40 million Americans experience daily limitations due to a serious illness. The number will continue to grow as the Baby Boomer generation continues to age.

Medical care for serious illness is very expensive. The sickest 5% of the population cost half of health care dollars.

More than 12 million people live with serious illness for years. Only 11% of those patients are in the last year of life.

The potentially devastating effects of serious illnesses can be mitigated by thoughtful planning and development of an advance care plan.

Palliative care offers person-centered and holistic care to a person living with serious illness, without sacrificing access to medical treatments.

There are not enough caregivers for patients living with serious illness, or the resources to support them.
What is serious illness?

There is no single definition of what constitutes a “serious illness,” but there is no doubt that it raises serious challenges for patients, loved ones, and providers. For the purposes of this discussion, we will consider the illnesses to which the Centers for Disease Control and Prevention (CDC) attributes the leading causes of death and disability: heart disease, cancer, chronic lung disease, stroke, Alzheimer’s Disease, diabetes and chronic kidney disease, which are leading cost drivers in the $3.5 trillion in annual U.S. health spending.¹

While many people with these conditions can live a relatively normal life with appropriate medical management, we will focus on when patients reach the stage where treatments begin to lose their impact and the end of life nears.²

Other definitions of serious illness include two or more hospital stays and visits with three or more doctors within the past three years,³ or the presence of one or more serious illnesses plus functional dependency, cognitive impairment, frailty, and heavy reliance on family or other caregivers.⁴

Who has serious illness?

Quantifying the number of people living with serious illness is challenging given the competing definitions. In 2013, the CDC estimated that 40 million people limited their usual daily activities as a result of a serious illness.⁵ When the definition is limited to patients living with one or more serious medical illnesses as well as functional dependency, cognitive impairment, frailty and heavy reliance on family and other caregivers, it’s estimated that 12 million adults and 400,000 children have a serious illness.⁶

Americans are aging at an unprecedented rate. Each day approximately 10,000 people turn 65.⁷ As people age, they are more likely to face serious illness and require significant medical care as well as help with activities of daily living (ADL) such as eating, dressing, and bathing. Currently, more than 5 million Americans are living with Alzheimer’s disease and related dementias (ADRD). The number of ADRD diagnoses is expected to more than double by 2050.

How much does serious illness cost?

People living with serious illness make up a small percentage of the overall population - and are heavy users of health care. Appropriately, most health care dollars are spent on the highest need, most vulnerable patients. In 2016, half of the total health care dollars was spent on 5% of the population. People in the top 5% had an average annual spend of approximately $50,000, while the top 1% of health care utilizers spent $109,750.⁹

However, while the most expensive patients are certainly the sickest, not all of them are at the end of life. In 2011, researchers found that many people who make up the top 5% of health care utilizers are living with serious illness, and just 11% of the sickest patients are in the last 12 months of life.⁹

The challenges of serious illness go far beyond the financial cost, however. The mental, emotional, and spiritual stress of living with a serious illness or caring for someone with a serious illness takes a toll.

1  https://www.cdc.gov/chronicdisease/resources/infographic/chronic-diseases.htm
2  https://www.thectac.org/key-initiatives/advanced-care-project/
5  https://www.cdc.gov/nchs/data/series/sr_10/sr10_259.pdf
9  https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4638261/
What are the challenges?

Health Disparities

Disparities in care occur in all aspects of the health care system, including the care of people with serious illness. Socioeconomic status and race can significantly impact the patient’s health care experience. For example, racial and ethnic minorities experience disparities in access to care, receipt of care and quality of care, all of which leads to late diagnosis of serious illness and negative health outcomes.\(^\text{10}\)

Access to Palliative Care

Palliative care focuses on providing relief from the symptoms and stress of serious illness with the goal of improving quality of life for both the patient and the family. Palliative care is appropriate at any stage of illness and does not require a patient to forego curative care. Instead, palliative and curative care can be provided simultaneously. In order to access palliative care, a patient must first know it is an option, understand the benefits of palliative care and then have access to the services. For those living in rural areas, access to palliative care is sparse, with just 17% of rural hospitals with 50 or more beds reporting the presence of palliative care programs.\(^\text{11}\) The absence of palliative care programs creates a barrier to important services for patients.

Impact on Mental Health

People living with serious illness experience challenges that may not be directly related to their condition. According to a project conducted by the Harvard T.H. Chan School of Public Health, *The New York Times*, and the Commonwealth Fund:

- 62% of people with serious illness report feeling anxious, confused, or helpless.
- 48% have emotional or psychological problems caused by their condition.
- 32% reported isolation and a lack of companionship.\(^\text{12}\)

Quality of Life

Most people diagnosed with a serious illness will live for several years with their condition. Their main goal – and challenge – is to ensure that they maintain a high quality of life. In some cases, providing more medical care can sometimes harm a patient’s quality of life, and it can be difficult to determine what is appropriate for that person.

The patient’s desires should always come first. Any care decisions that are made should respect the patient’s wishes and allow the patient to have the best quality of life for the longest time available.

People with serious illness should have the opportunity to make their wishes known in a way that clearly informs doctors and family before interventions are made that may do little to help the patient, and could even diminish their quality of life.

Aging Population

The leading cause of death in the United States is heart disease.\(^\text{13}\) While heart disease can occur at any age, people over the age of 65 are more likely to develop heart disease.\(^\text{14}\) Approximately four out of five people who die from heart disease are 65 or older.\(^\text{15}\) As the American population ages, the instances of heart disease will continue to rise, as will the associated costs. The CDC Foundation expects the annual cost of heart disease to exceed $818 billion by 2030.\(^\text{16}\)

Alzheimer’s patients often live for many years with serious illness before they reach the end of their life. Currently there are approximately 5.8 million Americans living with Alzheimer’s Disease or other dementias. That number is expected to grow to 14 million in 2050.\(^\text{17}\) The average life expectancy for a person with Alzheimer’s Disease is 8 to 10 years, with some

\(^{10}\) [https://www.healthaffairs.org/do/10.1377/hblog20140730.040327/full/]
\(^{12}\) [https://www.commonwealthfund.org/sites/default/files/2018-10/Schneider_HealthCareinAmerica.pdf]
\(^{13}\) [https://www.cdc.gov/heartdisease/index.htm]
\(^{14}\) [https://www.nia.nih.gov/health/heart-health-and-aging]
\(^{15}\) [https://wa.kaiserpermanente.org/healthAndWellness/index.html?item=%2Fcommon%2FHealthAndWellness%2FConditions%2FHeartDisease%2FageAndGender.html]
\(^{16}\) [https://www.cdcfoundation.org/pr/2015/heart-disease-and-stroke-cost-america-nearly-1-billion-dai-medical-costs-lost-productivity]
people living as long as 20 years. There is no treatment or cure for Alzheimer’s and caring for a person with Alzheimer’s can take a toll on caregivers. Alzheimer’s patients demonstrate why it is important for patients to make their wishes known to ensure they can maintain their quality of life through serious illness and at the end of life.

**Caregivers**

Patients with serious illness also face challenges resulting from a lack of caregivers, and burnout among those who are available. People who take on the role of caregivers are providing some of the most important services needed for patients with complex medical needs but their compensation is low, and their benefits are limited. From 2008 to 2018 these workers experienced little to no pay increases. The combination of low pay and limited benefits can lead to low job satisfaction, high rates of burnout, and high rates of turnover.

In 2017 approximately 41 million family caregivers provided long term services and support (LTSS) to their loved ones without pay. A 2015 study found that the average age of unpaid caregivers was 49, among them 34% over the age of 65. A 2013 study by AARP found that Americans would see a dramatic decline in the caregiver support ratio over the next 20 years from seven potential caregivers for every person in the high-risk years of 80-plus in 2010, to four caregivers for every person 80-plus in 2030.

Approximately 4.5 million people are employed in the workforce to provide LTSS. Of those, 2.3 million workers provide in-home care while the rest provide care in settings such as residential care homes, nursing homes and hospitals. The direct care workforce is expected to grow by 41% between 2016 and 2026.

**Policy Recommendations**

Being diagnosed with a serious illness creates significant challenges for patients and their families, especially when they are impacted by the social determinants of health (SDOH) such as poverty and food insecurity. But several key policy changes can dramatically improve the quality of life for patients and caregivers alike:

**Make Spousal Impoverishment Protection Permanent**

Medicaid’s “spousal impoverishment protections” allows a person who needs nursing-home level of care to qualify for Medicaid while allowing their spouse to retain a modest amount of income and resources.

Since 1988, federal law has required states to apply these protections to spouses of people receiving institutional LTSS. Beginning in 2014, Congress extended the protections to cover spouses of people receiving home- and community-based services (HCBS).

The Affordable Care Act (ACA) provided a 5-year expansion of the HCBS protections, which has been renewed several times and currently lasts through approximately March 2020. Extensions have been limited to just a few months, leaving states in a constant state of flux regarding this important protection for low-income, medically complex patients.

Congress should permanently authorize this commonsense protection and ensure that spouses of medically complex patients are not bankrupted by the costs of caring for their loved ones.

**Make Money Follows the Person Permanent**

The Money Follows the Person (MFP) demonstration program, originally authorized under the Debt Reduction Act of 2005 and re-authorized by the ACA, goes hand-in-hand with the spousal impoverishment protection to ensure that people with serious illness have a meaningful choice to receive Medicaid LTSS. MFP has helped more than 90,000 Medicaid enrollees transition out of nursing and other facilities back to living in their communities. MFP has also helped 43 states and the

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District of Columbia develop the needed infrastructure to enhance people’s access to HCBS, while helping states shift more of their resources to HCBS and reduce expenditures on institutional services.\textsuperscript{25}

Congress has authorized several short-term extensions of MFP, but states need more assurance that the funds will be available. Instead of another short term extension, Congress needs to make MFP a permanent, funded program.

**Increase Access to Palliative Care**

Palliative care is often confused with hospice care. While hospice is for those nearing the end of life, palliative care can be utilized at any point in a patient’s life, including when a person is undergoing medical treatments. Palliative care can be provided in a community or institutional setting.

There are major obstacles to palliative care, including a complicated patchwork of payments made up of traditional Medicare, grants, philanthropies, and Medicare Advantage plans, which have more flexibility than traditional Medicare and limited insurance coverage. Most of the financial hurdles could be overcome if palliative care were a covered benefit, and federal and state lawmakers should pursue efforts to make it a fully covered benefit, separate from hospice care.

Another barrier is the lack of providers who understand palliative care. From the use of palliative care and who can use it to administering it, there is a shortage of doctors and nurses who can assist patients with this type of care. Patients expected to need access to palliative care are expected to grow by 20\% over the next 20 years, while the workforce of palliative and hospice care staff is expected to grow by less than 1\%. The Palliative Care and Hospice Education and Training Act (PCHETA) seeks to increase the number of permanent faculty in palliative care at accredited allopathic and osteopathic medical schools, nursing schools, social work schools, and other programs, including physician assistant education programs. The goal of PCHETA is to promote education and research in palliative care and hospice, and to support the development of faculty careers in academic palliative medicine.

PCHETA, also known as HR 647, was passed by the House of Representatives on October 28, 2019, and awaits action in the Senate. Passage of PCHETA would ensure that more providers understand and recommend palliative care, which would be a benefit to people living with the challenges presented by serious illness.

**Increase Public Awareness of and Access to Palliative Care**

A public awareness campaign that educates policymakers and others about palliative care and how it differs from hospice care would be beneficial to people living with serious illness and their caregivers. Studies show that once palliative care is better understood, most people think the care would be beneficial.\textsuperscript{26} Helping people understand their care options before they experience a serious illness would encourage people to plan ahead – thus preserving the dignity of decision making and allowing for a patient-centered journey through serious illness.

**Continue the trend of facilitating people’s choice to die at home**

In December 2019, the *New England Journal of Medicine* published a study indicating that, for the first time since the mid-20\textsuperscript{th} century, more Americans are dying at home than in the hospital.\textsuperscript{27} Most people prefer to die at home, but the lack of an advanced care plan is a common barrier. Two possible solutions include increasing the use of Advance Care Planning (ACP) and digitizing plans that are made. ACP is a covered Medicare benefit that allows patients to complete an advance care plan during their annual wellness visit. An advance care plan lets doctors, facilities, and loved ones know precisely how a person wants their end of life journey to be.

Having a plan allows the person to have dignity at the time of death and allows family members the comfort of knowing they have comported with their loved one’s wishes. Creating a plan can be difficult because it requires discussing a challenging topic—one’s own mortality—that many people may prefer to avoid. Medical practitioners should facilitate conversations to help patients create advance care plans.

Once an advance care plan is created, meaningful access to the document by the patient’s providers is essential. A Massachusetts study found that just 33\% of people with an advance care plan had the plan scanned into their medical

\textsuperscript{26} https://www.healthaffairs.org/do/10.1377/hblog20140730.040327/full/
\textsuperscript{27} https://www.nejm.org/doi/full/10.1056/NEJMct1911892
record and that when ACP documents were most needed, only 26% of people with a completed advance care plan had the document accessed. In the same study, a patient and family focus group revealed that several had the unfortunate experience of ACPs not being found in time or not being honored. Education on the importance of an ACP, as well as the importance of making the documents easily accessible, can help ensure dignity for people at the end of their lives.

### Improving Access and Affordability to Long-Term Care Coverage

Long-term care (LTC) insurance helps protect millions of Americans and their families from the potentially significant costs associated with LTC. Understanding the intensive and often expensive care those with serious illness need, LTC insurance can be particularly helpful for those patients and their families. Policy solutions that would ensure access to the benefits that LTC insurance can provide include:

- Launching a national educational campaign to help consumers understand both the need for and benefits of long-term care coverage.
- Providing tax incentives for employers to offer long-term care coverage to employees. Incentives may include:
  - Making long-term care coverage available through Internal Revenue Code (IRC) Section 125 cafeteria plans and Flexible Spending Arrangements (FSA);
  - Allowing tax-free premium payments for long-term care policies either from or within their 401(k)s, 403(b)s, IRAs, and other retirement plans; and
  - Permitting employees to make additional contributions to their Health Savings Accounts (HSA) to pay for long-term care premiums.
- Allowing patients to access long-term care insurance benefits that support healthy, independent living and aging in place before they are technically eligible.
- Allowing for different types of financial protections against inflation for long-term care policies. This would encourage more innovation among long-term care insurers as they design new types of policies for consumers.

### Health Insurance Providers Support People Battling Serious Illnesses

#### Cambia Health Solutions

Cambia Health Solutions (Cambia) is a leader in improving the way people and families living with serious illness experience health care through its long-standing commitment to palliative care. That commitment spans the entire enterprise - from its strategic philanthropic efforts to its health insurance plans in Washington, Utah, Idaho, and Oregon. As an organization, Cambia’s goal is to transform health care and create a pathway to a health care system that is person-focused and economically sustainable.

More than a decade ago, Cambia recognized the significant challenges facing people living with serious illness, as well as the lack of true palliative care available to the seriously ill population. Armed with that knowledge and a dedication to transforming the medical experience into a human experience, Cambia’s philanthropic arm, the Cambia Health Foundation, began investing in palliative care program development, public awareness, and workforce and capacity development.

Over the last decade, the Foundation has invested more than $44 million in building palliative care programs from hospital-based care to community-based programs, and programs that specialize in pediatric palliative care. The Foundation also supports the development of emerging palliative care leaders through its Sojourns Scholar Leadership Program. Sojourns Scholars receive a two-year, $180,000 grant to carry out an innovative and impactful project in the field of palliative care and execute a leadership development plan designed to support the individual’s growth as a national leader in the field.

29 [https://www.ahip.org/issues/long-term-care-insurance/](https://www.ahip.org/issues/long-term-care-insurance/)
30 Currently, providing these types of benefits may cause LTC insurance policies to forfeit its tax qualified status. Issuance of legislation or regulatory guidance that allows for these benefits would help consumers remain healthy and independent longer.
31 HIPAA and many states require LTCI policies to offer a benefit that automatically increases a policyholder’s benefit at an annual compounded rate of 5 percent. This inflation protection offer is expensive and discourages consumers from seeking protection altogether. Eliminating or revamping inflation protection would meet the diverse needs of consumers. Given that “one-size-fits-all” solutions do not work for everyone, it is important for consumers to have a variety of products and options from which to choose when evaluating their LTC protection needs.
In 2014, Cambia’s regional health plans, Regence, began offering Personalized Care Support for individuals experiencing serious illness, supporting them and their families holistically through advanced care planning, medical benefits, psychosocial benefits, and specially trained case management. Palliative care is available to any enrollee, at any stage of serious illness or recovery from an injury and can be provided at the same time as curative therapies.

Once enrollees in need of palliative care are identified, the person is partnered with a specialized palliative care case manager who works with the individual and his/her family to identify challenges, goals, and how to achieve those goals. The enrollee can receive a host of services, including in-home counseling, which Regence provides to the enrollee as well as caregivers regardless of the caregiver’s health insurance provider.

More recently, the health insurance provider has taken advantage of new Medicare Advantage flexibilities to provide meals, therapeutic massage, and eliminate patient cost sharing for outpatient services for those receiving palliative care. Working with the provider network to ensure appropriate training and knowledge of palliative care, Regence incentivizes providers who discuss goals of care with their patients. Very often, individuals who receive palliative care wish to avoid hospitalizations and aggressive treatments. To determine success of the Personalized Care Support program, the health plan measures patient and caregiver satisfaction, advance care planning claims, hospice election rate and the engagement in case management.

Cambia is focused on changing the way people experience health care. Their goal is to make the journey more person-focused and economically sustainable from birth through natural completion of life. They support palliative care because it improves the patient and caregiver experience for people whose lives are impacted by serious illness. More information about Cambia’s enterprise efforts is available at www.cambiahealth.com.

**Cigna**

Appropriate care for people with serious illness is essential from the very beginning of diagnosis. Cigna recognizes the importance of caring for the whole person through the entire serious illness journey and has created programs designed to support their members and the member’s caregivers.

Cigna’s approach to serious illness is holistic every step of the way. A care manager works with the member to assess health status as well as any social needs that might impact health and quality of life. Once the care manager determines an individual’s needs s/he works with Cigna’s internal teams and external vendors to develop a plan that will best support the member. Because treatment adherence is so important to physical health, particularly for those living with serious illness, Cigna identifies obstacles that limit an individual’s ability to follow their prescribed treatment.

The Cigna care managers are trained to recognize challenges related to compliance with prescribed medications—such as affordability issues or other factors related to medication access—and work with members to find solutions. For certain individuals living with a behavioral health condition that prevents a member from becoming medically stabilized, Cigna has developed an approach to address both the behavioral and physical needs of the patient.

Recognizing that some members experience challenges getting to a doctor’s office, Cigna developed a program that allows a member to receive a visit from a primary care doctor or a nurse practitioner from the comfort of home. During those visits, the patient’s medications are reviewed and reconciled, their vaccines are provided and the person’s need for access to social services is reviewed. Should a member require hospitalization, Cigna ensures a safe transition home by providing meals and checking on the safety of the environment and availability of social supports.

Cigna’s approach to caring for individuals with serious illness is tailored for each member’s need. All benefits available are reviewed and used to best support the member.

As a person’s serious illness progresses and the need for intervention changes from managing disease progression to preparing for a quality end of life, Cigna provides an advanced care program to assist members with care planning, hospice transition, and support at the end of life. To aid in the journey, members have access to in-home palliative care that provides emotional and spiritual support to the member as well as the member’s family and caregivers. Cigna’s home-based program can include a nurse practitioner, RN, social worker, chaplain, and other identified individuals that may serve the needs of the member or their family and caregivers. Goals of care are discussed frequently to make sure that the member’s wishes are at the center of the care plan. The member’s primary care provider is also made aware of the member’s condition and ongoing conversations.
Cigna’s advanced care program offers an additional layer of care and extends the reach of the primary care provider into the member’s home. While end of life is not the focus of Cigna’s serious illness care, helping members to experience a quality, self-determined, and well-supported journey guides the full continuum of care. More information about Cigna’s efforts is available at www.cigna.com.

**InnovAge**

Unlike most managed care organizations, InnovAge serves a specific set of older adults through its Program of All-inclusive Care for the Elderly (PACE). The average age of an InnovAge participant is 75 with an average of six chronic conditions, requiring ten medications. To qualify for PACE, individuals must be 55 or over, live in a PACE service area, require nursing home level care, and be able to live safely at home with some support. All of this makes PACE program participants unique and in need of a high level of service. While discussions of serious illness often involve end of life care, the goal of InnovAge is to allow individuals to stay as independent as possible throughout the progression of serious illness.

InnovAge PACE participants receive comprehensive care through an Interdisciplinary Team (IDT) that includes physicians, nurse practitioners, dentists, occupational, physical, speech and recreation therapists, registered dieticians, social workers, transportation employees, personal care workers and more. Most services are provided at a PACE center in the participant’s community, which they visit on average three times per week. The team meets regularly, along with the individual, to provide input on an individual’s care needs and provide customized care plans. With the program participant, the IDT conducts two comprehensive assessments per year and frequently discusses the participants’ personal goals, including living with serious illness and end-of-life choices. Because of the high-touch and person-centered approach, 94% of InnovAge members have documented advanced directives. The InnovAge Clinical Policy Guidelines Committee supports the work of the IDT by helping to ensure that high quality, evidence-based care is being provided. InnovAge’s commitment to evidence-based care is demonstrated by their recognition that all its Colorado centers operate as Patient Centered Medical Homes (PCMH) and this model is being expanded to the company’s other centers.

With its focus on all-inclusive care, addressing the social determinants of health (SDOH) is embedded in the PACE model. In addition to the full scope of the IDT, InnovAge members have access to transportation to and from the PACE center and any specialist visits as well as a personally tailored meal plan created by a registered dietitian. Meals are provided at the PACE center, given to an individual to take home, or personnel visit participants’ homes to assist with shopping and meal preparation. InnovAge works to ensure stable housing and, in some cases, subsidizes stable housing for members.

Appropriate medication management, ensuring preventative screening and providing holistic care has resulted in positive outcomes for InnovAge members. Thanks to physical and occupational therapy as well as an overall focus on falls education, InnovAge participants report fewer falls and have higher confidence than others their age. A unique clinical exercise program provides prescribed and monitored exercise, resulting in lower blood pressure, weight loss, and reduction in medications. A proper diet accounting for all chronic conditions, provided by a registered dietitian, has resulted in improved A1C levels for several members. Vaccination rates for influenza and pneumonia are more than 92% and 90%, respectively.

The wrap-around, interdisciplinary approach sets the PACE model apart from other care models for frail seniors. InnovAge is focused on bringing the program to more eligible seniors in more communities to allow them to continue living life on their terms. More information about InnovAge’s efforts is available at www.MyInnovAge.com.

**Conclusion**

It is never easy for a patient to receive a diagnosis with a serious illness. Patients and their loved ones must navigate treatments, planning, setbacks, and numerous challenges while dealing with complicated emotions and fears. Recognizing the difficulties of serious illness, health insurance providers have set out to help, support, and ease the journey for patients, caregivers and loved ones. Ensuring access to tools, education, and services for patients and their loved ones during a difficult time can provide the opportunity to plan, allow patients to maintain their dignity and choice, and support loved ones to know their role and how best they can help.

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32 PACE is a Medicare and Medicaid program that helps people meet their health care needs in the community instead of going to a nursing home or other care facility.