observe and assess your client's emotional state. People react in different ways to a positive result. Some people show little emotion, others react with emotional outbursts. The counsellor's role is to assist clients to deal with their emotions as they are expressed.
- ✘ Address your client's needs and concerns. This discussion must be driven by the client and not by the counsellor. This means that you should respond to the issues and topics brought up by your client, but not tell your client how he or she is feeling or what emotions he or she might be going through.
- ✘ Find out if the client has had a pre-test counselling session and what was discussed. Sometimes people are tested for HIV without

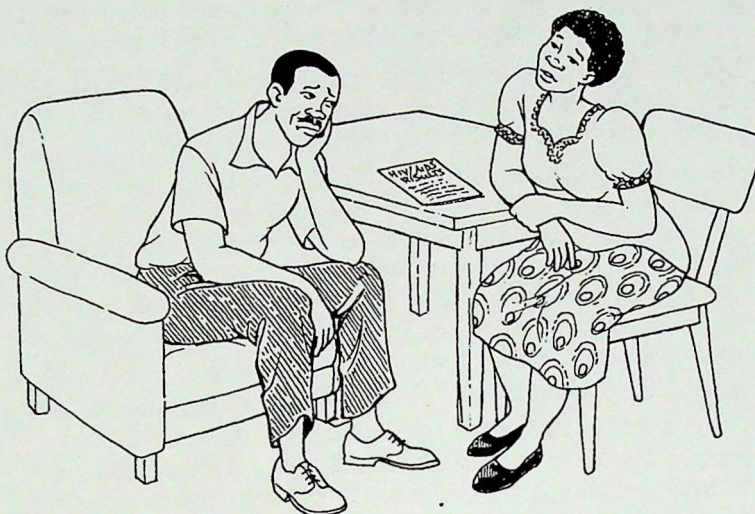
pre-test counselling. In this case, you should try and cover the most important pre-test issues in your post-test counselling session.

- ✘ Discuss survival skills and strategies for positive living. These include risk reduction, nutrition, and stress management. They are explored in greater detail in this booklet.
- ✘ Disclosure of HIV status is a very important issue at the time of post-test counselling. Explore to what extent this has been discussed during pre-test counselling. Has the client thought about whom to tell about the result? Who are the people that the client can rely on for support? Do not rush your client into making decisions about disclosure. This is a big step that has to be considered carefully.
- ✘ Remember that your main task when counselling a person who has just received a positive HIV test result is to provide emotional support and information. If you do not have the information, refer your client to another counsellor or to another source of information or support.
- ✘ After receiving a positive HIV test result, many people find it hard to concentrate on specific issues. Your client's mind is racing – many points covered in the counselling session will be quickly forgotten. Encourage your client to return for further sessions of supportive counselling where issues can be dealt with as they become important and relevant. Make a follow-up appointment.

Testimony 2: reactions to the results

People react differently when we give them their HIV test results. Women usually cry – sometimes for more than half an hour. Some people get very angry. Women get very angry with their husbands. Men are often defensive. They ask, “where did I get it from?” Some people insist on another test. Others just feel helpless. As counsellors, we wait and observe our clients' reactions until they are ready to talk.

**“Some people
get very angry.”**



Stress management

Dealing with stress is an important survival skill.

A person who is stressed may show the following signs and symptoms:

- ✂ social withdrawal, loss of interest in surroundings;
- ✂ moodiness, irritability, or intolerance;
- ✂ difficulty falling asleep, or early morning waking;
- ✂ constant fatigue, difficulty in getting out of bed;
- ✂ upset stomach, loss of appetite, over-eating;
- ✂ headaches or pain in the neck and shoulders;
- ✂ loss of sexual desires or urges;
- ✂ loss of ability to concentrate;
- ✂ loss of interest in activities, apathy;
- ✂ poor performance at work or in school;
- ✂ pacing or restlessness;
- ✂ increased use of alcohol, tobacco, or other drugs.

Possible causes of stress that are related to HIV infection may be:

- ✘ receiving the result of a positive HIV test;
- ✘ involuntary disclosure of a positive HIV test;
- ✘ break-up of family or of a relationship;
- ✘ death of a spouse or child;
- ✘ financial difficulties;
- ✘ loss of employment;
- ✘ inability to talk about one's problems;
- ✘ isolation due to expected or actual stigma;
- ✘ belief that death is imminent;
- ✘ fear of dying.

As a counsellor, you should help your clients manage their stress:

- ✘ Encourage your clients to talk about the issues troubling them.
- ✘ Discuss potential sources of support. Who can your clients turn to for help? With whom can they share their worries and concerns? Sources of support can be found amongst family, relatives, friends, church groups, support groups, or counselling organisations.
- ✘ Encourage your clients to rest, relax, and get enough sleep. Some people find it relaxing to pray, meditate, or to talk to themselves in private. Physical exercise is very effective for stress management. Encourage your clients to take up yoga, go jogging, join an aerobics class, or go dancing.
- ✘ Encourage your clients to spend time with other people and help them identify people they feel secure with.
- ✘ Try to identify the problem. It is easier to deal with stress once you know what is causing it.
- ✘ Death or sickness in the family is a common cause of stress. Another booklet in this series provides *counselling guidelines for palliative care and bereavement*.

People are affected differently by stress. After a stressful event some people "shut down" and adopt a life style of mere survival without joy or expectations. Others react by becoming over-active and pushing themselves harder. It is important that you help your clients in either extreme to recognise this behaviour as a reaction to stress. Encourage

them to adopt techniques like affirmation (I am..., I can..., I will...) and relaxation (meditation, exercise) to help them return to a pace and a style of life that is comfortable for them.

Remember that some stress can be positive. Knowing that they are HIV positive has motivated many people to plan their lives more carefully and deliberately. They are achieving much more because they have developed a positive attitude to life.

Affirmation

Look in the mirror
and tell yourself:

"I AM strong
I CAN stay healthy
I WILL beat HIV."

Disclosure of HIV status

Another booklet in this series provides *counselling guidelines on disclosure of HIV status*. Whom, when, and how to tell about your HIV status are very important decisions for a person living with HIV. You should be aware of the following disclosure issues when counselling for survival skills:

- ⌘ People who plan to disclose their HIV status need a lot of support and emotional preparation.
- ⌘ The respondents, whom your clients want to disclose their HIV status to, should have correct information about HIV and AIDS, and should have an open and non-stigmatising attitude towards people living with HIV. You may need to help some clients prepare their respondents.
- ⌘ Some clients may ask for your presence when disclosing their HIV status. The presence of a counsellor can support both your client and the confidante. Remember that finding out that a loved one is infected with HIV can be very stressful.
- ⌘ Encourage your clients to be selective about disclosure. There are advantages and disadvantages to disclosure in each situation.
- ⌘ People should never be forced or pressured to disclose their HIV status; they must only do so when they feel ready to deal with the

consequences. The client and not the counsellor has to decide whom to tell and when. This may be difficult for the counsellor who may know the client's family or sexual partner.

- ⌘ Talking to somebody who is HIV positive may be very helpful to a person who is considering disclosure. Some support groups of people living with HIV have trained volunteer counsellors. They have personal experience of sharing information about their HIV status and can give guidance to your client. Joining a support group and talking to other people living with HIV is always a good idea, and it is particularly helpful for reaching a decision on disclosure.

Treatment and medicines

There are at least 15 different types of medicines known as anti-retroviral drugs (ARVs). None of these drugs can cure AIDS or eliminate HIV, but if taken in the right combination, they can slow down the progression from HIV infection to AIDS.

Until recently, the drugs have been very expensive. However, an intensive international lobby has resulted in the reduction of price in some countries, and the movement is gaining ground all over Africa. ARVs are already available in specialised clinics and big hospitals in all major cities, however still at a price that places them out of reach of most of the population.

The currently available ARVs have to be taken for life. An effective treatment requires that at least three different drugs are taken at the same time. The drugs have major, and sometimes life-threatening side-effects. In countries where these drugs have been available for a long time, about one in three persons stops taking them because of side effects or inability to follow the very strict drug regimen.

There are a number of other medicines that are known to be beneficial to people living with HIV through their action of preventing common opportunistic infections. These are generally much more affordable and more widely available than ARVs.

As a counsellor, you should be aware of the types of medical treatment available to people living with HIV in your community, and how to access these treatments. However, it is not wise to discuss medical therapies with your client unless you have expertise in this area.

There are, however, alternate therapies being explored by PLWHA groups all over the world, whether they have access to ARV treatment or not. Many of these therapies have proven beneficial. You should explore among local support groups what types of natural or alternative medicines are available. The main guidelines in recommending alternative therapies are that you should not believe any claims of a "cure" of AIDS; the treatment should not do any harm to the patient; and it should not waste the patient's money without providing any benefit.

Taking vitamin supplements, improved nutrition, prevention and early treatment of minor infections and avoiding stress can help prolong your client's life. Prompt attention to minor aches, pains, skin rashes, or injuries is essential for health and survival.

Here are some alternative therapies that PLWHAs have found useful. Remember that therapies such as aromatherapy, herbal remedies, reflexology, and hypnotherapy require a qualified practitioner:

- ✂ meditation – the process of relaxing daily in a quiet setting to focus deeply on body energy and breathing techniques;
- ✂ relaxation – taking a short break away from work or chores to rest and control your breathing and body's response to increased tension;
- ✂ massage – kneading or rubbing parts of the body to promote circulation, suppleness, pain relief or relaxation;
- ✂ aromatherapy – the application of fragrant essential oils to relieve tension and certain minor ailments;

REMEMBER!

Everyone gets sick at times. Colds, flu, allergies, food poisoning, upset stomach and fatigue are not necessarily HIV related. Anyone can suffer these ailments. But if you are HIV positive, you need to give your body additional help to fight diseases.

- ✂ herbal remedies – the treatment of ailments with plants. There are many effective and widely known herbal remedies for common ailments such as diarrhoea. Some herbal remedies, for instance the African potato, are believed to boost the immune system and help fight off infections;
- ✂ reflexology – a form of therapy where pressure is applied to specific areas on the feet and hands, which stimulate the blood supply and nerves to create a relaxing and healing effect on other body parts;
- ✂ art therapy – drawing, painting or other forms of art as a way of relaxing or expressing emotions;
- ✂ hypnotherapy – inducing a state of deep relaxation and concentration in which deeper parts of the mind are accessible for the treatment of emotional problems.

Remind your client to “listen to your body”. If eating in a certain way or receiving a certain type of treatment makes your client feel better, it will almost certainly be beneficial.



Nutrition

Good nutrition is the only form of therapy that is available to most people. It is generally affordable because unrefined and unprocessed foods tend to be cheaper, though healthier.

Nutrition as a therapy can improve the quality of life for people living with HIV because it can help them feel in charge. It allows them to do something practical to help themselves.

People living with HIV need to protect their immune system because it is weakened by the HIV infection. They can do this by paying attention to two rules:

1. **Do not give your immune system other things to fight. You are most vulnerable to the effects of HIV when your body is trying to fight off other types of infections or when it is weakened by stress or exhaustion.**
2. **Strengthen your immune system by providing your body with the necessary nutrients to remain strong. This means eating a healthy and balanced diet.**

As a counsellor, you should become familiar with the rules for healthy eating in order to advise your clients.

When foods are "refined" it means that all the goodness has been removed. You are paying more for less value. When foods have been "processed" it means things like colourings and preservatives – which can be harmful to your health – have been added.

The Golden Rules of Healthy Eating

Eat **WHOLE** (unrefined) foods.

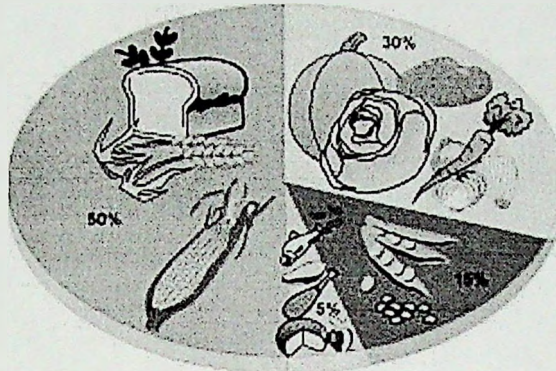
Eat **NATURAL** (unprocessed) foods.

Eat **INDIGENOUS** (not imported) foods and foods that are **IN-SEASON** (fresh foods that have not been stored for a long time).

Drink **CLEAN** water (boiled for ten minutes or filtered).

Eat **LITTLE** and **OFTEN** - 5 times daily (every 3 hours). This applies especially to people with appetite loss or weight loss.

A healthy plate should look like this



Whole Grain (50%) – Grains should be whole, even if ground for thick porridge. For example, sorghum, millet, whole ground maize, whole wheat bread made from whole wheat flour, brown (unpolished) rice, barley, oat porridge, brekweet, or maltabella.

Vegetables (30%) – Combine yellow (pumpkin, butternut, carrots, and sweet potato) with white (onions, leeks, cabbage, cauliflower) and green vegetables (spinach, rape, broccoli, okra, pumpkin leaves). Eat lots of vegetables every day.

Pulses (15%) – Pulses should make up the majority of protein in the diet: lentils, peas, nuts, dry beans, peanut butter, chick peas, beans, and soya (soya mince or TVP). Soya and round nuts are “perfect proteins”. Just like meat all the others must be combined with whole grains to make 100% protein.

Side Dish (5%) – This group should make up no more than 5% of the total amount eaten. It includes:

- ✂ fruits: eat when fresh and when in season. Avocados, tomatoes and peppers are also in this group.
- ✂ meat: little or no meat is recommended. Fish and chicken are best. If meat is desired, eat liver, kidney or heart as they are high in iron.
- ✂ dairy: milk, cheese and milk products should be eaten very sparingly. Don't eat any dairy at all when you have diarrhoea, except yoghurt and lacto, which are good at all times. Eggs are good occasionally.

More samples of healthy foods



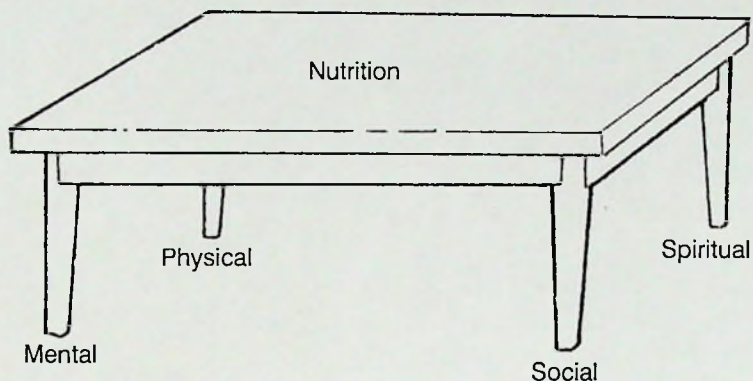
Foods to avoid

- ✂ Sugar and all foods containing sugar: this includes cool drinks, cakes, sweets and cookies.
- ✂ Tinned, processed and refined foods.
- ✂ Strong tea and coffee: rooibos tea, herb tea, fruit tea, bush tea and decaffeinated coffee can be good substitutes.
- ✂ Alcohol and tobacco.
- ✂ Red meat and pork: liver and kidney are best if you crave red meat.
- ✂ Cooking oil: except olive oil or cold pressed oils. Heating oil to cook with it destroys any goodness. Use it for salads only. Fats (dairy products) should be used sparingly and not at all when you have diarrhoea.

REMEMBER!

It is important to keep emphasising the role of nutrition in disease prevention, and the relationship between nutrition and the immune system.

The table of health



Health to achieve long-term survival with HIV can be compared to a table with four legs representing mental, physical, spiritual, and social health. The top of the table is nutrition.

Mental – Encourage your clients to learn to co-exist with the virus. By giving your clients accurate and positive information about HIV and the immune system, you can help them adapt their lifestyle to overcome the immediate threats of HIV infection and to adopt a mental state in which they are not always feeling fragile and in danger.

Spiritual – Encourage your clients to seek spiritual support, whatever their religious and cultural background. Prayer or meditation can induce deep mental and spiritual relaxation and renewal.

Physical – Encourage your clients to learn the practical steps they can take to improve and maintain health e.g. exercising.

Social – Encourage your clients to join a support group and to become active in the community. Social isolation because of fear of being rejected or because of past experiences of rejection is bad for your clients' health and survival.

Paying attention to all of these aspects of health ensures a better and longer life.

Testimony 3: changing my diet

I didn't find it hard to change my diet. I was determined. I was sick and I wanted to get better. If you are not sick, it is harder to change because there is no incentive. My family found it very funny when they saw me boiling sorghum or wheat. They didn't see the sense in not having fried food or meat. But in the end they adopted this diet too because they saw that it saved a lot of money.

Sometimes it is difficult for people to change their diet when they have not disclosed their HIV status to their family, or when they are the only people in the family who want to change – especially if they are not earning the money. If you cannot do everything, the most important thing is to identify the foods that make you sick and to avoid these foods. I know that if I eat sugar, cooking oil, or coffee I get sick, so I NEVER take these foods.

Vitamins and minerals

Vitamins and minerals are natural substances contained in food which are needed by your body in very small quantities for many different functions, including boosting your immune system. They are called micro-nutrients. If you follow the guidelines for a healthy diet, you are eating all the micro-nutrients you need.

Many people living with HIV take additional micro-nutrients in the form of tablets. But remember, vitamin tablets are no replacement for a healthy diet. If your client is poor, do not recommend spending money on vitamin preparations. The priority should be a balanced nutrition for the family. If there is money left over, then your client may consider vitamin supplements.

One combination recommended by PLWHA groups consists of zinc, vitamins A, C, and E and selenium (ZACES). ZACES is an infection-fighting combination of vitamins and minerals. It increases the body's natural resistance and protects against the side effects of medications.

Zinc	1 x 10mg tablet, twice daily
Vitamin A	1 x 25,000 I.U. tablet, once daily
Vitamin C	2 x 500mg tablet twice daily (or 4 x 250mg twice daily)
Selenium	1 x 100mcg tablet daily (or 2 x 50mg twice daily)
Medox 12x12	1 tablet daily
Garlic	Up to 5 cloves a day

**Garlic is nature's
antibiotic!**

Take up to 5 cloves of
garlic per day - to keep
the doctor away! If you
don't like the taste of
fresh garlic swallow a
whole peeled clove
like a tablet.

You can double the number of times you take ZACES if you are taking antibiotics, or suffering from a cold, flu, an infection, or stress.

Reproductive and sexual health

After receiving the result of a positive HIV test, some people feel "off" sex, some feel dirty or "contaminated", and some believe that they can no longer have normal sexual relations. Yet a person living with HIV has the same sexual feelings and needs as anyone else, and there is no reason why these should be denied. Counsellors can help people understand this. At the same time they must make their clients aware of the risks so they can make informed and responsible choices about their sexual and reproductive lives.

You should be able to talk to your clients freely and objectively about sex. This means that you have to build a relationship of trust. Condom use is a key issue to be discussed. You have to impress on your clients that consistent use of a male or female condom in every act of sexual intercourse is important for their own health and the health of their partners. If the partner is not infected, then he or she risks becoming infected with HIV. If the partner is already HIV positive, then both partners risk re-infecting each other, and thereby increasing the number of virus particles in their system. This may result in a faster progression of the HIV infection to AIDS. Therefore, strict condom use or practising non-penetrative sex will protect both partners, whatever their status.

Other important counselling issues related to reproductive and sexual health include:

- ✂ family planning;
- ✂ abstinence;
- ✂ partner notification;
- ✂ sexually transmitted diseases;
- ✂ changes in the menstrual cycle;
- ✂ transmission of HIV from mother to child.

Your role as a counsellor is to:

- ✂ provide accurate and relevant information so that your client can make informed choices;
- ✂ give and explore options;
- ✂ recognise and respect the uniqueness of your client;
- ✂ be aware of your own beliefs and values;
- ✂ know when to refer your client to another counsellor or agency for more appropriate and accurate information.

Your clients may be concerned about whether or not they can have children. You need to advise them on the risks of HIV transmission to the child. Most of the transmission occurs during labour or through breastfeeding. However, most children born to HIV-positive mothers are not infected with HIV, and there are interventions that can reduce the risk of HIV transmission to the infant.

HIV-positive women who wish to conceive should seek out good antenatal and obstetric care. After delivery, they should avoid breastfeeding or practise "safer breastfeeding". The four components of safer breastfeeding are:

- ✂ exclusive breastfeeding for up to six months;
- ✂ condom use during the lactation period;
- ✂ proper positioning and attachment of the baby during every feed; and
- ✂ immediate medical attention for minor infections of the breast or lesions in the baby's mouth.

Remember!

Not all HIV-positive mothers will pass the infection to their babies. On average, one in three babies born to HIV-positive mothers will be infected. This means that most babies born to HIV-positive mothers are not infected with HIV.



Self-awareness

As a counsellor, you should be aware that your own attitudes, beliefs, and life experiences will affect the way you react to the client and may influence the outcome of the counselling session.

Your understanding and interaction with the client may be influenced by your:

- | | |
|------------------------------|------------------------------------|
| ✂ religious beliefs | ✂ fears |
| ✂ social status | ✂ unfinished business |
| ✂ marital status | ✂ prejudices |
| ✂ gender | ✂ race |
| ✂ age or stage in life cycle | ✂ own ability to deal with stress |
| ✂ HIV status | ✂ culture (traditions and values). |

If you feel that your work is being influenced by negative feelings or prejudices towards the client, you must seek counselling to deal with the issues yourself, and refer the client to somebody else for counselling. An important goal in counselling is to make clients aware of their strengths and positive characteristics. If you project a judgmental and disapproving attitude towards the client, you are undermining what you are trying to achieve.

You should also be aware of the language you use when talking to your client. If you use words like "AIDS victim" or "AIDS sufferer" you are undermining your objective to build the client's inner strength and self-confidence. If your body language signals distance and it appears like you are trying to shield yourself from your client, then you may reinforce your client's feelings of shame, guilt, and isolation that you want to overcome through counselling.



Supportive counselling

After the initial post-test counselling, a person living with HIV will often require further supportive counselling sessions. These sessions can cover a wide range of issues depending on the client's needs. Supportive counselling should instil hope in the client and strengthen the client's will to live on.

Supportive counselling may be centre-based – the client coming to see the counsellor when they need advice and support. Or it may be home-based. The advantage of home-based supportive counselling is that clients may be seen in their own environment. It may not be very expensive if it is well planned, because several clients can often be seen in one visit. It is an opportunity to get to know clients better, to know their social and material situation, and to get to know their families and support networks.

Examples of supportive counselling activities include:

- ✂ setting up tasks or goals (remember to check or follow up on goals on next visit or session);
- ✂ providing a "sounding board" (being a listener) for clients to express their concerns or talk about particular issues;
- ✂ working with the family, e.g. to improve the client's social support, or to help create more openness within the family;
- ✂ helping clients to improve their communication skills, especially if they are preparing to disclose their HIV status;

There are limitations to remember:

- ✂ Supportive home-based counselling requires a lot of resources. It is time consuming and it often requires transport.
- ✂ A long-lasting supportive counselling relationship may create material and emotional dependency on the counsellor.
- ✂ Some clients may feel that their privacy is being invaded by the counsellor.
- ✂ As a counsellor, you may become too involved with a small number of clients, which will reduce your overall effectiveness in your job.

Supportive counselling often involves repetition of things that have been discussed before. Clients who are stressed or upset will not absorb information the first time they hear it because of their emotional state. Be patient and be prepared to repeat discussions and to restate important messages several times.

Testimony 4: how counselling helped me

I had my first counselling session five years after I found out I was HIV positive. I was down. I had lost weight. I had lost hair. I had even lost hope. I got my first counselling from my bed.

When I was told that I was HIV positive, the doctor gave me four years to live.

At this time I had a three-year-old son.

It was after four years that my health started to deteriorate. I had been

waiting for this time and expecting that I would die because that is what the doctor had told me.

**"Because she was
also someone with
HIV I knew I
could trust her."**

The counsellor asked me "Are you prepared to leave your son behind?" I knew that I was not. She told me about stress management, visualisation, affirmation, and nutrition. She gave me the support I wanted. Because she was also living with HIV I knew I could trust her.

After two months of seeing her I was up and about again. I changed my way of living and my relatives saw the positive change in me. I disclosed my HIV status to my relatives and they were not shocked. They knew that I could handle it.

Because I now had something to live for, I needed to work. I started knitting and set up my own business. I worked in business until I received money to train to be a counsellor. I now work as a counsellor at The Centre in Harare. My son is 16. I have to see him through High School. I am looking forward to greater things.

Peer counselling

Peer counselling overcomes barriers caused by class, age, gender, sexual orientation, or HIV status. Peer counsellors have similar characteristics and experiences as their clients.

The advantages of peer counselling are that:

- ✂ it is easier for the client to feel at ease with a counsellor and the discussion will therefore be more open and free;
- ✂ most barriers and boundaries between counsellor and client are removed, e.g. language, age, gender, etc.;
- ✂ the sessions are informal and tend to be more spontaneous;
- ✂ the counsellor and the client frequent the same social circles and often live or work in proximity. This makes the counselling sessions more accessible and often more affordable for the client;
- ✂ the peer counsellor may provide a role model for the client that is easy to emulate;
- ✂ counselling may be linked to group support if several peers meet together.

The disadvantages of peer counselling are that:

- ✂ knowledge may be limited within the peer group so there may be misinformation and misconceptions;
- ✂ confidentiality may be compromised by the informal nature of the interactions;
- ✂ dependency on the counsellor may develop because of the easy access and the frequent social contact;
- ✂ there may be tendencies to compete within peer groups;
- ✂ problems of some clients may be trivialised as everybody in the peer group may face similar hardships.

In peer counselling it is important to remember the following:

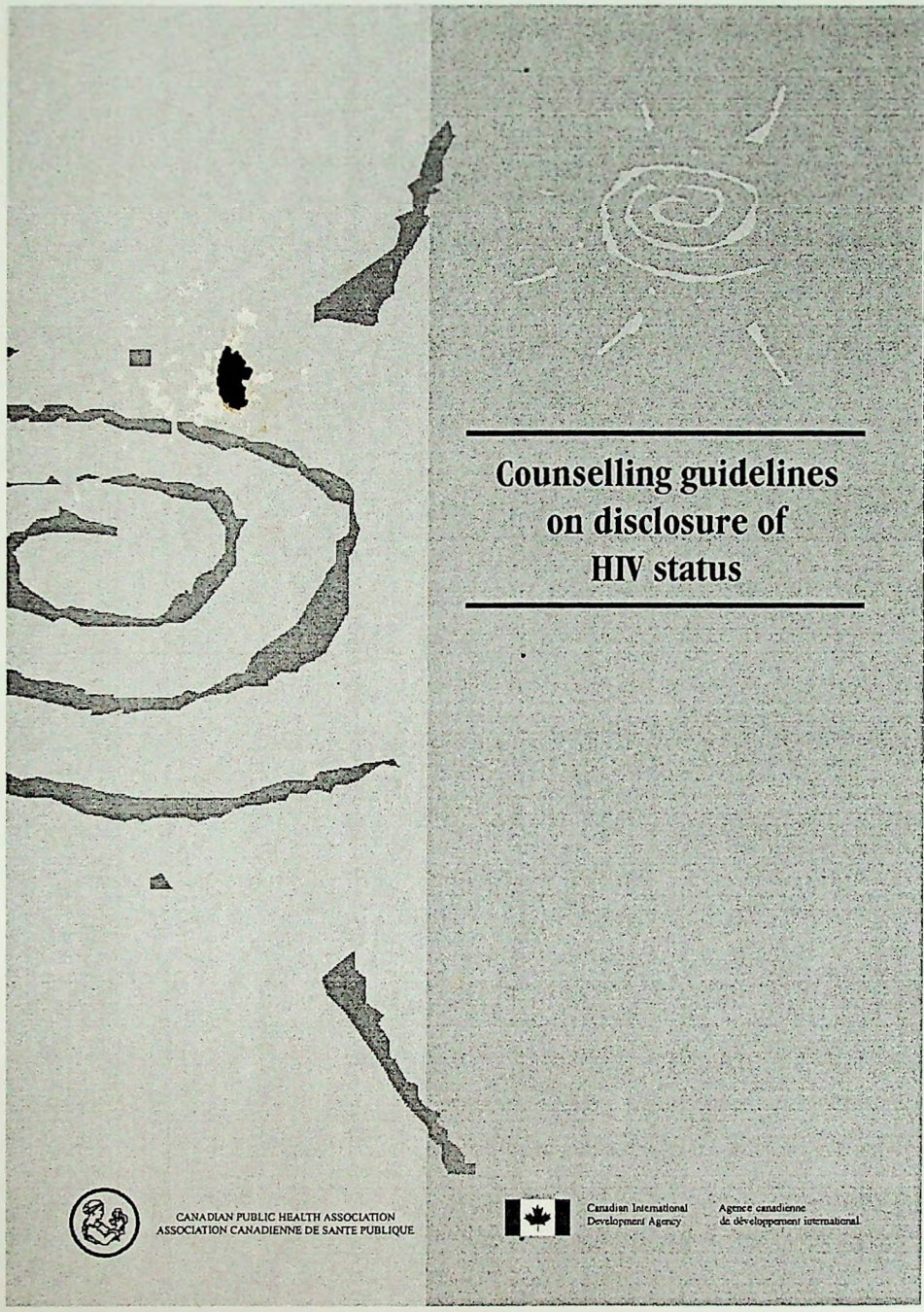
DO:	DO NOT:
<ul style="list-style-type: none">✗ establish ground rules✗ respect individuality✗ acknowledge the limitations of counsellors✗ refer when stuck✗ listen	<ul style="list-style-type: none">✗ judge or penalise✗ take over the burden✗ argue✗ ignore✗ instruct



Supporting the counsellor

Counsellors spend most of their time listening to others and giving other people support, but to do their job well, they too need support. The types of support that counsellors need include:

- ✂ back-up support and personal protection when facing angry clients or potentially violent spouses and relatives;
- ✂ an incentive for motivation, such as acknowledgement for hard and reliable work;
- ✂ psychological and emotional support (debriefing and counselling sessions);
- ✂ retreat (time away) to allow collecting new energy;
- ✂ adequate logistic support, e.g. a counselling room with privacy, transport, communications facilities;
- ✂ professional development and training to keep up to date on issues of importance;
- ✂ networking, exchange visits, and counsellor support groups, to keep in touch with their peers.



**Counselling guidelines
on disclosure of
HIV status**



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Counselling guidelines on disclosure of HIV status

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Foreword

This publication is a first in a series of guidelines on counselling people who are infected with HIV, who are concerned about being infected with HIV, or who are living with or caring for people with AIDS. Each booklet in the series is designed to offer practical guidance on specific counselling issues. The publications are designed for use by volunteer counsellors, non-professional counsellors, and professional counsellors who do not have extensive experience in counselling in the context of HIV.

Each booklet is the result of a workshop organised under the SAT Programme "School Without Walls" initiative that brought together professional counsellors, people living with HIV, and staff of AIDS Service Organisations from Southern Africa. The booklets reflect their unique experience and take account of their specific expertise. Further publications on different counselling issues are in production, eventually making up a complete counselling kit to be used as reference material.

The SAT Programme is a project of the Canadian International Development Agency implemented by the Canadian Public Health Association. It has been on the forefront of supporting the community response to AIDS in Southern Africa since 1991. The School Without Walls is an initiative of the SAT Programme to validate, promote, and diffuse the unique Southern African experience and expertise in responding to HIV. The SAT Programme is profoundly grateful to the volunteers and professionals who have made this publication possible and who are supporting SAT in the preparation of further publications in this series.



Southern African AIDS Training Programme
Programme d'Afrique australe de formation sur le sida

SAAIDS



Counselling guidelines on disclosure of HIV status

Creating these guidelines

These guidelines are based on the experiences and advice of people from across southern Africa who are either living with HIV or who have extensive experience of counselling people living with HIV. The guidelines were produced by the Southern African AIDS Training Programme (SAT) with funding from the Canadian International Development Agency. They were written and designed by Southern Africa AIDS Information Dissemination Service (SAfAIDS), on contract to the SAT Programme. Cartoons were drawn by Joel Chikware.

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Important terms

HIV status: in these guidelines we use the term 'HIV status' to refer to HIV positive status.

Voluntary disclosure refers to when the client shares information about their HIV status with other people. This may be partial or full disclosure (see below). A counsellor should help the client to identify possible impacts on their decision.

Full disclosure is when the client publicly reveals their HIV status to a person or organisation, for example, a family member, friend, support group or to the media. Before a client discloses their HIV status, a counsellor can assist them to explore who to tell, how and when to tell. In this way, the client remains in control of what to say and how to say it.

Partial disclosure means that the client will only tell certain people about their HIV status, for example, a spouse, a relative, a counsellor or a friend. Counsellors need to assist their clients to think carefully and prepare them for the range of possible outcomes before disclosing their status. The client may not be able to control what happens, once they have disclosed. Most cases of involuntary disclosure arise from situations where a client decides to partially disclose their status and without their knowledge the information is made public by an individual or organisation.

Non-disclosure means that the client does not reveal their HIV status to anyone.

Involuntary disclosure happens when someone reveals someone's HIV status without their approval or even without their knowledge.

Shared confidentiality. Disclosure is usually on the understanding that people will not tell others, unless they have been given permission.

"I disclosed my HIV status to prove to my community that there is a need to do something about HIV and AIDS"

Decisions, decisions— who, what, when and how

When someone discovers they are infected with HIV, they face a difficult decision about whether to tell anyone.

If they opt for disclosure, they may need your support. They will need to decide who to tell, how and when to tell them. Disclosure is to be encouraged, but it is important that people take time to think through the issues carefully. Their choices can have major implications.

These guidelines – developed from the direct experience of people living with HIV and AIDS – are to help those who may be called upon to counsel or advise people who are either thinking about disclosure or who are trying to cope with the consequences of involuntary disclosure.

By raising key issues and sharing practical hints, the guidelines are designed to promote informed choices about disclosing HIV status and improved coping strategies following disclosure.

Reasons to consider disclosure

People thinking about revealing their HIV status need to be clear about whether to choose partial or full disclosure. If they are able to disclose their HIV status, it can have the following benefits.



- ✂ Disclosure can help a person accept their status and reduce the stress of coping on their own. "A problem shared can be a problem halved".
- ✂ Disclosure can help a person access the medical services, care and support that they need.
- ✂ Disclosure can help people protect themselves and others. In particular, openness about HIV status may help women negotiate for protected sex.
- ✂ Disclosure means that people may be better equipped to influence others to avoid infection.

- ⌘ As more people disclose their HIV status, it will help to reduce the stigma, discrimination and denial that still surrounds HIV and AIDS.
- ⌘ People may suspect the person's HIV status, particularly if they show symptoms of AIDS. Openness about their HIV status can stop rumours and suspicion. It can also reduce the stress caused by "keeping a secret".
- ⌘ Disclosure promotes responsibility – it can help the person's loved ones plan for the future.

"I would make my disclosure to the closest persons to me, and only when I am prepared"



Testimony 1: fear, love and support

"I tested HIV positive in July 1990. What made me disclose? I believe it was fear. Fear of illness. Fear of the unknown. I felt so alone and needed to talk to someone. I just could not handle it on my own.

Love and support from everyone around me made it easier. Their acceptance gave me strength and courage to keep telling more people. I wouldn't have told so many if the first people had rejected me.

If I had to do it again, I wouldn't do it differently. My friends have always given me support, so I guess I'd still tell them first".

**"What made me disclose?
I believe it was fear.
Fear of illness ... of the
unknown. I felt so alone
and needed to talk to
someone"**

What is counselling?

Counselling is a structured conversation between two or more people that assists one of the participants to work through particular problems he or she faces, for example, disclosure of HIV status. Counsellors encourage people to recognise and develop their own coping capacity, so they can deal more effectively with problems.

The need for effective counselling

Despite their need for support, many people feel unable to tell relatives or friends about their HIV status for fear of stigma and rejection. Even if they do reveal their HIV status they may not receive the emotional support and information they require. They may be overwhelmed by thoughts and fears about the future, the possible consequences to them and others, feelings of guilt, anger, shock and despair. People may need support to tell family members about their HIV status, and the family may need support to cope with their feelings about the information. Although disclosure of HIV status is usually advocated as a way to reduce stigma and to protect uninfected partners, this is a complex situation and there are many factors to consider before disclosure takes place. This is why counselling is essential.

General guidelines on effective counselling

These are some basic, practical guidelines for those without formal counselling training who find themselves in a situation where counselling is required.

- ✘ Listen attentively to the client; give them time to say what they need and be patient. Help them express their feelings and emotions and show warmth and caring for the person.
- ✘ Treat clients and their families with respect and be reliable and consistent. Accept people as they are and avoid moralistic judgements.
- ✘ Try to avoid giving advice; rather let clients work through issues and make their own decisions with your help.
- ✘ Help the person focus on issues where they can achieve some positive change, rather than being overwhelmed by the problems of HIV and AIDS. Help them identify others they can rely on and receive help from.
- ✘ Do not pretend to have skills, knowledge or resources you do not have – know when (and where) to refer clients for more specialised help.

Testimony 2: disclosure & a new lease of life

"I was tested unknowingly in 1988 and the result was disclosed in the ward where everybody heard. I was shocked and felt humiliated. When I got home, I only told my husband. I hoped he would support me but he accused me and after a short while he abandoned me.

I suffered alone for the next five years without telling anybody. I wasted away because there was nobody to advise me on what to do. I did not tell my parents and sisters about my HIV status because they were very negative on the issue of HIV.

"The miraculous change came when I got my first counselling ... It was like I started living again. I stopped mourning"

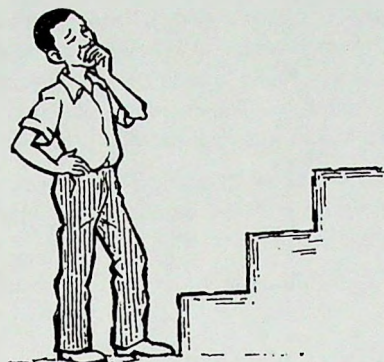
The miraculous change came in 1993 when I got my first counselling at The Centre in Harare. It was like I started living again. I stopped mourning for myself and started getting confident. I now knew the right foods to eat and how to avoid stress. I became a happy person and started gaining back my weight.

This big change was noticed by many people. I started talking much more about HIV issues, but not referring to myself. When I saw that they were now understanding I revealed my status to them. They were not shocked.

I was introduced to other people living with HIV and AIDS and started feeling comfortable talking about the illness. I started participating in a radio programme. At home my sisters made sure that whenever I went for the programme they would change the radio station so that my son would not hear my voice.

Unfortunately, one day he heard me and identified my voice. I had to give him a lot of counselling because he was so depressed. I am happy to know from his response that he would never shun me and up to now he is very supportive.

As for myself I talk freely about it at work, at home, or at conferences and workshops".



Steps towards disclosure

Disclosure is a process and not an event. It is a major decision that can have consequences for the person living with HIV and those around him or her. It is important that people do not rush into disclosure, but think it through carefully and plan ahead. Planning allows for possible prediction and control of the process of disclosure.

The ideas and advice below can be shared with a client.

- ✂ Help the client to take time to think things through. Make sure it is what they want to do and assist them to plan how they are going to go about it.
- ✂ Identify sources of support, such as groups for people living with HIV and AIDS, church members and counselling organisations.
- ✂ Role plays and "empty chair" enactment techniques could be used to help the client prepare for disclosure.
- ✂ Provide support and reassurance to the client and help them to accept themselves positively.
- ✂ Discuss about sexual partners who need protection from infection.
- ✂ Prepare the client for a shocked and even hostile reaction. This often happens, but you can reassure the client that with time people close to them should learn to accept their HIV status.
- ✂ Help the client to realise that once a decision to disclose has been reached, it may be easier to start with those nearest to them: relatives, family, friends, or someone they are very close to and trust.

- ✘ When a client has decided to disclose their HIV status to someone, assist them to think about the likely response. They will need to assess how much the person they plan to disclose to knows and understands about HIV and AIDS. This will help the client decide what they need to tell the person and how to tell them so it is less traumatic for both of them.
- ✘ It is important for a client to be strong enough to allow others to express their feelings and concerns after their disclosure. A counsellor can assist the client to work on these issues over time.
- ✘ Provide the client with information and support to "live positively".

"You have to decide for yourself if it is the right thing to disclose your status. It is helpful when you can be open, but you shouldn't judge others who may not be ready to divulge their status"

Testimony 3: life needs courage

"I decided to come out publicly because a lot of Swazis are dying and they think HIV is a problem in other countries but not ours.

I have had problems with my wife's family. They accuse me of being unfeeling and insensitive – to them it was humiliating that everyone knows my status. But my wife stood by me and we are still together.

"In the long run I have always felt good about the choice I made by disclosing my status"

In the long run I have always felt good about the choice I made by disclosing my status. It feels good not to have kept it to myself. Just talking about my situation has helped a lot of HIV positive people and their relatives. My advice is to remember that life needs courage"

Counselling process of disclosure

- ⌘ Allow the person to develop trust in you and feel at ease.
- ⌘ Get to know them, in particular about what HIV and AIDS means to them.
- ⌘ Assess the person's ability to cope and establish their sources of support.
- ⌘ Discuss the implications of disclosure fully, to help the person consider in advance the reactions of family, friends, work colleagues and others.
- ⌘ Help the person develop a plan on disclosure. This should cover any preparations they need to make before disclosure, who they will inform first, how and where they will disclose and the level of disclosure.
- ⌘ The counsellor needs to work with the client on the implications of disclosing to inappropriate persons or groups.
- ⌘ Arrange to see the person again – at a date and time agreed by both of you – to review this process.
- ⌘ Counsellors have to protect their clients against undue pressure to disclose.



Possible consequences of disclosure

The stigma attached to HIV and AIDS means that disclosure can sometimes lead to negative consequences, especially in the short term. Possible consequences include:

- ⌘ Problems in relationships, whether with sexual partners, family and friends, community members, employer or work colleagues.
- ⌘ The experience of rejection. People who have disclosed their HIV status may feel that people are constantly judging them. They need to be prepared for this and be ready to make full use of the support that is available.
- ⌘ Disclosure can result in pressure being placed on people living with HIV or AIDS to assist in AIDS work and become role models.



Possible consequences of non-disclosure

Sometimes it seems that there is too much to lose by disclosing HIV status. But non-disclosure can also have major consequences. It is useful to discuss with the client the following potential consequences of non-disclosure.

- ⌘ *Lack of support* – family and friends may not give the support the client needs and they will have to deal with everything on their own.
- ⌘ *Risk* – placing others at risk of infection, particularly sexual partners and increasing the risk of re-infection for the client.
- ⌘ *Lack of care* – the client may be unable to access appropriate medical care, counselling or support groups if they are not open about their status.
- ⌘ *Suspicion* – people may become suspicious of the client's actions because they do not understand their HIV status.

Coping mechanisms

Whether they opt for disclosure or non-disclosure, or experience involuntary disclosure, it is important for clients to try to adopt positive ways of coping with stress and anger. There are many options, for example, song, prayer, long walks, spending time with family and friends, or joining a support group. A counsellor can help the client to explore what works best for them.

Disclosure of HIV status for gay people

Disclosure can be particularly difficult for gay people. Gay people may find it hard to discuss their sexuality with a support group of non-gays. In such settings they may have to counter discrimination and stigma attached to their sexuality.

Gay people should be advised to seek help and counselling from the gay community and to join support groups that are sensitive to their needs and to protect uninfected partners. This is a complex situation and there are many factors to consider before disclosure takes place. This is why counselling is needed.

Testimony 4: 'coming out twice'

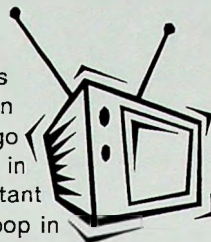
"Being gay and HIV positive in Zimbabwe has devastating stigmas attached. Disclosure of sexual orientation and HIV status for homosexual people often leads to discrimination at the work place, in the community and within the family.

This makes it very difficult for gay people to find help and often leads to them living isolated lives and suffering the complications of HIV and AIDS alone.

"Being gay and HIV positive has devastating stigmas attached"

It is difficult and often impossible for a gay person to join a support group and disclose his or her sexual preference, because of homophobia and negative attitudes. That is why it was necessary for us to start the Gays and Lesbians Association of Zimbabwe (GALZ) HIV & AIDS Support Group in 1998"

The media and disclosure



People living with HIV and AIDS have the same rights as anyone else to privacy, confidentiality and respect in their dealings with the media. They may choose to go public about their status. However, they are not always in control of the situation. Since most people are still reluctant to reveal their HIV status, a disclosure story is a scoop in many countries and communities. The journalist may decide what questions to ask and what to emphasise, and they do not always feel obliged to check back for accuracy. This can lead to misrepresentation of facts.

If you are called upon to counsel or advise someone who is thinking about disclosure in the media, what guidelines should you follow? These are some practical guidelines that a counsellor can offer to people thinking of talking to the media:

- ✘ Assist the client to establish their motive for disclosing to the media. Advise them never to be pressurised to give an interview when they are not ready.
- ✘ Assist the client to carefully select the journalist that they want to work with and help them prepare for the interview. They should have clear objectives for the meeting. It may help for them to write down everything they want to say in advance. This helps them to control the focus of the story.
- ✘ The client should ask for the meeting to be recorded and insist on reading the story before it is printed. Sometimes this is not possible, but the client can request a discussion to clarify issues before the story is printed or broadcast.
- ✘ Inform the client that if they do not like the way an interview develops, then they are at liberty to terminate it and explain why they have done so.
- ✘ Advise the client to think carefully about having their picture taken. If in doubt, they are entitled to decline to be photographed.

Safeguards when disclosing HIV or AIDS to the media

People living with HIV/AIDS strongly feel that safeguards are needed to protect them from exploitation from the media—newspapers, magazines, the radio or TV. Many journalists still fail to see anything positive to report

about HIV/AIDS – to them it is still a "gloom and doom" story and the issue of morality often is pushed to the forefront.

Counsellors can help clients thinking of disclosing their HIV status to the media to consider the following issues:

- ⌘ The client needs to be sure that they are prepared for the general public to know about their HIV status.
- ⌘ The client needs to try and ensure that what they have disclosed to the media is going to be reported correctly.
- ⌘ If the client seeks partial disclosure, it is advisable for them to use a non-disclosure form, such as the one provided in these guidelines. This sort of agreement can be binding in a court of law.
- ⌘ Counsellors and their clients can help improve reporting on HIV/AIDS by cultivating a good relationship with the media. Establishing such a relationship can help the media to be more sensitive and avoid use of words and phrases that are negative.

"I am now full-time public about my status and I will continue until behavioural change is established among people, especially youths in Zambia"

The media and payment for stories

Some people living with HIV or AIDS feel that since the media is making money out of their stories, they should be paid for giving interviews. However, this can create ethical problems for journalists. It is important to realise that when a person living with HIV/AIDS and a journalist agree to do a story, each is trying to achieve something different although sometimes their objectives can merge.



Payment can complicate the motive for telling the story and can lead to allegations of selfishness and money-making on the part of the person living with HIV or AIDS. Establish if payment is involved at the outset.

"My view is that going public is an important way to reduce stigma. The more we reveal our HIV status, the more difficult it is for society to stick to its attitudes towards people living with HIV or AIDS "

Non-disclosure form

The form overleaf can be used as a safeguard against exploitation from the media and media personnel. Please photocopy the form if you wish to use it.

Non-disclosure form

I, _____

do hereby state that I:

- ☒ Am a Person Living with HIV or AIDS (delete as appropriate).
- ☒ Have agreed to speak to or be interviewed by _____ of _____ with regard to my HIV status.
- ☒ Have been offered remuneration for my story in the sum of _____, **or** that I have not been offered remuneration for my story (delete as appropriate).
- ☒ Participate in the interview on the following grounds:
 - ☒ That I shall not be identified either by name or by any description that is likely to identify me.
 - ☒ That the said _____ or his/her employer _____ or his/her friends, relatives or associates shall not be permitted to sell, cede or in any other manner give or assign the rights to my story to any other person or organisation without my specific written consent.
 - ☒ That any story written about me and concerning my status as a Person Living with HIV or AIDS shall not be published until I have had sight of the draft and agreed to the same.
 - ☒ That any departure or deviation from the above conditions shall entitle me to full redress including but not restricted to damages for loss of privacy and dignity and any consequential damages arising therefrom.

Signed by:

Date:

PERSON LIVING WITH HIV or AIDS

UNDERTAKING BY INTERVIEWER

I do hereby state that I have read and understood the above declaration and hereby state that I agree to the conditions attaching thereto.

Signed by:

Date:

INTERVIEWER