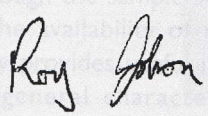
Dear Readers,

Several things for your attention:

1. A year ago we discontinued ***check*** (continuous home evaluation of clinical knowledge) which originated with the RACGP, and created our own ***CPD*** (care of patients and their disorders). Any feedback would be appreciated.
2. We also started a 'per-edition' option for obtaining 'CPD' points. A number of readers have taken up that opportunity. Last year a quiz was created to cover the whole year's editions. This year, the quiz has not been included with this edition. However, for anyone who would like to do the quiz and make up their CPD points, please contact me by faxing (012) 346-3359 or e-mail: royjobson@mweb.co.za – I will forward you the quiz by return e-mail or by fax. Please ensure that your name and contact details are included! The questions will vary in format and will cover all the information in each edition (not just the CPD section!). The Academy will award 18 points (3 points per edition) for each passing mark of 70% or over. If you have been submitting your 'per-edition' points by the required deadline, you should already have ten points, which can be increased to twelve points for this (August/September 2001) edition. In other words, we're offering a total of 30 points for the year. The closing date for requests to receive the quiz is 30 September, 2001 and the closing date for returning the completed quiz is 31 October, 2001.
3. Since the last edition dealing with so-called 'natural' food supplements/medications, was published I have been informed of an extraordinarily useful resource on this topic. It is a weekly e-mail newsletter called 'Natural Medicine News®', which is 'available to practitioners, educators, and students of the health professions for non-commercial, and personal use'. It has no advertising, and is edited on a voluntary basis by Professor Forrest Batz from California. To subscribe, send an e-mail request, along with name, academic degree, institutional/work affiliation, location, and title, to: fbatz@sonic.net
4. The Department of Health have published a set of nine booklets containing HIV/AIDS policy guidelines. These are available from local DOH offices or from the AIDS Directorate, DOH, Pretoria (012) 312-0152. Although the booklets are free of charge, postage costs will need to be paid if they're not being collected from the offices. Thanks to Dr Anne Wright for alerting me to this resource. I'd like to pay tribute to Dr Colleen McIver and her booklet: 'A guide to low cost clinical management of HIV/AIDS patients'[1] which was published through the Department of Family Medicine at Wits and which filled a gaping void in available resources. I for one have found it particularly useful, and it still contains information not available elsewhere.
5. My co-author for this edition of ***CPD*** is Dr David Cameron who has extensive experience in palliative and terminal care. Your contribution is sincerely appreciated, Dave. Many thanks. I've learnt a lot and I'm sure the readers will also appreciate your practical and humane approach to this topic.



Roy Jobson

Our Patient

Johannes, our HIV-infected patient (see February-March, April-May, June-July 2001 editions of CPD) is now 36 years old. He has been on HAART (triple therapy) for over five years. Three years ago he had a myocardial infarct from which he almost did not recover, as he had fairly extensive cardiac damage. Fortunately he was attended to within minutes of the incident and survived.

The irony is that he had managed, with your encouragement, to completely stop smoking four years before this incident, and he had been following a moderate exercise programme. He does **not** have a family history of coronary artery disease.

Question 1.

What was the most likely cause of his heart attack?

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Answer 1.

He developed premature coronary artery disease consequent to atherogenesis promoted by the protease inhibitor he was taking. Protease inhibitor-associated lipodystrophy (PIAL) is well described. Metabolic consequences of PIAL include:

- increased insulin resistance with increased plasma insulin and decreased oral glucose tolerance
- decreased cortisol,
- moderately increased total serum cholesterol, and markedly increased serum triglycerides. Of all the protease inhibitors, dyslipidaemia is reputed to be most marked with ritonavir.[2]

The most common cause of life-threatening cardiac disease in persons in the later stages of AIDS is 'AIDS cardiomyopathy'.[3]

FURTHER HISTORY

Johannes did not make a complete recovery from the infarct, and became what is known as a 'cardiac cripple' in some circles. Now, apart from his HAART (*without* a protease inhibitor!), he is also on medication to treat his cardiac failure, a recurrence of oesophageal thrush, and prophylactic medication against *Pneumocystis carinii* pneumonia (PCP). His lipid profile is maintained within acceptable limits using conservative measures.

Question 2.

What are the medications for the above *infections* likely to be?

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Answer 2.

Fluconazole is an effective antifungal agent in managing oesophageal thrush. It is prescribed as 200mg po daily for 5-14 days with repeated courses as necessary.[4] Remember that good oral hygiene is imperative and ensure that no dental caries (which may be colonised by *Candida*) are present. Chlorhexidine mouth wash can be used twice daily continuously.[1] Ketoconazole 150-400mg daily po for at least 14 days or itraconazole 200mg po daily for 14 days are alternatives. For patients who cannot take oral medications: Fluconazole 200mg IV daily for 5-14 days is recommended.[4] The WHO has recommended that fluconazole should replace ketoconazole since it is more cost-effective and associated with fewer adverse effects.[4]

Cotrimoxazole is used as prophylaxis in PCP. Survival in persons with AIDS has been markedly increased through prophylaxis against PCP, primarily through use of cotrimoxazole, dapsone, or aerosolised pentamidine. Antipneumocystis medication is recommended for AIDS patients with CD4 lymphocyte counts <200/microlitre. It is said that some patients who receive HAART and who have a CD4 count that remains above 200/microlitre for more than 3 months can safely discontinue PCP prophylaxis.[5] However, with Johannes's overall clinical picture, this would not be recommended, and he needs to stay on life-long prophylaxis. The dosage of cotrimoxazole for prophylaxis is 2 x 80/400mg (i.e. 2 x single-strength tablets, or 1 x double-strength tablet) daily, Mondays to Fridays; or Dapsone 100mg twice a week (e.g. Mondays and Thursdays).[6]

FURTHER HISTORY

In spite of a supportive family and all your help, Johannes starts to deteriorate in front of your eyes. He has several episodes of severe diarrhoea and has lost the sight in one eye.

Question 3.

What are the most likely reasons for his diarrhoea?

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Answer 3. Persistent diarrhoea in the advanced AIDS patient can be classified as follows:[7]

imaginatively likened to a veld fire or a pizza pie![9] Ganciclovir IV is the drug of first choice. Foscavir and valaciclovir have also been used to treat patients with CMV retinitis. Again your clinical discretion is needed in terms of Johannes's total medication load. To what extent is his monocular blindness disabling? The above agents may provide symptomatic relief in AIDS patients with CMV, and the infection is often slowed, tissue destruction diminished and survival increased.[10]

FURTHER HISTORY

Unfortunately Johannes continues to deteriorate almost daily, and this once vibrant, fun- and life-loving young man seems to be vanishing slowly in front of your eyes. Clearly he would seem to be dying.

Question 9.

Would you discontinue the anti-retroviral (and other) drugs?

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Answer 9.

Although it is extremely difficult to be certain when someone with advanced AIDS is dying, there comes a time when such treatment is no longer doing any good and may even be contributing to unpleasant side effects. Just swallowing pills becomes an ordeal. At this point you would need to discuss the decision to stop therapy with Johannes and his family.

Question 10.

Of what value is a family conference at this stage?

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Answer 10.

It is extremely valuable. The purpose of a family conference is to mobilize all available resources to care for Johannes in this stage of his illness. Open communication can be encouraged to ensure that everyone is "on the same wave-length".[11]

Question11.

How would you arrange such a family conference?

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Answer 11.

If Johannes is sufficiently awake and aware, you could discuss the purpose of the meeting with him and ask which family members should attend. If he is unable to participate, plan the conference with Johannes's main caregiver.

Choose a suitable venue where there is sufficient space and enough privacy. Allow each one present an uninterrupted chance to say how they perceive the situation and what they feel they can do to help. It is an interesting observation that those family members who are actively involved in the care of a dying relative, cope with their grief much better than those who avoid the task. The relief of having participated in the burden of care, seems to enable people to deal with their grief more easily when death occurs.[12]

Plan for sufficient time for the family conference and remember to switch off your cell phone! If the setting is in a hospital or hospice, it is a good idea to have another staff member present so that when you leave, this person can continue to help the family work out a practical care-strategy. This staff member can also be a valuable means of comfort and support to the family. Appropriate care of dying patients involves team-work.

Question 12.

If a conflict or disagreement arises amongst Johannes's family during the family conference, how do you manage this?

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Answer 12.

Try to focus everyone on the task of caring for Johannes. It is not an appropriate time to try to resolve major, long standing family conflicts. Although you may be able to deal with minor issues, keep reminding yourself and the family that your main task is to facilitate a plan of care for Johannes. You may need to recommend referral to a counselling agency for family therapy if a can of worms (or a series of cans!) has been opened.

Question 13.

What issues should be focused on in such a conference?

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Answer 13.

The family is likely to want to know 4 things.

- What is happening now?
- How long has Johannes got?
- What complications are likely to happen between now and then?
- What are the options if such a complication does occur?

You should ensure that the following issues are also addressed:

- Where should Johannes be looked after? Can they cope at home or should he be admitted to a hospice or hospital?
- Are his legal and financial affairs in order?

- Has a decision been made about funeral arrangements? Is a burial or cremation planned?
- Is his identity document accessible so that the death certificate can be accurately completed?

NB. Do not exclude Johannes's children from the family conference.

Question 14.

Johannes is now very drowsy and sleeps most of the time. He has difficulty swallowing and appears to be in pain when he is moved. How would you make him comfortable?

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Answer 14.

Keeping him comfortable is important. Forced feeding is unlikely to be helpful. If his mouth is cleaned and kept moist with ice chips or small amounts of water, intravenous fluids will be unnecessary. Regular pressure care is vital. Pain can be controlled with oral morphine solution. This needs to be given every 4 hours by the clock – and not prn! Once Johannes stops swallowing altogether, a syringe driver is very useful.

Question 15.

What is a syringe driver and how is it used?

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Answer 15.

A syringe driver is a simple mechanical pump that slowly empties a syringe and delivers a small steady dose of medication via a thin plastic tube and "butterfly needle" inserted *subcutaneously* at any suitable site on the chest, abdomen or thigh. It can be set to run in over 24 hours. It is very effective in keeping a dying person comfortable and in addition is a great time-saver for nursing staff. The dose of morphine required is about a third to a half of the total oral dose he has needed in 24 hours. The butterfly needle is kept in place with a small transparent adhesive dressing, such as 'Opsite'. A syringe driver can even be set up at the person's home. Your local hospice will be happy to loan you one, and help you to care for your patient if s/he wishes to die at home.

Question 16.

What do syringe drivers cost and where can they be obtained?

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Answer 16.

Syringe drivers vary in price.

Local suppliers are

- Braun Medical (011) 548-5500, or speak to Lindsay Hall 082-901-1837, Cost R2500.
- SIMS (Graseby), speak to Brett Winson 083-229-9709, Cost R5500.

Question 17.

Can other drugs also be given via a syringe driver?

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Answer 17.

Yes, several drugs can be administered simultaneously. All the information you may need can be obtained at www.palliativedrugs.com or at www.pallmed.net .The latter is particularly useful in terms of the compatibility of drugs that can be administered together.

Despite the pressure on resources and facilities, a peaceful, pain-free death is an achievable reality even in South Africa. Organisations such as Hospice can greatly assist you, your patients and their families. If there is no Hospice near you, perhaps you need to start one! Allowing patients to die in pain is not acceptable. Recently a California court awarded $1.5 million damages against a doctor for failing to provide adequate pain relief to a patient dying of lung cancer![13]

For more information about a Hospice in your area, contact The Head Office of the Hospice Association of South Africa on (021) 531-2094. There are about 40 Hospices in Southern Africa.

Question 18.

Johannes dies. How do you feel? How *should* you feel? Does your own response (or lack of it) bother you sometimes?

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Answer 18.

Josef Stalin, former dictator of the Soviet Union during the Second World War, who was responsible for the deaths of millions, said, "The death of one person is a tragedy, the death of a million is a statistic!" In the public sector doctors are presently dealing with advanced AIDS patients *every day* and it is inevitable that we will protect ourselves emotionally by remaining detached to varying degrees. The epidemic has only just started. How do you plan to deal with it and it's consequences in your own life? Do you have a safety net of your own? Do you feel free to ask for help? Do you know where doctors can go for help? Can you recognise when you're being pushed beyond your limits? (Or have

you already decided to book your flight to Canada?) Is turning one's back any better than "pulling the trigger"?

Question 19.

The family have decided on cremation of Johannes's body. Do you need to see the body after death, and what diagnosis would you fill in on the death certificate and cremation form?

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Answer 19.

Yes, you do need to personally view the body after death. You are also required by law to make an accurate disclosure of the cause of death and any contributing factors. The dilemma that faces you is that you are also required to maintain your patient's confidentiality even after death.[14] This reinforces the value of a family conference. If Johannes has given permission to disclose his diagnosis everything is fine, but if he has denied this permission you are between a rock and a hard place. You will have done your duty if you complete the death certificate ***accurately*** and then seal it before handing it to the undertaker.[14]

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