

## RESOURCES

### Provider Education on Palliative Care

Resource	Website	Description
MJHS Institute for Innovation in Palliative Care e-Learning Page	<a href="https://www.mjhspalliativeinstitute.org/e-learning/">https://www.mjhspalliativeinstitute.org/e-learning/</a>	Free and fee-based CME/CE-accredited multidisciplinary webinars for continuing education on numerous topics related to palliative care, hospice, symptom management, and having serious illness discussions.
National Hospice and Palliative Care Organization	<a href="https://www.nhpco.org/education/">https://www.nhpco.org/education/</a>	On-demand online learning courses, webinars, certificate programs and additional resources for hospice and palliative care.
The Conversation Project	<a href="http://app.ihl.org/lms/onlinelearning.aspx?CatalogGUID=debbdb58-726f-4a20-ac4a-7796b7d94d37">http://app.ihl.org/lms/onlinelearning.aspx?CatalogGUID=debbdb58-726f-4a20-ac4a-7796b7d94d37</a>	Free, four-lesson online course for providers. Offers guidance on communication strategies and suggestions for having serious illness discussions with patients.
Ariadne Labs	<a href="https://www.ariadnelabs.org/areas-of-work/serious-illness-care/resources/#Downloads&amp;%20Tools">https://www.ariadnelabs.org/areas-of-work/serious-illness-care/resources/#Downloads&amp;%20Tools</a>	A provider guide for identifying patients' values and goals of care.
SPIKES Protocol for Delivering Serious News	<a href="https://www.ethics.va.gov/goalsofcaretraining/spikes.pdf">https://www.ethics.va.gov/goalsofcaretraining/spikes.pdf</a>	A brief provider guide for communicating serious news with patients and families.
VitalTalk	<a href="https://www.vitaltalk.org/">https://www.vitaltalk.org/</a>	Evidence-based training programs to improve provider communication skills for having serious illness discussions.
Gundersen Health System ACP Resources for Clinicians	<a href="https://www.gundersenhealth.org/for-clinicians-professionals/advance-care-planning/">https://www.gundersenhealth.org/for-clinicians-professionals/advance-care-planning/</a>	Provides a staged approach for advance care planning discussions using the <i>Respecting Choices</i> evidence-based model.
Center for Palliative care, Harvard Medical School	<a href="https://pallcare.hms.harvard.edu/courses">https://pallcare.hms.harvard.edu/courses</a>	Offers a variety of CME/CE-accredited multidisciplinary training courses and workshops in palliative care.
Partnership Enhancement Program (PEP)	For more information about PEP training, contact: <a href="mailto:PEP@cff.org">PEP@cff.org</a>	A full-day communication skills training course for CF teams sponsored by the Cystic Fibrosis Foundation, based on relationship-centered healthcare theory from the Academy of Communication in Healthcare.

## TRAIN-THE-TRAINER MANUAL FOR SITE EDUCATORS

<b>Palliative Care Tools for CF - User's Guide</b>	<a href="https://my.cff.org">https://my.cff.org</a> . Access requires registration. Resources can be obtained by searching for "Palliative Care Toolkit"	Provides resources for communication with patients about palliative care and programming for provider education.
<b>Center for Bioethics and Medical Humanities</b>	<a href="https://www.bioethics.northwestern.edu/education/epec.html">https://www.bioethics.northwestern.edu/education/epec.html</a>	Offers fee-based CME/CME-accredited e-learning courses in palliative care and other provider resources.
<b>American Association of Colleges of Nursing</b>	<a href="https://www.aacnnursing.org/ELNEC/Courses">https://www.aacnnursing.org/ELNEC/Courses</a>	Offers online and in-person fee-based CME/CE-accredited courses on palliative care and various trainings for educators.
<b>National Association of Social Workers</b>	<a href="https://www.socialworkers.org/Practice/Aging/Aging-Professional-Development/ESPEC">https://www.socialworkers.org/Practice/Aging/Aging-Professional-Development/ESPEC</a>	Ten-hour CE-accredited new interactive course especially for social workers on palliative care topics that incorporates online and instructor-led training with reflective exercises, mentored role plays and group discussions.
<b>Serious Illness Conversations</b>	<a href="https://seriousillnessconversations.org/resources%2C-downloads">https://seriousillnessconversations.org/resources%2C-downloads</a>	Provides a serious illness conversation guide for providers and new upcoming courses on communication skills.

**CFF Guidelines for Palliative Care and Other Topics**

<p><b>CFF Evidence-Informed Consensus Guidelines for Delivery of Palliative Care for Individuals with CF</b></p>	<p>Kavalieratos D, Georgiopoulos AM, Dhingra L, et al. <a href="#">Models of palliative care delivery for individuals with cystic fibrosis: Cystic Fibrosis Foundation evidence-informed consensus guidelines</a>. <i>J Palliat Med</i>. 2021 Jan;24(1):18-30. doi: 10.1089/jpm.2020.0311. Epub 2020 Sep 16. PMID: 32936045; PMCID: PMC7757696.</p>
<p><b>CFF Consensus Guidelines for the Care of Individuals with Advanced CF Lung Disease</b></p>	<p>Kapnadak SG, Dimango E, Hadjiliadis D, et al. <a href="#">Cystic Fibrosis Foundation consensus guidelines for the care of individuals with advanced cystic fibrosis lung disease</a>. <i>J Cyst Fibros</i>. 2020 May;19(3):344-354. doi: 10.1016/j.jcf.2020.02.015. Epub 2020 Feb 27. PMID: 32115388.</p>
<p><b>US Cystic Fibrosis Foundation and European Cystic Fibrosis Society Consensus Recommendations for the Management of Nontuberculous Mycobacteria in Individuals with CF</b></p>	<p>Floto RA, Olivier KN, Saiman L, et al.; US Cystic Fibrosis Foundation and European Cystic Fibrosis Society. <a href="#">US Cystic Fibrosis Foundation and European Cystic Fibrosis Society consensus recommendations for the management of nontuberculous mycobacteria in individuals with cystic fibrosis</a>. <i>Thorax</i>. 2016 Jan;71 Suppl 1(Suppl 1):i1-22. doi: 10.1136/thoraxjnl-2015-207360. PMID: 26666259; PMCID: PMC4717371.</p>
<p><b>CF Pulmonary Guidelines on Chronic Medications for Maintenance of Lung Health</b></p>	<p>Mogayzel PJ Jr, Naureckas ET, Robinson KA, et al.; Pulmonary Clinical Practice Guidelines Committee. <a href="#">Cystic fibrosis pulmonary guidelines: Chronic medications for maintenance of lung health</a>. <i>Am J Respir Crit Care Med</i>. 2013 Apr 1;187(7):680-9. doi: 10.1164/rccm.201207-1160oe. PMID: 23540878</p>
<p><b>CF Pulmonary Guidelines on Pulmonary Complications: Hemoptysis and Pneumothorax</b></p>	<p>Flume PA, Mogayzel PJ Jr, Robinson KA, et al.; Clinical Practice Guidelines for Pulmonary Therapies Committee; Cystic Fibrosis Foundation Pulmonary Therapies Committee. <a href="#">Cystic fibrosis pulmonary guidelines: Pulmonary complications: Hemoptysis and pneumothorax</a>. <i>Am J Respir Crit Care Med</i>. 2010 Aug 1;182(3):298-306. doi: 10.1164/rccm.201002-0157OC. PMID: 20675678.</p>
<p><b>CFF Consensus Guidelines for Lung transplant</b></p>	<p>Ramos KJ, Smith PJ, McKone EF, et al.; CF Lung Transplant Referral Guidelines Committee. <a href="#">Lung transplant referral for individuals with cystic fibrosis: Cystic Fibrosis Foundation consensus guidelines</a>. <i>J Cyst Fibros</i>. 2019 May;18(3):321-333. doi: 10.1016/j.jcf.2019.03.002. Epub 2019 Mar 27. PMID: 30926322; PMCID: PMC6545264.</p>
<p><b>CFF and European Cystic Fibrosis Society Consensus Statements for Depression and Anxiety</b></p>	<p>Quittner AL, Abbott J, Georgiopoulos AM, et al.; International Committee on Mental Health; EPOS Trial Study Group. <a href="#">International Committee on Mental Health in Cystic Fibrosis: Cystic Fibrosis Foundation and European Cystic Fibrosis Society consensus statements for screening and treating depression and anxiety</a>. <i>Thorax</i>. 2016 Jan;71(1):26-34. doi: 10.1136/thoraxjnl-2015-207488. Epub 2015 Oct 9. PMID: 26452630; PMCID: PMC4717439.</p>
<p><b>CFF Pulmonary Guideline on Pharmacologic Approaches to Prevention and Eradication of Initial Pseudomonas Aeruginosa Infection</b></p>	<p>Mogayzel PJ Jr, Naureckas ET, Robinson KA, et al.; Cystic Fibrosis Foundation Pulmonary Clinical Practice Guidelines Committee. <a href="#">Cystic Fibrosis Foundation pulmonary guideline. Pharmacologic approaches to prevention and eradication of initial Pseudomonas aeruginosa infection</a>. <i>Ann Am Thorac Soc</i>. 2014 Dec;11(10):1640-50. doi: 10.1513/AnnalsATS.201404-166OC. PMID: 25549030.</p>
<p><b>CFF Clinical Care Guidelines</b></p>	<p><a href="https://www.cff.org/Care/Clinical-Care-Guidelines/">https://www.cff.org/Care/Clinical-Care-Guidelines/</a></p>

## Professional Organizations for Palliative Care

Organization	Website
American Academy of Hospice and Palliative Medicine	<a href="http://aahpm.org/">http://aahpm.org/</a>
National Hospice and Palliative Care Organization	<a href="https://www.nhpco.org/">https://www.nhpco.org/</a>
Social Work Hospice & Palliative Care Network	<a href="https://www.swhpn.org/">https://www.swhpn.org/</a>
Hospice and Palliative Nurses Association	<a href="https://advancingexpertcare.org/">https://advancingexpertcare.org/</a>



## **PROJECT SUMMARY FOR *IMPROVING LIFE WITH CF***

Our project, Pragmatic Implementation Trial of a CF Primary Palliative Care Intervention (PIs: Georgiopoulos & Dhingra; CFF GEORGI19QI0/GEORGI20QI0)—is also known as ***The Improving Life with CF*** study. This project is designed to complement the new CFF palliative care guidelines by building a framework for a nationally generalizable model to improve best practices in generalist-level palliative care in CF.

### ***What is the Improving Life with CF* intervention?**

Our aim is to create, implement, and evaluate a CF-specific primary palliative care intervention in 5 diverse CF centers by linking routine palliative care needs assessment to processes that increase the ability of the CF care team to manage identified problems and improve clinical skills through educational programming.

The infrastructure for the intervention has been developed in collaboration with multiple organizations. Massachusetts General Hospital is the lead site, the MJHS Institute for Innovation in Palliative Care is the Data Coordinating Center and education hub, and the collaborating sites are Emory University, Mount Sinai Beth Israel Medical Center, Northwell Health, and Stony Brook Health. ***The Improving Life with CF*** Advisory Board includes 16 multidisciplinary experts in CF and palliative care, along with community stakeholders.

The intervention features 4 key elements:

1. Routine annual and “triggered” screenings of individuals with CF and their family caregivers, followed by appropriate triage based on a prompt assessment
2. Provider education, including Best Practice Treatment Guides for managing common problems, expert CME/CE webinars, and a Train-the-Trainer approach to on-site skills development
3. A quality Improvement toolkit
4. Patient and caregiver educational materials

In this study, each participating CF center will introduce routine palliative care screening for all individuals with CF from birth through adulthood, and their family caregivers (e.g., parent, partner/spouse). Each site will collect process measures (such as the proportion of individuals followed at the CF center who were screened in each quarter) to monitor the uptake of this new system-wide intervention in the practices. In addition, to evaluate the initial effectiveness of the intervention on patient-reported outcomes, adolescents and adults with CF (ages 12 years and above), and caregivers of CF patients of all ages, will be recruited from each participating site to complete optional questionnaires at baseline before implementation, and again 2 years after palliative care screening and provider education is introduced. Patients and caregivers who are not interested in participating in these research questionnaires will still be offered the palliative care needs assessment, as a routine part of standard care.