Appendix 18 – CF Trust consensus documents, factsheets & leaflets

These are available on the CF Trust website – <u>https://www.cysticfibrosis.org.uk/life-with-cystic-fibrosis/publications</u>. Press ctrl+click on titles.

Consensus Documents

For more clinical information see:

European Cystic Fibrosis Society Standards of Care Available in Open Access

HS National Programmes of Care and Clinical Reference Groups, Internal Medicine – Group A, A01 Cystic Fibrosis

Read the <u>guidelines on NTM infection</u> issued by Thorax, the international journal for health professionals working in respiratory medicine.

Standards of Care and Good Clinical Practice for the Physiotherapy Management of Cystic Fibrosis. Third edition. April 2017.

Consensus document outlining standards of care and good practice for physiotherapy. Published: April 2017

Nutritional Management of Cystic Fibrosis. September 2016.

Consensus document on nutritional management of cystic fibrosis. Published: September 2016

<u>NTM guidelines. November 2017 (amended March 2018).</u> Suggestions for infection prevention and control of *Mycobacterium abscessus.* Published: November 2017

Standards for the Clinical Care of Children and Adults with Cystic Fibrosis in the UK. Second edition. December 2011.

Consensus document outlining standards of care. Published: December 2011

<u>Pharmacy Standards of Care. November 2011</u> Consensus document outlining pharmacy standards in CF care. Published: November 2011

Laboratory Standards for Processing Microbiological Samples from People with Cystic Fibrosis. First edition. September 2010.

Consensus document outlining laboratory standards for processing microbiological samples. Published: September 2010

Antibiotic Treatment for Cystic Fibrosis. Third edition. May 2009.

Consensus document on antibiotic treatment for cystic fibrosis. Published: May 2009

<u>Methicillin-resistant Staphylococcus aureus (MRSA). April 2008.</u> Consensus document on MRSA. Published: April 2008

<u>European cystic fibrosis bone mineralisation guidelines. February 2011.</u> Consensus document on bone mineralisation in cystic fibrosis. Published: February 2011

<u>Pseudomonas aeruginosa infection in people with Cystic Fibrosis. Suggestions for</u> <u>Prevention and Infection Control. Second Edition. November 2004.</u>

Consensus document on prevention and infection control of Pseudomonas aeruginosa. Published: November 2004

The Burkholderia cepacia Complex - Suggestions for Prevention and Infection Control. Second edition. September 2004.

Consensus document on suggestions for prevention and infection control of Burkholderia cepacia Complex. Published: September 2004

Management of Cystic Fibrosis-related Diabetes Mellitus. June 2004. Consensus document on managing CF-related diabetes mellitus. Published: June 2004

National Consensus Standards for the Nursing Management of Cystic Fibrosis. May 2001.

Consensus document on standards for nursing management of CF. Published: May 2001

Factsheets, information packs and publications -

https://www.cysticfibrosis.org.uk/the-work-we-do/publications/factsheets-and-informationpacks

Information packs

New diagnosis information pack Pre-school and primary school pack Secondary school pack Leaving school Family planning pack Transplant booklets Bereavement resources End of life planning Festival planning information

Factsheets

Diagnosis

<u>Diagnosis in adulthood</u> <u>Family genetic testing - 'cascade screening'</u> <u>The sweat test for cystic fibrosis</u>

Related complications

Bone health Cystic fibrosis-related diabetes. Liver disease Melioidosis and tropical travel Urinary incontinence Pelvic floor exercises (female) How to improve your posture

Treatments

Home intravenous therapy Inhaled therapy Lung transplantation Portacaths Steroid treatment

Nutrition

Achieving a healthy weight in cystic fibrosis Drinking alcohol. Eating well for children with cystic fibrosis Leaving home and eating well Nutrition and pregnancy Pancreatic sufficiency in babies with cystic fibrosis Pancreatic insufficiency in babies with cystic fibrosis. Post-lung transplant nutrition for people with cystic fibrosis Salt in the cystic fibrosis diet Staying hydrated and cystic fibrosis Weaning for babies with cystic fibrosis

Physiotherapy

<u>Physiotherapy leaflets</u> <u>Physiotherapy for adults</u> <u>Physiotherapy for babies and toddlers</u>

Living with cystic fibrosis

Disability Living Allowance (DLA) Employment Financial help Individual healthcare plan for schools Prescription charges The Cystic Fibrosis Trust Support Service Advance care planning form. Transition

Transition from paediatric to adult care: guide for young people Transition from paediatric to adult care: guide for parents Transition from paediatric to adult care: guide for commissioners and hospital / clinical teams