

Review



European Cystic Fibrosis Society Standards of Care: Framework for the Cystic Fibrosis Centre

Steven Conway^{a,*}, Ian M. Balfour-Lynn^b, Karleen De Rijcke^c, Pavel Drevinek^{d,e,f}, Juliet Foweraker^g, Trudy Havermans^h, Harry Heijermanⁱ, Louise Lannefors^j, Anders Lindblad^k, Milan Macek^{l,m}, Sue Madgeⁿ, Maeve Moran^o, Lisa Morrison^p, Alison Morton^q, Jacqueliën Noordhoek^r, Dorota Sands^s, Anneke Vertommen^t, Daniel Peckham^u

^a Paediatric and Adult CF Units, Leeds Teaching Hospitals Trust, UK

^b Royal Brompton Hospital, Sydney Street, London, UK

^c Cystic Fibrosis Europe, Belgium

^d Department of Medical Microbiology, 2nd Faculty of Medicine, Charles University, Prague, Czech Republic

^e Department of Paediatrics, 2nd Faculty of Medicine, Charles University, Prague, Czech Republic

^f University Hospital Motol, Prague, Czech Republic

^g Department of Microbiology, Papworth Hospital NHS Foundation Trust, Papworth Everard, Cambridge, UK

^h Cystic Fibrosis Centre, University Hospital Leuven, Belgium

ⁱ HagaZiekenhuis, Department of Pulmonology & Cystic Fibrosis, The Hague, The Netherlands

^j Copenhagen CF Centre, Rigshospitalet, University Hospital, Copenhagen, Denmark

^k Gothenburg CF Centre, Queen Silvia Children's Hospital, Göteborg, Sweden

^l Department of Biology and Medical Genetics, University Hospital Motol, Prague, Czech Republic

^m Second School of Medicine, Charles University Prague, Prague, Czech Republic

ⁿ Department of Respiratory Medicine, Royal Brompton Hospital, Sydney Street, London, UK

^o National Referral Centre for Adult Cystic Fibrosis, Pharmacy Department, St. Vincent's University Hospital, Ireland

^p Gartnavel General Hospital, West of Scotland Adult CF Unit, Glasgow, UK

^q Adult Cystic Fibrosis Unit, St James's Hospital, Leeds, UK

^r Dutch Cystic Fibrosis Foundation, The Netherlands

^s Department of Pediatrics, Institute of Mother and Child, Warsaw, Poland

^t Cystic Fibrosis Centre, University Hospital Leuven, Belgium

^u Adult Cystic Fibrosis Unit, St James's Hospital, Leeds, UK

Abstract

A significant increase in life expectancy in successive birth cohorts of people with cystic fibrosis (CF) is a result of more effective treatment for the disease. It is also now widely recognized that outcomes for patients cared for in specialist CF Centres are better than for those who are not. Key to the effectiveness of the specialist CF Centre is the multidisciplinary team (MDT), which should include consultants, clinical nurse specialist, microbiologist, physiotherapist, dietitian, pharmacist, clinical psychologist, social worker, clinical geneticist and allied healthcare professionals, all of whom should be experienced in CF care. Members of the MDT are also expected to keep up to date with developments in CF through continued professional development, attendance at conferences, auditing and involvement in research. Specialist CF Centres should also network with other Centres both nationally and internationally, and feed Centre data to registries in order to further the understanding of the disease. This paper provides a framework for the specialist CF Centre, including the organisation of the Centre and the individual roles of MDT members, as well as highlighting the value of CF organisations and disease registries.

© 2014 European Cystic Fibrosis Society. Published by Elsevier B.V. Open access under [CC BY-NC-ND license](#).

Keywords: CF Centre; Multidisciplinary team; Continuing professional development

* Corresponding author.

E-mail address: steven.conway@doctors.net.uk (S. Conway).

<http://dx.doi.org/10.1016/j.jcf.2014.03.009>

1569-1993/© 2014 European Cystic Fibrosis Society. Published by Elsevier B.V. Open access under [CC BY-NC-ND license](#).

Contents

1.	Introduction	S5
2.	Framework for the paediatric and adult Centres	S6
2.1.	The Centre	S6
2.2.	The multidisciplinary team	S6
2.3.	Access to other specialists	S7
2.4.	Centre infrastructure	S7
2.5.	Segregation	S7
2.6.	Access to specialist investigations	S7
2.7.	Miscellaneous	S8
2.8.	European policy aspects of CF Centre care	S8
3.	Framework for the specialist doctor	S8
3.1.	The CF consultant	S8
3.1.1.	Knowledge	S8
3.1.2.	Skills	S8
3.2.	The clinical lead	S8
4.	Framework for specialist nursing care	S8
4.1.	The role of the CF Clinical Nurse Specialist	S8
4.2.	Access, availability and facilities	S9
4.3.	Key stages for delivery of care	S9
4.3.1.	Diagnosis	S9
4.3.2.	Pre-school	S9
4.3.3.	School age	S9
4.3.4.	Adolescence	S9
4.3.5.	Transition from paediatric to adult care	S9
4.4.	Adult issues	S10
4.5.	Transplantation and end-of-life issues	S10
4.6.	Core competencies, qualifications and professional development	S10
4.6.1.	Core competencies	S10
4.6.2.	Qualifications and professional development	S10
5.	Framework for physiotherapy care	S11
5.1.	The role of the CF physiotherapist	S11
5.2.	Regular assessment and therapy	S11
5.2.1.	Inhalation therapy	S11
5.2.2.	Airway clearance therapy	S11
5.2.3.	Postural and musculoskeletal assessment	S11
5.2.4.	Exercise capacity	S11
5.2.5.	Non-invasive ventilation	S11
5.2.6.	Other considerations and assessments	S12
5.3.	Service provision	S12
5.4.	Professional development, research and availability	S12
6.	Framework for dietetic care	S12
6.1.	The role of the specialist CF dietitian	S12
6.2.	Clinical governance, research and quality framework	S12
6.3.	Dietary assessment	S13
6.3.1.	The annual assessment	S13
6.4.	Service provision framework	S13
6.5.	Key considerations of service provision	S13
6.5.1.	Inpatients	S13
6.5.2.	Home treatment	S13
6.5.3.	Outpatients with CF-related diabetes	S13
6.5.4.	Shared care	S13
6.5.5.	Transition	S13
7.	Framework for microbiology	S13
7.1.	The role of the CF Clinical Microbiologist	S13
7.2.	Overview of laboratory services	S14
7.3.	Clinical microbiology services and the CF MDT	S14
7.4.	Clinical advice on treatment of infection	S14
7.5.	Infection prevention and control	S14
7.6.	Role in clinical research and data collection	S15
8.	Framework for medicines management	S15

Download English Version:

<https://daneshyari.com/en/article/6240944>

Download Persian Version:

<https://daneshyari.com/article/6240944>

[Daneshyari.com](https://daneshyari.com)