

Diabetes in cystic fibrosis on the rise

As treatment for cystic fibrosis improves and patients live longer, more CF-related diabetes is being diagnosed. **Helen Cunliffe**, a pharmacist at St James's University Hospital, Leeds, reports from a meeting of CF pharmacists

The severity and increasing incidence of cystic fibrosis-related diabetes (CFRD) is giving cause for concern, said Rachel Rowe, consultant diabetologist, Wythenshawe Hospital, Manchester. CFRD was rare until the 1980s but the increased survival of patients with CF means that more patients are being diagnosed with CFRD. The mean age a CF patient with diabetes is approximately 18–20 years. Mortality increases six-fold, because the diabetes has an adverse affect on pulmonary function. At least 90 per cent of CF patients aged 40 will have diabetes and the increasing survival of patients means that there will be more patients with CF-related diabetes and for a greater number of years than before. The pharmacist can expect to see more diabetes-related complications.

Patients are screened for diabetes from the age of 12 years. Diagnosis of CFRD is more difficult than type 1 diabetes. The insulin resistance changes a lot in CF and patients “jump in and out” of diabetes, requiring dramatic alterations in drug treatment. Patients lose beta and alpha cells (which make glucagon) resulting in profound hypoglycaemic attacks in untreated patients. Dr Rowe reported that subcutaneous glucose sensors were useful in understanding the problems patients were having with diabetes control and determining appropriate insulin therapy. Pharmacists should also be aware of drugs used in the treatment of other CF conditions which may affect the patient's diabetes.

Adolescent transition

Caroline Harris, clinical psychologist, Leeds Adult Cystic Fibrosis Unit, talked about her experiences with patients with CF and paediatric liver disease. She pointed out that adolescence is associated with an increase in difficulties in treatment adherence for chronic disease and that there are reports of it being a “distressing” period. She said that the national service framework for children and young persons recognises that transition should be a guided, educational and therapeutic process. Dr Harris said that transition can be problematic for not only the child but also the parent, and the CF team or individual professionals working with the family.

She emphasised the importance of talking about transition of care to the child and family from an early age so that the family considered the move from a paediatric CF unit to the adult CF unit to be a normal progression, which in turn reduces anxiety at the time of transfer. The transfer of care should be made as easy as possible by holding a CF transition clinic with both paediatric and adult CF staff attending. She felt it was inappropriate for an adult to be treated within a paediatric clinic

because the paediatric team wanted to “hold on” to their patient.

Dr Harris described how developing a unique identity is the major psychological task of young adulthood and to achieve this goal, the young person must negotiate an autonomous relationship from their parents, define themselves as an adult, and construe themselves as sexually mature in a physical and social sense. Whereas normal adolescents start to seek more support from their friends than their family, illness in adolescence has the opposite effect in that patients start to rely more on family and relatives, parental anxieties come into play and there are difficulties in “letting go”. Ill health confuses the developing person's sense of self and future, and young people with CF may become more aware of death.

Adherence to drug treatment is a common problem and Dr Harris suggested that less coercion and more collaboration was effective, for example by developing a relationship with patients, being prepared to compromise where possible and setting small goals. It is also necessary to accept that levels of adherence will vary from time to time and recognise that not sticking to regimens is normal adolescent behaviour. Patients' choices should be respected.

Antibiotic treatment

Hospital treatment with intravenous antibiotics is more effective but also more expensive than home treatment. This was the conclusion of a study by Judith Thornton, pharmacist and honorary research fellow at the University of Manchester, who presented the results of her surveys, which have been published (*Thorax* 2004;59:242–6, and *Journal of Cystic Fibrosis* in press). Home intravenous antibiotic therapy is increasingly popular with patients with cystic fibrosis and although there is published evidence looking at clinical outcome of patients there were no published economic evaluations.

The study compared home and hospital treatment at the Manchester Adult CF Unit, in 2000–01, as a one-year retrospective study. One hundred and sixteen patients were eligible, with 454 courses of intravenous antibiotics given.

Patients on home treatment prepare and administer antibiotics themselves. Clinical outcome was judged on FEV₁, FVC and body weight.

At one year the study demonstrated that the clinical outcome after one course of treat-

Cystic Fibrosis Pharmacist Group

The Cystic Fibrosis Pharmacist Group (CFPG) is open to all pharmacists with an interest in cystic fibrosis.

The group holds an annual meeting and has an e-mail discussion forum, which is a useful tool for pharmacists working with CF patients to support each other.

Membership is free and information can be obtained by contacting Helen Cunliffe (e-mail Helen.cunliffe@leedsth.nhs.uk).

ment in hospital is better than after home treatment. After one year, clinical outcome is better in patients who receive most of their treatment in hospital. Factors which may have had impact on the results included lack of supervision and monitoring of physiotherapy, diet and adherence at home.

The second part of the study considered a cost comparison between home and hospital treatment. Hospital treatment was significantly more expensive than home treatment at £22,609 vs £13,525.

The study was further extended as an economic evaluation to calculate the incremental cost-effectiveness ratio (ICER). The results, analysed against a decline in FEV₁ of less than or equal to 2 per cent from baseline average over one year, showed that hospital treatment was significantly more effective than home treatment but at a price — around £70,000. Other pharmacists suggested that if a home care company was used to supply the antibiotics the outcome may have been different as adherence may be better and the cost differential would be less.

Dr Thornton suggested that further studies should look at quality of life comparisons with home and hospital treatment.

Oxygen therapy

Mary Dodd, a physiotherapist at Wythenshawe Hospital spoke about the oxygen therapy. She highlighted the change in home oxygen service in England and Wales in early 2006.

Although the new contact is designed to relieve current problems with the oxygen supply, her concerns were that, owing to budget restraints, patients would be given concentrators routinely, which she believed was not appropriate for all patients. She stressed the need for the form to be completed fully to prevent patients from being given a conserving device and a concentrator automatically, when it was not intended.

The annual meeting of the **Cystic Fibrosis Pharmacist Group** took place in Manchester on 24 November