

ever. This document is shown to the family should they knock on your door wanting explanations and this will cover you in your actions. I think that no doctor has a right to interfere, but there is debate on it.

Dr Brink: Let us assume that our patient does die and this information has not been disclosed. The death certificate has to be completed. The family has access to this document and it would see that AIDS was the cause of death.

Dr Barker: Justice Edmond Cameron, formerly a judge of the Constitutional Court, currently of the Supreme Court, submitted a legal opinion outlining the legal status of the death certificate. It is not a death certificate — it is a medical certificate relating to the cause of death. He points out that the sole statutory purpose of this certificate is to satisfy the Home Office and Registrar that the death was not due to unnatural causes that need to be investigated. He stated that, where the revelation of a particular disease such as HIV/AIDS could be damaging to the relatives, it was his opinion that it was perfectly legitimate for a doctor to write “natural causes” or “pneumonia” and simply to leave out contributing causes, although he knew HIV/AIDS played its part. Remember that nobody dies of AIDS — they die of the diseases facilitated by AIDS.

My standpoint still is that you are free if it is in your patient's interest and the interest of your patient's family, not to write this down. Remember that this is a public document — on the payment of R5 anybody on the street can walk into the office and pick up that death certificate. There is no confidentiality.

A completely new death certificate will be available, probably within the next eighteen months. It provides the patient's name, age and all the details of whether the death is due to a natural or unnatural cause. Underneath is a perforated page with a most carefully-designed user-friendly form. This form has a small computer number at the top, which is protected by strict access codes that are only available to people who have absolute right to that type of information. This is totally unidentifiable information that tells you everything there is to know about the patient, including his smoking habits.

Dr Brink: Earlier you referred to the importance of an equal relationship. There is an excellent book entitled *A meeting between experts*. On the one hand, there is the medical practitioner with the knowledge of medical science and, on the other, the patient with his/her own fears, concerns and needs. When the two experts meet we have to try and find the common path and explore the way in which this can actually be achieved. We need to look forward to avoid some of the problems that could occur.

Many of the issues that could arise can certainly be addressed or pre-empted where there is a sound, trusting, open and honest doctor-patient relationship. This establishes a forum where many of these issues can be discussed openly, where we can at least inform the patient of the consequences of a decision, so there is an understanding by the patient of the road that he/she wants to take. Perhaps our job basically is to return control to the patient, to restore the patient's psychological autonomy.

We also need to be aware of where our patient is in terms of his or her own development and growth. We need to know what he/she is trying to do and what he/she is trying to achieve. We have to have a deep understanding of our patient. But we must also remember for our own part that uncertainty can also effect our decision to reveal information and we must be wary of exercising control of information to minimise our own fear and discomfort. Through being open and discussing things with our patients we will not avoid ethical dilemmas that arise for they are there all the time. We will at least have an open relationship and one where there is trust on both sides; trust in terms of the patient, in terms of ourselves and we with our patient. With that we can address the issues that arise and find solutions together. ●

HIV AND LIFE: A PATIENT'S EXPERIENCE

Based on a talk given by Toni at an HIV symposium in Durban, 15th March 1998

I have been HIV-positive for 8 years. I was 22 years old, living with my boyfriend for two years, when I had a phone call one day at work from my general practitioner. He asked: “Do you know that your boyfriend is HIV-positive, or that he has AIDS?”

I do not think I can ever put into words what I felt that minute. It was devastating. I think that if I could have died right then I would have, but it did not turn out that way. I went for my test but it took two weeks to get it back, simply because the doctor that I saw at that stage had the specimen re-checked just to make sure the result was correct.

I am not sure whether the doctor knew how to handle the situation, or if it was because he knew my family very well, as my mother had worked for him for a number of years. Maybe his reaction was either just that of a human being or he might have been scared for my family as well.

My relationship with my boyfriend started to crumble. I didn't consult the doctor frequently, as I was very healthy then and still am reasonably healthy. My relationship with my doctor deteriorated, as I was upset because of the way in which he told me about my boyfriend. I spoke to no one and my boyfriend did not want me to tell anyone that I was HIV-positive. I think he was scared that all might find out — to him it was bad enough that I knew about it already.

I kept quiet.

Eventually my relationship fell apart. I was not feeling well and I found out that I was pregnant as well. His response was: “This is your appointment for your abortion”. This was about eight months after I had found out that I was HIV-positive and I did not want to have an abortion right away. I was really desperate to talk to somebody. I did not speak to my parents. My father is a preacher and I don't know why I did not then want to tell my parents. It might have been because I did not want to hurt them, as I knew they would be hurt and very sad. I did not know what my family knew about HIV, so I kept it to myself. The pressure on me kept building up. You go to work every day, you smile to everybody, but you have this huge secret and you are just so scared anybody will find out. It causes a lot of stress.

One day, in the newspaper, I noticed ATIC's telephone number. Eventually I got the courage to phone and I had my first counselling session with a lady. She told me a lot about choices, having the baby or not, what could and could not happen. The only thing at the end of the day was that I had to make the choice. I was 23 years old then and I really did not know what to do. I wanted to have a baby and I was supposed to be married by then to this man, but my life did not work out the way we planned it.

The end came a couple of weeks after I saw the ATIC counsellor for the first time. I had a huge fight with my ex-boyfriend as all he wanted to do was get rid of the baby. He did not want to have anything to do with me or the pregnancy. What I did was not his choice, but emotionally everything just crumbled and I phoned my parents in Ladysmith. I told them that I was in a huge crisis and that they would not want to hear about it over the telephone. My father came straight away and we spent the whole day together and we talked about it. I had to tell him everything that happened, that I was going to probably die of AIDS and that I was pregnant.

It could not have been easy for him either. He has certain standing in his community too. My dad is a very strong person and he took it very well and together we went to see Liz, the counsellor from ATIC. I think for the first time in his life he said that I would have to make the decision about the abortion myself. Whether or not I chose to abort the child, he would never hold it against me. All that he wanted was what was best for his girl. When I did choose to have Calvin I think he was quite happy that I made that choice.

Actually I must say this: I loved being pregnant and I could do it again one day. I appreciated it and I was very healthy throughout my pregnancy. It was great, even the birth. I must have been lucky, because it was one of those two-hour-twenty-minute labours and it was great.

What happened when I went to hospital and I had my baby? We were stuck in a corner room somewhere. Calvin was not allowed to go with the other babies and I was having lots of fun playing with my baby, while Liz went ballistic. She went and said that this was not allowed. I know now also that what they did was not right, but I was much too happy with my little baby to worry about it. Calvin was tested three days after he was born and he tested positive. At that stage he was a very healthy, bouncing little boy. I was very new at motherhood and I don't think it affected me that badly then. I felt guilty but it did not affect me badly and he just blossomed; he was really a fat little baby right up to his first year.

It was shortly after his first year that he actually started to get sick, very sick. Everything that you can imagine went wrong, with diarrhoea and horrible sores all over him. All the weight he had gained in his first year he lost and he did not gain a single kilo the entire year. Later in the year he developed pneumonia for the first time and ended up in hospital for seven days in an oxygen tent. A month later he was back in hospital a second time, with pneumonia, and things just did not look good. It was really, absolutely devastating.

It was at the same time that he had his second test to confirm the HIV and it came back positive. It was then that the full force of what was happening hit me. My baby was going to die of AIDS and it was all my fault, as I had made the decision. At that stage I had been in a support group for a couple of months and were it not for the group, I do not think I would ever have coped with that whole thing. People I met in the support group were just wonderful. I did not have transport when I lived in Durban so I used to catch a bus, but they transported me and they looked after us. I would just say that something was wrong and everyone was there for me. It was the most fantastic thing that happened in my life and it was also in this period that I eventually managed to cope with the virus. Up to that stage, the depression, the sadness, the anger, were there. You just cannot believe the whole scene - it was too unreal to be true. The support group and counselling is what I should have had right from the beginning. Eight years later, I still need counselling every now and again. One would think that, after coping with it and learning so many new things about the virus, one would cope better with it. Things get better, but there are always things that come back. There is not a single part of my life that is not touched by this virus.

My little boy was very very ill and it was at this stage that Mom and Dad said that I must move back to Ladysmith. I finally agreed that I could not cope on my own, so I moved to Ladysmith with a completely different type of support. My emotional support and my friends I left behind, but what was important at this stage of my life was to see that my son was doing well.

He started to get better and better and everything was going very well, except for me. I lived in my mother's house and I think I put on about 17 kilos in a year, due to my mom's cooking, but I am happy to say I lost most of it again. We had this whole new life. I tried to make friends, but things did not stay the same.

Calvin got better and I did not. I was working at a factory there when my health started to deteriorate. The CD4 counts dropped below 200 (viral loads were not available at that stage) and it was sort of scary. I kept on having infections, although I would not say it was deadly serious infections yet, but I had thrush non-stop, throat infections non-stop, always swollen glands, always feeling tired. I think I was overworked too. The company that I worked for had a really good AIDS policy and when I started to feel the effects of the virus at that stage I received a disability pension, which was good because in the first six months my CD4 count went back up to just over 300. I had time to rest and just lead a more relaxing life.

It was in 1996 that I actually got the disability pension, but it did not stay like that either. Nothing ever stays the same and about six months after I stopped work, my CD4 counts were fine. I was using a new Stellenbosch product, but my CD4 count started dropping again. I had a viral load last year about June and it was 30 000, which was not so bad. In October I had another viral load and suddenly it was 1,3 million. I thought something strange must have happened. We kept on testing, I had another test, it dropped to 700 000. By then my CD count had started dropping again and was below 300 again. At the moment my viral load is 400 000 and my CD count is about 270.

The doctor I saw at that stage suggested that I should consider taking treatment, but I could not ever afford treatment. I have always been so healthy and suddenly to have to realise that I am at a stage where I should consider treatment, it was psychologically devastating for me. I had a hard time to make a decision. I kept on going back to the doctor, saying: "Please just do one more viral load. Can we do one more and see, maybe there was something else wrong?" but it did not change.

Eventually I agreed. The doctor came back after a conference in Johannesburg with a new combination and it suited my pocket slightly better, although it is still expensive. However, if I work very hard then I can actually manage it. It is the DDI and Hydroxyurea and, after waiting two months, I have now started the treatment. I have been on it for nearly four days now. I don't know how soon I will know if there is a difference or not, but I am supposed to go back for tests in six weeks' time and I am sure I will know then.

I just want to mention one or two other things that happened.

When I moved to Ladysmith I was already quite public, I was on television, in the newspapers and so on and obviously a lot of people knew that I had the virus. The first doctor that Calvin and I went to, he was stunning and he still is. If Calvin gets sick, he would get up at two or three o'clock in the morning to come over and just see that he is fine.

I must say, Calvin is doing absolutely wonderfully well. He is six years old, he is in pre-school and he will go to school next year. I was reminded of his health situation last year when he ended up back in hospital with pneumonia and in an oxygen tent for three days, but he recovered very quickly.

Within a week he just completely recovered and our doctor in Ladysmith goes out of his way to find out everything he can. He speaks to doctors we saw here in Durban, pediatricians and everybody and he is really fantastic.

The other bad thing that happened during last year was that I lost my medical aid. I was on a medical aid through a previous company that I worked for and when I changed jobs I stayed on their medical aid and the company that I worked for went bankrupt. Consequently I was no longer on a medical aid. To me that is very scary. If Calvin suddenly gets sick again I do not know what I am going to do. I have been going myself to a provincial hospital to an AIDS clinic, but when it comes to my son, I will sell my car if I have to, to get him in to a hospital for absolutely the best treatment. That is how it has always been and that is why he is so healthy.

One last thing I would like to say: a lot of people think that it is very courageous and brave for me to stand up and tell people about what has happened. I just want to say it is not. It is really scary to do it and as well as I might look and as happy as I am, it is not like that every day. It always affects my life. I went out to a function in Ladysmith last night and when I got home I wanted to die. I didn't want to go in to my house, I just felt so depressed and lonely and this is something that it has also caused. I have no relationship with anybody special. I have many reasons for that, but it is not a happy face every day that you see.

Questions:

Toni, we as a profession failed you in informing you in the correct way. If you reflect back on how you received the information about the diagnosis, how would you have liked to have heard? Could you tell us what emotions you felt and how would

"I do not think I can ever put into words what I felt that minute. It was devastating. I think that if I could have died right then I would have, but it did not turn out that way..."

you have liked to have been approached?

First of all, I would have preferred it if the doctor phoned and said: "Something came up - can you come and see me in my office?" and not tell me over the phone, "Your boyfriend has AIDS". I think that very minute it was completely devastating. There is no easy way. There is no way to describe how it felt and maybe if he had a list of counsellors or arranged counselling it might have helped. What I did not mention earlier was the one day I did ask this doctor for someone to talk to, his answer was, "What is the use?" I think that was the one really really big thing right from the start. I just wanted to talk to someone desperately.

Do you feel that being public about your infection has made it easier for you or more difficult?

This is just a very personal opinion, but for me it has definitely been easier. I do not have stress about hiding it. After I decided to go public, I told my friends one by one. I told my employers, I told my family and I knew who supported me, so if there was anybody out there who wanted to stigmatise me or discriminate against me it was their problem, not mine. I definitely feel that it made a huge difference in my life.

How is your son coping in school, in terms of being discriminated against?

There is no discrimination at all at school. His name was on the waiting list and when I went to the school to enroll him, I sat with the headmistress and I told her about it. She was hesitant about it: she said she did not know what to do and that she was going to call the inspector of education and all that. I walked out of the door and I phoned ATIC. I said there might be a problem and before a week was over ATIC went in, educated the personnel and the parents and I have to this day not had one single problem with Calvin in school, nothing. In fact he is quite a charmer. ●

**Application for Membership
of the Academy of Family
Practice/Primary Care SA**



I.....
(full name in block letters) being a General Practitioner registered with the South African Medical & Dental Council, hereby apply for membership of the SA Academy of Family Practice/Primary Care.

I support the aims of the Academy and agree to abide by the Constitution of the Academy (a copy of the Constitution is available on request).

Registration fee:	R 30,00
Subscription for 1998/9:	R285,00
	R315,00
VAT 14%	R 44,10
Total	R359,10
Voluntary Levy*	R 75,00*
	R434,10

**Voluntary Levy for
Community Projects*

Qualifications: _____

Date of Qualifying: _____

SAMDC Registration No.: _____

Postal Address: _____

_____ Code: _____

Tel (H): _____ (W) _____

Fax: _____

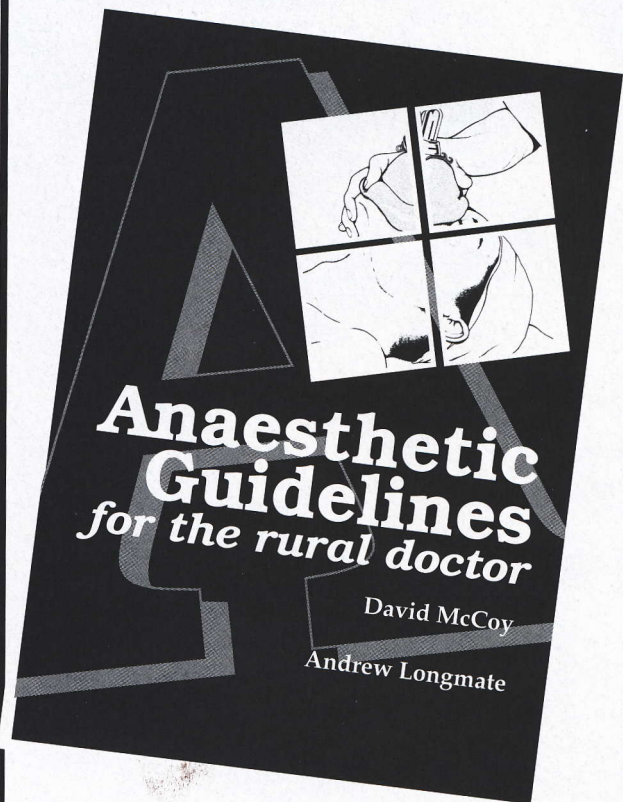
Amount submitted: R _____ Date: _____

Signature: _____

Please post, with your payment, to: The Administrative Secretary, PO Box 2731, Rivonia 2128

Available shortly...

A concise guide, in A5 format, which deals with many of the problems frequently encountered in the rural setting.



Anaesthetic Guidelines for the rural doctor

David McCoy
Andrew Longmate

Anaesthetic Guidelines for the rural doctor

by David McCoy and Andrew Longmate

Price: R100 excl VAT @ 14%

This price does not include postage and packing.

Name:

Postal address:

Number of copies required:

**Please send orders to: Anaesthetic Guidelines Orders,
The South African Academy of Family
Practice/Primary Care, 30 Savell Avenue, Glenashley,
4051, South Africa, or fax it to (031) 527-812.**