

Cystic Fibrosis Nutrition Care during the Novel Coronavirus Covid-19 Pandemic

PREAMBLE

The novel coronavirus disease 2019 (COVID-19) pandemic has created a rapidly evolving public health crisis. Although there is much to learn about this coronavirus, authorities agree that the primary mode of transmission is through respiratory droplets transmitted from person to person.

The purpose of this document is to provide guidance to Cystic Fibrosis (CF) registered dietitian nutritionists (RDNs). This document does not seek to replace existing policies within a facility and instead aims to provide information to aid decision making in the nutrition care for individuals with cystic fibrosis. Individuals with CF are prone to lung infections due to the pathology of the disease. It is unclear if individuals with CF are at increased risk of COVID-19¹, but individuals with CF who contract COVID-19 may be at increased risk of severe illness². Recent advances in CF care, particularly with the cystic fibrosis transmembrane conductance regulator (CFTR) modulation therapies have likely improved COVID-19 outcomes for individuals with CF. However, challenges remain regarding demand for ventilators and triage policies that may not benefit individuals with CF³. The Academy of Nutrition and Dietetics recently published an evidence-based nutrition practice guideline for individuals with CF and this guidance is still applicable⁴. The current document addresses considerations for providing medical nutrition therapy (MNT) in-person and remotely, including nutrition counseling considerations during the COVID-19 pandemic, telehealth and other resources. Each setting will likely have facility-specific policies and procedures which need to be adhered to.

The COVID-19 pandemic is an evolving situation. Substantial ambiguity and variation in practice along with very limited evidence creates the need to adapt, revise and to use the best available information. RDNs have the opportunity to provide excellent care to clients and families by staying abreast of the latest developments.

IN-PERSON VS. REMOTE MEDICAL NUTRITION THERAPY

Ideally, CF RDNs will provide MNT remotely when possible, not only for safety reasons, but to preserve personal protective equipment (PPE) as well⁵. RDNs should ask supervisors about options for working and meeting with clients remotely, since rules may have changed due to the pandemic crisis. When working from home, confirm expectations for responsibilities, accessibility and hours worked with your supervisor.

Routine well care visits should be conducted by telehealth to

*avoid unnecessary risk of exposure.*⁶

If an in-person CF RDN is needed, RDNs still may be able to work from home and be "on call", traveling to the clinical setting only when necessary. If possible, RDNs should rotate being on call and coming into the facility so that a limited number of RDNs are physically present at a time. Check with your individual facility about guidelines for which health care professionals can see which clients and with what restrictions. Be creative about virtual visits even for hospitalized clients. Adhere to social distancing recommendations and wear appropriate PPE whenever possible. Limit direct contact with clients who have tested positive for COVID-19 or who have symptoms. Follow protocol for areas that have been designated for clients who have tested positive, shown symptoms or reported exposure.

NUTRITION ASSESSMENT

Monitoring weight status is a crucial aspect of nutrition assessment for individuals with CF⁴. CF RDNs recommend the following:

- Ask adult clients to weigh themselves at home (note: validity may be affected, so document that weight is self-reported).
- For infants, try to connect parents to resources or encourage them to buy infant scales to track weight if they do not have one already.
- Consider utilizing a triage system using a nutrition screening score from the patient's last clinic visit, their age and weight-for-age percentile to determine priority for receiving scales for older infants and toddlers up to 2 years of age.

Barriers to nutrition assessment:

- Availability of scales is a major barrier for nutrition assessment: Consider applying for grants, requesting donations or utilizing education-type funds to provide scales for parents who need them. Prioritize providing scales for 0-6-month-old infants.

NUTRITION COUNSELING

RDNs should continue to provide MNT based on evidence-based guidelines. However, CF RDNs working in the field suggest additional considerations for counseling during the COVID-19 pandemic.

- Communicate with clients, their families and caregivers, and support client mental health and wellbeing to help alleviate any anxiety and fear they may have about COVID-19.

- Be aware that some clients, families or caregivers may need referrals for psychological or social work support in the context of the pandemic⁶.
- Encourage clients to continue to focus on consuming a variety of nutrient-dense foods and beverages and provide resources for inexpensive and healthy meals. Continue to encourage a healthful eating plan and adapt recommendations to client circumstances including grocery store access and food insecurity⁶.
- Consider menus and resources for clients who may be self-isolating and/or ill due to coronavirus. Self-isolation, job losses, food insecurity, anxiety and depression may be exacerbated at this time and all these issues can affect nutrition status and care.
- For children with CF, schedules and routines may be different than normal. Consider sending a schedule template to all caregivers to make sure everyone is on the same page regarding feeding, medications, etc.
- For clients who may be food insecure, particularly due to the recent economic environment, provide appropriate resources for consideration.
- Suggest using local pharmacies that ship prescriptions for oral or enteral nutrition supplements and other durable medical equipment to clients without prior authorizations.
- Consider ways to connect with your clients and their families. For example, Terri Schindler MS, RDN, from University Hospitals Cleveland Medical Center, suggests asking “patients and families to email picture updates... I particularly enjoy seeing the babies since I would normally be following them in clinic every 1-4 weeks. I think the families enjoy sending the pictures, too. And of course, it is always fun to see the families in their home settings for telehealth visits. Just an idea to strengthen connections and bring some sunshine into your day.”

TELEHEALTH TIPS AND RESOURCES

During the COVID-19 pandemic, many more RDNs will be consulting with clients remotely, often from their own homes. CF RDNs who have piloted working remotely with CF clients suggest the following based on their experience:

- Check with your institution to see what communications technology is allowable and keep checking in as these technologies are changing rapidly in many facilities.
- When calling clients remotely, they may not recognize your number and therefore may not pick up the phone. A potential work-around may be to call your hospital's operator and request connection to an outside line, so that the client sees the call is coming from the hospital.
- Use *67 to block your cell phone number from registering on your client's phone. Some RDN's have sent emails to

clients telling them to expect a phone call at a certain time from a blocked or anonymous caller.

- Consider a phone call/telehealth script for high nutrition risk client contact between visits, including things to ask considering the quarantine (i.e. addressing physical activity, access to food, distal intestinal obstructive syndrome/constipation prevention)⁷.
- RDNs should safeguard the privacy of patients and keep their personal health information secure.
- The following are telehealth resources that some CF RDNs suggest. The information about providers and services contained in this document does not constitute endorsement or recommendation by the Academy of Nutrition and Dietetics.
 - Jabber App
 - EPIC may provide the option for telehealth visits if the client is signed up for MyChart.
 - VidyoConnect software can be used for telehealth visits. This is a client-safe telehealth platform. RDNs can email a link to families in their homes where they can sign consent and download the app to their phone, iPad, or computer with a camera.
 - Vivus also has telehealth services available that are HIPAA compliant/secure
 - Doximity can be used to make telephone calls and displays your clinic phone number when calling clients with your personal cell phone. This service requires an MD/NP who is already registered with app to refer the RDN.
 - doxy.me (<https://doxy.me/>) is a free service for healthcare providers to meet with clients/families or the CF team.
 - RightFax can be used for e-faxing info to durable medical equipment, insurance, etc., if you are working remotely and can get it added to your laptop.
 - CF teams can meet via Zoom, WebEx or Bluejeans.

• Billing for Telehealth

- RDNs should confer with their billing departments to determine if telehealth can be billed as a face-to-face visit due to CMS and state waivers. RDNs may be also be able to provide some services via telephone. Seek clarification from each payer regarding what communications technologies are permitted and how claims should be submitted for services.
- There may be an option to enroll as a “provider” with an NPI number under the outpatient contract and credentialed with the insurance companies.

For additional help with Telehealth related issues, refer to Academy of Nutrition and Dietetics' telehealth resources for RDNs at www.eatrightpro.org/coronavirus-resources.

SUMMARY

As the COVID-19 pandemic unfolds, RDNs must adapt and work with medical teams to provide nutrition care to individuals and families. Examples include:

- Conduct telehealth visits with the medical team.
- Assist with getting infant scales in the home for fast-growing babies to monitor the growth and adjust enzymes as needed.
- Identify agencies for assistance with food security.
- Identify school lunch programs that can home deliver meals for 1-2 weeks at a time vs picking up every day.
- Ensure families have sufficient amounts of formula, enzymes, vitamins at home and switch to mail order pharmacies.
- Listen to the patient's needs and refer to appropriate resources: psychology, physical therapy, social work, etc.

"This COVID-19 crisis is an opportunity to do things in health care you may have never thought you could."

-Judith Fulton, MPH, RD, CSP,
Children's Hospital Colorado

The preceding are suggestions from Cystic Fibrosis dietitians working with clients during the COVID-19 pandemic. Special thanks to contributor Catherine McDonald, PhD, MS, RDN, CSP. This document was published to the Academy of Nutrition and Dietetics' online Coronavirus (COVID-19) Professional Resource Hub on May 19, 2020. For practitioner resources, webinars and ongoing Q&A about coronavirus preparedness, patient care and the delivery of nutrition services, visit eatrightPRO.org/coronavirus-resources. For consumer handouts, articles and activities, visit eatright.org/coronavirus.

References

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2. Centers for Disease Control and Prevention. Groups at Higher Risk for Severe Illness. <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/groups-at-higher-risk.html>
3. Ramos KJ, Pilewski JM, Faro A, et al. Improved Prognosis in Cystic Fibrosis: Consideration for Intensive Care During the COVID-19 Pandemic. *Am J Respir Crit Care Med*. 2020; doi: 10.1164/rccm.202004-0999LE.
4. Academy of Nutrition and Dietetics Evidence Analysis Center. Cystic Fibrosis Evidence Based Nutrition Practice Guideline 2020. Available at www.andeal.org/topic.cfm?menu=5876.

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6. National Institute for Health and Care Excellence. COVID-19 rapid guideline: cystic fibrosis. www.nice.org.uk/guidance/ng170/chapter/1-Communicating-with-patients-and-minimising-risk
7. U.S. Department of Health and Human Services. Notification of Enforcement Discretion for Telehealth Remote Communications During the COVID-19 Nationwide Public Health Emergency. Available at: www.hhs.gov/hipaa/for-professionals/special-topics/emergency-preparedness/notification-enforcement-discretion-telehealth/index.html. Accessed May 1, 2020.

Additional Resources

Academy of Nutrition and Dietetics. Nutrition Care Manual. <http://www.nutritioncaremanual.org>. Accessed April 29, 2020.

Academy of Nutrition and Dietetics. Pediatric Nutrition Care Manual. <http://www.nutritioncaremanual.org>. Accessed April 29, 2020.

Academy of Nutrition and Dietetics Evidence Analysis Center. Cystic Fibrosis Evidence Based Nutrition Practice Guideline 2020. Available at www.andeal.org/topic.cfm?menu=5876. <https://www.andeal.org/topic.cfm?menu=5876&cat=6044>

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Healthwell Foundation. COVID-19 Ancillary Costs. www.healthwellfoundation.org/fund/covid-19-fund/

Pulmonary Fibrosis Foundation. COVID-19 Resources. www.pulmonaryfibrosis.org/medical-community/covid-19-resources