



# CAPE<sup>TM</sup>

Cancer Advocacy & Patient Education

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 **AONN** Academy of Oncology  
Nurse & Patient Navigators<sup>®</sup>

## About CAPE

- The Cancer Advocacy & Patient Education (CAPE) initiative aims to create a web-based library of best-practice information that providers in a specific cancer space can give to their patients and caregivers at each point of interaction.



# Mission Statement

## *OUR MISSION*

*To improve patient experience from cancer diagnosis, treatment, through survivorship/ end of life care with personalized education*

## *OUR VISION*

*Engage, inform, and empower newly diagnosed cancer patients utilizing a predetermined quality-of-life model to reduce distress and improve patient experience between diagnosis and first treatment and then through their patient journey*

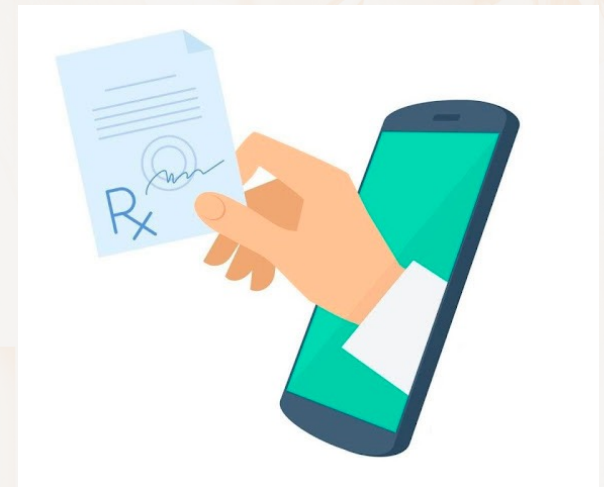
# Main Objectives

- To make the time between diagnosis and treatment as productive and meaningful as possible for patients with cancer and their caregivers through interactivity and education to meet patients' psychosocial needs
- Improve communication and shared decision-making around diagnosis, testing, and treatment between the patient (and caregiver) and their cancer treatment team
- To ensure patient understanding of their diagnostic and treatment journey individualized to their disease state



# Benefits of Digital/Social Prescribing

- The concept of digital prescribing in the care of cancer patients is communication, forming relationships, and providing information/resources that support and empower patients through their cancer journey
- Through communication and assessment, healthcare providers and navigators assist patients and caregivers to identify areas of focus or need, such as taking an active role in decision-making, tips for self-care, and dealing with financial concerns
- Social prescribing is essential to the clinical toolkit of healthcare providers and navigators to tackle wider social determinants of ill health by focusing on what matters to patients as opposed to what's the matter with the patients
- Healthcare providers and navigators would utilize the digital tool to select the relevant modules that may relate to a patient, curate relevant resources, and print/e-mail them to the patient





## Foundational Work

### Building the coalition

### Quality-of-life framework identified

### Literature search

- CLL Example: A total of 5393 articles were screened, 873 full text publications were reviewed, and 59 relevant articles were identified.
- At the request of the advisory board, an additional 236 articles were screened, 64 full text publications were reviewed, and 16 articles were identified.

### Identifying the modules

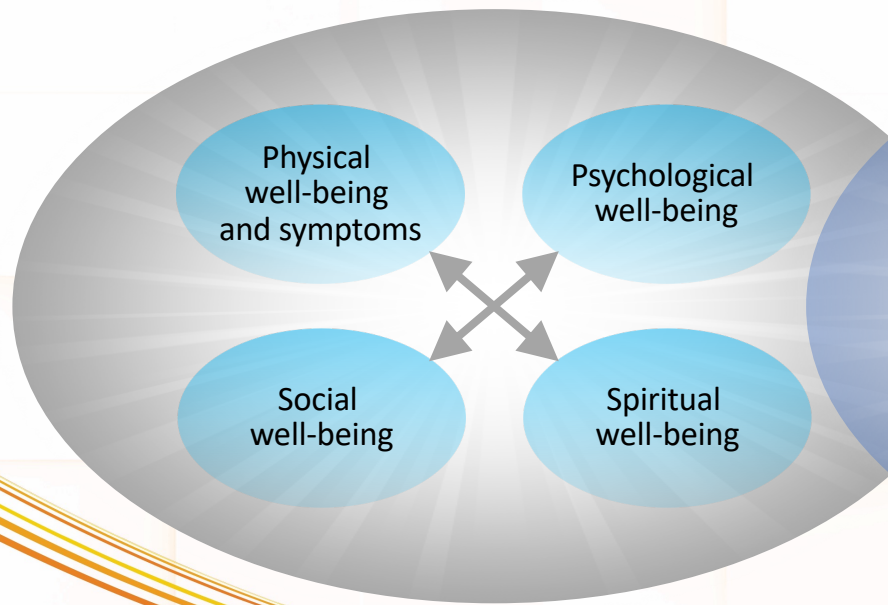
- Developing modules based on the domains that represent the most prominent areas of concern for CLL oncology patients and their caregivers

### Narrowing the resources

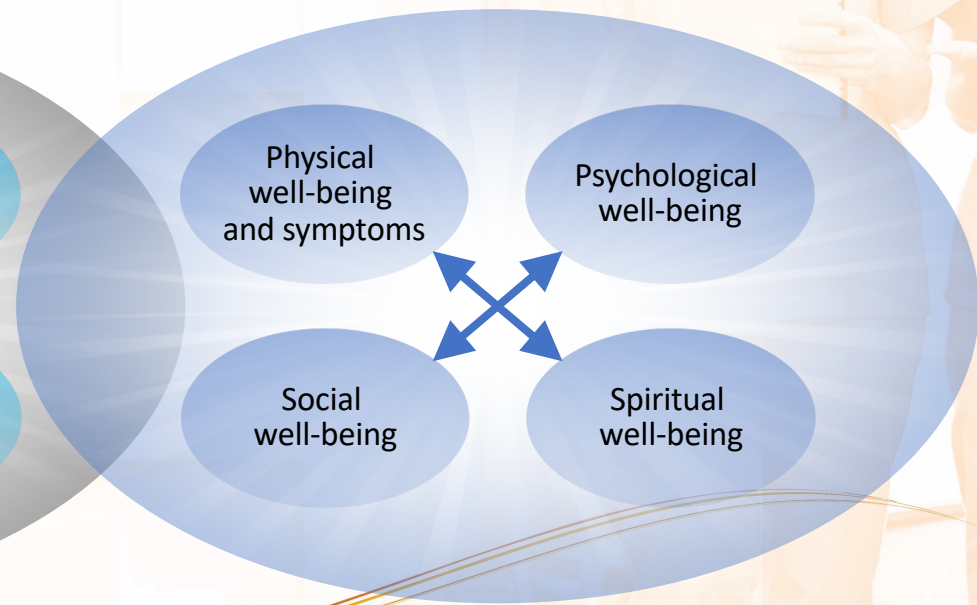
# Quality-of-Life Model Applied to CLL Cancer

- Fujinami R, et al. Quality of life of family caregivers and challenges faced in caring for patients with lung cancer. *Clin J Oncol Nurs*. 2012;16(6):E210-E220.

Patients with CLL Cancer



Family Caregiver



# Identifying Patient Facing Materials



Identify evidence-based patient materials



Identify validated patient assessment tools



Types of Educational materials

Videos, apps, handouts/printed material, websites, resource/support tools



## Evidenced Based Practice (EBP):

“EBP is a paradigm and life-long problem-solving approach to clinical decision-making that involves the **conscientious use of the best available evidence with one’s own clinical expertise** and **patient values and preferences** to improve outcomes for individuals, groups, communities, and systems”  
(Staffer et al, 2013)

Staffer M, Sandau K, Diedrick L. (2013). Evidenced-based practice models for organizational change: overview and practical applications. *Journal of Advanced Nursing*. 69(5):1197-1209.



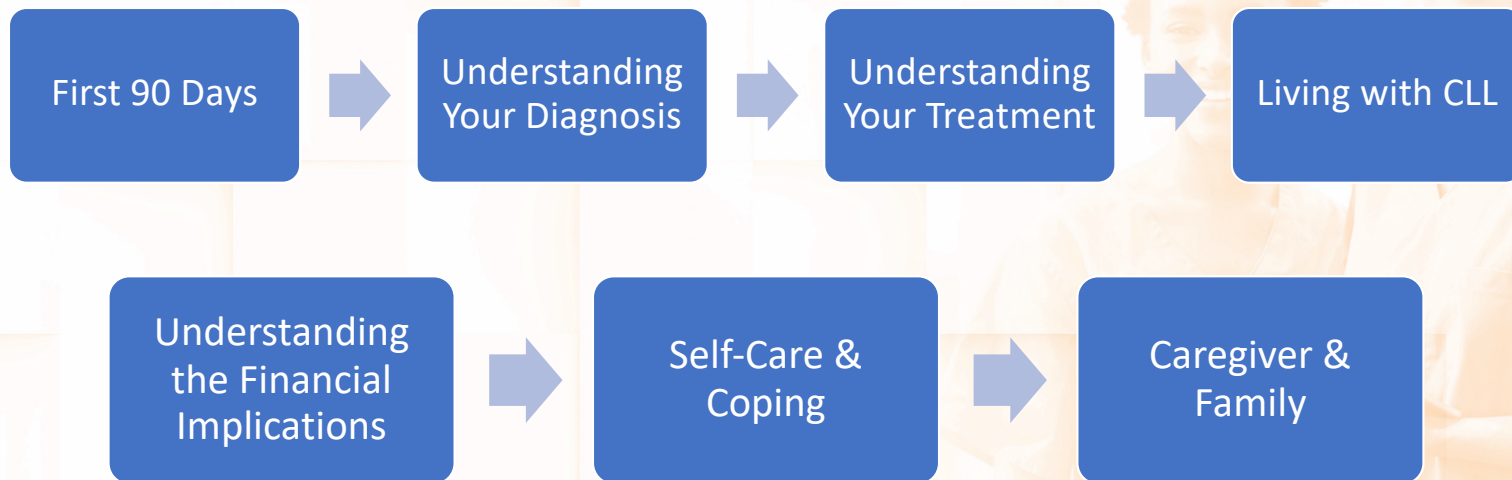
Health literacy is defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions."



<https://www.accc-cancer.org/home/learn/Patient-Centered-Care/health-literacy>



# CLCL CAPE Modules



# CLL Platform

The screenshot displays the CLL CAPE website interface. At the top left is the logo for CLL CAPE, with the tagline 'Cancer Advocacy & Patient Education'. To the right of the logo is a navigation menu with links for 'LUNG CANCER', 'CLL', 'RCC', and 'LOGOUT'. The main content area is titled 'Chronic Lymphocytic Leukemia' and features a vertical list of eight expandable topics, each with a plus sign on the right. To the right of this list is a 'Get Results' section with a sub-heading 'Your Selection' and the text 'Selected health topics will appear here', followed by a 'GET RESULTS' button.

**CLL CAPE**  
Cancer Advocacy & Patient Education

LUNG CANCER   CLL   RCC   LOGOUT

## Chronic Lymphocytic Leukemia

- First 90 Days +
- Understanding your Diagnosis +
- Understanding your Treatment +
- Living with CLL +
- Understanding the Financial Implications +
- Self-Care & Coping +
- Caregiver & Family +

**Get Results**  
**Your Selection**  
Selected health topics will appear here

GET RESULTS



# CLL Platform

The screenshot displays the CLL Platform interface, divided into two main sections: a course structure on the left and a 'Get Results' summary on the right.

**Course Structure (Left Panel):**

- First 90 Days** (Collapsible header, + icon)
- Understanding your Diagnosis** (Collapsible header, - icon)
  - Video Introduction to the CAPE CLL program**
    - Video Introduction to the CAPE CLL program (Video icon) **PREVIEW**
  - Introduction to the Module**
    - Video Introduction to Module 1 (Video icon) **PREVIEW**  
Understanding Your Diagnosis / What is CLL?
  - CLL Understanding Diagnosis**
    - Newly Diagnosed with CLL (Website icon) **PREVIEW**  
Your CLL diagnosis is just a starting point. Even though the path ahead may seem unclear or even insurmountable, armed with knowledge you can take control.
    - CLL Basics: What You Need to Know (Website icon) **PREVIEW**  
Mission and vision of the CAPE CLL Program
    - An Overview of Current CLL Treatment Approaches (Video and Transcript icons) **PREVIEW**  
What chronic lymphocytic leukemia (CLL) treatments are available now?
    - Practical Advice for Coping with a CLL Diagnosis: What's Next? (Video and Transcript icons) **PREVIEW**

**Get Results (Right Panel):**

**Your Selection**

- ✓ Newly Diagnosed with CLL **X**
- ✓ CLL Basics: What You Need to Know **X**
- ✓ Diagnosed with CLL? AN Expert Outlines Key Steps **X**

**GET RESULTS**

## Integration of CAPE into Workflow

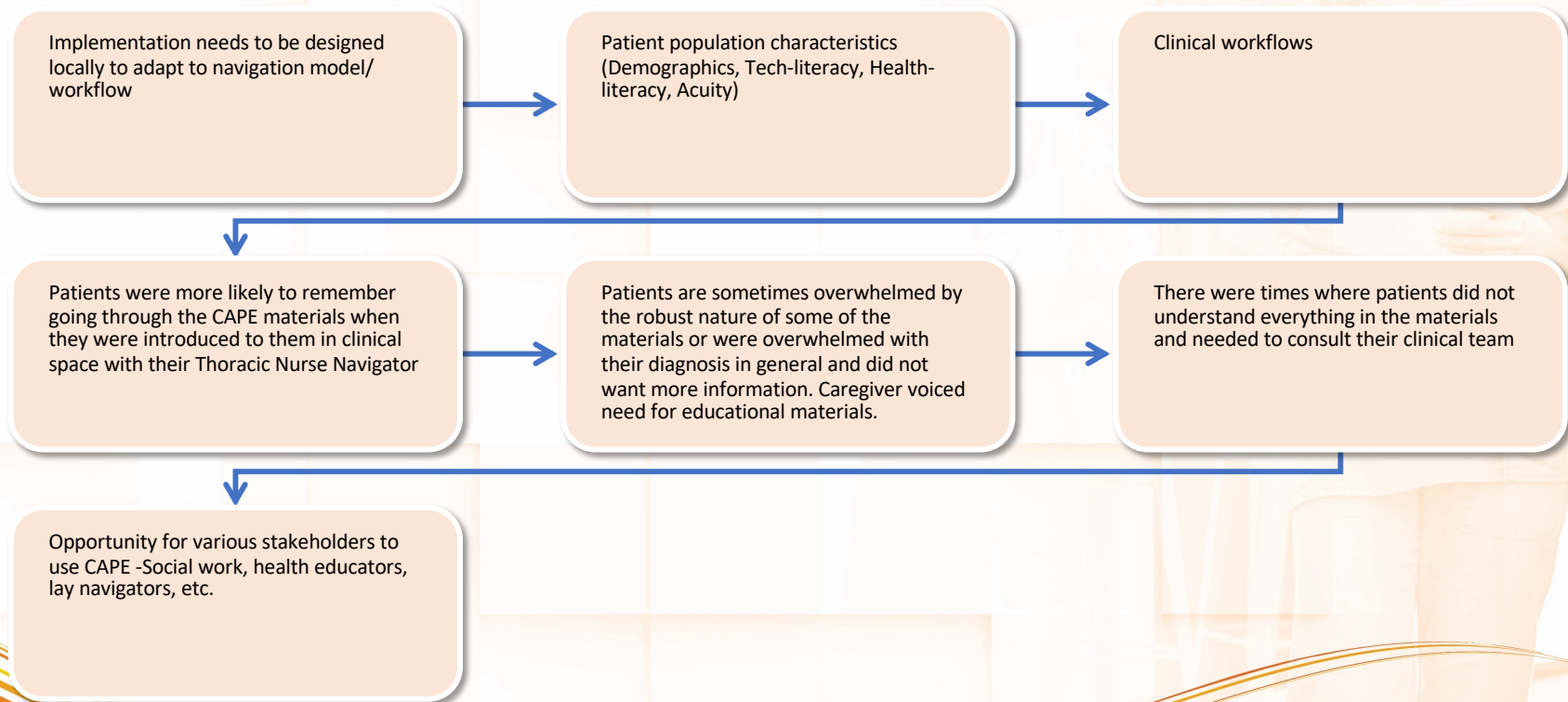
Start at intake and build upon education throughout trajectory

Newly diagnosed patient waiting for appointment

Provide digital prescription at each step of cancer journey



# Preliminary Insights- CAPE Lung



# Cancer Advocacy & Patient Education (CAPE)

## Perspectives from Patients & Providers

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### BACKGROUND

The Cancer Advocacy & Patient Education (CAPE) Lung Cancer Initiative is a web-based patient education platform that warehouses best-practice resources and educational materials. Created by the Academy of Oncology Nurse and Patient Navigators (AONN+), CAPE is designed to improve patient education and enhance patient care. CAPE permits navigators and other cancer care team members to send patients “e-prescriptions” that contain personalized education, customized for each patient’s circumstances and treatment status. AONN+, in collaboration with Fox Chase Cancer Center (FCCC), conducted a pilot study to evaluate patient and healthcare provider feedback regarding the CAPE resources and to assess CAPE implementation at 4 cancer centers (2 urban medical centers and 2 rural medical facilities).

### OBJECTIVES

The pilot study was commissioned with 2 objectives:

- Could the participants identify at least 2 benefits of CAPE?
- Could the participants identify at least 2 possible barriers to CAPE implementation?

### METHODS

Fifty-three English-speaking patients with non–small-cell lung cancer were enrolled in the CAPE program within 12 weeks of their diagnosis. Participants completed a baseline survey, received personalized e-prescriptions (printed or via e-mail), and completed a 1-month follow-up survey over the phone with the FCCC research team about their experience with CAPE. Implementation strategies were site-specific and tailored to meet the needs of each site’s clinical workflows. The FCCC research team conducted an analysis of the perceived usefulness and educational value of CAPE across the diverse sites, and conducted interviews with staff members using the Consolidated Framework for Implementation Research to better understand the differences between sites and guide future dissemination.

### RESULTS

Of the 53 patients enrolled, 16 patients reported viewing the CAPE materials, and the majority of those patients felt that CAPE helped them understand their diagnosis and treatment options. The patients who recalled receiving CAPE materials felt that the resources equipped them to talk with their doctor. Notably, the patients were more likely to remember receiving the materials when enrollment was in-person

“When diagnosed with cancer, a patient and their family’s quality of life is often impacted immediately. AONN+’s intention with the CAPE platform is to provide evidence-based education that is high quality and delivered in real time to meet the patient’s needs at what can be an overwhelming time. Navigators have a unique opportunity to use the CAPE platform to support their role in providing timely personalized education to their patients.”

– Emily Gentry, BSN, RN, OCN, HON-ONN-CG

with their navigator, which was how the study was implemented at the urban sites. As with many technology-based patient resources, several factors influenced effective CAPE implementation: overwhelmed patients, short-staffing, low technology literacy, and provider handoffs, which varied between the rural and urban sites. Overall, providers felt that CAPE is a great resource for patients, that it fit within their patient workflow practices, and matched patient educational needs.

### CONCLUSIONS

The majority of the patients who used the CAPE resources viewed it positively. However, some patients felt overwhelmed by their diagnosis or other external factors, so their ability to use or absorb the information provided through CAPE was diminished. Based on these findings, AONN+ believes there are strategic points in the patient care process at which CAPE could be introduced into the treatment trajectory. A one-size-fits-all approach to implementation timing may not be optimal. The insights from these preliminary findings will guide future implementation and dissemination of CAPE.

AONN+ acknowledges Takeda Oncology for its support and funding of this innovative, leveraged, and evidence-based program.



References:  
1. Fleisher L, Kenny C, Landau Z, et al. (2019) An educational tool (CAPE) improves patient education & patient education (CAPE) lung cancer initiative. *Journal of Oncology Management and Survivorship*. 2019. <https://doi.org/10.1177/2374873819850000>  
2. Landau Z, Kenny C, Bellomo C, et al. (2019) Lung cancer patient education: a patient education platform (CAPE) for lung cancer patients. *Journal of Oncology Management and Survivorship*. 2019. <https://doi.org/10.1177/2374873819850000>  
3. Gentry E, Pixley A, Landau Z, et al. (2019) Implementation and maintenance of a patient education program of advocacy and opportunities for further integration. *Journal of Oncology Management and Survivorship*. 2019. <https://doi.org/10.1177/2374873819850000>





**NOW AVAILABLE!**



**Cancer Advocacy & Patient Education**

to

**ENGAGE, INFORM, AND EMPOWER PATIENTS**

*"Because every hero needs a CAPE"*

A comprehensive online library of information for oncology professionals to disseminate to patients at each point of interaction.



**The CAPE Resource Center for Chronic Lymphocytic Leukemia is now available. Register today!**

Coming Soon



**Women's Health** **CAPE**<sup>TM</sup>  
Cancer Advocacy & Patient Education



**Women's Health** **CAPE**<sup>TM</sup>  
Cancer Advocacy & Patient Education

# Access CAPE

<https://aonnonline.org>



## Overview of CAPE

The objective of the Cancer Advocacy & Patient Education (CAPE) initiative is to create a web-based library of best-practice information that providers in the cancer space can give to their patients and caregivers at each point of interaction. The objectives are:

- To make the time between diagnosis and treatment as productive and meaningful as possible through interactivity and education to meet patients' psychosocial needs
- To improve communication and shared decision-making around diagnosis, testing, and treatment between the patient, caregiver, and the cancer treatment team
- To ensure patient understanding of their diagnostic and treatment journey, individualized to their disease state

The CAPE program's web-based platform will allow navigators and healthcare providers to deliver a personalized digital prescription to cancer patients and caregivers of cultivated, evidence-based, best-of-the-best resources based on their physical, psychological, social, and spiritual well-being needs to make the time between diagnosis and treatment as productive and meaningful as possible. By providing education, improving communication, sharing decision-making, and ensuring patient understanding through interactivity and personalized resources of the CAPE program, navigators and healthcare providers can engage, inform, and empower newly diagnosed cancer patients, resulting in reduced distress and an improved patient experience. The education platform will assist the identification of interventions or tools to improve quality of life throughout the disease process.

Please use the icons below to access each platform.



## AONN + CAPE Web Site



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Thank you

