



Photograph: WFP/Brenda Barton, 2003

Q&A

with Stephen Lewis

In June 2001, UN Secretary-General Kofi Annan appointed **Stephen Lewis** as his Special Envoy for HIV/AIDS in Africa. In an interview with *Registered Nurse Journal*, Lewis talks about Africa's HIV/AIDS pandemic, the desperate need for treatment, and his vision for the Stephen Lewis Foundation. Lewis is a passionate advocate, a committed world citizen, and a brilliant strategist. ►

RNJ: Describe your role.

SL: I travel to individual countries. I meet with the political leadership, including the president or prime minister and go over the policies they have to combat AIDS. I meet more often with the ministers of health and education to take a hard look at what they're doing. I meet with the religious leadership because the religious leadership has been in a state of denial and silence and they have access to the whole population and can do a tremendous piece of educational work if they are engaged.

I meet with the United Nations to go over the work of the individual agencies and how they're supporting the government. I meet with the diplomatic community to get a sense of what individual Western countries are doing. And I always insist on spending at least 50 per cent of my time in the field observing the effort to interrupt mother to child transmission in birthing centres, the prevention programs in schools and communities, or dealing with treatment to the extent that treatment is incorporated.

In the process, I can get an overall sense of civil society. Before I leave the country I try to hold a press conference to discuss what I've seen. Sometimes it's a need for resources, sometimes it's a need to develop the human capacity, and sometimes it's a need to bring in generic drugs or to improve the prevention programs in the schools. I come back to New York...and meet with Kofi Annan and say, "Sir, this is what I found, this is where I think the emphasis should be, this is what you might want to consider for the speeches you make, this is what we might ask United Nations to do that they're not now doing."

RNJ: What are the barriers to HIV/AIDS relief in Africa?

SL: The issues are pretty straightforward.

1. The desperate need for treatment. Treatment brings hope, treatment encourages people to get tested and know their status because if they're HIV positive it's not the end of the world, they can have their lives prolonged.

2. The question of infrastructure, the capacity to deliver treatment and prevention programs. So many people have died and these are such incredibly poor societies and



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everything in the health-care systems is so fragile anyway, the assault as a result of AIDS is really horrendous.

3. The third thing is human capacity. In most other calamities in Africa whether it's drought, or famine, or disease it's been the very old and the very young who die. In AIDS, it's all of the middle generations who die. So you lose your human capacity. So in addition to the infrastructure you need tremendous training and tremendous regeneration of capacity.

4. And finally the incredible number of orphans present a problem for the countries involved. The communities are too poor to absorb all the orphans and the grandmothers are getting older and older as they're trying to look after these kids.

RNJ: Were you prepared for what you would encounter in Africa?

SL: No, I was completely unprepared for it. I didn't understand the emotional impact of dealing with so much death on an ongoing basis and the sense of impotence, futility and rage one feels when there are so many people dying who shouldn't be dying.

I've had a love affair with Africa for 44 years. I was first there in 1959 for more than a

year...I have visited it continually, but I never imagined what I've now seen over the last two years and four months of this job. It's just been annihilating to see entire countries falling apart and knowing that it isn't necessary.

RNJ: How are the nurses and health-care providers coping with the crisis?

SL: The two anchors of the system in Africa are nurses and community health workers. The community health workers follow people into the community and make sure there is decent home care for those who are ill and dying, and the nurses deal with the basic response to the ill person when they enter a hospital or clinic. It's the nurses who are the heroes; there are so few (of them) and they are so incredibly overloaded. I've been on shifts in hospitals in Malawi and in Zambia where you've got 70 and 80 people to a ward...and honestly there are occasions when the ward is staffed by one nurse. These are critical cases; these are people who are within sight of death. It's just absolutely overwhelming; these are big wards and the role of these nurses is just incredible.

RNJ: What, if any, progress has been made?

SL: We've made progress, but the progress has been very, very slow. And the most painful thing about the progress is that it is so slow that countless numbers of people are dying unnecessarily. We haven't yet come to grips with the pandemic. We haven't yet begun to turn it around and that's a very painful thing to recognize.

RNJ: Are generic drugs the answer to the HIV/AIDS pandemic?

SL: The greatest single problem for Africa continues to be resources. That's beginning to crack; there are some glimpses of more money, but nowhere near the need. And that's money for everything, not just for treatment because you've got a horrendous catastrophe unfolding. The death spiral has just begun, the highest number of deaths will emerge between 2004 and 2010. The people who were infected in the late 80s and early 90s are now at a stage of full-blown AIDS and beginning to die in ever-larger numbers.

If there is to be treatment it has to be with generic drugs in order to keep the

prices down. The brand name drugs are still three to five times the cost of the generic drugs even at the lowest prices the brand name companies have been able to achieve.

If Africa got the resources, which the rich countries have promised and never delivered, you would be able to put huge numbers of people in treatment. You would probably be able to reach the target that the World Health Organization (WHO) has set of three million people in treatment by the year 2005.

RNJ: Will Canada deliver on its commitment to manufacture and export generic drugs?

SL: Incredibly enough, yes. I am close enough to the legislation to know that it's going to be broader than we imagined. The brand name drug companies will have the right of first refusal. So if a country like Malawi comes and says we want drugs at this price, the brand name drug company will be able to decide if it will do it at that price, but the government is giving it only 20 days to respond. And if they decide they don't want to do it at that price, which is likely, then the generic companies will be able to bid and start to manufacture and export.

And I have every reason to believe Paul Martin is absolutely and single-mindedly determined to see this through.

RNJ: Tell us about the Stephen Lewis Foundation.

SL: The foundation emerged in my mind when I saw the carnage on the ground. I just felt so frantic and so impotent I wanted for a moment in time to be Bill Gates so that I could give communities a little bit of money because you don't need millions of dollars to change life for small communities.

The worst of it all was the women who were dying in their thatched huts in awful circumstances while their children stood and watched them die. Children become orphans when their parents get sick, they don't become orphans when they die. And their kids are frantic; these orphan children who didn't have any money for school fees, didn't have any food, didn't know how to grow food because their parents died and didn't transfer to them any knowledge of agriculture. And these very brave people liv-

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ing with AIDS; there are many countries where very few people are public about their illness.

The Canadian people have been incredibly generous. People have been responding strongly and our objective is to get the money right to the grassroots, not filtered through government, not even filtered through one of the excellent non-governmental organizations, but going right to community.

Much to my surprise and pleasure, we have 10 projects that we are now funding in seven countries. By the end of this year, we will have given out somewhere between \$200,000 and a quarter of a million dollars. And we have raised \$650,000 in six or seven months. The grants are anywhere from \$15,000 to \$30,000 and yet that amount of money can transform life in a community.

RNJ: How can organizations like RNAO and individual RNs help?

SL: The tremendous need is for training. It's hard to transplant nurses from Ontario or North America to clinical conditions in Africa simply because there's a whole cultur-

ON NOV. 6, the federal government introduced legislation aimed at getting cheaper medicines into the hands of people suffering from AIDS and other diseases in the world's poorest countries. While Paul Martin, the Liberal prime minister-in-waiting, backs the initiative, he would need to revive the bill to put it back on track and make Canadian history by being the first country to introduce and pass this groundbreaking legislation.

al adjustment, language and everything else. But the tremendous work that can be done by way of training all over the continent, training on how to handle treatment, training on how to handle very ill patients, training on counseling, which is so desperately needed everywhere in Africa. Things that nurses here take for granted that can be done there. The question of twinning of some hospitals between Canada and Africa. For example, the British Columbia Women's Hospital is looking at a twinning relationship with the university teaching hospital in Lusaka, Zambia.

In addition to that, any money that one can raise, as long as you're confident it's getting to the right place, can be very, very, helpful.

In a concrete way, it's first of all raising consciousness, but then finding ways to help with the human capacity and the training. That's the best contribution that can be made.

RNJ: How do you maintain hope that positive change is possible in the face of so much death and devastation?

SL: It's kind of devastating constantly to see the desperation as societies unravel. On the other hand, there is so much sophistication at the grassroots in Africa, particularly among the women.

My feeling about these things has always been "what the hell's the use of giving up." You never get anywhere by giving up so you just grit your teeth and keep on fighting and one day you break through. One day, seven to 10 years from now, they say we'll have a vaccine. One day we may get enough money to prolong people's lives five, 10 or 15 years. And therefore the orphan problem will be less acute because the best way of dealing with orphans is to keep their parents alive. Those are the things that keep the hope up.

I know I want to do this until I have a personal sense that things are moving and the pandemic can be defeated. I really want to have a strong sense on the ground that things are turning around and I want to be there for that. **RN**

For more information about the Stephen Lewis foundation visit www.stephenlewis-foundation.org

LESLEY FREY IS ACTING DIRECTOR, COMMUNICATIONS FOR RNAO.