

PALLIATIVE CARE

FACT SHEET

NPAF

National Patient
Advocate Foundation

Improving Quality of Life for Patients, Families, and Caregivers Coping with Serious Illness

Background

What is Palliative Care?

Palliative care focuses on relieving pain, symptoms, and stress of serious illness. It is a team-based approach involving specialty-trained doctors, nurses, social workers, and other professionals that provide an extra layer of support to improve quality of life for the patient and family. By determining patients' goals of care through skilled communication, treating distressing symptoms and coordinating care, palliative care meets patients' needs and helps them avoid unwanted and expensive crisis care. Palliative care is appropriate at any age and at any disease stage and can be provided *at the same time* as curative treatments.

The Issue

1. There is a lack of understanding and awareness of palliative care.

Gaps persist in professional, public, and policymaker understanding about the benefits of providing palliative care as part of disease-directed treatment throughout the illness experience. Palliative care is expected to increase, however, as the public becomes more aware of its benefits. Once informed about palliative care, public opinion research reveals that 92% of people would likely consider it for themselves or their families¹.

2. Access to palliative care is limited - particularly in communities.

Palliative medicine has become the fastest-growing medical specialty in the US, and most large hospitals now have palliative care programs². Yet millions of seriously ill adults and children do not have access to palliative care from the point of diagnosis throughout the course of illness, and its availability is highly variable by region and state. Even in hospitals that provide palliative care, only a small fraction of the patients receive it because programs remain understaffed and under-resourced. The next phase of growth requires integration of palliative care into the community - nursing homes, assisted living facilities, physician office practices and home care - where the majority of seriously ill adults and children actually receive their care.

3. The specialist palliative care workforce is in short supply.

Specialty-trained palliative care clinicians are too few in numbers to reach all patients and families in need. To address this workforce gap, front-line treating clinicians need training in primary palliative care competencies addressing basic symptom management, communication, and care coordination so they can routinely address patient function, independence, and quality of life throughout disease-directed treatment, and draw on specialty level palliative care expertise to assist them on more complex cases with higher symptom burden or other challenging circumstances.

Did You Know?



Palliative care improves quality of life and may increase survival.



Palliative care reduces patient and caregiver burden.



Palliative care results in higher quality care at lower costs.

¹ 2011 Public Opinion Research on Palliative Care, A Report Based on Research by Public Opinion Strategies: https://media.ccapc.org/filer_public/3c/96/3c96a114-0c15-42da-a07f-11893cca7bf7/2011-public-opinion-research-on-palliative-care_237.pdf

² America's Care of Serious Illness, 2015 State-By-State Report Card on Access to Palliative Care in Our Nation's Hospitals: <https://>

The Solution

Studies have shown that palliative care produces significant improvements in clinical outcomes, including relief from pain and symptoms, less anxiety and depression, and improved quality of life for patients and families. Patients feel supported by ongoing discussion of their greatest concerns and hopes, and are relieved to have help with difficult decision making and with knowing what to expect and how to handle it. Family caregivers feel supported and more satisfied with the care they are able to provide. In small studies among cancer, COPD, and hospice patients, palliative care has even been shown to contribute to significantly better survival rates.

Palliative care is an evidence-based solution to improving value that can be widely implemented. To benefit from palliative care, patients, families, and health professionals must be aware of these services, and they must be reliably accessible and available in all settings where seriously ill adults and children live and receive their care. In addition,

key stakeholders including the Institute of Medicine, have recognized a need for additional training in palliative care for most doctors and nurses based on the value this care provides to patients and their families.

NPAF supports quality care policies that:

1. **Improve awareness** for patients, families, and professionals about palliative care, its benefits and its availability.
2. **Expand access** to palliative care services and workforce skills training in all care settings.
3. **Boost research** support to build the palliative care evidence base for improved quality care delivery.
4. **Develop new person-centered quality measures** and standards that prioritize skilled communication to help match treatments with patient and family values and preferences.
5. **Integrate patient- and caregiver-reported outcomes** in quality improvement initiatives and value-based payment reforms.

In the 115th Congress, NPAF is working with the Patient Quality of Life Coalition to support

THE PALLIATIVE CARE AND HOSPICE EDUCATION AND TRAINING ACT (PCHETA), H.R. 1676 / S. 693

Legislation that will improve care quality and the quality of life of patients, families, and caregivers coping with serious illness by improving and expanding palliative care awareness, access, training, and research.

Key Provisions of PCHETA

- **Access and Education:** Establishes educational initiatives that would increase public and health professional awareness of the benefits of palliative care and services available as an extra layer of support for adults, children, and families confronting serious illness.
- **Workforce Development:** Creates initiatives to ensure there are sufficient numbers of palliative care specialists to: 1) teach all clinicians the core knowledge and skills of palliative care, 2) conduct the research needed to enhance the evidence base, and 3) provide high-quality palliative care for the most complex populations of seriously ill adults, infants, children, and their families.
- **Enhanced Research:** Directs National Institutes of Health (NIH) funding for palliative care research to strengthen clinical practice and person-centered quality healthcare delivery.

ABOUT NATIONAL PATIENT ADVOCATE FOUNDATION

The National Patient Advocate Foundation, the advocacy affiliate of the Patient Advocate Foundation, represents patient voices, both the powerful stories of individuals and the collective needs of the community. Our staff and advocates work at the local, regional, and national level to promote equitable access to affordable, quality health care for people with serious and chronic illnesses. We are thought leaders in developing person-centered policies that promote communication, shared-decision making, quality care improvement, and safety-net services navigation supporting quality of life for all patients and caregivers.