1 Holm S. Goodbye to the simple solutions: the second phase of priority setting in health care. *BMJ* 1998;317:1000-2.
2 Sabin JE. Fairness as a problem of love and the heart: a clinician's perspective on priority setting. *BMJ* 1998;317:1002-4.
3 Chinitz D, Shalev C, Galai N, Israeli A. Isreal's basic basket of health services: the importance of being explicitly implicit. *BMJ* 1998;317:1005-7.
4 Klein R, Day P, Redmayne S. *Managing scarcity: priority setting and rationing in the National Health Service.* Buckingham: Open University Press, 1996.
5 Smith R. Viagra and rationing. *BMJ* 1998;317:760-1.
6 Royal College of Physicians. *Setting priorities in the NHS: a framework for decision making* London: Royal College of Physicians, 1995.
7 New B, Le Grand J. *Rationing in the NHS: principles and pragmatism*. London: King's Fund, 1996.
8 5. Daniels N, Sabin J. The ethics of accountability in managed care reform. *Health Affairs* 1998;17:50-64.
9 Hunter D. Rationing: the case for "muddling through elegantly." *BMJ* 1995;311:811-3.
10 Braybrooke D, Lindblom CE. *A strategy of decision: policy evaluation as a social process.* New York: Free Press, 1970.

The teenager with epilepsy

Has special needs

Even for healthy teenagers, coping with emerging adulthood is a major challenge. A chronic disability such as epilepsy simply magnifies the problems of adolescence, and the penalties for seizures at this time are far more severe than in childhood. Epilepsy and its treatment have a direct bearing on major aspects of lifestyle such as education and employment prospects, driving ability, the use of alcohol and recreational drugs, relationships, contraception, pregnancy, and parenthood. Self consciousness is paramount and deviations from peer group norms assume great importance: epilepsy can be disastrous for an adolescent's self esteem and sense of identity.

Adolescents with epilepsy are often caught between paediatric and adult medical disciplines, with neither service specifically addressing their needs. The Liverpool group advocates multidisciplinary consultations with a neurologist, paediatric neurologist, and specialist epilepsy nurse.[1] Whatever the setting, the consultation must focus on the needs and independence of the teenager, with the parents taking a back seat. If possible, part of the consultation should be with the teenager alone: an opportunity arises while examining the patient in a separate cubicle.

The same principles of clinical management apply in adolescence as in any age group, but for the teenager the problems are more pressing and the long term consequences of mismanagement more serious.[2] A correct diagnosis of blackouts is essential. The diagnostic process in teenage epilepsy must take account of three situations. Firstly, some epilepsies, such as juvenile myoclonic epilepsy, present in adolescence and carry specific implications for management.[3] Secondly, some childhood onset epilepsies, such as benign childhood epilepsy with centrotemporal spikes, consistently remit in adolescence.[4] Thirdly, common conditions such as vasovagal syncope, psychogenic non-epileptic attack disorder, and migraine often present first in teenagers and may mimic epilepsy.

Optimal seizure control is central to managing epilepsy. When anti-epileptic drugs are indicated the ideal is to prescribe the lowest effective dose of a preparation with as few side effects as possible, given as a once or twice daily dose. A vigorous approach to seizure control is justified since interventions often have progressively less impact as epilepsy and its consequences become established. Surgery for epilepsy is much underused but potentially curative in some patients with localisation related epilepsies. The argument for surgery in children and adolescents is not just that it is effective[5]; it can also prevent the social, educational, and developmental handicaps which, once established, may persist even with good control of seizures.

Compliance with drug treatment is a particular problem in adolescence. As at any age, the reasons include denial of epilepsy, concern over side effects, and complacency about good seizure control. For teenagers there is also an intense peer pressure to conform—their tablets a reminder with each dose that they are different—as well as rebellion against parental involvement in the management of their epilepsy. Side effects are extremely important at this age since even mild cognitive dysfunction may permanently harm education and employment prospects. Cosmetic effects limit the usefulness of certain antiepileptic drugs (such as phenytoin) in young people.

Several lifestyle issues merit discussion. Young women taking enzyme inducing antiepileptic drugs must be warned about potential failure of oral contraceptives. More importantly, all women of childbearing age taking antiepileptic drugs need to know of their possible teratogenicity. There is some evidence that folate reduces this risk for enzyme inducing medications[6] and valproate.[7] Given that at least 30% of teenage pregnancies are unplanned, a pharmacological dose of folate 5 mg daily seems a sensible addition to any antiepileptic regimen.

Advice on regular sleep is particularly important in idiopathic generalised epilepsy, the commonest form in teenagers. Complete abstinence from alcohol is unnecessary, but teenagers must recognise its potential for interacting with drugs and impairing sleep quality and so provoking seizures. The influence of recreactional drugs on epilepsy is unknown. The risk of exposure to computer screens and flashing lights often concerns patients and parents. Photosensitive epilepsies may present in the teenage years, but such exposure is harmless to most teenagers; a baseline electroencephalogram is helpful in refining this advice. A discussion of sudden unexpected death in epilepsy is sometimes appropriate and is touched on in a helpful patient information booklet.[8]

Epilepsy affects educational and employment prospects, with career choices being inevitably restricted by the diagnosis.[9] Further restrictions imposed by parents, suggested by peers, or initiated by the patient are sometimes inappropriate. Such restrictions can threaten independence, deny opportunities for friendship, and encourage social isolation. A common sense approach is needed towards leisure and sports activities, both patient and parents often having to accept living with a degree of risk. The problems faced by teenagers with epilepsy

BMJ 1998;317:960–1

apply, often to a lesser extent, across the range of patients with epilepsy. As we improve our services for this vulnerable group, the lessons learnt can only benefit people with epilepsy as a whole.

Philip E M Smith *Consultant neurologist*

Epilepsy Unit, University Hospital of Wales, Heath Park, Cardiff CF4 4XW

1 Appleton RE, Chadwick DW, Sweeny A. Managing the teenager with epilepsy: paediatric to adult care. *Seizure* 1997;6:27-30.
2 Besag FM. Modern management of epilepsy: adolescents. *Baillière's Clin Neurol* 1996;5:803-20.
3 Timmings PL, Richens A. Juvenile myoclonic epilepsy. *BMJ* 1992;305:4-5.
4 Kurtz Z, Tookey P, Ross E. Epilepsy in young people: 23 year follow up of the British national child development study. *BMJ* 1998;316:339-42.
5 Ventureyra EC, Higgins MJ. Complications of epilepsy surgery in children and adolescents. *Pediatr Neurosurg* 1993;19:40-56.
6 Biale Y, Lewanthal M. Effect of folic acid supplementation on congenital malformations due to anticonvulsant drugs. *Eur J Obstet Gynaecol Reprod Biol* 1984;18:211-6.
7 Elmazar MMA, Thiel R, Nau H. Effect of supplementation with folinic acid, vitamin B_6 and vitamin B_{12} on valproic acid induced teratogenesis in mice. *Fundamental and Applied Toxicology* 1992;18:389-94.
8 Preston J. *Epilepsy and the young adult*. London: Epilepsy and the Young Adult,1996.
9 Thompson P, Oxley J. Social aspects of epilepsy. In: Laidlaw J, Richens A, Chadwick DW, eds. *A textbook of epilepsy*. 4th ed. Edinburgh: Churchill Livingstone, 1993:661-704.

Dying from heart failure: lessons from palliative care

Many patients would benefit from palliative care at the end of their lives

Increasing interest and research into the care of the dying over the past 25 years have resulted in better symptom control, psychological support, and choice for people dying from cancer and their families.[1] Little attention has been paid, however, to patients with other life threatening diseases, such as AIDS, neurological conditions, respiratory failure, and heart failure. Palliative care, with its emphasis on the care of patients whose prognosis is limited, on quality (not quantity) of life, and on a multidisciplinary approach, may benefit patients other than those with cancer. One such group is patients dying from heart failure.

Heart failure is the only major cardiovascular disease with increasing prevalence, incidence, and mortality. Incidence and prevalence both increase dramatically over the age of 75 years—up to 43.5 and 190 per 1000 population respectively.[2] With age adjusted mortality from cardiovascular disease declining and the size of the elderly population growing, the absolute number of individuals living with compromised cardiac function is expected to increase dramatically over the next few decades.[3] Modern treatments for heart failure slow but do not arrest progression of the disease. Despite the wealth of therapeutic advances, quality of life in chronic heart failure is poor[4] and discomfort and distress often worse than in cancer.[5]

In the United Kingdom only one study has investigated symptoms in terminal heart disease: the regional study of care for the dying.[6] This was a population based retrospective survey of a random sample of people dying in 20 English health districts in 1990. People who died from heart disease, including heart failure, had experienced a wide range of symptoms, often distressing and often lasting more than six months.[7] In addition to dyspnoea, pain, nausea, constipation, and low mood were common and poorly controlled. At least one in six had symptoms as severe as those in patients with cancer managed in hospices or by palliative care services. Although many were thought to have known that they were dying, open communication with health professionals was rare.[8]

In the United States the SUPPORT study included 263 patients with heart failure.[9] It showed severe symptoms in the last three days of life in patients with heart failure: 65% were breathless and 42% had severe pain. Forty percent of these patients received a major treatment intervention in the last three days of life, suggesting that doctors had not recognised the closeness of death. A salutary finding was that intervention by specially trained nurses to enhance decision making and improve patient care had no impact on symptom control or other outcome measures.

In heart failure, as in most diseases, the first step towards symptom control is optimisation of treatment of the underlying disease. The regional study of care of the dying suggests that this is not enough. The need for improved symptom control and greater emphasis on quality of life has been recognised,[10 11] but research into and provision of services for care of patients with end stage heart disease have been neglected.[12] Nurse practitioners have been advocated to help with patient management and may be effective.[12] Several trials are underway, but these may be premature since the needs of these patients have not been defined. Cost effective, appropriate, and acceptable services for these patients cannot be developed in the absence of good information on what their needs are and when to intervene to improve their lives.

The findings of the SUPPORT study suggest that the use of resources for the care of patients with heart failure will need to be imaginative to be effective. Anecdotal evidence exists that palliative care teams have managed patients with heart failure successfully using the same approach that helps cancer sufferers, but conventional hospice and specialist palliative care services could be overwhelmed by heart disease. Indeed, different models of care may be needed since patients with heart failure are more prone to sudden death than patients with cancer and do not necessarily have a clearly defined terminal phase. Specialist heart failure nurses may founder if they work in isolation. Palliative care is recognising the need to take stock of other terminal illnesses. Now is the time to collaborate and accelerate this change.

Louise M E Gibbs *Locum consultant in palliative medicine*

Royal Marsden Hospital, Sutton, Surrey SM2 5PT

Julia Addington-Hall *Senior lecturer in palliative care*

Department of Palliative Care and Policy, Guy's, King's, and St Thomas's School of Medicine, London SE5 9PJ

J Simon R Gibbs *Senior lecturer in cardiology*

National Heart and Lung Institute, Charing Cross Hospital, London W6 8RF (SimonGibbs@compuserve.com)

BMJ 1998;317:961–2