

INTEGRATING PALLIATIVE CARE INTO POPULATION MANAGEMENT: A Toolkit for Health Plans and Accountable Care Organizations

ENGAGEMENT AND ASSESSMENT



“Even the best palliative care will be of little use without the ability to engage patients to understand their needs and preferences.” Randy Krakauer, MD

What it is and Why it's Important

While there is a science to identifying individuals with serious illness, there is an art to defining their needs and the shared-decision-making required to address them. Best practice in health plan and ACO case management requires that the staff responsible for outreach and assessment must have the skills to:

- Hold meaningful conversations to understand values and goals, and help individuals translate those into treatment preferences and priorities
- Assess needs and distress across the full range of physical-psycho-social-spiritual spheres
- Determine what is really needed to support the entire family, taking into account practical and financial considerations

Too often case management focuses on physical needs and adherence to the treatment plan prescribed by the treating clinicians, but such an approach is often insufficient for the populations facing significant symptom burden and life-threatening illness. A different set of communication and assessment skills are needed for the seriously ill population.

Note that the term “case management” as used in this guidance encompasses nurse case management, care coordination, health coaching, patient navigation, and all other patient guidance and support.

Best practices in Engagement and Assessment

A. Case manager hiring and training

Successful engagement is dependent on the ability of the case manager to create a trusting relationship and to build on it to provide expert support and assistance. This requires:

- the ability to gather the individual and family’s “back-story”
- knowledge about course of and expectations of the illnesses
- knowledge of the types of support available and how to mobilize it

In hiring case managers, the following qualifications should be sought out:

- Human warmth and interest in the stories and circumstances of other people
- Positive and optimistic attitude
- Educated and have real experience in either nursing, social work, gerontology, or psychology
- Strong capabilities to assess, plan, coordinate, and monitor services
- Resourceful and creative in identifying and covering social and medical services
- Excellent advocacy skills with a community-based mindset
- Interest and ability in meaningful advance care planning conversations
- Able to assist patients and families in thinking through choices, rather than explaining what to do
- Utilize a patient and family centered approach
- Case management certification preferred.

The strongest serious illness case management programs look for staff members that are eager to work with this population.

Even well-qualified case managers will need extensive training to do this job well. Training should encompass all the likely concerns and issues facing individuals with serious illness and their families; role-playing is an effective mechanism for this. Training is also necessary in expected disease progression and treatment options (and their various pros and cons). Clinical knowledge of the more common illnesses – cancer, dementia, heart failure, COPD, and end-stage kidney disease – must be strengthened in training, so that case managers can hold conversations about expectations without referring the patient and family back-and-forth to multiple sources.

Skills in motivational interviewing and “cultural humility” round out the full slate of competencies needed. Selection and training might be followed by a period of review and mentoring by experienced case managers. If telephonic, calls should be recorded and reviewed carefully for a minimum of two weeks after hire. Ongoing mentoring not only allows the new hire to continue to hone their knowledge and skills, but also allows the plan or ACO early indication of whether the new hire can truly be comfortable in assisting patient and family decision-making without making recommendations or “steering” the conversation.

Health plans including Kaiser Permanente and Aetna have found improved quality, satisfaction and cost from a strong team of well-trained case managers.¹ There are a growing number of training courses and resources available to strengthen case manager communication and assessment skills specific to supporting those with serious illness, including those available through the Center to Advance Palliative Care (CAPC) – consider the [curriculum guide for case managers](#) as a starting point to develop a training program.

¹ Randall Krakauer, Claire M. Spettell, Lonny Reisman, and Marcia J. Wade, Opportunities to Improve the Quality of care for Advanced Illness, *Health Affairs*, 28, no.5 (2009): 1357-1359.

B. Engagement skills and processes

As noted above, successful case management of the seriously ill depends on forming meaningful connections with people, and comfort in holding difficult conversations. Effective conversations simply cannot be had by reading a script or through a smart phone application. A barrage of questions, checklists, or flow charts can be overwhelming and limit the opportunity to more thoroughly identify needs. ***The bottom line: allow sufficient time for case managers to make a deep human connection, and success will follow.***

Whenever possible, treating providers should be contacted before contacting the patient. This not only enables the case manager to gather as much background information as possible, but also to obtain the clinician's buy-in for additional support.

Other successful engagement strategies include:

- Contacting someone shortly after a hospitalization or emergency department visit
- Starting the conversation by asking the individual's permission to discuss their situation with them
- After that, start by asking what the individual/family already know – do not make any assumptions that they are aware of their state of illness or prognosis
- Ask what is worrying them most about their situation, and then use the response to guide next questions
- Emphasize that the goal is to maximize their quality-of-life while they are going through this difficult illness
- Being “present” when someone is in an emotional or difficult place
- Being well versed in describing palliative care services, sometimes without using the term “palliative care,” and always making sure not to confuse palliative care with end-of-life care or hospice
- Asking open-ended questions to discern the person's or families' understanding of the illness, their concerns and priorities (rather than going through a yes/no checklist or conversation)
- Incorporating Motivational Interviewing/Appreciative Inquiry techniques to improve activation and self-management.

Consider this example, excerpted from a case note:

Wife stated member passed away with Hospice. Much emotional support given to spouse. She talked about what a wonderful life they had together, their children, all of the people's lives that he touched - they were married 49 years last Thursday and each year he would give her a piece of jewelry. On Tuesday when she walked into his room he had a gift and card laying on his chest, a beautiful ring that he had their daughter purchase. She was happy he gave it to her on Tuesday - on Thursday he was not alert . . . Also stated that Hospice was wonderful, as well as everyone at the doctor's office, and everyone here at [the health plan]. She tells all of her friends that "when you are part of [this health plan], you have a lifeline." Encouraged her to call CM with any issues or concerns. Closed to Case Management.

The depth of the human connection between this case manager and the person's wife is obvious. This level of engagement resulted from a program that was entirely telephonic. Clearly this case manager has combined training, experience and empathy. She took the time to assess and understand the clinical issues, and the psychosocial issues. This is one of many such examples that illustrate why a palliative care-based case management program can be effective and produce real satisfaction and impact. What might have been the result had this case manager merely read scripted material or focused on adherence?

C. Assessments

The needs of seriously ill patients and their family members will vary enormously. Comprehensive assessment across all aspects of well-being – physical, psychological, social, spiritual, and financial – will help to ensure that the services made available to the person and family align with their needs.

Best practice suggests that symptom burden and functional status should be assessed initially, as these can also serve as screening for level of palliative care need. Even the most sophisticated identification processes will result in “false positives,” and physical assessment will reveal whether function is truly impacted.

The following are the more common physical assessment tools.

Assessment Needed	Key Assessment Tools
Symptom Burden	<ul style="list-style-type: none"> • Pain Assessment and Documentation Tool (PADT) • Condensed Memorial Symptom Assessment Scale (CMSAS) • Edmonton Symptom Assessment Scale (ESAS) • National Comprehensive Cancer Network Distress Thermometer
Functional Status	<ul style="list-style-type: none"> • Karnofsky Performance Status Scale • Palliative Performance Scale • Australia Modified Karnofsky Scale • Meets Home Health Homebound Definition: needs supportive devices, special transportation, or assistance of another person to leave the home; or leaving the home is medically contra-indicated

From these assessments, a person can be risk-stratified into Low, Medium and High Need:

- Low Need -- Patients with low symptom burden or minimal functional impairment; serious but stable illness.
- Medium Need -- Physical symptoms are severe or are unstable, or function is greatly compromised, impeding self-care.
- High Need – Significant symptom burden along with functional limitations

The level of need can dictate whether palliative care needs can be met by the treating provider team, specialty palliative care consultation, ongoing palliative care co-management, or specialized palliative care programs, often home-based. See Section 3: Services, for how to match level of need with services.

For those individuals within the Medium and High Need categories, additional assessment should follow, to enable a holistic response to the individuals’ needs. The table below describes the additional assessments that a clinical team can provide in order to assess appropriateness for certain services.

Assessment Needed	Why Assess?	Assessment Tool
Depression	Depression and psychological distress commonly co-occur with serious illness, and are treatable	<ul style="list-style-type: none"> • PHQ-9
Caregiver Burden	Family members shoulder tremendous direct care responsibilities, with significant physical, emotional, functional, and financial consequences.	<ul style="list-style-type: none"> • Zarit Burden Interview (ZBI-12)
Social Needs	Social determinants such as housing, food insecurity, trauma, illiteracy, and poverty strongly impact health status and utilization.	<ul style="list-style-type: none"> • Limited consistent assessment tools are used. Some health plans and ACOs are developing their own tools referencing

		resources such as the Institute of Medicine’s publications on caring for those with serious illness. ²
Spiritual Needs	Questions of meaning, purpose, and connection to a faith community are of high priority to most individuals with serious illness.	<ul style="list-style-type: none"> • Beck Hopelessness Scale

Referrals to appropriate services or supports can then follow these assessments. Again, please see Section 3: Services, for more detailed information on services.

Getting started

1. Start by evaluating case management skills and processes already in place.

Prior to designing and implementing a case management program that will help care for people with serious illness, it is important to assess what you already have in place with regard to both training for case managers and support for those with serious illness. The remaining steps would be addressing the gaps, rather than building entire programs.

2. Integrate palliative care training into existing training.

Most complex case management programs use motivational interviewing as the basis of the services they provide. Determine where palliative care principles like psycho-social-spiritual assessment, goals of care discussions, and advance care planning can fit into the existing training protocols. For example, CAPC training for case managers in communication skills can be added to help case managers shift the conversation focus from promoting adherence to clarifying values and preferences.

In addition ensure that clinical skills training for palliative care is also supplemented by operational training. This may take coordination with utilization management to develop workflows for authorizing services individuals with serious illness may need more frequently. By coupling clinical skills and operational training, case managers can apply their skills directly to the care covered by an individual’s particular benefits.

3. Assess technology and data resources.

It is recommended that in addition to assessing training potential and plans, a technology and data assessment also be completed. A technology assessment should include the case management platforms that are used to keep track of cases and the pathways that may form between an analytics team, outreach, case management, and utilization management. For example, in order to track people in need of palliative care services by their treating providers, the system should have a place to flag such people and document their goals of care. Documented goals of care and any advance care planning should also be available to network providers.

Practical considerations for implementation

1. Assessments should be done for specific purposes, not for the sake of complete assessment.

Keep in mind that overburdening the individual or family caregiver with too many assessments leads to frustration and exhaustion. Assessments should be brief, appropriately prioritized and timed, requiring coordination internally and, where possible, with the treating providers.

2. Weigh the pros and cons of telephonic or in-person case management

² Institute of Medicine, “Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life” September 17, 2014

Some contend that for managing the complex and highly-variable needs of the seriously-ill population, telephonic case management is insufficient, yet there is good evidence that, when executed correctly, telephonic is just as effective as in-person. Plans and ACOs should consider the culture of their organizations, their relationships with treating providers, and the cost-benefit of in-person case management when deciding on the best approach. A health plan or ACO can combine or adopt variations of these alternatives as well.

OPTIONS	Advantages	Disadvantages
Telephonic	<ul style="list-style-type: none"> • Economies of scale • Greater flexibility to extend hours for access • Some people may prefer telephonic due to convenience, greater accessibility if unable to travel, or personal issues (embarrassment in sharing details face to face) 	<ul style="list-style-type: none"> • More challenging to build trusting relationships with people via telephone • Difficult to assess social, housing, food, family dynamics that influence care • Limited access to treating providers or ability to directly deliver needed services (e.g. not able to write a prescription)
Practice Embedded or In-Person	<ul style="list-style-type: none"> • Able to build strong relationships with clinicians • Access to clinical record • Face-to-face interactions with patients and clinicians can improve engagement 	<ul style="list-style-type: none"> • May be pulled from case management duties to cover day-to-day clinic duties • Less flexibility in case management staffing • Overhead costs (space, travel) • Requires patient's ability to travel unless this is part of a home-based model

3. Evaluate whether a dedicated case management team would be appropriate

Whether building or buying case management services, one key design decision that health plans and ACOs will need to make is whether to develop a dedicated case management team just for people with serious illness, with specially trained case managers who have well-honed skills in communication and assessment. The table below summarizes the options:

Case Management Approach	Short Description	Considerations
Dedicated case management team	Specially trained team with assigned caseload that meet internal criteria for serious illness.	<ul style="list-style-type: none"> • Allows team to work together as a unit, building team processes like morning huddles to review cases with medical directors. • Opportunity to enroll members in a specific case management program, providing opportunities to manage enhanced benefits based on the unique needs of the patient and track outcomes. • More flexibility in managing caseloads to allow adequate time for complex case management • Important to collaborate and cross-train with other case managers in high-cost, complex care teams to avoid duplication and member confusion.
Integrate with existing case management teams	Train all case managers in the core principles and practices of palliative care.	<ul style="list-style-type: none"> • Must ensure that all case managers have access to training in pain and symptom assessment and goals of care and understand the basics of palliative care and the needs of those with serious illness. • Must ensure all case managers are empowered and have the necessary support to take the time necessary to address member needs. • Limits the ability to develop consistent experiences, offer enhanced benefits, and in some cases demonstrate outcomes.
Referring to network providers for case	Refer those with serious illness to network providers with available case	<ul style="list-style-type: none"> • Some health plans and ACOs are electing to provide claims and other program support to network providers who are then taking on the case management role for those with serious illness. This often requires contract amendments, and often new payment models.

management	management expertise and services.	<ul style="list-style-type: none"> • For those health systems that are providing their own case management, it is recommended that the health plan clearly define criteria for high quality services, such as designated training, outreach response times, and tracking of certain palliative care metrics. • Important to collaborate and cross-train with other case managers in high-cost, complex care teams to avoid duplication and member confusion.
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4. Coordinate with member/patient education vehicles

Regardless of how a health plan or ACO elects to implement its case management services, there is an important role they can play in educating their entire population on this topic. Member/patient education vehicles can be used to explain what palliative care is, and also encourage family conversations on wishes and values. Resources might also include information on how to communicate someone’s wishes to their treating provider.

Some health plans and ACOs have launched targeted campaigns to educate their members – regardless of health status – on family discussions. For example, Blue Cross Blue Shield of Massachusetts promoted The Conversation Project (www.theconversationproject.org) to an employer group and a New York State ACO adopted Respecting Choices (www.respectingchoices.org), encouraging family discussions about their values and planning ahead. Payers can promote publicly available educational materials such as those available at www.getpalliativecare.org to members so they can learn what palliative care is and its role in supporting those with serious illness.

Considerations for Pediatrics

Just as case managers working with adults would need strong knowledge in the clinical conditions faced by the target population, the same is true for those case managers working with children – they would need to understand the perinatal, neonatal, and pediatric conditions. In addition, further training is needed to ensure that case managers have the skills to help parents in their anticipatory grief and in communicating with healthy siblings and extended family.

Assessment tools for the psychosocial needs of seriously ill children or their parents are limited. The [PedsQL](#) “a modular approach to measuring health-related quality of life (HRQOL),” with surveys based on age and a proxy survey for parents. In addition, a consensus process has resulted in [assessment standards](#), which health plans and ACOs can use to create their own assessment tool(s).

For more guidance, two resources for case managers working with pediatric populations are included in the Additional Resources section: a) CAPC’s Pediatric Palliative Care Field Resource Guide may be a helpful resource; and b) provider resources available through the Courageous Parents Network.