Reflections on death in childhood

SIR,—During a regional survey of childhood asthma deaths I recently interviewed the parents of 24 children who had died from this cause. These deaths were all unexpected, most parents having been led to believe that asthma could not be fatal. For me, like Mother Frances Dominica (10 January, p 108), the experience confirmed that parents never really get over the death of a child. Perhaps the saddest revelation was that only a few parents had received support and explanation either at the time or subsequently:

"The nurses were changing shift when we arrived and we were just told to wait. She was getting bad by then . . . then she just went stiff in my arms and all her colour drained away from her. I shouted for the nurse. We were pushed out of the cubicle and I never saw her after that. . . . I just don't know what happened to her. I saw her two days later in the chapel of rest. She was covered up to her neck. I wanted to touch her but they wouldn't let me. I think they had done a postmortem and didn't want me to see. We never had any contact from the hospital. If only someone had come and explained what happened to her—not at the time but maybe a few days later. . . ."

Many parents had been overwhelmed by guilt and anger, which was sometimes compounded by a defensive response from medical staff. Insensitive behaviour by those present around the time of death is never forgotten. Conversely, one parent commented that the nurses cried when her child died and found comfort in the fact that they shared her distress, yet it is thought to be "unprofessional" to show our feelings.

Several of the siblings suffered the well documented depression and behaviour disturbance,¹ but none had received the necessary expert help.

Death in childhood is fairly uncommon in our society, and thus few have developed the ability to deal with it. Nevertheless, over 5000 children aged between 1 week and 15 years die in England and Wales each year. How can we improve our skills? The hospice movement has contributed a great deal, but many deaths are unexpected and so there can be no preparation or anticipatory grieving. The Foundation for the Study of Infant Deaths has made some excellent recommendations,² but more must be done.

Paediatricians should interview parents after any childhood death,³ and there must be effective communication between doctors, accident and emergency staff, hospital chaplains, social workers, pathologists, and coroners. Wider publicity should be given to self help groups, such as Compassionate Friends. Regular multidisciplinary workshops on dying and bereavement (available to all staff in my own hospital and usually over-subscribed) are to be recommended.

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1 Pettie, MSA, Lansdown RG. Adjustments to the death of a sibling. *Arch Dis Child* 1986;61:278-83.

2 Lady Limerick, Downham MAPS. Support for families bereaved by cot death: joint voluntary and professional view. *Br Med J* 1978;ii:1527-9.

3 Newton RW, Bergin B, Knowles D. Parents interviewed after their child's death. *Arch Dis Child* 1986;61:711-5.

The unrelenting burden on carers

SIR,—Following Mr Robert Anderson's leading article (10 January, p 73) I would like to draw your readers' attention to the work of the Association of Crossroads Care Attendant Schemes, which specialises in giving practical help and support to carers.

We provide trained, paid care attendants who look after a severely handicapped or elderly person while the carer has a break. We help 8000 families throughout the United Kingdom and have undertaken several studies ourselves. The latest of these describes the characteristics of carers, their relationship to the disabled person, the factors which affect their ability to care, the extent to which they have any relief from caring, and their feelings and worries about caring and with the future.¹ The study was based on 700 carers.

The main message of the report is to ask how many more reports have to be undertaken before any action is taken. Carers' needs have, in fact, been well documented and well known for many years. The problem has been that instead of implementing the findings of the studies and surveys more money has been spent on more studies.

The issues that arise from caring for a severely disabled or elderly person at home have not been properly addressed or properly thought through. There is so much emphasis on community care, so much lip service paid to it, but it has always been the cinderella of health care. Norman Fowler, Minister for Health, has recently been to America to study community care for victims of the acquired immune deficiency syndrome and has come to the conclusion that it is better for them to be cared for in their own homes. The Crossroads model of care, relating very closely to statutory and voluntary organisations, is proved and has a national network of people who are not only experienced but have the commitment, enthusiasm, and tenacity required to develop this commonsense approach to bringing the dignity of true caring to disabled people who wish to remain in their own homes.

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1 Association of Crossroads Care Attendant Schemes. *Cause for concern*. Rugby: Association of Crossroads Care Attendant Schemes, 1986.

Inoperable aortic stenosis in the elderly: benefit from percutaneous transluminal valvuloplasty

SIR,—Dr Graham Jackson and his colleagues have confirmed in their excellent and thorough article (10 January, p 83) that aortic balloon valvuloplasty is a relatively simple technique that can be remarkably beneficial for the old, sick, or infirm patient with aortic stenosis who otherwise would not be considered fit for aortic valve replacement.

We were also impressed by the early reports,^{1,2} especially by the safety of the technique, and we therefore carried out balloon aortic valvuloplasty in five patients. Unlike Dr Jackson and colleagues, we did this in a district general hospital without surgical cover as many of the patients were sick and unwilling or too unwell to tolerate the long journey to our local surgical cardiac centre. All our patients had severe aortic stenosis and were not considered for aortic valve replacement because of age (82, 63, 77, 76, and 89 years) or severe pulmonary oedema with poor left ventricular function (one patient aged 63) or because surgery was considered too risky (the 77 year old had additional mitral regurgitation and a left ventricular aneurysm). All patients had the preoperative gradient (70-120 mm Hg) reduced by 50% and did extremely well with considerable improvement in their symptoms. Like the authors we have found that two dimensional echocardiography and Doppler studies are essential for assessment before and after

dilatation. Balloon aortic valvuloplasty can therefore be carried out in a district general hospital without undue risk provided two dimensional echocardiography with Doppler and cardiac catheterisation facilities (x ray screening) are available.

We feel therefore that this technique will be used more widely and that it may come to be considered as an alternative to aortic valve replacement, even in younger or fitter patients (with considerable saving of time and expense). However, we agree that it is time to do a proper trial to compare balloon valvuloplasty with aortic valve replacement in a selected group of patients.

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- 1 Cribier A, Saoudi N, Berland J, Savin T, Rocha P, Letac B. Percutaneous transluminal valvuloplasty of acquired aortic stenosis in elderly patients: an alternative to valve replacement? *Lancet* 1986;i:63-7.
- 2 McKay RG, Safian RD, Lock JE, et al. Balloon dilatation of calcific aortic stenosis in elderly patients: postmortem, intra-operative and percutaneous valvuloplasty studies. *Circulation* 1986;74:119-25.
- 3 Cribier A, Letac B, Lancelin B, et al. Percutaneous balloon valvuloplasty (PBV) for acquired aortic stenosis: preliminary immediate results of the French registry. *Circulation* 1986; 74(suppl II):208.

SIR,—Although Dr Graham Jackson and colleagues (10 January, p 83) conclude that percutaneous transluminal valvuloplasty should not be used as an alternative to routine aortic valve replacement, their article does imply that the results in some groups are at least as good and perhaps better than with surgical treatment. Although this technique is an interesting development, we think that it should be given the same high level of scrutiny as has the surgical management of critical adult aortic stenosis.

Although we would not dispute the claim that avoiding surgery in a group of patients with other terminal disease is reasonable, we are concerned by the suggestion that this procedure may be a good alternative to surgery in the older patient or in a nebulous group of patients whom the authors define as "unacceptable surgical candidates."

The authors quote a mortality for surgery of 7-10%. This figure comes from a review of surgery in the elderly (>65 years)¹ and actually represents the late mortality for the group expressed as a linearised occurrence rate (% per patient year), many of the deaths being attributable to natural causes. The early mortality for the group of 190 patients was 4.7%. In a similar review of cardiac surgery in the elderly in this hospital the mortality in a similar time frame was 2.5% (1 out of 40 patients).² This must be set in the context of the results for all patients referred in this hospital for isolated aortic valve replacement over 10 years, when the mortality was 2.4% in 900 consecutive patients. This included all emergency cases. The United Kingdom cardiac surgical register for 1984 revealed a mortality of 4.1% in 2073 cases.³ This again included all cases. During the past two years at Papworth Hospital the only deaths that have occurred within 30 days of operation for isolated replacement of the aortic valve were in two patients who suffered cardiac arrest in the ward before surgery and in whom cardiac output could not be re-established before operation. One of these patients also had severe triple vessel coronary artery disease.

In contrast to these results, the authors reported one death out of eight cases. Although their series was barely large enough to be more than anecdotal this was a mortality of 12.5%. The group from Rouen recently reported the results of the French multicentre trial.³ There had been one death out of 158 cases during the procedure, but a further 14 patients died within six days of valvuloplasty (mortality 9.5%). The cause was