

THORAX

Editorials

Consumer, carer, provider, purchaser – developing care for adults with cystic fibrosis: a specialist service

A successful structure for the care of adults with cystic fibrosis must be devised within the framework of the current NHS reforms. By the year 2000 there will be over 3000 adults with the disease – equal to the number of paediatric patients; thereafter there will be more adult than paediatric patients because of the longer survival which it has been predicted will extend into the fourth decade,¹ and the reduction in the birth rate.

Respiratory physicians need to develop this area of growth in their specialty. Over the next decade all respiratory physicians will, of necessity, acquire practical experience of cystic fibrosis – either during training or as consultants – because of the increasing size of the adult population with the disease. This will test the clinical and personal skills of carers where the end point will remain death of a young adult from pulmonary sepsis. Additionally, cystic fibrosis will provide clinical and scientific research potential for decades to come.

Cystic fibrosis is distinguished from other respiratory diseases by the ability of young adults, with a sharply focused and limited future, to enunciate their perceived requirements for care. There are few diseases where the patients publish their own national and international magazine and organise meetings. Many have greater knowledge and understanding of their disease than most doctors. This collective demand for defined standards of care is a potentially powerful factor in the provider/purchaser system in the NHS. It is likely to be more powerful than the laudable recommendations for care by the British Paediatric Association² and the Royal College of Physicians,³ which have defined high standards of care but which the management of the NHS at regional and higher levels of responsibility have refused to adopt.

In this issue of *Thorax* Walters *et al* report a comparison between specialist cystic fibrosis clinics and general clinics based on a questionnaire of adult patients,⁴ which should be read carefully by every respiratory physician. Some of the themes discussed are specific to cystic fibrosis, but other issues raised are common to all small specialist respiratory services such as chemotherapy for lung cancer and disordered sleep support. All these have a high cost and low volume turnover and do not fit easily into the current block contract model.

The need for cystic fibrosis centres is virtually undisputable. Walters *et al* report that adults with cystic fibrosis prefer to attend specialist centres, where they receive more intensive care and a more satisfactory service than in a general clinic. This is not surprising and should not upset the general respiratory physician. A specialist centre for cystic fibrosis consists of a multidisciplinary team exper-

enced and expert in all the complexities associated with such patients. Much of the experience is gained simply by caring for a “critical mass” of patients. Perhaps more challenging is how centres (paediatric and adult) compare with each other. A cystic fibrosis centre should deliver an exemplary service to patients, perform peer reviewed medical and scientific research, innovate and critically assess new treatments, provide postgraduate training, and improve communication with general practitioners and physicians in district general hospitals. These are some of the different areas where a cystic fibrosis centre may both succeed and fail.

Specialist cystic fibrosis centres, by practising in a holistic manner, have isolated both general respiratory physicians and general practitioners from experience of the disease. The former feel bypassed and the latter feel they are only there to prescribe expensive drugs. It may become difficult for specialist centres alone to cope with the large number of patients with cystic fibrosis reaching adulthood. Conversely, all patients with cystic fibrosis in a health region should be seen at least annually at a specialist centre. In particular, those with severe disease should be seen frequently. Judging the correct time to introduce a feeding gastrostomy, nocturnal ventilation, and referral for transplantation can be a difficult decision, even in an experienced centre. Clearly there needs to be greater sharing of care and knowledge between physicians running specialist services, general practitioners, and general respiratory physicians. Communication and education need to be fostered between all three groups.

However, it is pointless to develop specialist care in a region if flows to such centres of expertise across district boundaries are inhibited both by competition and limited finance. In each health region the recent NHS reforms have devolved responsibility for the purchasing of care to multiple purchasers including consortia, individual district health authorities, and general practitioner fundholders. Specialist services with high costs and low patient numbers do not fit easily into block contracting. Equally, lack of information does not help multiple purchasers in reaching an informed decision as to the value and quality of the care they are contracting to buy.

It was against the background of the purchaser/provider system that the government commissioned the Clinical Standards Advisory Group (CSAG) to report on access to and availability of specialist services.⁵ Specific reports were produced on cystic fibrosis, neonatal intensive care, childhood leukaemia, and coronary artery bypass grafting. With regard to cystic fibrosis, it was recommended that centres should coordinate therapeutic developments such

as gene therapy (from which patients would be excluded if they did not attend a centre), improve information systems, and that district health authorities should develop consortia to purchase defined specialist care supplemented by shared care arrangements. The government response recognised that a more sophisticated and flexible contracting process was required for the purchasing of such specialist services than the case-insensitive block contracts. An essential purpose of establishing an improved contracting process would be to provide stability for specialist units. The current annual cost of running an adult cystic fibrosis unit of 150 patients can be calculated according to disease severity at approximately £1.5 million.⁶ Each year this funding must be realised from multiple purchasers within a health region. Purchasers may be unwilling to buy this care, or perhaps will run out of money towards the end of the financial year, as has happened with general surgery. If this occurred cystic fibrosis centres would be financially destabilised, unable to expand, or to accept new referrals.

There are two remedies to this threat. Firstly, as the article by Walters *et al* in this issue of *Thorax* emphasises, adults with cystic fibrosis and parents of paediatric patients, as consumers, are well organised to tell purchasers that a significant component of their care should be received in a cystic fibrosis centre. Secondly, the NHS Management Executive (NHSME) has just published a report⁷ in which some of the key issues addressed include: (a) the need for purchasers to be informed about the nature and development of the service; (b) the importance of the contracting process being long term rather than annual; (c) the importance of the provider dealing with a lead pur-

chaser, who would monitor quality standards and activity, rather than a multiplicity of purchasers; and (d) the need for mechanisms which would allow for pump-priming of innovations and new technology within contracts. More is discussed, but it remains to be seen whether a practical guide can become useful practice.

In order to practise specialty medicine respiratory physicians will have to continually adapt, evolve, and forward plan the structure of their units in tandem with NHS changes, accepted standards of care, and the wishes of the patients whose knowledge of high quality care is ever expanding. Additionally, politicians and health managers will have to take into account the wishes of informed patients.

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- 2 British Paediatric Association Working Party on Cystic Fibrosis. Cystic fibrosis in the United Kingdom 1977-1985: an improving picture. *BMJ* 1988;297:1599-603.
- 3 Royal College of Physicians. *Cystic fibrosis in adults; recommendations for care of patients in the United Kingdom*. London: Royal College of Physicians, 1990.
- 4 Walters S, Britton J, Hodson M. Hospital care for adults with cystic fibrosis: an overview and comparison between special cystic fibrosis clinics and general clinics using a patient questionnaire. *Thorax* 1994;49:300-6.
- 5 Clinical Standards Advisory Group. *Cystic fibrosis: access and availability of specialist services*. London: HMSO, 1993.
- 6 Robson M, Abbott J, Webb AK, Dodd M, Walsworth-Bell J. A cost description of an adult cystic fibrosis unit and cost analyses of different categories of patients. *Thorax* 1992;47:684-9.
- 7 NHS Management Executive. *Contracting for specialised services: a practical guide*. Report EL(93)98. Leeds: Department of Health, 1993.