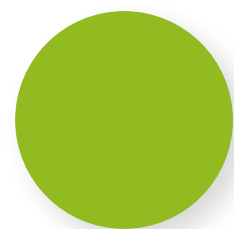


Patient Navigation in Cancer Care 2.0
Guiding patients to quality outcomes™

Geriatric Cancer Care:

A Resource Guide for the Navigator



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ACADEMY OF ONCOLOGY NURSE & PATIENT NAVIGATORS: MISSION AND VISION

The mission of the Academy of Oncology Nurse & Patient Navigators (AONN+) is to advance the role of patient navigation in cancer care and survivorship care planning by providing a network for collaboration and development of best practices for the improvement of patient access to care, evidence-based cancer treatment, and quality of life during and after cancer treatment. Cancer survivorship begins at the time of cancer diagnosis.¹ One-on-one patient navigation should occur simultaneously with diagnosis and be proactive in minimizing the impact treatment can have on quality of life.² In addition, navigation should encompass community outreach to raise awareness targeted toward prevention and early diagnosis, and must encompass short-term survivorship care, including transitioning survivors efficiently and effectively under the care of their community providers.³

The vision of AONN+ is to increase the role of and access to skilled and experienced oncology nurse and patient navigators so that all patients with cancer may benefit from their guidance, insight, and personal advocacy.



The endorsement mark certifies that the information presented in educational seminars, publications, or other resources is considered by AONN+ to be reliable and credible.

PFIZER ONCOLOGY: OUR COMMITMENT

Pfizer Oncology is a committed partner in the cancer care community, dedicated to humanity's quest for longer, healthier, happier lives. Our goal is to improve the life of every patient with cancer and positively impact all who deal with this disease. One way we demonstrate our commitment to this goal is through our support of the patient navigation movement occurring throughout the United States.

Ask your Pfizer Oncology Account Manager about *Patient Navigation in Cancer Care 2.0* to support your commitment to making a difference in the lives of patients and in shaping the future of cancer care. Additional information regarding this program can be found at www.patientnavigation.com.

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I. INTRODUCTION

The cancer landscape is constantly changing, with significant and growing barriers to optimal cancer care and services.^{1,2} The older adult community (ie, those aged ≥ 65), the fastest growing portion of the cancer population, faces more challenges than most, for which nurse and patient navigators play a vital and central role.³⁻⁵

Navigators can assist older patients in accessing specialized care, coordinating resources to support treatment planning and care management, and helping minimize barriers to care.⁵ As we discuss the growing older adult population, recognize that it comprises 3 separate groups based on age categories: the young old, those aged 65 to 74 years; the middle old, those aged 75 to 84 years; and the oldest old, those aged ≥ 85 years.⁶

As presented in the **Figure**, the US population is changing, shifting the demographic trend to that of an older population.⁷ This shift has the potential to increase healthcare gaps and to expand the need for geriatric navigation.⁸ As with the entire healthcare system, this dramatic increase will affect the incidence



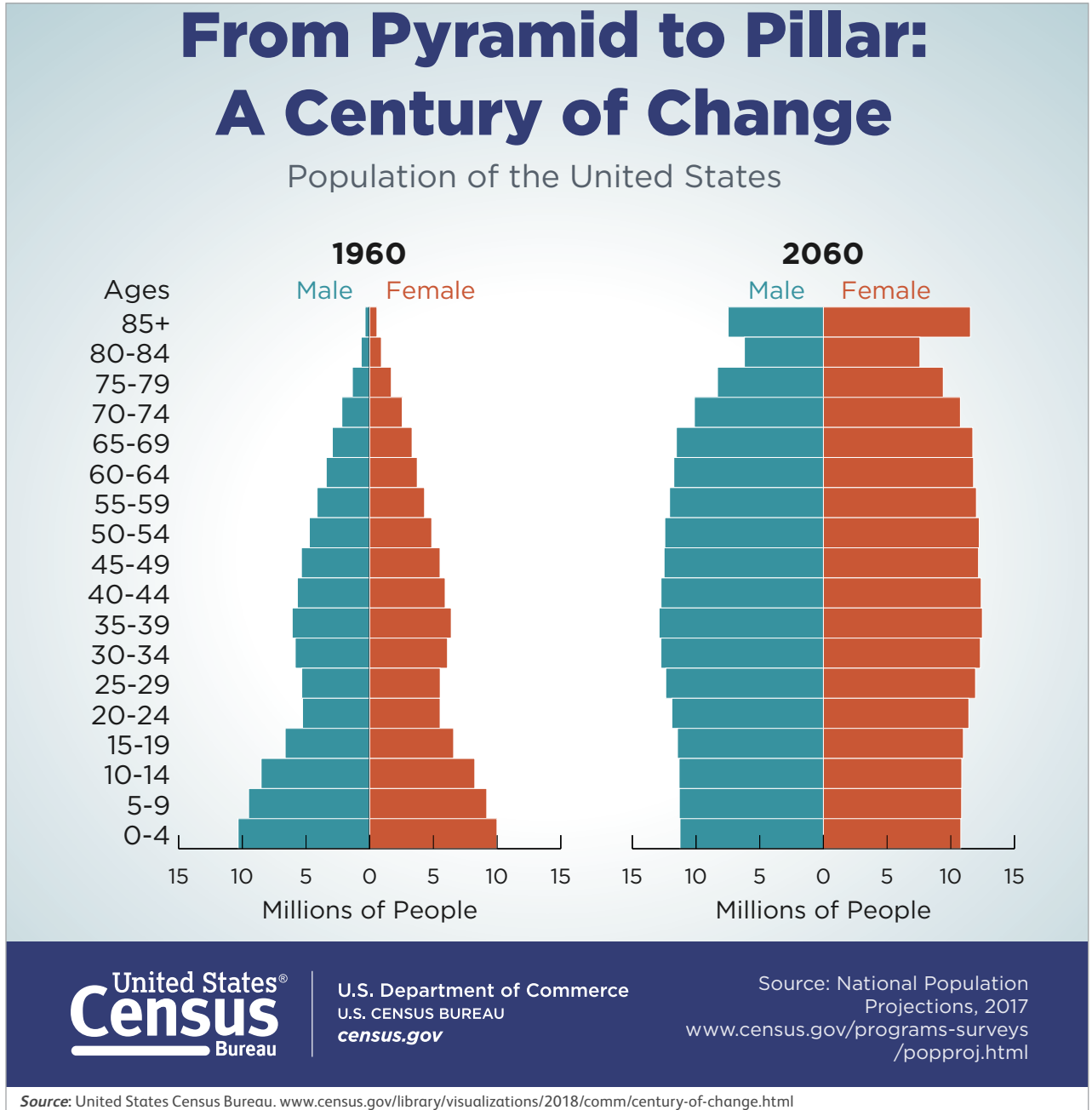
NOTES FOR NAVIGATORS

YOUNG OLD = PATIENTS AGED 65-74

MIDDLE OLD = PATIENTS AGED 75-84

OLDEST OLD = PATIENTS AGED 85 AND ABOVE

FIGURE. From Pyramid to Pillar: A Century of Change



of cancer, burden, and care.⁸ Increasing age remains one of the strongest risk factors for the development of cancer, and currently, approximately 60% of all types of cancers are diagnosed in those aged ≥ 65 years.^{3,9} As this older population increases, so too will the number of older adults who are diagnosed with cancer and the overall number of older adults living with cancer as cancer survivors.⁸

Within the older adult population, there also exists an especially vulnerable group defined as the “oldest old,” those aged ≥ 85 years. *Cancer Facts & Figures 2019* devoted a special section to “Cancer in the Oldest Old,” explaining that “adults ages 85 and older are the fastest-growing population group in the US...the number of adults ages 85+ is expected to nearly triple from 6.4 million in 2016 to 19.0 million by

2060.”⁸ In addition, this age-group is the population of cancer survivors, creating an increased gap for geriatric-specific survivorship and caregiver support. Even if a relatively small proportion of the overall population, this group represents a much higher proportion of healthcare utilization. In short, their needs for additional support are the highest of any group.⁸

It is vitally important that navigators receive adequate tools and resources and recognize the specialized needs of the older patient population to provide excellent care, and maximize the patient experience. This toolkit is designed to help foster a working knowledge of challenges and barriers frequently faced by older adults and to encourage thoughtful, evidence-based assessment and use of best practices when working with these special patients and their caregivers.

This toolkit includes:

- Principles of geriatrics and geriatric oncology
- Introduction to geriatric assessment
- An overview of the physiological, functional, and cognitive changes in older adults
- Considerations regarding health literacy and social determinants of health
- Racial, ethnic, cultural, spiritual, and geographic considerations
- Distress and psychosocial needs
- Communication considerations
- Clinical trial enrollment
- Palliative care
- Nutritional considerations
- Caregiver support
- Resources for navigators, patients, and families/caregivers.

Overall, it is crucial to recognize that the management of cancer for older adults is a multidisciplinary team activity. Every member of the team, especially navigators, has an essential role to play in ensuring optimal care.¹⁰ In many respects, the navigator’s role is central to the care, as access, coordination, and management are interdependent and require thoughtful, ongoing attention to multiple issues.¹¹ This report provides a guide to make this important responsibility easier for navigators in order to better support patients. By using these tools, we may increase the chances that our older adults may receive the best possible care and outcomes from a diagnosis of cancer, treatment, and survivorship.



NOTES FOR NAVIGATORS

Do not make assumptions about patients’ abilities based on chronologic age because physiologic age provides a greater assessment of overall health.

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II. PRINCIPLES OF GERIATRICS AND GERIATRIC ONCOLOGY

Geriatrics is a subspecialty of medicine that focuses on health promotion, prevention, diagnosis, and treatment of disease and disability in older adults.¹ Hallmarks of geriatric medicine include promoting a patient-focused, “whole-patient” assessment and management plan with emphasis on maintaining function and independence. Geriatric medicine endeavors to individualize care by assessing multiple characteristics that differ among older adults of the same chronologic age, such as comorbid conditions, physical and cognitive functions, social support, emotional health, and nutritional status, and by aligning care with patient-centered goals.¹

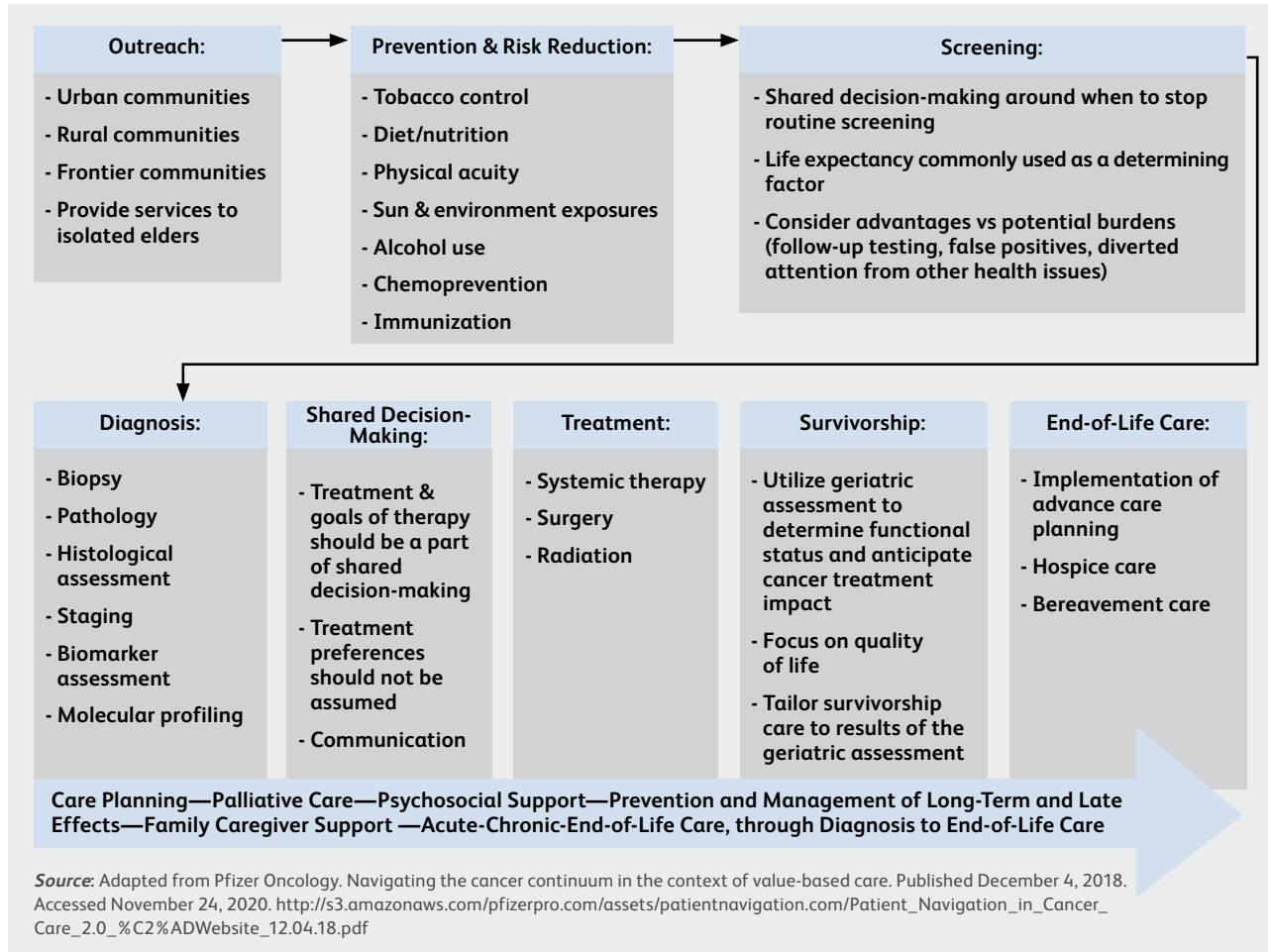
Geriatric oncology is a multidisciplinary field focused on providing specialized care to older adults (ie, those aged >65 years) diagnosed with and surviving cancer, bringing the principles of geriatrics into oncology.^{2,3} The field of geriatric oncology includes a focus on research, education, and clinical practice.^{2,3} The field of geriatric oncology is relatively new as a specialty with a small number of oncology providers nationally who have undergone specialty training in both geriatrics and oncology (dually trained geriatric oncologists).³ Whereas many academic centers may have a geriatric oncologist or geriatric oncology programs (often collaborations between oncology and geriatric medicine), most community practices do not have access to specialty-trained geriatric oncologists or geriatric oncology practitioners.³

Instead, most older adults are cared for by medical oncologists and general practitioners who often lack specialized geriatric training.³ Therefore, leading organizations, such as Association of Community Cancer Centers (ACCC), American Society of Clinical Oncology (ASCO), AONN+, International Society of Geriatric Oncology, The Gerontological Society of America, Cancer and Aging Research Group (CARG), and Oncology Nursing Society, among others, have dedicated publications and thought groups to support geriatric oncology and to define best practices as they relate to caring for older adults with cancer.⁴⁻⁹

A multidisciplinary approach to care is essential for older patients with cancer, and the navigator plays a key role in the cancer continuum, from outreach and screening through diagnosis, treatment, access to palliative care, survivorship, and end-of-life care (**Figure 1**).¹⁰ A note of significance is that chronologic age alone should never be used to determine a patient’s functional, cognitive, and emotional abilities. Physiologic age, or the measure of how well or poorly a person functions, is a much better determinant.¹¹ You may care for a 65-year-old patient with multiple comorbidities, poor nutritional status, and a refusal to stop smoking. Likewise, you may care for an 85-year-old patient who walks 3 miles per day, has no significant health issues, eats a diet full of fresh fruits and vegetables, and has a rich social network. Although the 85-year-old patient is chronologically older, their physiologic age is much younger, potentially making this patient a better treatment candidate than the 65-year-old patient. The key is appropriate evaluation.

Survivorship also brings forth some challenges in the older adult population.¹² Many of these patients have other comorbid conditions in combination with their cancer diagnoses, a condition called multimorbidity. Treatment can be challenging for any patient, and the long-term and late side effects often associated with cancer treatment can be especially severe in this population. Common late side effects seen in this population include cancer-related fatigue, cognitive dysfunction, treatment-induced peripheral neuropathy, and bone health issues.¹² As with all patients with cancer, it is important to ensure older adults receive a treatment summary and survivorship care plan to ensure a proactive approach to monitoring for posttreatment side effects and long-term disabilities.¹²

FIGURE 1. Continuum of Cancer Care for the Older Adult Patient



In addition, it is important when discussing the cancer continuum to include an early introduction to palliative care.¹³ Palliative care services provide essential support to older adults and should be accessed from the moment of diagnosis.¹³ Palliative care focuses on symptom management, decision-making, multilevel support for patient and family, and maintenance of quality of life.^{13,14} It is beneficial to patients of any age and at any stage of illness, but palliative care can provide tremendous service to older adults who may be at elevated risk of increased treatment impact.¹⁴ Patients can still be given curative or life-prolonging treatments when receiving palliative care,¹⁵ and the navigator can serve as an advocate to ensure patients are provided access to these services. Palliative care is not hospice care. Hospice care is reserved for those patients with a life expectancy of ≤ 6 months and requires that curative or life-prolonging therapy associated with the primary diagnosis be stopped while full care to ensure the highest possible quality of life is continued and even enhanced. Hospice care focuses on symptom management, pain relief, and quality of life for those nearing the end of life.¹⁶



NOTES FOR NAVIGATORS

Chronologic age by itself is never a determinant of ability to care for oneself, one's functional ability, or one's cognitive ability.

Hospice care is reserved for those patients with a life expectancy of ≤ 6 months and requires that curative or life-prolonging therapy associated with the primary diagnosis be stopped while full care to ensure the highest possible quality of life is continued and even enhanced. Hospice care focuses on symptom management, pain relief, and quality of life for those nearing the end of life.¹⁶

The Value of Geriatric Assessment

Older adults are a specialized group often facing increased barriers to care and treatment risks, and it is only through proper, evidence-based assessment that these barriers and risks can be recognized and minimized.¹⁷ Assessment can help the practitioner evaluate physiologic age, functional status, and life expectancy and, in turn, determine the best treatment path for that individual. This evidence-based approach is called a “geriatric assessment.”¹⁸

A geriatric assessment is a “multidimensional assessment designed to evaluate an older person’s functional ability, physical health, cognition and mental health, and socioenvironmental circumstances” as part of treatment planning.¹⁸ The comprehensive geriatric assessment (CGA), a foundational approach from the field of gerontology, is often delivered in a multidisciplinary format and is considered the gold standard of geriatric assessment (**Figure 2**).^{19,20} However, completion can take several hours and requires specialized skill. What makes the CGA such a valuable tool for planning care? Per the ACCC, the CGA:

- Provides a detailed evaluation of medical, psychosocial, and functional problems in older patients with cancer.
- Can identify areas of vulnerability, predict toxicity and survival, assist in clinical decision-making, guide the development of individualized treatment plans, improve provider–patient communication, and predict treatment completion.²⁰

Geriatric specialists value CGA and the thorough patient evaluation associated with this tool, but consistent administration has proved challenging.¹⁸ There are, however, other validated tools that can provide assessment to improve care of geriatric patients. As a navigator, you can advocate for your older adult patients by learning physicians’ processes for evaluation and familiarizing yourself with the tools used as well as how results are analyzed and implemented to guide patient care. Some available tools that were recommended by the committee of experts who helped create this resource are listed below. Note that the G8 (Geriatric 8) and VES-13 (Vulnerable Elders Survey-13) are patient self-assessments and can often be taken electronically and, in some cases, loaded directly into the patient’s electronic health record.²⁰

- G8: www.siog.org/files/public/g8_english_0.pdf
- VES-13: www.rand.org/health-care/projects/acove/survey.html
- Mini-Cog® for cognitive screening: <https://mini-cog.com>
- CRASH (Chemotherapy Risk Assessment Scale for High-Age Patients), which estimates the risk of toxicity: http://siog.org/files/public/viii.6_extermann.pdf
- CARG Chemo-Toxicity Calculator: www.mycarg.org/?p=251

Findings show that assessments affect treatment planning, with initial treatment decisions changing from 5 to 50% of the time after assessment.²⁰ No matter what tool is used, it is clear that any assessment to determine physiologic age and health status is extremely important for this patient population. In a recent publication, ACCC shared this patient story, describing the effect of geriatric assessment²⁰:

A man in his early 80s, diagnosed with metastatic lung cancer, was looking for a second opinion. During his first consult with his medical oncologist, the patient was advised to get his affairs in order and to consider hospice services. The patient and his family asked to be referred to a senior adult cancer clinic for further assessment. When he arrived for his comprehensive geriatric oncology assessment, he was on oxygen and could not get out of his wheelchair unassisted. Through his communication with the geriatric oncology team, he expressed his desired goals/outcomes: gardening and being with his grandchildren. The geriatric oncology team evaluation consensus was that his impairment was due to his cancer, and he did not have comorbidities that were a barrier to treatment.

FIGURE 2. Comparison Between Generalized Patient Assessment and Comprehensive Geriatric Assessment

USUAL ASSESSMENT	
MEDICAL Presenting Symptoms or Illness	<ul style="list-style-type: none"> • Details • Functional impact • System review
Past Medical History	<ul style="list-style-type: none"> • Review medical record • Risk factors • Screening status • Health promotion activities
Medications	<ul style="list-style-type: none"> • Indications and effects • Comprehension • Compliance • Polypharmacy
COMPREHENSIVE GERIATRIC ASSESSMENT	
COGNITION	<ul style="list-style-type: none"> • Dementia • Confusion • Mood • Alcohol • Substance abuse
FUNCTIONAL STATUS	<ul style="list-style-type: none"> • Activities of daily living (ADLs) • Instrumental activities of daily living (IADLs) • Lifestyle • Recent life changes • Rehabilitative potential
OBJECTIVE PHYSICAL PERFORMANCE	<ul style="list-style-type: none"> • Gait speed • Timed up and go • Short physical performance battery
PSYCHOLOGICAL STATUS	<ul style="list-style-type: none"> • Anxiety/depression • Mental health inventory
NUTRITION	<ul style="list-style-type: none"> • Weight loss/gain • Dental
COMMUNICATION	<ul style="list-style-type: none"> • Language • Hearing • Vision
ENVIRONMENT	<ul style="list-style-type: none"> • Home safety evaluation, current living environment, its appropriateness to function and prognosis • Accessibility • Hazards
SOCIAL SUPPORT	<ul style="list-style-type: none"> • Family situation & availability • Caregiver network, including caregiver burden, deficiencies, and potential • Finances • Community supports and services required and received

Sources: College of Family Physicians Singapore. Management update on functional decline in older adults, 2012. Taken from: Unit No. 1 Physical Function. *Singapore Fam Phys.* 2012;38(suppl 1):10. Available at: www.cfps.org.sg/publications/the-singapore-family-physician/article/81_pdf. Last accessed April 22, 2019.
 Mohile et al. (2015). Geriatric Assessment-Guided Care Processes for Older Adults: A Delphi Consensus of Geriatric Oncology Experts. Figure 2. *J NCCN*, 13(9).
 Note: This chart represents combined data from both sources.
 This is not an exhaustive list.

Source: ©Association of Community Cancer Centers. Reprinted with permission. Originally published in "Multidisciplinary Approaches to Caring for Older Adults with Cancer." Available at www.acc-cancer.org/geriatric

FIGURE 3. Instrumental Activities of Daily Living Scale

Patient Name: _____ **Date:** _____
Patient ID # _____

LAWTON - BRODY INSTRUMENTAL ACTIVITIES OF DAILY LIVING SCALE (I.A.D.L.)			
Scoring: For each category, circle the item description that most closely resembles the client's highest functional level (either 0 or 1).			
A. Ability to Use Telephone		E. Laundry	
1. Operates telephone on own initiative-looks up and dials numbers, etc.	1	1. Does personal laundry completely	1
2. Dials a few well-known numbers	1	2. Launders small items-rinses stockings, etc.	1
3. Answers telephone but does not dial	1	3. All laundry must be done by others	0
4. Does not use telephone at all	0		
B. Shopping		F. Mode of Transportation	
1. Takes care of all shopping needs independently	1	1. Travels independently on public transportation or drives own car	1
2. Shops independently for small purchases	0	2. Arranges own travel via taxi, but does not otherwise use public transportation	1
3. Needs to be accompanied on any shopping trip	0	3. Travels on public transportation when accompanied by another	1
4. Completely unable to shop	0	4. Travel limited to taxi or automobile with assistance of another	0
		5. Does not travel at all	0
C. Food Preparation		G. Responsibility for Own Medications	
1. Plans, prepares and serves adequate meals independently	1	1. Is responsible for taking medication in correct dosages at correct time	1
2. Prepares adequate meals if supplied with ingredients	0	2. Takes responsibility if medication is prepared in advance in separate dosage	0
3. Heats, serves and prepares meals, or prepares meals, or prepares meals but does not maintain adequate diet	0	3. Is not capable of dispensing own medication	0
4. Needs to have meals prepared and served	0		
D. Housekeeping		H. Ability to Handle Finances	
1. Maintains house alone or with occasional assistance (e.g. "heavy work domestic help")	1	1. Manages financial matters independently (budgets, writes checks, pays rent, bills, goes to bank), collects and keeps track of income	1
2. Performs light daily tasks such as dish washing, bed making	1	2. Manages day-to-day purchases, but needs help with banking, major purchases, etc.	1
3. Performs light daily tasks but cannot maintain acceptable level of cleanliness	1	3. Incapable of handling money	0
4. Needs help with all home maintenance tasks	1		
5. Does not participate in any housekeeping tasks	0		
Score		Score	
Total score _____			
A summary score ranges from 0 (low function, dependent) to 8 (high function, independent) for women and 0 through 5 for men to avoid potential gender bias.			

Source: Best Practices in Nursing Care to Older Adults, The Hartford Institute for Geriatric Nursing, New York University, College of Nursing, www.hartfordign.org.

Source: www.alz.org/careplanning/downloads/lawton-iaidl.pdf. Accessed November 2, 2020.

The team had a discussion with the family, explaining that the lung cancer was not curable, but molecular testing could help determine if it was treatable. An *EGFR* mutation was identified. The patient was treated and within 2 weeks he was out of the wheelchair and back to gardening. Without a geriatric assessment, a medical team may have dismissed the patient as elderly based on his appearance, and foregone treatment. He lived for about 2 more years before going into hospice.²⁰



NOTES FOR NAVIGATORS

If your hospital or physician's office cannot offer comprehensive geriatric assessment, remember there are several other validated tools that can provide geriatric screening to help improve patient care.

Although we recognize the importance of the CGA and physician assessment of geriatric patient status, you must be asking, "What can the patient navigator do to help with geriatric assessment?" There are a few self-assessment tools your older adult patients can use when working with you, such as the *Instrumental Activities of Daily Living Scale* (Figure 3).²¹ Any results from these assessments should be shared with practitioners involved in the patient's care. A navigator can also empower a

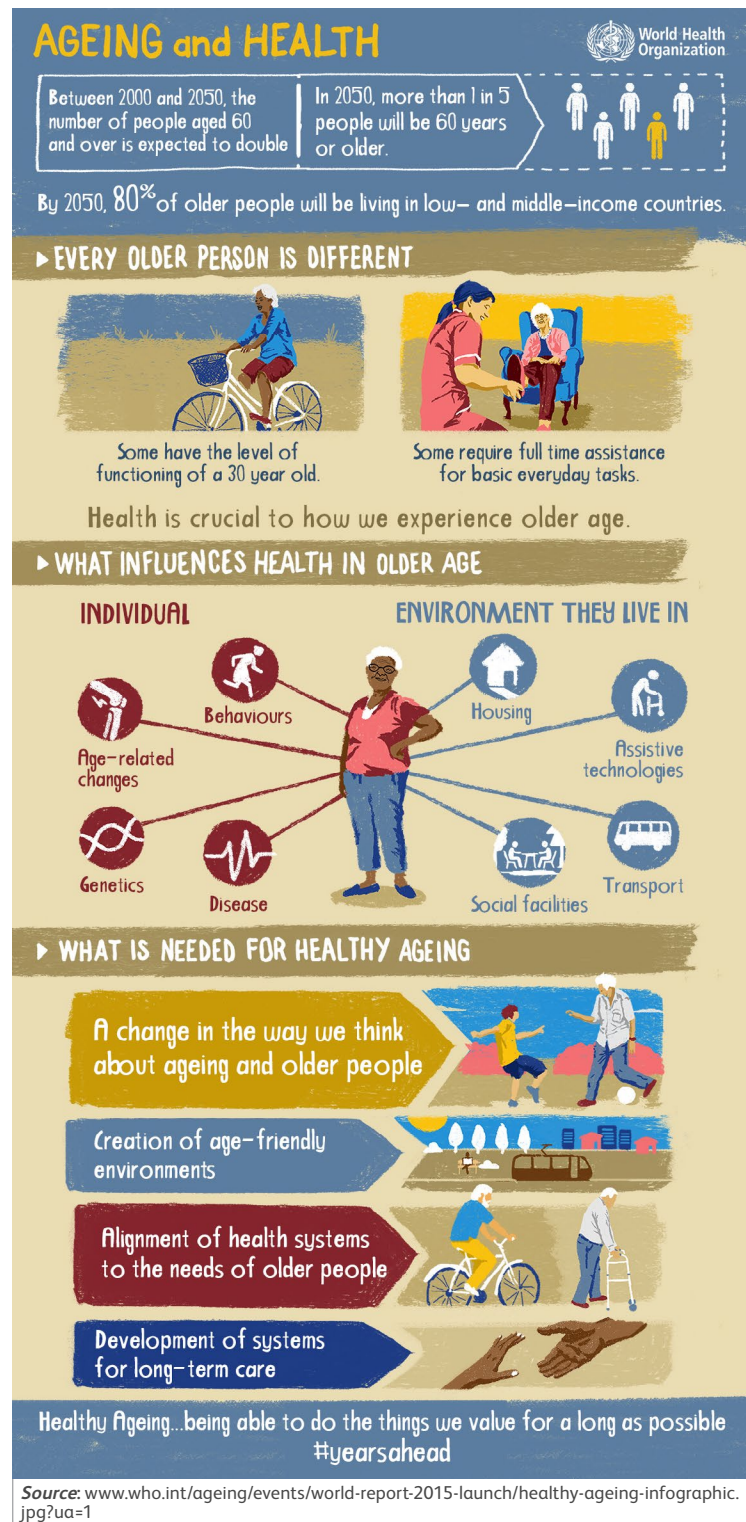
patient to ask their provider about the CGA. *Practical Assessment and Management of Vulnerabilities in Older Patients Receiving Chemotherapy: ASCO Guideline for Geriatric Oncology* (<https://ascopubs.org/doi/10.1200/JCO.2018.78.8687>) has detailed information about the use of these tools and others.²²

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III. FUNCTIONAL IMPAIRMENT

A thorough review of the changes associated with physical aging will help set a foundation for geriatric care that we can then translate into our discussion of geriatric cancer care. As a reminder, many of these changes affect older adults in various ways (Figure 1).¹ For example, you may have a 65-year-old patient experiencing many of these changes and presenting numerous navigation and treatment challenges. Likewise, you may work with an 87-year-old patient with full function who remains completely independent and has minimal barriers. This overview provides you with the necessary knowledge to assess each patient individually and determine their personal needs. As a reminder, chronological age by itself is never a determinant of ability to care for oneself or of treatment plan design.² A holistic approach is foundational when working with older adults to evaluate and navigate each person individually.³ As we review these physiological changes that, in turn, can affect functional and cognitive ability, keep in mind that these changes can be part of the normal aging process, although some patients may experience more pronounced changes than others, reinforcing the importance of individualized assessment.⁴ In addition, some medications and treatments may contribute to functional changes caused by aging, placing the patient at increased risk of further functional decline.⁵ Navigators must be able to recognize these changes, as they can negatively impact the patient's ability to remain compliant with a treatment plan if not properly assessed and discussed with the multidisciplinary treatment team.⁶

FIGURE 1. Physiologic Changes of Aging





NOTES FOR NAVIGATORS

- Older adults may be sensitive to room temperature. Help ensure they are comfortable during office visits⁷
- Increased risk of skin injury and delayed wound healing can create discomfort with certain medical procedures^{7,8}
- Thinning skin can tear easily. Be cautious and gentle when touching patients' arms or providing mobility assistance⁸
- Educate patients and caregivers about the importance of infection prevention and proper skin care⁸
- Mucosal changes can impact patients' mouth, gums, and teeth. Ensure geriatric patients attend regular dental visits and stress the importance of oral health⁹
- Medications that require being absorbed through the fat layer may not work as directed due to age-related skin changes⁸

Integumentary System Changes

As one ages, the outer layer of skin becomes thinner, subcutaneous fat decreases, and blood vessels become more fragile, placing older adults at increased risk for skin tear, skin injury, bruising, and skin infection.⁸ Skin elasticity also changes, which can create a weathered appearance in patients who spent a great deal of time in the sun throughout their lives.⁸

Older adults are at greater risk of secondary infection caused by decreased wound-healing rates—up to 4 times slower than in younger adults.⁸

Older adults experience decreased blood supply to the dermis, which increases heat loss and decreases sweat gland activity. Older adults, therefore, have more difficulty regulating their body temperature. They may become cold easily but can also experience dangerously high body temperature if they become overexerted.^{7,8}

Melanocyte activity declines, which is why hair turns gray or white as we age. This increases older adults' risks for sunburn and skin cancer and can make skin look more translucent. Education about proper use of sunscreen and the importance of wearing hats outdoors is key.⁸

Sensory and Perceptual Changes

1. Vision Changes

There are multiple structural eye changes that occur with aging. These changes can cause the eyelid to turn inward or outward, and they can also make eyes water more frequently.⁷

It can become difficult for older adults to distinguish blues from greens, so using warm tones like red, orange, and yellow may help with vision issues. Encourage older adults to utilize a red light in a dark room instead of a regular nightlight to help improve nighttime visibility.¹⁰

The lens, cornea, and pupil also change as one ages. Presbyopia, which results in difficulty in focusing on close-up objects at rest or in motion, is a common result of these changes.¹⁰

Older adults may have a more difficult time adjusting to changes in lighting and may have difficulty seeing clearly in the dark. They may also be more sensitive to glare.^{10,11}

A person's visual field may decrease as eye muscles decrease. You may find that some older adults have increased difficulty looking upward or moving their eyes side to side. It is also common for older adults to have decreased peripheral vision, which can create a safety hazard.¹⁰

2. Hearing Changes

Because the ears function to support both hearing and balance, age-associated changes may create issues with hearing but may also make it more challenging for older adults to keep their balance.¹⁰

Presbycusis is the name for age-related hearing loss. Some of the difficulties associated with this type of hearing loss may include¹⁰:

- The ability to hear high-frequency sounds may decline
- Distinguishing between certain sounds may become more difficult
- Background noise may become problematic, especially when trying to speak in a conversation

Older adults may also experience an increase in ringing of the ears (tinnitus) and an increase in ear wax buildup or impaction, which can also cause hearing issues.¹⁰

There are also 5 distinct changes that occur in the inner ear, ultimately creating issues with hearing higher frequency noises, speech discrimination, and problems localizing sound.⁷

Many consonant sounds are actually spoken at higher frequencies, including the *t*, *k*, and *ch* sounds, so these sounds may be difficult for older adults to hear.⁷

3. Changes in Smell and Taste

As we age, we may experience a decreased ability to differentiate between tastes, as the number of taste buds decreases and saliva production decreases.¹⁰

Due to decrease in mucus production and loss of nerve endings, sensitivity to odors may also decrease. This loss of sensitivity may decrease one's ability to smell odorants, such as smoke, gas leaks, or chemical spills. Other pleasant scents, like favorite foods, coffee, or perfumes, may also be undetectable.¹⁰

A loss in smell and taste may prevent older adults from wanting to eat. Tobacco use, certain diseases, or medications may contribute to issues with smell or taste.¹⁰

4. Changes in Peripheral Sensation

Sense of touch may dull with age. Older adults may have trouble distinguishing cool from cold and warm from hot. Older adults may have a decreased reaction to painful stimuli.¹⁰



NOTES FOR NAVIGATORS

- Ensure all patient-facing materials are in a large font to make them easier to read^{11,12}
- Minimize glare from computer screens and tablets by reducing overhead lighting^{11,13}
- Monitors and television screens may appear fuzzy. Ensure patients are wearing eyeglasses if prescribed and enlarge the screen when able^{11,14}
- Use pictures and images to enhance written communication¹⁵
- Recognize that small print on medication bottles or paperwork may make reading difficult and offer to assist older adults by providing instructions or copies in larger font if able¹⁶
- Encourage keeping a magnifying glass at home^{11,17}
- Educate on the importance of regular eye exams^{11,18}

Patients may have difficulty sensing their feet in relation to the floor, which can create difficulties with ambulation as well as a safety hazard. Additionally, older adults receiving cancer treatment may experience numbness in hands and feet, which can result in tripping, falling, or difficulty grasping items.¹⁰

With aging, changes may occur in a patient's ability to feel touch and sensation, which may be due to reduced blood flow to the nerve endings, effects of other health conditions, or surgery. These changes often make it more difficult to recognize vibration, touch, and pressure.¹⁰

Cardiovascular Changes

1. Changes Impacting the Heart

Due to changes affecting the sinoatrial node, older adults may have a slower resting heart rate.¹⁹

The heart may increase in size and the walls of the heart may thicken, causing the heart to fill with blood more slowly. Older adults are at greater risk for abnormal heart rhythms, like atrial fibrillation. This risk can be attributed to age-related changes or may be related to a history of heart disease.

Heart valves become thicker and stiffer, increasing potential for heart murmur.¹⁹

2. Changes Impacting the Blood Vessels

Baroreceptors are receptors located in the heart and blood vessels. They are sensitive to changes in your blood pressure and send messages to inform the brain that blood pressure is too high or too low. These receptors become less sensitive as we age. Normally, these baroreceptors help maintain a constant blood pressure despite movement or position change. Older adults may begin to experience orthostatic hypotension, causing dizziness when standing up from a bed or chair or when moving from a lying or



NOTES FOR NAVIGATORS

- When speaking with patients on the phone or via telemedicine, make sure to minimize all outside noise. Ask patients to turn down television, radio, or other competing noise²⁰
- Face-to-face communication is preferred. Be sure to sit directly in front of the patient and face him/her directly when speaking. This will allow the patient to read your lips and will also ensure you stay in one place. Your words can become muffled or trail off if you consistently turn your head or walk away during a conversation²¹
- Confirm that the patient speaks and understands English. If the patient needs a translator, contact the appropriate translator services
- Speak clearly and loudly, but do not shout. Shouting can often make you more difficult to understand²²
- Use visual aids to assist in communication¹⁵
- If the patient uses a hearing aid, ensure he/she is wearing it and that it is turned on
- Minimize background noise (computer noise, copy machines, other people talking, etc) when meeting with the patient²⁰
- Once the conversation is complete, ask the patient to summarize the discussion to ensure accurate hearing and understanding²³

sitting position to a standing position, which can be a significant safety issue.¹⁹

The aorta becomes less flexible, which may increase blood pressure.¹⁹

3. Changes Impacting the Blood

As the total amount of water in the body decreases with age, so does the amount of blood (blood volume) carried by the bloodstream, which puts the older adult at increased risk for dehydration.¹⁹

Red blood cell production decreases, creating a slowed response to blood loss or anemia. White blood cells important to immunity (neutrophils) may decrease, increasing overall infection risk.¹⁹

4. Some Common Cardiovascular Issues in Older Adults

While changes associated with aging can contribute to cardiovascular disease or illness, medications, stress, physical exertion, and other comorbidities can all increase the likelihood of cardiovascular issues in older adults.¹⁹

- Angina—chest pain
- Arrhythmias—irregular heart rhythms
- Coronary artery disease (CAD)—often caused by hardening of the arteries
- Congestive heart failure (CHF)—increases in frequency in patients aged 75 and above
- High blood pressure (hypertension)
- Orthostatic hypotension (OH)—a common condition characterized as a drop in blood pressure that occurs when a person sits or stands up. OH can cause lightheadedness, dizziness, or even fainting.
- Blood clots
- Varicose veins
- Peripheral vascular disease (PVD)—may make walking painful



NOTES FOR NAVIGATORS

- Be empathetic toward a patient's decreased ability to smell or taste. These changes can greatly impact quality of life and increase psychosocial distress¹⁰
- Ensure nutritional consult is completed for patients experiencing this type of sensory loss. They may struggle to maintain proper nutrition²⁴
- If your patient lives alone, he/she may be at an increased safety risk if unable to smell smoke or other potential hazards¹⁰



NOTES FOR NAVIGATORS

- Recognize that these changes can increase risk of fall. Ensure patient areas are free of area rugs or other potential fall hazards²⁵
- Because older adults may experience a decreased sensitivity to pain, be sure to assess skin routinely, as they may be less likely to recognize pain associated with a wound¹⁰
- Numbness in hands and feet can create significant safety risks²⁶



NOTES FOR NAVIGATORS

- Recognize the impact diet, cholesterol level, obesity, diabetes, high blood pressure, and smoking can have on cardiovascular health and educate/encourage your patient to follow physician-recommended plans to decrease risk¹⁹
- Assist your patient to move slowly from lying to sitting to standing to avoid dizziness associated with orthostatic hypotension²⁷
- If your patient finds walking painful, ensure wheelchair assistance is available
- Be aware that some patients may not be able to keep up with your walking pace or walk far distances²⁸
- Make sure your patient has a place to sit—some patients may be unable to stand for long periods of time
- Due to increased risk of injury due to effects of aging-related cardiovascular changes, it may be useful to teach patients and caregivers how to stop bleeding from a skin wound.²⁹
- Moderate exercise remains one of the best ways to improve cardiovascular health, even for older adults. Ensure they discuss exercise with their physician¹⁹

Pulmonary Changes

- The bones around the lungs may change shape, ultimately changing the shape of the ribcage. These changes can decrease the lungs' ability to expand and contract.³⁰
- A weakened diaphragm can also decrease inhalation and exhalation strength, decreasing oxygen levels and increasing carbon dioxide levels.³⁰
- Older adults may experience decreased cough reflex, which makes it more difficult to clear the lungs and airway.
- Changes to lung tissue and the part of the brain that controls breathing may create increased risk for shortness of breath.³⁰

Renal and Genitourinary Changes

- The kidneys help control the body's chemical balance by removing waste and extra fluid. In older adults, changes occur that decrease the kidneys' ability to remove waste as quickly. The kidneys also filter blood more slowly as one ages.³¹
- Age-related changes to the bladder include reduced bladder elasticity, muscle tone, and capacity, which can lead to urinary urgency or potential urinary incontinence. Older adults are also at increased risk for urinary tract infection (UTI).^{7,31}
- Decreased hormone production increases nighttime urination.³³



NOTES FOR NAVIGATORS³⁰

- Encourage smoking cessation³²
- Assess for shortness of breath upon exertion and provide ambulatory assistance as needed
- Recognize that obesity, smoking, and other medical issues can exacerbate breathing issues or age-related pulmonary changes. Encourage patients and caregivers to follow any physician-recommended plans

- In men, the urethra can be blocked by an enlarged prostate (benign prostatic hyperplasia). In women this could be due to bladder or vaginal prolapse.³¹

Oropharyngeal and Gastrointestinal Changes

- Decreased saliva production can place older adults at risk for multiple issues, including problems with chewing, tooth decay, gum disease, yeast infection (thrush), and swallowing issues.³⁵
- Side effects from cancer treatment and from medications used to treat certain other conditions can reduce saliva production and cause dry mouth in older adults.³⁵
- Less effective chewing and decreased food clearance put older adults at increased risk for aspiration.⁷
- Changes in the stomach may increase the frequency of gastritis and increase sensitivity to medications that can irritate the gastrointestinal tract, such as nonsteroidal anti-inflammatory drugs. Older patients also experience decreased gastric motility with delayed emptying, which can increase risk for constipation. Certain medications may exacerbate constipation issues.⁷
- Reduction in protective mucosa and gastric acid production can occur, placing older patients at increased risk for infection and stomach upset. Other changes that can occur in older patients include malabsorption of micronutrients such as xylose, folic acid, copper, and vitamin B₁₂, and severe reflux esophagitis during endoscopy due to decreased esophageal sphincter tone.⁷

Hepatobiliary Changes

- Liver mass and blood flow decrease with a person's age. Multiple liver functions are impacted by increased age, including a decreased ability to process caffeine; however, standardized liver function tests are minimally impacted by these changes.⁷
- You may see higher low-density lipoprotein (LDL) cholesterol levels in older adults due to the liver's decreased metabolism of LDL. Older adults may experience an increase in gallstone formation.⁷



NOTES FOR NAVIGATORS

- Nocturnal urgency can increase risk of falls. Encourage patients to decrease caffeine intake and limit fluids in the evening to avoid getting up to go to the bathroom during the night³⁴
- Ensure patients and caregivers understand that all medications, vitamins, herbal treatments, or other supplements should be approved for use by their physician to prevent medication interaction or adverse reactions due to decreased renal clearance³¹



NOTES FOR NAVIGATORS

- Monitor patients for constipation and ensure reporting to physician, as overuse of over-the-counter laxatives can lead to diarrhea and dehydration
- Recognize that certain medications can increase risk for constipation or diarrhea, putting older adults at increased risk for malabsorption or altered drug absorption
- Recognize that patients may be at increased risk for acid reflux. Ensure patients receive dietary guidance if reflux issues increase with cancer therapy³⁶



NOTES FOR NAVIGATORS⁷

Due to liver changes associated with aging, older adults are at increased risk for issues related to medication metabolism.³⁷

Musculoskeletal Changes

- Older adults experience a decrease in muscle mass and muscle strength. These changes can increase exercise intolerance, can impact a patient's gait, and can place him/her at increased risk for falls.³⁸
- Bones can become thinner and more fragile, putting them at increased risk for fracture. Additionally, the bones lose calcium and other nutrients and minerals.³⁸
- Joints become less flexible and older adults may see a depletion of cartilage in the joints. There is also an increase in joint inflammation and arthritis.³⁸
- As we age, our lean body mass is replaced by fat with a redistribution of body fat and a decrease in muscle tissue.^{7,38}
- Osteopenia and osteoporosis place older adults at increased risk for bone fracture and vertebral issues.³⁸
- Older adults may experience changes in stature and height related to potential shortening of the trunk or spine and/or decrease in foot arch.³⁸

Immune System Changes

As we age, we are increasingly susceptible to infection.⁴⁴

There is reduced efficacy of vaccination in older adults, so flu, pneumonia, tetanus, and other vaccinations should be kept up to date per physicians' recommendations (**Figure 2** and **Figure 3**).^{44,46,47}

Older adults are at greater risk for cancer due to the immune system's decreased ability to fix cellular defects. Older adults



NOTES FOR NAVIGATORS

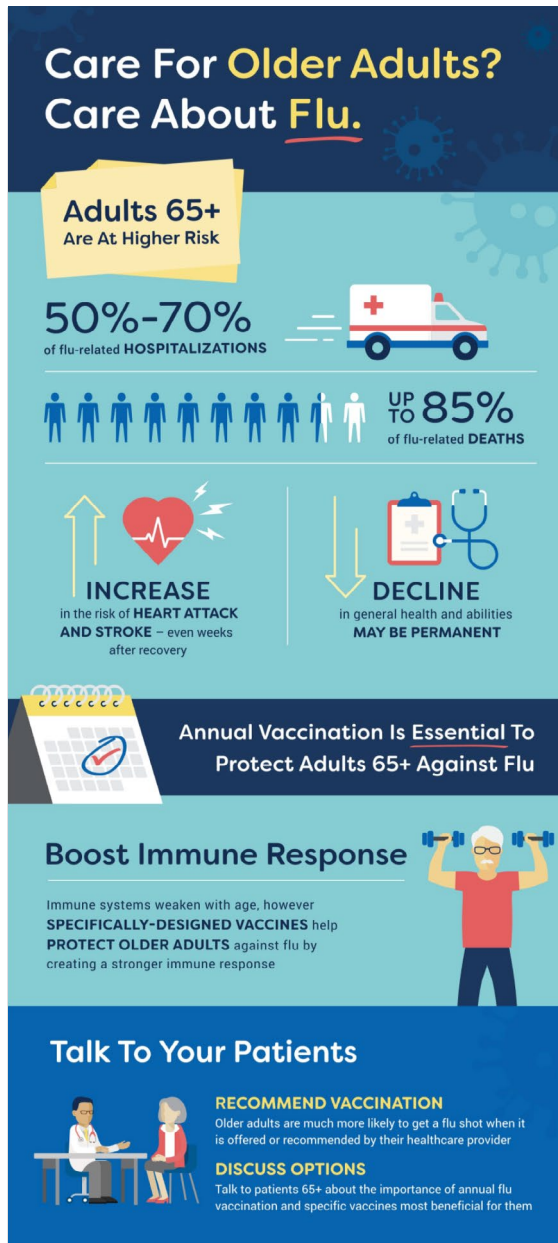
- Encourage light physical activity to maintain range of motion and muscle strength³⁸
- Provide patient education about importance of bone density screening if ordered by the physician³⁹
- Provide ambulatory assistance if needed, as patients may have trouble walking long distances⁴⁰
- Patients may experience issues at home if they are unable to climb stairs⁴¹
- Public transportation may become a barrier to care if patients are unable to climb stairs into a bus or subway car⁴²
- Ensure any medications, herbs, or home treatments used for arthritis pain are discussed with the physician
- Offer nonmedication arthritis treatment options such as massage, water activities, yoga, or hot/cold therapy, as appropriate⁴³



NOTES FOR NAVIGATORS

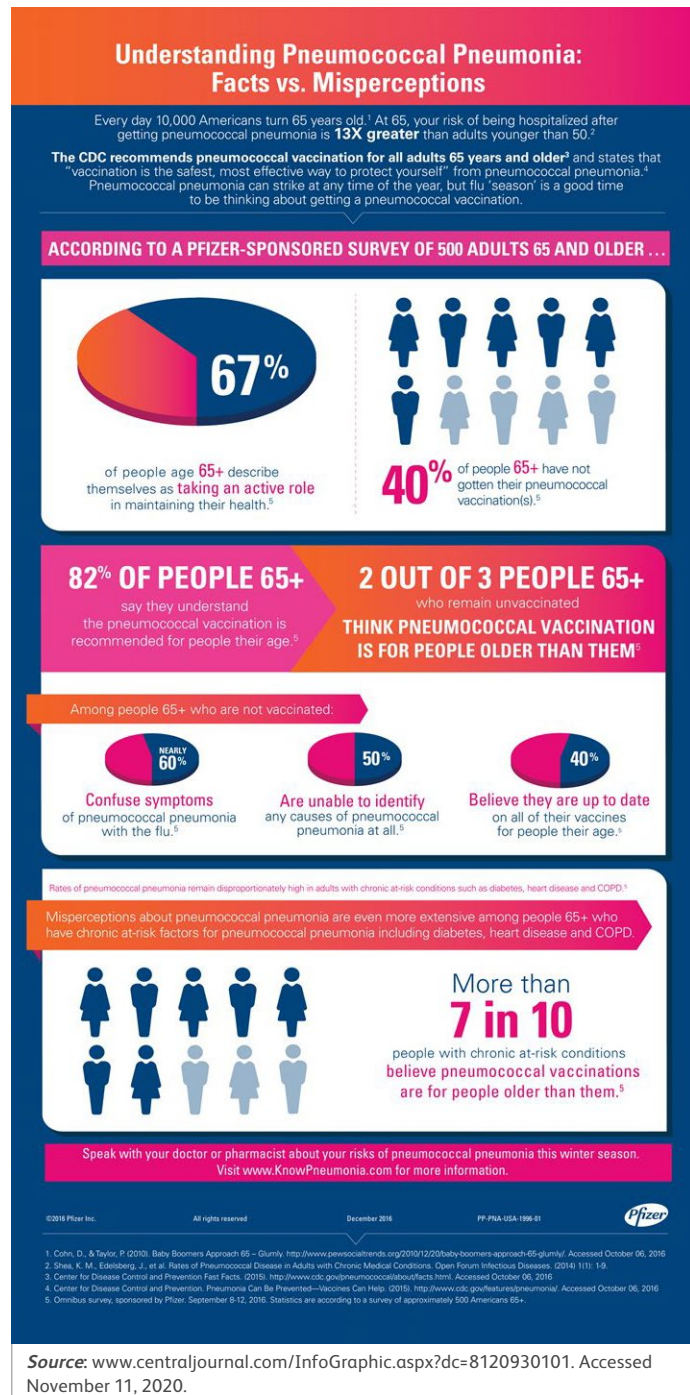
- Recognize older adults' potential increased risk for infection. Encourage proper handwashing and other infection-prevention tactics and follow these guidelines yourself to keep your patients healthy⁴⁵
- Ensure patients are receiving appropriate nutrition to support the immune system⁴⁴
- Discourage alcohol and tobacco use⁴⁴

FIGURE 2. Influenza Vaccination for Older Adults



Source: Acquired from <https://i2.wp.com/www.nfid.org/wp-content/uploads/2019/08/Care-for-Older-Adults-Care-About-Flu-Infographic.jpg> on September 25, 2020, courtesy of the National Foundation for Infectious Diseases.

FIGURE 3. Pneumococcal Pneumonia Vaccination in Older Adults



Source: www.centraljournal.com/InfoGraphic.aspx?dc=8120930101. Accessed November 11, 2020.

experience age-related chronic inflammation, which may lead to the development of chronic disease or autoimmune issues.⁷

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IV. COGNITIVE IMPAIRMENT

There are multiple nervous system and cognition changes that can occur as part of the aging process.¹ These changes can affect older adults' adherence to medication regimens (eg, missing or taking too often), as well as their ability to remember appointments or lengthy instructions.² Some of the cognitive changes associated with aging are listed below³:

- Decrease in neurons (nerve cells) and neurotransmitters
- Changes in cerebral dendrites, glial support cells, and synapses
- Compromised thermoregulation (ie, the ability to regulate internal body temperature)
- Slowed motor skills and potential deficits in balance and coordination
- Decreased temperature sensitivity and reaction time
- Slowed information-processing speed
- Increased risk of sleep disorders
- Increased risk of delirium
- Increased risk of neurodegenerative diseases
- Blunted or absent fever response

Although these changes are possible and some minor alterations in cognitive function may be considered normal, it is not normal for older adults to experience significant cognitive changes or memory loss.⁴ To best care for older adults with significant cognitive changes, it is important to understand the differences between some of the most commonly recognized memory disorders—dementia and Alzheimer's disease.

Dementia is a broad term used to describe any group of symptoms associated with memory loss, behavioral changes, and/or loss of cognitive function.⁵ There are many types of dementia, but none is a normal result of aging (see **Figure**).⁶ Patients with dementia may experience mild, moderate, or severe issues with learning, memory, language and motor skills, or social cognition that interfere with activities of daily living.⁵

- Alzheimer's disease is the most common cause of dementia
 - Alzheimer's disease comprises nearly 60% to 80% of all dementia cases.
- Other types of dementia include the following^{7,8}:
 - Vascular dementia
 - Lewy body dementia, a type of dementia in which protein deposits develop on the cerebral cortex and cause confusion and memory loss
 - Parkinson's disease, which in advanced stages can produce dementia similar to Alzheimer's. The disease more commonly leads to problems with movement and motor control.
 - Frontotemporal dementia, a name describing several separate types of dementia that affect the frontal lobe or temporal lobes of the brain.



NOTES FOR NAVIGATORS

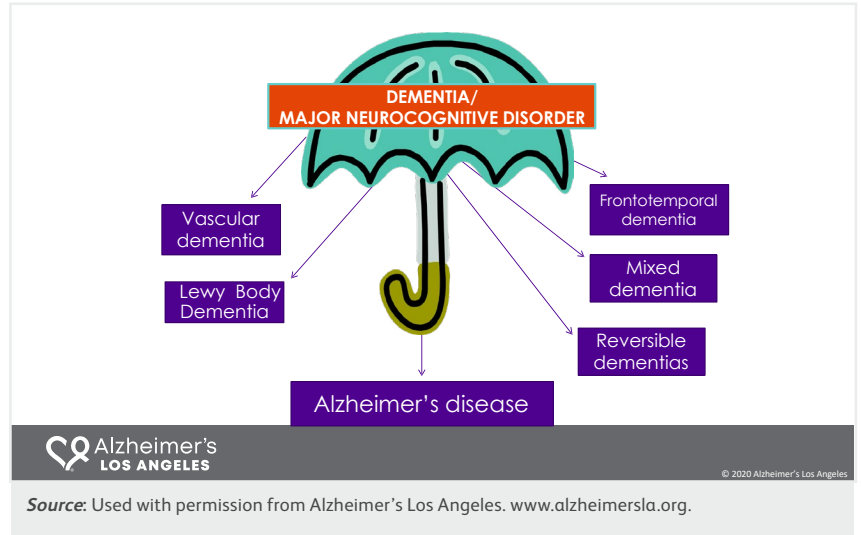
- Dementia is not a normal result of aging
- Dementia is a broad term used to describe a group of symptoms associated with memory loss, behavioral changes, and/or loss of cognitive function
- Alzheimer's disease is one particular cause of dementia

Alzheimer's disease, as stated above, is the most common cause of dementia. It is not a normal part of the aging process but is a progressive disease in which dementia symptoms grow worse over time. As explained by the Alzheimer's Association⁹:

The most common early symptom of Alzheimer's disease is difficulty remembering newly learned information because Alzheimer's disease changes typically begin in the part of the brain that affects learning. As Alzheimer's disease

advances through the brain, it leads to increasingly severe symptoms, including disorientation and mood and behavior changes; deepening confusion about events, time, and place; unfounded suspicions about family, friends, and professional caregivers; more serious memory loss and behavior changes; and difficulty speaking, swallowing, and walking.⁹

FIGURE. Types of Dementia



NOTES FOR NAVIGATORS

- Alzheimer's disease is a progressive disease in which dementia symptoms grow worse over time⁹
- Alzheimer's disease accounts for 60%-80% of all cases of dementia⁹

Although Alzheimer's disease is still not completely understood, it is believed that plaques and tangles form in the brain, causing nerve cell damage and death.⁹ Treatments focus on slowing the progression of the symptoms because there is no cure or way to reverse loss of cognitive function in these patients.⁹ To learn more about Alzheimer's disease,

access the Alzheimer's Association's *2020 Alzheimer's Disease Facts and Figures – On the Front Lines: Primary Care Physicians and Alzheimer's Care in America* (www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf).


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V. COMMUNICATION CONSIDERATIONS

Strong communication is the backbone of every quality navigator–patient relationship; however, older adults may experience sensory and cognitive changes that can create communication challenges.^{1,2} If you are to overcome these challenges, you must be able to use a variety of techniques to assess and meet your patient's specific communication needs (**Figure 1**).³ As with all age-groups, keep written and verbal communication free of medical jargon, overcomplicated language, and abbreviations; keep written communications simple and direct.⁴ Also pay close attention to your nonverbal communication. Your facial expressions, posture, eye movements, gestures, tone of voice, and other nonverbal characteristics can greatly affect how you are perceived and how comfortable your patient feels.⁵

FIGURE 1. Communication Tips for Caregivers


COMMUNICATION TIPS FOR CAREGIVERS



Communicating with people with dementia can seem hard, but it doesn't have to be! Let these person-centered tips be your guide.


1 ALWAYS SPEAK TO THE PERSON AS AN ADULT

Don't speak or talk down to your care partner as though he/she is a child. People with dementia are adults that have lived full, rich lives. But do use concrete, clear language, and use words that are familiar. Be sure to speak slowly and clearly, using a relaxed tone of voice, and maintain eye contact.




5 ELIMINATE ENVIRONMENTAL DISTRACTIONS

Simple changes to the environment can improve everyday functioning and enhance communication. Light, sound, rooms, and walkways should be assessed for environmental barriers.



2 ALWAYS INCLUDE THE PERSON IN THE CONVERSATION

Use lead-in information and opinion-seeking questions ("How is your daughter, Marge, the viola player?" or "Did you enjoy your breakfast?"). Use nouns, not pronouns, and don't talk as though your care partner isn't there.




6 ALLOW ENOUGH TIME FOR A RESPONSE

Have conversations with your care partner. Be patient in waiting for their response. Talk with them, not to them. Sometimes they won't respond. No problem, simply move on to a different subject.


3 SPEAK POSITIVELY

Avoid using "don'ts" or commands. Avoid criticizing, correcting, or arguing. Compliment your care partner often.



7 USE AND ENCOURAGE NON-VERBAL COMMUNICATION

You can communicate without words using facial expressions, gestures, and touching.



4 BREAK TASKS AND INSTRUCTIONS INTO CLEAR, SIMPLE STEPS


Avoid complicating tasks by presenting clear and simple steps to follow. Don't provide too many choices (this can become overwhelming), and don't give instructions or information too far in advance.

8 BE PATIENT, FLEXIBLE, AND UNDERSTANDING

Remember that a person with dementia is trying to make sense of a world that seems to have gone seriously off-track. Even simple, ordinary daily tasks have become challenging.

9 TAKE CARE OF YOURSELF!

This is essential! As a caregiver, you are probably used to putting others' needs ahead of your own. But you must take time to refuel so you are not running on empty. Do something just for you.



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Sources: Alzheimer's Association (www.alz.org)
Navigating the Alzheimer's Journey: A Compass for Caregiving by Carol Bowlby Sifton, Health Professions Press
The Best Friends Approach to Dementia Care by Virginia Bell and David Troxel, Health Professions Press

www.healthpropress.com

Source: Used with permission from Health Professions Press website (www.healthpropress.com/wp-content/uploads/2016/07/Communication-tips-for-caregivers.png).

Hearing Loss

Hearing loss in older adults can greatly challenge communication and can leave older adults frustrated and distressed when they misunderstand or are misunderstood. As Older Adult Sensitivity Training (OAST) explains, hearing loss is one of the most common sensory deficits: “Hearing loss affects approximately one third of adults 65 to 74, half of people over 75, and two thirds of those over 85. The degree of hearing loss may range from mild to severe.”^{5,6} Many times, older adults experiencing hearing loss exhibit certain behaviors to compensate, and you may be able to identify potential hearing loss in someone simply by paying attention to some cues. Older adults may:

- Speak in a particularly loud voice⁷
- Position their head so the “good ear” is facing what they are trying to hear⁸
- Have a “blank look” or expression or appear inattentive if they don’t realize someone is speaking to them⁸
- Ask for conversations/words to be repeated⁸
- Lack reaction (they likely misunderstood the message)⁸
- Answer questions inappropriately because they misunderstood the question^{7,8}
- Talk at inappropriate times in the conversation because they don’t hear others speaking
- Fail to notice environmental sounds, especially those with a high pitch.⁸

There are additional steps you can take to help break down communication barriers for those patients experiencing hearing loss:

- **Reword your message.** If someone misunderstands you, don’t simply repeat the same message to that person over and over. Instead, try explaining the same thing with different words. Show patience and protect the patient from embarrassment⁸
- **Provide context.** Use phrasing, such as *D* as in dog and *T* as in tiger. When providing numbers, say each number individually. If the patient needs to take a medication at 8:30 am, you may choose to phrase your message like this: “Mrs. Jones, this is your new pill [hold up the bottle and show the label]. Take 1 pill every day at 8-3-0, *a* as in apple and *m* as in Mary.”⁹
- **Make sure there is adequate lighting.** Hearing impaired will be able to see your face, especially if he or she reads lips.⁸

In addition, be aware of what OAST refers to as “false impressions.” Some hearing-impaired older adults, especially in certain cultures, may nod or smile to be polite; that does not mean, however, that your message is understood. Always ask patients to repeat or “teach-back” any information they must remember by saying, “Can you repeat back to me the instructions I just gave you? I want to make sure I explained the steps clearly.” Pfizer’s *Patient Navigation in Cancer Care 2.0* Toolkit provides an excellent overview of the ask-tell-ask approach, one of the best methods for assessing knowledge and understanding, sharing information, and educating patients and their families: http://s3.amazonaws.com/pfizerpro.com/assets/patientnavigation.com/Patient_Navigation_in_Cancer_Care_2.0_%C2%ADWebsite_12.04.18.pdf.

Other tips to help break down barriers include the following^{8,9}:

- Ask if the person is able to hear you
- Make sure you have the person’s attention before speaking; a light touch or calling his or her name should work
- Talk face-to-face and avoid telephone conversations
- Keep your face clear and don’t chew gum

- Use low-speaking tones and don't shout
- Speak distinctly
- Use visual cues, such as diagrams or written materials, when needed.

Visual Limitations

As with hearing changes, visual changes can also present communication challenges. As a reminder, you may commonly find the following vision changes in older adult patients^{8,10-12}:

- Decreased acuity and ability to focus
- Decreased contrast sensitivity
- Decreased adaptation to light/dark
- Increased lighting requirements
- Decreased visual field
- Decline in color vision and color sensitivity
- Increased sensitivity to glare.

To break down communication barriers with those patients experiencing visual changes or loss of vision, it can be helpful to remember these tips^{8,13}:

- Talk directly to the person
- Announce your presence and comment before you leave
- State what you are going to do before you do it
- Give clear directions
- Offer assistance
- Allow needed time
- Orient the person to a new environment by describing the setting (eg, explaining the restroom location, asking if it's too light or too dark)
- Be a sighted guide: When walking, offer your arm and allow the person to grasp it. Walk approximately a half-step ahead, but do not push, pull, or grasp the patient's arm
- Use low-vision aids, such as a magnifying glass, signature writing guide, or supplemental lighting.

What do you do if you have written information, such as appointment details, to give to the patient?

There are tactics you can use to make written materials more reader-friendly for those experiencing age-related vision changes. First, use a large font (at least 14 point) and make sure it is easy to read.

Create contrast between the letters and the paper—black ink or black felt-tip on white paper is best.

Although you may love to write with green ink, don't use it. Make sure when you're printing materials to use matte printing paper; glossy paper creates more glare and makes the document difficult to read.

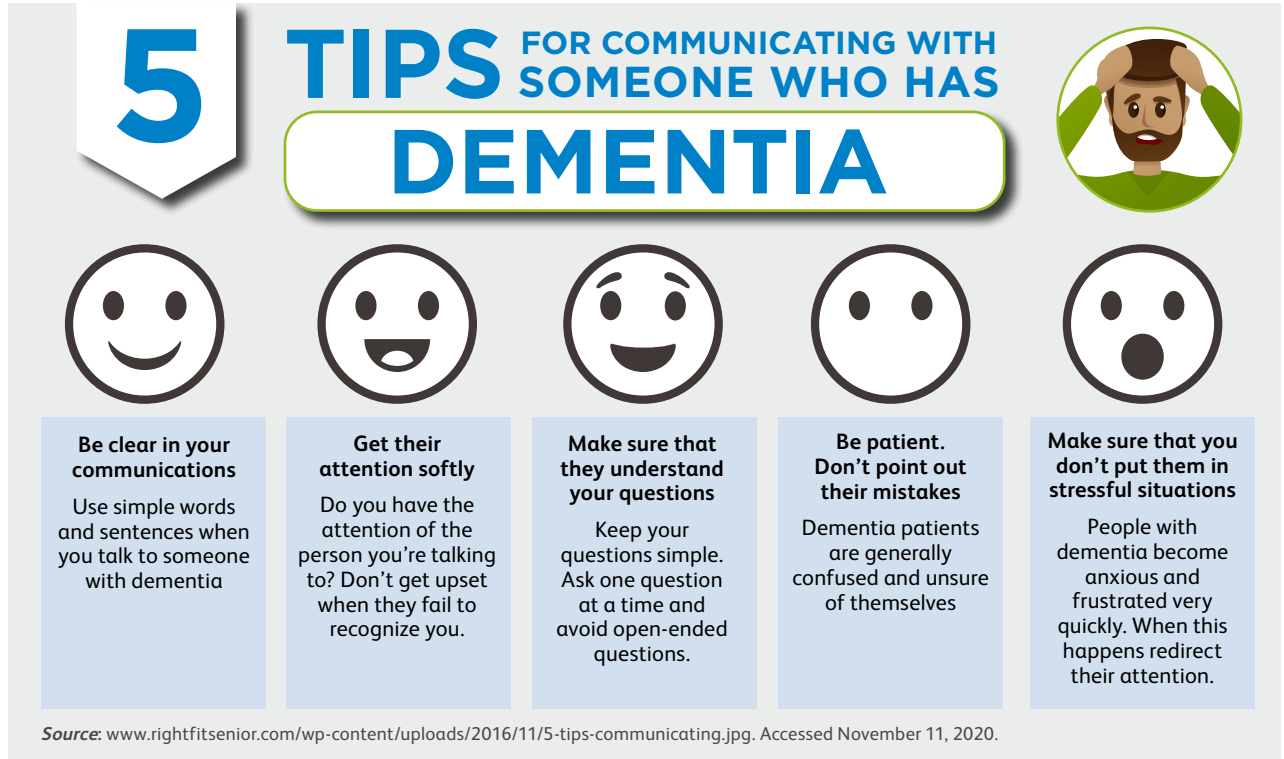
Finally, increase the amount of white space on the page by increasing your line spacing.^{8,14}

Cognitive Changes

Finally, there are some techniques to use when communicating with patients experiencing common age-related cognitive and memory changes to ensure successful communication. Age-related cognitive changes, although not dramatic, can create potential communication issues. There are some simple tips you can use to vastly improve your interactions:

- Present concepts one at a time so the patient can focus on each concept individually^{9,15}
- Minimize or eliminate distractions to promote attention, learning, and memory

FIGURE 2. Tips for Communicating with Someone Who Has Dementia



- Allow older adults more time to process new information. Demonstrate new skills, and ask them to teach them back to you
- Create an unhurried, relaxed environment that gives older adults time to retrieve cognitive information without focusing on speed of response or fine motor skills.^{16,17}

Patients with more profound (not age-related) cognitive issues may present additional communication concerns. As the healthcare provider, you should remain calm and understanding and always be sure to show the patient respect. “Dementia” is an umbrella term for a group of symptoms that decrease a person’s memory or thinking and interferes with daily life.¹⁸ Remember, many different diseases may cause dementia—Alzheimer’s disease is only one of them. Patients may experience dementia syndromes for a variety of other reasons as well, including brain tumor, traumatic brain injury, stroke, and alcohol abuse.¹⁸ **Figure 2** shows some general tips for communicating with older adults who are living with dementia.¹⁹

The most common cause of dementia in older adults is Alzheimer’s disease, which is a progressive disease that changes memory, communication, and behavior over a period of time and can present multiple communication challenges specific to the patient’s stage.¹⁸ The Alzheimer’s Association provides a thorough discussion of communication changes throughout the continuum of the disease, but some common complications you may see in patients include difficulty finding words, repeating words, speaking less often, relying on gestures instead of speech, losing train of thought, having difficulty organizing words in a logical pattern, and reverting to speaking a native language.⁷ Below, you will find some strategies for communicating with patients with Alzheimer’s disease from the early stage of the disease through the late stage.²⁰

Alzheimer’s disease may cause patients to repeat the same questions or become frustrated or potentially combative.²¹ How can the patient navigator communicate effectively if the patient becomes combative?

Daily Caring offers 10 tips for handling aggressiveness related to Alzheimer's disease or dementia.²²

1. Set realistic expectations and recognize the aggression as a side effect of the disease, not a personal attack
2. Try to identify the cause or trigger
3. Rule out pain as a cause for the behavior
4. Use a gentle, positive tone of voice and a reassuring touch, if appropriate
5. Validate the patient's feelings
6. Calm the environment
7. Play the patient's favorite music
8. Shift focus to a different activity, something they typically enjoy
9. Remove yourself from the room
10. Maintain your safety and the safety of your patient, and call for help if needed.

Early-Stage Alzheimer's Disease: Strategies for Communication²⁰

- » Don't make assumptions about a patient's ability. The disease affects everyone differently
- » Don't exclude the patient from conversations
- » Speak directly to the patient rather than the caregiver or companion
- » Take time to listen
- » Give the patient time to answer. Don't interrupt unless the patient asks for help
- » Ask which methods of communication the patient prefers
- » Show empathy and engagement

Middle-Stage Alzheimer's Disease: Strategies for Communication²⁰

- » Engage in one-to-one conversations in quiet places with minimal distractions
- » Maintain eye contact
- » Ask 1 question at a time
- » Ask yes-or-no questions instead of open-ended questions
- » Do not criticize or correct and avoid arguing
- » Give visual cues
- » Give the patient time to answer questions. Be patient and provide reassurance
- » Provide written notes, which may be helpful
- » Demonstrate empathy and engagement

Late-Stage Alzheimer's Disease: Strategies for Communication²⁰

- » Approach the patient from the front and identify yourself, even if you've met previously
- » Encourage nonverbal communication — if you don't understand what the person is trying to say, ask them to point or gesture
- » Use touch, sights, sounds, smells, and tastes as a form of communication
- » Consider the feelings behind words or sounds—the emotions expressed may provide you with more information than the words the patient is saying
- » Show the patient dignity and respect—do not talk down to him or her or act as if he or she isn't there
- » It's okay if you don't understand or know what to say. Be present and patient

Navigator/Patient Conversations: Attitudes About Aging

Age bias or ageism is stereotyping or expressing prejudice and discrimination against someone or oneself based solely on his or her chronologic age.²³ As Williams examines in her article *Invisible, Unequal, and Forgotten: Health Disparities in the Elderly*, when a group of individuals with a mean age of 75+ years were surveyed about their experiences with age bias, “More than 77%...reported experiencing one or more incidents of ageism, and over half reported that the episodes occurred more than once.”²⁴ Negative perceptions of the elderly can be conscious or unconscious, so as a navigator, it’s essential that you reflect on your own attitudes about aging, end of life, and geriatric care to determine whether you harbor any unconscious bias toward older adults.²⁵

The types of ageism reported by the older adults in the above survey included “being ignored or addressed with an insulting name, being treated with less dignity and respect, or being patronized.”²⁴ Older adults should not be ignored; if they have a concern, it is up to the healthcare provider to understand and help alleviate the concern.

Always show patients respect by asking them how they would like to be addressed. Do not use childish terms like “sweetie,” “honey,” and “darlin’” when addressing older adults. These terms can be perceived as disrespectful and condescending.²⁶ There is also a common misconception among the medical community that “senility” is a natural part of the aging process.²⁴ Cognitive decline is not a normal finding in older adults, and failing to recognize acute decline as a symptom may prevent the diagnosis of dementia or, in cancer care, be missed as a symptom of possible brain metastasis.²⁷

In addition, you may find some older adults who also assume pain, poor health, sadness, and functional impairment are just part of getting older,²⁴ and these patients may feel they are “too old” to seek treatment for a diagnosis of cancer. Once again, navigators play an integral role by providing education and ensuring geriatric assessment has been completed.

Navigator/Patient Conversations: The Initial Patient Interview

When navigating newly diagnosed geriatric patients, as with all patients, it is helpful to plan a structured agenda that will allow you to guide the conversation during what can be a stressful time for the patient and caregiver. It is important to assess the patient and caregiver’s preferred form of communication, such as written, spoken, or illustrated. If the patient has no cognitive deficits, proceed with open-ended questions to gather clues to the physical, emotional, social, and practical support the patient may need. You may have to vary your communication style, technique, and medium to meet the older adult’s preferences and needs.²² For patients who are experiencing cognitive or memory issues, you will want to ask very direct or yes/no questions to limit confusion. Basic questions to include in your initial interview may be:

- What do you currently know about your cancer?
- Whom do you want to include in discussions about your cancer and its treatment options?
- What is important to you?
- What are you hoping for?
- What is your understanding of your clinical situation?
- What type of communication do you prefer? Are handouts helpful? Do you like telephone calls? Video chats?
- Do you have Internet access or an e-mail address? Do you use a smartphone?



NOTES FOR NAVIGATORS

- Do not speak negatively about aging or older adults
- Cognitive impairment or memory loss is not part of the normal aging process²⁷
- Do not use infantilizing terms such as “sweetie,” “honey,” or “darlin’” when addressing older adults²⁶

You can learn more about the initial patient interview in Pfizer's *Patient Navigation in Cancer Care 2.0* Toolkit: http://s3.amazonaws.com/pfizerpro.com/assets/patientnavigation.com/Patient_Navigation_in_Cancer_Care_2.0_%C2%ADWebsite_12.04.18.pdf

Navigator/Patient Conversations: Discussing Difficult Topics

Many navigators have difficulty discussing potentially challenging topics such as sexuality, finances, mental health, and death/dying; however, these topics are essential parts of the human experience and can be greatly affected during the cancer continuum.²⁸ The navigator–patient relationship provides an excellent opportunity to delve into more challenging issues to ensure quality of life is upheld and barriers to treatment are minimized (see **Table**).²⁹ Some older adults may be too embarrassed to discuss sexual health without you initiating the conversation. This does not mean that older adults are not concerned with sexual health; it is a stereotype to assume that once a person reaches a certain chronologic age, he or she is no longer interested in sex or intimacy.²⁸ In fact, most older adults continue to enjoy sexual activity and cherish intimacy with their partners just as much as younger patients do, so it's important to discuss any sexual side effects that cancer treatment may cause or any potential body image issues related to surgical procedures.²⁸ Permission, limited information, specific suggestions, and intensive therapy (PLISSIT) is a common method used by clinicians to discuss sexual health and function (**Figure 3**).³⁰ Older adults also may be less likely to discuss depression and anxiety symptoms, making distress assessment even more important.²⁸ For some older adults, there is a lack of understanding of mental health concerns because the subject of mental health was considered taboo for much of their lives and not routinely discussed with others.²⁸ For other patients, cultural standards may demand stoicism, leading them to avoid any discussion of emotional discomfort.²⁸ When discussing emotional health with older adults without cognitive dysfunction, think about different ways of phrasing to avoid yes/no questions. Instead of asking "Have you been feeling depressed?" ask "How are you feeling about your diagnosis?"²⁸

Regardless of the subject matter, there are some general strategies navigators can use when planning potentially difficult conversations³¹:

TABLE. Suggested Tips for Difficult Conversation

Create a comfortable/private environment	
Sit at eye level	
Ask permission	Before discussing difficult information, assess how the patient wishes to receive the information. "Is it ok if we talk about some difficult information?"
Start the conversation	Always start the conversation with addressing the patient's agenda, concerns, and goals. "Let's start with what's been the biggest concern for you." This demonstrates that you respect and honor the wishes of your patient and their family through compassion and superb listening skills. In discussing their goals, agree on the big-picture goals before specific treatment/medical interventions
Track emotional information	Track and pay attention to the emotional information that you are receiving from the patient, as well as the cognitive information, while moving the conversation forward one step at a time using open-ended questions to identify concerns
Reiterate the communication	Reiterate the communication and clarify what you can do to assist before you discuss what you are not able to do. Repetition may be necessary, as stressful situations can inhibit retention

Source: Adapted from Baile WF, Buckman R, Lenzi R, et al. SPIKES—a six-step protocol for delivering bad news: application to the patient with cancer. *Oncologist*. 2000;5(4):302-311.

- **Be prepared:** Plan your thoughts around the conversation and make notes of talking points or practice the conversation
- **Know your limits:** It's okay to be human. Rate your feelings on a scale of 1 to 10 before the conversation and then again after the conversation
- **Be honest:** Acknowledge that what makes you uncomfortable may also make the patient uncomfortable, but that doesn't mean the conversation is not important. Most patients are grateful for your willingness to discuss these issues
- **Determine what's so difficult:** Before diving into conversation with a patient, uncover what it is about the topic that makes you uncomfortable. Do you lack knowledge? Do you lack confidence? Is there a personal reason you feel uncomfortable?
- **Consider using a communication framework:** One example is SCARS (Setting, Communicate with kindness, Ask, Reflect and respond, Summarize and plan)
- **Ask:** Ask about the patient's understanding and what is important to him or her. Does the patient want someone else present? Consider cultural, psychosexual, and religious/spiritual needs and don't make assumptions. "Listening is different than waiting to speak"
- **Awareness:** Recognize where your patients and their loved ones need guidance and support, and have conversations at the patient's pace
- **Partner:** If for whatever reason you are unable to discuss a certain issue with a patient (perhaps it's culturally inappropriate for a female patient to discuss certain issues with a male navigator), find another qualified healthcare provider to lead the discussion
- **Practice:** Try conducting the conversation with another patient navigator, particularly if that patient navigator is familiar with the patient
- **Timing:** If the patient isn't ready to talk, don't push. Acknowledge where the patient is and ask if you can return to the topic another time.

FIGURE 3. The PLISSIT Model

P Permission	LI Limited Information	SS Specific Suggestions	IT Intensive Therapy
<p>Give patients permission to address sexual issues related to their cancer care by asking open-ended questions about their concerns</p> <p>Obtain permission from patients to discuss issues in more detail based on their answers</p>	<p>Provide targeted information on specific issues raised by the patient</p> <p>This can take the form of information based on the navigator's own knowledge, handouts and brochures, or lists of resources the patient can use for additional learning</p>	<p>Provide targeted suggestions and strategies based on specific issues and concerns raised by the patient, including collaboratively coming up with follow-up approaches</p> <p>Be prepared to refer the patient to another clinician with more specialized knowledge on this topic</p>	<p>Some patients may need a referral to a sex educator, sex therapist, or other sexual health specialist</p> <p>Other options include psychologists or psychiatrists who specialize in sexual issues</p>

Source: Adapted from information in Palmisano Bianca. PLISSIT model: introducing sexual health in clinical care. *Psychiatry Advisor*. Published January 4, 2017. Updated 2020. Accessed September 20, 2020. www.psychiatryadvisor.com/home/practice-management/plissit-model-introducing-sexual-health-in-clinical-care

Communication Strategies and Telehealth

In response to the recent COVID-19 crisis, many healthcare providers have greatly expanded telehealth services; however, these services had already begun to gain popularity as possible solutions to decrease patient transportation and scheduling issues and to manage the shortage of healthcare professionals.³² These services can include but are not limited to making and participating in appointments via video conferences, video, or digital monitoring of activity (eg, physical therapy or wound care); using wearable technology for monitoring; using smartphone applications; or using a patient portal for scheduling appointments, viewing laboratory and test results, and messaging the physician.³³

Navigators can help acclimate patients to these new technologies if patients have the basic requirements, such as hardware (eg, a computer or mobile device) and Internet access. It is essential to use a layered approach when assessing patient comfort and ability. Does the patient know how to use the Internet? If not, is he or she comfortable discussing care over the telephone? The patient portal is a great tool to use for assessment of skills. Ask the patient to access the patient portal and watch to see how comfortable he or she is with that technology. Patients must be educated on how to access and use telehealth services before being required to do so. Prepare print instructions with screenshots that can help older adults remember the steps for using the technology.³⁴ In addition, do not assume that all older adults lack interest or knowledge about technology; many older adults are well-versed in technology because of learning on the job or interacting with their children and grandchildren. It is important to assess patient skills so you are able to provide the right level of support to help your patient feel comfortable.

There are multiple advantages to using telehealth in the older adult population, including the following:

- Telehealth reduces mobility challenges whether mobility challenges are related to physical mobility, transportation issues, or geographic isolation
- Patients often receive better/more frequent monitoring of chronic conditions with use of wearable technology. Chronic issues such as congestive heart failure can be monitored continuously with electronic reports delivered in real time to medical personnel
- Telehealth can help minimize caregiver burden. Video conferencing with a healthcare provider can be quick and easy to schedule. The caregiver no longer has to help to transport the patient to in-person appointments, and the caregiver is able to join telehealth visits, even if he or she lives separately from the patient
- Remote electronic monitoring relieves the caregiver of monitoring duties and anxieties about when to call the doctor
- Smartphone applications and social media can be used to track behavior modification, such as smoking cessation, and increase communication opportunities between patient, caregiver, and practitioner.³⁵

There remain, however, some challenges with telehealth in the older adult population, including:

- Discomfort with technology: Although some older adults are tech-savvy, others may be tech-avoidant. If a patient or caregiver has never used a computer before, transitioning to telehealth can present challenges³⁶
- Inconsistency in comfort: Some patients may be quite adept at using technology during one visit but have no recollection of how to use the system at the next visit
- Access to broadband Internet: There is still a large percentage of Americans who lack access to broadband Internet or who live in areas where broadband Internet is not available or the signal is too slow for a reliable connection.³⁷ For these patients, direct telephone calls may provide a better option
 - If the patient is also experiencing financial issues, it is common to quit paying the phone bill. The patient navigator needs to confirm a functional telephone number. It may also be necessary to keep the telephone numbers of other family members who live nearby and have access to telephone service

- Many rural areas and Reservations have limited access to the Internet, Wi-Fi, and cell phone towers. The navigator may need to be creative when determining communication strategies. Work with the patient and family member(s) to create an individualized plan
- In addition, some older adults still work. Although they may not have access to technology at home, these adults may have access from work
- Digital literacy: Older adults may not be as adept with new technology and may require more coaching and education on how to use at-home monitoring systems or wearables
- Access to smartphones: Do not assume that all patients have access to a smartphone. If they do, you can educate them on how to download and use helpful applications
 - Some patients, especially those living in poverty or on a very small income, may use older model cell phones. This can create confusion, as when the navigator asks, “Do you have a cell phone?” The answer is “yes”; however, the phone is not a smartphone. Be sure to ask follow-up questions like “Are you able to send and receive texts from your telephone?” to clarify
- Data security and privacy: Older adults may need reassurance as to how their personal information is being stored and used and privacy is protected.³⁵

Telehealth and Patient Navigation

With recent expansion of telehealth services, the patient navigator role and its focus on care coordination become even more critical. As more services, appointments, and patient interactions occur via video conferencing, telephone, and chat, the coordination of these services becomes more challenging, placing the patient navigator in a pivotal role on the multidisciplinary telehealth team.³⁸

Navigators, like the other members of the care team, now have greater access to technology and can use telehealth to connect with patients and perform televisits, the telehealth counterpart to in-person interactions. This addition of technology into the patient navigator workflow has created a new term: telenavigation.³⁸

FIGURE 4. Barriers to Care and Telenavigation Interventions

GEOGRAPHICAL LIMITATIONS/LACK OF TRANSPORTATION

- Telehealth technologies can be used to cut down the need for in-person visits for patients
- Virtual consultations can be used to conduct medical histories, monitor vital signs, discuss imaging and lab test results, etc

CLINICAL TRIALS

- Telemedicine can facilitate trial eligibility assessment, consent, and participation
- It can also be useful during clinical trial follow-up, including symptom assessment and management
- Navigators can maintain information on available oncology clinical trials and direct patients and caregivers to appropriate options

CANCER GENETICS

- Telemedicine can be used to expand access to cancer genetic services through virtual visits with genetic counselors and other providers
- Navigators can provide additional information and education on genetic testing and assist with scheduling

COMMUNICATION BETWEEN MEMBERS OF THE CANCER CARE TEAM

- Navigators can serve as a point of contact between patients and various cancer care providers and coordinate all communications and services

PALLIATIVE CARE

- Telehealth technologies (including mobile home-based technologies) can be used as a part of palliative care delivery
- Navigators can assist with scheduling and provide information and other resources

COST OF CARE

- Navigators can inform patients about existing support services, programs, and other forms of financial assistance created by pharmaceutical companies, government agencies, nonprofits, and others
- Navigators can also assist patients and caregivers in determining eligibility for these services and help fill out and submit all necessary documentation

Sources: Sirintrapun SJ, Lopez AM. Telemedicine in cancer care. *Am Soc Clin Oncol Educ Book.* 2018;38:540-545. Rowett KE, Christensen D. Oncology nurse navigation: expansion of the navigator role through telehealth. *Clin J Oncol Nurs.* 2020;24:24-31.

Although patients continue to experience barriers to care and may face additional barriers related to telehealth access or use, telenavigation presents an exciting opportunity to “deliver these services virtually to patients at a location near their home, regardless of the distance they may be from a specialized cancer clinic or comprehensive cancer center.”³⁸ To help strategize your virtual communications and consider how you may provide excellent patient care and assist in removal of barriers across a virtual environment, refer to **Figure 4**.^{38,39} It outlines several common barriers to care and provides potential telenavigation interventions to help resolve these barriers.

Of additional relevance for older adults, the Centers for Medicare & Medicaid Services (CMS) has updated its telehealth coverage and payment options. It's important for patient navigators to familiarize themselves with these updates to help educate patients about their Medicare coverage:

Expanded CMS-covered telehealth services include telehealth visits billed by the following providers who are practicing within their scope of practice: physicians, nurse practitioners, physician assistants, nurse midwives, certified nurse anesthetists, clinical social workers, clinical psychologists, registered dietitians, and nutrition professionals. Subject to state laws, CMS telehealth coverage includes telehealth visits, virtual check-ins, and eVisits (including advance care planning [ACP]) conducted via telephone, audio/visual technology, secure text message, e-mail, and/or patient portal. To date, this expanded CMS telehealth coverage does not cover telehealth clinical care provided by licensed registered nurses.⁴⁰

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VI. SOCIAL DETERMINANTS/SOCIOECONOMIC CONSIDERATIONS

HEALTH LITERACY CONSIDERATIONS

RACIAL AND ETHNIC DISPARITIES

FINANCIAL TOXICITY

GENDER-RELATED HEALTHCARE DISPARITIES

Social Determinants/Socioeconomic Considerations

Healthy People 2020, created in 2010 with a multiyear plan to improve the health of American citizens, highlights social determinants as those that "create social and physical environments that promote good health for all."¹ For older adults, many of these determinants greatly affect both access to and understanding of cancer care as well as their overall quality of life (**Figure 1**).¹

One particular social determinant that often goes undiscussed is elder abuse (**Figure 2**).² Abuse can appear in many different forms, including actions that cause physical pain or suffering but also those causing emotional, mental, or psychosocial trauma.³ Sometimes, signs of abuse can be subtle, but it is important for navigators to be aware of potential high-risk situations and know their role in reporting the abuse.³

The foremost objective of patient navigation is the identification of barriers to care.⁴ Each of the social determinants identified presents specific challenges for older adults, and as a navigator, you have the opportunity to help identify these issues and attempt to minimize or resolve the barriers they present. The only way to uncover these barriers is to talk to your patient and family/ caregiver(s) and ask appropriate questions. It simply is not possible for navigators to have all of the answers for the myriad of patient issues and concerns; instead, use your experience to develop your skills and to locate community resources.

To learn more about **social determinants and patient navigation**, view the following learning guide developed by

FIGURE 1. Social Determinants of Health

Those determinants listed in **blue** are of distinct significance to the older adult population:

Availability of resources to meet daily needs (eg, safe housing, local food markets)

Access to educational, economic, and job opportunities

Access to healthcare services

Quality of education and job training

Availability of community-based resources in support of community living and opportunities for recreational and leisure-time activities

Transportation options

Public safety

Social support

Social norms and attitudes

Exposure to crime, violence, and social disorder (eg, elder abuse)

Socioeconomic conditions

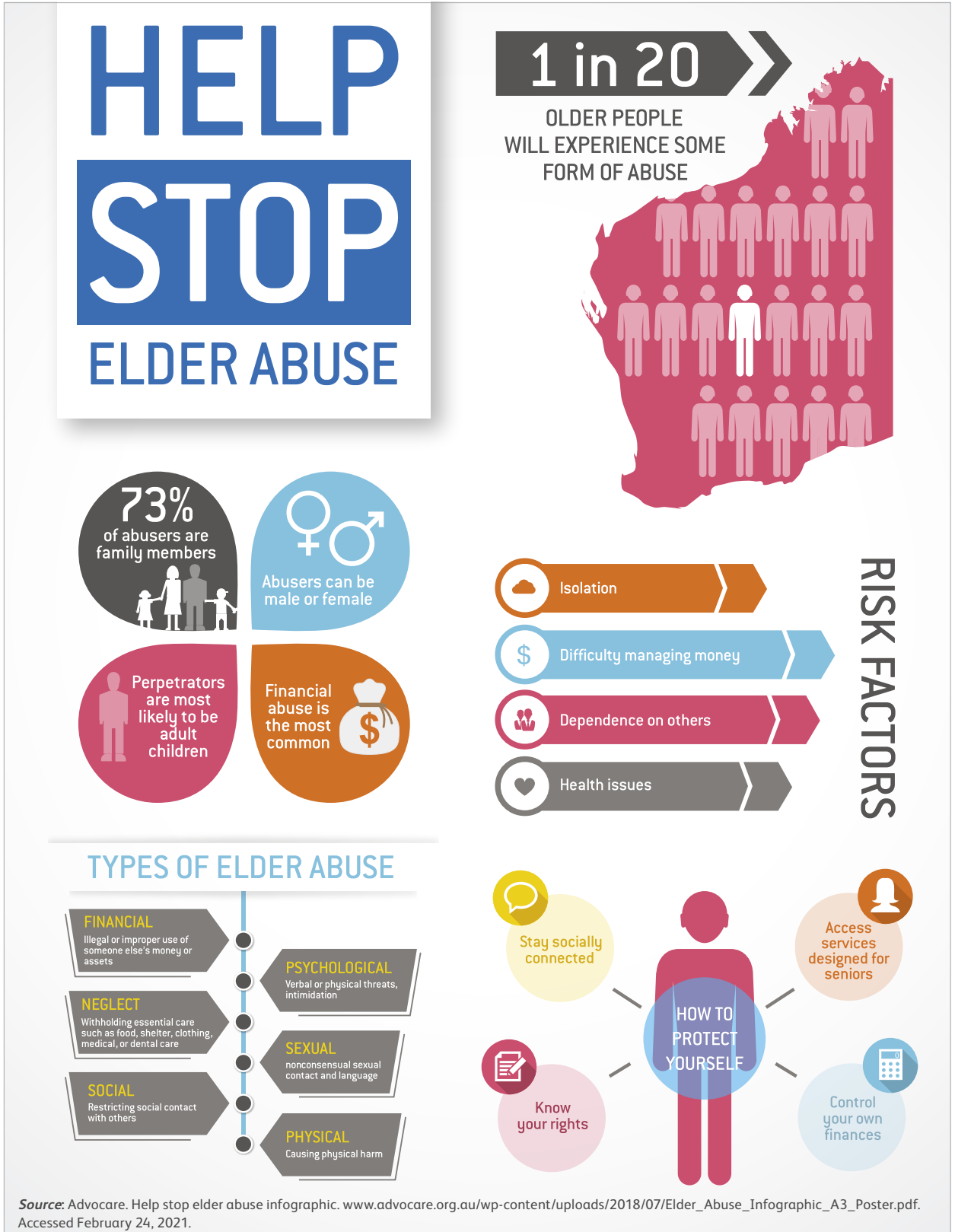
Language/literacy

Access to mass media and emerging technologies

Culture

Source: HealthyPeople.gov. Social Determinants of Health. Accessed February 24, 2021. www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-of-health.

FIGURE 2. Elder Abuse



AONN+: <https://aonnonline.org/education/learning-guides/81-understanding-social-disparities-to-navigate-patient-cancer-care>

To learn more about **aging and socioeconomic status**: www.apa.org/pi/ses/resources/publications/factsheet-age.pdf

To help **connect older adults to local resources**, use the Eldercare locator: <https://eldercare.acl.gov/Public/Index.aspx>

Health Literacy Considerations

As navigators, you all know how complex the medical system can be and how especially complex cancer care can become for those with limited medical knowledge.⁵ Older adults are particularly vulnerable to poor health literacy in cancer care.⁶ What is health literacy? Health literacy is not the same as general literacy. Instead, it “includes such skills as the ability to comprehend prescription bottle labels, follow written and oral health instructions, and understand physician dialogue,” and it’s likely that a person’s health literacy may be much lower than his or her general literacy.⁶ Unfortunately, poor health literacy can become a tremendous barrier to care, preventing individuals from remaining compliant to treatment, increasing overall cost of care, and preventing adequate symptom management.⁶ In many older adults’ lifetimes, healthcare has transformed. Many older adults grew up in times when medical knowledge and technology were limited and there was little shared decision-making between physicians and patients.^{7,8} Preventive medicine wasn’t a focus—people only went to the doctor when they were sick, and they followed the doctor’s orders to get well. Cancer was much less understood and treatments were painful and limited. Of course, each person is an individual, and one’s health literacy is determined by a variety of factors, including culture, socioeconomic status, education, language, and other variables.⁹

The study of health literacy has risen in the United States over the past several decades, and many studies attempt to correlate poor literacy and health literacy levels with poor health outcomes. Think about how most healthcare organizations disseminate information: educational materials are often provided in booklet or handout form; discharge instructions are often written in paragraphs; prescription bottles may have small text or confusing words. On top of that, many of these documents include medical jargon or complex information.^{6,10} Rima E. Rudd examines this in “Health Literacy Considerations for a New Cancer Prevention Initiative”:

Findings indicated that older adults demonstrate significantly lower and problematic proficiencies related to the use of prose materials (information presented in sentence and paragraph format), related to the use of document materials (such as schedules, forms, charts, or labels), and for quantitative tasks (such as adding up numbers or figuring a percentage). In the United States, almost three quarters of adults aged 60 years and older (71%) have limited prose literacy skills; more than 80% have limited document skills, and 68% have limited quantitative skills. Furthermore, proficiencies in each of these areas decrease as age increases.¹⁰

MR is a 70-year-old patient with pancreatic cancer who has been prescribed fentanyl for pain. She lives with her daughter and 4 great-grandchildren. The children’s mother is in and out of the house and has a history of drug abuse. At a recent visit, you note that MR is grimacing when walking into the room, and she seems to be in pain. You ask her about her medication and she admits she caught her granddaughter stealing the medication from her bedside table. She says she is okay and is able to tolerate the pain. She doesn’t want you to contact the doctor or tell anyone about her granddaughter, as she doesn’t want to get her in trouble.

So, what is a navigator to do? First, assess all materials provided to patients. Reading levels should be at or below a fifth- or sixth-grade reading level, and all materials should be free of medical jargon or complex instructions.¹¹ Also, ensure there is adequate spacing on pages for written notes. As Rudd explains, older adults:

...dislike forms with large amounts of text and forms that provide too little space for their responses. They found it difficult to find critical information when it is not highlighted in some way or to follow instructions in materials when they are not written in the same order in which they are supposed to be carried out.¹⁰

In addition, polypharmacy has become a large health literacy issue for older adults. They are often taking numerous medications to treat multiple comorbidities and can be confused by the regimens.^{12,13}

Navigators can help with providing tools and tips for keeping organized and work with caregivers by educating them on the medications and the proper dosing schedules and amounts.

There are several health literacy screening tools and multiple health literacy communication guidebooks for developing written materials. For further information, visit the links below:

Centers for Disease Control and Prevention (CDC): www.cdc.gov/healthliteracy/developmaterials/guidancestandards.html

Centers for Medicare & Medicaid Services (CMS): *Toolkit for Making Written Material Clear and Effective*: www.cms.gov/Outreach-and-Education/Outreach/WrittenMaterialsToolkit

Office of Disease Prevention and Health Promotion (ODPHP): *Health Literacy Online: A Guide for Simplifying the User Experience*: <https://health.gov/healthliteracyonline>

US Department of Health & Human Services: Usability Guidelines for Content Creation and Design: www.usability.gov



NOTES FOR NAVIGATORS

- Highlight critical information
- Use single-syllable words when able
- Always provide easy-to-understand definitions of medical terms
- Present information in graphics and bullets, not just paragraphs of words; provide space for note-taking or drawing pictures
- Minimize medical jargon
- Ask the patient and caregiver to explain to you what they understand and assess their responses. Any written instructions should offer simple steps in the order in which they should be completed
- Use health literacy tools/guidebooks to hone your knowledge and skills

Racial and Ethnic Disparities

Older adults may face an intersectionality of age, race, and gender disparities in the United States.¹⁴ Since the foundation of the Secretary's Task Force Report on Black and Minority Health, compiled in 1985, the government has followed and reported on health disparities, particularly racial health disparities.¹⁵ In 1985, it was reported that "forty-two percent of cumulative deaths by age 70 among African Americans were shown to have been avoidable if African Americans' mortality profile matched that of whites."¹⁵ Racial and ethnic disparities include language barriers, access to physicians, access to quality care, access to and compliance with screening and medical treatment, and evidence-based management of chronic illness. These disparities create concern that older adults who are members of racial and ethnic minorities are at even greater risk of poor health outcomes:

Race affects the health of minorities throughout their life course through both perceived and structural mechanisms. Experiences of discrimination and bias lead to increased stress and unhealthy adaptive behaviors across all socioeconomic statuses. Structural discrimination creates patterns in life chances through “neutral” policies and practices that affect groups differently. Social Security, for example, has a gender-neutral set of criteria for earning service benefits that has the effect of leaving an inequitable number of older women struggling economically in old age.¹⁵

Hurdles such as the ones listed above can prevent older adults from receiving care. It has been found that “older adults in general, racial and ethnic minorities, and women are less likely to receive healthcare services. The percentage of recommended care declines with advancing age (ie, greater than 50% education for those sixty-five and older).”¹⁶

Why is this so important? By 2030, 1 in 5 Americans will be classified as geriatric and 1 in 4 older adults will be an ethnic or racial minority.¹⁶ As a navigator, you must be able to assess potential disparities and help connect patients to resources they need. As Kolb et al. explain, “Several studies have shown that African American and Hispanic women tend to be diagnosed with more advanced-stage cancers and are less likely to receive standard of care in a timely manner.”¹⁷

Similarly, American Indians and Alaska Natives experience challenges in accessing cancer care, which also contributes to delays and later stage of cancer at the time of diagnosis.¹⁸ In the United States, the indicators that researchers use most commonly to measure the effect of socioeconomic status on health are educational attainment, occupation, and income.¹⁹ Compared with other populations in the United States, American Indian/Alaska Native peoples are more likely to have lower socioeconomic status and also more likely to live in poverty than whites.²⁰ They also have less access to cancer prevention and screening and other healthcare services than people with higher socioeconomic status.²¹ Additionally, in 2017, about 16% of American Indian/Alaska Native peoples in the United States have not completed high school, compared with about 7% of non-Hispanic whites.²² Not completing high school has been associated with health risk behaviors.²³ Adult American Indians/Alaska Natives may tend to engage in behaviors and have health conditions that increase their risk for certain chronic conditions. They are more likely to be obese, use tobacco, and have diabetes or high blood pressure.²⁴⁻²⁷ Additionally, American Indian/Alaska Native peoples have less access to healthcare coverage and are less likely to have a personal healthcare provider.²⁸

Navigators, as patient advocates, can connect with these patients at time of diagnosis and break down barriers to ensure timely care occurs.²⁹ Navigators also have the ability to affect unhealthy daily practices and racial disparities in cancer screening. As we think about the social challenges some older adults may face—decreased health literacy, cognitive or physiologic deficits, transportation issues—in combination with racial and ethnic disparities, it becomes easy to see that minority older adults potentially face what may feel like insurmountable obstacles to quality health and cancer care.

In their study, *Health Disparities and Cancer*, O’Keefe et al. provide a thorough discussion of racial disparities across common tumor types. When analyzing lung cancer disparities, pinpointed opportunities for navigator impact can be spotted quickly:

Studies have shown an association between lower socioeconomic status and higher risks of cancer, including lung cancer, and a greater likelihood of presenting at a more advanced disease stage...Black Americans are almost three times more likely to live in poverty than Whites...and poverty is associated with increased incidence of lung cancer and the likelihood of presenting at a more advanced (nonlocalized) stage, which is related to poorer prognosis and survival. Adding to the complexity, individuals with a lower [socioeconomic status], indicated by both poverty status and education attainment, are also more likely to be current cigarette smokers.³⁰

Although this particular discussion relates racial disparities between African Americans and white Americans, this could just as easily describe disparities for all racial and ethnic minorities living in low socioeconomic areas. Navigators can affect this cycle by helping to create outreach programs and leading at-risk minorities to lung cancer screening and smoking cessation programs.³¹

Similarly, screening plays an essential role in early staging of breast cancer. Studies have shown that women who receive routine mammograms have a 10% to 25% less chance of dying of breast cancer when compared with women who do not receive screening.³²⁻³⁴ Hence, screening saves lives.

Between 2000 and 2010, there was a large increase in breast cancer mortality disparity ratio.³⁰ In 2000, the ratio of black women/white women deaths was 30.3% and that increased to 41.8% in 2010.³⁰ A breast cancer study conducted by Vidal et al. indicates decreased survival outcomes, substantial healthcare disparities, and underuse of hormone therapy in African American patients when compared with white patients.³⁵

The Intercultural Cancer Council also documents some specific racial and ethnic disparities reported in the older adult cancer population³⁶:

- Cancer survival rates among elderly American Indian/Alaska Natives are the lowest among all US subpopulations.
- Elderly and certain ethnic groups receive substandard care and generally have poorer mortality compared to younger, white, or more affluent patients.
- African Americans/Blacks and Native Americans/Alaska Natives treated for colorectal cancer receive less intensive therapy and have poorer survival than non-Hispanic/Latino whites...in addition, older colorectal patients are less likely to receive adjuvant chemotherapy after surgical removal of a colon or rectal tumor than younger patients.
- There is a lack of basic data about aging minority populations. This is largely caused by small sample sizes of these populations and language barriers that prevent certain racial and ethnic groups from participating in survey research.
- Disparities in practice patterns exist between younger and geriatric patients with bladder cancer.
- In 2006, only 38% of American Indian/Alaska Native elderly men had a prostate-specific antigen test. This is significantly lower than the US elder rate of 61%.
- Although the inability to speak English constitutes a major barrier for elderly Asian American women when seeking healthcare, it is further complicated by the fact that many Asian elderly believe the healer is supposed to make a diagnosis without much discussion and with little or no physical contact. Thus, physicians who ask too many questions, request too many tests, or suggest probabilities of outcomes are likely to lose credibility among the elderly.



NOTES FOR NAVIGATORS

- Recognize racial and ethnic disparities as they exist in cancer care
- Educate yourself on common racial and ethnic groups and disparities in your community
- Recognize your own unconscious biases that may add to these systemic issues
- Serve as a patient advocate to ensure all groups receive evidence-based, quality care
- Strategize ways to improve cancer screening and prevention activities for minorities in your community

Health disparities prevent patients from accessing screening, from accessing quality treatment, from maintaining compliance with treatment plans, and from achieving positive health outcomes. As a patient navigator, there are steps you can take to help minimize these disparities, including providing patients with a medical translator when one is needed, engaging in community outreach programs to ensure all populations are given the same cancer screening opportunities, minimizing patient barriers to care, and facilitating patient–provider communication while consistently serving as a patient advocate.³⁷

Geographic Disparities

Geographic disparities exist in healthcare, and these challenges can greatly affect older adults.³⁸ Geography affects culture which, in turn, affects attitudes toward treatment as well as availability to treatment. Characteristics that define geographic areas include³⁹:

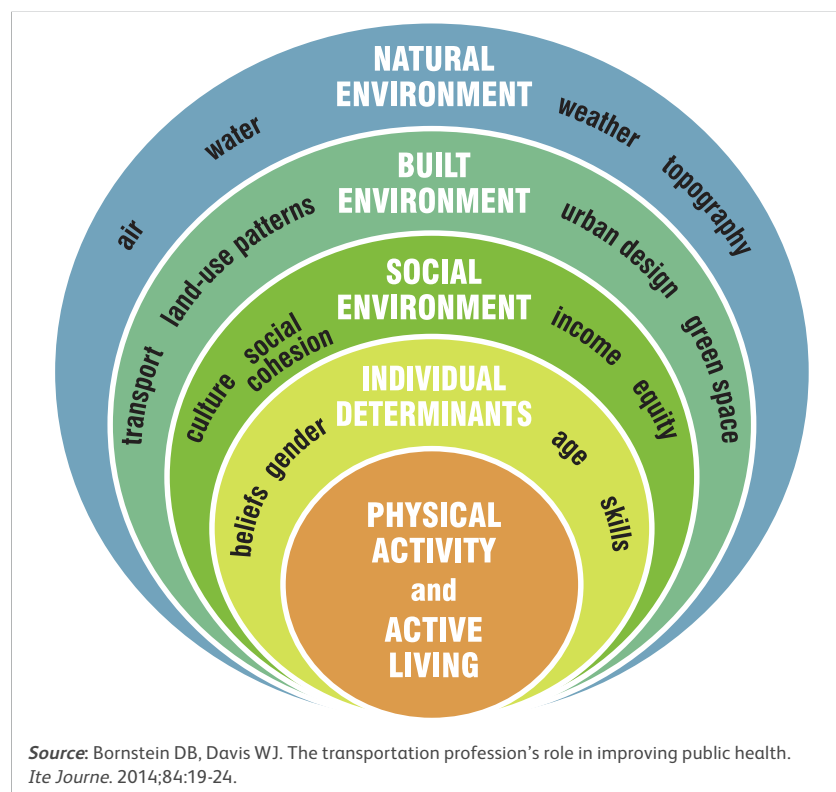
- Population density
- Distance from population center
- Distance from healthcare service
- Travel time to reach a population center
- Travel time to reach a healthcare service
- Availability of paved roads
- Travel-inhibiting weather
- Availability of healthcare services.

Based on these characteristics, areas can be defined as frontier, rural, suburban, or urban, with frontier areas receiving special designation as those most sparsely populated and with the most limited resources.³⁹

Repeated studies have proved that patients living in frontier and rural geographies are at greatest risk of health disparities and negative health outcomes.⁴⁰⁻⁴² In **Figure 3**,⁴³ note the various socioecologic determinants that affect patients' ability to access care and recognize how patient navigation services provide critical outreach and support to those communities with limited resources.

In addition, when available, the patient navigator should collaborate with a community health representative or community health aide to provide assistance for patients in remote areas, most commonly transportation.⁴⁴

FIGURE 3. Socioecologic Determinants of Health



Source: Bornstein DB, Davis WJ. The transportation profession's role in improving public health. *Ite Journe.* 2014;84:19-24.

Financial Toxicity

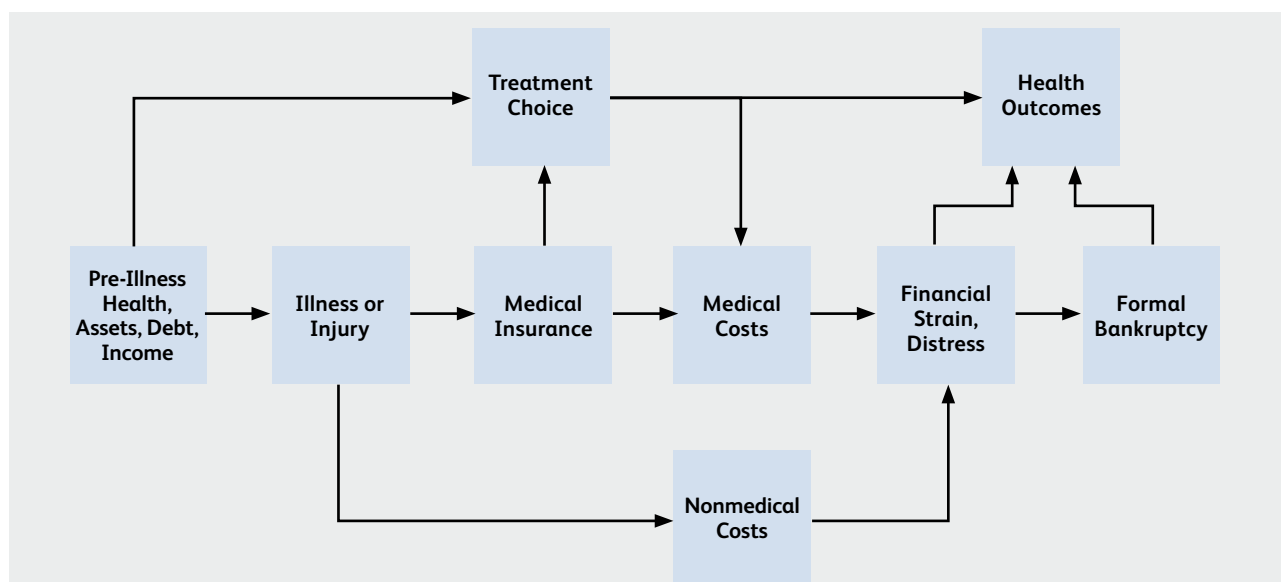
The growing cost of healthcare and specifically cancer care presents challenges for all age-groups, but there are unique challenges for the older adult population.⁴⁵ Financial toxicity has been defined as financial burden that results in psychosocial distress, diminished patient outcomes, and poor quality of life.⁴⁶ Financial toxicity has become a true healthcare burden and has been associated with increased risk of patient noncompliance.⁴⁷

Many older adults may be retired and living on a fixed income of social security benefits and savings while others may continue to work full- and part-time jobs to pay expenses.^{48,49} Do not assume that older adults are retired from the workforce. They may face distress related to loss of work and income due to cancer treatment scheduling just like younger patients. In addition, older adults may be struggling to pay for multiple prescription medications, may have difficulty accessing Medicare benefits, may be uninsured, or may face multiple physician bills related to other comorbidities. As social security benefits decrease (keep in mind that some Americans are unable to contribute to social security and, therefore, will collect no benefits in older age), the risk of financial distress increases.⁵⁰ **Figure 4** presents a framework designed by the National Cancer Institute to show the interrelatedness of cancer diagnosis and treatment, financial burdens, and health and financial outcomes.⁵¹

As a patient navigator, you must be able to assess your patients for financial distress/toxicity. Screening tools to assess distress and food insecurity can help you broach the discussion about a patient's financial status/concerns.⁵² Recognize that some older adults may not want to burden you with their financial concerns or may assume there's nothing you can do to help them.⁵³ They may also prefer to keep information about money and finances private; however, as the patient advocate, it is important to ask the questions and help determine whether a patient is at risk of financial crisis.

Once these issues are identified, the most important step a navigator can make is to refer the patient to a financial counselor, financial navigator, or social worker, if one is available.⁵⁴ If your community is without one of these resources, there are multiple government and local organizations that provide assistance

FIGURE 4. Financial Burdens and Outcomes in Cancer Care



Source: PDQ Adult Treatment Editorial Board. PDQ Financial toxicity and cancer treatment. National Cancer Institute. Updated September 19, 2019. Accessed September 26, 2020. www.cancer.gov/about-cancer/managing-care/track-care-costs/financial-toxicity-hp-pdq

with such things as food, rent/mortgage support, and utilities payments. To learn more about assisting patients with financial issues, access the resources listed below:

Insurance Resources

<https://trriagecancer.org/cancer-health-insurance-finances-cost>

<https://trriagecancer.org/QuickGuide-Medicare>

<https://trriagecancer.org/QuickGuide-MedicareExtended>

<https://trriagecancer.org/QuickGuide-Medigap>

Cancer Legal Resource Center

<https://thedrlc.org/cancer/publications-webinars/patient-legal-handbook>

Navigator Resources

AONN+: With Emerging Oncology Therapies and Rising Patient Responsibilities, Financial Navigation Will Have a Greater Role in Cancer Care

<https://aonnonline.org/component/mams/?view=article%&artid=945:with-emerging-oncology-therapies-and-rising-patient-responsibilities-financial-navigation-will-have-a-greater-role-in-cancer-care&Itemid=0>

AONN+: How to Navigate Patient Financial Toxicity Webinar

<https://aonnonline.org/component/mams/?view=article&artid=833:how-to-navigate-patient-financial-toxicity&Itemid=0>

Association of Community Cancer Centers (ACCC) Financial Advocacy Bootcamp

www.accc-cancer.org/home/learn/financial-advocacy/boot-camp

Gender-Related Healthcare Disparities

Gender health disparities exist in the older adult population. A 2010 study highlighted gender disparities in the use of hospital and physician care for similar health issues; women were substantially less likely to have hospital stays and had substantially fewer physician visits than men with similar health profiles.^{55,56} In addition, the study contends the following:

Not only did older women have more frequent reports of functional limitations and disability, but older women were also twice as likely to live alone as men. Women with healthcare problems may thus be more isolated, limiting their ability to obtain medical care.⁵⁶

Another patient population facing gender-related health disparities is the lesbian, gay, bisexual, and transgender, queer or questioning (LGBTQ+) older adult community, sometimes referenced as Generation Silent (**Figure 5**).⁵⁷ As Charles Emler explains in his article *Social, Economic, and Health Disparities Among LGBT Older Adults*, there are substantial health disparities in older members of the community, including poor physical health and disability, higher incidence of HIV, and increased psychosocial distress.⁵⁸ In addition, older LGBTQ+ adults not only face health inequity when compared with heterosexual peers, but they also face varying degrees of inequity within the LGBTQ+ subgroups, especially for those who identify as bisexual, transgender, older than age 80, or HIV positive.⁵⁸ A 2012 study found that older patients who identify as LGBTQ+ also face economic disparities, often living at or below the economic poverty threshold, and in 2011, older LGBTQ+ adults were recognized as an at-risk and underserved community by the Institute of Medicine.^{58,59} Another rising concern for LGBTQ+ older adults is long-term care:

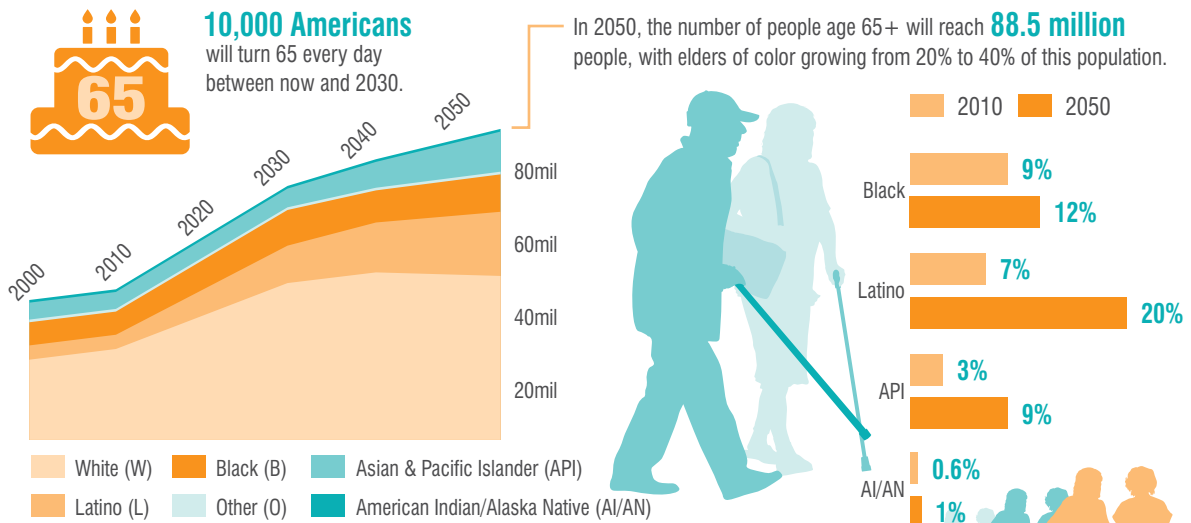
LGBT adults living both in the community and in long-term-care facilities feared being mistreated or ostracized by peers, as well as by long-term-care staff in retirement facilities... Thus, continued work on improving the competency and sensitivity of service providers, including those working in long-term care, will be critical for developing compassionate and sensitive care in the coming years.⁵⁸

FIGURE 5. LGBT and Racial Disparities in Older Adults

LGBT HEALTH, RACIAL DISPARITIES AND AGING BY THE NUMBERS

OVER THE NEXT SEVERAL DECADES, our country will grow increasingly older and more diverse. LGBT elders of color are an important part of this demographic shift—yet the available research, highlighted in the report *Health Equity and LGBT Elders of Color*, shows that they often face economic insecurity and heightened health disparities while remaining largely invisible in public policy discussions on aging.

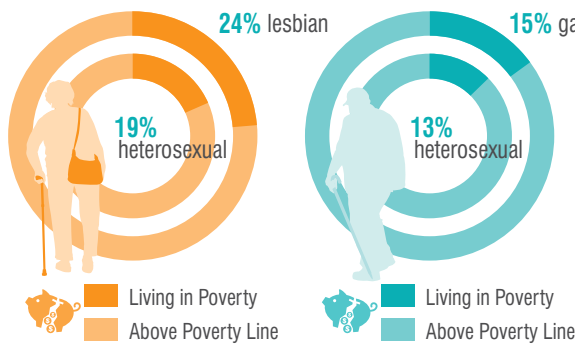
The number and diversity of people age 65+ in the U.S. is growing by leaps and bounds.



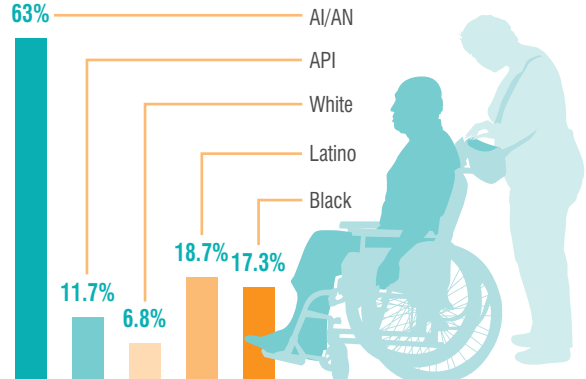
BY 2050, THE NUMBER OF LGBT OLDER ADULTS will more than double in size to **3 million** people, based on conservative estimates.

LGBT elders of color are at heightened risk of economic insecurity...

More lesbians and gay men live in poverty than their heterosexual counterparts—a disparity that persists as they age—and transgender people are 4X more likely to live in poverty than the general population.



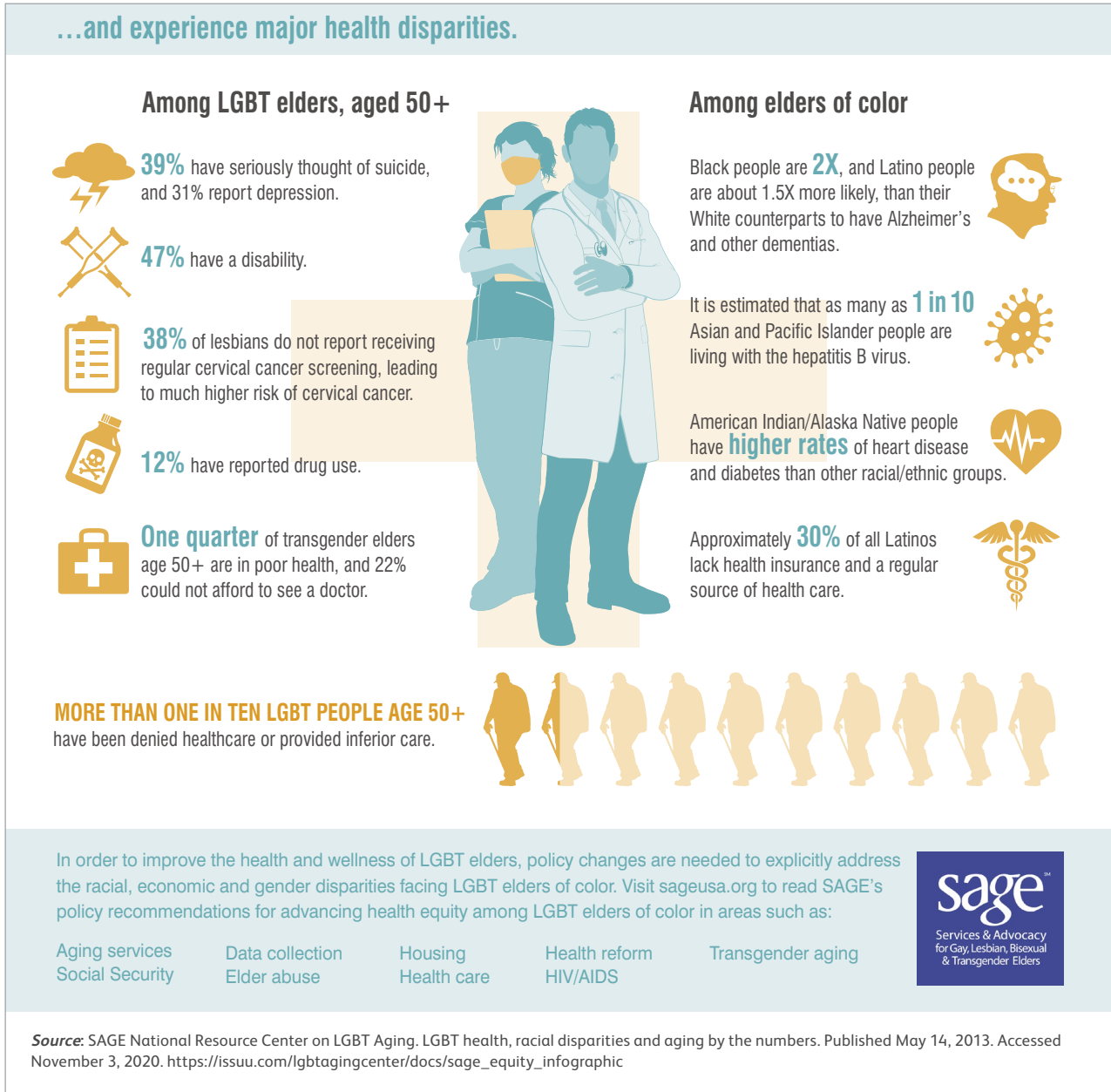
Many elders of color lack sufficient income to sustain them throughout their retirement years, and face higher poverty rates than White elders.



ONE REASON IS EMPLOYMENT DISCRIMINATION, which has affected the long-term financial stability of many LGBT elders of color, many of whom are concentrated in sectors with low wages, few labor protections, routine discrimination and limited health and savings options.

(continued)

FIGURE 5. LGBT and Racial Disparities in Older Adults



As a navigator working with older members of the Lesbian, Gay, Bisexual, Pansexual, Transgender, Genderqueer, Queer, Intersexed, Agender, Asexual, and Ally (LGBTQIA+) community, you may find that older adults do not openly share information about their partner or relationship.⁶⁰ These generations are labeled as “pre-Stonewall” meaning they lived as gay men and women before the Stonewall era of the 1960s.⁶¹ In a 2006 survey of LGBTQ+ Baby Boomers:

- 32% of gay men and 26% of lesbians stated that their greatest concern around aging was discrimination due to sexual orientation
- >50% did not have confidence that they would be treated with dignity and respect
- 12% of lesbians had zero confidence that they would be treated respectfully.⁵⁹



NOTES FOR NAVIGATORS

- Don't assume that all elderly patients are heterosexual
- Don't assume that because your patient is gay, he or she will be comfortable disclosing this information
- Avoid assuming that being gay, lesbian, or bisexual is not a difficult issue for many patients
- Do not force labels or "out" any patient who isn't ready
- Create an inclusive environment by displaying LGBTQ+-friendly graphics in a visible location or by including LGBTQ+ magazines in the waiting area
- Adapt patient forms to be inclusive (ie, use spouse/partner instead of husband/wife)

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VII. DISTRESS AND PSYCHOSOCIAL NEEDS SPECIFIC TO AGING ADULTS

PSYCHOLOGICAL REACTIONS AND COPING

CULTURAL AND SPIRITUAL CONSIDERATIONS

Distress and Psychosocial Needs Specific to Aging Adults

Many patient navigators are familiar with distress screening and the National Comprehensive Cancer Network (NCCN) distress thermometer, but as this toolkit uncovers some of the specialized challenges faced by the older adult population, you will begin to understand why distress screening this population is vitally important for uncovering barriers and potential risks for noncompliance.¹ The first toolkit in this series, *Navigating the Cancer Continuum in the Context of Value-Based Care*, offers a thorough introduction to the NCCN distress thermometer and how it can be used by navigators to provide patient-centered care. To access the toolkit, visit http://s3.amazonaws.com/pfizerpro.com/assets/patientnavigation.com/Patient_Navigation_in_Cancer_Care_2.0_%C2%ADWebsite_12.04.18.pdf.

The NCCN distress thermometer allows for self-evaluation across multiple types of distress, including emotional, social, spiritual, and physical distresses.² As navigators, you know that cancer diagnosis and treatment can cause multiple psychosocial issues; however, it is important to note that older adults can experience even greater distress across their cancer continuum.³ There are multiple risk factors for distress in older adults, including financial issues, family dynamics, chronic pain and illness, difficulty with mobility, frustration with memory loss, life changes, decreasing independence, prescription medications, and the loss of a spouse or close friend.^{1,2} Some specific times during the cancer continuum in which patients are increasingly vulnerable to feelings of distress are during a diagnostic workup, treatment failure, finding a suspicious symptom, and discharge from the hospital.⁴

In addition to the NCCN distress thermometer, there are 2 additional distress screening tools you may wish to incorporate into your practice. The Cancer Support Community (CSC) offers an electronic tool called Cancer Support Source[®], which is “the first comprehensive cancer distress screening program developed for community-based hospitals, physician practices, and advocacy organizations to integrate screening, referral, and follow-up care, through a single, streamlined program.”⁵ This particular resource not only provides a way to measure patients’ distress levels across the multiple types of distress, but it also provides individualized, customized resources based on the results.⁶ Having a tool like this can minimize the navigator’s search for resources. To access and implement this tool at your organization, you must contact CSC. A link to learn more about Cancer Support Source is provided here: www.cancer-supportcommunity.org/find-support/distress-screening#tab2.

The other recommended screening tool is the Symptom Distress Scale, which was developed by Dr Ruth McCorkle at Yale University. This scale is designed specifically for patients with cancer and provides a week-by-week, self-reported analysis of symptom-related distress.⁷ Fields are scored on a 1- to 5-point Likert scale. For the complete assessment, scores can range from 13 to 65; the higher the score, the greater the distress.⁷ (See **Figure 1**.)

Each of these recommended tools provides the opportunity to assess patient distress across the various subtypes of emotional, social, spiritual, and physical distresses. The patient’s family or caregiver can also be valuable resources when assessing patient distress and may have valuable information to share. A cancer diagnosis, worsening of a cancer prognosis, financial worries, and generalized anxiety about one’s future can all create emotional distress.⁸ Unfortunately, although older adults may experience greater instances of

emotional distress, professional mental health services are severely underutilized by this group.⁹ Why? Reasons may include inadequate funding for mental health services; lack of collaboration and coordination among primary care, mental health and aging service providers; access barriers; stigma surrounding mental illness and treatment; denial of problems; and lack of trained professionals in the provision of geriatric mental health services.⁹ In addition, of great concern are suicide rates; older adults account for 1 in 5 suicides and have the highest suicide rate of any age group.⁹ So, how can a navigator recognize

FIGURE 1.

Report your symptom distress over the past 7 days:

NAUSEA 1

- I seldom if ever have nausea
- Once in a while (1 day a week)
- Not very often (2-3 times a week)
- Fairly often (4-5 days a week)
- Often. I have nausea every day and/or continually throughout the day

NAUSEA 2

- I am never or almost never nauseous
- I usually don't have nausea, but when I do it is very mild and lasts less than an hour
- When I have nausea, it is mildly distressing for about an hour or 2
- When I have nausea, I feel very ill for 2-3 hours
- When I have nausea, I am very ill for 4 or more hours

APPETITE

- I have my normal appetite and enjoy my food
- My appetite is usually, but not always, pretty good (~6 days a week)
- I don't really enjoy my food 2-3 days each week
- I have to force myself to eat my food 4-5 days each week
- I cannot stand the thought of food every day of the week

INSOMNIA

- I sleep as well as I always have
- I occasionally (once a week) have trouble getting to sleep and staying asleep
- I frequently (2-3 nights a week) have trouble getting to sleep
- I have difficulty getting to sleep and staying asleep 4-5 nights a week
- It is almost impossible for me to get a decent night's sleep any night of the week

PAIN 1

- I never, or almost never, have pain
- I have pain once in a while (1 day a week)
- I have pain several times a week (2-3 times a week)
- I am in some degree of pain 4-5 days each week
- I am in some degree of pain every day or almost every day of each week

PAIN 2

- When I do have pain, it is very mild
- When I do have pain, it is mildly distressing
- When I do have pain, it is usually fairly intense
- The pain I have is very intense
- The pain I have is almost unbearable

FATIGUE

- I never, or almost never, feel tired or fatigued
- I feel fatigued about 1 day a week
- I feel fatigued 2-3 days each week
- I feel fatigued 4-5 days each week
- I feel fatigued every day or almost every day of each week

BOWEL

- I have my normal bowel pattern
- My bowel patterns occasionally (1 day a week) cause me some discomfort
- My bowel patterns sometimes (2-3 times each week) cause me considerable discomfort
- I have considerable discomfort 4-5 days each week because of my current bowel patterns
- I am in almost daily discomfort because of my current bowel patterns

CONCENTRATION

- I have my normal ability to concentrate
- I occasionally (1 day a week) have trouble concentrating
- I fairly often (2-3 days a week) have trouble concentrating
- I have considerable difficulty concentrating 4-5 days each week
- I have considerable difficulty concentrating every day or almost every day of each week

Symptom Distress Scale. Adapted from: McCorkle R, Cooley ME, Shea JA. A user's manual for the symptom distress scale. Accessed September 21, 2020. http://fhsson.mcmaster.ca/apn/images/stories/pdfs/Symptom_Distress_Scale_user_manual.pdf

PATIENT STUDY:

Mrs Jane Smith is an 82-year-old woman with breast cancer who you have navigated for approximately 1 month. Mrs Smith lives with her 62-year-old daughter, who always attends appointments with her.

On your most recent visit, you notice that Mrs Smith looks thinner than when you last saw her, and you ask her about her weight loss. She states that she's been too tired to eat and that when she does, she has a "sour stomach." You know that Mrs Smith is an avid dominoes player at the local senior center, but when you ask about that, she tells you she hasn't gone to the senior center in a couple of weeks. Two of the regulars there recently passed away, she explains, and she just hasn't really felt like going. Her daughter states that her mother has seemed distracted and has required more reminding than usual to take her pills.

emotional distress in older adults? Use your communication skills, active listening skills, and knowledge of distress symptoms to assess whether there is cause for concern. If, at any time, you are concerned about a patient's well-being, escalate those concerns to the patient's physician.

After reviewing this case study, do you think Mrs Smith displays any potential symptoms of emotional distress? As a reminder, emotional distress can present itself in multiple ways, but some common symptoms include the following^{4,8}:

- Persistent sad, anxious, or empty feeling
- Feelings of hopelessness and/or unrelenting pessimism
- Thoughts of suicide, suicide attempt
- Loss of interest in activities or hobbies
- Fatigue and decreased energy
- Difficulty concentrating, remembering details, and making decisions
- Insomnia, early-morning wakefulness, or excessive sleeping
- Overeating or appetite loss
- Persistent aches or pain, headaches, cramps, or digestive problems that do not ease with treatment.

In addition to emotional distress, patients may also experience symptoms of social, spiritual, or physical distress.

Social Distress: Symptoms may include the following:

- Sexual and intimacy issues
- Seclusion from family/friends
- Depression
- Loss of interest in usual activities.

Spiritual Distress: Symptoms may include the following:

- Feelings of anger and hopelessness
- Feelings of depression and anxiety
- Difficulty sleeping
- Feeling abandoned by their God, higher power, Creator
- Questioning the meaning of life or suffering
- Questioning beliefs or sudden doubt in spiritual or religious beliefs
- Asking why this situation occurred
- Seeking spiritual help or guidance.

Physical Distress: Symptoms may include the following:

- Increased pain
- Trouble sleeping
- Depression
- Restlessness
- Fatigue
- Nausea/vomiting
- Swelling

- Constipation/diarrhea
- Mouth sores/swallowing issues.

Additional education about the types of distress and how the navigator can assist in assessing and connecting the patient to appropriate resources can be found at the Academy of Oncology Nurse & Patient Navigators website.

Use the following link to access *How Does Psychosocial Distress and Barriers Influence Oncology Patient Navigation in Acuity* webinar: <https://aonnonline.org/education/learning-guides/72-how-does-psychosocial-distress-and-barriers-influence-oncology-patient-navigation-in-acuity>

Access this link to learn more about Psychosocial Care and Distress Screening: <https://aonnonline.org/component/mcme/?view=course&courseid=16:psychosocial-care-and-distress-screening-2>

Psychological Reactions and Coping

The aging process can present numerous physical, emotional, psychological, and social challenges, and for older adults facing a cancer diagnosis, these issues can become amplified (see **Figure 2**).^{1,10} It is important to recognize many effects aging can have on one's psychological well-being.¹¹

- **Major life changes:** Older adults often face multiple life changes from retirement to loss of a spouse or loved one, to moving to a retirement home or community. These changes may lead older adults to lose sense of self, especially if self-esteem and self-value were directly tied to their career. Loss of a spouse or loved one can change the home dynamic, especially if the surviving adult served as a caregiver for the deceased. Even if the loss was not recent, it can be difficult for older adults to transition to a so-called new life. The surviving adult may now find himself or herself more reliant on others or in need of having a caregiver of his or her own. Moving into retirement homes, assisted living, or retirement communities can change older adults' schedules and lifestyles. Routines they once followed may no longer exist, and new routines may need to take their place
- **Fear of the future:** These anxieties can be associated with premortality fears and concern about becoming dependent on or burdensome to others
- **Memory and learning:** Memory and learning issues can be frightening and create anxiety about potential dementia or Alzheimer's disease. However, there are multiple reasons older adults may experience issues with memory, including sleep deficiency, medication side effects/polypharmacy, depression, stress, and vitamin deficiency. It's important for navigators to ask older adults about their sleep habits, to ensure medication routines are clearly understood and followed appropriately, and to routinely screen for distress. These steps can help identify potential problems early and potentially prevent negative side effects such as memory loss
- **Loss of independence:** Patients may find themselves needing rides to appointments or assistance with activities of daily living, leading to feelings of loss of independence. In addition, caregivers can also experience loss of independence when a family member becomes completely dependent on his or her support
- **Grief and loss:** It is likely that the longer a person lives, the more friends and family he or she will see die. These multiple losses can make older adults feel vulnerable and depressed
- **Ageism and discrimination:** Older adults face a great deal of stereotyping and discrimination, even in healthcare. Some physicians treat older patients as disposable or assume older patients aren't worth aggressively treating because of their chronologic age. This ageism makes it more challenging for patients and caregivers to advocate for themselves and can also make the "perception of older Americans as frail, dependent, and isolated" a self-fulfilling prophecy.

If a navigator recognizes signs of depression in patients, what solutions or coping mechanisms are appropriate to recommend? Report any concerns to the patient's physician. Some older adults require antidepressant medication, whereas others need opportunities to socialize or volunteer to combat feelings of isolation or worthlessness.¹² Talk with the patient and ask questions to see if you can determine the root cause behind the emotion. Work with the patient/caregiver to create a strategy to help resolve issues that may negatively affect their well-being.

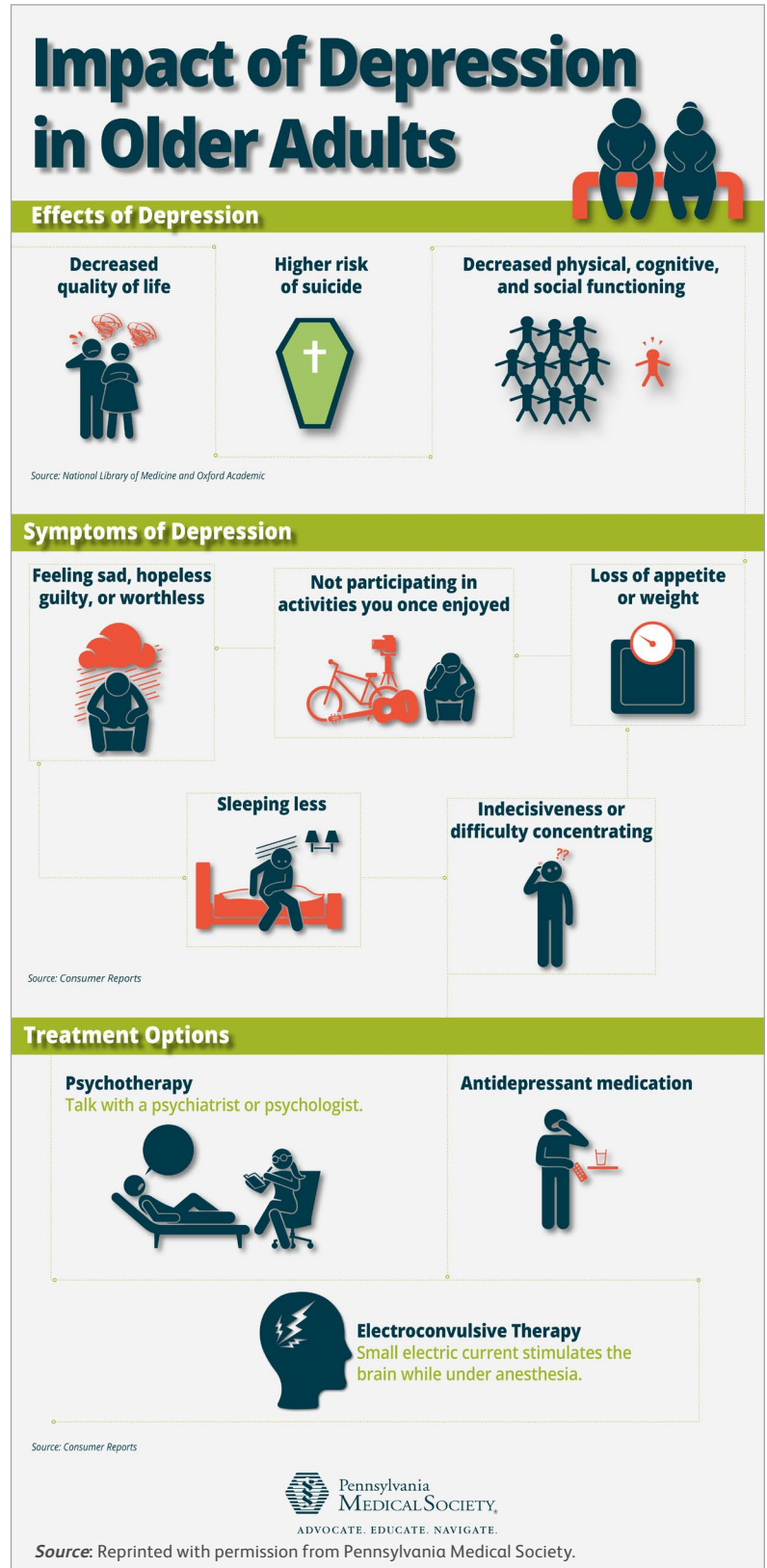
Cultural and Spiritual Considerations

Culture describes specific behaviors, practices, values, beliefs, customs, and norms found within specified groups.¹³ It is vital for navigators to ask about, respect, and consider patients' cultural needs.¹⁴

The National Center for Health and Aging defines cultural competency as vitally important, especially in working with older adults: Healthcare professionals must focus on healthcare services that are respectful of and responsive to the health beliefs, practices, and cultural and linguistic needs of diverse patients, which can help bring about positive health outcomes.¹⁵ The organization continues by providing 4 main reasons why culture competence in care of older Americans is so important¹⁵:

1. Patients are at higher risk of receiving poor quality care and experiencing negative health consequences when healthcare professionals do not promote and provide culturally competent care.

FIGURE 2. Impact of Depression in Older Adults



CONTEMPLATE THE FOLLOWING SCENARIO:

Your Native American patient with breast cancer asks you whether she is able to sit in a sweat lodge to treat her “radiation burns.” You are unfamiliar with the concept of a sweat lodge and aren’t sure how to respond.

- Admit you’re unfamiliar with a sweat lodge
- Ask the patient to teach you about what a sweat lodge is, how it works, and what cultural significance it has
- Listen and learn
- Serve as a liaison between the patient and the radiation oncology care team by escalating the patient’s question to that office/physician. By connecting with radiation oncology, you keep lines of communication open, ensuring they are also aware of the patient’s cultural needs and the request
- Ask to visit the sweat lodge leader to explain your concerns about the intense heat in the lodge and the patient’s side effect of the skin feeling like it is burning. Most leaders insist that the patient sit near the door and exit as frequently as needed or sit outside the sweat lodge while others inside pray for her and one another. Few are able to remain inside safely the entire duration of the sweat lodge. Traditional Indian healers also can be available to wait and pray outside with the patient
- Allow the radiation oncology office to provide final recommendations

2. The aging population is diverse in terms of race and ethnicity, gender, sexual identity, language, education, etc. With this growing diversity of the US population, healthcare providers are increasingly called on to address their patients’ needs. Provision of culturally competent care can increase quality and effectiveness, increase patient satisfaction, improve patient compliance, and reduce racial and ethnic health disparities.
3. Racial and ethnic minorities have higher morbidity and mortality rates from chronic conditions than do their white counterparts.
4. Higher proportions of minorities do not have a regular source of care or health insurance. In the United States, the most common minority groups that navigators must familiarize themselves with include the following:

Middle Eastern or Arab	Alaskan Native
African American and Creole	American Samoan and Guamanian
Asian American	Hispanic American
Pacific Islander	LGBTQ+
Native Hawaiian	Jewish Communities
American Indian	Jehovah’s Witnesses
Islamic Communities	Other Religions

If you would like to learn more about various cultural groups and how they’re defined, access the National Institutes of Health OMB Directive 15: <https://grants.nih.gov/grants/guide/notice-files/not-od-15-089.html>.

It’s not possible to know all customs, traditions, and practices within these cultures, nor are you expected to learn them all.¹⁴ It is important, however, to recognize that not all cultures define older adults the same way or share the same ideas about aging.¹⁶ Whereas some cultures may view aging negatively, in other cultures, older adults are taken in and cared for by family members through the end of their lives—for

these cultures, hospice care is not considered an option. For example, until recently, there were no homeless people living in Tahiti because the culture considered everyone a relative, and families invited homeless to come live with them. With Westernization influencing the island cultures, this practice is beginning to be less common. Some cultures revere their older members, considering them the most learned, most important members of society. In some American Indian cultures, older adults are referred to as “elders” and because of lower overall life expectancy, members of the community are labeled elder as early as ages 45 to 50 years. In addition, to become a culturally sensitive and competent practitioner, there are some practices you can adopt.

Recognize your unconscious biases—you may have some unspoken biases against particular cultural practices or traditions.¹⁷ You cannot allow your opinions, values, or ideas to impede on the care you give to others. Recognize these biases, admit to them, and ask yourself if you are able to do the following:

- Provide culturally competent care to those whose ideas/values/beliefs may differ greatly from your own
- Admit when you don’t know; it’s okay to be unfamiliar with someone’s culture. If your patient asks to participate in a tradition of which you have never heard, respond in a positive, open-minded manner: “I am unfamiliar with that tradition. I would love for you to teach me more about it and to help me know how I can support your needs.”

An additional cultural aspect of the older adult population is the historically paternalistic view of the physician–patient relationship. For most older adults, but especially those among the oldest old (ie, those aged ≥ 85 years), healthcare has changed drastically over their lifetimes; nevertheless, this paternalistic view can persist.¹⁸ A paternalistic view idealizes that physicians always make decisions in the patient’s best interests and should be trusted, even if the patient is capable of making his or her own decisions.¹⁹

You may hear your geriatric patient say things like “I trust the doctor. He knows best” or “The doctor knows what’s better for me than I do. I’ll do whatever she says.”²⁰ Now, in the age of shared decision-making, most physicians expect patients to participate in their care decisions. As a navigator and facilitator of patient–physician communication, you can encourage patients’ involvement in their care decisions by asking them open-ended questions related to their goals.²¹ Use this link to access a Seek-Help-Assess-Reach-Evaluate (SHARE) approach fact sheet to learn more about this tool to guide shared decision-making: www.ahrq.gov/sites/default/files/publications/files/share-approach_factsheet.pdf.

Because cultural needs and support are important for navigators to assess and assist with, spirituality is also a significant topic for assessment.²² A patient’s spirituality can be an important part of coping with a cancer diagnosis and should be supported by the navigator. For many patients, religion and spirituality provide psychological benefits, health-promoting practices, and social benefits. The most important step a navigator can take is assessing patients’ spiritual needs via some basic questions²³:

- Do you consider yourself spiritual or religious?
- What importance does your faith or belief have in your life?
- Are you a part of a spiritual or religious community?
- How would you like me, your healthcare provider, to address these issues in your healthcare?

In addition, it is important for navigators to provide referral to clergy or spiritual leaders when requested and to help support and advocate for patients’ religious beliefs and practices.²⁴

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VIII. ATTITUDES IN THE ENVIRONMENT AND QUALITY OF LIFE

AGING AND CUMULATIVE INEQUALITY

PALLIATIVE CARE IN THE GERIATRIC ONCOLOGY POPULATION

HOSPICE CARE AND END OF LIFE

Attitudes in the Environment and Quality of Life

Ageism is defined simply as discrimination on the grounds of chronologic age, and although ageism has always been prevalent in healthcare, the aging of the baby boom generation and the increased life expectancy of older adults have helped to shine a spotlight on this issue.¹ In the article titled "How Ageism in Health Care Is Affecting Society," Seniorliving.org provides a synopsis of the prevalence of ageism in healthcare and a list of 6 dangers created by ageist attitudes²:

1. Practitioners belittling geriatrics and gerontology as a profession: Ageist comments, humoring or downplaying older adults' predicaments, and other manifestations of ageism contribute to the stigmatization of geriatrics as a profession and specialization that is frustrating and less rewarding.
2. Undertreating older patients: Using statements such as "It's normal to be depressed because you're old"; ignoring complaints about lifestyle, relationships, or home life; failing to conduct tests on patients experiencing headaches, confusion, and memory loss because "it's normal for older people to experience these things"; assuming that older patients are sexually inactive and failing to treat erectile dysfunction, sexually transmitted diseases, or HIV.
3. Overtreating older patients: Universal screening measures that can result in exaggerated diagnosis followed by unwarranted treatments that result in serious patient complications.
4. Ageist talk in the healthcare setting: Use of "elder speak," which is similar to baby talk. Assuming all older adults are deaf and shouting in their ears. Talking about older adults in front of them without acknowledging they are there.
5. Ageism innate to older adults: Some older adults have ageist views themselves. Those who think symptoms such as low libido, depression, and chronic pain are just part of getting old usually do not receive treatment for these issues. They also generally lead less healthy lifestyles (eg, limited physical activity, poor diet) as well.
6. Institutionalized ageism: Physician and institutional practices like opting not to treat Medicare patients or failing to support physicians specializing in geriatrics.

As a patient navigator, it is imperative that you assess your own perceptions about aging and older adults and ensure you do not subscribe to ageist talk.

Social Isolation

Social isolation, which can be defined by a lack of belonging socially, decreased engagement with others, few social contacts, or a deficiency in fulfilling relationships, has been proved to negatively affect quality of life, especially for members of the older adult population.³ Social isolation can occur for



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If you witness ageism, serve as an advocate for that individual.

a multitude of reasons, including the inability to socialize because of health-related issues, death of one's circle of friends, loss of spouse and family members, and immobility, but it can greatly affect your patient's psychosocial health.⁴ In addition, studies on social isolation have shown association with "increased risk of all-cause mortality, mortality from coronary heart disease/stroke, rehospitalization, falls, cognitive decline, and death from suicide."³

Aging and Cumulative Inequality

As we know from our understanding of cancer biology, cancer risk increases with age, and although the older adults comprise most patients newly diagnosed with cancer, they remain an underrepresented population in cancer clinical trials, which are often classified as first-line treatment for several cancer types.⁵⁻⁷ So what are some of the barriers preventing geriatric participation in clinical trials? Multiple studies offer similar summaries of barriers^{8,9}:

- Physicians' perceptions about treatment tolerance, drug metabolism, and age bias
- Protocol eligibility criteria related to age, comorbidities such as high blood pressure, life expectancy, and functional status
- Lack of patient social support
- Need for extra time and resources to enroll older adults
- Patient logistical and financial barriers
- Patient concerns about quality of life and toxicities.

Fortunately, the patient navigator can play a pivotal role in helping older adults access clinical trials.¹⁰ For example:

- Improve your own knowledge and awareness of the importance of oncology clinical trials by using resources like these from the National Cancer Institute: www.cancer.gov/about-cancer/treatment/clinical-trials
- Serve to improve communication between patients and providers. Ask patients about interest in clinical trials, and encourage patients to discuss their interest with their physician
- Advocate for your older adult patients and ensure they are not being inappropriately excluded from pursuing all treatment options.

Palliative Care in the Geriatric Oncology Patient

Early inclusion of palliative care services is essential for older adults facing a serious disease, such as cancer.¹¹ Palliative care teams function in a multidisciplinary model to provide medical, social, emotional, and practical support to patients and caregivers, and these services can be provided in hospitals, nursing

homes, outpatient clinics, or at home.¹² In addition, many insurance policies, including Medicare and Medicaid, cover palliative care services.¹² For the older adult patient, palliative care can be especially helpful for pain management and advance care planning.¹³ Pain management can be challenging for geriatric patients as they often feel pain differently, and chronic pain can create a significant barrier to care and



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- Early access to and utilization of palliative care services are vitally important
- Navigators play a key role in coordinating between the members of the cancer care team and ensuring adequate palliative care is included

cause great psychosocial distress.^{14,15} In the palliative care setting, pain can be assessed by medical professionals, and nonpharmacologic therapies using social workers, nutritionists, and chaplains or spiritual leaders can be used with more traditional medication interventions.¹⁶ Palliative care is a crucial part of the older adult's treatment plan and can make a substantial difference in both quality of life and the ability to manage treatment side effects, yet these services remain underutilized:



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Never assume that your older adult patient is better prepared to face a terminal diagnosis because he or she is at a chronologically advanced age.

Older adults with cancer can benefit from early enrollment in palliative care services. Early utilization of palliative care is associated with symptom relief, improved mood, reduced depressive symptoms, improved quality of life and survival, overall satisfaction with treatment outcomes, and reduced cost of care. Despite the scientific evidence of the benefits associated with palliative care services, there are several barriers to palliative care utilization in older patients with cancer and older adults utilize palliative care services to a lesser extent compared with their younger counterparts.¹⁷

Hospice Care and End of Life

Hospice care focuses on providing quality-of-life services when a life-limiting illness is determined no longer treatable.¹² Some research has shown that patients diagnosed with cancer who are nearing the end of life (EOL) face greater decline in quality of life when compared with patients under hospice care who do not have a cancer diagnosis.¹⁹ It is imperative that these issues receive proper assessment before admission to hospice care to ensure quality of life remains high through EOL.

As a patient navigator, you have the opportunity to advocate for early referral to palliative care services and hospice care (see **Figure**).¹⁹ These resources are able to assist with advance care planning (ACP), which is a face-to-face conversation to discuss the patient's healthcare wishes if he or she becomes unable to make care-based decisions.²⁰ These wishes can then be documented in advance directives such as a living will or healthcare power of attorney.²⁰ To learn more about the basics of ACP, visit www.nia.nih.gov/health/caregiving/advance-care-planning.

ACP is central to EOL planning; however, it can be a challenge due to oncologists' lack of training and other barriers to communicating about EOL issues with patients.²¹ Nevertheless, these conversations, although difficult, have been shown to greatly affect quality of life:

Several studies have documented the benefits of ACP to dying individuals and the health system at large. Conversations about EOL care preferences have been associated with greater likelihood of an individual receiving treatment that is consistent with his or her wishes, earlier referral to hospice, and overall better quality of life near death.²²

It is also important to recognize that age does not correlate with acceptance of death or dying.²³ Never assume that your older adult patient is better prepared to face a terminal diagnosis because he or she is at a chronologically advanced age. It can be just as challenging for older adults to accept a terminal diagnosis as it is for younger patients, and chronologic age does not equate with a willingness to discuss EOL issues. Broach the topic empathetically, and remember that mortality is difficult for all patients and caregivers to face.

FIGURE. Distinguishing Between Palliative Care and Hospice Care



Source: Centers for Medicare & Medicaid Services. Palliative Care vs Hospice Care. <https://www.cms.gov/Medicare-Medicaid-Coordination/Fraud-Prevention/Medicaid-Integrity-Education/Downloads/infograph-PalliativeCare-%5BJune-2015%5D.pdf>. Accessed November 20, 2020.

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IX. NUTRITIONAL CONSIDERATIONS

Nutrition evaluation and education are essential for older adults traversing the cancer continuum.¹ Some physiological changes of aging, such as dentition issues, taste changes, and gastrointestinal issues (eg, constipation and diarrhea), can make eating a challenge and place older adults at risk of malnutrition.¹ Discuss nutrition as part of your initial navigation assessment and in your regular visits. Ask how many meals they eat, what they had for each meal the day before, and how they prepare their food.²

That, partnered with any physical deficiencies, can give insight into older adults' ability to achieve adequate nutrition. Don't assume that everyone knows what constitutes a "healthy" diet, and especially with older adults, consider comorbidities such as diabetes mellitus and heart disease as well as potential food–medication interactions before making any nutritional recommendations.^{3–5} In addition, be sure to assess whether older adults have trouble accessing food because of limited ability to carry on daily activities, to afford groceries, or to prepare and cook foods.⁶ If you feel the patient is in need of a nutrition consult but one has not been ordered, advocate on your patient's behalf and express your concerns to his or her physician. The oncology registered dietitian is a vital member of the patient's multidisciplinary team.⁷ If the patient is struggling with obtaining food for any reason, use your local resources to help eliminate these barriers. Many tools exist to assess patient access and ability to obtain food.^{8,9} Navigators can incorporate these tools into their patient interactions to ensure any food insecurity is recognized and the patient is referred for assistance. The tool, the *United States Department of Agriculture's U.S. Household Food Security Survey Module: Six-Item Short Form*, can be reviewed here: www.ers.usda.gov/media/8282/short2012.pdf.

One common finding in older adults is xerostomia or dry mouth.¹⁰ Although dry mouth may sound benign, it can present many nutritional challenges. Patients may experience mouth sores, mucositis, and mouth pain, which can prevent them from eating.¹¹ You may also find that many older adults have dental issues or wear dentures, which can create a need for easy-to-chew foods and can make eating unpleasurable, making early nutritional intervention key.^{10,12} In addition:

Due to the natural aging process and prevalence of comorbidities, the elderly are very susceptible to poor nutrition status and malnutrition during their cancer journey. Malnutrition itself has many consequences including impaired immune response and wound healing, fatigue, reduced muscle strength, and reduced response and tolerance of cancer treatment.¹²

Patients are also at risk of dehydration if not getting adequate intake and greater risk if experiencing vomiting and/or diarrhea.¹³ In addition, older patients are at higher risk for constipation, which can be caused by inadequate food and fluid intake, lack of exercise, and medication side effects. (**Figure 1**).^{14,15} It is also of importance for navigators to recognize that nutrition and intake must be aligned with treatment planning and modified when toxicities and side effects are experienced, so patients may be challenged to vary their diets.¹⁶

Navigator Interventions

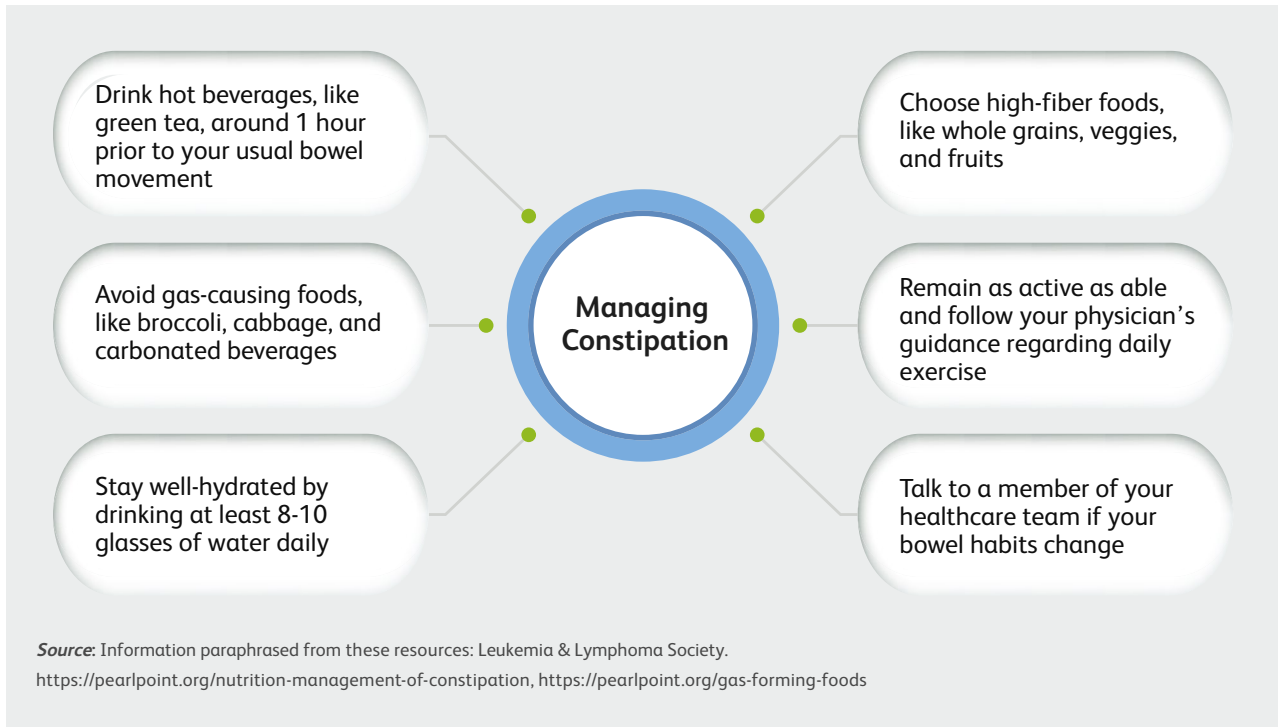
- Use graphics like **Figure 2** to introduce older adults to the foods and beverages recommended for healthy aging.¹⁷ Explain the types of food and why they are important, but also review the dividing lines on



NOTES FOR NAVIGATORS

Early detection of patients at risk for malnutrition, along with early nutrition prevention and intervention, is crucial.

FIGURE 1. Managing Constipation in Older Adults



the plate, which show how much of that food older adults need in relation to the others. For example, the grains section of the plate consists of one-quarter of the plate's entirety, whereas one-half of the plate consists of fruits and vegetables.

- Include the following question as a standalone parameter for determining risk for malnutrition: "Have you gained or lost weight without trying?" Some treatments may cause fluid retention that the physician needs to address, so be sure to assess both weight loss and weight gain.¹⁸ See **Figure 3** for more information on spotting malnutrition and tips for good nutrition at home.¹⁹
- A validated screening tool can help identify those in need of nutrition assessment and counseling by a dietitian.²⁰ Ask patients to complete the Self Mini Nutrition Assessment and give it to their physicians. The link to the assessment can be found here: www.mna-elderly.com/forms/Self_MNA_English_Imperial.pdf.
- If your facility lacks a registered dietitian or nutrition support, introduce patients to outside resources, such as Dial-a-Dietitian, and recipe books and resources from *Nutrition for Strength*. All can be accessed via this link: www.nutritionforstrength.com/resources.
- Be sure to discuss vitamins, supplements and herbals, and home remedies, and collect information as part of a medication assessment. Navigators should recommend that patients discuss any supplement or home-remedy use with their physician.²¹

Here is another simple nutrition assessment you may wish to use when navigating older adults.

This resource can be used to help patients eat to heal postsurgery.

FIGURE 2. My Plate for Older Adults

MyPlate for Older Adults

Fruits & Vegetables
Whole fruits and vegetables are rich in important nutrients and fiber. Choose fruits and vegetables with deeply colored flesh. Choose canned varieties that are packed in their own juices or low-sodium.

Healthy Oils
Liquid vegetable oils and soft margarines provide important fatty acids and some fat-soluble vitamins.

Herbs & Spices
Use a variety of herbs and spices to enhance flavor of foods and reduce the need to add salt.

Fluids
Drink plenty of fluids. Fluids can come from water, tea, coffee, soups, and fruits and vegetables.

Grains
Whole grain and fortified foods are good sources of fiber and B vitamins.

Dairy
Fat-free and low-fat milk, cheeses and yogurts provide protein, calcium and other important nutrients.

Protein
Protein rich foods provide many important nutrients. Choose a variety including nuts, beans, fish, lean meat and poultry.

Remember to Stay Active!

Tufts UNIVERSITY **JEAN MAYER USDA HUMAN NUTRITION RESEARCH CENTER ON AGING** **HNRCA** **AARP Foundation**

Source: "My Plate for Older Adults" Copyright 2016 Tufts University, all rights reserved. "My Plate for Older Adults" graphic and accompanying website were developed with support from the AARP Foundation. "Tufts University" and "AARP Foundation" are registered trademarks and may not be reproduced apart from their inclusion in the "My Plate for Older Adults" graphic without express permission from their respective owners. <https://now.tufts.edu/sites/default/files/MPFOAPR.jpg>



NOTES FOR NAVIGATORS

- Advise patients and caregivers to shop for seasonal produce to ensure maximum freshness and increase dietary variety²²
- Fresh, frozen, and canned fruits and vegetables may have a similar amount of nutrients²³
- Patients should watch for added salt or sugar in canned fruits and vegetables and choose "low sodium" or "no salt added" options when possible²³
- Healthy liquid vegetable oils include soy, olive, corn, and canola²⁴
- A good tip is to keep a day's supply of fresh fruit on the table or counter for easy access and as a visual reminder of healthy snack choices²⁵
- One cup of raw, leafy vegetables equals 1 serving; ½ cup of other cooked or raw vegetables also equals 1 serving²⁶
- One medium-sized apple, banana, or orange equals 1 serving; 1/2 cup of fruit purees and freeze dried fruit also equals 1 serving²⁷
- A 3-4 ounce portion of cooked lean meat, poultry, or fish equals 1 serving²⁸

FIGURE 3. Signs You Might Not Be Getting the Nutrition You Need

A Guide for Adults

How to Spot and Talk About Symptoms That Could Mean You're Malnourished

Poor nutrition and eating problems can put you at risk of being malnourished. Malnutrition threatens your health and your ability to recover from injuries or illnesses. That's why it is important for you to know what symptoms to look for and when you need to address them.

If you were recently hospitalized, been given directions regarding your diet, or been told you need a bit more nourishment, it is particularly important that you keep, follow, and share this information with those who care for you.



What You Need to Watch For

Since malnutrition may not be immediately apparent, you need to watch for, write down, and talk about any changes you notice in:

- Your appetite
- How much food you eat
- Your bowel habits
- Your weight
- Your daily activity levels
- Swelling in your belly, legs, ankles, and feet



You're doing OK if you can say: *"I feel good. I eat three meals a day and have the energy to do what I want."*

When You Need to Be Concerned

If you notice any of the following warning signs, you need to discuss them with your healthcare provider:

- Sudden loss or decrease in appetite
- Eating less than 75% of a normal meal for more than a week
- Episodes of nausea, vomiting, or diarrhea for more than three days
- Unplanned weight loss greater than 10 pounds
- Decrease in activity level



Schedule an appointment if you find yourself saying: *"I haven't wanted to eat anything since I started this new medication..." "I'm not finishing my meals like I used to..." "My stomach has been upset for days..." "My clothes don't seem to be fitting like they had been..." "I don't have any energy..."*

When You're in Danger from Malnutrition

The following are dangerous signs that you could be malnourished:

- Eating half as much as you normally do for more than a week
- Persistent nausea, vomiting, or diarrhea
- Sudden and rapid weight loss with noticeable muscle and/or fat loss
- Swelling in your feet, ankles, legs, or belly
- Feeling confused or having increased memory loss



Act immediately if you find yourself saying: *"It's been over a week and I can hardly eat a bite..." "I can't stop going to the bathroom..." "My feet and ankles are swollen..." "I can't concentrate when my family is talking to me ..."*

FIGURE 3. Signs You Might Not Be Getting the Nutrition You Need

How to Spot and Talk About Symptoms That Could Mean You're Malnourished

Keep Watching and Keep Talking

Don't take changes in your nutrition for granted. Be aware of what you may have been thinking or saying about how you've been eating and how you've been feeling. Share your conversations and symptoms with your healthcare provider. **Don't wait for them to ask!**

You're at the Highest Risk If...

You need to be constantly watchful for the warning signs of malnutrition if you are 85 years old or older. A number of acute or chronic diseases also put you at a much higher risk. Be sure to talk with your healthcare provider if you suffer from any of the following:

- Injury or Trauma
- Any diseases requiring multiple medications
- Cancer
- Chronic Obstructive Pulmonary Disease (COPD)
- Kidney or Liver Disease
- Gastrointestinal Dysfunctions such as Inflammatory Bowel Disease
- Depression or Dementia

Visit the Malnutrition Solution Center

Take advantage of the valuable information and free resources that can help you, your family members and caregivers identify and understand malnutrition available at nutritioncare.org/malnutrition.

Here you can:

- Learn from the true-life stories of patients who've suffered from malnutrition
- Download nutrition tips and helpful posters on spotting malnutrition in children and adults
- Learn about other resources for older adults, including links to local Meals on Wheels programs

This information is adapted from a video presented by Angela Newton, MBA, RD, and the ASPEN Malnutrition Committee. The video and other resources on malnutrition can be found at nutritioncare.org/malnutrition.

Tips for Proper Nutrition and Staying Healthy



Eat **three balanced meals every day** that include protein and fiber from fruits, vegetables and whole grains

Stay **hydrated** with fluids (8 cups per day for most adults)



Follow your **healthcare provider's or dietitian's orders** for any diet restrictions including fluids

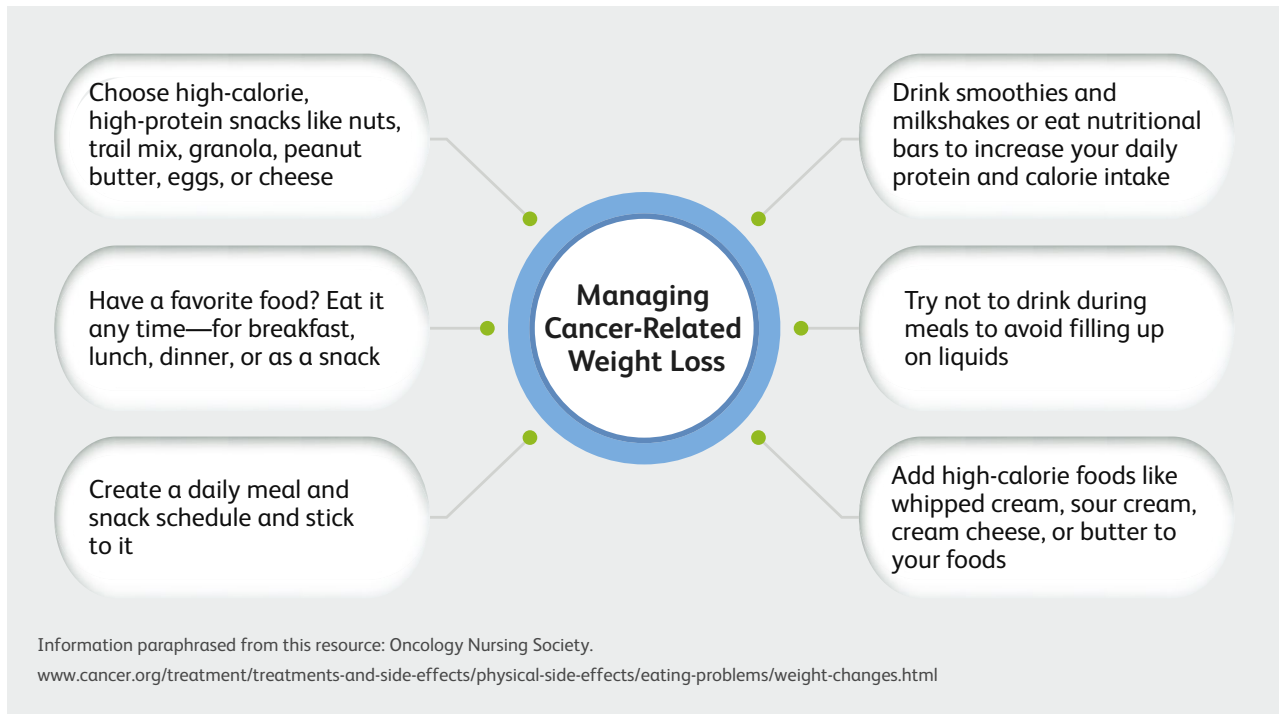
Know your **bowel habits** (frequency and consistency)



Check your weight weekly and write it down

This series of nutritional graphics (Figures 4-7) can be used to discuss symptom management with patients and caregivers or as resources to share.

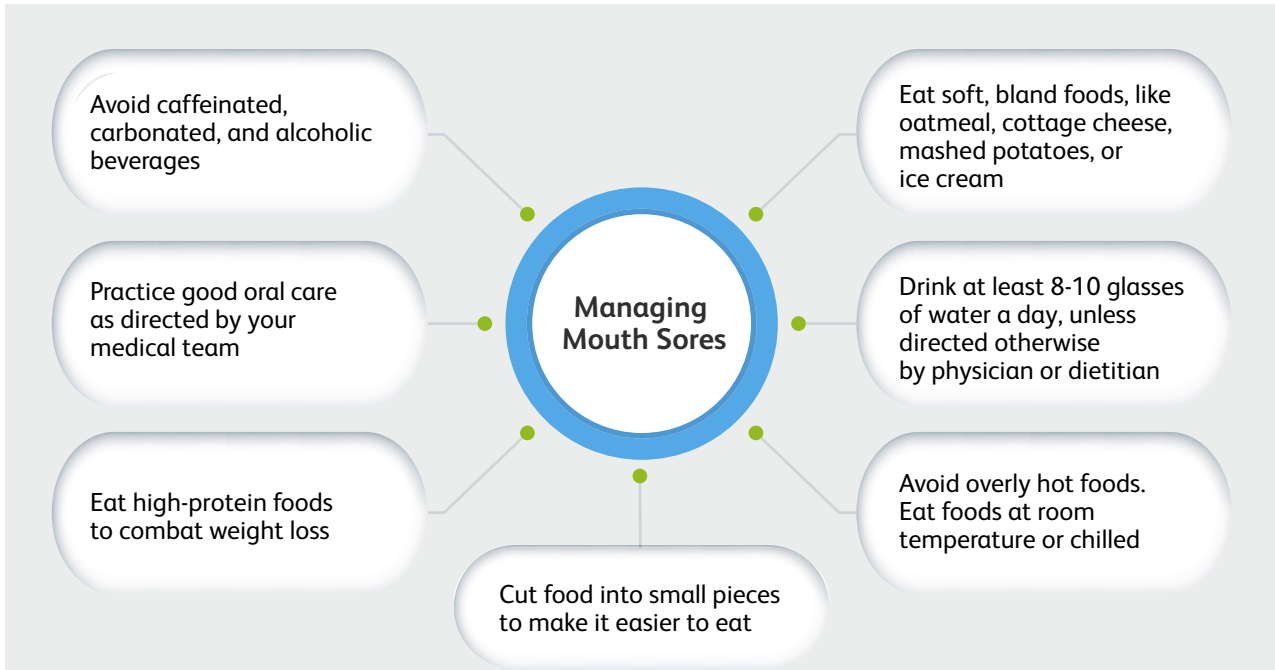
FIGURE 4. Nutrition Tips to Help Manage Weight Loss



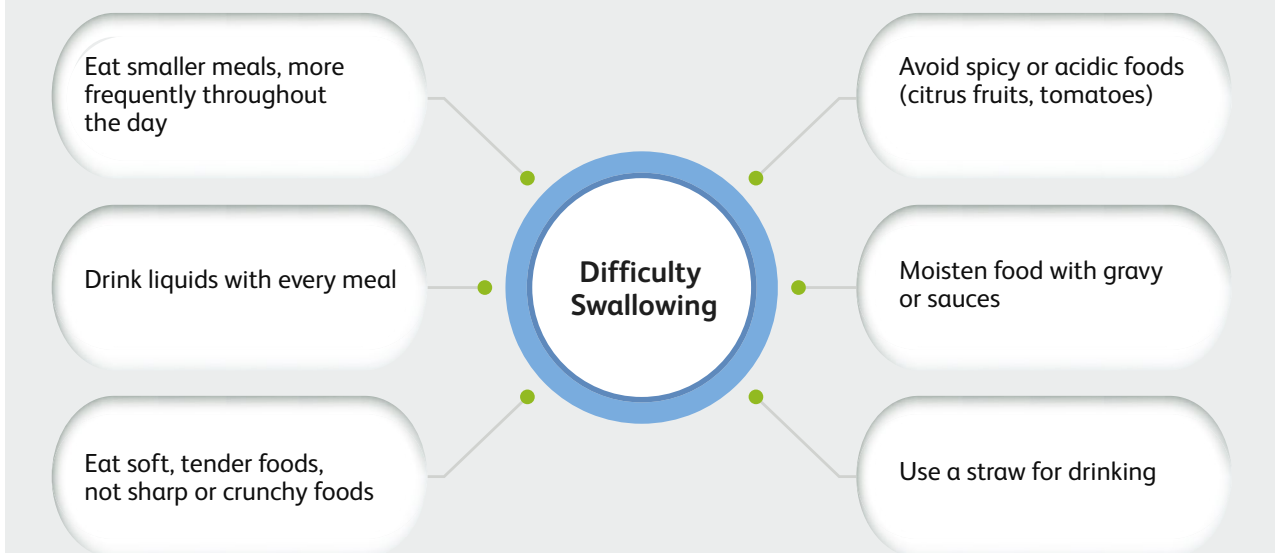
NOTES FOR NAVIGATORS

Monitor patients' nutritional preferences, challenges, and successes over time as they may change, which will require modifications to symptom management approaches.

FIGURE 5. Nutrition Tips to Help Manage Difficulty Swallowing and Mouth Sores



Information paraphrased from this resource: Leukemia & Lymphoma Society.
<https://pearlpoint.org/nutrition-management-of-sore-mouth-throat-and-tongue>



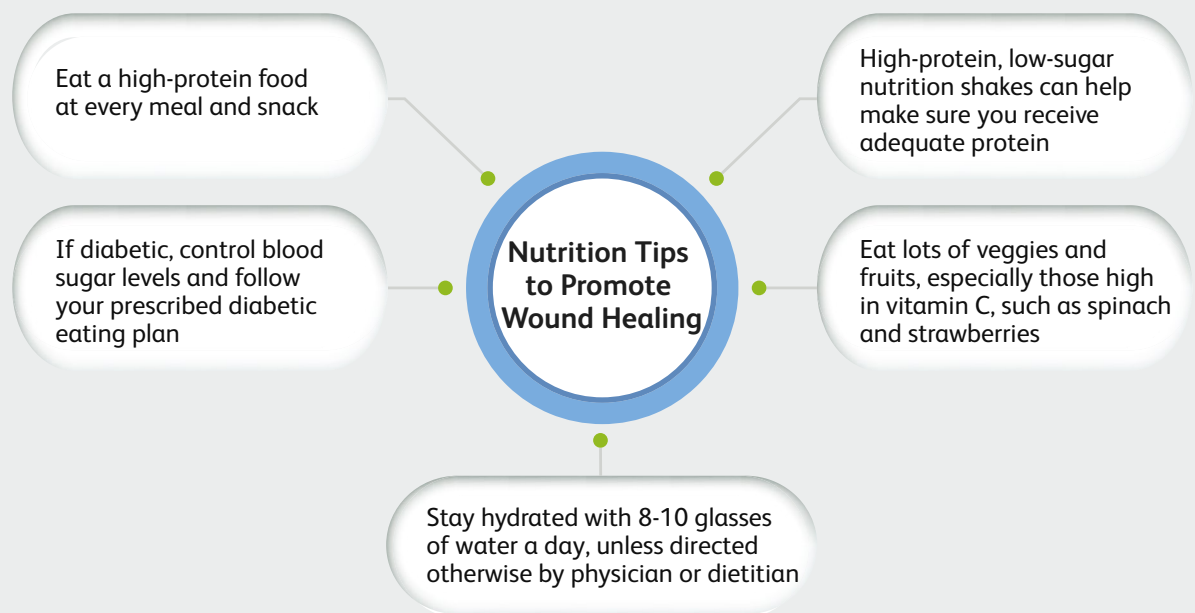
Information paraphrased from this resource: Leukemia & Lymphoma Society.
<https://pearlpoint.org/are-you-having-a-hard-time-swallowing>

FIGURE 6. Nutrition Tips to Help Manage Taste Changes and Wounds



Information paraphrased from this resource: ASCO.

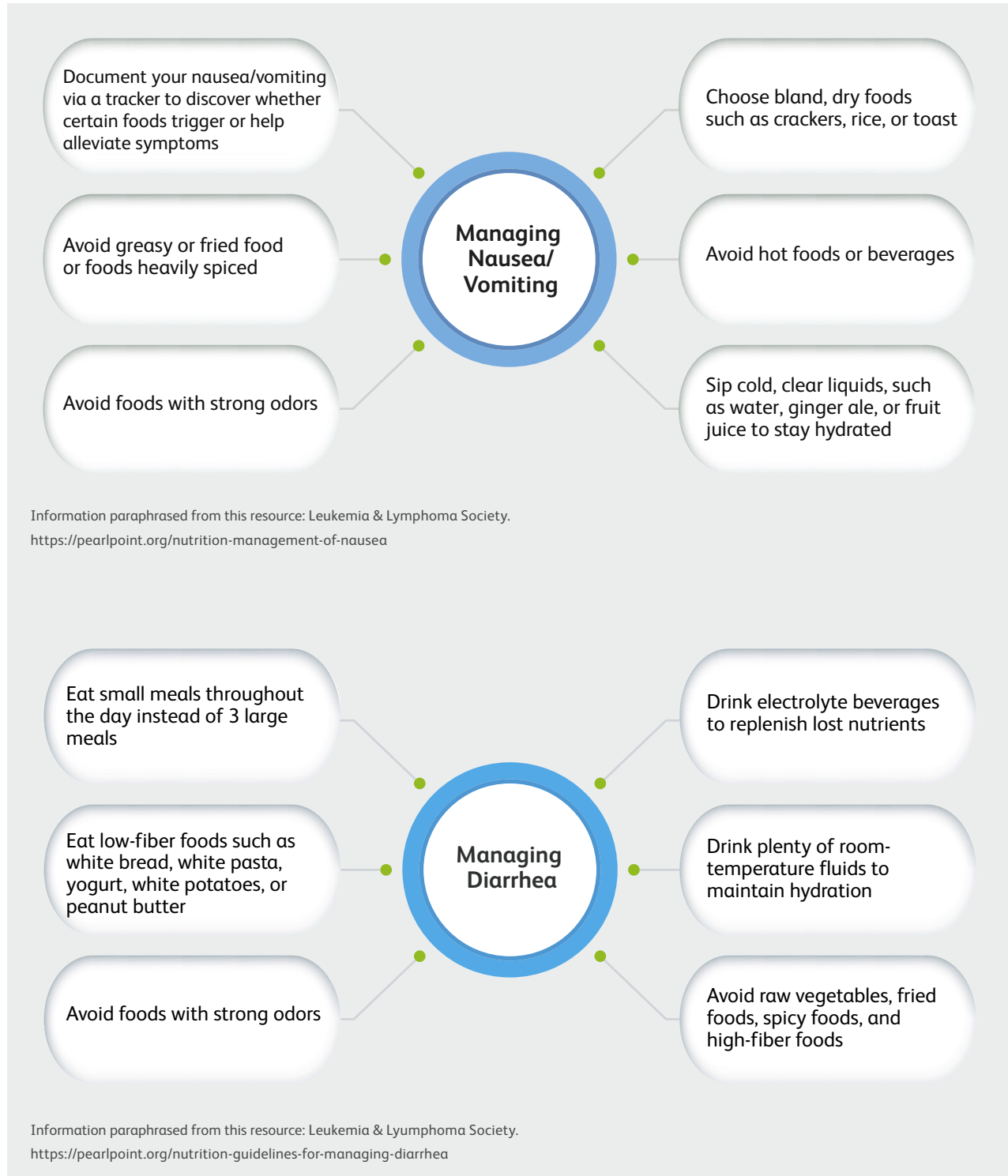
www.cancer.net/coping-with-cancer/physical-emotional-and-social-effects-cancer/managing-physical-side-effects/taste-changes



Information paraphrased from this resource: EatRight.org.

www.eatright.org/health/wellness/preventing-illness/nutrition-tips-to-promote-wound-healing

FIGURE 7. Nutrition Tips to Help Manage Nausea, Vomiting, and Diarrhea



References: 1. Presley CJ, Dotan E, Soto-Perez-de-Celis E, et al. Gaps in nutritional research among older adults with cancer. *J Geriatr Oncol.* 2016;7:281-292. 2. American Optometric Association. 6 nutrition questions you should be asking patients. Published July/August 2015. Accessed June 28, 2021. www.aoa.org/news/clinical-eye-care/health-and-wellness/6-nutrition-questions-you-should-be-asking-patients?ss=y 3. Cena H, Calder PC. Defining a healthy diet: evidence for the role of contemporary dietary patterns in health and disease. *Nutrients.* 2020;12:334. 4. Parkview Health. The importance of knowing how food affects your medication. Updated December 2, 2019. Accessed June 28, 2021. www.parkview.com/community/dashboard/the-importance-of-knowing-how-food-affects-your-medication 5. Zulman DM, Asch SM, Martins SB, et al. Quality of care for patients with multiple chronic conditions: the role of comorbidity interrelatedness. *J Gen Intern Med.* 2014;29:529-537. 6. Food Research & Action Center. Hunger is a health

issue for older adults: food security, health, and the federal nutrition programs. Published December 2019. Accessed June 28, 2021. <https://frac.org/wp-content/uploads/hunger-is-a-health-issue-for-older-adults-1.pdf> **7**. Battista B. Your care team: oncology dietician. SERO. Published April 7, 2014. Accessed June 28, 2021. <https://treatcancer.com/blog/oncology-dietitian> **8**. US Department of Agriculture. Survey tools. Updated September 9, 2020. Accessed June 28, 2021. www.ers.usda.gov/topics/food-nutrition-assistance/food-security-in-the-us/survey-tools **9**. Humana. Food insecurity and health: resource toolkit. Published unknown. Accessed June 28, 2021. https://populationhealth.humana.com/wp-content/uploads/2020/06/Food_Insecurity_Toolkit_2020_Final.pdf **10**. Gonsalves WC, Wrightson AS, Henry RG. Common oral conditions in older persons. *Am Fam Physician*. 2008;78:845-852. **11**. Cancer.net. Dental and oral health. Updated June 2019. Accessed June 28, 2021. www.cancer.net/coping-with-cancer/physical-emotional-and-social-effects-cancer/managing-physical-side-effects/dental-and-oral-health **12**. Wound Care Advisor. Meeting the nutritional needs of elderly cancer patients. Accessed September 22, 2020. <https://woundcareadvisor.com/meeting-the-nutritional-needs-of-elderly-cancer-patients> **13**. Mayo Clinic. Dehydration. Accessed June 28, 2021. www.mayoclinic.org/diseases-conditions/dehydration/symptoms-causes/syc-20354086 **14**. Leukemia & Lymphoma Society/Pearlpoint Nutrition Services. Nutrition tips for managing constipation. Accessed September 15, 2020. <https://pearlpoint.org/nutrition-management-of-constipation> **15**. HealthDay. Constipation and aging. Published June 12, 2021. Accessed June 28, 2021. <https://consumer.healthday.com/encyclopedia/aging-1/misc-aging-news-10/constipation-and-aging-647576.html> **16**. Blasiak J, Chojnacki J, Pawlowska E, et al. Nutrition in cancer therapy in the elderly-an epigenetic connection? *Nutrients*. 2020;12:3366. **17**. Tufts University. My plate for older adults. Published 2016. Accessed November 2, 2020. <https://hnrc.tufts.edu/myplate> **18**. American Cancer Society. Weight changes. Accessed June 28, 2021. www.cancer.org/content/dam/CRC/PDF/Public/8889.00.pdf **19**. American Society for Parenteral and Enteral Nutrition. A guide for adults: how to spot and talk about symptoms that could mean you're malnourished. Aging Healthfully Newsletter. Published September 2019. Accessed November 2, 2020. https://www2.illinois.gov/aging/CommunityServices/Documents/AgingHealthfullyNewsletter_Attachments_September2019.pdf **20**. Guigoz Y, Vellas BJ. Malnutrition im Alter: Das Mini Nutritional Assessment (MNA) [Malnutrition in the elderly: the Mini Nutritional Assessment (MNA)]. *Ther Umsch*. 1997;54:345-350. **21**. US Food & Drug Administration. Mixing medications and dietary supplements can endanger your health. Updated October 27, 2014. Accessed June 28, 2021. www.fda.gov/consumers/consumer-updates/mixing-medications-and-dietary-supplements-can-endanger-your-health **22**. Whole Family Living. Guide to buying local, seasonal produce. Accessed June 28, 2021. www.wholefamilyliving.com/whole-family-guide-buying-local-seasonal-produce **23**. American Heart Association. Fresh, frozen or canned fruits and vegetables: all can be healthy choices! Published unknown. Accessed June 28, 2021. www.heart.org/en/healthy-living/healthy-eating/add-color/fresh-frozen-or-canned-fruits-and-vegetables-all-can-be-healthy-choices **24**. Everyday Health. How to choose a healthier, tastier cooking oil. Updated December 11, 2018. Accessed June 28, 2021. www.everydayhealth.com/healthy-recipes/oils.aspx **25**. Lewis R. Great snack ideas for elderly. LoveToKnow.com. Published unknown. Accessed June 28, 2021. https://seniors.lovetoknow.com/Snacks_for_Elderly **26**. Lehman S, How many vegetables should you eat every day: an age-by-age guide for babies and beyond. Verywell Fit. Updated September 17, 2020. Accessed June 28, 2021. www.verywellfit.com/recommended-vegetable-servings-per-day-by-age-2506868 **27**. Amidor T. How much fruit should you eat? Food Network's Healthy Eats. Accessed June 28, 2021. www.foodnetwork.com/healthyeats/2013/02/how-much-fruit-should-you-eat **28**. American Heart Association. How much protein should I eat in a serving? Infographic. Accessed June 28, 2021. www.heart.org/en/healthy-living/healthy-eating/eat-smart/nutrition-basics/how-much-protein-should-i-eat-in-a-serving

X. CAREGIVER SUPPORT NEEDS

As a navigator, you are likely aware that many patients rely on caregivers—those family members, friends, and significant others who help them with activities of daily living (ADLs) and other tasks.¹ Berry et al. categorize these tasks into 4 distinct units:

1. ADLs, such as transportation and meals
2. Medical care, such as wound care, medication management, and injections
3. Social support, such as companionship, encouragement, and communication with friends and family
4. Advocacy, such as helping with providers or insurers.²

In addition, as a patient's illness progresses, so do the caregiver's responsibilities, creating even more demand on "time, energy, and emotional resources."² Cancer caregiving can present a myriad of challenges, and caregivers of older adults with cancer can face substantial burdens that affect their own health and quality of life.¹ Caregivers are essential members of the multidisciplinary team, as they know the most about the patient, have knowledge about symptoms or side effects the patient is experiencing, and can offer details about patient needs. Unfortunately, many caregivers have reported that they do not receive the support they need from the patient's healthcare team. A 2010 survey uncovered the following areas in which caregivers reported they would like greater support:

- **Information about keeping the patient safe at home**
- **How to find time for themselves**
- **How to manage their own physical and emotional stress**
- **Help with balancing work and family responsibilities**
- **Education on how to effectively talk with physicians.³**

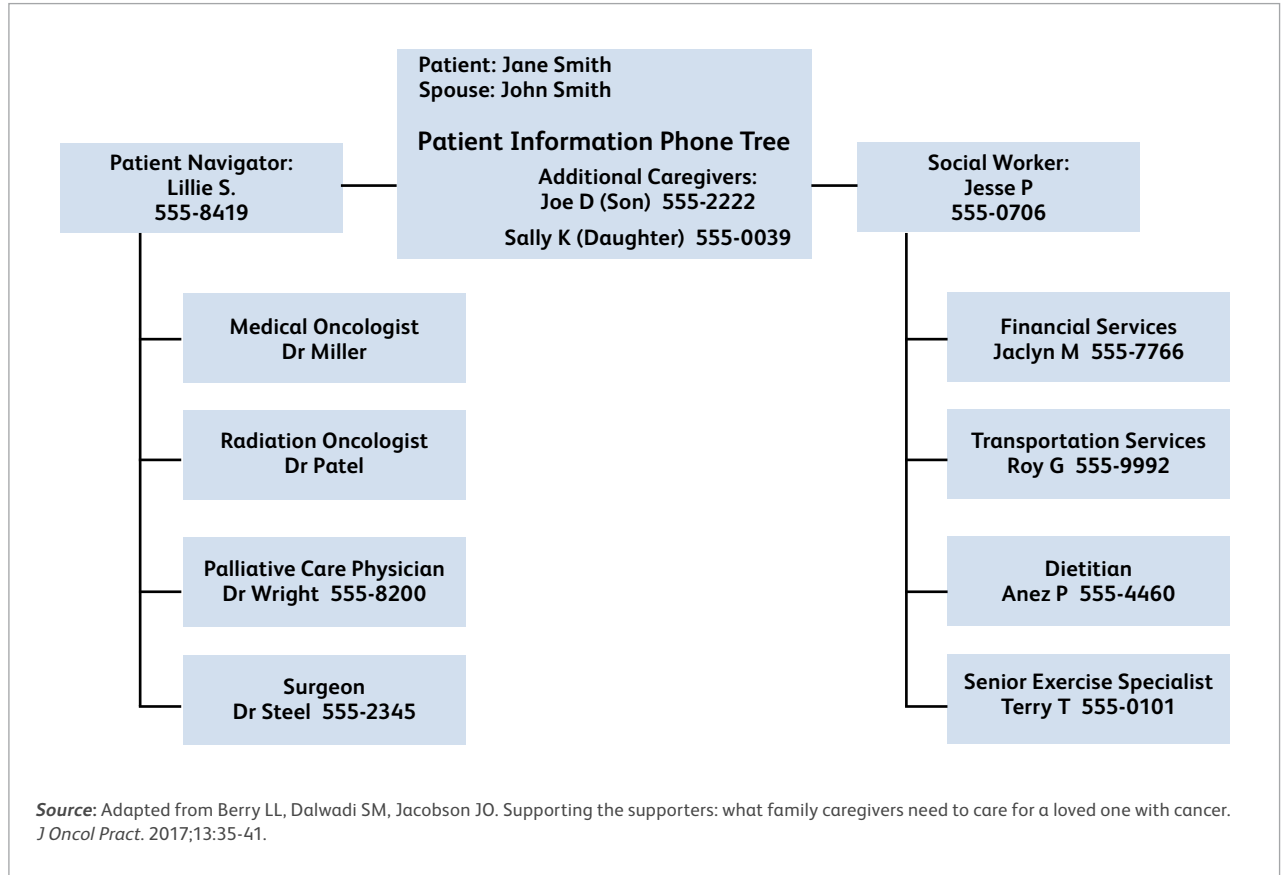
The caregiver role can create multiple competing demands and psychosocial stresses.¹ In the older adult population, the caregivers are often older adults themselves; in fact, the average age of today's caregiver is 50, and the average age of today's care recipient is 70. Because older adult caregivers could easily slip into the frail older adult category by ignoring their own medical, social, emotional, and functional needs, it is important to evaluate their circumstances.³ In some instances, navigators may work with 70-, 80-, or 90-year-old caregivers caring for a spouse or loved one with cancer. As we know, ability and health status are not determined by chronologic age; nevertheless, a caregiver experiencing mental or emotional caregiver strain has a higher mortality risk.^{4,5} In addition, many caregivers attempt to balance caregiving with a job, financial responsibilities, and other family responsibilities.⁶

To support the caregiver and provide excellent information for the entire multidisciplinary team, the creation of a Care Team Tree (see **Figure**)² can provide a snapshot of all primary and secondary caregivers and serve as a resource guide for the caregiver when questions or concerns arise.

Additional interventions the navigator can perform to assist in easing caregiver burden include the following:

- Take time to speak with the caregiver one to one. You can do this via a videoconference meeting, a telephone call, or other medium at a time convenient for the caregiver. This direct one-to-one time with you can allow the caregiver to openly express feelings of anger, sadness, and depression without worrying about hurting loved ones
- Provide educational resources proactively and ask caregivers to "teach-back" or show on videoconferencing any instructions given from the clinical team
- Provide information about caregiver education courses or support groups from your hospital system if possible and encourage participation

FIGURE. The Care Team Tree



- Assist caregivers by serving as the liaison between the physician care team and the home caregiving team. Clarify doctors orders, assist in scheduling appointments, set up transportation assistance, explain medication orders, and help the caregiver organize the details
- Refer the caregiver to any appropriate support services offered by your organization or community, such as financial counseling, integrative care, respite care, and community support resources, to name a few.²

Finally, recognizing and assessing the dyad dynamics between the patient and caregiver can be helpful for navigators.⁷ How do the patient and caregiver communicate and interact with one another? Sometimes, caregivers and family members won't let patients do things for themselves; they hover, coddle, and may even answer questions on the patient's behalf without letting him or her speak. Other times, the patient has been abandoned by the family, only to see family members appear during times of chronic illness to fight about what care the patient should or should not receive. It is important for navigators to obtain a clear picture of family dynamics to best serve the patient and his or her caregiver.⁸ An overly anxious caregiver may provide you an opportunity for a one-to-one discussion about the importance of self-care when caring for others. It is also important for navigators to ensure caregivers are aware of patients' wishes and help advocate for patients when communicating those wishes.⁹

The Cancer Community Support site has a section for caregivers that can be shared to further support family and friends in this role whether they are near or far. These links are:

www.cancersupportcommunity.org/living-cancer-topics/caregivers

www.cancersupportcommunity.org/living-cancer-topics/caregivers/support-distance

References: 1. National Cancer Institute. Support for caregivers of cancer patients. Updated August 6, 2020. Accessed June 18, 2021. www.cancer.gov/about-cancer/coping/caregiver-support 2. Berry LL, Dalwadi SM, Jacobson JO. Supporting the supporters: what family caregivers need to care for a loved one with cancer. *J Oncol Pract.* 2017;13:35-41. 3. National Alliance for Caregiving in Collaboration with AARP. Caregiving in the U.S.: A focused look at those caring for someone age 50 or older: Executive Summary. Accessed November 5, 2020. https://assets.aarp.org/rgcenter/ill/caregiving_09_fr.pdf 4. Schulz R, Beach SR. Caregiving as a risk factor for mortality: The Caregiver Health Effects Study. *J Am Med Assoc.* 1999;282:2215-2219. 5. Yates ME, Tennsted S, Chang BH. Contributors to and mediators of psychological wellbeing for informal caregivers. *J Gerontol.* 1999;54:12-22. 6. American Cancer Society. If you're about to become a cancer caregiver. Updated October 31, 2019. Accessed June 18, 2021. www.cancer.org/treatment/caregivers/if-youre-about-to-become-a-cancer-caregiver.html 7. Lyons KS, Zarit SH, Sayer AG, Whitlatch CJ. Caregiving as a dyadic process: perspectives from caregiver and receiver. *J Gerontol B Psychol Sci Soc Sci.* 2002;57:P195-P204. 8. Jabbari B, Rouster AS. Family dynamics. In: StatPearls [Internet]. Accessed June 18, 2021. www.ncbi.nlm.nih.gov/books/NBK560487 9. Schubart JR, Reading JM, Penrod J, et al. Family caregivers' characterization of conversations following an ACP event. *Am J Hosp Palliat Care.* 2018;35:1161-1167.



XI. NAVIGATION IN THE CONTEXT OF AGING ADULTS WITH CANCER

In today's climate of value-based healthcare, increased healthcare spending, and decreased healthcare resourcing, navigation has become an increasingly valuable option for tackling these issues.¹ In 2020, cancer-related costs were expected to reach \$173 billion per year, and part of that increase in cost is related to an expanding older adult population and the high costs associated with geriatric care.² Studies have shown that patient navigation, by focusing on the goals of oncology navigation through the entire care continuum, decreases resource use and overall cost.² In addition, with a focus on increased quality, patient satisfaction, and decreased costs, innovative navigation programs, such as the Patient Care Connect Program at the University of Alabama at Birmingham Health System Cancer Community Network, help define excellence in geriatric navigation practice:

The program focuses on enhancing the health of patients, with emphasis on patient empowerment and promoting proactive participation in health care. Navigator training emphasizes palliative care principles and includes development of skills to facilitate conversations about ACP [advance care planning]. Lay navigators are integrated into the healthcare team, with the support of a nurse supervisor, physician medical director, and administrative champion. The intervention focuses on patients with high needs to reach those with the greatest potential for benefit from supportive services. Navigator activities are guided by frequent distress assessments, which help to identify patient concerns across multiple domains, triage patients to appropriate resources, and ultimately overcome barriers to care.²

This toolkit has offered an overview of tools, tips, and concepts to guide patient navigation practices when working with older adults. It's important to revisit some basic navigation concepts, including goals of navigation (**Figure 1**)³ and navigator competencies (**Figure 2**).⁴ The goals of navigation when working with older adults do not vary from those when working with oncology patients in general; instead, use the tools and resources in this toolkit to provide geriatric-sensitive, individualized care to patients aged ≥65 years while also remaining true to the core tenants of navigation: Coordinating care, education, advocacy, identifying barriers to care, and providing support.

In addition, the core competencies of navigators concerning continuum of care and survivorship remain consistent with those for general oncology navigation (**Figure 3**).⁵ It is your role as the navigator to incorporate your specialized knowledge and resources related to geriatric oncology care into your core practice.

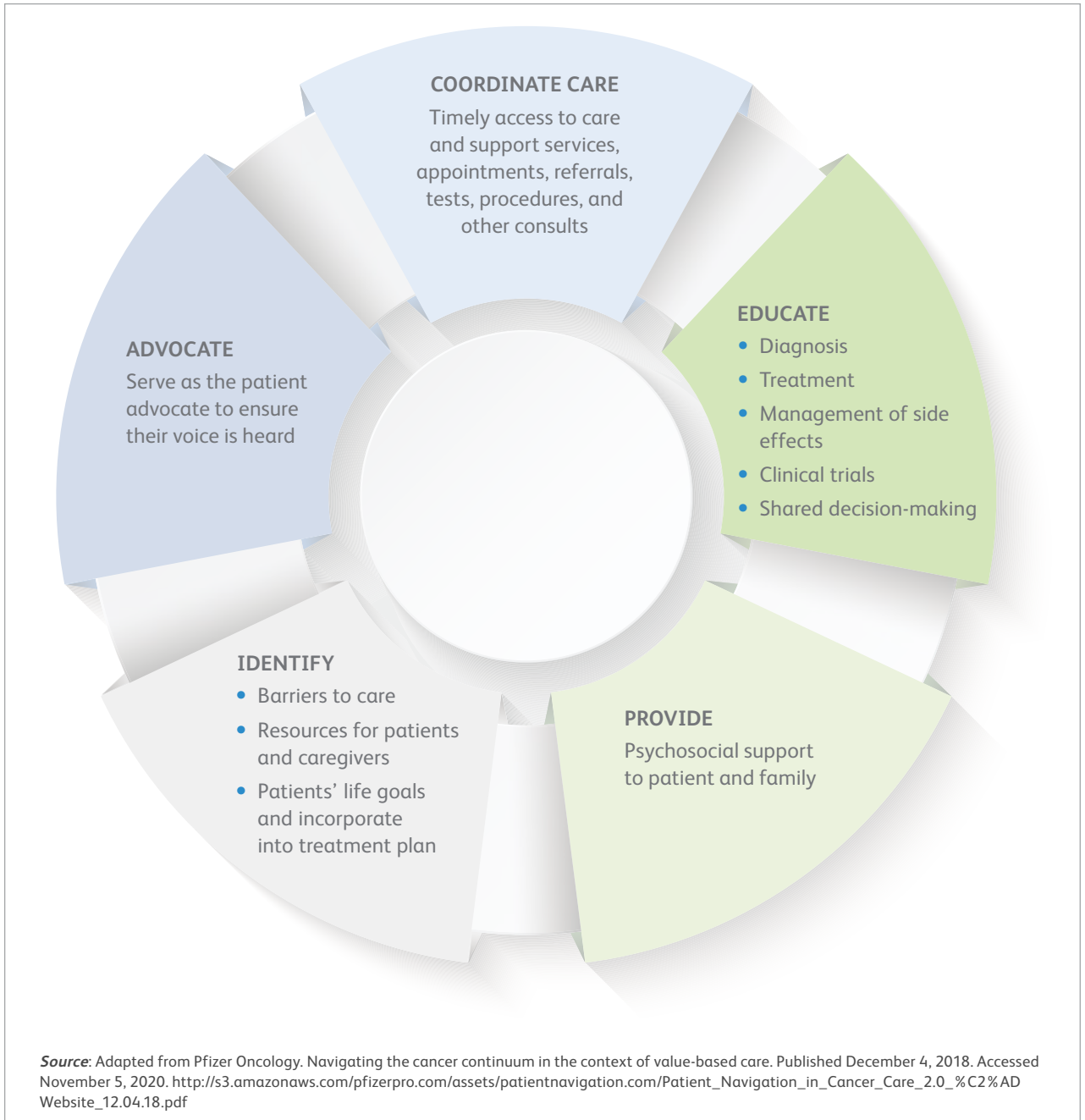
FIGURE 1. The Goals of Oncology Navigation

FIGURE 2. Competencies of the Navigator with Regard to Continuum of Care/Care Transitions

- Understanding the Chronic Care Model
- Identification/intervention of clinical and service barriers to care
- Understanding the patient care process/cancer care continuum (prevention/screening, risk assessment, diagnosis, clinical trials, treatment, survivorship/end-of-life care) and providing referrals to appropriate disciplines and transitions across the continuum of care based on a comprehensive assessment
- Providing patient-/family-centered education (screening, diagnosis, treatment, side effects and management, survivorship/end of life)
- Identifying models of navigation
- Understanding and practicing cultural awareness
- Understanding and practicing health literacy
- Increasing communication among the healthcare team/multidisciplinary approach to care
- Participating in tumor board/cancer conference
- Understanding of National Comprehensive Cancer Network Guidelines, Commission on Cancer, Institute of Medicine, and other national standards in relation to oncology care
- Using evidence-based guidelines and tools in the assessment, intervention, and evaluation of patient care
- Understanding of clinical trials (eligibility, enrollment criteria)
- Understanding of and participation in performance/process improvement across the continuum of care
- Understanding of available institution, community, and state/national resources; collaborating with available community resources
- Providing psychosocial support and empowering the patient and family with treatment decisions

Source: Bellomo C, Goetz P. Continuum of care and care transitions. *J Oncol Navig Surviv.* 2016;7:30.

FIGURE 3. Competencies of the Navigator in Survivorship

- Establishing goal setting, life goals
- Integrating survivor's goals/preferences into plan of care
- Providing survivorship education on late and long-term effects
- Coordinating plans of care
- Understanding of palliative and hospice care
- Understanding of Commission on Cancer Standard 3.3 Survivorship Care Plan
- Understanding of Institute of Medicine report *From Cancer Patient to Cancer Survivor: Lost in Transition*

Source: Bellomo C. Survivorship/end-of-life care. *J Oncol Navig Surviv.* 2017;3:124-126.

References: 1. Strusowski T. Navigation metrics and value-based care. Academy of Oncology Nurse & Patient Navigators. Published September 26, 2017. Accessed June 18, 2021. <https://aononline.org/expert-commentary/navigation-101/867-navigation-metrics-and-value-based-care> 2. Rocque GB, Partridge EE, Pisu M, et al. The Patient Care Connect Program: transforming health care through lay navigation. *J Oncol Pract.* 2016;12:e633-e642. 3. Pfizer Oncology. Navigating the cancer continuum in the context of value-based care. Published December 4, 2018. Accessed November 5, 2020. http://s3.amazonaws.com/pfizerpro.com/assets/patientnavigation.com/Patient_Navigation_in_Cancer_Care_2.0_%C2%ADWebsite_12.04.18.pdf 4. Bellomo C, Goetz P. Continuum of care and care transitions. *J Oncol Navig Surviv.* 2016;7:30. 5. Bellomo C. Survivorship/end-of-life care. *J Oncol Navig Surviv.* 2017;3:124-126.



XII. EXAMPLE RESOURCES FOR OLDER ADULTS WITH CANCER, CARETAKERS, AND LOVED ONES

Because resources often change, review each of the links provided in this section to ensure they are up-to-date and accurate before sharing with patients or caregivers. Pfizer (and the Geriatric Care Toolkit Committee) is/are not responsible for the content on these third-party sites.

General Resources

N4A (National Association of Area Agencies on Aging)

www.n4a.org

United States Department of Labor

www.sparq.doleta.gov/login.cfm

National Council on Aging

www.ncoa.org

AARP (formerly known as the American Association of Retired Persons)

www.aarp.org

Programs of All-Inclusive Care for the Elderly Benefits (PACE)

www.medicaid.gov/medicaid/long-term-services-supports/pace/programs-all-inclusive-care-elderly-benefits/index.html

National Institute on Aging

www.nia.nih.gov

MyHealthfinder

<https://health.gov/myhealthfinder>

The National Directory of Home Modification and Repair Resources

<https://homemods.org/national-directory>

Cancer.Net Resources for Older Adults

www.cancer.net/navigating-cancer-care/older-adults/resources-older-adults

CancerCare Support for Elderly

www.cancercare.org/tagged/elderly

National Caucus and Center on Black Aging

<https://ncba-aging.org>

Financial Resources

Medicare.gov Medicare Cost Overview

www.medicare.gov/your-medicare-costs/index.html

Special Committee on Aging Financial Fraud and Abuse Hotline

www.aging.senate.gov/fraud-hotline

National Association of Area Agencies on Aging Tips to Avoid Financial Exploitation

www.n4a.org

Senior Assistance Programs

www.needhelppayingbills.com/html/senior_assistance_programs.html

Financial Assistance for Senior Citizens

www.debt.org/advice/financial-assistance-for-senior-citizens

(continued)

Exercise Resources

Exercise and Seniors

<https://familydoctor.org/exercise-seniors>

Exercise for Older Adults

<https://medlineplus.gov/exerciseforolderadults.html>

Exercise for Seniors

www.independence4seniors.com/resources/exercise-for-seniors

Nutrition Resources

Meals on Wheels

www.mealsonwheelsamerica.org

USDA Nutrition.gov Food Assistance and Nutrition Programs for Seniors

www.nutrition.gov/topics/food-assistance-programs/nutrition-programs-seniors

USDA ChooseMyPlate for Older Adults

www.choosemyplate.gov/browse-by-audience/view-all-audiences/adults/older-adults

Support and Caregiver Resources

Eldercare Locator

<https://eldercare.acl.gov/Public/Index.aspx>

Age in Place

www.ageinplace.org

National Association of Professional Geriatric Care Managers

www.aginglifecare.org/ALCA/About_Aging_Life_Care/ALCA/About_Aging_Life_Care/What_you_need_to_know.aspx

HomeAdvisor Home Accommodation Cost Guide for People with Physical Disabilities

www.homeadvisor.com/cost/disability-accommodation

Hospice Foundation of America

www.hospicefoundation.org

National Alliance for Caregiving

www.caregiving.org

Seniors' Guide to Aging at Home Safely and With Dignity

www.mortgagecalculator.org/helpful-advice/aging-with-dignity.php

New Beginnings Addiction Prevention for Seniors

www.newbeginningsdrugrehab.org/guide-to-addiction-prevention-for-seniors

Addiction Support

www.rehabspot.com/alcohol/who-alcoholism-affects/seniors

CancerCare Living With Cancer Support Group for Patients Age 65 and Older

www.cancercare.org/support_groups/129-living_with_cancer_a_group_for_older_adults_65

GLOSSARY OF TERMS

A

Activities of daily living (ADLs): Skills required to manage one's basic physical needs, including personal hygiene or grooming, dressing, toileting, transferring or ambulating, and eating.

Ageism: Stereotyping, prejudice, and discrimination against people based on their age.

Alzheimer's disease: A brain disorder that seriously affects a person's ability to carry out daily activities. It involves the parts of the brain that control thought, memory, and language, and symptoms include loss of memory, confusion, difficulty thinking, and changes in language, behavior, and personality. Also called Alzheimer's dementia.

Amyotrophic lateral sclerosis (ALS): A group of rare neurologic diseases that involve the nerve cells (neurons) responsible for controlling voluntary muscle movement, such as chewing, walking, and talking. The symptoms get worse over time, and there is no cure or effective treatment to halt or reverse the progression of the disease.

Angina: Chest pain or discomfort due to coronary heart disease and occurs when the heart muscle does not get as much blood as it needs.

Aorta: The body's main artery.

Arrhythmias: A problem with the rate or rhythm of your heartbeat. It means that your heart beats too quickly, too slowly, or with an irregular pattern. When the heart beats faster than normal, it is called tachycardia. When the heart beats too slowly, it is called bradycardia. The most common type of arrhythmia is atrial fibrillation, which causes an irregular and fast heartbeat.

Atrial fibrillation: The rapid, irregular beating of the left atrium (upper chamber) of the heart. People may have no symptoms, but others may experience a fluttering feeling in the chest above the heart, chest pain, lightheadedness or fainting, shortness of breath, and fatigue.

B

Baroreceptors: Receptors that relay information that comes from blood pressure. There are high-pressure arterial baroreceptors and low-pressure volume receptors, which are both stimulated by stretching of the vessel wall within the autonomic nervous system.

Benign prostatic hypertrophy (BPH): A benign (not cancer) condition in which an overgrowth of prostate tissue pushes against the urethra and the bladder, blocking the flow of urine.

Biological age: This calculated age is assessed by a person's physical and mental functions and takes many lifestyle factors into consideration, including diet, exercise, and sleeping habits. Also referred to as physiological age.

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Blood clot: Platelets (a type of blood cell) and proteins in your plasma (the liquid part of blood) work together to stop the bleeding by forming a clot over the injury. Normally, your body will naturally dissolve the blood clot after the injury has healed. Sometimes, clots form on the inside of vessels without an obvious injury or do not dissolve naturally and it may detach from where it started. Deep vein thrombosis (DVT) is a type of clot that forms in a major vein of the leg or, less commonly, in the arms, pelvis, or other large veins in the body and can travel through the heart to the lungs where it becomes wedged, preventing adequate blood flow. This is called a pulmonary (lung) embolism (PE) and can be extremely dangerous.

C

Cataracts: A clouding of the lens in the eye with common symptoms of blurry vision, colors that seem faded, glare, double vision, or a halo around lights.

Cerebral dendrites: Antennae-like projections that are designed to receive communications from other cells.

Chronological age: Number of years a person has been alive.

Comprehensive geriatric assessment (CGA): A multidimensional assessment of an older person which considers health and well-being and formulates a plan to address issues which are of concern to the older person (and their family caregivers when relevant), arranges interventions according to the plan, and then reviews the impact.

Conductive hearing loss: Hearing loss that occurs because of a mechanical problem in the outer or middle ear due to bones of the ear not conducting sound properly or the eardrum is not vibrating in response to sound.

Congestive heart failure (CHF): A condition in which the heart cannot pump enough blood to meet the body's needs. The weakening of the heart's pumping ability causes blood and fluid to back up into the lungs. It also causes fluid to build up in the feet, ankles, and legs (edema). Other effects include tiredness and shortness of breath.

Coronary artery disease (CAD): The arteries that supply blood to the heart muscle become hardened and narrowed due to the buildup of cholesterol and other material, called plaque, on their inner walls. As it grows, less blood can flow through the arteries, the heart muscle cannot get the blood or oxygen it needs, and this can lead to chest pain or a heart attack.

CRASH: Chemotherapy Risk Assessment Scale for High-Age Patients score that offers a validated, clinically applicable means of predicting significant differences in the risk of severe toxicity in older cancer patients starting a new chemotherapy and is a useful tool to individualize treatment choices on an objective basis.

D

Delirium: Sudden severe confusion due to rapid changes in brain function that occur with physical or mental illness.

Dementia: Loss of mental function that is severe enough to affect your daily life and activities.

Dermis: The middle layer of skin that contains blood vessels, nerves, hair follicles, and oil glands. It provides nutrients to the epidermis or outer layer of skin.

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Detached retina: Separation of the light-sensitive membrane (retina) in the back of the eye from its supporting layers. Symptoms can be bright flashes of light, blurred vision, new floaters in the eye that appear suddenly, or decreased peripheral vision that seems like a curtain or shade has fallen across the vision.

Diabetic retinopathy: Uncontrolled diabetes can damage the small blood vessels in the retina, the back part of your eye. It is a main cause of decreased vision or blindness.

E

Electronic health record: Also called EHR or EMR. A chart at a healthcare facility with medical information in an electronic format for computer access.

F

Fatigue: A feeling of tiredness that if persists for weeks, needs to be evaluated by a doctor. It is time to see your doctor.

G

Gastroesophageal reflux disease (GERD): When a muscle at the end of your esophagus (the tube that carries food from your mouth to your stomach) does not close properly, this allows stomach contents to leak back, or reflux, into the esophagus and irritate it.

Geriatrics: Geriatrics is the branch of healthcare that focuses on the unique health needs of older people.

Geriatric 8 (G8): This screening tool contains 8 questions around food intake, weight loss, mobility, neuropsychological problems, body mass index, prescription use, health status, and age to identify elderly cancer patients who would benefit from comprehensive geriatric assessment.

Glaucoma: A group of diseases that can damage the eye's optic nerve when the fluid pressure inside the eyes slowly rises. There are no symptoms at first and eventually one will lose their peripheral or side vision. They seem to be looking through a tunnel.

Glial support cells: Also called neuroglia and are non-neuronal cells in the central nervous system (brain and spinal cord) and the peripheral nervous system that do not produce electrical impulses. They provide support and protection for neurons.

Glomerular filtration rate (GFR): A blood test that checks how well your kidneys are working.

H

Health literacy: How well a person can find and understand the health information and services that they need. It is also about using the information and services to make good health decisions.

Heart murmur: A blowing, whooshing, or rasping sound heard during a heartbeat that is caused by turbulent (rough) blood flow through the heart valves or near the heart.

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Hospice care: End-of-life care. A team of healthcare professionals and volunteers provides it. They give medical, psychological, and spiritual support. The goal of the care is to help people who are dying have peace, comfort, and dignity.

Hypercapnia: A buildup of carbon dioxide in the bloodstream.

Hypertension: High blood pressure that develops over time as you get older or can be caused by another medical condition.

I

Instrumental activities of daily living (IADLs): Complex activities that are related to the ability to live independently in the community, such as managing finances and medications, food preparation, housekeeping, and laundry.

Intercultural Cancer Council (ICC): A nonprofit organization that works to promote policies, programs, and partnerships to eliminate inequity in cancer treatment among racial and ethnic minorities as well as the medically underserved populations in the United States.

K

Kyphosis: A curving of the spine that causes a bowing or rounding of the back. This leads to a hunchback or slouching posture.

M

Macular degeneration: Also called age-related macular degeneration (AMD) and is a disease that destroys your sharp, central vision. It is a leading cause of vision loss in Americans aged ≥ 60 years. Blurred vision is a common early symptom.

Malnutrition: “Bad nutrition” is a condition in which there is a difference between the amount of food and other nutrients that the body needs for proper growth and health and the amount that it receives or takes in (absorbs).

Medicaid: Government health insurance that helps low-income people in the United States to pay their medical bills. The federal government sets up general guidelines for the program, but each state has its own rules and one must meet certain requirements to get Medicaid assistance.

Medicare: The US government’s health insurance program for people aged ≥ 65 years. Some people aged < 65 years can qualify for Medicare if they have disabilities, such as permanent kidney failure or amyotrophic lateral sclerosis. It does not cover all medical expenses or the cost of most long-term care.

Melanocytes: Cells that color the skin.

Middle old: Elderly adults between the ages of 75 and 84 years.

Mini-cog assessment: A 3- to 5-minute test that includes recalling a 3-word list of objects and drawing a clock and is used to screen for mild cognitive impairment (MCI). People with MCI may notice changes in their memory and other mental functions.

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N

Neurons: Nerve cells that receive sensory input from the external world and send motor commands to our muscles that control skeletal muscle activities, such as walking, breathing, speaking, and swallowing.

Neuropathy: Damage or dysfunction of one or more nerves that typically results in numbness, tingling, muscle weakness, and pain in the affected area.

Neurotransmitters: A specialized chemical messenger (eg, dopamine, norepinephrine, serotonin) that sends messages from one nerve cell to another.

Nocturnal: Events that happen at night.

Nutritional Health Checklist: The American Academy of Family Physicians developed the questions to address the prevalence of malnutrition among older adults. It differentiates among adequate nutritional status, malnutrition risk, and malnutrition.

O

Older Adult Sensitivity Training: An interactive training program about the specific needs and challenges of older adults where participants experience sensory changes associated with aging through simulation.

Oldest old: Elderly adults over 85 years of age.

Orthostatic hypotension: A sudden fall in blood pressure that occurs when a person assumes a standing position.

Osteopenia: A condition that begins with bone mass loss and the bones get weaker. It is very common with aging.

Osteoporosis: A disease that thins and weakens the bones. The bones become fragile and fracture (break) easily, especially the bones in the hip, spine, and wrist; it is more common in older women.

P

Palliative care: Treatment of the discomfort, symptoms, and stress of a serious illness received at any stage of an illness. The goal is to make you comfortable and improve your quality of life.

Parkinson's disease: A type of movement disorder that happens when nerve cells in the brain do not produce enough of a brain chemical called dopamine. Symptoms such as trembling of hands, arms, legs, jaw and face, stiffness of the arms, legs, and trunk, and slowness of movement begin gradually, often on one side of the body and then they affect both sides.

Peripheral neuropathy: Peripheral nerves carry information to and from the brain as well as carry signals to and from the spinal cord to the rest of the body. Peripheral neuropathy means these nerves do not work properly. Symptoms may be tingling or burning in the arms and legs or weakness.

Peripheral vascular disease (PVD): Peripheral arteries and veins carry blood to and from your arm and leg muscles and the organs in and below your stomach area. PVD involves damage to or blockage in the blood vessels distant from your heart—the peripheral arteries and veins.

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Polypharmacy: Taking more than one medicine to treat a single condition or taking different medicines to treat more than one health problem.

Postvoid residual (PVR): A test that involves passing a catheter into the bladder following urination to drain and measure any urine that is left in the bladder after urination is completed. The PVR is a simple but effective technique for diagnosing bladder dysfunction.

Presbycusis: Hearing loss that creates difficulty hearing high-pitched sounds and verbal sounds, such as s, z, sh, and ch. Background noise makes it even more difficult for these individuals to hear.

R

Retina: Part of the eye that senses light.

Retinopathy: Occurs when disease has damaged the retina. There can be partial or complete loss of vision. It may develop slowly or suddenly and can get better on its own or lead to permanent damage.

S

Sensorineural hearing loss: Damage to the inner ear often caused by heredity, infection, trauma, ototoxic drugs, and other variables.

Sinus node (SA node): An area of the heart where the electrical impulse that signals your heart to contract begins and the signal travels through the heart along a set electrical pathway. This is your heart's natural pacemaker.

Stem cells: Cells with the potential to develop into many different types of cells in the body. They can divide and renew themselves over a long time, be unspecialized, so they cannot do specific functions in the body or have the potential to become specialized cells, such as muscle cells, blood cells, and brain cells.

Synapse: A physical gap between 2 neurons that functions as the site of information transfer from one neuron to another.

T

Telehealth: The use of communications technologies to provide healthcare from a distance, such as computers, cameras, videoconferencing, the Internet, and satellite and wireless communications.

Temporal arteritis: Inflammation and damage to the blood vessels that supply blood to the head, neck, upper body, and arms, also known as giant cell arteritis.

Thermoregulation: Skin acts as a body temperature regulation. When the skin is exposed to a cold temperature, the blood vessels in the dermis constrict. This allows the blood, which is warm, to bypass the skin and the skin then becomes the temperature of the cold it is exposed to. Body heat is conserved since the blood vessels are not diverting heat to the skin anymore.

Tinnitus: A ringing in the ears that can sound like roaring, clicking, hissing, or buzzing. It may be soft or loud, high pitched or low pitched, and be heard in either one or both ears.

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U

Urinary incontinence (UI): Loss of bladder control with symptoms that can range from mild leaking to uncontrollable wetting. It becomes more common with age, and women experience UI twice as often as men.

V

Varicose veins: Swollen, twisted veins that you can see just under the skin. They usually occur in the legs but also can form in other parts of the body.

Vulnerable Elders Survey-13 (VES-13): A screening tool that can be administered by nonmedical personnel in approximately 4 minutes in person or over the telephone to assess vulnerability among elderly patients in various clinical and research settings.

Y

Young old: Elderly adults between the ages of 65 and 74 years.

Sources: World Health Organization. World report on aging and health 2015. Accessed September 21, 2020. https://apps.who.int/iris/bitstream/handle/10665/186463/9789240694811_eng.pdf National Cancer Institute Dictionary of Cancer Terms. Accessed September 25, 2020. www.cancer.gov/publications/dictionaries/cancer-terms. US National Library of Medicine MedlinePlus Medical Encyclopedia. Accessed September 23, 2020. <https://medlineplus.gov/encyclopedia.html> National Institute of Neurological Disorders and Stroke. Amyotrophic Lateral Sclerosis (ALS) Fact Sheet. Accessed September 23, 2020. [www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Amyotrophic-Lateral-Sclerosis-ALS-Fact-Sheet#:~:text=Amyotrophic%20lateral%20sclerosis%20\(ALS\)%20is,for%20controlling%20voluntary%20muscle%20movement](http://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Amyotrophic-Lateral-Sclerosis-ALS-Fact-Sheet#:~:text=Amyotrophic%20lateral%20sclerosis%20(ALS)%20is,for%20controlling%20voluntary%20muscle%20movement)

