

# Cystic Fibrosis Role Statement

Developed by members of the Cystic Fibrosis Interest Group

## Introduction

Accredited Practising Dietitians (APDs) are recognised professionals with the qualifications and skills to provide expert nutrition and dietary advice. APDs are qualified to advise individuals and groups on nutrition-related matters.

APDs have university training accredited by DA, undertake ongoing professional development and commit to evidence-based practice. They comply with the [Dietitians Australia Code of Conduct for Dietitians & Nutritionists](#) and commit to providing quality service.

APD is the only national credential recognised by the Australian Government, Medicare, the Department of Veterans Affairs, the National Disability Insurance Agency and most private health funds as the quality standard for nutrition and dietetics services in Australia. It is a recognised trademark protected by law.

## Purpose of this role statement

- To define the role an APD may fulfil when working in the area of cystic fibrosis
- To promote the knowledge and expertise of an APD, broadly and in the area of cystic fibrosis and beyond National Competency Standards
- To advocate for dietetic services

## Knowledge and skills in this area of practice

Entry level dietetic competencies ensure all APDs can conduct assessments, diagnose nutritional issues, and develop, monitor and evaluate interventions. Within a particular practice area, APD skills and knowledge will range from entry level to highly skilled. Within this continuum APDs can either fully manage the patient, seek support to continue seeing the patient or refer the patient on.

The following list of skills and knowledge required to work in cystic fibrosis are:

### Knowledge

- Familiarity with the pathophysiology of cystic fibrosis, interdisciplinary management and nutrition co-morbidities (cystic fibrosis-related liver disease, CFRD, cystic fibrosis-related bones disease, distal intestinal obstruction syndrome, pancreatic insufficiency, pancreatitis, intestinal inflammation).
- Specific knowledge about pancreatic enzyme replacement therapy, including preparations available, mechanisms of action and dosing recommendations.
- Knowledge of pathophysiology of CFRD and evidence-based pathways for patients diagnosed with CFRD and abnormal glucose tolerance.
- Specific knowledge about the impact of CFTR modulator therapy on nutrition parameters.

A 1/8 Phipps Close, Deakin ACT 2600 | T 02 6189 1200

E [info@dietitiansaustralia.org.au](mailto:info@dietitiansaustralia.org.au) | W [dietitiansaustralia.org.au](http://dietitiansaustralia.org.au)

Dietitians Association of Australia | ABN 34 008 521 480

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## Skills

- Ability to provide evidence based, specific and tailored nutrition advice to the individual with cystic fibrosis, considering the changing physiological and psychological needs related to disease state, treatment and life stage (adolescence, pregnancy, transplantation).
- Ability to provide nutrition education to people with cystic fibrosis-related diabetes (CFRD), using a variety of tools such as: food/blood glucose records, carbohydrate counting, glycaemic index, portion modelling, meal planning, label reading, cooking/recipe adjustments and behaviour modification.
- Interpretation of markers of nutrition status of individuals with cystic fibrosis (oral glucose tolerance tests, fat soluble vitamins, inflammatory markers, DEXA scans).
- Undertaking and interpreting body composition assessments, and indirect calorimetry (where facilities are available).
- Employ chronic condition management approaches to facilitate long-term management, including partnering with individuals with cystic fibrosis and their caregivers, goal setting and motivational interviewing.
- Ability to recognise the impact of cystic fibrosis transmembrane conductance regulator (CFTR) modulator therapy on nutrition recommendations and outcomes.

## Activities entry level APDs would conduct:

- Complete the nutrition care process in collaboration with patient and multidisciplinary team to determine the individual energy, salt and fluid requirements based on factors such as lung function, pancreatic function, nutrition co-morbidities, anthropometric and body composition measurements, growth history, biochemical indices and physical activity.
- Communicate nutritional aspects of care with the individual with cystic fibrosis, their caregivers and the cystic fibrosis team to ensure continuity of care.
- Conduct regular nutritional surveillance of all individuals with cystic fibrosis attending their service, with all aspects of nutrition and gastrointestinal status being reviewed.
- Determine realistic goals for nutrition therapy in collaboration with the patient, their caregivers, and the cystic fibrosis team.
- Provide comprehensive advice to assist in maintaining an optimal weight and in the management of other cystic fibrosis co-morbidities.
- Seek support from a more experienced clinician about cystic fibrosis nutrition management.

## Activities APDs working at a higher level would conduct:

- Overseeing the nutrition care of complex cases including end-stage lung disease, end-stage liver disease, renal disease.
- Provide individualised medical nutrition therapy for complex CFRD cases including poorly controlled and unstable blood glucose levels, potentially including insulin dose adjustment requirements where the APD has appropriate credentialing and mentoring with advanced scope of practice.
- Act as a nutrition resource person for the training, education and development and support of others involved in cystic fibrosis care e.g. mentoring/supervision of students or less experienced dietitians as well as various other health professionals.

- Lead nutrition and/or multi-professional quality improvement activities, research and/or audits. For example, implementing foodservice models of care for cystic fibrosis nutrition requirements.

Any individual practitioner should refer to the [Scope of Practice Decision Tool](#) to determine if a task is within their scope of practice.

### **Activities APDs working in this area do not usually undertake:**

- Sole nutritional management of patients without the support of an interdisciplinary team.

## **Appendix – Background**

Cystic fibrosis (CF) is the most common lethal autosomal recessive genetic condition affecting Caucasian populations.<sup>1</sup> CF is a multi-system condition characterised by abnormally high sweat chloride and sodium levels, progressive lung disease and pancreatic insufficiency. Over 90% of individuals with the condition experience one or more gastrointestinal complications. Optimising growth and nutrition in individuals with CF has been shown to positively influence lung function and survival.<sup>2</sup>

Although, it is well established that interdisciplinary care delivers the best outcomes for people with CF,<sup>3</sup> dietitians play an important role in identifying growth and nutrition issues that be related or unrelated to CF and may require specific interventions. As the life expectancy of individuals with CF continues to increase and advancements in medical therapies, this poses new roles for the CF dietitian such as identification and management of obesity and renal disease in conjunction with the management of their CF requirements.

## **References**

1. Saxby N, Painter C, Kench A, et al. In: Bell SC, ed. Nutrition Guidelines for Cystic Fibrosis in Australia and New Zealand. Sydney: Thoracic Society of Australia and New Zealand; 2017.
2. Solomon, M, Bozic, M & Mascarenhas, MR. Nutritional Issues in Cystic Fibrosis. *Clin Chest Med.* 2016; 97-107.
3. Mahadeva, R, Webb, K, Westerbeek, RC, Carroll, NR, Dodd, ME, Bilton, D, et al. Clinical outcome in relation to care in centres specialising in cystic fibrosis: cross sectional study. *BMJ.* 1998; 316, 1771-1775.