

## People living with serious illness have certain needs that may be overlooked by standard case management protocols

A serious illness – defined as a health condition that carries a high risk of mortality and either negatively impacts a person’s daily functioning or excessively strains their caregivers – creates unique burdens for the patient and family. When these areas remain undiscovered and unaddressed, [avoidable emergency department visits](#) and hospitalizations often result. Care managers can begin to address these with targeted screening and assessment tools.

## Evidence-based Assessments to Reveal Areas of Distress and Gaps in Care

Depending on the individual’s situation, the [recommended assessments below](#) should *replace* some of the standing assessments, particularly for those members with advanced stages of illness, such as metastatic cancer or oxygen-dependent COPD.

### → Symptom Burden

Many people with advanced illness experience symptom distress that can be better managed, thus improving their quality of life.

- [Revised Edmonton Symptom Assessment System](#) (ESAS)
- (For more information about pain assessment, please see the [CAPC Comprehensive Pain Assessment Course](#))

### → Functional Impairment

The health care delivery system pays inadequate attention to functional abilities. Assessing impairment may reveal significant unmet needs.

- [Palliative Performance Scale \(PPS\)](#)
- [Karnofsky Performance Status Scale](#)

### → Anticholinergic Burden (if patient over age 65)

Many common medications can cause adverse events and increase mortality in older adults. Screening for burden is a first step to deprescribing.

- [Anticholinergic Burden Calculator](#)

### → Caregiver Burden

Overwhelmed caregivers not only experience their own health issues, but are a major risk factor for the patient’s avoidable utilization.

- [Zarit Burden Interview](#)

Other assessments may also be warranted:

- For those who may be in spiritual distress, the [Beck Hopelessness Scale](#)
- For patients with cancer diagnoses, the brief [National Comprehensive Cancer Network Distress Thermometer](#) may be a useful replacement for the recommendations above.

## What to Do Next

Members/patients with high symptom burden, poor functional ability, high anticholinergic burden, high caregiver burden, and/or high overall distress will require additional interventions.

First, the patient and family should be educated about their illness and what to expect, through the provision of “anticipatory guidance.” They should also have an opportunity to clarify their goals and values in light of these expectations, and receive help to make treatment decisions that align with those goals. Some of [CAPC’s online communication courses can help with this](#).

Second, their treating provider should be informed of these unmet needs and heightened risks, and consider how the care plan can be adjusted to better manage symptoms and stresses, as well as to align with goals. It is also important to alert treating providers of the need for de-prescribing. [CAPC’s online course](#) can help with this.

Third, for those with significant needs per assessment, referral to a specialty palliative care team can help to [improve quality of life](#) for both the patient and family. Be aware of palliative care clinicians in your network. The [Palliative Care Provider Directory](#) can help you locate palliative care teams in hospitals, offices, nursing homes, and home-based services.

*NB: When suggesting a palliative care consultation to a member/patient, explain that this specially-trained team can provide an added layer of support to help them get the care they deserve. It may be prudent to avoid the term “palliative care” until explanation has been provided.*

Always follow your organization’s policies and procedures when speaking to patients, coordinating with treating providers, and making referrals.