

## **Note of meeting held on 30 January 2007**

Rosie Barnes, Chief Executive of the Cystic Fibrosis Trust, and Oli Lewington, who has CF and is on oxygen, met with Jeanette Howe and Mary Grafton of the Department of Health to discuss the issues that have arisen in relation to the provision of oxygen over recent months.

We outlined the main problems to the Department of Health and they in turn explained what was in hand to improve matters. Both sides agreed that whilst things were still not perfect there had been significant improvement over recent weeks.

Problems discussed included:

- Difficulty in getting through on the telephone;
- Encountering staff who may be
  - rude or unhelpful
  - insensitive
  - sympathetic but ill-informed and unable to address the problem;
- An inability or an unwillingness to supply portable or liquid oxygen in sufficient quantities for the needs of people who were trying to keep up with their education, hold down jobs and maintain their social life whilst their health was deteriorating;
- Deliveries which failed to deliver enough oxygen for a week or for a reasonable period of time, thereby triggering the whole process of having to telephone all over again;
- An exhausting, frustrating and demoralising process for people who are ill, weak and tired and just haven't always got the energy to battle on with such an unresponsive system;
- The weight of portable "lightweight" cylinders is still a problem for many people with CF who are often slightly built and whose health is deteriorating. Smaller Oxylight-type cylinders are not usually available;
- Staff of some of the service contractors have been rude and callous when these problems are raised with them. (It must be said, to be fair, that many of the delivery staff have been extremely sympathetic and supportive and have tried to be helpful);
- Orders are overlooked or lost;
- Conflicting advice from different technicians;
- Inability to supply appropriate soft nasal cannulae;
- Problems with faulty tubing and connections.

All in all, patients have found the service extremely poor and very worrying. To summarise, they have found it difficult to get through on the phone. When they have got through on the phone, they have not always been able to talk to somebody who is courteous, sensitive and well-informed about the need of those requiring oxygen. It would also seem that the service contractors do not have the necessary products to meet their obligations.

One concern that we raised was that some people with Cystic Fibrosis had been waiting for over 12 months for a promised Assessment of Need visit. Apparently this is not the job of the service contractors. The Assessment of Need is for the health professional treating you to carry out – the Specialist Consultant, or a member of the team, in consultation with you, the patient. The Assessment of Need helps decide the right kind of oxygen therapy service for you, so that the health professional can order this from the service contractor. It is the service contractor's job to meet that order.

The HOOF (Home Oxygen Order Form) is an order sent by the Consultant to the service contractor to supply the oxygen in the appropriate form. There is a Department of Health website which can be accessed for further information; its details are [www.homeoxygen.nhs.uk](http://www.homeoxygen.nhs.uk). There is also a complaints procedure and as part of the development of this service complaints are being monitored, it is important that if anyone does have cause for concern they should register a complaint.

We hope this is helpful. Do keep us posted of any further experiences you have with your oxygen suppliers – good or bad.