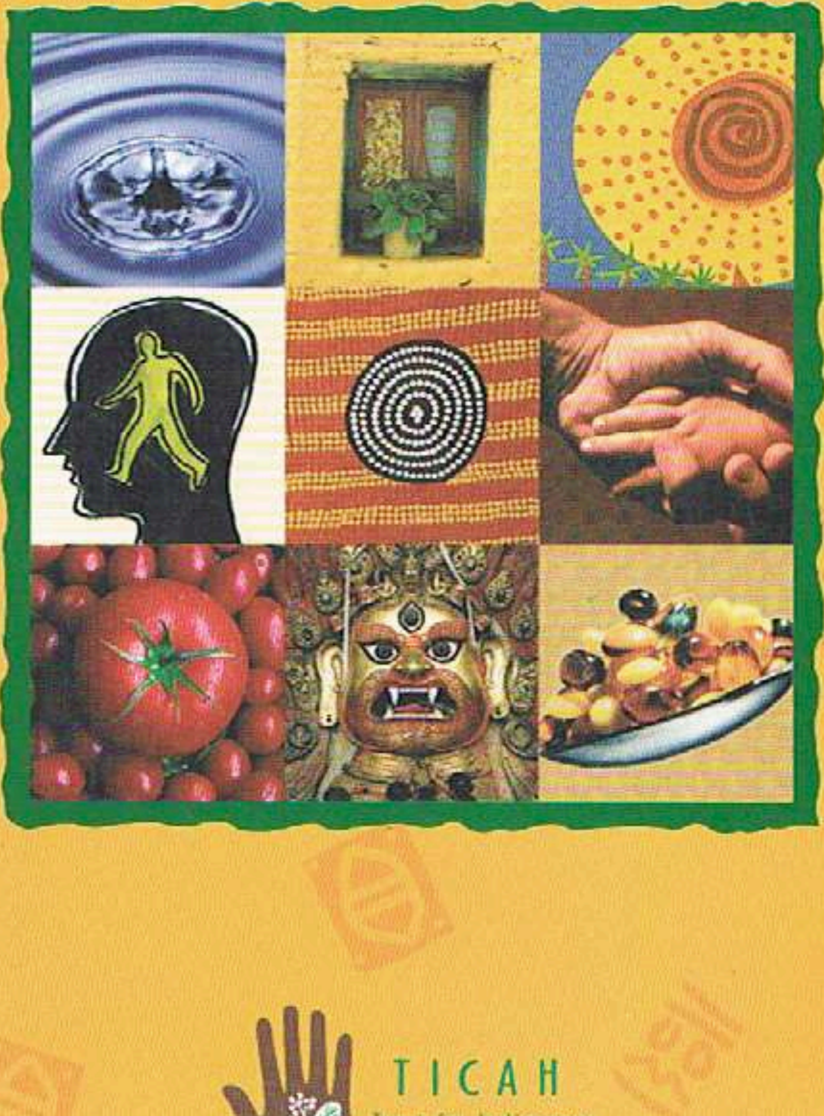
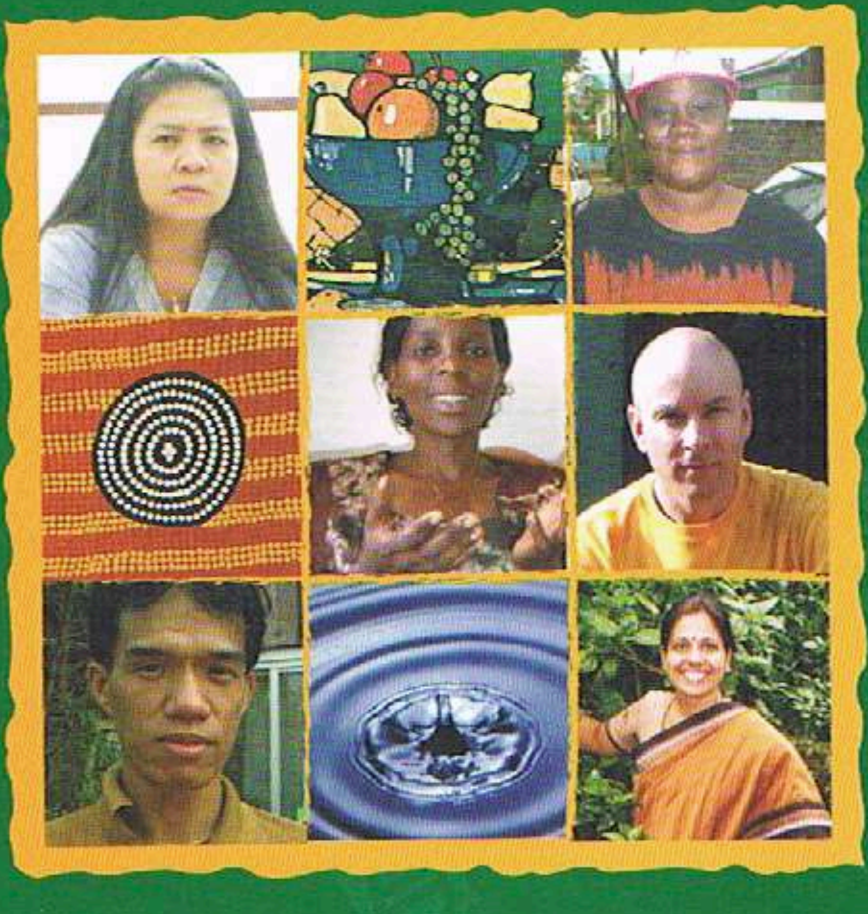
Nine Lives

Treatment Stories of Positive People



TICAH
Trust for Indigenous
Culture and Health

Listening To Those Who Live It



No longer speaking
Listening with the whole body
And with every drop of blood
Overtaken by silence
But this same silence is become speech
With the speed of darkness.

...The universe is made of stories,
Not of atoms.

Muriel Rukeyser, *The Speed of Darkness*

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NINE LIVES

"The universe is made of stories, not of atoms."
Muriel Rukeyser, *The Speed of Darkness*

WHEN WE LISTEN, WE LEARN. WHEN WE SHARE OUR EXPERIENCES, WE BENEFIT.

Nine Lives is a testimony to this, and a taste of more to come. Together, a group of us asked friends and acquaintances to share their stories, to tell us the ways they have cared for themselves since learning they were HIV-positive. We also talked with care providers - doctors, nurses, healers - and asked them to tell their stories to us. We asked everyone what advice they had for others. We asked what they would do differently if they could start all over again. While we all know at heart that only those walking a path can truly know what is on that path, we sometimes do not take the time to stop and listen. To put together *Nine Lives*, that is what we did. We stopped and listened.

We began this project because we thought we could learn from hearing about the choices people have been making and the ways in which they have thought about 'treatment,' about staying healthy or getting healthier. Indeed, we did learn a lot from listening. We learned that taking care of one's health is intimately linked with having reasons to live, and feeling that we are worthy. We learned the power of attitude and acceptance, and, as one person put it, that "hope is the strongest medicine". We learned that the reactions of friends and loved ones to our status shapes almost everything else about the care we give to ourselves, and the care we seek and receive from others. We learned that choices about treatment are directed by a combination of things - culture, ideas about our bodies, knowledge, medicines and services available, family circumstance, friendship networks, sexual life, community support, living conditions, and money.

We learned that people listen to their care providers with a grain of salt. Almost everyone adjusts their prescriptions to their own reactions and realities. Some begin by following the advice of their doctors to the letter; others never could, or choose not to. We learned that food plays a central role in everyone's self-care, and not having the capability to feed oneself properly is a huge problem facing positive people of limited financial circumstance. As Anne Owiti, one of our care providers, said, "Food, food, food. The first and last is food."

We share *Nine Lives*, this first edition of the *Listening To Those Who Live It* series as a way of honoring the experiences of people who are coping with illness, with stigma, fear, and self-doubt. We also witness and honor those positive experiences, the opportunities presented by coming closer to our mortality, realizing that life is precious. As Inviolata told us, "I have come to realize that we are all wonderfully and beautifully made and I do not think there will be any person in this world like me. Other people are that way too. I cling to that feeling and it makes me feel very important. I cherish life."

We dedicate this collection of stories and quotations to everyone who smiled through heartbreak to find the words to share their strategies for coping, who remembered the names of herbs and vitamins, showed us their prescriptions for medicines, taught us about exercise and attitude, even opened the pages of their journals. In the process of doing this work, we experienced firsthand one positive result of sharing our status and our stories. That was the blessing of improved relationships and better communication. We also experienced a closer relationship to Spirit. Many people rediscover their faith through coming to terms with calamity. Others undergo profound changes in their personalities. As Udorn said, "I think I have become a lot calmer. They're almost calling me 'ex-monk' because I have become much more calm and patient now. Before, I used to be hot-headed and impatient. My decisions were always sudden. Now I take time, like I'm another person."

We also heard the litany of negative consequences of infection. Work life suffers. Economic problems tax everyone, often way beyond means. Also, stigma - both our own towards ourselves and that directed at us by others - can create overwhelming obstacles in every direction. When we cannot admit our situation to others without fear of attack and discrimination, when we cannot go to a doctor because we know our conversation will not be confidential, when we feel ashamed at having possibly infected others, our own health suffers. Stigma affects health. Negativity can be as difficult to overcome as a skin fungus.

Of course, there was a lot of talk about medicines, herbal preparations, food, rest, and even breathing. We learned very specific things about which herbs, vitamins, or foods were good for which condition - from yam for throat infection, to aloe vera for rash, turmeric for stomach upset, *kokum* fruit (a reddish fruit found on the coast of western India) for appetite, yoga for nerves, *omena* (little dried fish) for anemia, and *ma grude* (lime) for pox. We heard many experiences in managing the side effects of anti-retrovirals. This wealth of treatment information suggests how much more work needs to be done to study and share our strategies with one another.

From the care providers we interviewed, and whose stories are not yet included among the nine in this collection, we learned the vital importance of a positive attitude. As Vinay and Sanjeevani Kulkarni told us, "One thing is to make the patient believe that he can survive this, which is most important. The belief that I am going to survive, I want to survive, and it's good to survive, this is the most important thing." We learned about treatment strategies. As pharmacist James Njoroge told us, "We look for three things in the herbs we have. One, we look for the herbs which are effective in boosting the immune system, because we realize it's the major area affected when people are infected with HIV. Secondly, we look at how the multiplication of the virus can be stopped through the use of herbs that produce the same results as ARVs. Thirdly, we look at herbs that can treat opportunistic infections." We listened to the stresses care providers experience when helping patients with little money make the right decisions and the hardship of administering some drugs. "The costs of preparing the patient for ARVs costs ten times the price of the drugs," said Surendra Patel, an infectious diseases physician. "As a service provider," said Anchalee Poontajak, "I would like to remind others to consider other aspects of the lives of positive people, because the ARV trend is so strong nowadays. They should not forget our lifestyles. How we take care of ourselves is important. Our behaviors can strengthen our health." And we also learned about the problems which care providers themselves face. "Few remember the stresses experienced by care providers," said Mary Okumu. "We absorb plenty of tensions, and therefore need support groups to help rejuvenate psychologically."

The similarities between people of very different circumstance will stand out as you read these testimonies. Whether we found out we were positive at age 14 or 45; whether we feel guilty about how we were infected or do not dwell on it at all; whether we have money enough to seek 'the best' treatments and foods or have to scrape by on poor diets with limited nutritional value, we have things in common. Regardless of the stage of illness, everyone acknowledges the potential of herbal medicine. Some have apprenticed with traditional healers and have become skilled in using diet, meditation, exercise or traditional medicine to treat opportunistic infections. Some have become counselors for others, sharing knowledge about healthy living.

These stories teach us that the meaning of 'health' or 'healthy living' differs from place to place and person to person. In *Nine Lives*, our effort is to honor and learn from the embodied experience of real people in real places. While the global HIV/AIDS world has, like other international public health efforts, been largely led by the allopathic and biomedical traditions, these stories call on us to also pay attention to other medical approaches. Close-mindedness and charlatanism are two great enemies to all of our efforts to find appropriate treatment and care. What we are aiming for is care of the highest possible standard which is responsive to the circumstances in which we live. In many of our communities, traditional medicine is not merely ancillary to allopathic medicine, but is our only, and sometimes, our preferred approach. In others, the availability of ARVs is cause for tremendous hope and excitement, but also raises concern about it drawing all attention away from prevention, and from our range of successful strategies for staying healthy, and thereby postponing or precluding the need for ARVs.

In these nine stories, we see disparities in our sense of our rights, our empowerment, and our available information, in addition to gaps in the actual range of treatments accessible to us. We find heightened skill in health self-awareness. All of us learn to read the signs of our own bodies because jobs could depend on the ability to stave off a telling skin infection. Our health can be greatly affected by being able to prevent a respiratory problem from becoming pneumonia, and our lives depend on our becoming attuned to the signs our bodies give us.

In our collective explorations, we have found that organizations of positive activists are very different in their definitions of treatment and in their demands. Some believe that anti-retrovirals are the best treatment for AIDS and access to them is our most urgent need. Others treat ARVs as a last resort. Some push for more access to herbal medicines and food; others focus on rights and livelihoods. Some focus on prevention as well as treatment. Some seek access to a range of services and care, combining therapies from the local garden and the local temple with ingredients from the international pharmacy. All believe that treatment must take into account the broader circumstance of our lives.

We hear it said that statistics are the numbers with the tears washed off. These are the stories with the laughter and the tears left in. For those who will take one look at this publication and say, "This is not a random sample," we answer that it was never meant to be. We believe that there is truth in every story here, and truth in all of the others we have collected, which are not yet included. While we do have young and old, discordant and concordant couples, poor and less poor, brown, black, yellow, red, and white, we acknowledge that this collection still does not represent everyone. It may not be statistically significant, but it is clearly real.

We women and men who asked people to talk about their treatment experiences, and their experiences treating and caring for others, are ourselves a wide range of individuals. Some positive, some negative, some not sure - we are a diverse, but not random sample. We talked with people from Asia and Africa because this has been our initial focus and this is where most of us live. We did reach a little bit across the oceans to the Americas, and are anxious to do this more. We wonder what European experience has to teach. We hope that *Nine Lives* is just a beginning of our shared work to listen more carefully to people's experiences related to the epidemic, particularly as it concerns treatment.

We recognize and are grateful for the many, many kindred efforts which have gone before - from the International Community of Women Living with HIV/AIDS' *A Positive Woman's Survival Kit*, to *My Positive Life* by AIDS ACCESS in Thailand, to *Long Life... Positive HIV Stories* by the Bambanani Women's Group in South Africa to *XX/XY: Voices of women and men living with HIV* by Point of View in India - just to name a few. All of our testimonials about living positively move us further on our shared path, and give others insight into our choices and experiences.

When we say we want to listen to these stories, we mean active listening, bringing these voices into discussions about policies, about funding, about priorities, and about protocols. Why should we listen actively? What questions does this approach raise and how does it get us closer to the answers? What is the benefit of discussing questions like the ones we raise here?.

> •Is there a mismatch between AIDS treatment budgets and actual people's preferred treatment regimens? If so, what should we do about it?
> •In what ways are our policies inclusive of a range of treatments?
> •How does good ARV treatment differ according to our size, our illness, our lifestyles, or the other medicines and treatments we are taking?
> •What about care for the vast majority of positive people who do not meet the protocols for ARV therapy? How can we devote conscientious attention to promoting strong immune systems - to staying healthy, rather than only treating illness?

- Is there any correlation between the length of known infection and treatment outcomes for specific therapies? Is there evidence that repeated use of some herbal medicines should be of concern?
- How, in general, is Asia different from Africa in terms of our treatment aspirations and experiences? How can we shape our delivery with this in mind? How can we learn from one another?

These individual stories lead us back to question structural realities which shape the epidemic and our responses to it. Individual vulnerability brings us back to the systems which create it. Listening to people share their decisions and their fears brings us face to face with the lived effects of stigma, of guilt over our sexuality, of silence and ignorance surrounding our bodies, of our yearning to live, our need for love. It shows us that our blood, whether it has signs of HIV antibodies or not, runs through veins shaped at every level by what lies outside our skin. In biomedical and social scientific terms, these stories are 'anecdotes,' perhaps interesting, but of no statistical or replicable significance, and, therefore, holding little relevance to policy. We believe otherwise. If we can trust our shared desire to heal and to care for ourselves and others, if we can welcome all honest efforts to bring our ways of knowing to bear on the great challenges of this epidemic, our work will be better for it. There is no single right answer to any of the questions we pose. There are many answers for many circumstances.

Readers of *Nine Lives* and participants in our panel at the Global Village during the 2004 Bangkok XV International AIDS Conference, can decide for themselves what the value is of listening to these stories and reflecting on them. All of us who labored to listen, to translate, to transcribe, to understand, and to edit these stories have greatly benefited from the experiences shared, the knowledge acquired, and the trust built. And this is just the beginning!

The Trust for Indigenous Culture and Health (TICAH) wants to be of service to this work, and welcome partners from far and wide, whoever you are. We dedicate ourselves to finding ways to reach out even more, to place ownership where it belongs, and to speak truth to power.

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SAITHARN PRAI-NGAM

SAITHARN PRAI-NGAM of Chiang Rai province in northern Thailand is a 38-year-old mother of two daughters. She has been infected since 1994-95. She started using anti-retroviral medicines for a year after she tested positive, but decided to stop, as prolonged consumption of these drugs would not have been good for her health. Since then, Saitharn has relied on alternative therapies. She is currently the chairperson of a self-help group located at a public hospital in the Viang Kaen district of Chiang Rai, and is also a student at the traditional medicine program in Chiang Rai.

Tell me a little bit about yourself?

I am the ninth child of my parents. My folks are poor farmers; their lives were tough. I preferred a more comfortable lifestyle, so I studied hard and dreamt of becoming a teacher. Because we were so many children in the family, my mother could not afford my education. When I graduated from the higher secondary school, I started working. I worked in a department store for four years. When you work in a department store, your life is bound there. You cannot travel and you are not in touch with the outside world. So I decided to find another job, and hoping for a new life, I returned home.

While in Chiang Rai, I met my mate and had a child. Then my marriage fell apart, ending in a separation. After we separated, I came home and became a childcare worker, and later worked as a nurse-aid in a public hospital in Chiang Rai. I went out on a few dates then, and met the father of my youngest child in Viang Kaen Hospital. I chose him because I wanted to start a new family after the failure of my first marriage. We had a daughter, my second child. He was a good father but occasionally he strayed.

How did you know you got infection? And when?

My second husband had several girlfriends. Some worked as commercial sex workers in Bangkok. At that time, HIV/AIDS was not yet well known. After about two years, my husband started to show signs of wasting away. He used to be plump. I did not have a clue about his condition but I asked him to have a medical examination. I told him to beware of HIV/AIDS. He said that he had already had an annual medical check-up and that he was fine. We worked in different hospitals. I had to take care of the children in addition to my routine duties.

It was very stressful. I was worried about contracting HIV. What would the future of my children be? Who would take care of my mother? She was old, and I am the youngest daughter. I was supposed to take care of the house, because my elder brothers and sisters are all married and have their own homes. I went to consult a friend. She warned me not to take a blood test, saying that I would be too worried knowing the result.

I took her advice. I bought nutritional supplements for my husband but that didn't help. Even worse was that he developed diarrhea and other symptoms of being positive. I knew a little bit about HIV/AIDS. Over the next few days, I cried every time I thought about the consequences, and finally decided to take the blood test. Before I took the blood test, my senior peers at hospital nearby taught me about *dhamma*[1] and the meaning of life. They were vegetarians and observed the precepts of Buddhism. They consoled me until I was able to face facts.

I took an anonymous blood test at a peer's home, not at the hospital. She also checked the result of the test for me. I took the test because if I were HIV-positive, I could plan for early care. I asked her about the test results a few days later, but she did not reply. Instead she talked to me about the meaning of life. On the third day, I asked her again and told her that I was prepared for any consequence. She then told me that I was HIV-positive. I was quite plump then, surmising that probably only my husband was infected.

When I found out about my status, I came home to cry, worrying that others would know. Even weeks before, I had always cried in bed, worrying about contracting HIV.

When was that?

About 1994-1995. I cried a lot when I returned home and saw my child toddling. She was so cute! My mom was old. I was supposed to take care of her and the house. My dream was shattered. I cried and cried. I was worried that others would know. How would they treat us? At that time, I was the first one to work outside the village. I was the first one from our village who was educated in the city. The others are rural folk - they did not have electricity or money to invest in their children's education. At that time, high education was not the norm. Rich kids were not even interested in studying. I was the only educated person from an impoverished family. The villagers knew that HIV/AIDS was a deadly disease. They thought that only promiscuous persons get HIV/AIDS. Confronted with this problem, I was very confused.

After I found out the test results, I consulted the hospital director, asking what to do next. I don't know when I got the virus. However, when I gave birth to my second child in 1992, I took her to see a doctor and he warned me not to breastfeed her. I had no idea whether he advised this because he knew about my HIV status or not. I breastfed her for about 20 days and then I had to return to work. My baby cried; she was sick, so I took her to the doctor. He said that the baby could not take my milk. It contained some substances, acids perhaps. I wonder if he knew then. My husband became sick in 1993.

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[1] The teachings of Lord Buddha

Did your husband know about your blood test result? Did he take a blood test?

I did not tell him. I pressed him hard but he did not confess. He only said that he had had an examination. When I took the blood test, I knew right away that he had HIV/AIDS. A blood test was no longer necessary. I saw him cry in bed so I urged the doctor to convince him to take a blood test. Other health workers also tried to convince him. He eventually agreed to an anonymous blood test. Once he knew the test result, he was very tense. He cried because he loved our daughter dearly. He thought that HIV/AIDS was deadly, so he was very tense. He could not accept anything - his reaction was totally different from mine. I am still hopeful.

When did your husband pass away?

He passed away in 1994, only a year after he knew of his HIV status. He was able to fight it for only a year. He was stressed because of his heavy workload. He also bought insurance for our daughter and asked his sister to look after her when he passed away. He might have thought that since I was also HIV-positive, I would shortly follow him to the grave. His sister is a teacher, still single and financially secure. She has everything, a car and a house. We could depend on her should he die. He was very sick only once and then passed away.

Have you fallen ill after you got HIV?

I have never had any opportunistic infections. I'm even surprised myself. I am no longer on anti-retroviral therapy. I have not taken any anti-infective medicine. Once diagnosed HIV-positive, I did not have much knowledge. I was on anti-tuberculosis drugs for six months. At that time DDI and AZT became available, so I took them for about a year out of ignorance. Then I had second thoughts about the drugs and started exploring alternative treatments. I bought books on self-care and systems in the human body. I learned that nutritious diet, exercise and relaxation would be good for my health.

I have never been admitted to the hospital. Perhaps only once, when I got food poisoning, but it was not related to being HIV-positive. During the first two years, I ate only vegetarian food because the person I consulted was a vegetarian and a devout Guanyin[2] follower. Then my relatives told me to quit because it was not nutritious, and because I also participated in many training courses where meals provided were not always vegetarian. After changing to regular food, I gained some weight. I socialize more now. Once in a while, I let go and treat myself. I have to be watchful always, knowing what is going on. I have to know my conditions always, whether I'm feeling fatigued or refreshed.

From where did you find out about alternative treatment? Are you interested in self-care?

It's my interest. Initially it was thought that HIV/AIDS is deadly and there was no effective medicine. I wondered where this disease came from. Why did it just emerge in Thailand? Was there any treatment or vaccine? After taking good care of myself for a while, there might be some medication. This line of thought stems partly from my research background, trying to gain more knowledge on self-care and nutrition.

I also did not want to die at that time. I was young, only 20-plus when my husband passed away. If I took good care of myself using traditional medicine, I would survive. I was interested in traditional medicine because I heard there was no treatment for HIV/AIDS. My relatives also recommended a few medicinal plants. They said that I would be strong if I tried them. Initially I tried the local medicinal plant, *fa talai jone* (a local medicinal plant). We call it '32 benefits'. Why are there so many benefits to it? I simmered it and had the broth which was bitter.

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[2] Chinese Buddhist deity of compassion and mercy

Have you taken *fa talai jone* since your relatives recommended that you simmer it? And how do you take it?

I don't take it on a daily basis. Incidentally, another villager became HIV-positive. Both of us visited each other often. We discussed, looked for this medicinal plant and simmered it together. We did not take it on a daily basis. Initially we took it daily, but later we alternated it with other medicinal plants, like *bo ra phed* (a local medicinal plant). At that time our local wisdom was limited to the two medicinal plants.

And after that? Tell me what you have used. Which medicinal plants have you stopped using?

Here [at the hospital] they started a traditional doctors' club, which has become famous. They provided traditional medicine broth and sauna. I was interested and took the traditional medicine. I have been fine ever since. Now we have a holistic healthcare team and a permanent staff. I told the supervisor to provide the service weekly. Occasionally, we cannot make it, but at least we provide traditional sauna once a month. We have continued this activity since then.

Some say that traditional sauna causes hair loss. I have done this for the past eight years, and I still retain my hair. Nor have I developed any nodules. In the sauna, we inhale aromatic vapors of several medicinal plants, mostly local herbs like *plai* (a local medicinal plant), turmeric and ginger. They are good for our lungs and help dilate the bronchi. Now I know the benefits of each medicinal plant.

We formed a self-help group and selected the group's name together. It is called Saitharn Rak. Since then, we have got funding and many organizations have provided assistance to our PLWHA group. We organize monthly meetings, explore existing traditional medicines and request additional funds to produce encapsulated traditional medicines. We processed seven-eight medicinal plants - bitter cucumber, *bo ra phed*, *fa talai jone*, among others - and put them in capsules. Initially, we followed the regimen strictly, taking them daily. However, we now know more about nutrition and the importance of receiving sufficient nutrients. We do not have to take traditional medicine in capsules. We learn more and more as time passes.

In addition, I read many books and learned that green vegetables help prevent cancer. At first, I did not know that positive people harbor cancerous cells. If I had known, I would have eaten a lot of fresh vegetables. I have to keep up with new knowledge, not only on medicinal plants and diet, but also on mental health. Mental health is very important. I have bought many *dhamma* books.

I encounter so many problems daily. When I go out, nobody knows that I am HIV-positive. If someone wants to date me, I have to think about it. I long for a stable family, and feel that something is missing. But I feel it would be sinful if I did not reveal my HIV status. All these problems. I have to deal with these emotions. I occasionally practice meditation, but spend most of my time reading *dhamma* and philosophy books. I have tried to meditate, but it does not work with me much. I just read and contemplate. I have many books. Whenever I'm down, I reach for these books.

Is there any other alternative treatment and therapy that you practice?

I exercise regularly, especially aerobics. I think exercise is very good for my health. When I found out that I was HIV-positive, I asked the doctor about HIV/AIDS because I was afraid of dying. He said that HIV/AIDS is about the white blood cells. If the white blood cells are low, I will get opportunistic infections. I imagined that if HIV is in my body, it will react or consume my white blood cells every second. What should I do to boost the number of my white blood cells to counter HIV?

So I asked the doctor how I could increase the number of white blood cells in my body. If I sit idle, my white blood cells will all be consumed. I studied books about immunity and found that white blood cells could be boosted. I was elated and promised myself that I would boost my white blood cells. If I have sufficient white blood cells, I can live with HIV/AIDS and we can become friends.

I wanted to know about the source of the white blood cells. Some textbooks said that there are seven locations in the human body. I studied all this and shared what I had learned with new members of our PLWHA group. I would explain about systems in the human body and the alternative treatments that we use. An example is the thymus gland; its function is to produce white blood cells. It is also related to our mental health. Then I go on to others like the bone marrow. Bone marrow can also produce white blood cells.

It is said that white blood cells are produced when our bodies are warm. How can we keep our body warm? That can be done through exercises until the aerobic point is reached. If the aerobic point is achieved, our bodies will be warm, and the bone marrow will produce white blood cells. So I started doing aerobic exercises to boost the white blood cells and my strength. I learned that on my own. From then on, I practice aerobic exercises for 30 minutes, thrice a week, following an aerobic exercise videotape.

The staff here knew nothing about aerobics, but they heard the *thum, thum, thum* noise from our office in the evening. We had been doing exercises for about a year. Then at the beginning of the second year, the government announced a policy to promote aerobic exercises. Finally, I became the leader of the aerobics group organized by the hospital. They sent me to Chiang Rai for further training.

Despite being HIV-positive for a long time, I have never been sick. I can do just about anything. Every other day, the housewives in the community join me here to have aerobics class together in the evening. I am pleased with my exercise, because if we achieve the aerobic point, we can increase the number of white blood cells in our bodies.

Is there any alternative treatment that you've stopped doing? Has anyone recommended that you try anything that you've discontinued?

Most of what I have tried in the past was what I had learned myself. Like the medicinal plants - I heard that the *Hmong*[3] had traditional medicine that could cure HIV/AIDS, but I was too afraid to try it. My neighbor said that eating toads or whole small house lizards could cure HIV/AIDS. I did not believe him. How can you be cured from HIV/AIDS by swallowing the house lizard whole? I was a vegetarian and observed the precepts then. How can you take away other lives to enable you to live? I could not eat them.

So you have not followed others' advice?

No, I haven't followed them and I haven't believed them right away. I listen and study first. I have never traveled to places to get traditional medicine or visited any famous doctor. If our members go to those places, I will reach them right away and discuss their treatment with them.

For instance, some of our members hired a car to get V1[4]. I explained the implications to them but did not go with them. Then came Nulight[5]. It is 15 *baht* ($0.38) a tablet! It contains chlorophyll and was

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[3] A hill tribe ethnic group living in the North of Thailand

[4] V1 Immunitor is a controversial oral vaccine which is licensed by Thai FDA as a food supplement in 2001

[5] A food supplement

imported from the United States. Some health staff sold it to rich patients. They said that it was good for the patients' health. This medication is in the aqueous form and is made in the US. It may cost only 50 *satangs* (Thai cents; equivalent to $ 0.1) a tablet in the US, but we buy it for 15 *baht* ($0.38). They thought that I was knowledgeable because I was the chairperson of the group, so they contacted me to sell the product. I would get a commission of 1,500 *baht* ($37.5) per bottle. If I could sell a bottle of 1,000 tablets, I would get 400 tablets free. But I wondered where those 400 tablets would come from, if not from those sick people.

There was another product. They came with a video presentation on the product. The health promotion staff showed it and boasted about its detoxification properties and its ability to prevent joint pain and other diseases. It might be good, but the villagers with an income of a little over 1,000 *baht* ($25) could not afford it. If they wanted to detoxify their bodies, they could use blended *rang jued*[6], which works well. Despite its usefulness, this product might contain some toxic substances.

Then we have the garlic tablet and fungi. Positive people don't have that much money. They cannot afford anti-retroviral medicines. How can they afford to pay 1,500 *baht* for food supplements, such as garlic tablet and *ling zhi fungi* (holy mushroom)? I asked them about the source of this mushroom, and when it was produced. Normally the fruiting body develops during the rainy season. I asked whether they cultivate the fungi, and if so, whether they use any chemical in the cultivation process. Where are those chemicals now? We don't know whether the product got any mold, how they processed it, or how many nutrients it contains. Compared to 1,500 *baht* for a bottle, for 100 *baht* ($2.5) people can get fresh fruits or homegrown vegetables. These two options are far more nutritious.

I work for the group and I really love doing this. Sometimes I get tired of convincing people. Some bed-ridden PLWHA would like to recover, so they believe what they are told. I have to ask them whom they would rather believe - a healthy PLWHA or a health promotion staff.

Why don't you use anti-retroviral medicines? You have used them before, haven't you?
I used them for about a year. My CD4 was 900-plus then. The doctor did not know that my CD4 was 900-plus. I was afraid of dying and I thought that it was good so I took them.

I got the medicines from Chiang Khong Hospital. They recruited 12 positive persons. When the positive persons went to receive the drugs, some took them but some did not, and some took them occasionally. To me, it was like an experiment. I took two medicines for a year, and my CD4 increased to 1,040. I have my CD4 level checked every two-three years because I wanted to know the result of the treatment. After my CD4 level increased, I gave my medication to another sick patient. Sometimes, I gave my medication to others because I was doing well. So I quit the medicines. At that time my CD4 was 1,400.

So you've stop taking the anti-retroviral medicines.
I stopped because I gave mine to others. I did not have any knowledge about them. Then, there was a protest in front of the Ministry of Public Health to demand DDI. I thought then that the medicine might be good, so I was back to taking the medicines again for another two-three months. Then my supervisor and other colleagues told me that if I did not take it persistently, it might not be good for my health. I finally decided to quit and started alternative treatments. I did not think that prolonged use of the medication would be good either. The information I learned from the training changed my perception constantly.

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6. Local medicinal plants

Did you have any side effects when you took the medicines?

None. I got a potbelly. After stopping the medication, I was told that it would be similar to putting a piece of stone on top of the grass. The grass would become white, but when we removed the stone, the grass would grow more vigorously. If I stopped the medication, the virus would multiply rapidly. I found that it was not true. I have stopped taking the medication for six-seven years and nothing has happened. However, my CD4 level has declined somewhat. Now my CD4 is around 600.

You then turned back to traditional therapies?

I took traditional medicine regardless of the anti-retroviral therapy. I have to focus more on traditional medicine because I know now that my CD4 level has declined. I have to take better care of myself, find additional alternative options. I have to be more diligent, exercise more and grow my own vegetables. I cannot always ask for vegetables. If I get them elsewhere, I will not know whether they apply any chemicals when they grow them or not. I have to grow them myself.

Please explain about self-care according to your understanding.

From my understanding, holistic care covers physical health, mental health and relationships with others in the community, including our mind, spirit and soul. Nobody told me about the things I'm doing today. It comes from my conscience. I can do many things and gain many benefits from there. An example is growing aloe and other medicinal plants. Firstly, we have got to use them. Secondly, we have got recognition of our achievements from the boss and from funding agencies. Besides, there is no loss, only benefits if you keep growing them. This stems from my conscience - we do things, get results and acknowledgement, which leads to happiness.

Do you think that the self-care method that you use can be applied to treat AIDS-related illnesses or opportunistic infections?

Yes, to some extent. However, the use of medicinal plants is not for those who have full-blown AIDS. We focus on balancing the systems in the body. You cannot use medicinal plants to treat the symptoms when you already have tuberculosis or fungal brain infection. My method focuses on good health. If you are in good health, you will not get any disease. You have to focus on prevention. Waiting until you have fallen ill is not recommended. However, if sick patients come in unwilling to reveal their HIV status and relatives want to prolong their lives, then we use ARVs. We have to use modern medication along with traditional medicine. If the person is still healthy, I recommend alternative treatments, telling them that ARVs are not the only choice.

How about the cost of alternative treatment? Is it a problem among PLWHA?

Alternative treatments could be affordable because we have plenty of medicinal plants, traditional doctors, the *Hmong* and tribal doctors in the area. Besides, each family normally has relatives who have tried traditional medicine. So they are likely to have extensive experience in medicinal plants. Ethnic people have their own traditional medicine formula.

There is one traditional doctor who understands and assists us. Whenever we visit him, we gain useful knowledge. He is very nice and is willing to help us. He gave us knowledge on herbs and how to use them.

Medical treatment definitely has higher costs. As for alternative treatment, you have to eat daily, and we do that. It is up to the individual's diligence and conscience. If the patient is lazy, just waiting for modern medicines, alternative treatment would not work well for them.

As part of the health staff at the hospital, the physician was about to give me anti-retroviral therapy in 2000. They were worried about me when they saw how hard I worked. I did not want to jump at his offer because I was still healthy and there might be other alternatives I could use. I did not want to take medicines at eight every morning and night all my life. It's too complicated. If I take traditional medicine, whether I take it or not, it is not a problem. Timing does not have to be precise. I can take it whenever I want to. That's the advantage. Besides, it is low cost. I don't have to pay for it, just pluck it from the gardens.

What is the most challenging aspect of being HIV-positive?
The most challenging part about being HIV-positive is dealing with social functions, keeping in mind my diet and the possibility of diarrhea. I should not eat things that are not good for my health. Everyday I risk my health by consuming things that I'm not supposed to. I have many friends and I attend several parties. I drink alcohol, beer sometimes. However, I know how much I can handle. That's my risk. As for other aspects, I'm OK.

Do you think that you will have more control of your risk behaviors, including diet, when you are in the village?
If I stay home or stay in the village, I will have more control because I eat homegrown vegetables. However, when attending social functions, some do not know of my HIV status, and I occasionally lose control. I have to fix this by taking traditional medicines.

Since you were diagnosed HIV-positive, has your life changed in anyway?
My life has changed completely. I used to be a housewife, knowing nothing. Being HIV-positive, I have attended many training courses, gained a lot of new knowledge. I used to be shy of the microphone; now I can handle it all. From never helping others, I have helped many who are less fortunate. I used to think that there is no opportunity for me as a positive person, but I'm an AIDS worker now.

What are the best and the worst parts of self-care that you've been doing?
The best part is the holistic self-care that I've been doing all along since I got HIV. Our group is wellknown for the traditional medicine which is provided free of charge. PLWHA do not have to spend money on the traditional medication we produce.

The worst part is mental health. I'm occasionally tense; I cannot control myself. If my mental health is not good, it will affect my body. I work continuously and encounter problems constantly. One of my problems is that I am a stressful person and think too much, which gives me more stress. I have to take tranquilizers. Sometimes when things are really bad, I wake up at two every morning. I have to find a way to deal with it and find the real cause of the problem. I apply the *dhamma* techniques I have learned about from books to control myself. I have to deal with my stress.

Being the chairperson of the PLWHA group, I have a heavy workload. Sometimes I go to bed at midnight and wake up early. I cannot rest during the weekends. I work at the hospital from Monday to Friday. During the weekend, I'm off to class. I have a lot of homework so I get very tense. I have to read books to understand myself more. If I have problems with others, I have to observe my emotions.

Now flashback to when you just learned of your HIV status. If you could change anything, would you do things differently?
I would take better care of myself. I would show those who discriminate against HIV-positive people

that they are wrong. It's true that many positive people die, but we don't all behave the same way. Some may be drunkards, some make things worse by becoming commercial sex workers. That worsens the situation. I have to take better care of myself and become a role model. People cannot stigmatize positive people because we can do better than normal people.

If others would like to learn from your experience, what would you advise them?

I would tell them about my experiences, from the time I was diagnosed as HIV-positive until now. About the mental and physical care. I would recommend that they exercise, and explain its benefits and drawbacks. I would talk about systems in the human body and recommend necessary behavioral changes. People need to change perceptions and physical behaviors if they want to adopt alternative treatment. I think that I'm capable of doing that.

In your opinion, can every positive person do what you just described? What would be the incentive for them?

The incentive is our health. Do we want to live? Do we want to have a good quality of life? The incentive is that we want to be like ordinary people, don't we? Being HIV-positive does not mean that we are inferior or worthless. These are the incentives that drive us, enable us to live like ordinary people.

Nowadays I wonder whether there is HIV in my body and whether it's still real. If there is and we can live together, I will live forever. I do not think that I will die of HIV/AIDS if I take good care of myself and be diligent [about proper practices]. For example, *pak poo* (local vegetable) has anti-retroviral properties. They recommend that you blend and drink it raw. Can you do that? If you cannot do that, then you won't be healthy. I cannot imagine that everyone is able to do that.

Anything else about self-care?

What I'd recommend is my own experience. I've been HIV-positive for 11 years, and I have gained a lot of experience. There are many issues of self-care. We have to take it seriously and continuously. Not just listen to it and not do anything. I would like to encourage continuous learning and development. Once you have built your own capacity, help others. You will gain strength and happiness. However, don't fantasize. Some are too optimistic. Some sick patients dream that they will get cured, but they don't follow the rules. When things do not turn out the way they dream, they suffer. However, if we set our expectations and work towards them, we will succeed. I want everyone to have a dream and work really hard to enable us to live happily with HIV. If we behave well and gain acceptance from society, our relatives and friends, we will be happy.

SIVUYILE POTHOLE

SIVUYILE POTHOLE is originally from Port Elizabeth on the Eastern Cape in South Africa. He is 26 years old and currently lives with his father in Grahamstown, but moves around, spending time with each member of his family. He loves to travel, so he does this by changing his living environment from time to time.

Sivuyile was diagnosed with HIV in December 2001 and was put on a double ARV combination. He stayed on this for a year before stopping the treatment in December 2002, as he was feeling better and could no longer afford the drugs. He moved to Pretoria in January 2003, and by April, he developed peripheral neuropathy, which damaged his nerves. As a result of this, he could not walk. He returned home to his family in the Eastern Cape where he started a triple cocktail therapy, which he took for about eight months before stopping, as he could not afford the medication. Since then, he has been visiting a traditional herbalist who continues to treat him.

Please tell me a little bit about yourself.

My name is Sivuyile Pothole and I am 26 years old. I am single, unemployed and presently I live with my father in Grahamstown. I originally come from Port Elizabeth in the Eastern Cape of South Africa. I have six step-sisters and brothers, because my parents separated and married different people. I used to work as an Information Technology lecturer, but had to stop in April 2002 because I was too ill and weak to carry on working.

I took a year off work because of my illness and then got a new job in Pretoria in January 2003. But I had to stop working after a few months as I developed a problem, as a result of which I couldn't walk.

So I moved back to the Eastern Cape in May 2003. I had no choice but to return home because I needed to be with family and friends. I haven't worked since then. It worries me sometimes that I can't do anything, but I hope that I will walk again.

How did you come to know you were HIV-positive?

I used to live in Randburg[1] with my girlfriend whom I infected. We have broken up since. I had a persistent throat infection that lasted for a long time - more than three months. During that time, I went to see a private doctor for treatment for my throat infection, and he advised me to do a HIV test. He himself carried out my HIV test. I didn't think it wise to change doctors. As soon as my results came back positive, my doctor advised me to go on ARVs and I started a regime of Nevirapine and Combivir.

How long ago was this?

This was four years ago, in December 2001.

What was your immediate experience on learning you were positive? How did you feel?

I was not really surprised because of the lifestyle I had. I didn't feel anything and did not need any counseling. It was like God punishing me for all the wrongs things I have done.

How has your health been since that time? Had you already been ill before?

Besides the throat infection, I had not been ill before my diagnosis. Since I found out about my status, I have had pneumonia, TB and pleural effusion[2], as a result of which I was admitted to hospital in Johannesburg for three months. At this time, I was also on the six-month TB treatment and taking ARVs as well. I had to take a year off work because I was so ill and weak.

In early 2003, I started to get problems in my lower body and legs. I did not feel normal from the waist down. The feeling is not completely gone, but quite far gone. I especially have problems working my lower back, which means my ability to walk is affected. By April, I couldn't walk and so I had to leave my new job. I went to the public hospital in Johannesburg, where they put me through a lot of tests and told me that I had peripheral neuropathy, and that my nerves were damaged. They do not know what causes this damage and say that they cannot give me any treatment for the problem. The only thing I can do is exercise and hope that it will work. I don't know how this relates to being HIV-positive and I still want to find out for myself.

Who has helped you and in what ways?

My family has helped me emotionally and financially. I get a lot of financial support from my mother and father. At the moment, I am staying with my aunt. A doctor I used to see when I was working in Johannesburg, also organized for me to buy ARVs at a discounted price when my CD4 count was low. The combination of Nevirapine and Combivir cost R1400 ($216) but I got it at R750 ($115). I'm not sure how the doctor got the drugs so cheap for me, but I paid cash for them and I think it was because he had good connections.

Can you tell me about the kinds of therapies, medicines, and treatments you have used?

When I was first diagnosed, I used the combination of Nevirapine and Combivir as my CD4 count was very low - it was 63 when I started treatment and my viral load was high. My doctor told me that I had to go on ARVs because my CD4 was so low. He also told me to be careful of what I eat - to eat normal

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[1] A town off the northwestern edge of Johannesburg

[2] A serious lung infection

healthy fruit, vegetables and chicken, and to drink lots of water. He said that I should avoid red meat. I started taking the Nevirapine and Combivir combination in December 2001, and by March I was feeling much better and was able to return to work. But I think my doctor failed me because he didn't inform me about the choice I was making to take these drugs for the rest of my life. I didn't know anything, so I didn't ask.

I took the drugs for a year, and during that time I didn't notice any side effects. Nor did I feel that they affected my lifestyle. When you take these drugs you have to take them 12 hours apart. At first, it is tough, but then you get used to it. I was living by myself and cooking for myself, and had no one to help me. When I started feeling better, I stopped taking the drugs. I thought they were like normal tablets that you take until you feel better. Then I started using immune boosters combined with required nutrition for positive people. My main reason for stopping the drugs was because I ran out of money to pay for them. When I stopped taking the combination, I found out about immune boosters from the local pharmacy and started using Moducare[3].

By April, I was having such bad problems with my legs and lower back that I could not walk. So, I went to the public hospital for tests and they told me I had peripheral neuropathy. They didn't know what had caused it and they couldn't do anything to treat it. The only thing I could do was to exercise.' Now I go to physiotherapy at the local government hospital thrice a week. I have to pay for this but it is not very much, so it's not a problem. I have been using a wheelchair since I stopped walking. Sometimes I try to use crutches, so I can be upright and get up and walk around the house when I am feeling better. Earlier I could not use anything; I couldn't even sit up. My condition is improving, but it's very, very slow. When I went for these tests, I also did a CD4 count. I can't remember what it was, but I know that it was higher than before.

In May 2003, I moved back to the Eastern Cape, so I didn't see my doctor in Johannesburg again. I had to move back because I needed the support of my friends and family when I couldn't walk or work. I went to see another doctor and she suggested I take treatment again. I had another CD4 test when I started seeing her, so she would know what my condition was. I can't remember what the count was, but it was better. She was the one who told me I couldn't take the same drugs as before because I had developed resistance to them already. If she had not told me about the resistance, I would not have known. I could do all the things that I could do before and I didn't feel any different. But to the doctor it was obvious that I would have resistance, because you are not supposed to stop taking these drugs for longer than a certain period, maybe a month.

She put me on a different combination because of the resistance I had developed - a triple cocktail of drugs, the names of which I can't remember. I paid R600 ($92) a month for the drugs because I got a cash discount; normally they cost R800 ($123) if you buy them from the pharmacy. The doctor explained that when you start taking these drugs, you are not supposed to stop. She said, 'If I put you on these, you can't just stop taking them." You know, there was nothing else I could do; as soon as my CD4 went below 200 I had to take them.

I took these drugs until November 2003, but I had to stop because I ran out of money. I just couldn't afford them anymore. At that time I had to pay for them, but now there is a government roll-out that pays for ARVs if you have a CD4 count below 200. My health hasn't changed since I stopped. That is why it's so easy to stop. The damage continues and you don't even know. When I decide to go to the

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[3] A booster available off the shelf in any pharmacy

roll-out program, they will have to put me on something else because I have developed resistance to this triple cocktail as well. I have already started taking ARVs, so I will have to take them for the rest of my life.

At the same time, I started to see a traditional herbalist in May last year when I moved back. I found her through one of my friends who was also a patient, so it was a matter of trust. I went to her because people suggested that I try another route to deal with this illness. I was seeing both the doctor and the herbalist at the same time. My herbalist doesn't know that I am on ARVs - she didn't ask and I didn't tell her. Since May last year, I have been using traditional medicines, and also eating the African potato.

Which treatments have you continued to use up to today? Which ones did you use in the past but no longer use? Why?

When I was using the combination course, I was not told that I should not stop using it, so I stopped because I was feeling better and I couldn't afford to pay for it anymore. After a while, I had developed resistance to it and I could not go back to it. I then used the triple cocktail, which is extremely expensive and again, for financial reasons, I had to stop taking it after seven or eight months.

Now I am continuing with the traditional medicines. The traditional medicine I use is called *Imbiza*[4], which I have been using for about a year now. The herbalist told me that it reduces the viral load. I don't know exactly what it contains; only the herbalist knows and she is supposed to keep it a secret. She is trying to get the medicine tested at a laboratory. I have evidence of its positive effects on people's health. She has shown me test results that show that the viral load is going down, and so is the CD4 because it doesn't have to fight the virus anymore. I have not had any physical changes from taking this medication. The only way to tell if there is a change is by doing the tests. I haven't checked my load or my CD4. It costs a lot of money to have a viral load test, about R700 ($108) or R800 ($123), and a CD4 test is R200 ($30). Right now I'm using it because I have seen it work on other people.

I also use garlic and ginger regularly because I was told they are good for me. I cook them with my meals. I also eat them raw, but they don't taste that good, so I only do that once in a while!

What has your experience been with anti-retroviral therapy?

The experience has been good but I have had to stop because of the high cost. I didn't suffer from any side effects while I was taking ARVs, and my health improved. The most noticeable thing was that after taking the drugs for a while, I regained my strength. Before, I couldn't walk very far without having to stop for a rest. After taking the ARVs, I was able to walk like before. In the Eastern Cape they have just started with a new program where the government is supposed to give those free ARVs to those who are infected. If you have a CD4 count below 200, then you qualify for free ARV treatment. South Africa has faced a problem with lack of ARVs and our people are dying. I have definitely felt the effects of the government's non-delivery of adequate drugs.

Do you regard your approach to therapy and treatment as holistic? Is one treatment or practice key? Would you regard some of your treatments, therapies, or practices as complementary?

It has not been holistic when it comes to access to information. When I used the combination cocktail, I was not informed that I would have to take it for the rest of my life, hence I took an uninformed decision

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[4] A combination of many herbs in a liquid form.

to stop taking it when my CD4 count went up. It was even worse in Gauteng[5] than in the Eastern Cape - there some medical practitioners don't have adequate information about managing the disease. At least here my doctor talked to me and explained about resistance and that I have to stay on these drugs for the rest of my life.

Traditional medicine is more of a holistic approach because the traditional healer talks to you about your lifestyle and the nutrition that one must follow while taking the medicine, and talking to you about the disease is a type of counseling. Before you start the treatment, she wants you to check your CD4 count and then start the medication. After six months of taking the medicine, you go for another test to check your CD4 count.

Are there cases in South Africa where some traditional healers work with established health institutions?

Whenever I go to the herbalist, I normally hear her talk of an initiative which is being started where traditional healers can work with health departments to try and get their medication recognized and prescribed, so that they can work with professional medical doctors. She says that there are some healers who are already doing a pilot project with certain hospitals to treat HIV-positive patients. This partnership is very crucial, because certain doctors are recognizing that herbal medicine is important in decreasing the viral load.

What kinds of medical or health advice have you had over this time? From what kinds of practitioners or others? How have you felt about this care?

I have been given advice by my family and from medical practitioners, mostly about changing my lifestyle, eating habits and exercise. The advice that was given has helped me understand and manage the disease much better. I read a lot and that adds to the advice that I get. Family support has helped me cope emotionally with the disease.

Do you feel like you have a good sense of the various treatments available for AIDS-related illnesses?

Yes, I have been through hell and back, and in another life I could qualify as a specialist doctor of HIV/AIDS. I have read a lot about the virus and how to deal with it. I can help others by sharing what I have read and what I have been through. I read all the pamphlets from the hospital. In these they talk about CD4 cells, so I read more about this and about viral loads as well. Most people don't even bother; they don't even know what a CD4 cell is. I make it my mission to know all there is to know about my condition.

How has money, or your financial situation, influenced your treatment choices? What has been your experience with the cost of various categories of care and treatment?

Finances have had a huge implication on my treatment. Like I said earlier, I had to stop working because I got so weak, which meant that I could not afford ARVs. Then I moved back home to the Eastern Cape, which is a rural province, not a wealthy one. My mother is a primary school teacher, and my father works with the local municipality, and they both don't earn much. My aunt was the one who bought the triple cocktail, but I can't expect her to foot the bill constantly. So I decided to use traditional medicine which is cheaper.

Now I am not earning. It worries me. I try not to get stressed and surround myself with the positive things in my life, like my friends and my family. Stress is the one thing that kills people in this condition.

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[5] One of South Africa's nine provinces. Johannesburg is the capital.

Have you changed your life because you are positive? If so, how?

Definitely, yes. I have changed my nutritional habits. I don't have a girlfriend, nor do I have a work life because I can't work anymore. I changed my eating habits straightaway when I was diagnosed and started taking the double combination. You see, I was a bachelor, which meant that I didn't cook; I only bought burgers. I had to stop relying on them for my nutrition. I used to drink Coca Cola, but I had to stop, and now I drink only 100 percent juice and water.

Have others changed in the way they respond to you when they learn you are HIV-positive? If so, what have you learned from this experience?

The only people I have told about my status are my family and best friends, because I don't want to face unacceptance and blame. They have accepted my status and me, and have provided emotional, financial and spiritual support. This has taught me to appreciate them more, and not take them for granted. In fact, I am much closer to them than I was before I found out about my status. Now I change my environment by staying with each one from time to time. I like to be on the move and travel a lot. Now I can't do it the same way.

What has been your most difficult health challenge during this time?

The most difficult health challenge has been the peripheral neuropathy because I have to be in a wheelchair and can't work. I can live with it because I can't do anything about it. I've learned a lot about not taking things for granted, especially walking. It's not easy when you reach adulthood and become a cripple. Maybe it would have been easier if it had happened when I was a child. I have developed very strong willpower, which I didn't know that I had. Now I have two things to deal with - my disability and my disease. Most people would have given up, but not I. I had so much going for me before. All I want now is to get up, to walk and to work. Then I can forget about my disease.

What have been the best and worst aspects of your treatment experiences?

The worst experience of the ARV treatment was stopping my intake of it, but it was good for me because my CD4 cell count went up. The traditional medicine decreases the viral load of the disease, and the traditional healer that I am seeing has shown me a few of her patients who had been bedridden, and after taking her medicines, are now living full lives by working. More importantly, they have gone back to have HIV tests and the virus is not traceable in their blood.

If you could go back to when you first knew you were positive, what would you do differently?

It would have been different if I had known about developing resistance. I would have taken the ARVs anyway because I had no choice. You have to do what the good doctor tells you. But then if I had stopped, it would have been my choice and I would have known the consequences and the trouble I was getting into.

What can others learn from your treatment experiences? What advice would you share with others?

Once you start the combination course, don't stop. Get information. If you can afford the treatment, try to adhere to it, and also eat healthy food. You should check your CD4 count and viral load regularly and change your lifestyle.

I have a problem with the government's policy on HIV/AIDS. The bureaucrats who do not support it have friends who are even dying of the disease, but what makes it easier for them is that they have access to treatment because they are better off financially than us. With the elections, they announced the roll-out of ARVs, but at first this was only rolled out in Gauteng. Here in the Eastern Cape, nothing was done for a while. It upset me because the ANC[6] won the elections and the implementation of their promises was not carried out.

But now, they have started the program here in April 2004. You have to go to a clinic where they test you, and if your CD4 is below 200 they put you on the program. I haven't heard of anybody actually going on the program, but that is probably because they keep it private and confidential because of stigma. I know that they do give proper counseling at these clinics and hospitals, especially about ARVs and resistance. I have to say I do feel good about this program because otherwise people couldn't afford these drugs. They were dying and now they can live because they can get the drugs for free.

I think traditional healers need to be recognized and included in discussions on treatment, as they have helped a number of people. I don't get counseling because talking to my family is a form of counseling for me, and I don't want to advertise my status to people I don't know. Hence, I am not active in speak-out sessions or involved with groups that work in areas of HIV/AIDS. I get a grant of R700 ($108) but that is not enough to cover medical costs. You qualify for this grant if you have a CD4 count of less than 200. It doesn't meet my needs in terms of treatment; it's just for nutrition. It is not difficult to get this grant; all you have to do is go to the Social Services with a form from your doctor saying that you have a CD4 count below 200. Once you've given it to them, you have to wait for their approval. I haven't heard of anybody being checked about whether their CD4 count is increasing. I think maybe it's forever.

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6. African National Congress

VEENA SHENOY

VEENA SHENOY works as an organizer with VALORED (Value Oriented Education), a primary educational development program in the south Indian state of Karnataka. In 1992, when her husband was being treated for a drinking-related liver problem, she discovered she was HIV-positive.

Determined not to use ARVs, Veena developed her own therapy, using a mix of household ingredients, herbs and natural foods. In October 2003, she formed the Karavali Positive Women and Childrens' Network (KPWCN⁺) to enable positive people to lead a good life through positive thinking and alternative treatments.

What were the circumstances in which you found out that you were positive?
In 1992, my husband was very ill. Since 1978, he used to drink and smoke a lot. Even on our wedding day, he drank - he couldn't live without alcohol. Because of his drinking problem, we drifted apart. In 1992, I came to Mangalore - he worked in another city. Then in 1995, he came to me and said he wanted to live with me. I lived with him for the sake of my son. I didn't think that he went to other women. Sexual relations between us were very limited. Looking into each other's eyes lovingly, touching each other, living together - this was what I wanted from my husband. Property, going out, etc., I didn't want all this. I have always been very simple. But he never gave me companionship. I never experienced the love of a husband, not even for one day.

He was an employee in a bank with a salary of Rs.14,000 ($315), but he was greedy for money. He started a business of textiles, but he made a huge loss. This was a big source of tension for him. To pay off his debts, he started another shop. With this, his tensions increased. The more businesses he started, the more he started drinking. He went off to Mumbai, without even telling me. There he didn't pay attention to the food he ate, he had extreme tension. Debtors would collect at the house from morning till night, demanding their money. I was all alone, so everyone caught hold of me and I got tension.

After three months, I got a phone call saying that he was admitted in the hospital. He had lost a lot of weight and was very thin. He had loose motions, ulcers, TB, jaundice, sugar problems - all together. Drinking had caused his kidneys to fail. He had lost all hope. I was very upset then. I decided to leave everything and go to the *ashram* (retreat).

I worked with the community at that time. But I wanted to leave everything and go to the *ashram*. The founder of VALORED, the organization I work with, told me, "Don't go. We have a small house within our compound. Stay here and work because you work well." But he laid down the condition that my husband could never come there. So I lived alone in one room without either my husband or son.

What happened to your husband?
He died in January 2004. But while he was ill, I looked after him like I would a child. I treated him with herbal medicines, juices from leaves, soup. The doctors had given him up for dead; no one believed he could live. Then a nurse told me, "He might have AIDS. Get yourself tested because you might be infected too." I immediately got my test done. He didn't get his test done, but I wanted to test myself. No one in the hospital suspected he had AIDS. He was even operated in the hospital. Once I got my test done, I found out that I was positive.

And did you know what HIV was then?
At that time, I hadn't even thought about HIV. A month before that, because I was a social worker, I had decided to do a program on HIV. I had studied all about it, but had never thought about it on a personal level. Having HIV changes your perspective. When you are infected, you think differently.

The doctor told me, "Don't tell anyone you're infected, because everyone will shun you, you'll lose your job and even your mother won't come near you." Then he asked me, " Have you ever slept with anyone else even once?" I didn't like his counseling. The dietician told me, "Don't you know anything about HIV? You have only four-five years more to live. If you take ARVs, you'll live for maybe five more years, otherwise, you'll die soon." I told her to tell me about nutrition - after all, she was a nutritionist. But she didn't tell me anything.

The counselor was my friend; we had done a lot of street plays together. She was also an agent for ARVs. She told me, "Have the ARVs. You earn a lot of money so you can afford it." ARVs cost between Rs.800 ($20) to Rs.20,000 ($450). My salary then was Rs.4,500 ($100) per month.

So did you take ARVs?
My parents, brothers and sisters had helped me with so much money, so many times, that I felt bad to take money from them. It's horrible to live being dependent on other people. So I decided that I wouldn't use any medicines. I wasn't interested in allopathic drugs because they are costly, and I wasn't interested in taking chemicals. By taking chemicals, ARVs, you get skin problems, pneumonia, your kidneys are affected. Immunity increases but there are a lot of side effects. If your kidneys fail, what chances do you have to live? I thought, "I don't want this; I will never take ARVs".

I also decided to tell everyone that I was HIV-positive because I couldn't live a lie. My mind is like that of a child. So I decided to tell everyone that I'm positive. Even if they shunned me, I didn't care. This world is such a big place; I could go anywhere.

I asked my director whether he would fire me. He said no, but told me not to tell anyone, as I would have a problem with my field work. I was popular in the community because I used to work sincerely. I had received such warmth and acceptance from them, so I told them I have HIV. They didn't shun me. They all decided that Veena must not die; she must live. They studied about HIV and found out about it. Now we all sit together, sit, eat, sleep. I go out, eat in a hotel - I don't have any restrictions. Everyone now knows about HIV, they've all read about it; they know it doesn't spread through contact, and they tell me we can all live together.

As HIV-positive people, we can tell people the truth about HIV. We can change things by talking about our experiences. Our words have power. I tell people, "I am like you. There's no difference between you and me. I am like I was earlier."

Then how did you treat yourself?

I didn't take medicines, but everyone was worried that I would fall sick without them. So my friends said, take *ayurveda*[1]. They all introduced me to an *ayurvedic pandit* (scholar). *Ayurveda* is also very costly; a poor person can't afford it. I thought, I am a part of nature. I don't support globalization. So I started studying about herbal medicines.

I was then introduced to William D'Silva, a social worker and researcher in Germany, as well as an expert in herbal medicines. He told me about a few medicines which I could make on my own, since I didn't want to buy any medicines. Before I met him, I used to travel all over the place, in tiny villages, asking who the herbal medicine doctor was, so I could meet him. I used my salary to travel all over, but I didn't find any answers. I wanted to know what this disease was all about, or if there was a medicine for AIDS, but nobody seemed to know. *Ayurvedic* experts didn't know the answers, neither did allopathic doctors.

So what exactly did he teach you?

William D'Silva told me to use aloe vera. I knew about this, but then I studied and researched all about aloe vera. He told me to drink its juice. Aloe vera gel has the capacity to cure 75 diseases - it doesn't let viruses increase. In Germany, they have introduced it as a treatment for AIDS. I couldn't find aloe vera anywhere in my town. I finally found it in one nursery, but one plant cost Rs.175 ($4). I was very poor and didn't have the money. So I started searching for a cheaper plant. I went to Salem, another town, where I found one plant for Rs.3 (5 cents). I filled two gunny bags with plants and brought them to the AIDS hospital in my hometown, and told them to distribute it among the patients. There was a vest vendor who used to go to Salem very often, so I told him to buy me aloe vera from there.

The other thing William D'Silva taught me about was oil massage. He mixed every type of natural oil - coconut, sesame - there are seven or eight types - added *tulsi* (basil), aloe vera and heated it. He warmed it and massaged it all over the body. This rejuvenates the cells. He massaged me for six days all over. It was a continuous process of teaching massage. Another thing he introduced me to was a home remedy given to women for three months after they deliver a baby. This increases immunity, makes the blood pure and the muscles strong. It consists of black pepper and *kaljeera* (black cumin). We used everything that is in the kitchen - onion, garlic, *jeera* (cumin), *dhania* (coriander), *voma* (Bishop's Weed) - all these are mixed together.

Then, I would go to HIV hospitals all over and start giving speeches about what I eat, what William had

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[1] The ancient Hindu science of health and medicine

told me to eat. Wherever there was a network of NGOs, I would make speeches. I would tell people, 'This is what I eat and I'm fine. You should try it too'.

Is that how you started trying to help others?
At that time, I had known I was positive for about a year. I came to Bangalore for a program, and I met Sumathi. She was part of a network, which she asked me to join. I didn't know about networks before that; I used to talk to people on my own. I realized that everyone in the network was very selfish and no one monitored who did what work. The network didn't do anything to help a positive woman who was pregnant; in fact, they made her have an abortion. They would say, 'It's a great thing that we're HIV-positive, because we've been given a chance to be famous; we have more facilities now.' I felt awful seeing this. I thought something was wrong with the networks and the organizations, so I broke free from them.

I went back to my village and Sumathi told me she'd join me. At Manipal KNC Hospital, they have a group for all the people who have tested positive. I took all the leaves, food, and natural medicines and brought them to the group. There, I made a speech on all that I eat and drink. The doctor was angry with me, but everyone in the network liked it. There were 40 people at that meeting, and at the next meeting no one came! They had all got the confidence to treat themselves at home.

Then I started making public speeches. One of the women there told me that she worked with an *ayurvedic* doctor, but didn't know about all these medicines till today. She said that I should do a program for all the positive people. Two months before the program, I worked very hard all alone to make sure everything was ready. Do you know how much energy is needed to organize a program by yourself?

But everyone told me that I must keep my status a secret. I told them I don't want to hide my status. By not revealing their HIV status, infected people die from the inside. By keeping their status a secret, no one listens to their demands. Why should they die under the weight of this secret? The organizations said that they'd support me, but no one gave me money. So I collected my friends and got each one to sponsor an aspect of the program. The program was a huge success, 300 people came. I openly admitted I was HIV-positive. It was featured in all the papers. I knew that I would have to say this, otherwise people wouldn't know about HIV.

But the KNC doctor was angry and threatened me. He is an agent for ARVs. He told me, 'You are advocating herbal remedies and shunning ARVs - now prove to me that they work!' I told him, 'You prove to me that allopathic medicines work.'

These doctors give ARVs?
Yes. And they get commissions. He told me to prove *ayurvedic* drugs work. I told him I don't take *ayurveda* because I don't want to give Dabur[2] business by buying the products they sell. I use only what is natural.

Till then I was working secretly, but now it's been splashed all over the papers. People with HIV can change people's outlook towards the infection - I know this. Today, even though a lot of rich people have HIV, they don't talk about it. It's only the poor who talk about it. They don't even take any medicine; all they want is something to eat and drink at the end of the day. People are so scared about the disease because there's no cure for it. Chicken pox, plague are spread through contact and so they're dangerous, but HIV doesn't spread and it's not a disease; it's an ongoing process in which immunity

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[2] A popular ayurvedic product company

decreases. If it's not a disease, why should we take medicines? That's why I've decided that I won't take any medicines. Today, I eat everything that is natural within limits. I don't eat even a single medicine.

What does your diet consist of?

The things that are very bad for positive people are *dalda* (vegetable oil), tomato, *maida* (flour), sugar, coffee, tea, soya - soya is very bad. Everyone says it's good, but it's not good for health. This isn't good even for people who are healthy to eat on a daily basis. I never use sugar or *dalda* - these are very bad. There's no fiber in flour. That's why it stays in the stomach and cannot be digested easily. Even *dalda* doesn't have fiber and so cannot be digested easily - this in turn ruins our health.

Even tomatoes?

Tomatoes contain as many vitamins as it does poison. That's why even if it good, it can harm us eventually.

In the morning, I eat mango leaves, but not the paste - that's bad for you. After you get HIV, you develop the mental abilities to sense the onset of any opportunistic infections. I don't believe AIDS and HIV have any link. HIV-infected people can live for many years; it doesn't have to develop into AIDS. AIDS is caused when you eat things that lower your immunity. We need to think about our nutrition. Right now you have strength, but slowly this goes down. My husband was like this. Even though he was infected, he didn't die of HIV; he drank himself to death. He developed an ulcer because he drank so much.

Our daily routine, lifestyle, food, and environment - all these are responsible for immunity. If in your environment, everyone shuns you, says things about you, if you live in fear, this lowers immunity. Environment includes people, their behavior towards you, pollution, toxins, even in your food. All the food we eat today is sprayed with pesticides. All the spinach we eat is grown in mud which has been sprayed with pesticides to grow better vegetables, but actually we've spoiled it. With this, we will definitely get some disease.

We are children of nature, but today nature no longer remains natural. If you have fever and drink the water left over after cooking rice, it won't cure you because even that has toxins. Earlier, there would be insects in the rice after storing it for two-three months, but now they spray it so there are no insects. Fruits are also sprayed. We need to find a natural way to boost immunity.

I don't believe it can be cured through yoga and *pranayam* (breathing). I do yoga myself. With yoga and *pranayam*, the fear of HIV is removed from the mind, but HIV isn't destroyed. Even today, people are not clear whether HIV is a disease. I agree that the HIV virus must exist. There are 35 viruses in our body and doctors want to treat each virus with medicine. But I believe that by eating natural food, raising self-esteem, giving love, eating healthy food and drink, people can live a good life for however long they live. I have HIV, but I don't believe it's a disease; it's a process. Diabetes, cancer are all diseases; this is not a disease.

What do you eat everyday?

See, our bodies contain a lot of toxins. To remove the toxins, I use *hing* (asafoetida), rock salt - it helps people with blood pressure - I put this in my food. I use this in vegetables instead of regular salt, just a little bit. *Hing*, pepper, onion and *haldi* (turmeric) - all these prevent the virus from spreading according to *ayurveda*. We should add all these to food. I put *haldi* in milk and drink it, I put extra in my vegetables. I drink tea with pepper in it, *tulsi*, *sambarballi* (Indian borage), and *brahmi*, (Indian pennywort), lemongrass, ginger - I put all these in water, boil it, add *gur* (jaggery) - I never use sugar - I drink this mixture. I add milk if I want, otherwise drink it plain.

I have read a research paper where they gave *neem, tulsi, amla* (gooseberry), and *gur* mixed with *ghee* (clarified butter) to patients. I started eating this mixture and suggested this to people. *Neem* has the power to increase immunity, and *tulsi* has the highest capacity to increase immunity. Today people say that *tulsi* is not good, that it can cause abortions in pregnant women. But this is not true. *Tulsi* is used for cough syrups and can cure naturally and increase immunity. You can also make *chutneys* from every leaf - *brahmi*, etc. So I used to tell people about all this. I also do *kattisnan* (sitting in a bucket of water) - this removes the toxins from the body.

You just sit in a bucket?

Yes, I take a big bucket and sit in it with my legs out. Water reaches upto my chest and my stomach is in the water. It removes toxins from the body and prevents stomach problems. Also, if you have back pain, it goes. I used to have back pain for 10 years, and also had a migraine problem. Then I started doing *kattisnan* and I can't tell you how much energy it gave me. My back pain was gone. I did it for a few days everyday, then an *ayurvedic* doctor suggested that I wet the clothes I wear close to my stomach area, even when I go out, or when I sleep.

It's like this - if we leave a vegetable dish out for three-four hours, it will become bad; similarly, our stomach contains years of hot food and even though we don't know it, this is the cause of all our problems. The food we eat everyday needs to be digested daily. If you wet the stomach area, you can pass urine, even get good bowel movements. All the toxins leave your body and you feel no pain. My migraine that had occurred for 10 years suddenly stopped. My confidence increased and I started telling people to do these things.

Can you tell me what else you eat?

Potatoes, sweet potatoes, yam are all natural so you should eat those, as well as leafy vegetables. *Doodhi* (zucchini) makes the body cool internally so you should eat a lot of that. Also, you should eat onion and garlic as they increase your immunity, either the entire pod, or cut it into pieces as a salad mixed with carrots, beetroot, cucumber. Sprouts are great for us - they rejuvenate dead cells in the skin. Especially for people with HIV, their cells die fast, so eating two spoons of sprouts is very good for you. I make different salads everyday - onion, sprouts and coconut one day; cucumber, onion and beetroot the next. Try and eat every kind of vegetable, and every part of the plant - flower, roots, fruits, buds, leaves - it's natural, so you should eat all this. The bark of the Ashoka tree is very good - you should make a juice of this to purify your blood.

I also drink water left over after boiling *ragi* (a kind of cereal), with a little jaggery everyday. *Ragi* is *navadhani* - it is part of a mixture that contains all the vitamins and nutrients. Rice, sprouts, *tuvar* (lentils), *ragi, jowar* (a kind of wheat) are washed, dried and made into a powder, which is mixed with hot milk and a little jaggery. You get all the nutrients and strength by drinking this.

Where do you get all this?

I grow a lot of medicinal plants in my garden. *Amla* is very important - you should eat it everyday. I break it and mix it with salt or *gur*. *Gur* has wine so you should eat this everyday as well as *amla*. You can make *chutney* of this using salt water.

Shatavari (asparagus) and *ashvagandha* (winter cherry) is very good to make muscles very strong. You should also eat a lot of fiber, like the husks of wheat. After you make a *chapatti* (bread), you shouldn't throw this away. You should keep all the outside fiber of every food.

Even papaya should be eaten everyday and you should eat 10 papaya seeds everyday. This helps remove worms from the stomach. Also, the grass we use for *Ganpati pooja*[3] - *dibramkur* (wheatgrass) - is called green blood and it has the capacity to remove toxins from the body. You should have this for 25 days. Bitter gourd, clove, custard apple, date plum, mint, banana and drumstick are also very good for people who are HIV-positive. I don't buy anything - I only use things that I have, which I can see around me. This is the power of medicine. Marketing is done only for money, but we can treat ourselves at home. Even our food should have medicinal properties.

And you tell people about all these natural cures...

A lot of people who come to me are very poor, so I don't buy anything. I can't take money from them, but I give them advice about things they can get easily like *amla*, *tulsi*, *neem*, pears, pomegranates - straight from the trees.

Earlier, I had never thought of setting up an organization. But after I did the first program, lots of people started coming to my house. I don't have a family, so I thought that all these people can be my family and this can become my life. I never had meetings, but people would meet with me outside and drop in, or would read about me in the paper and then phone me for counseling. So many people have been ready to kill themselves because they have HIV. Then they've read about me in the paper and have stopped.

People come to my house secretly. Even though we have a women and children network, more men have started coming to us. At first, I would get scared because I thought they've come to kill me because the doctors were threatened by the organization. They would come at night at around seven till almost 9.30-10 at night. The men would tell me that they couldn't tell their secrets to anyone else, not even their wives because they would get upset and commit suicide. If they tried to use a condom, they would get suspicious; if they told the wife to cook good food for them, she would get angry and say, 'Why can't you eat ordinary food like the rest of us?' A woman's mind is very smart; she can gauge situations very quickly. If they stocked up on medicines, the family members would get suspicious. I felt bad for them and decided that the Women and Children Network would help men also.

What about the women?

Most women are not educated; they're thrown out of their house. Some have young kids and are widows. They don't even have saris to wear, and have broken *chappals* (slippers). They are so poor and they spend so much money on HIV treatment that they have no money left. Some people come to my house but don't have money to return home - I give it to them. My salary gets over in 15 days.

I asked for help through the newspapers - for people who could give education to positive people, supply nutrition powder, medicines - not ARVs, but vitamins, proteins; who could give them knowledge and training in *ayurvedic* use of plants. Nobody came forth. For the last six months, the mayor of Mangalore is the only one who helped me. Most of the people who came after reading the papers were people with HIV. I asked them what they wanted. They said they wanted books for school, uniforms, bags, fees for school. They don't take any medicines - they are very poor, but very smart and don't have any health problems.

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[3] Worship of the elephant god, Ganesha

When you did the HIV test, did you also do the CD4 test? How much was it?
342. I didn't do it after that.

How is your health now? Is it okay?
For the past two years, I was totally fine. But I didn't have time to eat, everyone used to harass me - positive people, organizations, even my friends. I am the *taluka* (zonal) organiser for VALORED. I sleep at midnight, and am up at six in the morning and start work immediately. People start coming to me. My friends felt that I was very arrogant because I refused to form an organization - they used to harass me. I got a lot of mental tension and got herpes. My face was clear earlier, but now it's pockmarked because of herpes. I was in hospital for 10 days last month.

So what did you take for the herpes?
I took ayurvedic medicines in the hospital. I took *chandan arishta* (a paste of sandalwood). They applied this on my body. I also took *shatadhout gritha* (a paste used to cure herpes by putting it in the mouth), and an enema once to clean out my stomach.

But you didn't take any antibiotics, medicines?
Nothing! I was there for 10 days. I was pretty serious, but now I'm fine.

Have you had any other opportunistic infections?
I never got fever, cough, cold - anything.

How long have you been doing all these treatments?
For the last two years. Only food itself isn't important - you need positive thinking, an atmosphere of love, you must believe that you have power, strength, resources to fight the disease and not die. I believe this is not a disease. There are so many causes for lowered immunity. I will never use any medicines - if I die, I will die naturally. I'll live a normal life. Even if I die, I don't mind - that's what I feel.

How do you manage to stay positive?
All this has happened in my life, but should I declare that I'm HIV-positive and cry till I'm dead? Everywhere you look, you see sadness. If you have expectations, you will be unhappy. Earlier, I used to have expectations from my husband. Now I realise that there's no happiness in that. I've realised that your happiness and peace of mind can be found within yourself. People are very selfish, but now I don't think like this. Now I am alone, but I live happily - that's my nature. What's the point of unhappiness? You die of unhappiness. I am happy and I want to live!

You had said that you do yoga - do you do it everyday?
Actually, if you do yoga everyday, it's good for you. If I have time during the day, I do it. But all day long, there are people in my house, and if I want to do it at night, I fall asleep. That's why for 15 minutes every afternoon, I do *shavasan*[4] and I relax. While I relax, I treat each part of my body very lovingly. Earlier, I never used to think about the parts of my body; now I think about it a lot - that I want this part, this has a lot of energy. I need all the parts of my body to do work.

I lovingly treat each part of the body - its cells, bones - and concentrate on each part. I concentrate on the *kundalini shakti*[5] and the *chakras*[6] - from the *mooladhara chakra* to the *sahasrar chakra* - I don't know the truth behind this, but it gives me peace and happiness. There are seven *chakras* in our body.

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[4] A yoga pose where you lie still like a corpse. [5] The power of consciousness that is coiled in a latent form, in the base of the spine. [6] A series of energy fields or centers of consciousness in the body.

These extend from the toes to the head. These are our life - our *jeeva* (soul) is here. I concentrate on these *chakras*, moving from down to up. I imagine the world as a good place, where everyone is happy, there is no sadness. So if anyone is rude to me, I have the capacity to forgive them. I accept the negative in me and try to improve myself.

Do you ever turn to prayer or god?

No. I am a trained classical singer and sing *bhajans* (devotional songs). But I am a lover of people. I never I thought of myself as Hindu. I would not see Christians differently, Muslims differently. All I think about is that they are human beings. If Christ is a god, so is Ram, and so is Allah. People think that gods are different but I think they're all the same. I believe in *shakti* (a powerful force) - whatever the *shakti*. But I don't believe in Ram, Krishna, all that. God is one - if there is a god, it is one. God is in humankind everywhere. We get separated in the name of religion. I go to a church, live with Muslims, that's why I have never kept a picture of God in my house. I sing God's songs and prayers. When I sing, I forget all about my happiness, sadness, struggle.

I still can't figure out why you started a network.

The reason behind the network is this: there's nothing for people who are HIV-positive - no treatment, facilities for positive people, nothing. No one even talks about treatment. In government hospitals, no one listens or pays attention to HIV patients. Even if there are beds available, they are made to sleep on the ground. They can't move about. Even on their deathbeds, they aren't given IVs. They're given very little food, with a little *ras* (gravy), and told to eat it. No one checks on them, there is no doctor for them. They don't even have proper counseling.

In my town there are so many people who are infected with HIV, but in the whole of our district, there isn't a single doctor to see to their needs. I felt very sad seeing this. I thought even I might have to face this later. Honestly, I used to cry earlier, but now I feel there's so much work to be done. I've written a letter to the District Collector asking him to ensure that there are two-five beds for HIV patients in all government and private hospitals. When I was in hospital, they discriminated against me, so what will they do to poor people?

I have not formed an organization, but when I joined the network, a lot of people started joining me and asking me what to do. 15 people came to me and I arranged to feed them rice. I didn't take any money from them. There is an organisation called Sisters of Charity in Mangalore - I asked them for rice and nutrition powder for these 15 poor people. I wrote to them and started a dialogue with them and they gave it. I went to the church and asked for clothes and books for these people. This was so good! So what's the need to form an organization?

A lot of HIV-positive people are ready to do work. Even William D'Silva doesn't pay his income tax to the government - his income is about Rs.250,000 ($5,500), but gives it to an HIV patient. She gives oil massages to other patients. Isn't that good? Our system is such that we don't spend any extra money, like an organization does. Even if I have to organize a program, I tell people about my expenses and they help me. My mother gives me Rs.2,000 ($45) a month, so I have a total of Rs.6,000 ($140) per month including my salary, which I spend on all this. I don't aspire to form an organization. This is the Karavali NETWORK, not an ORGANIZATION.

And what do you'll do?

We've done three workshops so far. One was on increasing self-esteem and self-confidence. One was on food. In North India, *gau mutra* (cow's urine) is very famous. I got this and gave it to all the HIV-positive people - they need a medicine for reassurance. The next time, they told me that they made their own medicine from the *gau mutra* and they felt stronger. I was amazed! I didn't drink it though because it was stinking! But it was good for them. They're all fine.

Do you want to tell me anything else about treatment?

I have decided not to take ARVs and I haven't taken them till today. *Ayurveda* research is being done across the world and I want to spread that. I don't think of *ayurveda* as a medicine; it is natural, just like air is oxygen and we need it. Water is natural, so is vegetation. It has proteins, it's bitter, but we need it. We label it as medicine, but we need all these things. We need to incorporate sweet, bitter, spicy foods in our diet - we don't necessarily eat bitter foods - we need to balance our diet.

There should be research on this - how to remove toxins from the body - and this information should be disseminated among HIV-positive people. Marketing medicines is not good - it should be dropped. People are selling *ayurvedic* products for Rs.1,000 ($25) as HIV treatment. Instead, we advise poor people what vegetables to eat - why should we spend money? These people waste a lot of money marketing HIV products. I don't want money - I'm happy the way I am. My sisters tell me not to work, to rest. But before I die I want to remove the fear of HIV from people's hearts and minds.

What's the secret to your good health? What gives you the strength to go on?

Several factors give me the strength. One is the environment in which I live and work, which is very good. Everyone in my office loves me, society has accepted me. On the other hand, the food I eat gives me energy. I don't eat too much non-veg food. Actually, you shouldn't eat too much of any food - eat everything in moderation; you need to control your food intake. If you eat too much non-veg food, it causes stomach problems, and problems with cancer as well. So you should eat more of natural foods. Good, *sattvik* (natural) food is good for you, so that's also a reason. It rejuvenates the cells.

The mind is also affected by the food you eat. And the lifestyle - how I live my life. I read about *ayurveda*, go out into the community, talk to people, teach them, dance, sing, I'm part of their families - there's purpose in my life. I've found purpose in being an organizer - everyone accepts me and my work has been effective. I bring about development of education and tell people about the government's new education policies.

I believe it is essential that I live. I am needed by so many people. So I would say, lifestyle, environment, food - all add up to living a good life. The main reason I would say is belief in myself. It is important to be able to live with yourself, in spite of all the unhappiness in the world. I think a lot about myself - what my character is like, whether I'm good, whether I've hurt anyone. I talk to myself. I find the answers within myself to live a good life.

But should your CD4 count drop below 200, will you still not take ARVs?

No, because the CD4 count fluctuates, not because of HIV. Even if I get some other fever, it will drop. I had herpes a month ago, so it must've dropped. If I don't eat, when I am tense, immunity can drop. If I think negatively also, my immunity can drop. I think I will never take ARVs - I've decided this. I want to die without taking ARVs. I want to be an experiment. People keep telling me to take ARVs so that I will live. I tell them I can't just live with ARVs. I'm living well, now leave me alone!

DON BLISS

DON BLISS is 44 years old. He was raised in the town of Mason, Michigan, in the United States of America, and has lived in Chicago, Austin, Washington, DC and Oakland. He currently lives in a tiny apartment in the Tenderloin district of San Francisco. He moved to this neighborhood to reduce his expenses and save money to move to Brazil where his boyfriend lives.

Don is a social worker, collecting disability support payments from the government. He was diagnosed as HIV-positive in 1995, when he found he had unusually large swollen nodes in his groin. In November 2000, he had surgery for a type of skin cancer and started anti-retroviral therapy in March 2001 as a result of this. He has stayed well informed about the treatment options for HIV because of his work as a social worker and his life as a gay man.

Since his HIV diagnosis, Don has taken nutritional supplements and become more conscious of his diet. He has his blood tested every three months and varies his supplements according to his CD4 and CD8 counts. In addition to his diet, he places a lot of emphasis on the importance of a spiritual practice and exercise regime.

How did you know you were infected?

My lymph nodes swelled up and stayed swollen for an inordinate amount of time (three-four months). That is what started me worrying. As a gay man living in those days and times, I often wondered and worried about getting infected, but this is what prompted me to start worrying about it in a more concrete way.

I started worrying about it around May, June to September 1994. I was in graduate school then, and I did not want to be distracted during my last semester. I knew that I wouldn't be able to finish graduate school if I found out I was infected. But then I decided that I wouldn't be able to finish in any case if I kept worrying about it and didn't find out. Finally, I went to a testing clinic when it became more distracting *not* knowing if I was HIV-positive. So eventually I tested in February 1995 and learned that I was positive the following month.

What was your immediate experience on learning you were positive? How did you feel?

I felt like I was in a movie. It was as if I could see every leaf on every tree, every detail on every car exterior, and every stone in the asphalt. And I could feel the earth rotating, gravity holding me down. I felt like if it were not for gravity, I would have floated in mid-air. It was a very physical experience.

I remember feeling numb and in shock. I do not remember the counselor or the building, although I could take you there. I simply remember leaving and noticing that the colors and the details of the world seemed sharper, crisper. I walked to the park that was half a block from my house, a beautiful urban park in the middle of Washington, DC. The testing center was six blocks from my house. I smoked a cigarette, which I tend to do when I'm depressed or stressed. I can't remember if I was smoking regularly at that point or had bought them for the occasion.

And then, I just said to myself, "Well, I'm not dying right now, so all there is to do is keep on living." I began going about my daily routine pretty much as before, although I did begin reading all I could get my hands on about HIV and seeking out support systems and ways I could involve myself in the communities and causes of people who have HIV.

Did you share the diagnosis with loved ones?

I didn't tell anyone for a couple of weeks, not even the psychotherapist I had been seeing for a few months. Finally I told him. Then I told a classmate with whom I had grown close, about six weeks later, and she was stunned that I was dealing with this. I didn't tell anyone else until I graduated several weeks later, because I didn't want to be inundated with telephone calls and have to deal with that while finishing my degree.

I then wrote a letter which I sent to each of my friends and most of my family members, telling them on the back whom I had told and inviting them to share it with whomever they felt comfortable in order to get the support they needed. It was important to me to tell each one of them in the same way, to honor the relationships in the same way, even though they didn't appreciate getting the news in the form of a letter.

Did you experience illness after becoming infected?

A few weeks after I believe I was exposed, I got sick like I have never been sick before or since. I was so nauseated that I could hardly move - I had to lie perfectly still in my bed. My body felt like it had an electric current running through it, like someone had plugged me into an electrical socket. And I got a rash all over my body of tiny hives, which lasted for several days. Despite the fact that I was in Washington, DC, an epicenter of the pandemic, neither my primary care doctor (known to be gay-friendly in the days before there were many openly gay doctors) nor the dermatologist mentioned HIV to me. The dermatologist even did a biopsy on a couple of the spots.

I wasn't acutely sick after that, but was chronically sick in the sense that my GI symptoms, my gastro-intestinal symptoms, worsened. Even before getting HIV, I had a sensitive GI system, a 'nervous stomach', and I would get chronic colitis, irritable bowel syndrome. These symptoms worsened. I used to get fatigued. I was more sensitive to marijuana and cigarette smoke (if I smoked even a little marijuana and then only one cigarette, I could get extremely nauseated), my appetite could be iffy, and so on. In other words, I began to have some type of symptoms pretty much right away.

What treatment did you take?

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Since adding anti-retroviral therapy, can you describe any changes in your experience of managing your body over this time?

I'm not sure I could describe changes. It seemed like I had quite a time in some ways adjusting to the ARVs. It felt like my body forgot how to sleep. So for months after I started them, I had a terrible time sleeping. I was sleeping three, four, maybe five hours a night, every night and I could not sleep more. That was horrible and lasted for probably six months, maybe longer.

It seems like something different happened with my GI system. I remember adding more supplements specifically for my GI system at that time. I can't remember if it actually improved my symptoms, but I was more concerned about just supporting my gut health, you know, my intestinal health, because of the toxicity of the anti-retrovirals and everything that I was taking.

I also believed that because of the supplements that I was taking before and after that, I have actually had fewer side effects. Again this is not so much experience, but belief.

In terms of the medications, besides the fact that I felt like my body forgot how to sleep for a while, I was actually quite shocked at how quickly I got used to them. Because sometimes people feel nauseous and generally yucky for four to six weeks afterwards and I really didn't have much trouble. In the first couple of weeks, I had some of that, though it wasn't usually enough to impede my daily functioning in any way. A couple of times I was so sick I didn't think I was going to be able to do anything that day and then it would pass after an hour or maybe two.

When you said you were so sick, what do you mean?

Just nauseated, light-headed, dizzy, maybe I broke out in a sweat. It was just like general malaise, fluey kind of stuff, but I never vomited or anything. I was taking this one medication, Videx, which I am still taking, although I'm taking a newer formulation now - Videx EC[10] - that's been out for almost three years now. But I don't think it was available when I first started it.

So there were these round tablets and they're not very thick, but they're big and you had to chew them. A lot of people would crush them up and mix them with juice. I knew somebody who was so sick from taking them, every time he drank the stuff, he would get really sick just thinking about drinking it and the taste of it. It was just horrible. I heard horror stories about people reacting just to the horrible taste of this stuff. And I would just pop it in my mouth and chew it, and to me it was like, "What are we talking about?" Again, my experience was very different. I actually did a ritual before I started on that medication and I think a lot of it is about mindset.

What sort of ritual was it?

Well, I don't remember too much of it, but I do remember that the night before, or maybe it was the morning I started, I got out each of the pills and I put them in front of me and made a little kind of altar. And I asked the universe to bless my decision to start them, and that was the gist of it. I did some kind of prayer around it and I used different words - I might have used God or the Universe or All-That-Is or Spirit-of-Life because, to me, it's all the same so I use different words at different times. I usually don't use God actually, but sometimes I do. So I did a little prayer, a little blessing of the medication. I just did it; it was actually quite spur of the moment. I didn't really plan it. It wasn't really conscious, and then I just did it.

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[10] "Enteric Coated", time-released capsules. The California AIDS Drug Assistance Program covers the cost of this medication.

Have you done anything like that before or since?
No, I haven't. Although I do it sometimes, like when I'm doing yoga or when I'm praying in general or when I'm breathing. Sometimes I'll just invite all that is good and healthy in with the breath and then ask that everything I don't need and that's unhealthy for me be released with the exhale.

Do you regard your approach to therapy and treatment as holistic? Is one treatment or practice key?
Well, that's an interesting question, because I would certainly say that all of what I do is key at this point, including the anti-retrovirals. But I was doing a lot of other things before I started ARVs and all of those certainly were key to me. But they're also complementary in that I take some of them because I'm taking the ARVs, to mitigate against side effects or to support my body's use of the ARVs.

Other than that I would say that exercise is key, nutrition is key and spirituality is key. Having a spiritual practice or a spiritual consciousness is key.

What kind of medical or health advice have you had over this time?
I have, of course, seen one or another medical doctor for the entire time. And my acupuncturist has certainly given me advice before. I've seen body workers or energy workers as well.

Do you learn new things from these practitioners? Or do you already actually know it? It seems like you came in as a peer almost.
Yeah, in some ways it can feel like that. Certainly I'm much more of a collaborator than someone who needs to be educated. But actually things around diet have been very helpful. I should mention the nutritionist, but also my acupuncturist, because they told me a lot about things that maybe I should avoid or add, or eat more of, or less of. That's been really helpful. And actually I don't know if I learned some new things or just developed a new focus or a new rekindling of awareness from my nutritionist and those kinds of people. And there's always new information. I certainly don't know it all and information is changing all the time as well. There's always something new that I learn or can incorporate into what I know, even from my doctor. But of course I'll also push her to get more information.

Like with this recent trouble that I've been having with my liver, I never seem to get enough input, which is really unfortunate, because it's prompted me to think about changing doctors at some time. I don't know if this is true or not, but I tend to think that maybe it's because I'm in this non-profit community clinic. I wonder if I had Medicare[11] whether this thought process would be more freely accepted by doctors in private practice and if I wouldn't have a better experience with my doctor. But I don't know. It's probably just fantasy considering our medical model and our medical system right now. But I always feel like, "Gosh I didn't get enough time." And frequently I will be with her for a half-hour. I'm never just there for five or ten minutes and then rushed out the door, but I always feel like it's not enough.

So I keep making these appointments lately to talk about my liver and what's going on. I was vaccinated twice against Hepatitis B, but somehow I contracted it about a year ago. Ever since then, my liver enzymes have never returned to normal and keep spiking. And you know, when your liver is challenged, it is important not to challenge it further than necessary. I really push my doctor to think about the medications I'm taking, because she was pushing me to think about the supplements.

So I actually went and sat in her office. She has this medical textbook that lists all of the potential supplements that people could take and their potential for hepatic toxicity. I went through it item by

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[11] State funded medical program for the elderly and permanently disabled that allows clients access to private medical practices, public and other clinics.

item and eliminated some that were potentially hepatotoxic[12] or cut them way back, and in general have cut way back on my dosages. So even though I've been taking some of these things for a long time, I'm taking less of them now than I have been in the past – almost everything, if not everything. I also did it for financial reasons, but it was primarily because of my liver.

Now I've gone back to her and said, "Look, I want to know, do you think that there's any chance that this might be causing a problem?" And so when I was there last time she did take the time. She knew that Viramune[13] has potential for causing problems with the liver when first prescribed and often people have to stop it. You're supposed to do your first lab work two weeks, or maybe a month after you start a new medication. But I wouldn't wait a month. Anyway they'd see problems with the liver right away and that means that person can't take Viramune. I wanted to know about the long term. So I sat in her office this time while she went online, and sure enough there is a potential for problems to develop later on. So I could be having some problems as a result of Viramune, which again I pushed her to find out. So it's kind of a two-way street, because I'm always thinking about these things.

How does money or your financial situation influence your treatment choices?
Well, it influences it dramatically. First of all what was interesting to me was that when I went on disability and my doctor looked at my medical record in preparation to send it to the Social Security Administration, we discovered that I have been complaining about fatigue since 1995, which was a shock to me and I think also to her.

It was like, "Wow!" Because one of the things that I know from being a social worker, and also from working with people with HIV/AIDS, is that often the information is not in the medical record and there's not enough information in the medical records. So every time I go to my doctor I have a list of all of the symptoms I've been experiencing because I wanted to make sure that if I ever had to apply for disability, everything would be in the record.

But that was one of the things that came to light. The irony is that I always felt that because I had to work I couldn't take care of myself. There's so many things that an otherwise healthy person ought to do, shall we say, for their well-being. It is all the more important that we do it. In fact, a lot of it becomes very critical to quality of life on a day-to-day basis, but also for longer-term survival.

And I never felt like I could do all that stuff, because I had to work full-time. So it got in the way of my going to acupuncture and to the gym and to yoga and doing some kind of meditation, gathering information, doing support groups, whatever it was. It always felt like I could not do it. I just didn't have the time even when I had the money. Again it was a financial, sort of economic consideration, which is ironic. When I've worked part-time or been out of work, in some ways it's much easier, because then I could get some services for free. But it has been very difficult to pay for my supplements.

Do you know about how much you spend on them?
It's down from what it was. I think it's probably closer to $200 to $250 a month and it was more like $300 to $350 or maybe even more. Yeah, I think actually I calculated it once at $350 to $400. I'm not sure, but it's down a lot now because I've cut back on the amounts.

Now I've started this yoga practice and it's expensive to go to classes. First of all, I can't practice in my apartment if I want to and there aren't free classes offered. Well, there are some great instructors,

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[12] Injurious to the liver.

[13] A drug containing nevirapine, a non-nucleoside reverse transcriptase inhibitor (NNRTI).

Central YMCA, urban, in the middle of the Tenderloin, and with a frequent class card I can actually pay $4 per class, which is really good. But it's another expense.

Actually for that reason, more so than anything else, I started getting some more free food to offset the expense. But sometimes I feel guilty, because I feel like other people need this because they're more disabled or whatever. But then if I don't get that I can't do other things that support me in my well-being, in my health. You constantly struggle with these kinds of moral issues.

Have you changed your life in any way because you are positive?

First of all, I moved to California because of my diagnosis. This man I considered my best friend in the whole wide world was living here, and when I was diagnosed I thought "I have to do everything I want to do before I die, right now". Kind of dramatic I know, but it was true. I did, and I wanted to live where he was living. Here. So that's actually why I moved across the country - literally because of my diagnosis.

I also got a severance payment that I received at almost exactly the time I was diagnosed, or a month before. I was working for a company for three years and was laid off, and received a portion of my salary in severance, in the amount of $20,000. It was great not to have to work in my last few months of graduate school, but I think I would have been more focused on getting a job and getting on with my life if it weren't for my diagnosis, instead of wasting three or four months and frittering all that money away before deciding to move to California.

In terms of my spirituality, I think I had come back to a spiritual path before that, but it's made it more of a priority, or maybe fostered my continuing to value that part of my life. Exercise - I'd never been to the gym before and I started going now. Since I was a child, I've thought about having a yoga practice and now finally I'm doing it. Of course it's years into my diagnosis, but I'm finally doing it now.

I would actually say that in terms of my sex life, it's made me more reckless. Because I got infected in a way that you're not supposed to be able to get infected. At least that's what I believe. People say "Well, you're not sure about that." But I'm pretty sure. I think what I've realized is that because I got infected being so careful, now I'm less careful. I never practiced unsafe sex before, but I will now. In some circumstances I practice unsafe sex and I never did before.

Did you go through any other changes?

I have become less tolerant of what I'll call bullshit in my life, whether those are people or jobs. I'm much more discriminating about what I do with my time and how I spend my time and energy. I'm much more intolerant of things that don't seem to support my well-being. So this certainly impacted my job in that way. It's what prompted me to start the organization that I started. I didn't want to work in a place where I didn't want to work and I knew that if I started my own organization I'd want to work there.

In 1998, I received some money from the viatication[14] of my two life insurance policies and started a non-profit psychotherapy center with that, here in San Francisco. One of our primary target areas of service was people with HIV. I saw the organization as a culmination of my life's work, as my dream, my child. I never could quite recruit the support that I needed and never quite developed the

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[14] In the US, people with HIV cannot hold life insurance policies. Instead they can viaticate these policies i.e. sell the life insurance policy to a private third party who then gives the policy holder a portion of the proceeds and becomes the irrevocable beneficiary of the policy. Some companies offer this as a benefit to their employees.

willingness to let the organization go. It struggled for four or five years while I worked way too much and way too hard to carry the load of it myself.

What does the organization do now?

We got behind on some taxes but didn't carefully monitor the amount, because we didn't have the money to pay them anyway. When we got some money together and added up what we owed, my co-manager freaked out and told our entire staff that money was missing from the organization and that I had stolen it. This is someone who I had considered one of my closest friends here in the Bay Area. I had known her for years, lived with her, attended the same church, had many mutual friends and acquaintances, and so on.

Board members - all friends of mine too - stepped in to clean up the mess. There was no money missing, of course, and it is unclear to this day why she behaved the way she did. Within a week of her accusations, the small staff we had (around eight part-time employees) refused to work with me, saying that they were not sure whom to believe, or that they didn't feel I took good enough care of them emotionally during the crisis of the accusations. The Board had her confidence, so their stepping in seemed to be fine. However, they couldn't seem to understand how devastated I was by what happened, and proceeded to destroy their relationships with me, professionally and personally. To this day I do not have contact with any of them, and am very conflicted and pained about what happened.

Have other people changed in the way they respond to you because you are HIV-positive?

Well, I think that I have lost a friendship over it and I know that I've lost a boyfriend over it.

I think it's really changed my family relationships probably more than anything. I think it's made people more inclined to express their feelings about me to me. Like how much they value me and stuff like that. It's less so with friends, because we've always been like that, but definitely with my family.

Some of my family members whom I thought would be indifferent were really devastated and upset. And some that I thought would be really devastated and upset, were more like, "Okay, we'll deal with this". But one of the things that people tend to do is they demand that you tell them and share with them if you're having a health challenge or if you're not doing well. They demand to know and yet they never ask.

I think that's for a couple of reasons. They don't want it to be a focus of their relationship and interactions with you. Or they don't want to worry, to be thinking about this all the time, and yet they demand to know. When I was diagnosed, I promised one of my sisters that I would tell her if anything were going on with me health-wise. At the time, she was the only family member with whom I maintained close contact. Last month I asked her to be released from that agreement, because I was never sure when to tell her anything, and I also felt confident that we were all in the same loop now.

But I also think that I lost a friendship over HIV because people say goodbye in different ways. When they know you have HIV, even today, a lot of people think that means goodbye, and they may choose to eliminate you from their life today so they don't have to do it more painfully later on. I think that's what one friend of mine did. We had some issues in our friendship before, but we still managed to maintain it. But after that, he pretty much disappeared. Although every now and then he'll surface again and just say hello.

Who has helped you during this time and in what ways?

In general, my friends have helped me tremendously with their emotional support. My family has also really been quite good in this regard. Many friends and family have helped me with financial and practical support as well. My doctors and treatment providers have been wonderful. I have the best acupressurist (shiatsu massage[15]) and have met countless quality providers of Western-style or other types of treatments. And I never forget society and the government, because I recognize how lucky I am to live in a city and state and country where services are as good as they are for people with HIV, and I recognize that although my government pension is pitiful, I couldn't get by without it. So I am grateful for what my community and my country do for me in this situation as well.

What has been your most difficult health challenge during this time?
Most difficult... that's difficult. Because to me it's really the ongoing stuff - it's the fatigue and the GI symptoms. But then in a certain kind of way the melanoma was the toughest.

Because it was a rude awakening, kind of a slap in the face. But also the liver stuff is really difficult because what I know now is that people with hepatitis have a higher instance of liver cancer. And these medications are hard on the liver, so it limits my options for the medication. I may have to switch imminently because of that. I can't seem to get my liver enzymes down and keep them down. So that's kind of scary. The people who have hepatitis and HIV live, but they don't live as long as people with just HIV, or just hepatitis for that matter.

I really don't want to stop or change any more of my supplements because I'm not convinced that they have anything to do with it. Although I've actually been thinking about it just to satisfy my doctor and whatever curiosity or concern I might have, even though it's minor. I might just stop everything, all of my supplements for a month to see what happens.

What have been the best and worst aspects of your treatment experiences?
The best aspect, or aspects, I would say, are the respect that I have felt from my treatment providers in terms of collaborating with me in my care, and also just the good tenderness and the sensitivity and the gentleness and the sweatness and the empathy. It hasn't been without exception, but so many of the people who work in the field are very dedicated and very good-hearted and very kind and very sweet, and it's just really nice to experience that.

The worst aspect of my treatment experience I would actually say - I don't know if this is fair - is the weddedness to a Western style of doing things, in a Western approach to medicine. I don't see this a lot because I find my way through it and find providers who are much more open-minded. But I do see it a lot and it's certainly how we approach even allocating funding for HIV-related services.

If you could go back to when you first knew you were positive, would you do anything differently?
I don't think so. Well in retrospect I would. I don't know if this has anything to do with my diagnosis though, but I would spend my money differently. I not only worked so many hours and so hard for free, but I probably neglected my health in a lot of ways, because I was working like such a crazy person. I think I only got 40 percent of one policy and then 50 percent of another policy and it added up to $45,000. I spent it all on the organization and I would really like to have that $45,000 now.

I ended up fighting with them constantly, over something we shouldn't have been fighting about. It was like they couldn't understand that I was devastated by these accusations and by the conduct of the staff and how they reacted. Then there were people who told me they treasured the environment that I

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[15] A pressure-point massage designed to regulate the flow of life energy in the body, and bring the body back to balance.

created, even though they were later able to do what they did - refuse to work for me, resign and use the organization's clients to start private practices.

There was this guy who worked there one day a week who said, "I've always considered this my main job though, because this is where my heart is and I so valued what you've created here." And everybody loved the place and the atmosphere and the clients and everything, and all of a sudden they just turned on me. This woman has never apologized and her accusations destroyed the organization. It's still very painful for me.

What do you think other people could learn from your treatment experiences?

What can people learn from my experience? Oh gosh! I used to speak to adolescents about what it was like living with HIV and I would try to emphasize the importance of safer sex. I had to be careful what I said, but I would say, "Anytime you have one wet body part touching another wet body part, there is some risk of infection and you never know who's infected." You know, again, I got infected in a way that they say you can't get infected. I would also emphasize taking care of oneself - emotionally, physically, spiritually - because it's all important. And if you have HIV, it is all the more critically important. And so just take care and be good to yourself.

And then I would also always tell them, live your dreams. Don't be afraid to do something because of what may happen. You never know how much time you have left on this earth. None of us knows, but the awareness of that is all the more acute if you have a life-threatening illness that is generally fatal. It may be fatal much later than it used to be, but it's still generally fatal. And sure, there are some long-term non-progressors and so I don't refer to it as a fatal illness, but it is generally fatal. So live your dreams and be true to yourself.

In terms of just treatment experiences, I would say be educated and advocate for yourself and do not be intimidated by treatment providers. Because sometimes, in fact in my experience, many times, you know more than they do, if not about everything, then about some things. So educate yourself, advocate for yourself and do not be intimidated by medical authorities or any other authorities. You always have some power. It's finding that power, finding a way to express that power. Advocate for yourself and stand up for yourself and for what you want and what you know is good for you.

And take care of your health and yourself holistically. I think that's really, really, really important. So many people are suffering the long-term side effects of these medications and I think one of the reasons I'm not is because of my generally good nutrition and the anti-oxidants that I take, which support that good nutrition. Never mind all the other stuff, but just the anti-oxidants and my multi-vitamins and the micronutrients that I get[16]. The healthier we are generally, the more we're going to be able to tolerate the effects of this chemotherapy and these medications, which are very toxic.

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[16] Don's daily medication consists of the following pharmaceuticals: Acyclovir 400 mg bid, Epivir 150 mg bid, Lipram-UL20 1 capsule tid, Lorazepam .5 mg prn, Videx EC 400 mg qd, Viramune 200 mg bid. He also takes the following daily supplements: Acetyl L-Carnitine, Aloe Vera Gel, Alpha Lipoic Acid, Beta Carotene Complex, Bupleurum Liver Cleanse, Calcium/Magnesium Blend, Cat's Claw (Una de Gato), CoQ10, Dehydroepiandrosterone (DHEA), Evening Primrose Oil, Flax Oil, Green Tea Extract, Intestinal bacteria (acidophilus, etc), L-Glutamine, Liv-A-Tox, Live-Clean, Multivitamin, N-Acetyl-L-Cysteine (NAC), N, N-Dimethyl Glycine (DMG), Phosphatidyl Choline, Psyllium, Reishi/Shitake/Maitake Mushroom Extract, Saw Palmetto, Selenium, Silymarin (Milk Thistle), Vitamin C, Vitamin E.

AMINA ACHIENG

AMINA ACHIENG is a 36-year-old mother of three children. She lives in Mombasa, Kenya, and is the chairperson of the Society of Orphans Against HIV/AIDS Network. Amina tested positive in 2000, but resolved not to use anti-retroviral therapy. Since 2001, she has been using herbal therapy, and stresses the importance of spiritual care. Amina also uses musical therapy to relieve stress, and keeps herself updated on new alternative therapies by surfing the Internet.

Please tell me a little about yourself.

I was born on 3rd May 1968. I belong to the Luo tribe[1], and was born in East Gem in the Siaya district[2], but I live in Mombasa. In 1986, I married my husband, a Muslim from Mombasa, and changed my religion from Christianity to Islam. Currently, I work as the chairperson of the Society of Orphans Against HIV/AIDS Network in Mombasa.

When did you know you were HIV-positive?

My husband moved in with a woman whose husband, I suspect, died of HIV/AIDS. Finally, in 1999, I raised this issue with him, but he told me that as a Muslim male he is entitled to marry even 10 women! He then told his new girlfriend about my concerns and she was really annoyed.

She went and told his family members, who preferred her to me because she is Muslim and I am not, and they demanded that we all go for an HIV test to prove the truth. They arranged for a doctor to test us at the Africa Air Rescue (AAR) clinic in Mombasa, whom they had paid off.

When the results came, mine was positive and theirs negative. But later I learned that she had bribed the doctor, because my husband is now at the stage of full-blown AIDS, while his other wife is on

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1. The Luo tribe is the largest of Kenya's non-Bantu ethnic groups with a population of 4.2 million who survive by farming and fishing
2. A district in Western Kenya

ARVs. After the results, I could never live peacefully with my husband. This was four years ago, in 2000.

I decided to get another opinion and went for the test again after three months at Kibera Community Self Help Program (KICOSHEP) and the Kenya Medical Research Institute (KEMRI), but the result still came positive.

Did you experience any illness during this time?
I used to have a dry cough and earaches all the time but I never knew what the problem was. It was only when the test came positive that I realized the problem was because of my status.

What was your immediate reaction on learning you were positive?
I was angry, devastated, especially when my husband and his other wife said that I was the only one who was sick and they were not. I was lost for words and felt betrayed, because I knew that I had been faithful all along. I believe my husband thought that he could buy everything with money. He abandoned me to live with his girlfriend and I had no emotional support from anyone.

My husband moved out immediately, but continued to say that he was my husband. In 2002, he gave me a divorce under the Sharia law. We had three children. Two girls and one boy. They are now 16 years, 13 years and 8 years old. Now two of my children live with my sister and my eldest daughter is in a boarding school.

How has your health been since that time? Had you already been ill before?
God has been on my side. I have never had major illnesses apart from little infections. At times, I get pounding headaches and feel fatigued. Occasionally, I have got malaria, which really affects my immune system. But generally, I am very healthy because of the way I live. I am really careful about my health and take a lot of precautions not to fall ill, even about getting the flu.

Who has helped you and in what ways?
First, I tried to help myself by trying to accept that this had happened. Although I grieved about it - knowing that I had a terminal disease that leads to death - being a community health worker helped me. Since then, I have volunteered with Mapendo Induction Women's Association and Action Women's Association on AIDS, both organizations supporting women and children living with AIDS.

Before I started my current work, I volunteered with Mapendo. We used to do counseling and that is where I learnt a lot of information on HIV/AIDS, and on herbal treatment. This experience made me realize that I was not alone in the fight against HIV/AIDS, and with proper information and the right attitude towards life, I could conquer anything.

I also had the knowledge and foundation of positive living and this has also supported me a great deal. I got support from members also working in the areas of HIV/AIDS in the region, and my family really played a tremendous part in coming to terms with the disease. They took care of my children, which they still do. Currently, two of my children are staying with my sister.

I also surf the Internet to get the latest information on treatments for HIV/AIDS and how the disease can be managed. I share my experiences with other people using herbs and knowledge gained from herbalists.

But my most memorable experience is what I learned from herbalists and traditional doctors. Most of all, spiritual care is very important. It gives me encouragement, strength and peace to live. I also use musical therapy, which is very important. It makes me cry when I use it. I really cry my heart out and remove all the stress in my body, and try to cherish the good moments in my life.

Which therapies have you continued to use up till today?

Because of my knowledge of positive living, I knew from the word go that I should live healthy by eating a balanced diet. So as soon as I found out I was positive, one of my friends told me about *neem*. At times when I feel feverish I boil the bark from the *neem* tree. When it has boiled, I inhale the steam and it unblocks my chest, especially when it is congested. Drinking the mixture also treats malaria. I used to take it once a week, but now I take it only once a month, when I have flu. I only take it for three days at a time. This is because I do not want my system to get used to the medicine.

I regularly use a herbal medicine known locally as *maruhani*, which is a cleansing herb that helps clear the digestive system and keep it clear of worms. I mix this with another herb called *mouringa*, which is an immune booster. *Mouringa* is a plant regularly used by Indians, which they eat with their food. I blend the two medicines and drink this everyday to help build my immune system. I also use *maruhani* to remove intestinal worms, which are a problem for people with HIV. Pumpkin is also very good for worms if you eat it frequently. I have never experienced any side effects with these medicines.

I also use another herb, locally known as *subili*, which is a species of aloe; it is like charcoal and very bitter. I use it to clean my blood and I take it every day as well. I also use another Indian herb, *jambul*, which I buy from the local chemists that sell Indian herbs and medicines *(Duka la dawa)*. I mix it with water and make it into a drink, which removes impurities from the blood. It is used to treat gonorrhea, diabetes, indigestion, and diarrhea. Consilk, a herbal tincture, is also available as a powder at Indian shops and is used to treat diabetes and bladder control problems.

When I have not eaten anything for a long time, I tend to get nauseous. To avoid this, I drink plenty of water to cleanse my system. In fact, first thing in the morning, you should drink the fresh juice of a lemon, but if you have ulcers, you should dilute the juice with hot water and drink it.

I have been using herbal therapy since 2001.

Have you tried anti-retroviral therapy?

I have never taken ARVs since I found out that I was positive because from the beginning, I knew I would not be able to afford it. My doctor also told me that if I take care of myself to make sure that my CD4 count does not go down, I can live a healthy life by using herbal therapy.

I have not tried anti-retroviral therapy. I don't even think about it, after considering and understanding the usage, side effects and facts about anti-retrovirals and their guidelines. I have seen my colleagues go down fast due to the side effects. From some of the experiences my friends have undergone, people on ARVs are prone to anemia and lipodystrophy[3], among other illnesses, and we have realized over long periods that the drugs appear to be causing side effects that were unheard of years ago, which is scary.

I studied about anti-retrovirals and the latest information about treatment guidelines in Seattle,

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[3] A disorder of adipose (fatty) tissue characterized by a selective loss of body fat. Patients with lipodystrophy have a tendency to develop insulin resistance, diabetes, a high triglyceride level and fatty liver.

Washington. I also interviewed people on them. If the policies of donors and the Government of Kenya do not reflect those who have already started ARV treatments, and where they are and how their viral load is reacting, and also which treatment is working and which ones are not, then there is no policy that we can say is good for those who are positive like us.

I see treatment as a lifetime therapy - once you start, you have to continue. But what if in the long term you cannot afford it and the viral load reverses and multiplies even faster? In my opinion, first a healthy diet is essential. This is what many of us are able to follow. I chose to use alternative therapy along with good eating habits to complement each other because the side effects are not as toxic as anti-retrovirals, and this is cheap and best if properly administered, because it is natural. I felt it was better to try herbal treatment first and see how it worked with me.

What problems have you had while using herbal therapy and how do you treat them?

When I have thrush[4], I take garlic, remove the skin, and then I use a clean cloth, dip it in white vinegar and then wrap one piece of garlic and insert it in my vagina, especially after my periods. This really helps to clean all the impurities. I normally put it in the morning and every evening for three days. Garlic especially helps with opportunistic infections and also with the digestive system.

Sometimes I chew garlic and ginger together, followed by a drink of hot water, or else, just gargle with salt and hot water. It is very good for sore throat, which I get often. *Nduma* (yam), when peeled and chewed raw, also helps in treating tonsilitis and throat infections. Moreover, I apply this ginger-garlic mixture to mouth wounds.

When I have rashes, I use coconut oil mixed with *sim sim* (sweet potato) and apply it on my body or face, and this also helps a great deal. The other alternative is aloe vera soap, which we make ourselves as women who are living with the virus. Aloe vera is also very good if you have very dry skin. You can blend aloe vera with Vaseline and then apply it to the skin. This is also good for spots. Some people infuse *neem* in water and then wash children in the water. It is good for boils, herpes, rashes and dry skin.

For lack of appetite, I use a powder made from a tree found in the Coastal region of Kenya called *afuyawanda*. After blending it, you put it in the mouth, and it not only increases your appetite but also cures mouth sores. *Mkambera* from Western Kenya also does the same. Another herb that is good for loss of appetite is coriander. On the Coast, there is a lady who blends *cannabis sativa* (marijuana), and if one uses very little of this, it also helps with appetite.

I live normally and eat normally like any other person. The only difference is that I have to watch what I eat. It is important to be careful with what you eat. I eat a lot of vegetables. About twice a week, I blend garlic, ginger, red onions, green pepper, and at times mix them with bananas or oranges and drink the juice. This helps my body to become healthy. The other vegetable I use for my digestive system is locally called *muchunga*[5]; it is very bitter but very useful.

What other herbal therapies and treatments have you learned about?

For people living on the coast, malaria is a big problem. I have learned that they take the leaves of the *mahatma* bush and boil them. The concoction is very bitter, so people generally inhale it as steam with a towel over their heads, but it is better to drink it. It is a strong medicine and can only be taken for three-five days.

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[4] A yeast infection of the mouth and throat, characterized by patches of white, caused by the fungus Candida albicans

[5] A leafy vegetable grown by the Taita tribe. It is very bitter and many people don't like to use it because of this. It is normally cooked by boiling or frying.

If I get *uvimbe* (swellings of the glands), I treat this by using *comfrey* powder (blackwort), which now comes pre-packaged and is easily available. I mix a spoonful of powder in water and drink it. Sometimes when I am very stressed, I get nosebleeds. I find that the best way to deal with stress is through massage, talking to someone or listening to music.

For me, herbal treatment has worked. For example, whenever I lose my appetite, I use coriander, and it helps me with an allergy I develop from eating meat. At times I get diarrhea, especially when I eat outside my house and whenever I travel. When I got typhoid, this really disturbed me a great deal, but I used blue gum[6]. I mixed blue gum with lemon in hot water and drank it thrice a day for a week, and it worked. Since then, I have recommended it to people who have also used it a lot. Another thing that is good for diarrhea is to swallow a few papaya seeds.

In the beginning, I really used to worry about my future and that of my children. I went through depression and developed ulcers. Through research on the Internet, I read that a mixture of soya beans and blue gum could treat ulcers. I did not use the blue gum, but I got better.

Another thing I use is turmeric. I mix the powder with water and drink it everyday when I feel I need it. It is good for purifying the blood, for stomach problems like swelling and gas, and for coughs as well. If you make a paste with the powder, it is very good for healing skin problems such as boils and wounds since it stops scarring and bruising.

Besides *neem*, do you use any products from trees?
The bark of the *mkokoraanda* tree, which grows in Tanzania, is brought to Mombasa by traders. You boil the bark and drink it. This is good for menstrual cramps and clotting, as it dilutes the clots and eases the flow. It is also good for easing muscle stiffness and cramps, as well as for treating bronchitis since it cuts down the mucus and blood. I use it to ease the stiffness in my muscles sometimes.

Cageria Americana is another tree from Tanzania. You boil the bark and gargle with the liquid to ease sore gums. Another tree, also from Tanzania is *Cageria Africana*. Again, you boil the bark and drink it. This is good for easing arthritis, numbness of joints and waist pains. It helps purify the system and reduces discharge from syphilis. The *muda* tree is grown on the coast. Chewing the bark and the twigs and swallowing your saliva helps to ease problems with amoeba and hard stools. Boiling the bark and drinking the liquid is good for bilharzias[7], gonorrhea and blood in the urine.

Finally, *mtungukula* is a brownish powder, which has a texture like sawdust. It is imported from Tanzania. You mix the powder in water and boil, and then drink half a cup. This is good for easing stomach pains when it is tight and painful. It is also supposed to be good for asthma.

Do you regard your approach to therapy and treatment as holistic? Is one treatment or practice key?
I regard my approach to treatment as very holistic. I use herbal treatment, which I combine with spiritual therapy. Since I started using this holistic approach, I am proud to say that I am so healthy, you cannot even know that I am positive unless I tell you. I also regard other treatments, therapies and practices as complementary, especially when dealing with opportunistic diseases. For me, treatment includes emotional, physical, nutritional, psychological and, at times, modern medicine to treat opportunistic diseases.

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[6] The gum from the eucalyptus tree

[7] Also known as Schistosomiasis, it is a worm infection acquired through contact with fresh water in some tropical and subtropical regions

Do you feel you have a good sense of the various treatments available for AIDS-related illnesses?
I get the latest information and health advice from books, newspapers, doctors and herbalists. I read a lot and also do my own research on the Internet, among other places. The advice I get from doctors and health practitioners is usually holistic (mentally, physically, spiritual, emotional and psychological) for positive living. You can't separate any of these fields for they are intertwined. And putting this together, I feel great changes.

There is a wide range of anti-retrovirals that are available and no government guidelines on their use. Therefore, I strongly believe that there is need for the government to publicize the ARVs, which seem to be working best. They should also recommend anti-retroviral therapy as an alternative, not a panacea for treatment. There is also a need for adequate data.

So the question I would like to ask now is this: Are people who are starting ARVs fully aware about what they are getting into before they start? I am lucky that I have all the information to know what I am getting into and the side effects - what about them?

My experience with the virus has shown me that at times those who are infected are so timid and they become more vulnerable, so that they fail to reason and ask questions. For me, treatment therapy is effective if one has basics - good health and food. You cannot use anti-retrovirals on an empty stomach.

Do you go for CD4 tests and find out if this treatment is working for you?
I normally get tested once a year, and whenever I have opportunistic diseases I see my doctor. One of the things he does is to test my CD4 count. Currently it is 500.

How has money, or your financial situation influenced your treatment choices?
At first, it was very expensive to use a lot of food supplements, and going for extensive therapy dried up my resources. But since I started using alternative therapy and locally nutritious foods, all that has changed. I can say I am in charge of my life once again and I know what to eat at what times, and when I am ill, I know what to apply.

Have you changed your life in any way because you are positive?
Yes, especially eating habits. I make sure I eat a healthy diet. In fact, I am even more energetic and active. Experience has added passion to my work. Sexual practices, no. I have not had sex since I found out I was infected and my husband treated me badly. But what I do know is that when I am ready to do it again, I will definitely use condoms, because I know if I do not protect myself against re-infection, I will expose myself to various strains of the virus. This is what I usually tell my colleagues.

I have abstained not because of fear but because I made that decision. Spiritually, yes. This experience has brought me even closer to God; it has made me realize that everything is possible, no matter how tough it might be. God can pull us through if we want.

Have others changed in the way they respond to you when they learn you are HIV-positive?
Yes. But now they don't believe their eyes when they see me healthy. People have a wrong image and view of people living with HIV/AIDS. They only see how positive people look - I mean thin, scanty hair, coughing - and that is why the rate of infection is always rising.

But for some, I have become a role model after sharing my experiences with them and the success of the alternative treatments/health and nutrition and how well it has worked for me. I think we have reached out to more people who don't have knowledge and such experience, only to be able to help them with what is within their reach, especially to those who cannot afford treatment.

What have been the best and worst aspects of your treatment experiences?

The best aspect is that the herbs I have been using don't have side effects and are helping, they are cheap, and they keep me healthy. The biggest challenge is mental health, which brings me fatigue. Because of my children's future, I tend to worry a lot, but now I take life in my stride.

If you could go back to when you first knew you were positive, what would you do differently?

Be composed, not panic and take life each day at a time because anybody can get infected.

What can others learn from your treatment experiences? What advice would you share with others?

It is important to assess, learn, and ask questions, gather all the information, as much as possible. Share with health providers, doctors and friends, and seek a second opinion before you can start treatment. Gather information and knowledge, talk to people, and try using herbal medicine - you won't regret it.

SONGSAK REONGSAWAD

SONGSAK REONGSAWAD, a 33-year-old native of Chiang Mai province of northern Thailand, has been living with HIV since 1989 when he was a college student. When he was in the third stage of AIDS, with a CD4 count of zero, he decided to end his life - but it was his willpower that helped him to pull through and recover. He has taken anti-retroviral drugs to boost his CD4 count in combination with traditional medicines and alternative treatments, most of which he taught himself. In the future, he hopes to pursue his Masters' degree and be accepted completely by society.

Could you tell me about yourself?

I have been living with AIDS since 1989 when I was 19 years old and studying in a vocational school. At that time, I also taught at a vocational college in Lum Poon province, but the salary was low and I needed money to cover my treatment. So I quit my job to work with a telecommunication company as an engineer.

How did you get infected?

I had sex with prostitutes, and also with my classmates. I didn't use condoms. I knew what condoms were for, but I had no idea where to get them and was too embarrassed to ask.

How did you know that you had AIDS?

I developed symptoms in 1992. I would fall ill, get fever, have a running nose, and then recover, but there was no reason for my illness. This went on for some time. My condition matched the symptoms of HIV that I had read about in a leaflet. So I went to have a blood test at a public health center. A health staff member there asked why I wanted to take the test and what I would do if I had HIV. I told him that I would commit suicide. So he refused to let me do the test. Then, I went to the center for the second time, and they asked the same question and my answer was still the same. So my request was rejected again. The third time, I told the health staff member that I would take care of myself and they agreed to test my blood.

The results indicated that I had HIV. I didn't believe it at first. I repeated the test for a second time, then again and again, mostly at anonymous clinics and private clinics around Chiang Mai. The test fee at that time was about 120 *baht* ($2.95). All test results confirmed that I had HIV. I cried all the time, even when ironing clothes, going to school, or riding my bike. I had no appetite for almost a month. A health staff member referred me to CDC 10 (Communicable Disease Control Region 10) in Chiang Mai for a PCP[1] preventive program.

I asked them how long I would be able to live. They said if I took care of myself, I would be able to survive another five years, but if I didn't, I'd have only three years left. I was stunned. I had no hope of survival. I had no idea about medicines and how to cure the disease. I did not dare to visit a hospital, as I was too scared that my secret would be revealed to others. My parents didn't know about it. Only my doctor and I did.

What happened then?

At that time, I taught at a vocational college. Once I heard about my positive status, it took a long time before I could summon up courage and resume my daily activities. I quit drinking and smoking, ate good food and slept well. From time to time, I developed a cough as I was in air-conditioned rooms most of the time.

During that time, I was also studying at Ratchamongkol in Chiang Mai for a Bachelors' degree in engineering. Studying, teaching and my hectic lifestyle made me forget about HIV. I didn't even have sex with others. Eight years later, when I started working, the symptoms developed again.

Did the company require a blood test in its application? Did you pass the company's health check-up?

A general check-up is required, including a blood test. I told the nurse who was in charge of the check-up that I had HIV. She still requested me to have the blood test. She wasn't wearing gloves so I cautioned her before withdrawing my blood. She didn't seem to believe that I was living with HIV, but thanked me for showing responsibility [to others' health]. I was afraid she might get HIV from me so I admitted to her that I was positive.

Four years later, there was another annual health check-up in my company. My blood report showed that I had problems with CD4 and lymphocytes. I hid the health report under my desk, fearing that others might find it.

Was the CD4 check included in the company's health check-up policy?

Yes, it was a company policy. Later I had another test at Chiang Mai Rama Hospital. I requested my doctor not to report my health status, but he insisted that it was his duty. I felt anxious, imagining what would happen if my boss found out. I became increasingly weak and often took days off from work. One day my boss asked why I visited the hospital so often and I told him I had HIV. He reported this to the company committee in the Bangkok office, and I was paid to leave my job.

How much did the company pay you?

They paid me the equivalent of six months' salary. I had consulted a public health staff member about whether I should inform the company of my HIV status. They suggested I should, so that the boss or

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[1] Pneumocystis carinii pneumonia

the company could help me out. But I thought that if I reported my HIV status to the company, it could be a two-edged sword; I could get fired quickly.

Did the company have a policy of hiring employees with HIV?

Not at that time. I understood that I lost my job because I couldn't work efficiently due to my health status. According to a labor law, employees who leave their jobs without a good reason continually for three months must automatically resign. The company used this condition to trick me; they let me take leave for three months and then asked me to leave. I was very disappointed. I begged them to let me keep my job, but was rejected after all.

At that time, the owner of the company happened to visit our area for a national election campaign. I wrote a letter to him, which I sent through his secretary, requesting my job back, even without salary. Instead, he gave me another 50,000 *baht* ($1,250). But I just wanted my job back. I didn't spend the money because it could be used up. I had already spent most of my savings for my treatment. I chose to go to private hospitals rather than public ones so I could keep my secret.

Finally, I asked my father to apply for a loan, which I used to establish my own IT shop. The revenue was used to support my family's expenses and my sister's treatment. She also got HIV but passed away in November 2003. She got the disease from her boyfriend. I had two siblings; now it's only me.

When did you tell your family that you have HIV?

Not until 1998 when I had a PCP treated at a private hospital. A staff member asked me about my daily life and if I knew the cause of my health problem. I told her I had HIV. She laughed, saying "Oh, you knew it already?", and I said I did. She then told my family about it. They all cried.

Where is your IT shop? Is it doing well?

My IT shop is at home in San Kam Pang district. I've operated it for three years. Business is doing okay. In the public eye, an Internet shop is regarded as a bad place for children. People believe that this business takes advantages of innocent children. Police often come check my shop. But what else I can do? I don't have any other things to do. I have asked for the government's help but never get an answer. Every time they end up with meetings and more meetings, and I'm fed up with waiting for the government's decision. I needed money, so I struggled to support my family. My friend gave me this idea for business.

Your friends at the company knew about your status?

Yes, I told them when I was about to leave the office. I wanted to test their sincerity, and when I finally told them, I found that my friend and his family were very nice to me. When dining together with them, I use my own glass, which has a mark on it. I also use my own serving spoons. I even use my own serving spoons and glass when I dine with my family at home and when I eat out socially. I want to make them feel comfortable.

What were the reactions of people when they found out that you were living with AIDS?

They changed. They became distant, started to avoid me and gossiped about me. Even my relatives forbade me to use their toilets.

And has their attitude changed since?

Yes. My relative's daughter also had HIV, which she got from her ex-husband. She got infected at around the same time as I did, but didn't tell anybody except me. Even her parents didn't know. I would take her to doctors, but her family misunderstood the reason. I was stressed because her parents would curse and accuse me when I took her for medical treatment. It wasn't my duty to be responsible and be emotionally abused for others as well. I couldn't stand it! One day I told her brother, whom she worked with, to let her work at home since she couldn't work outside. We both felt more comfortable once her brother understood our position. I told him that I could take her to participate in any treatment program, including an ARV program.

Has your lifestyle changed after the infection?

Yes. I drink only boiled water, not iced water, to avoid coughs. Iced water causes the body temperature to drop to below 37 degrees Celsius, which means the body must use more energy to heat itself. I also avoid marinated or raw food because it is full of bacteria. I avoid chemical food and sodas. Not only my eating habits have changed, but I've also started resting and meditating.

What spiritual activities do you follow?

I meditate in a sleeping position. It requires me to concentrate on breathing in and out. I did it every day when I was in the third stage of AIDS and my CD4 had fallen to zero. Now I meditate less frequently because I'm back in the first stage [of AIDS]. I told the doctor that I was sure that I would make it, and reverse my stage from three to one, and I did it successfully. My CD4 has risen to 481. My viral load, which is now 130,000, was reduced to 400-something. I am currently taking anti-retroviral drugs and also consume herbal medicines.

Alternative therapies and medicines help to prevent you from falling into the second stage. It is an option while the anti-retroviral drug is expensive. But when my HIV infection increased and my white blood cells couldn't fight back, I had to take anti-retroviral drugs. But I didn't quit the herbal medicine because I was confident of its effectiveness.

So far how long have you taken the anti-retroviral drug?

Since 2002. The first time I took it was at Mae On Hospital. I have been using the same formula all along. I have also used *mara kee nok* (bitter cucumber) and *fa talai jone* (a local medicinal plant) even before capsules were available. The good part is I can reimburse the herbal medication expenses from my health insurance now.

Besides eating modifications, what other behaviors or changes did you find in yourself?

Now, I control my mood and temper, and make sure I take enough rest. I know that medicine won't work if the patient is stressed out. Stress leads to physical effects like headache, high pressure, heart problems, fever and weakness. The mood is more important than drugs and exercise. However, exercise helps release good chemicals in the body.

Could you please tell me about your sexual life?

After the infection, I used condoms every time I had sex. But since my symptoms emerged, I have not had sex.

What other illnesses besides the third stage did you suffer?

I had PCP for three or four years. The drugs were so expensive - it cost about 50 *baht* ($1.25) per pill. I couldn't afford them, and I didn't know how to take the medicines, or that I would have to take the drugs continuously for prevention. Moreover, I had a fungal infection in my brain, swollen pancreas and enlarged lymph nodes. So I had to use the anti-retrovirals to cure them.

Once I was seriously ill and was admitted in the hospital under a heart stimulation device. I had to spend about three months in the hospital every time I was admitted. I weighed only 36 kg, while now my weight is 59 or 55 kg. depending on my food and rest. Carbohydrates make me gain weight. I toast bread before eating it to ensure there is no fungus. I don't eat white bread, or breads with baking powder.

Overall, do you feel better now?

Much better, but I still cough and catch cold from time to time like ordinary people. I have no more poxes; I soaked *ma grude* (lime) juice and applied it as AHA[2] treatment all over my body for three months until all the poxes were gone.

Who advised you about the *ma grude* treatment?

I experimented with it on my own. I have seen TV commercials about AHA and had my facial skincare at Pan Cosmetic. They used a treatment comprising of AHA. So, I had an idea that limes and *ma grude* can be good substitutes. Twice a day, I applied the juice over my body and left it there until it was time for my daily shower. When I got a bit better, I washed it off when it dried. I was also bald earlier because of HIV.

Did you consult physicians about this treatment?

Yes. They warned me that I might be allergic [to *ma grude* and lime] or get inflammation as a result of acid. But I wanted to give it a try. Before I had poxes all over my face and body, and my head was bald, my hair turned gray and brownish. Now I don't have a skin problem, and my hair has grown back. I have discussed this with a doctor, and he told me that human cells could be reproduced well under acid circumstances.

Overall you're doing well, except catching cold once in a while, is that right?

Now I'm healthy, but what isn't okay is that I want my quality of life back. I want to get back to work. I want to get my Masters' degree but I haven't yet received a scholarship. I need to get my medicine too.

Please tell me about your treatment experience. Besides the anti-retroviral medicine, do you take vitamins?

Yes. Vitamins help with appetite. Even a simple fried egg became tasty. I take vitamin B complex everyday. I also exercise and lift weights everyday for 40 minutes. Now my appetite is normal and I can sleep peacefully.

Do you eat home-cooked meals?

Yes, because the food sold outside contains substances that aren't healthy, like animal fat or vegetable fat made from coconuts. It contains unsaturated fat, which can give you rashes. Local people believed eating coconuts could result in an allergy. I avoid everything that could give me an allergy and affect my CD4 count. I do everything to keep my CD4 count high to fight germs. I look after myself as best as I can. I eat seasonal fruits like oranges. I don't eat meat or veal, but pork, fish, chicken, and vegetables are acceptable.

You're quite well informed on health and treatment. Where did you learn about this?

From my hands-on experiences and extensive reading. I have never attended any seminars. I have already learned to take care of myself. Mostly, I learned and tried things on my own. I carefully observed what would happen to me after each experiment or illness. Therefore I can tell what is good or bad for me. I always note this information down in a book about my treatment records.

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[2] Alpha-hydroxy acids which are widely introduced to use for skin care and treatment nowadays

What else do you do other than exercise and meditation? What about herbal treatment?
Since 1997, everyday I have four capsules of *kamin chan* (turmeric) and *mara kee nok*. It has become a habit. If I forget to take the capsules, I feel like something is missing. I want to take the complete dose because I hope to live without anti-retroviral drugs, and also so that my symptoms do not return.

Have you used *ya mor* (traditional medicine in pot)?
Yes I did, but not anymore. Whenever I hear about good medicines, I go in search of them. As for *ya mor*, I tried it and found it ineffective and likely to contain fungus. I saw that when my father simmered *ya mor* for muscle pains and set them aside for a while, fungus appeared on the surface. I dared not take it. So I decided to use better, cleaner herbs[3].

Did you ever use holy water?
Yes. My parents and friends went to pay homage to the spirits as they thought I was ill because of dark magic. After all this, I have realized that it is all about the power of my mind. The mind must believe I have to live; I want to travel to nice places. When I was admitted at the hospital [during the third stage of AIDS], I cried with my doctor every morning. A nurse said to me that if I didn't have the will to survive, no drugs would be effective. She asked if I believed in willpower. I said no, but I wanted to try. That was the first time I learned to meditate.

At that time, I couldn't meditate in a sitting posture because my back hurt due to the effects of Amphotericin B. Before learning meditation, I relied a lot on Pethidine[4], but one of its side effects was that my body was unable to digest food. I vomited after every meal, but I needed Pethidine every six-eight hours to ease the pain.

A nurse cautioned me that I was addicted. I said I don't think so. I just wanted it to feel more comfortable. Only 15 seconds after the drug was injected through the intravenous tube, I could feel peaceful, no pain, and could sleep. I told the nurse that I was not addicted to the drug, and I was going to prove it to them. Finally I successfully decreased my demands for Pethidine after learning and practicing meditation. I gradually recovered, and could also eat normally and had no more digestive problems. I felt healthy and energetic. A HIV patient in front of my room used morphine to ease his pain, which was worse than mine. Some medications have side effects, like making our bones hurt or our heads bald. It took three years for me to recover from the third stage of AIDS.

Do you still meditate in the sleeping posture today?
Yes, and sometimes I do meditation while I am working. Sometimes I get stressed at work. I alert myself by sticking a piece of tape to my forehead. This is a test of how much stress I have when I frown. Some patients might use mirrors to check their emotions but I prefer to use an adhered tape. I got this idea from watching foreign TV shows when I was in grade six.

Who advised you about herbal treatment?
I heard about it from friends and relatives. However, some doctors said some herbs contain steroids, which increases appetite but also provokes side effects in long-term users, like heart attack. For example, *gwao krue*[5], which contains female hormones, helps enlarge the breasts, but in fact it has steroids.

What about *mara kee nok* and *fa talai jone*?
I have read about their effectiveness from books, and felt hopeful of being able to buy time [until AIDS can be cured]. However, herbal medicines had less of an effect on me through time, since the HIV

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[3] Cleaner herbs like capsulated turmeric and *mara kee nok* [4] A strong analgesic drug [5] A local medicinal plant that provably contains phytoestrogen hormone

infection grew stronger. Now I have to use anti-retroviral drugs together with the herbal medication. But I do not underestimate the benefits of herbal medicines.

After using anti-retroviral drugs for three years, do you feel better?

Yes I do. However, I didn't take a full dose as advised. At first, I kept it a secret, but later I told my doctor. According to the doctor's prescription, I had to take two pills of Combivir[6] and three pills of Stocrin[7] per day. But I took half the dose of Combivir because it made me so dizzy, I couldn't work. The doctor warned me that HIV in my body might be resistant to drugs, but I insisted on trying it this way. My doctor wondered how I would survive without the full dose.

I could not take the full dose. I guess it is because the doses we used were not appropriate for Asians, who are smaller than Westerners. However, my doctor told me not to tell other patients about this because they might misunderstand that taking the inconsistent dose is acceptable. I promised to keep it secret. I still take only two pills out of the total of three, as I need to suppress my HIV symptoms.

Do you share your health practices with other positive people?

Yes. They are not interested in the tips I give them, but rather in what I have done to feel better. Actually it is my discipline for over three years that has made me better.

Some fellow PLWHA who have witnessed the recovery of my health from the third stage to the first stage of AIDS did follow my advice. Back then, I was dark, had chapped lips and suffered a great deal from side effects of Primaquine[8].

You have recorded your symptoms, haven't you? Please tell me about it.

Yes, I record details of my treatments, for example, how long I should be admitted for, what drugs my doctor prescribes, their doses, etc. Otherwise I don't dare take the treatment! Once I had a bad experience with an anti-dizziness drug. I have an allergy to it. When the doctor ordered it, I didn't know it by that name. I fell very ill when I was injected. Since then, I ask detailed questions and have turned into a very picky patient. If the doctor or nurses do not give me details, I don't allow them to do anything. I have recorded all the details in my book from time to time. I don't rely on my OPD card as my records could be scattered. I just want to be careful.

Do you still do this?

No, my health history is settled now. I use only some major medicines. I will do it again only when I have to use new drugs.

Do doctors and nurses understand your intention?

At first, they were annoyed. But the friendly way in which I approached them, reduced the gap between the care providers and me. We could be comfortable with each other. I used to joke with the doctors and tell them that if they did not explain what they were doing to me, I would not allow them to treat me. Now the doctors at Nakorn Ping Hospital all know me well.

What is your opinion of the holistic approach to treatment?

For me, it involves living well, controlling your temper, getting good exercise, eating the right food, being social and taking medication. These are all the elements in the holistic approach.

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[6] AZT + 3TC [7] Efavirenz [8] An anti-malarial drug

Do you think you have treated yourself following the holistic approach?
I don't actually understand what the word means, but I think so.

Do you think the holistic approach is the core treatment for HIV-positive people?
Yes, I think it's a can't miss. We have to balance all elements.

Do you believe that your treatment has made you healthier?
Yes, I feel confident. Also, the anti-retroviral drug is my priority together with mood and exercise. Actually there's nothing a patient can miss - herbal food, fruits, or vitamins.

Is herbal treatment expensive?
I have social insurance. When I still worked at a company, we could apply for limited reimbursement, so we usually received bad drugs. Now the social insurance provides better service. I get reimbursed for vitamin C and herbs. I chose the insurance with the government's back-up. My insurance covers 200 clinics and hospitals nationwide.

What is the most challenging health problem since you developed the infection?
It is the pox, as it revealed my true status. I was not confident about the way I looked when I went outside. When my weight started to drop, I would stay home and eat to regain my weight. Among the symptoms of HIV are poxes and a skeletal body. I had taken AZT, which responded to infra-red and radiant exposure. That is why I had to avoid infra-red and radiant exposure, or it would affect my skin.

What are the best and worst things that have happened since you started taking all these treatments?
The best thing that has happened is that I became healthier and successfully got back to stage one, which means I would be able to survive until a good drug is available.

The worst thing is that I missed out on chances. I cannot get a job and pursue my studies in any field. I think I am ready to study further, but I have a financial problem. I want to go to college, not only to develop myself but also to socialize.

If you could go back to the first day you knew you had the infection, what would you like to do differently?
I would strengthen my moral support. I would be strong and study further, not letting everything go.

Any advice you would like to pass on to other positive people?
I would tell them to eat nutritious food, avoid canned sodas, and try your own experiments. If you cannot give up certain favorite foods, then eat them in order to survive. But you shouldn't do it too often or too much. You should avoid squid and seafood because they contain formalin, especially if you are allergic to iodine. Do a lot of exercise to build up and strengthen muscle fitness. The hormone and glandular system can function actively.

Temper and mood are very important. When society alienates you, just stay away and don't try to fit in. It is not good for your health. Never ask for moral support from others. It all depends on you and your mind. My hopes were destroyed by my employer and the government, but now I can do everything on my own because I have hope. I have to create the best drug, which is my willpower, within me. I [in part] control my own destiny, whether to live or to be cured.

FLAVIA KYOMUKAMA

FLAVIA KYOMUKAMA is a 35-year-old former teacher from Kabale district in south-west Uganda. She is the mother of six children, three of whom have died of non-AIDS related causes. In 1994, she was infected with tuberculosis; in order to access anti-TB drugs, she agreed to be tested. The results showed that she was HIV-positive. Since then, she has been working towards a Masters' degree and manages an AIDS Helpline in Kampala.

In 2003, Flavia became part of the Development of ARV Therapy Project, a collaboration between the Ugandan government and USAID, where she is provided ARVs free of charge for five years. She now uses a combination of ARVs and herbal medicines. A firm believer in spiritual energy and healing, Flavia is part of the church choir and spends much of her free time singing.

Please tell me a little about yourself.

I was born in 1969. After my schooling, I trained as a teacher, but after some time I lost the job. In 2001, after a very nasty encounter, I separated from my husband with whom I had six children.

Our separation came about because he registered all the property we jointly acquired in his mother's name and in the name of two of my sons. My daughter and I were left out. This enraged me. I decided to pursue a Masters' degree to have a competitive edge in the job market and to be able to take care of my children. But when he heard that I wanted to pursue a post-graduate degree, he refused to let me study. I insisted on going ahead with my studies for the sake of my future. Since we could not agree, we separated and I enrolled for my Masters' program.

Presently, I manage the AIDS Helpline in Kampala, Uganda. The service offers support and information on AIDS through a telephone helpline.

How did you come to know you were HIV-positive?

In 1994, after I lost my third child, I was infected with tuberculosis. I went to Mlango Hospital for treatment, but there was no medicine in the general clinic. To get medicine, one had to enrol in a project that was experimenting with some TB drugs, and you could only enrol after your HIV status was established. To access the drugs, I agreed to be tested and the results showed I was positive. The people running the program then put me on anti-TB treatment for eight months. They did not provide any ARVs.

Up to this moment, I do not know who infected me. But certain things made me suspect that my husband knew he was positive but did not want to tell me. My husband had befriended a woman whose boyfriend had died, but I cannot say the deceased was positive. Another thing that made me suspect my husband was positive was that when I used to take my blood for CD4 tests, he took his as well, but I cannot remember him telling me that he was going for testing. We continued to live positively with the disease.

Are some of your children infected?

I have not bothered to know their status because they have not fallen sick. It would also be stressful for me if I knew one of them was positive.

What was your immediate reaction on learning that you are HIV-positive?

I had done a course on HIV/AIDS counseling to counsel students at my school. Also, my friend worked as a staff member at the project where TB drugs were being offered. She and her husband had counseled me on HIV/AIDS. This had prepared me to some extent, and when I was told of my positive status, I managed to handle it. The next thing I did was to tell my husband. He was not violent on hearing the news.

But I decided to keep it secret from my other family members and colleagues in the school where I taught. I waited to fall sick before I could tell them. It never happened.

How has your health been since you tested positive? Had you been ill before?

Before being tested, I had TB, which was the reason I found out that I was HIV-positive. After establishing my status, I suffered a skin rash that has lasted for three years since the problem was first diagnosed in 2001. Even now you can see the last sections that have yet to heal (she shows me one of her hands). During the same period, my CD4 count fell to 85.

Generally however, I have been well because of living well and having good food with the right calories, at the right time and of the right nutritional value.

Who has helped you and in what ways?

Several people have helped me - my husband, when I was still married, my family, friends, my church and NGOs. Since my husband and I were infected, we used to discuss the issue as a family and it was very comforting. I had a shoulder to lean on. There was a friend who had lost her husband to the disease and she counseled me as well.

Towards the end of my marriage, my family gave me both social and financial assistance. At that time, my husband was mistreating me after we disagreed on my intention to pursue further education. At the same time, I did not have a job. So my family helped me pay rent and provide food.

While pursuing my Masters' degree, two friends who I suspect were also positive but did not disclose their status to me, gave me the emotional support I needed. They understood what I was going through and acted just right. Later, I joined a post-test club through the National Community of People Living with AIDS (NACOLA). Through this community, I got food supplements donated by the World Food Program. And to keep myself busy I enrolled in the church choir. I also started getting employment at different places.

Can you tell me about the kinds of therapies, medicines and treatments you have used?
My first treatment was to accept the condition I was in. This helped me feel at ease with myself. This was the greatest treatment for me. Then I used some herbal medicine, as my mother has been especially keen on this and supplied me with some herbal medicines on several occasions. I have used all kinds of therapies - spiritual, nutritional, herbal, traditional and modern medicine - as no single one can stand alone. Currently, I am on ARVs.

Which therapies have you abandoned and why?
I have not abandoned any therapy. What has changed is the frequency and the quantity in which I take them, especially herbal medicine. The reason is that each therapy has a role to play. There are times when I use herbs to prevent opportunistic infections, particularly at those times when I see the telltale signs.

Spiritual therapy precedes other therapies. I also use herbs in combination with ARVs. Herbs help me avoid opportunistic infections when they start appearing. The effect of combining therapies is that you get maximum value from the treatment. Besides, herbs complement ARVs because I take them as nutritional products. In the morning for instance, when I feel unwell, I take *moring'a*[1]. This herb is good for the general well-being of the body.

When did you start ARV therapy?
I started using ARVs in April 2003.

What made you start ARVs in 2003 after living with the virus since 1994?
My body system was very good. I had tried to make sure that I had good nutrition, and put off any opportunistic infection before it developed into something big. But when I separated from my husband in 2001, I was very stressed. I suspect my immune system started to collapse then. As a result, in 2003 when I did my test, my CD4 count had dropped to 85. My doctor advised me to start ARVs.

Buying the drugs became an issue, and that is when I was told of some people running a project called the Development of ARV Therapy. It is a collaboration between the Uganda government and USAID. They provide ARV drugs free of charge. They have enroled me in the project and I will be part of it for five years.

Which combinations of drugs did you start with?
I started with Combivir and Tenofovir, which I am still using.

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[1] A herb usually dropped into a cup of tea

What has your experience been with ARVs?

When I first started using ARVs, I had an attack of nausea and my skin turned black. The doctors said I was reacting to the sulphur component in the drugs. Soon the reaction stopped and the color of my skin normalized after some months. These drugs also make my throat feel dry and I feel thirsty all the time, so I drink a lot of water.

But other than this, I have not had any major ailments while taking the drugs. If you comply with the drug regulations, they work and can prolong life. In fact, I am relaxed and think about the future because I know I will live longer. They give me hope in life as I am regaining my strength.

Were you counseled about these side effects before you started?

We were given a lot of printed materials on the possible side effects we could expect when taking the drugs. This had prepared me. I decided to drink a lot of water and have a very good diet to minimize these side effects. The reaction has stopped. Nevertheless, my fear remains that the major side effects may come up again in the future, since I have been told that the drugs are very toxic.

Do you do tests of the liver and other organs to see how ARVs are affecting them?

At least every month, the project coordinators take our blood and carry out tests. Although we are not given the results, they tell us how we are doing. If there is a problem with one organ, they usually change the regimen.

Since I started taking the drugs, personnel in the Uganda government-USAID project have carried out tests on my CD4 count every month. But we are not given the results. They just tell me that my counts are okay. And since I have not fallen sick, I believe all is well.

How do you balance taking ARVs and nutrition?

Since I started taking ARVs, I ensure that I have good nutrition. There are a lot of fruits and green vegetables in my diet. My consumption of carbohydrates is high to enable me to counter the weakening effect of these strong drugs. I also drink a lot of water, which together with a good diet, helps to neutralize the toxicity of the ARVs.

How do you find the cost of the drugs?

They are very expensive, and if it were not for the project, I would not be able to afford them. For now, the project enables me to plan and save some money that I will use to buy the drugs after the five years are over.

Tell me about the spiritual therapy you practice.

Spiritual therapy precedes all other therapies. You pray to God to enable other therapies to work well. I also use spiritual therapy to manage my stress and boredom. I go for fellowships, retreats and spend much of my free time singing in the church choir. Since testing positive, I have also increased the number of times I appear in the choir during practice sessions.

What about nutritional therapy? What types of food do you eat?

My staple foods are *matoke*[2], roots and beans. These are always freely available. I am very careful about my diet to ensure I give my body the best I can get. So during breakfast, I have

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[2] A plantain banana dish

and fruits like bananas, oranges, passion fruits or watermelon. Fermented porridge made using sorghum flour is always part of my breakfast menu. It has to be there. During dinner, I ensure that there are proteins in my diet. I eat foods like meat, fish and sometimes chicken. I also make sure that fruits are included in my evening diet.

My choice of fruits or other foods depends on what I derive from them. Bananas have vitamin B, which is good for me when I am on ARVs. Oranges provide me with vitamin C, which helps in protecting my body against diseases, while watermelon has rare minerals that are good for food absorption.

How does the price of foods affect your diet?

The price of food is not an issue because in our country, food is cheap. My family also supplies me with food like sorghum, sweet potatoes, beans and bananas from the rural area. My house girl gets fruits very cheaply from the market.

Since when have you used herbal medicine?

I have used herbs for about two years now. My mother is particularly keen on them. Through group therapy, I have also come to know more about some herbs and what they do. I am still using some of them, especially to protect my body from opportunistic infections. There are other concoctions I use to manage my skin problem. Otherwise I use them on a daily basis as nutritional supplements. However, some of them are bulky and bitter and I do not have the appetite for them. So I use them once in a while.

Give me some examples of the types of herbal medicines you use and what they do for you.

I use various types of herbs to help me stop a cough or treat skin problems like the one I have been experiencing. Herbs like *moring'a*, which is usually dropped into a cup of tea, come in handy when my entire body is not feeling well. The herb is expensive; a 50gm tin costs USh 2000 (around $1).

I get some of the herbs from the Center of Traditional Medicine in Kampala and others from friends. Herbs are generally cheap. You can pick them from the bush and prepare the concoctions yourself if you know how they look and what they do.

What kinds of medical health advice have you heard over this time?

I got information on proper nutrition and eating well from workshops and from friends. I also learned that I would have to reduce the amount of fat in my diet. The other advice I received is to stop drinking alcohol, smoking and abusing drugs. I have also learned about the importance of vitamins. During some workshops, herbalists said that herbs help improve immunity. They advised us on the dosage and asked us to be careful, because if abused, herbs can be toxic. To ensure these things are observed, they advised us to get the herbs from only registered practitioners.

I have also heard about the importance of compliance and adherence to drugs, and the side effects and nutritional requirements needed when on ARVs, as well as the importance of rest. The information has come from various practitioners like doctors, friends, counselors at the Joint Clinical Research Center in Kampala, herbal practitioners and lecturers at the university. Doctors and friends have also advised me to go to the gym, so I go there sometimes, or just do some dancing.

The most important advice I have heard is to do what I can to value my life and apportion my time well. I should not overburden myself with work, but ensure that I relax and visit friends. I also need to have a positive outlook to life and whenever there is a problem, to not panic but know that I can deal with whatever problems come my way.

How do you feel about this care?
The information is good, but sometimes it is inadequate especially when given orally. You miss some things and can translate them incorrectly. So it is better when it is written. In some projects we do an oral quiz and you feel you have understood the information well. Nevertheless, the information has empowered me because I can get updates on new drugs, and better and cheaper ones like Combivir and Nevirapine.

Do you feel that you have a good sense of the various treatments of opportunistic diseases?
Yes. I can treat common skin rash using herbal concoctions and other skin ointments. But I have to visit a doctor for advice on complicated diseases and infections. I can also manage ailments like malaria and cough. But in most cases, when I feel that I am going to get sick, I preempt it by taking a lot of vitamins, and fruits with vitamins B6 and B12.

In most cases, I use herbs and other cheaper conventional medicines to manage less serious opportunistic infections. For more serious infections like TB, I have to rely on the project to get treated.

How has money or your financial situation influenced your treatment choices?
Since I am part of a program, the money issue has not come into play. This might become an issue once the project comes to an end. Nevertheless, ARVs are expensive for the urban and rural poor, but somewhat affordable for the working class.

Have you changed your life in any way because you are positive?
My eating habits have not changed very much. There is however, an increase in the daily intake of fruits and my consumption of water is very high.

I actually work more now than I used to when I was a teacher. I look for private work because I need to invest for the future, and you know when you have HIV/AIDS, one needs investments. I have to plan for my own future and that of my three children. This has been the driving force for me to work hard.

Since I separated from my husband, I have got a new boyfriend who is also HIV-positive. But our sexual conduct is limited. We have decided to live separately, but religiously use a condom whenever we have sex so as to avoid re-infection. Also, since I have known of my positive status, I spend more time in the choir. This prevents me from being bored and gives me a lot to think about.

Have others changed in the way they respond to you when they learn that you are HIV- positive?
When I learned of my condition, the first person I discussed it with was my husband. He was not violent. Although my sister who has a medical background showed all the signs that she knew that I was infected, it took some years before I told my family and other people. Perhaps things would have been different if I had told them earlier.

When my family members and most people learnt of it, they were sympathetic and caring. Even those who disliked me were sorry. But some showed me a lot of pity, thinking they were not in danger of being infected. I told them that pity is not what I want. Instead they should empathize with me. My family has supported me a lot, particularly after I separated from my husband while I was infected.

They gave me the financial and social support I needed.

What did you learn from this?

I learnt that I am a loved person. I did not realize how much my family loved me until my husband threw me out. When this happened, I was full of anger and hatred. I lost interest in life and work. I hated hard work and lost so much time and a productive part of my life. Later on, I realized hate and anger is due to lack of information and this can be very destructive.

The experience has also taught me to be good to other people, because you do not know who will give you support when you need it. Humility helps one to get more information on how to manage this disease.

What has been your most difficult health challenge during this time?

The most difficult health challenge has been stress. When I separated from my husband, he took all the property we had jointly acquired. He also took the children with him. I was left alone. My immune system started to collapse and I lost my appetite for food. My CD4 count reduced drastically. It has taken me about three years to get over it. I am just recovering my appetite.

What has been the best and the worst aspect of your treatment experience?

My best moment was when I found there are drugs that could prolong my life, which I could get free of charge for five years through the USAID project. Due to these drugs, I have regained my strength and can explore many options as I can see a future ahead.

Potential employers are ready to hire me. Even now, I have more job opportunities than ever before. When I leave the helpline at the end of my contract, I have a job offer with NACOLA as well as VSO-Kenya. The latter has made me a very good offer. As part of the employment benefits, they will also give me drugs.

My worst experience was when I started taking drugs and saw the skin rash and the change in the color of my skin. I dreaded the other side effects that were yet to appear.

It is like I am in a Catch-22 situation. On the one hand, I am trying to reduce the virus, and yet I am courting other life-threatening conditions - liver toxicity, hypertension, and paralysis, which may appear due to the use of ARVs. These are contradictions that make you anxious and afraid.

If you could go back to when you first knew you were positive, what would you do differently?

I do not think I would do anything differently, because as a secondary school teacher, trained in counseling and HIV/AIDS, I was well equipped with the information when my status was first confirmed. Also, at that time, HIV/AIDS had become an accepted thing in this country.

What can others learn from your treatment experiences?

Treatment is effective if one complies with it and eats a balanced diet. Exercising and having a positive outlook to life is very important if the drugs have to work. People should also know that various treatments are both complementary and supplementary. One has to get spiritual therapy, and accept his or her condition as part of treatment. They should have time to love and be loved. Make time for work and other things as well so that you are not stressed. Basically, the disease should be treated through multi-approach management.

Some people are scared to take drugs that are given in projects, fearing what would happen when the project comes to an end. This fear is making them stay away from the projects. But they should know the war is to live another day, and five years is better than a day. Leave the future to what happens when that time comes. There might just be another similar project.

What advice would you share with others who are positive and those who are negative?

For those who are not infected, I urge them to guard themselves from getting infected and have compassion for those who are infected. If positive, continue to seek information and accept the condition you are in. Group therapy and other support networks can lend a lot of support. They should also look out for any information on HIV/AIDS.

They should further improve their nutrition - increase fruit and green vegetables intake, and water as well. They should remember herbal medicines can manage opportunistic infections, but they should be careful about where they get them.

For those who are infected and are not on ARVs, they should not feel depressed but instead live positively, eat well, and go on ARVs only when no other option exists. This is because ARVs are a lifetime treatment and have to be adhered to when traveling, sleeping or working. Lastly, they should remember HIV/AIDS is a manageable and preventable disease, and openness and acceptance have the capacity to postpone death.

GEORGE OWIRO

GEORGE OWIRO is married with two sons aged seven and five. He and his wife are originally from Kisumu, Kenya, but were raised in Nairobi where they married when his wife was 19 and he was 26. He now lives in Eastleigh, Nairobi and is 33 years old.

In 1997, both he and his wife tested positive for HIV; their sons, however, are negative. George has worked with a number of community AIDS service organizations in Nairobi's slums. He provides home-care and nutritional counseling to families coping with AIDS when he can - sometimes as a volunteer. Today he works only part-time at Abba Light Clinic and has a very hard time providing for his family. He often gets his transportation paid for by the organization, and then walks to work to save the travel money for food for his family. George's greatest concern is taking care of his wife and children and living to see his sons grow up.

How did you come to know you were HIV-positive?

Seven years ago, during the first year of my marriage, my wife was waylaid on her way home from casual factory work and was raped and sodomized by thugs who took everything she had. As my dear wife worked late into the night, I was preparing to go to church when she arrived home sobbing and bleeding. She told me what had happened and I did my best to console her, but she cried and cried and cried. I ran out to find the thugs, but they were gone. The following day, we visited a social worker who told us many other stories of rapes in our neighborhood, which were all much worse than my wife's experience. I kept asking, "Why me?" but at least my wife was still alive. The counselor advised us to go to the hospital for tests and treatment. As I had already lost my job and my small secondhand clothes business had closed down, we had little money in the house - probably only 25 shillings (less than 30 cents). The only way we could go to the hospital was to walk over ten kilometers. It took a week before we managed to get to the hospital. We never went to the police because we all agreed they would do nothing. Sometimes I wonder if this horrible incident was a blessing in disguise, because we do not know for sure that this is how we got infected, but it did make us aware of our status.

My wife was traumatized by the rape, and, though I wanted to use a condom when we made love, she was sensitive to this and felt that I now found her dirty. To console her, we were intimate and did not use a condom. Then one day I woke up and knew we had to visit a VCT (Voluntary HIV/AIDS Counseling and Testing) center together. We did and, as we watched the test results to see if a double line[1] appeared, we were frightened but we were together. Both our tests were positive. This was about one month after the rape. The counselor was totally burned out and her advice was not very helpful. She did not even mention our unborn child.

My own family has lost six or seven people to AIDS, including my father's younger brother, aunts, nephews and nieces. I was aware of AIDS but knew that my family felt a strong stigma, especially my father who is very strict.

What was your immediate experience on learning that you were positive?
I was so shocked and thought about so many things. But I knew I had a family to take care of, and if I decided to separate from my wife, our children would suffer. I also realized that all that I had achieved in life was now useless. So I started writing my will and looking for people who could take care of my sons if I died soon. But then I realized that living is like driving a car - we have to stay focused on the road ahead. We can check the side mirrors to know where we are, but we must look forward to move on.

After that, I went for tests where I met a friend who had lost his wife to AIDS and was very open about it. He was there to have his CD4 count tested and introduced me to a support group at WOFAK (Women Fighting AIDS in Kenya). He told me that my world would change like a miracle once I met people there. My wife was reluctant to go, but I went. And the encouragement I got there was amazing! I met so many friends who looked just fine and had been living with the virus for years. Since then, my wife has also joined a support group and learned how to cope. She gave birth to our first son, who turned out to be negative. Then, a little more than a year later, my wife got pregnant again. I asked her to flush it out but she said, "No, no, no, this is not in my culture." I realized that this was her decision. She did not breastfeed the second baby, and initially he was positive, but eventually at one year, he turned out to be negative. So, at this moment I can look at my son who is going to school and just feel so excited.

Are you able to be open with your family now?
No, I am not using my real name here because my family could not accept it. When my father's brother fell ill with AIDS, he was very judgemental. My dad handled the situation in a terrifying way. He accused him, "See, you keep running around with women! You see, who will take care of these children?" He spoke ill of my uncle and this was 1997. But just recently, we were watching a documentary on AIDS and my family again said that anyone infected with HIV was a bad person. My younger sister said that she would not share a mug of tea with that kind of a person. My wife and I just

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[1] This would mean that they had tested positive for HIV

looked at one another. They have a strong stigma towards HIV/AIDS. My family does not know anything about my status. Also, in Kenya, if I disclose my status first, our families will blame my wife. If she discloses hers first, they will all blame me. She also does not dare tell her family.

Life is what you make of it. Positive people are human beings. We need to be loved and protected. I am jobless, and I struggle to make ends meet. But I do not help take care of people who are ill because of HIV only for money. Take it from me. I love doing it because I love those people. Whatever they are facing is not their wish. We could be in the same situation these people are in. So, I often ask my mother, "Would you want people to run away from you?"

How has your health been since you were tested?

We have been fine, except for a few illnesses here and there. I have been fine except for a few chest pains that I have managed to get rid off. I also had pain in my joints that I have managed to ward off with time.

Sometime back, my wife had herpes zoster[2] on her back and she treated it promptly using a poultice from the leaves of *lantana kamara*[3]. It cleared the herpes. On another occasion, she treated some boils in the genital area also with *withania somnifera* (winter cherry). Since then, she has not got boils again.

Who has helped you and in what ways?

My friends helped me a lot over the years. The support group at WOFAK changed my attitude and gave me hope. Also our boss here at Abha Light Foundation, who is a homeopathic doctor, really helped me in the sense that I got advice from her on nutrition. I met her when she came to our support group to talk about nutrition and I was so impressed by what she told us, that I approached her and established a relationship with her. Now, when she has work she employs me. She has also shared a lot of health advice and gives me homeopathy and other natural treatments.

As you can see, these natural treatments have kept me going for the last three years. Apart from that, the boss has also given me a job that has ensured that I can take care of my family and eat the type of foods recommended for people who are living with the virus.

Can you tell me about the kinds of therapies, medicines and treatments you have used?

My nutrition has really changed because I no longer eat sugar, nor do I drink tea. I just eat porridge and groundnuts, and sometimes cassava for breakfast. At lunch, I have salads and boiled foods. I eat lots of green vegetables, bitter indigenous leafy greens. I love ground sesame sprinkled on my food or boiled into it to add nutrition and good taste. I also use a lot of whole grain, and usually mix about five ingredients to make my version of Kenyan *ugali* (cornmeal porridge): whole grain maize flour, finger millet, soya flour, whole wheat flour and cassava flour. For porridge, I usually mix about 10 ingredients: whole grain maize, finger millet, wheat flour, soya flour, green gram flour, groundnut flour, ground sesame and some other ground bean flours. At times I have herbal teas, which I like to flavour with cinnamon, ginger and cardamom.

I have learned to love salads. Sometimes I eat only a hearty salad for lunch with a variety of vegetables and a good salad dressing such as olive oil, vinegar or soy sauce. I know some of these items are expensive, but I'd rather have a little of some quality olive oil than a lot of cheap cooking fat, which is so bad for you. Vinegar is good to add in the diet because it boosts appetite, improves digestion and

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[2] Also known as shingles or zoster, it is a viral infection caused by the same virus that causes chicken pox. People with a weakened immunity for reasons like AIDS are prone to developing zoster

[3] A flowering weed that grows throughout Kenya

helps maintain the right acidity levels in the blood and intestines. I eat a lot more fresh foods than what is usual for Kenyans. These changes have created a lot of problems in my house and with my wife, who is really finding it hard to adjust.

We have been told that things like tea leaves and condiments like tomato ketchup have chemicals that stress our immune systems. As you see, the virus is already fighting us and we cannot add an additional burden to the immune system.

I used to have some abdominal pains but following the advice given in the book, *Great Health, Naturally!*, published by Abha Light Foundation, I started taking psyllium husk fiber everyday. Soon, the pains went away and my stools took on a healthier look. Those pains haven't returned.

Another thing I learned to eat is Brazil nuts as a source of natural selenium. At first it seemed that Brazil nuts were expensive, but you need only one nut a day so the cost is, in fact, very cheap (less than $1), which comes to only about 100 grams per month. After a few days on Brazil nuts, my fatigue and tiredness went away. I had a lot more energy and gained my appetite. When I can afford the olive oil, I also try to have an entire lemon-olive oil drink, which is described in this book. Basically, I mix one whole lemon minced very fine and strained with one cup of water and three teaspoons of olive oil, and add this to juice or water. After taking that my sleep becomes so easy. Even my digestion becomes so good. The drink is mainly to improve the function of the liver, though it does some other good things for the system as well.

I use herbal medicines occasionally that take care of my skin and the boils and joint pains that I feel. These include *withania somnifera* and aloe vera. I felt itchy all over my upper body so my doctor gave me some colloidal silver[4], which can be taken only for a short while, but is an effective natural antibiotic. The itchiness soon went away and didn't return.

I have not encountered any conventional medicine. I don't use any modern medicine because I fear the side effects and dependency on the drugs. Once you are entangled in the use of antibiotics, you become a slave to the drugs. The homeopathy and herbs that we are using here are natural, and you don't have to take a full dose to recover fully. The homeopathic pills are so small that you think they are not working but, if you ask me, they do work. You only take them when you are not feeling well and they work. I had chest pains some time ago but since I started homeopathy, I have seen changes and I don't feel pain anymore. The pain I had was a sharp piercing pain across the chest, which was not TB. My boss gave me homeopathic Bryonia 30 for three days and then the pains went and never returned.

You use your own experiences in the outreach and home-care work that you do. How do you show the importance of a good diet to people who have little money to buy food?

Good nutrition does not mean that you have to have a cup of tea, a loaf of bread and a kilo of meat. The people I work with are very poor. So I say, get even a quarter kilo of beans, a quarter kilo of soya, a quarter kilo of green leaves (kale), which are very affordable and nutritious. This is better than eating meat, which is hard to digest. Secondly, I tell them not to drink sweet milky or black tea. Just have inexpensive porridge mixed with different types of cereals. It has all sorts of nutrients. I also learned that the intestines of a cow are very rich in protein and also very cheap. Or I teach them to make a soup from bones of the marrow and add tomatoes and onions - it is very good for you.

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[4] A powerful, natural antibiotic and preventative against infections that acts as a catalyst to disable the enzyme that one-celled bacteria, viruses and fungi need for their oxygen metabolism

My own main treatment is my diet. When I was tested, I realized that positive living meant strengthening my immunity. Medicines have side effects and some chemicals cause harm. I asked myself how the old people in our communities lived for so long and were so healthy. How did they do this? In the olden days, they did not have cooking fat, margarine or cheese. These people ate whole foods and we are trying to learn to do this again in my family.

How do you know your approach is working?

Well, my wife did not believe in the diet like I did. She still enjoyed black tea with sugar and milk and fried foods like most of us Kenyans. But she realized I was right when she tested her CD4 count, which was 364. I did my test after her and mine was 893. So now she is changing.

Why did you get a CD4 test?

They were giving out a free supplement at the Kenya Medical Research Institute. They tested a lot of people, but only those with CD4 counts under 500 were accepted.

So, it sounds like your two main treatments are nutrition and homeopathy. Can you say a little more about homeopathy and why you use it?

Homeopathy has no harmful chemicals. It ignites your immunity to combat whatever attacks your body. I think this makes sense. My boss gave me a mini-kit of homeopathic remedies and a book on how to use each one. We have found that they work, so even my wife never leaves home without this mini-kit. She can tell you how to use *belladonna* (black cherry) for headache, *aconite* (monkshood) for colds and the flu, and *lycopodium* (American Ground Pine) for stomach disorders. We also use this kit to treat our two sons.

Have you tried anti-retroviral therapy?

The mention of ARVs scares me. There is a lady who uses the drugs and she has grown so old that she looks like she is 70, and yet she is only 40. Her face has changed and even her walking style has changed. She walks as if she has wounds on her feet. I read that many people in South Africa are rallying on the street for ARVs, but I have been so concerned about the side effects. Even though people can now get these medicines free, someone may give them to me for only six months, and then what will I do? I am jobless. Should I eat all the food in the house just to be able to take these medicines? And you know you have to take these drugs continuously, not to mention the cost and the time. If it were the last option then I would take them, but if we have any other options then I would opt out of the therapy because of the lethal side effects that I have seen on people.

At our clinic, we visit people who are too sick to leave home and I have seen very big changes in their health after the homeopathic remedies. But they cannot pay. What can we do but help them anyway?

Do you feel you have a good sense of the various treatments available for AIDS-related illnesses?

I have been told that I have to be very careful with any ailment that attacks me. The doctor has said that anything small must be taken very seriously. I know where to go when I am attacked by any ailment, I have a good sense of the opportunistic infections, and I know where they are coming from and how to handle them. The care I am getting is one of the best in the country, yet at times I scare myself with imagined fear. You see, I am not sick regularly like others. So, any time I fall sick, I irrationally fear that now I'm going to die because in fact, I have never been down completely, not even for a day.

How has money or your financial situation influenced your treatment choices?

All treatments cost money, and the whole idea of trying to treat AIDS has been turned into a trade. In this country, it is killing so many people who could have lived. But I can say that the traditional aspects of care and treatment are the best. Many of the caregivers are relying on results. They insist on nutrition as a major component of their treatment. Like here at Abha Light, we are always told things to eat along with the remedies we are given.

How has your life changed since you found out your status?

Spiritually I haven't changed but other aspects of my life have changed. I used to be a sportsman but with the kind of life I am living, I can no longer run because of the pain that I usually feel after training sessions. I can only do very light exercises.

My sexual life has changed too. I used to be a very romantic man and would indulge in a lot in sex with my wife, but we were warned that we could no longer do it because we risk re-infecting each other. So this has really slowed down my sexual activities with my wife. She understands the risks involved though.

Nowadays I can say that I know things I never would have known about life and health. I think of those positive people who are accused of having loose morals and I know that we could all be infected. There is no wrong here. I also see misguided people turning to the church. One of my friends, a young lady who died last year, asked me to go to overnight prayers all the time. I told her, "Look here, just be yourself. The God you used to know is the same God you know now. Why do you think going to church every night, every morning, will change things?" I believe we have a living God here inside us. I find my religion in myself.

Also, communication between my wife and me is very close. I know that she is the only person who knows whatever is within me and I am the only person who knows what is within her. We are very close and all our efforts focus on our family and kids. We are struggling for the young boys because we do not know how long we will live. In fact, my prayers when they were young were just to have the time to see my young boys to the age of 10 years - then God could take my life. Now, my eldest is already seven. I believe that the 10 years I was praying for may be given to me.

I am not really praying for a cure. I can have this condition for as long as is possible, I am ready for it. I can deal with this. You know, when we have our own parties, we refer to how long we have been positive as 'getting degrees'. So no one knows what we are discussing. Now I have a seven-year degree. I may live to get my 30 year degree, then I will be a lecturer! And at the same time, I will be a very good researcher because for these 30 years, I will live with the virus and I will do research for myself. In fact, I think I will have done better research than the doctors and professors!

SATISH DHOLE

SATISH DHOLE worked as a surgeon in the small coastal town of Ratnagiri in western India until he got HIV in 1994. The diagnosis shattered his health. His weight dropped from 68 kg to 38 kg. His CD4 count fell to 38, he got opportunistic infections ranging from herpes to cerebral atrophy, and in 1996, his doctor gave him only two months to live.

In 1998, four years after he was diagnosed as positive, Satish embarked on a treatment regimen based on a mix of healing traditions: ARVs, yoga, nutrition, breathing exercises, and spiritual healing. It is unusual for a doctor trained in allopathy to turn to other healing traditions, but Satish believes that his recovery truly began only once he had found mental peace - the acceptance to be at peace with himself and the world. Since that day, he has been on a sustained path to recovery.

In the last few years, Satish's CD4 count has increased to 273, and his weight is a constant 52-53 kg. He practices as a part-time physician and has set up a group for positive people. His wife, also a doctor, works in a government hospital. Both his wife and daughter are negative.

What were the circumstances under which you were detected to be positive?

It began gradually, and nobody could think of such a diagnosis in the beginning. It began on 17 October 1994, when I had a bout of very high-grade fever for only a day. With just one tablet of Ciprofloxacin[1], it disappeared. As everybody does, I stopped treatment with only one tablet. Before that, I used to go to the gym, I used to exercise regularly, I used to run. But after that episode of fever, I started feeling a little weak. I was about 68 kg before that. I started losing weight gradually from October till the next May.

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[1] An antibiotic used to treat bacterial infections in many different parts of the body

In May 1995, I saw a family with massive pulmonary tuberculosis. All of them - father, mother and children - all of them were suffering from tuberculosis. One of them needed an operation, so they had come to me. At that time I felt something going wrong in my chest, I don't know what, I can't explain it to you, but I felt that I was getting their infection.

In the last week of May, I started getting fever in the evening. About 100 degrees. I was working so I ignored it. In the second week of July, I got a severe sore throat, and high-grade fever, and it just did not come down. The fever used to range between 101-102 degrees. I took Bactrim[2] for the sore throat, and some other antibiotic, but I did not respond. I started feeling dehydrated, getting weaker.

One fine day I felt that I needed indoor care. I felt I needed to get admitted. So I contacted a local surgeon and asked him to admit me. I forced him to start IV fluids on me because I knew I was dehydrated. Nobody else could believe I was dehydrated, because till then my weight was 64 kg - the weight was not fitting into the picture.

I think I got admitted to hospital on 16 July 1995. My brother was to get engaged the next day.

Then?

I was put on IV fluids but the fever never came down. It remained persistently at 100 degrees, and would shoot up to 102, 103 degrees. So a physician was called, he examined me and went out of the room. The physician asked me to get my Elisa test done. The test was done, but the result was not revealed to me. The doctor assured me that everything was fine, but I knew something was wrong. Just the evening before, I had asked my wife to have a look at my throat. She examined me and said I had candiadiasis[3]. I could not believe it. I was shocked. That was the beginning of the disaster that was to unfold.

Nobody told me that I had tested positive on Elisa. But the moment the reports arrived, the doctor referred me to Dr V.R. Pai at K.E.M. Hospital in Pune, then one of the only doctors treating HIV. Everyone in the house was shocked. We went through disbelief, mental trauma and all the emotions that go with it, but we were still hoping against hope that it may not be true. Maybe he had done something wrong; maybe it was not correct.

By then my illness had crossed all possible limits. My fever used to range between 104-105 degrees; it never came back to normal. I was terribly dehydrated. I had lost all my appetite. I could not even eat a teaspoonful of food, water or anything solid.

So when did you actually learn that you were positive?

The Western Blot test was done at K.E.M Hospital, but for two days I was kept in the dark. By now, I had some inkling that something was terribly wrong with me. So when Dr. Pai came on his rounds, I asked him, "Just tell me what is wrong with me." I asked this question in a sitting position. But I was so weak, that by the time I finished, I fell back.

After I regained my composure, he told me I had HIV. It was a terrible thing to reveal. I just closed my eyes and said, 'Oh God'. And then everything was just over. My whole life was spoilt, in the sense that apart from the personal loss, my professional life was also spoilt. As a positive surgeon, you can't operate. This is a small place - it was like a big bomb going off and it destroyed me down to zero professionally.

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[2] An antibiotic that treats different types of bacterial infections such as urinary tract infections, bronchitis, ear infections, traveler's diarrhea, and pneumocystis carinii pneumonia

[3] Typically a vaginal yeast infection

What kind of treatment were you being given then?
I was in that hospital for about eight days. I suffered from all sorts of infections. I had herpes, I had severe diarrhea, I had fever, I had massive pulmonary cough, my whole left lung was fired, I was breathless, and in between I had massive tachycardia[4] with my pulse rate going up to 160.

After eight days, there was no improvement. I was just as bad as I was before. In between, the doctor had put me on AZT. At that time, AZT used to cost about Rs. 6,000 (US$ 133) a month. It was not available in Pune, so my brother had to go to the Cipla factory, 10-20 km away from Pune with a prescription and get it from there. The doctor put me on one 100 mg tablet, three times a day, which was inadequate, and was actually half the dose. We took an 'against medical advice' discharge because there was no improvement.

We came back to my hometown, Ratnagiri, on 28 July. Personally I wanted to die, if at all, in my own house, not in a hospital. Mentally I was ready to die. In fact I wanted to die, because all that I had learned in all these years, was literally washed away in two days. I also experienced apprehension, fear about the status of my wife, my child - my daughter was just a year old then, and it was terrible to think of their condition.

I had given up hope of ever living and was ready for death. The most horrible time was when my wife went for testing, and even more horrible than that was when my daughter was to get checked for HIV. Those 48 hours before we got their results was the most horrible time. But with all God's blessings, my wife tested negative, she's still negative, and my daughter turned out to be negative too.

And what happened with your brother's engagement?
I could not attend my brother's engagement. We explained my status to his in-laws - they thought about it for a day, but they are educated people and so they accepted it. I could not even attend his wedding.

Did you continue taking AZT at home?
When I came back home, the diarrhea, weight loss and fever continued. My hemoglobin dropped from 12 to 6.7 because of the side effects of AZT. The AZT was stopped because I could not tolerate it.

For three months from 16 July onwards, I did not sleep for a minute. When I yawned on 17 September, my face was so taut that I could not even yawn properly. When I finally slept between 1.30am and 4.30am, everyone was so happy, that finally my cycle was returning to normal. My mother told me that during this time, I looked like a dead man. I had no expression whatsoever. I would keep staring at the ceiling all day and night long. Then gradually I came back to my normal cycle, but I was bedridden and my weight was down to 43 kg. All activities were carried out in my bed itself. I used to use a bedpan, have my meals in bed. Just by getting up in bed and lying down I used to feel breathless, because of low hemoglobin, no resistance, multiple lesions, massive tuberculosis, and God knows what other complications I had.

What do you still remember of those days at home?
By the end of September, physiotherapy was started, and I started getting out of my bed. In the last week of September, for the first time in three months, I came out of my house and sat in a chair. It was a pleasant evening. I cried for 10 minutes because getting back to this stage seemed impossible.

In between, we heard that Dr. Pai had met with an accident and passed away on the Mumbai-Pune highway. A truck had struck his car and the gory description came in the papers. The description was

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[4] Increase in heart rate. An increase beyond 140 is considered dangerous.

a terrible reminder of death for me. It was like the God of death telling me, "I can take you any way I like, anytime." For me, it was living my death all the way through till 1998. It was not a happy, ordinary life. I would describe it as living my death.

During this period, I used to take about 17 tablets[5] a day. Apart from that, the local *ayurvedic* physician started me on two different medications - one of them was a *kada* or broth, which I took three-four times a day. I also drank wheatgrass juice everyday.

I also took streptomycin injections, which were terribly painful. There was no fat on my buttocks, so they were very painful. Every second day, the same side was used for injection. I tried my thigh once, but it was so painful that I could not stand. So it was decided that the buttocks were the ideal site. After three-four injections on each buttock, it was hell every time I had to be injected. It's a thick oily injection, which you have to inject with a large bore needle. There was no fat, no muscle, and it used to go very close to my bone. I used to yell literally for 10 to 20 minutes after every injection.

Why did you decide to have the *ayurvedic* broth?

Because, personally I believe you must take the best available in all practices. I don't say that *ayurvedics* or homeopaths are quacks. Personally I have experience of *ayurvedic*, homeopathic drugs that have worked very well, even before I was sick. So I thought why not try this out? That was our attitude, in the sense that if it is going to work, then I will be better; if it is not, then it is not harmful.

When this illness started, everybody was so shocked that they had all given up hope. But it was my wife who said, maybe if he pulls through this time, maybe after two years we will have some invention, some drug we will be able to buy. This was her attitude, and it is her attitude that saw me through this hell that I've been through. In 1995, no one expected me to live except my wife.

She was so calm, so composed, even through the acute illness. She was to appear for her post-graduate endopathology examination during my illness, but unfortunately she could not complete her post-graduation. She left her studies to stay with me and now she's a medical officer in a local hospital. It was her attitude, her willpower that saw all of us through these days of turmoil. If my wife were not there, I don't know, maybe I would've been up there.

And the physiotherapy was her suggestion?

Yes. The moment I started recovering, all of us being doctors here, we know that if I have to get back to work, then I would need some exercise, so why not try this?

One of the complications that developed was foot drop[6]. It was not evident but I could feel it because moving my right foot upwards was difficult after I came back from hospital. To recover from that I needed physiotherapy, and being a doctor myself, I knew I needed some exercise, at least to move my hand and legs.

So it started with just moving hands and legs, 10 times, three times a day. Then getting up and lying down, and after maybe 15 days of such therapy, I could walk with a walker in my own room. Just to walk twice in this room was difficult for me in the beginning. After 15 days of such exercise, I came out for the first time. Till then, the room was my everything - every activity was conducted in the same room.

How did you start recovering?

By then everybody, every Tom, Dick and Harry in Ratnagiri, knew about my HIV status. And it was a terrible time because nobody used to even come to me. Well, one fine day, a gentleman came and

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[5] These included chloroquin, ciprofloxacin, streptomycin injections, INH, ethamutol, PZM, parazedonum, Polybion syrup, haematinic syrup Dexorange, capsule Forcem.

[6] A significant weakening of the toe and ankle

offered me work as a part-time professor. It was a god-sent opportunity to get away from this vicious cycle of no practice, no income, just sit at home and think about yourself, think about your disease, think about your own death...

So I started work as a part-time lecturer in physiology and anatomy at a local college. I worked from 11.30am till 1.30pm, taking one-two lectures a day. Apart from that, the Indian Medical Association started a cancer detection centre. That was also a part-time job where I could examine, diagnose and refer. I started going there around 9.30am till 11.30am. This job lasted for about four months.

But you were healthy enough to do this?

Yes, I was back to my health. My weight picked up till 52 kg, my hemoglobin came up to around 10, 11 maybe, and I was in a position to work. I regained my strength, I used to exercise a bit with the Exercycle, my diet was fine, I used to eat a lot, maybe my TB treatment was working - I was still on anti-TB treatment. I'd stopped all ARVs, all *kadas*, all wheatgrass juice. I was taking only anti-tuberpostine.

But it was still a terrible time. To come home at 1.30, sit and do nothing. In February this job got over, so I was jobless again. My wife had to leave her post-graduation, find a job. For about four-five months, we were both jobless. Every negative thought used to run through my head. It was not depression; it was a combination of 'n' number of emotions put together, it's not explainable, what the feeling was.

And then?

Well, I remember we had gone for somebody's engagement that summer. While coming back, I was having a soft drink when I felt pain radiating from my back to my neck. That was the first indication of the illness. By the end of May, I was finding it difficult to swallow. It was difficult to get gas out of myself so I used to bend just to get that gas out. Nobody suspected what was going wrong because the throat was clear. In two months, I lost about 14 kg; my weight went down to 38 kg. I was a skeleton, lying down, not responding to any treatment.

I started getting ulcers in my mouth. Nobody could diagnose what it was. The number of ulcers in my mouth increased to about 23. My intake went down. I used to eat only potato chips, that too without any salt, chili powder or spices. Finally a stage came where I could not swallow, and I started drinking only half a bowl of milk, half a bowl of *kokum*[7] juice, and one or two glasses of coconut water. The pain was terrible - just to think of swallowing made me wild. I couldn't even swallow my own saliva. It was thick and very sticky, and I could not swallow it so I spat it out. I would keep a small bowl near my bed and spit in it. By the evening, the bowl used to get full.

Everybody was really tired of this sickness. My father was tired of it. It was terrible for my mother to see her son suffer so much. She used to cry everyday. We left no stone unturned - we tried allopathy, homeopathy, *pandas*[8], *bhagats*[9]. I had accepted that I am going to die one day, but through the course of illness the Almighty killed me without actually killing me.

During that period, I used to be highly irritable. I used to quarrel with everybody about small problems. I had no control over emotions, and the starvation for such a long period had produced cerebral atrophy[10]. The HIV itself leads to cerebral complications known as dementia. Fortunately, I could recognize everybody, but I lost orientation in time and space. But the cerebral atrophy had progressed to such an extent that I had lost control of my natural reflexes. I used to pass urine in my bed at night - it was difficult for me to control it. By then I was terribly afraid to even sleep.

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[7] A reddish fruit found on the coast of western India [8] Hindu priests [9] Traditional healers [10] Shrinking of the brain

At this stage, we decided that my daughter should not stay with us. So she was put in a boarding school near Bombay.

What treatment were you being given then?
I was again admitted to a hospital in Pune on 18 August 1996. My mother had shown my horoscope to an astrologer; he said if I was admitted on this day, I would get well, otherwise I wouldn't. So I was admitted on 18th August. I met Dr Vinay Kulkarni - he was the first physician to diagnose my ulcers as herpes. It was a relief! When I heard it was herpes, I mentally collapsed and I knew that I could pull through. Maybe I had a small .0000 percent chance of recovering. I was put on Acyclovir[11] drip, and I started eating a little food. The ulcers started healing with Acyclovir.

My aunt in America rang up at that time - she knew about my status. She told my family that there were drugs available in America, which she would send us. By then our financial condition had gone down, but she was ready to support us. She sent me a bottle of 90 tablets of Creximon[12], which used to cost Rs. 27,000 ($600).

Creximon was available in a big 800mg capsule form, and it was difficult for me to swallow capsules. The moment I saw the capsule, I refused to take the drug. Being irritable, plus the vomiting, and the fasting that goes with it (once I had vomited I could not eat for two hours), I got very angry and told them, no matter what the cost of the drug, there's no way I'm going to take it. I told them, no drugs, if at all, I'd take *ayurvedic* drugs.

My aunt called again, saying that there were two new drugs, Didanosile and Lamivudin, which were water-soluble and could be swallowed. That was the first time a two-drug combination was being tried. She sent us a supply of three-four months. So I had an uninterrupted supply without any problems. Then a third drug called Ritonavil was added to the therapy.

With Ritonavil, Didanosile and Lamivudin, my appetite increased, though my weight didn't. I used to still weigh around 47 kg. The cerebral atrophy effects went down. My energy levels increased, the number of opportunistic infections went down, but my CD4 count never came up - it was in the range of 40-60. I took this three-drug combination very regularly till May 1998, when I started developing oral cavities and my appetite went down. Dr Kulkarni suspected viral resistance to these three drugs. At that time, my treatment was changed to the current line of treatment, which is Didanosile, Stavudin and Nelfinavir. I have been taking this for the last six years - from May 1998 to May 2004.

And what has your experience been of these drugs?
Actually I am taking Nelfinavir at sub-optimal doses - the actual dose is three tablets, three times a day. What I'm taking is one tablet three times a day, but I am very happy with it and so far, so good.

This combination has suited you more.
Yes, it has worked well. But apart from this combination of drugs, from 1997 onwards I developed my own lifestyle and diet, on a trial-and-error basis. If I saw something new, I used to eat it in small quantities to see whether I could digest it or not. I started doing *yogasana*[13], *pranayam*[14] , and *sudarshan kriya*[15] daily. I attended Art of Living courses to learn the *sudarshan kriya*, and I learned *pranayam* and yoga on my own by following books.

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[11] An anti-herpes drug [12] A protease or anti HIV drug [13] Yoga postures [14] A yogic breathing technique
[15] An ancient breathing technique reintroduced by the Art of Living movement

How has this helped you?
I read certain books that claimed that *hatha yoga*[16] could cure anything and everything under the sun. I also realized that *yogasana*, *pranayam* and *sudarshan kriya* treat the negative aspect of the mind as well. To get over all this, not only do you need a good physique, but also a good attitude and a strong mind, which is able to accept the illnesses, but still has the power to fight back, and the hope that you will win one day. As I started practicing these, gradually things changed. I do yoga for an hour every morning, and after that *sudarshan kriya* or *pranayam*, one of the two. After that I do *kapalbharti*[17], which I've also learned. This induces a state of mental calm. Today I've come to a stage where my mind understands what's going on, what's wrong, what's right.

All these - yoga, *pranayam* and *sudarshan kriya* - are meant to balance your sympathetic and parasympathetic nervous system. In my opinion, HIV is a manifestation of the imbalance between these two nervous systems. So once I started following all these principles, there was a huge difference between what I was before and what I am today. The more expert you are in yoga, *pranayam* and *sudarshan kriya*, the healthier you are. There is something known as mind-body coordination, which is achieved through these three. It's not something I can explain; it has to be experienced. It means understanding your own body; it gives you a sense of what to eat, what will impact your body.

I followed a course that tried to balance the sympathetic and parasympathetic, and somehow it has worked in my case. Otherwise, with optimal doses of drugs and the current status of medicines, I should have developed resistance. Apart from that I should not have survived for so long and reached the level that I have. My CD4 was 38, today it is 273. I don't get any opportunistic infections. I am feeling fit enough to work eight hours a day. That is the biggest achievement that I can put forward for following this way of life. For a person whose CD4 was 38 once upon a time, to live for 10 years and to work eight hours a day is a dream come true.

So you're saying it's not just the ARVs that have taken you so far; it's the lifestyle change as well.
It's the lifestyle, the diet, the attitude - everything matters. During the course of the exercise, it's not that I never fell sick; I did. But my attitude was to overcome the problems; the resolve was there to fight. And of course the resources were there to fight - that is most important. Apart from that support, everything else mattered.

I was very lucky to be in a position where I could afford ARVs. When I started this therapy, it cost me around Rs.30,000 (US$ 666) a month for all three drugs. Today the cost has come down to Rs.2,000-3,000 (US$ 44-66) a month. In the beginning it was very difficult to manage the drug costs and the illness, but with the development of drugs, things have changed.

Personally speaking, I feel it is the lifestyle and attitude that matter. There are many centers that teach yoga, but until you understand why these things have to be done, it is very difficult to get output from anything, be it ARVs, lifestyle change, anything.

Do you regard your approach to therapy and treatment as holistic? Is one treatment or practice key? What would you say?
I don't know whether to call it a holistic approach. I feel it is not only the drugs and believe me, the diet I am following is one of the cheapest and simplest of diets.

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16. A form of yoga that prepares the body for the spiritual path via physical and breathing exercises, and asceticism
17. A breathing technique where you inhale passively, and exhale actively using abdominal muscles

What does it involve?

It does not involve any mega vitamins or anything. I have never taken any nutritional supplements throughout my illness, except when I took hematinic syrup during my first illness, which totally destroyed my teeth. I also had, and still have *panchamrut*[18] everyday. *Panchamrut* gave me a lot of energy, and reduced the number and duration of opportunistic infections. It made a tremendous difference to my health - it changed the way I looked, my strength. The *ghee* (clarified butter) in it, especially made from cow's milk, is very useful for the white blood cells' killing capacity, and I think this helps in that process.

My daily diet consists of *chappati* (bread), *dal* (lentils), all green vegetables and rice. I also eat a fistful of *channa* (roasted Bengal gram), groundnuts and jaggery everyday. There are many cereals and vegetables that are avoidable, generally those that are alkaline. There are certain vegetables that take 21 days to assimilate in our bodies - carrots, eggplant, *mooli* (white radish), and *masoor* (lentil). People who are *yogis*[19] avoid these vegetables. I started experimenting, starting with *masoor*, which gave me a lot of trouble - I developed diarrhea and stomach problems. I found that these all were probably alkaline. I also started avoiding cauliflower, cabbage, beans, and all vegetables that are sticky when cut open. I don't eat any processed food, tinned foods, or any foods containing Monosodium Glutamate (MSG) - no artificial flavors. I avoided eating out. You really don't need too much money for this diet - it's really very simple.

Gradually things improved. When my CD4 fell so low to 38, not only was my appetite totally lost, but also my capacity to digest and absorb. Nothing was left in my body.

It is the total lifestyle change along with drugs that helps. It is not only the drugs, not only the lifestyle change. You have to combine them and follow it regularly, day after day, week after week, month after month, year after year, and still be prepared to say, yes, I don't have any results.

How did you suddenly start yoga?

In July 1997, my father passed away. Just before that, we had had a big fight. My mother and I went to Mumbai, just to cool down. At that time, I had some mental peace. One day, suddenly the thought struck me that I've gone through so much of pain and still I am not dying. Maybe I am not destined to die with HIV.

We came back and shortly after that, my father passed away. It was a terrible blow for me. One of his friends had come to meet my mother. When he saw me, he could not recognize me. My mother told him all that had happened, and asked if he knew somebody who could help me. He suggested a Mr. Dongre from the nearby town of Kankavli. My mother wrote him a letter explaining our circumstances. Mr. Dongre came to meet me on 31 August 1997. That was our first meeting. He told me, "Don't worry. You will be all right."

Then he took my foot in his lap, put his hand on my head and said, 'Don't worry'. I just laughed at him. I thought he was mad - how could I believe any person who came and told me I would be all right? So I forgot about it.

After 15 days, he called and said he wanted to take me to the Pandharpur[20] shrine of Vithoba, the most religious place in Maharashtra. He came here with his wife, and took me to Pandharpur by car. Throughout the journey I was sitting next to him. He kept his arm on my thigh. We got to Pandharpur. That night he requested me to sleep along with him. He had a big room so I slept next to him. The next

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[18] A mixture of milk, sugar, honey, curds and ghee [19] Saints [20] A well known and highly revered Hindu religious site, dedicated to Vithoba, a form of Krishna

day we returned. Again I was sitting next to him, and he kept his arm on my thigh - nothing more was said, nothing more was exchanged.

When he left Ratnagiri, I realised that he had given me something. I don't know exactly what it was - the mental peace, the acceptance to be at peace with myself and the world - I have no words to describe it. Since that day, my attitude, behavior, everything changed. Irritability vanished, acceptance came.

I know it was he who changed this behavior. When I talk of determination and devotion, I believe it is his gift to me, so I don't call him a friend any more; I call him my *guru*[21]. Whenever I spend time with him, I get mental peace, happiness, and satisfaction. The fact that I can be happy in spite of my physical condition, and the familial and social turmoil, itself is a gift. He told me to do *jap*[22], which I started. The more I did it, the better it was.

I am here today only because of that *jap*. I've reached a stage when I can manage myself even when I am alone. It doesn't bother me whether I am going to die the next moment, or after 10 years - I don't even think of it. Even if it is in the next moment, I am ready for it. It is that sort of attitude of courage that comes automatically from within you. Whatever I am today is because of him.

But over the last six years since you've begun this new course of treatment, have you had any more episodes?

My personal observation is that after I started following this lifestyle even the disease was part of recovery. If I had a tummy upset, a body ache, cough and expectoration, everybody would tell me to rest. But I would tell them not to worry, as this was a part of the recovery. Even though I was looking sick, actually I was improving. If you look at the clinical picture, it was that of an illness, but internally I would feel that this is part of recovery. And time has proved it. For instance, if I were not recovering, my CD4, capacity and weight would not have increased. Today I'm 53 kg, at that time I was 47 kg. So I don't know how relevant this is - this is more of a scientific discussion.

What seems to have changed tremendously is that you're looking at the same things in a completely different way.

Whatever I have derived differs from the current medical scene a lot. People don't accept what I put forward or tell them, as they have not had the experience that I've gone through. It is very difficult to find somebody else who is so devoted to carrying out these things. If you tell somebody, do yoga, it's good for you, even a healthy person does not do it on a daily basis, forget about somebody who is sick. I have done yoga when my body was aching, I've done *sudarshan kriya* when I had fever, I've done *yogasana* when I was sick - it is just the dedication and determination that matter.

What has been your most difficult health challenge?

The most difficult health challenges were all three episodes and the drug resistance. The most difficult thing was that I was not able to earn anything for my family in spite of learning so much and working so hard. In the past nine years, I had no source of income. I see cases, but they are from such poor classes that they are not able to pay my fees. I don't charge them, so even with my practice, my income is not even Rs.1,000 (US$ 22) a month. That is the biggest thing I cannot digest. Now that I'm fine, I am still not able to earn - that is difficult.

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[21] Spiritual mentor or guide [22] Repeating of a holy name or muttered charm while turning beads, like a rosary

I have had a very good healthy childhood, and I cannot give the same to my daughter. That was another thing that was very difficult to digest. During my childhood we used to go out, we used to have fun, we used to go for holidays - that becomes a bit difficult with my status. I cannot go and eat anywhere else, I have to restrict my food. Then sometimes my daughter gets angry and says, "Why can't we go out anywhere?" That's a part of this.

But I guess the important thing is that you're here.
It is important for my wife, my mother. But for my kid, she is not of that age to understand all this. She looks at what all her friends are doing. That was the most difficult part. The experience was of not sending children to my house to play with my daughter. My daughter never had a problem going to anybody else's house, but she had a psychological problem as to why no one came to her house.

Apart from that, coming to terms with the fact that in spite of doing so many things, you are still going to fall sick, not be cured and people might still look at you and say you are sick.

How has this experience changed the way you work with your patients?
I believe it's the way one speaks. If you are experienced, then your words carry some weightage, some value; if you are not experienced then it's a hollow speech. It's the way you put things across. Somehow after going through all this, maybe I have developed the knack of putting things across in the right perspective, in a way that they understand. It's a whole spectrum in which you have to judge the patient's level of understanding and the level of your talk. In my opinion, my experience has taught me a lot of things. Generally I don't reveal my status to them, but now that we have formed a group of positive people, they know that I am also affected.

You've formed a positive people's group for the district?
Yes. For seven years, from 1995 to 2002, I could not practise because my CD4s were very low and there was always the fear that I might catch some contagious disease. It was only in May 2002 that I started practice. After that, I created my own NGO for positive people called Guruprasad. The name protects people's identities. It's a small NGO, we collect private donations. We try to help people in all possible ways. If someone wants money or assistance for rehabilitation, sewing machines, any small business. We don't give loans, whatever grants we get, we try to help. We give money for last rites, investigations - the routine needs of the patients are met with the funds that we collect. Apart from that, whenever we come together, it is a natural bonding between all those affected.

So now it seems like you have your hands full.
The goal is different - the ultimate goal is to cure myself - I don't know if I will help others or not. As a landmark, if I can take care of myself, if I can produce some extraordinary results, then I would say that all the efforts taken by my wife, all my relatives, all the money spent on me, it was worth it. If not, then yes, maybe I tried my best.

WHAT NEXT?

We began this project because we recognized that our best teachers about AIDS treatments included those of us who are making choices about our own care, and living the results of those choices. Before we began, we imagined that people's stories would bring to our attention a wider range of options than are often considered, and we were right. This work also compelled us to take stock of the wide range of ARV experiences that are out there. We intend to continue this work, this active listening and sharing, and hope to build on the exciting relationships formed around the process of printing these nine stories and collecting some fifty others. We have many ideas for the future of the *Listening To Those Who Live It* series, and welcome others. This is our working list of dreams and schemes:

- We would like to convene discussions in which treatment managers, donors, media, pharmaceutical companies, governments, researchers, medical staff, and others pause, listen, and strategize about how to make decisions about resources, research, and treatment and care programs with our lived experiences in mind.
- We would like to help improve knowledge management systems collecting patient and evaluative information shaping treatment programs so that they get better at including patients' needs and desires, living conditions, and care experiences. We would like to test such systems in communities.
- We would like to help put in place a website which initiates a useful way for us to 'talk' to each other across cultural and linguistic divides about our treatment, and which builds on the wealth of material already on the Internet to help us manage our care with the best and broadest possible information.
- We would like to support and contribute to improved collaborative research on existing herbal and other treatment approaches for AIDS-related illnesses, and for maintaining immune system health. We would like to explore the use of such remedies during 'holidays' from ARV medications for long-term users of this method.
- We would like to devise more effective ways to share the safest and most accessible herbal and nutritional therapies for immediate and self-directed use, and to build relationships around the world with kindred efforts and organizations interested in expanding notions of care and improving the match between treatment aspirations and treatments available.
- We would like to continue to build bridges of respect and collaboration between different medical traditions so we can come together around our shared aims of healing, alleviating suffering, and promoting health.

To get in touch with us, to be a part of this work, write to us at listening@ticahealth.org.

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