Book reviews

The Dying Child. By Jo-Eileen Gyulay. (Pp. 192; illustrated + tables. £6.25.) McGraw Hill: New York. 1978.

'Death itself is not painful'. This can hardly rank as a comforting thought, but it does help us a little to be able to separate 'death' from the suffering which precedes it, consisting of bodily discomfort, much unpleasantness, physical pain at times, and mental pain. The context from which I quote this remark is that of dealing with a dying child's questions and the help it gives to parents and to us, the staff, if we can separate pain from death.

Jo-Eileen Gyulay is one of those rare people who have become so familiar with death and dying that she is no longer afraid of them, and therefore is able to appreciate the extraordinary realism and fatalism with which many children can come to look at death. The fears, she says, are primarily the child's projections of what is emanating from the parents or family; and much can be done to diminish them. There is no doubt however, that the initial realisation that there will be no recovery from the illness, and that there will be separation from the mother and father and loved ones, is frightening to any child who is old enough for such realisations. The thought of a child suffering under such fears is unbearable; so we keep it a deadly secret and deny to the child the facts on which the realisation depends. But this game is terribly difficult to play; especially if it is attempted with a school-age child, preserving the secret and the denial right up to the end. Most of us have not the courage to play it any other way than by denial, secrecy, and dissembling. This is because we have not communicated with dying children, not allowed ourselves to listen and accept what a child is telling us about the events of the illness and the way things are going.

A large part of Jo-Eileen Gyulay's book is about this situation, the conflicting feelings it creates, and how to work towards what she calls a 'position of openness'.

In 2 chapters she outlines typical reactions and responses first in the pre-school child and then in older children,

from the time of diagnosis onwards, when the secure world ceases to exist and in its place comes a new environment filled with procedures, laboratory results, etc. centred on the disease. Children quickly realise 'at feeling level' that something bad is happening to them and to those near them.

Examples of such reactions are: the phenomenon of 'role reversal' in which children become the main source of comfort and support to the parents in their emotional devastation which the child perceives; reassuring them, showing much courage, and saying comforting words to them. Or, the most distressing reaction of all, when parents are blamed for allowing bad things to happen and anger and hate are vented on them, and extremely wounding things are said. Many other examples are given of mechanisms for coping, or typical behaviour that signifies not coping, by children of various ages and, of course, by parents. The difficulty of preserving openness is great, but the entanglements that go with denial are also great.

'In general', the author states, 'the stress of terminal illness does not bring families together—it divides them'. This is a sad and honest comment, made in spite of many heroic and touching statements of mothers, fathers, and the children themselves, which she quotes liberally. The stress is also liable to divide us, the staff, from each other and from our patients and their families, unless we learn to understand these reactions and to know what families go through.

Two misgivings nevertheless arise. The policy of openness involves 'telling' a child the truth about his condition. What is told, the author states, depends very much on the staff's attitude and that of the family. In paediatric practice in this country I think we would advocate that there should not be any 'telling', but simply that the child should have truthful answers or corrections when he tells us—i.e. any member of staff, at any stage, early or late in the illness, what he thinks is happening to him, or going to happen. The second is that the staff, as described in the book (which includes specialists directing treatment) for whom

the stress of the conduct of dying can be as divisive as it is for the family, have no one person to hold them as individuals or as a group in this stress. The conventional view concerning psychiatrists is that they are there for the diagnosis and treatment of mental illness or behaviour disturbance; and since death, grief, and mourning are not psychiatric illnesses but natural processes there is no place here for psychiatry. In fact, all people under these stresses, as individuals or as a team, require the support of a person who is trained in the understanding of human behaviour under stress—in other words a psychiatrist and in this context a child psychiatrist.

The author could well be such a counselling person, having acquired by long and painful experience the necessary knowledge and understanding. But as I have said, such people are rare. And there are many paediatric teams who must continue to stumble along, helped by this book if they possess it, but still in need of this trained person.

This book will help anyone if he will keep it at hand to refer to frequently when having to conduct the terminal illness of a child. It is admirably written, with great compassion.

There is a good index and a large bibliography with some 300 titles. Most of the books quoted are American and therefore are not always easy to obtain in the UK. Lindy Burton's *Care of the Child Facing Death* is not included, nor is Sylvia Anthony's *Child's Discovery of Death*, a pioneer book. Some of the articles or chapters are starred as being of particular interest to parents and, in the section on books for children about death, as highly recommended.

It is an impressive compilation. Jo-Eileen Gyulay is a nurse writing primarily for nurses, but her book is of particular value to paediatricians, as they cannot often achieve the same closeness with the patient and parents. In her text she does not refer directly to the bibliography; there is a back up. What she writes is direct from her own experience and the understanding it has given her.

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