

THE EDWARD W JOSEPH CF HOME CARE PROGRAMME

Thanks to a very generous donation from the Edward W Joseph Trust, the Cystic Fibrosis Trust has been able to establish a fund to promote increased care in the home - rather than hospital - for people with Cystic Fibrosis.

It is recognised that people (especially children) generally feel more comfortable and enjoy a greater sense of well-being if treated at home. The aim of encouraging people with CF to be cared for primarily in their own home is consistent with current best practice and is supported by the Trust's Research and Medical Advisory Committee.

A secondary aim is to promote improvements in home care by educational means, including talks and demonstrations from professionals and the production of educational materials; a video, for example, showing parents how they may improve their physiotherapy technique has been produced.

The criteria that need to be met in order to obtain support from the programme are:

- (i) that there is a likelihood of the person with CF being admitted to hospital unless additional, temporary support can be provided for them in the home; or the person concerned could be discharged from hospital earlier than would otherwise be the case if additional, temporary support could be provided for them at home;
- (ii) the family concerned is experiencing a period of significant stress owing to circumstances that cannot be resolved by the intervention of statutory agencies such as Health or Social Services (examples could include - illness of another child in the family, illness or absence of a parent or partner, temporary withdrawal of other community-based support, the introduction of new home-based treatment such as home intravenous treatment, or the person's CF entering its terminal stages);
- (iii) the support required is temporary and the need for it unlikely to reoccur in the short term;
- (iv) the support to be provided has been agreed with the local CF Clinic or Regional Centre;
- (v) the support will be provided by an appropriately qualified person who is familiar with the condition.

Individuals may apply for a grant from this programme either direct (by completing an application form for a welfare grant) or through a social worker or other health professional who has been involved in supporting the person with CF and the application must be endorsed by them.

Application forms and further advice can be obtained from our **Welfare Grants Officer** by telephoning the **Helpline; 0845 859 1020**, or from our website.