## EDITORIAL

**Amy and David, writing in this issue, have much to teach us about how it feels to be a youngster with cancer, how it feels to be the brother of someone with cancer and how it feels to lose your friend from the same disease that you have. For many counsellors and nurses, finding the right words to say to children who are suffering is so daunting, that they funk it. And yet children are acute observers, and when they also have the ability to express what they see and feel, we have to listen. Margaret Andrews, a social worker, felt inadequately trained and experienced when she was asked to take three Vietnamese children to see their mother's dead body—she would have funked it if she could, but a strong sense of duty drove her and she found, to her surprise, how healing it was for her charges and how rewarding, too, for her.**

**We publish, too, accounts of practice in Denmark and in Greece. In Greece, tragically, children were infected with AIDS through transfusions of blood to treat their haemophilia and thalassaemia. Tsiantis and Meyer have given us a very practical account of their work with young people and their families facing illness and death, which should be helpful to all those struggling with these issues in other countries too. Grief, as we learn, is a universal experience for humans and higher animals. Ms Hansen works with obstetricians to help parents who lose their baby and has presented us with a structured approach to the task which combines attention to mind and body. The work needs evaluation, in due course. In this country many centres are offering similar programmes and we would like to hear from readers in other countries about their practices with this vulnerable group.**

**Editor**

# Counselling HIV-Positive Young People with Thalassaemia and Haemophilia and their Families

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In this paper we present our experience and observations from work with multi-transfused children, adolescents and young adults who are HIV antibody-positive and with their families. In some cases, these patients display the symptoms of the disease from which they are dying. We shall focus on the issues which have to be considered in dealing with and counselling these patients and their families, with an emphasis on the question of bereavement care.

These multi-transfused patients have β-thalassaemia or haemophilia and are treated at the following clinics of the Aghia Sophia Children's Hospital in Athens, Greece; the Thalassaemia Unit of the Department of Paediatrics, Athens University Medical School (10 patients aged between eight and 23 years); and the Haemophilia Department of the same hospital (20 patients aged between seven and 21 years). The psychosocial intervention programme was implemented by an interdisciplinary team from the Aghia Sophia Children's Hospital, and its objectives were to help parents and other family members contain the anxiety of antibody-positive children and improve the interaction and communication within the family, between the family and their health carers, and between the family and the community.

### Psychological Impact of AIDS

The AIDS epidemic has caused great concern, and even panic, in public health services and throughout the world, and the disease has come to be described as the plague of our age. Many of the campaigns undertaken by the health services in various parts of the world have attempted to address issues related to the control of the disease and prevention of new cases.

On the other hand, systematic efforts have also begun to investigate the psychological impact on AIDS patients and carriers and their relatives. In many of these cases, AIDS patients and their families go through phases of social isolation, stigmatisation, feelings of futility and mourning reactions. Nichols[1] observes that among the stress factors which occur as a result of the disease is the fear that the disease may be passed onto others. This may cause particular problems for the healthy members of the family, who may react by avoiding the patient as a way of self-protection. Ambivalence becomes pervasive in that the traditional value of family responsibility for the patient's care and support is jeopardised, creating a new undercurrent of family stress and adding to the precariousness of the new situation. Discord among family members can ensue over the question of confidentiality, since no common consensus on the scope of information-sharing can be readily achieved on an objective level[2]. Bereavement is often exacerbated for the parents of patients who had previously envisaged the survival of their offspring. The behaviour mode is the result of the pre-diagnosis relations, previous grief experiences and overall adaptability to periods of incipient radical change[2].