

Review



European Cystic Fibrosis Society Standards of Care: Best Practice guidelines

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Abstract

Specialised CF care has led to a dramatic improvement in survival in CF: in the last four decades, well above what was seen in the general population over the same period. With the implementation of newborn screening in many European countries, centres are increasingly caring for a cohort of patients who have minimal lung disease at diagnosis and therefore have the potential to enjoy an excellent quality of life and an even greater life expectancy than was seen previously. To allow high quality care to be delivered throughout Europe, a landmark document was published in 2005 that sets standards of care. Our current document builds on this work, setting standards for best practice in key aspects of CF care. The objective of our document is to give a broad overview of the standards expected for screening, diagnosis, pre-emptive treatment of lung disease, nutrition, complications, transplant/end of life care and psychological support. For comprehensive details of clinical care of CF, references to the most up to date European Consensus Statements, Guidelines or Position Papers are provided in Table 1. We hope that this best practice document will be useful to clinical teams both in countries where CF care is developing and those with established CF centres.

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