

**CENTRE CARE/SHARED CARE/NETWORK CARE:  
CARE OF PATIENTS WITH CYSTIC FIBROSIS IN THE UK**

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# CENTRE CARE/SHARED CARE/NETWORK CARE

## INTRODUCTION

Cystic Fibrosis is one of the thirty-five specialised services recognised by the Department of Health in the Specialised Services National Definitions Set (2002).<sup>1</sup> The 'Review of Specialised Services (May 2007)' produced by Professor Sir David Carter for the Department of Health defines specialised services as being '*...provided in relatively few specialist centres...*', that they are '*...high cost, low volume interventions and treatments*' and that '*...effective integration with other key specialties is critically important*'.

The Review recommends that specialised services should be commissioned by Specialised Commissioning Groups (SCG) on a regional basis (by Strategic Health Authority (SHA) area) and that each Primary Care Trust in the SHA area should be required to be a member of the SCG. These recommendations were adopted in full and are now being implemented.

The majority of people with Cystic Fibrosis in the UK attend or receive all or some of their care from a Specialist CF Centre. These centres provide full care for the majority of patients and are staffed by a multidisciplinary team with appropriate expertise and training in the management of Cystic Fibrosis. Specialist CF Centres have access to relevant investigations and support from a range of medical and surgical specialties required to address the wide range of medical issues experienced by people with Cystic Fibrosis.

In some circumstances, particularly in the care of children, shared care arrangements between a Specialist CF Centre and a district general hospital have been developed as a means of improving local expertise and community support and minimising travel for children and their parents, thus offering quality care irrespective of the distance from the CF Centre. The drivers for these different arrangements are: historical practice which is influenced by patient preferences; the geography of various regions; and the availability of sufficient resources within the Specialist CF Centre to provide care to all potential patients.

These shared care arrangements vary from centre to centre; furthermore, different arrangements may be made by a Specialist CF Centre with the various district general hospitals with which it shares care.

A Consensus Group<sup>2</sup> was convened by the Cystic Fibrosis Trust to address these issues.

It is accepted that not all of the models that have developed in this way deliver best CF care. In some cases the model of care may be theoretically sound but its implementation may be inadequate. The discussion therefore focused on defining acceptable models of delivering best care and the clear principles that underpin them, whilst allowing for variations required for other circumstances (e.g. the geography of a region). This

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<sup>1</sup> Separate funding arrangements exist in Scotland, Northern Ireland and Wales.

<sup>2</sup> The Consensus Group comprised Consultants from Specialist CF Centres and from shared care Clinics, as well as CF Nurse Specialists, and other allied health professionals along with patient and parent representation. Their discussion took into account existing agreed standards, including the National Definition Set for Cystic Fibrosis and the 'Standards for the Clinical Care of Children and Adults with Cystic Fibrosis in the UK 2001' which was endorsed by all appropriate bodies. A full list of members is appended.

discussion took place in the context of a determination to drive up standards of CF care throughout the UK irrespective of the model of care in question.

## **MODELS FOR DELIVERY OF CF CARE**

### **RECOMMENDATION**

The level of expertise required both to treat and to delay the onset of the complex multi-system complications in Cystic Fibrosis can only be acquired by a multidisciplinary team of trained, experienced, specialist health professionals who see patients at a Specialist CF Centre.

The Consensus Group recommends that all patients with CF have their care delivered by a recognised Specialist CF Centre for treatment throughout their lives. This may involve an arrangement with a district general hospital to deliver CF care within a recognised network.

The Consensus Group recognises that patients have the right to choose where and how they receive care; both personal circumstances and geographical location may result in a patient choosing to receive care in a different setting. Best care is led by a Specialist CF Centre for all patients.

The Consensus Group recognises that care may be delivered according to the following age appropriate models:

### **CHILDREN WITH CF**

❖ Two models for the delivery of care for children with Cystic Fibrosis were recognised:

- *full care* delivered by a Specialist CF Centre, and
- *shared care* delivered by a Network CF Clinic which is part of an agreed designated network with a Specialist CF Centre.

Patients should be informed of the models of care available to them. It should be explained to patients receiving *shared care* that their Network CF Clinic is linked to and led by a Specialist CF Centre. They should be offered the opportunity to receive *full care* at a Specialist CF Centre if they so wish.

With *shared care*, some care may be delivered locally by a Consultant with a specialist interest in CF and a specialist<sup>1</sup> CF multidisciplinary team in conjunction with and under the overall supervision of the team at the Specialist CF Centre, who are ultimately responsible for the long term outcomes of patients with Cystic Fibrosis in their Network.

***Shared care must be delivered as part of an agreed designated Care Network with a Service Level Agreement and Standard Operating Procedures as laid down by the Specialist CF Centre.***

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<sup>1</sup> Staff in a shared care clinic at a district general hospital need to have or be acquiring specialist skills and need to demonstrate a commitment to continuing professional development by being a member of the relevant Specialist Interest Group and attending relevant meetings and conferences as appropriate.

Care delivered by a Network CF Clinic should be to the same standard as that delivered by the Specialist CF Centre. It is therefore essential that the Network CF Clinic is appropriately staffed with an experienced and trained specialist CF consultant and specialist<sup>1</sup> CF multidisciplinary team, as safe and appropriate care for people with CF can only be delivered by health professionals with an informed interest and training in CF. General or community doctors, nurses and allied health professionals working in isolation will not have the necessary experience, expertise and support to offer an adequate and safe level of care for people with Cystic Fibrosis.

The multidisciplinary team at the Network CF Clinic must have access to, and be prepared to ask advice of, the specialist multidisciplinary team at the Specialist CF Centre with whom the care is being shared, and who will have direct experience of a larger number of patients and the wide variety of complications associated with Cystic Fibrosis. The specialist CF Centre Consultant must be kept effectively apprised of the patient's condition and recommended treatment, and should be in a position to advise or intervene when appropriate or necessary. The Specialist CF Centre should similarly ensure that Network clinics are likewise informed. The CF Registry may be a useful tool to facilitate this.

The Annual Review (which may be carried out at a *Network CF Clinic* if the appropriate specialist facilities are available at the local hospital) will be carried out by the Specialist CF Centre team in conjunction with the local team and will include specialist investigations, dietary and physiotherapy assessment and will result in a full report on the patient. This will include care plans for the coming year and advice for the local Consultant and local multidisciplinary team at the Network CF Clinic.

#### **ADULTS WITH CF**

- ❖ Due to the increasing complexity of CF in adulthood, *full care* delivered by the multidisciplinary team from an adult Specialist CF Centre is the only model of delivery of care recognised for adults with Cystic Fibrosis. For patient convenience, some care may be delivered through an *Outreach Clinic* as part of an agreed designated network.

With *full care* the patient always sees the specialist Consultant and the multi-disciplinary team from the Specialist CF Centre, although not always at the Centre. This can involve the full team from the Specialist CF Centre regularly holding an *Outreach Clinic* at a district general hospital and the patient visiting the Specialist CF Centre on other occasions. An *Outreach Clinic* should be staffed by all of the multidisciplinary team from the Specialist CF Centre and not just by a specialist CF Centre Consultant alone.

Whilst inpatient care for adults will usually be provided at a Specialist CF Centre, the Consensus Group recognises that in some areas of the country, providing inpatient care only at a Specialist CF Centre may be very difficult due to geographical location. In such exceptional cases, it is accepted that inpatient care can be provided locally for routine interventions provided that strict protocols have been agreed. These include the multidisciplinary team at the Specialist CF Centre being notified and consulted on each episode of care, appropriate advice being obtained from the Specialist CF dietitian on feeding issues, and appropriate specialist inpatient physiotherapy being available.

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<sup>1</sup> See footnote on previous page for definition of specialist

This may also be appropriate for a person with Cystic Fibrosis who requires frequent hospitalisation close to the end of life and for whom regular inpatient episodes in a Specialist CF Centre a long way from home would be inappropriate.

The importance of Specialist CF Centre care has been recognised, accepted and recommended by the Royal College of Paediatrics and Child Health, the British Thoracic Society and the Royal College of Physicians of London. It is also recognised by the Department of Health in Definition 10 of the National Specialised Services Definition Set published in 2001. The US Cystic Fibrosis Foundation and the European Cystic Fibrosis Society also strongly endorse the principle and importance of Specialist CF Centre care (*Appendix*).

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## **ESSENTIAL CHARACTERISTICS OF SPECIALIST CENTRE CARE AND NETWORK CLINIC CARE**

### **SPECIALIST CENTRE CARE**

A Specialist CF Centre treats either children or adults. It usually has a minimum of 100 adults or children and many will have well over this number. Some larger Centres have reached a stage where their numbers are becoming unmanageable both for the CF team and the hospital infrastructure, including having enough CF beds for in-patients. It is recommended that when numbers reach 250 and are set to continue to rise, the development of alternative Specialist Centres is considered, as well as appropriately staffed Network Clinics for paediatric care.

The consultants and the multidisciplinary team at a Specialist CF Centre will have, and continue to gain, expertise in treating a wide variety of the symptoms of CF and will be able to offer an optimal and safe level of care to their patients.

As well as providing comprehensive care for patients, the team will have sufficient enthusiasm, time and resource to carry out and publish research. The Specialist CF Centre should also be actively involved in audit, education and training. Most improvements in the treatment of CF resulting in better survival and quality of life have been initiated and evaluated at Specialist CF Centres.

It is recognised that in exceptional circumstances the geographical location of a Specialist CF Centre may mean that the number of patients is less than 100 (although it will never be less than 50).

Designation as a Specialist CF Centre will be dependent on meeting the following criteria:

- A significant number of patients as outlined above
- A core multidisciplinary team (MDT) of CF specialist health professionals comprising:
  - at least 2 appropriately trained specialist consultant paediatricians or adult physicians
  - clinical nurse specialists
  - physiotherapists
  - dietitians
  - social workers
  - psychologists
  - pharmacists
  - coordinators, clerks and/or secretarial support
- Sufficient numbers of each MDT function in accordance with Cystic Fibrosis Trust guidelines and to provide effective cross cover
- Other medical and paramedical staff with experience of CF
- Expertise throughout the MDT in the specialised procedures required by people with CF
- Experience throughout the MDT in managing the complex problems that arise in patients with CF
- Taking responsibility for the annual review of each patient
- A commitment throughout the MDT to ongoing Continual Professional Development demonstrated by membership of the relevant Special Interest Group

- and attendance at relevant meetings and conferences, and a commitment to training the multi-disciplinary teams in a local Network Clinic
- Support of staff from other specialist services with experience in management of the related issues that arise in patients with CF
- Access to diagnostic and specialist laboratory facilities (e.g. genetic, ante/neonatal screening, sweat testing, microbiology, CT and other scanning, pancreatic function, gastrointestinal, liver, renal, spirometry etc.)
- A newborn screening programme
- Access to age appropriate surgeons experienced in the surgical management of CF
- Facilities for inpatient and outpatient treatment, including an appropriate number of beds for people with CF
- Participation in the UK CF Registry
- Participation in the Cystic Fibrosis Trust's programme of Peer Review
- Engagement with and understanding and control of funding, budgeting and contracting issues
- Active involvement in audit, education, training and research
- Written protocols for the delivery of care with Network Clinics, where relevant

The Consensus Group recommends two further aspects of care that are important to patients with Cystic Fibrosis. Firstly, that the patient knows and is known by the consultants and members of the multidisciplinary team responsible for their care. Whilst it is not imperative that the patient sees a named consultant on each visit to the Specialist CF Centre, it is important that the patient sees a named consultant at least twice a year and has access to him/her at times of particular concern.

Secondly, each patient with CF should be able to make contact with the Specialist CF Centre at any time, 24 hours a day 7 days a week, which should have access to an experienced CF doctor or a CF Nurse Specialist. A patient with CF with a serious exacerbation such as a pneumothorax or haemoptysis should always be able to access care via the specialist CF Centre. Patients with CF should be directly admitted to the CF Centre for routine and urgent care and only attend an accident and emergency department for life threatening emergencies. They should be transferred to the specialist CF Centre when their condition is stabilised. If this is not appropriate, for example if they are in a burns unit, the Specialist CF Centre team should be informed.

#### **NETWORK CF CLINIC (Paediatric shared care)**

A Network CF Clinic is led by a consultant with a specialist interest and experience in Cystic Fibrosis as evidenced in appraisal. There will be adequate dedicated programmed activities in CF each week including Direct Clinical Care and SPAs and clearly defined arrangements for annual leave and absence. In addition to ongoing CPD, the consultant will attend clinics with the Specialist CF Centre team from time to time. There should be a formal system in place (organised by the Specialist CF Centre) to support CPD for the Network Clinic team. These meetings should occur regularly and include the active participation of Network Clinic teams. They may include structured joint clinics.

Regular two-way communication between the Consultants and multidisciplinary team at a Specialist CF Centre and the Network CF Clinic will ensure that children treated in this way receive optimal care. All significant episodes of care as set out in the Service Level

Agreement will be communicated to the MDT at the Specialist CF Centre within five working days to enable full discussion of the patient at MDT meetings at the Specialist CF Centre. Routine letters should be sent out within fourteen days. The CF Registry could be an effective tool in communication as it offers web-based sharing of relevant clinical information. Serious acute exacerbations should also be communicated by telephone to the Specialist CF Centre within 24 hours. Conversely, any change in treatment recommended by the Specialist CF Centre should be communicated to the local team immediately (or within five days if not for an acute problem).

Designation as a Network CF Clinic will be dependent on meeting the following criteria:

- A core local multidisciplinary team comprising an appropriate number of named nurses, dietitians and physiotherapists, who liaise and work with the multidisciplinary team at the Specialist CF Centre and who are members of the appropriate Special Interest Group
- A Service Level Agreement between the Specialist CF Centre and the Network CF Clinic setting out the key elements of the service required
- Clearly defined protocols (Standard Operating Procedures) for the delivery of care as established by and agreed with the Specialist CF Centre
- A clearly defined process for nursing, physiotherapy, dietetic and psychosocial review either by, or in liaison with, the multidisciplinary team from the Specialist CF Centre
- Regular two way communication with the Specialist CF Centre as outlined above
- Agreed circumstances for discussion of individual progress and earlier review by the Specialist CF Centre
- Adequate inpatient and outpatient facilities that are sufficient to manage cross infection, including outpatient facilities at designated times and on designated days
- Access to “CF standard” microbiology
- Acceptance of and compliance with the Cystic Fibrosis Trust’s various Standards and Guidelines Consensus Documents, and the National Definition Set
- Attendance at regional training meetings and other ongoing CPD
- Participation in the CF Registry in conjunction with the Specialist CF Centre with which it is sharing care.

All patients attending a Network CF Clinic will be offered the opportunity to be seen by the multidisciplinary team from the Specialist CF Centre as follows:

- : Patients in bands 1,2&3 - at least 2x per annum
- : Patients in band 4 and above - to receive full care from the Specialist CF Centre, in conjunction with their Network CF Clinic. This would not preclude them from being admitted to a local hospital which has a well staffed Network CF Clinic, and where the care offered is in accordance with the recommendations of the Specialist CF Centre.

## **FUNDING<sup>1</sup>**

Under the proposed new arrangements for commissioning specialised services, all funding is likely to be directed to a designated Specialist CF Centre. Where appropriate, it will be the responsibility of the Specialist CF Centre to negotiate a Service Level Agreement and agree Standard Operating Procedures with a Network CF Clinic (or series

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<sup>1</sup> Separate funding arrangements exist in Scotland, Wales and Northern Ireland.

of Network CF Clinics) and to agree an appropriate amount of funding for the shared care that they are providing.

**Cystic Fibrosis Trust**  
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