

GLOSSARY OF TERMS

**ADVANCE CARE PLANNING**

A voluntary discussion about preferences for future care, held between an individual and his/her health care providers. Advance care planning helps individuals make decisions about their own care and communicate those decisions to others. Advance care planning can take into account personal preferences, values, and which types of treatments the individual wants or does not want under certain circumstances, among other considerations.

**ADVANCE CARE PLANNING AND GOALS-OF-CARE CONVERSATION SKILLS**

Health care professionals working with individuals living with serious illness need to have specific communication skills. These include: a) the ability to discuss prognosis and deliver serious news; b) the ability to hold [goals of care conversations](#goalsofcareconvo); and) c) the ability to hold [advance care planning](#advancecareplan) conversations. Professionals must be skilled in communicating with patients, family members, caregivers, and treating clinicians.

**ADVANCE DIRECTIVE**

Formal written or verbal instructions for health care delivery, if the patient is unable to make his/her own decisions.

**CAREGIVER**

An individual who provides unpaid care to a relative or friend to help that person take care of him/herself.

**CAREGIVER BURDEN** refers to the stress perceived by caregivers due to their role. Higher caregiver burden has been correlated both with higher spending for the patient with serious illness as well as poorer health outcomes for caregivers. Caregiver burden can be assessed and addressed through education, counseling, respite and assistance with a caregiver’s own personal care responsibilities.

**CASE MANAGEMENT/COMPLEX CASE MANAGEMENT**

A process where a case manager fully assesses a patient, plans and facilitates services to address the patient’s needs, and continually informs and coordinates the parties involved in the patient’s care. Most health plans and ACOs utilize case management to “quarterback” the care of those living with serious illness and/or multiple chronic conditions. Case managers can play a pivotal role in ensuring the assessment of a patient’s symptoms, the management of those symptoms, [advance care planning](#advancecareplan), and [goals of care conversations](#goalsofcareconvo).

**CONCURRENT CARE (in the context of serious illness)**

The delivery of disease-modifying treatment simultaneously with palliative care. Concurrent care is different from the prevailing Medicare hospice benefit, which, as defined below, requires patients to forgo disease-modifying treatment.

**“CORE” PALLIATIVE CARE SKILLS** refer to a combination of skills needed by any clinician when caring for a person with serious illness in [symptom assessment](#symassessment), [symptom management](#symmanagement), [advance care planning](#advancecareplan) and [goals-of-care conversations](#goalsofcareconvo). Ideally, all clinicians caring for people with serious illness can manage symptoms and hold needed conversations, requiring palliative care specialists only for intractable symptoms and/or difficult family dynamics. Effective clinical training programs exist to teach core palliative care skills.

**FUNCTIONAL ABILITY**

An individual’s ability to carry out “activities of daily living (ADLs),” specifically: eating, bathing, dressing, toileting, walking, and transferring from the bed. One’s functional abilities can be impacted by physical, emotional, and cognitive dimensions.

**FUNCTIONAL ASSESSMENT** refers to the process of identifying and describing how well an individual can perform each of the six ADLs.

**GOALS OF CARE CONVERSATION(S)**

The process of gaining an understanding of the patients’ values and hopes in the context of a serious illness, permitting a clinician to align the care provided with what is most important to the patient.

**HOME-BASED CARE**

Health care services rendered to patients in their home. Services often include nursing services, rehabilitation services (including physical and occupational therapies), nutrition services, social services, home health aide services for assistance with activities of daily living (ADLs—see [functional ability](#functionalability), above), and can also include physician services and other services.

**HOSPICE CARE**

Hospice care is a well-known and comprehensive delivery model of palliative care, often limited to terminally ill patients. The Medicare hospice benefit defines hospice eligibility as appropriate for patients when two doctors certify a prognosis of six months or less to live if the disease follows its usual course, and the patient agrees to forgo Medicare coverage for disease-modifying treatment. Other payers often follow the Medicare hospice benefit, but there is no requirement to restrict hospice access in this way.

**PALLIATIVE CARE**

Palliative care is specialized medical care for people with serious illness. It focuses on providing patients with relief from the symptoms, pain and stress of a serious illness—whatever the diagnosis. The goal is to improve quality of life for both the patient and the family. It is appropriate at any age and at any stage of a serious illness and can be provided along with curative treatment. Palliative care may be called by a different name such as “Supportive Care,” “Compassionate Care,” “Advanced Illness Management,” and “Personalized Care.”

**PALLIATIVE CARE “PROGRAM”** refers to a multi-disciplinary team with specialized training that is called in to assist the treating clinician(s) with the care of a patient living with serious illness. The program may provide [home-based care](#homebasedcare), and/or care in an office or hospital setting.

**SERIOUS ILLNESS**

Serious illness is a health condition that carries a high risk of mortality and either negatively impacts a person’s daily function or quality of life or excessively strains their caregivers.

**SYMPTOM ASSESSMENT**

Formal review of a patient’s symptoms, spanning pain, fatigue, drowsiness, nausea, constipation, loss of appetite, shortness-of-breath, depression, anxiety, and overall wellbeing. Symptoms can be due to the patient’s health condition(s) and/or to the treatment(s) for those conditions. Frequent assessment enables the care team to address symptoms in a timely manner.

**SYMPTOM MANAGEMENT** refers to clinical efforts to prevent, reduce and/or eliminate symptoms. This may or may not include pain medication.