PROJECT ECHO MINISERIES:

BEST PRACTICES IN DEMENTIA CARE

Hosted in collaboration with the
Alzheimer's Association

Seven weekly sessions
Thursday, 3 – 4 p.m. ET | March 7 – April 18

nhpco.org/projectecho

NHPCO

Summary and Wrap Up

April 18, 2024

Disclosures

Disclosure

The faculty and planners for this educational event have no relevant financial relationship(s) with ineligible companies to disclose.

Data Collection

In order to support the growth of the ECHO® movement, Project ECHO® collects participation data for each ECHO® program. Data allows Project ECHO® to measure, analyze, and report on the movement's reach. Data is used in reports, on maps and visualizations, for research, for communications and surveys, for data quality assurance activities, and for decision-making related to new initiatives.

Evaluation

Please complete program evaluation materials following each session.

Ground Rules and Video Teleconferencing Etiquette

- This is an all share-all learn format; judging is not appropriate
- Respect one another – it is ok to disagree but please do so respectfully
- Participants – introduce yourself prior to speaking
- One person speaks at a time
- Disregard rank/status
- Remain on mute unless speaking and eliminate or reduce environmental distractions to improve sound/video quality
- Use video whenever possible; make eye contact with the camera when you are speaking
- **Do not disclose protected health information (PHI) or personally identifiable information (PII)**

Today's Agenda

- Introduction of Faculty – NHPCO Team
- Didactic Presentation – Faculty
- Case Study Presentation – Faculty
- Discussion – Session Participants, Faculty, and NHPCO Team
- Key Takeaways – Faculty and NHPCO Team
- Closing Remarks – NHPCO Team

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Didactic Presentation

2024 ALZHEIMER'S DISEASE FACTS AND FIGURES

NEARLY
7 MILLION
AMERICANS ARE LIVING WITH ALZHEIMER'S

1 IN 3
SENIORS DIES WITH ALZHEIMER'S OR ANOTHER DEMENTIA

IT KILLS MORE THAN
BREAST CANCER AND **PROSTATE CANCER**
+
COMBINED

OVER **11 MILLION**
AMERICANS PROVIDE
UNPAID CARE
FOR PEOPLE WITH
OR OTHER DEMENTIAS

BETWEEN 2000 AND 2021, DEATHS
FROM HEART DISEASE HAVE
DECREASED 2.1%

WHILE DEATHS FROM
ALZHEIMER'S DISEASE HAVE
INCREASED 141%

N 2024, ALZHEIMER'S
AND OTHER DEMENTIAS WILL
COST THE NATION
$360 BILLION
$$$$$
BY 2050, THESE COSTS
COULD RISE TO NEARLY
$1 TRILLION

THESE CAREGIVERS
PROVIDED MORE THAN
18 BILLION HOURS
VALUED AT NEARLY
$347 BILLION

THE LIFETIME RISK FOR
ALZHEIMER'S AT AGE 45 IS

1 in 5 FOR WOMEN

1 in 10 FOR MEN

70% OF DEMENTIA CAREGIVERS
FEEL STRESSED WHEN
COORDINATING CARE

AND MORE THAN HALF
OF CAREGIVERS
SAID NAVIGATING
HEALTH CARE IS
DIFFICULT

3 IN 5 DEMENTIA CAREGIVERS
SAY LESS STRESS AND MORE PEACE OF MIND ARE POTENTIAL BENEFITS OF HAVING A **CARE NAVIGATOR**

56% SAY IT COULD HELP THEM BE
BETTER CAREGIVERS

For more information, visit alz.org/facts

ALZHEIMER'S ASSOCIATION

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A Review: Dementia Care Practice Recommendations

- ✓Person-Centered Care
- ✓Assessment and Care Planning
- ✓Information, Education and Support
- ✓Transitions and Coordination
- ✓Workforce

Person Centered Focus

- Know the person
- Person's reality
- Meaningful engagement
- Authentic, caring relationship
- Supportive community
- Evaluation of care practices

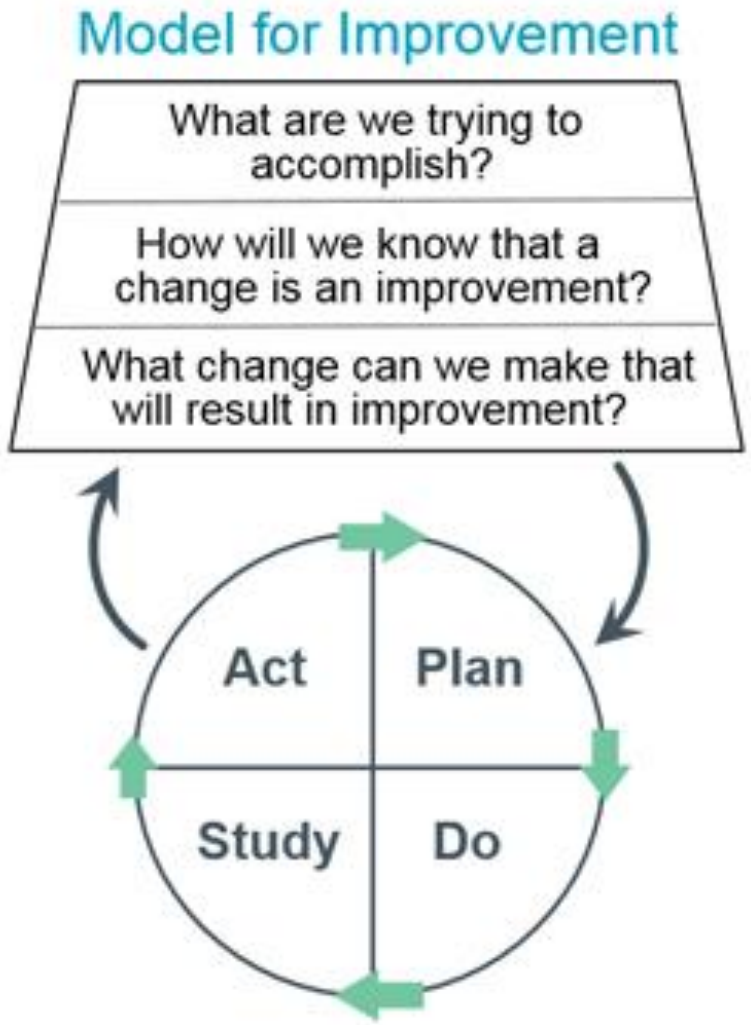
If you were a resident in a nursing home, what would be important to you?

Behaviors and Communication

- Social and physical environmental triggers
- Non-pharmacological practices
- Investment for implementation
- Protocols
- Evaluation of effectiveness

What do you think would most improve person-centered dementia care?

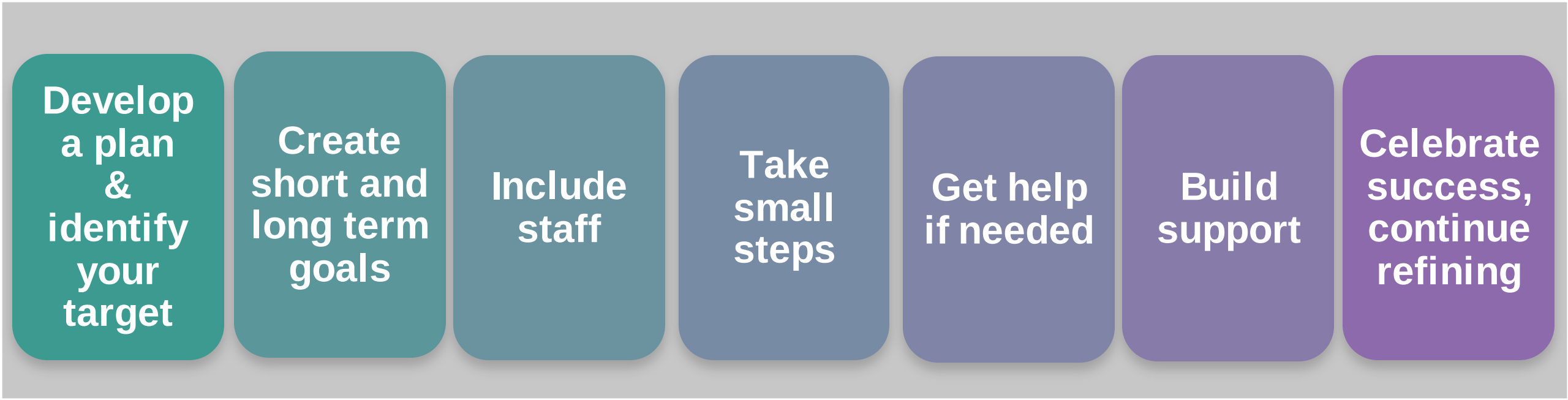
Evaluate…and do it again… and again… and again…

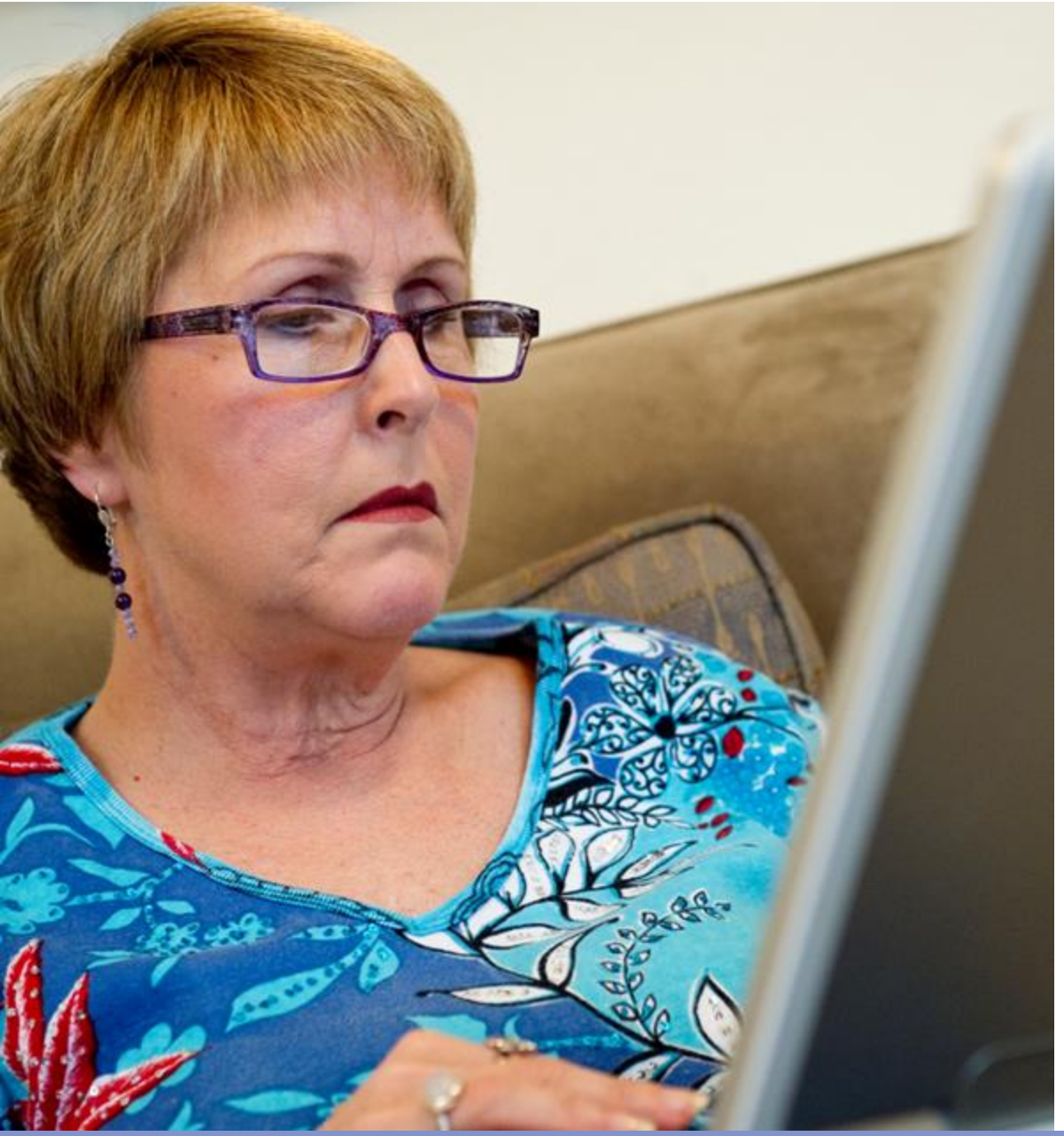


For more information visit :
Institute for Healthcare Improvement: ihi.org

How far down the path are you in the QAPI Journey

Putting it all together





ASSOCIATION SUPPORT

24/7 HELPLINE

1.800.272.3900

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COMMUNITY RESOURCE FINDER

alz.org/CRF

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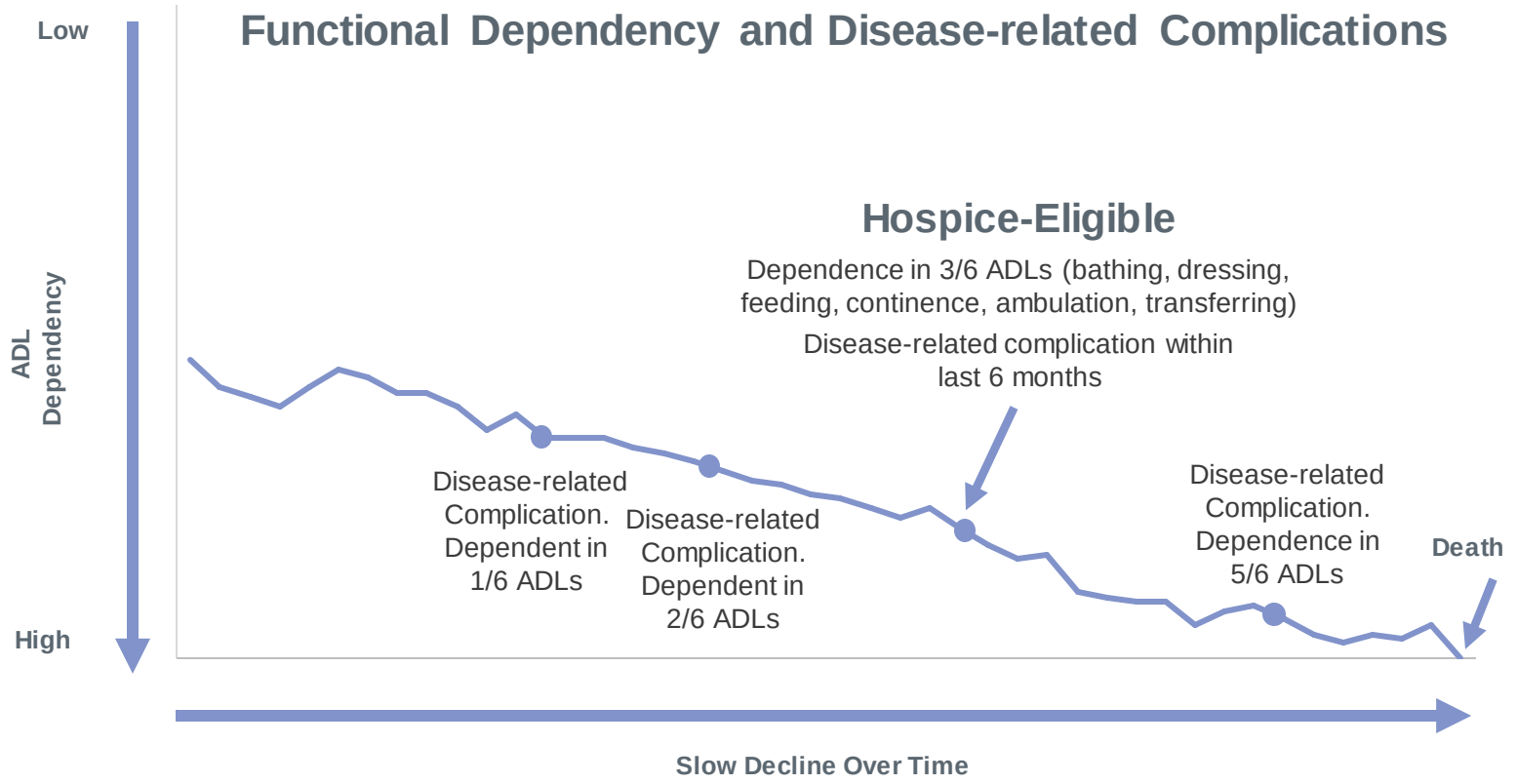
Table 2: FY 2022 Top 20 Principal Hospice Diagnoses, by ICD-10 code

Rank	"International Classification of Diseases, Tenth Revision (ICD-10)/Reported Principal Diagnosis"	Number of Beneficiaries	Percentage of all Reported Principal Diagnoses
1	G30.9-Alzheimer disease, unspecified	135,910	7.4%
2	G31.1-Senile degeneration of brain, not elsewhere classified	124,365	6.8%
3	J44.9-Chronic obstructive pulmonary disease, unspecified	78,630	4.3%
4	G30.1-Alzheimer disease with late onset	63,980	3.5%
5	I50.9-Heart failure, unspecified	52,375	2.8%
6	G20-Parkinson disease	52,155	2.8%
7	"I25.10-Atherosclerotic heart disease of native coronary artery withoutangina pectoris"	47,117	2.6%
8	"C34.90-Malignant neoplasm of unspecified part of unspecified bronchus or lung"	44,093	2.4%
9	U07.1-Emergency use of U07.1	43,505	2.4%
10	I67.2-Cerebral atherosclerosis	38,543	2.1%
11	I11.0-Hypertensive heart disease with (congestive) heart failure	36,860	2.0%
12	I67.9-Cerebrovascular disease, unspecified	35,120	1.9%
13	E43-Unspecified severe protein-energy malnutrition	33,111	1.8%
14	I63.9-Cerebral infarction, unspecified	29,291	1.6%
15	"I13.0-Hypertensive heart and renal disease with (congestive) heart failure"	27,455	1.5%
16	C61-Malignant neoplasm of prostate	24,806	1.3%
17	N18.6-End stage renal disease	24,565	1.3%
18	J96.01-Acute respiratory failure with hypoxia	23,329	1.3%
19	C25.9-Malignant neoplasm: Pancreas, unspecified	22,128	1.2%
20	"J44.1-Chronic obstructive pulmonary disease with acute exacerbation, unspecified"	20,928	1.1%

Source: *FY 2024 Hospice Wage Index and Quality Reporting Proposed Rule, Table 2*

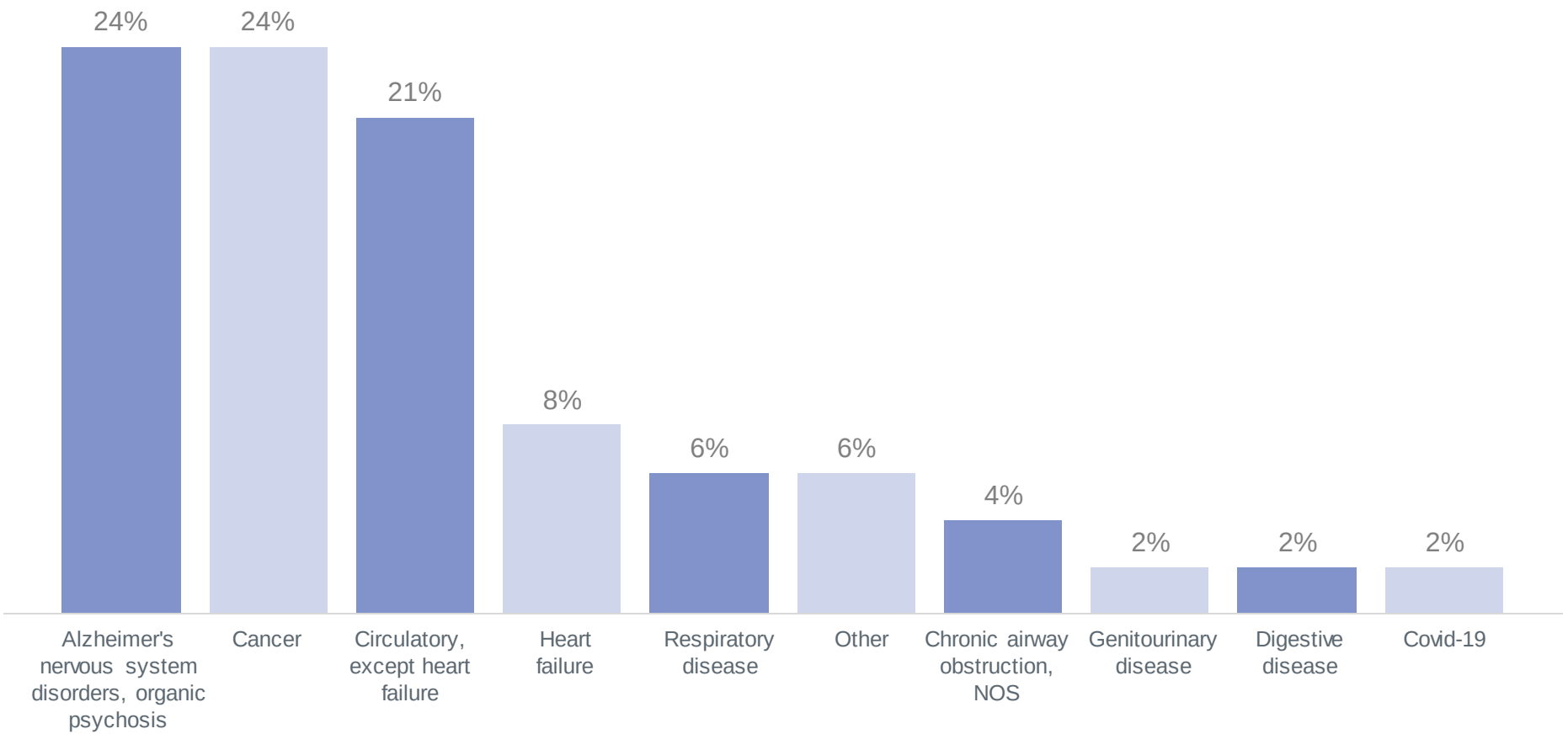
Dementia Natural History

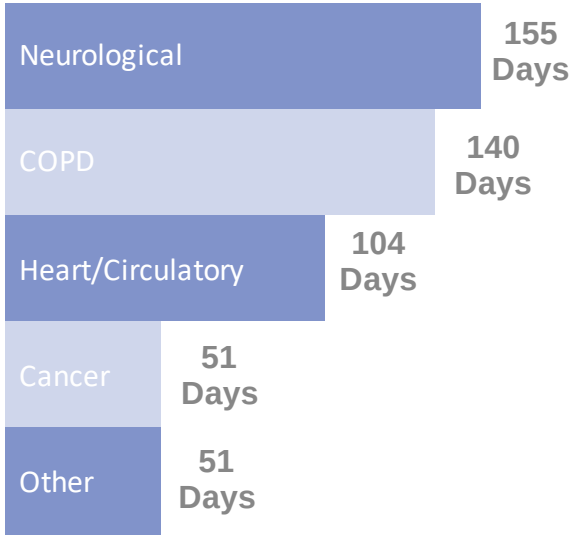


Disease-related complications include, but are not limited to:

- UTI
- Sepsis
- Febrile episode
- Delirium
- Pneumonia
- Hip fracture
- Difficulty eating or dysphagia
- Dehydration
- Feeding tube (decision)

Diagnosis Breakdown and Length of Stay





Comprehensive PCC Assessment

Experience of the person/care partner

Function and Behavior

Health Status and Risk Reduction

Disparities in Alzheimer's

- Black individuals >65yo are 2x as likely to develop Alzheimer's disease and Hispanic populations are about 1.5x more likely to develop Alzheimer's disease
- Earlier age of onset on average
- Missed or delayed diagnoses of Alzheimer's and other dementias are more common among Black and Hispanic older adults than among White older adults
- Black and Hispanic populations will eventually make up 40% of all patients with Alzheimer's disease in the United States, some statistics state this could be as soon as 2030

Caregiving

Who Are the Alzheimer's Caregivers?

11 million Americans provided

18 billion hours of unpaid care

$339 billion

- **Two thirds** are women and **one third** are daughters
- **One in three** is age 65 or older
- **More than half** take care of their parents
- One quarter of dementia caregivers are in "sandwich generation" of caregivers
- **41%** of caregivers have a household income of **$50,000 or less**
- **66%** live with the care recipient in the community

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Transitions of Care

- PLWD who live in residential or long-term care are more likely to experience frequent transitions in care
- Individuals with behavioral and psychological symptoms of dementia (BPSD) have high rates of care transitions and poorer outcomes

Dementia Quality Measurement Set: AAN, APA, and Other Stakeholders

Important considerations

- Dementia is a syndrome not a disease
- Umbrella term of numerous diseases/disorders that cause symptoms cognitive/functional decline
- Dementia is a terminal illness

Many individuals with dementia and their caregivers were not told of their diagnosis

Caregiver support is critical

Patients should be routinely assessed for changes in their functional abilities

- Safety screening, specifically related to driving, is an important assessment point
- Behavior and psychological symptoms are common in dementia, and often not appropriately assessed or treated

SPECIAL ARTICLE

Quality improvement in neurology

Dementia management quality measurement set update

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Dementia is a neurologic condition manifested by a substantial decline in multiple cognitive abilities that collectively render a person unable to function at expected levels and progressively impede independent ability to perform everyday activities. For decades, public health officials have warned of the coming tsunami of Alzheimer disease (AD), and dementia has even been characterized as the dominant scourge of modern times, replacing cancer.[1] Recently, hopeful signs have appeared, including reports from some longitudinal research studies that incidence of dementia is declining,[2] and from the federal government that research funding for AD and other dementias will approach $1 billion USD in 2017.[3]

The consequential nature of dementia cannot be underestimated. Although not often conceptualized as such, dementia is a terminal disorder.[4,5] According to the 2015 annual statistics available from the Alzheimer's Association, 1 in 9 Americans aged 65 and older has AD and 1 in 3 older adults who dies in a given year has been diagnosed with AD or another dementing disorder.[6] It is estimated that 14.7% of people older than 70 in the United States have dementia.[7] AD is listed officially as the sixth leading cause of death in the United States.[6] Further, the monetary cost of dementia in the United States ranges from $159 to $215 billion annually,[7] making it more expensive than heart disease or cancer. In 2014, unpaid caregivers provided nearly 18 billion hours of care to people with dementia, often at nontrivial cost to their own health and well-being.[8]

After passage of the National Alzheimer's Project Act of 2011, an Advisory Council for Alzheimer's Research, Care, and Services convened to advise the Department of Health and Human Services; the National Plan it produced in 2012 featured a prominent call for quality measures for the care of patients with dementia. Measurement of quality in care practices and services for persons with dementia and their caregivers remained an integral part of the Advisory Council's work in 2016.[9]

The first set of dementia management quality measures was developed and published in 2013 by the American Academy of Neurology (AAN) under the American Medical Association (AMA) Physician Consortium for Performance Improvement (PCPI) performance measure development model.[10] Previously convened by the AMA, the PCPI Foundation is now an independent foundation comprising multiple organizations focusing on the advancement of measurement science, quality improvement, and clinical registries. The Centers for Medicare and Medicaid Services (CMS) incorporated select measures into the Physician Quality Reporting System (PQRS), at that time the main quality reporting program through which eligible professionals and group practices reported information on the quality of care provided to their patients with Medicare. Measures may be incorporated into CMS' Merit-based Incentive Payment System (MIPS), which replaced PQRS in 2017.

In 2014, the AAN and the American Psychiatric Association (APA) assumed joint stewardship of the dementia management measurement set, with the exception of the Cognitive Assessment measure, for which the PCPI retained stewardship. In 2015, the AAN and the APA formed a multidisciplinary Work

Supplemental data at Neurology.org

GLOSSARY

AAN = American Academy of Neurology; AD = Alzheimer disease; AMA = American Medical Association; APA = American Psychiatric Association; BPSD = behavioral and psychiatric symptoms; CMS = Centers for Medicare and Medicaid Services; DSM-5 = Diagnostic and Statistical Manual of Mental Disorders, 5th edition; MCI = mild cognitive impairment; MIPS = Merit-based Incentive Payment System; NQF = National Quality Forum; PCPI = Physician Consortium for Performance Improvement; PQRS = Physician Quality Reporting System.

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Go to Neurology.org for full disclosures. Funding information and disclosures deemed relevant by the authors, if any, are provided at the end of the article.

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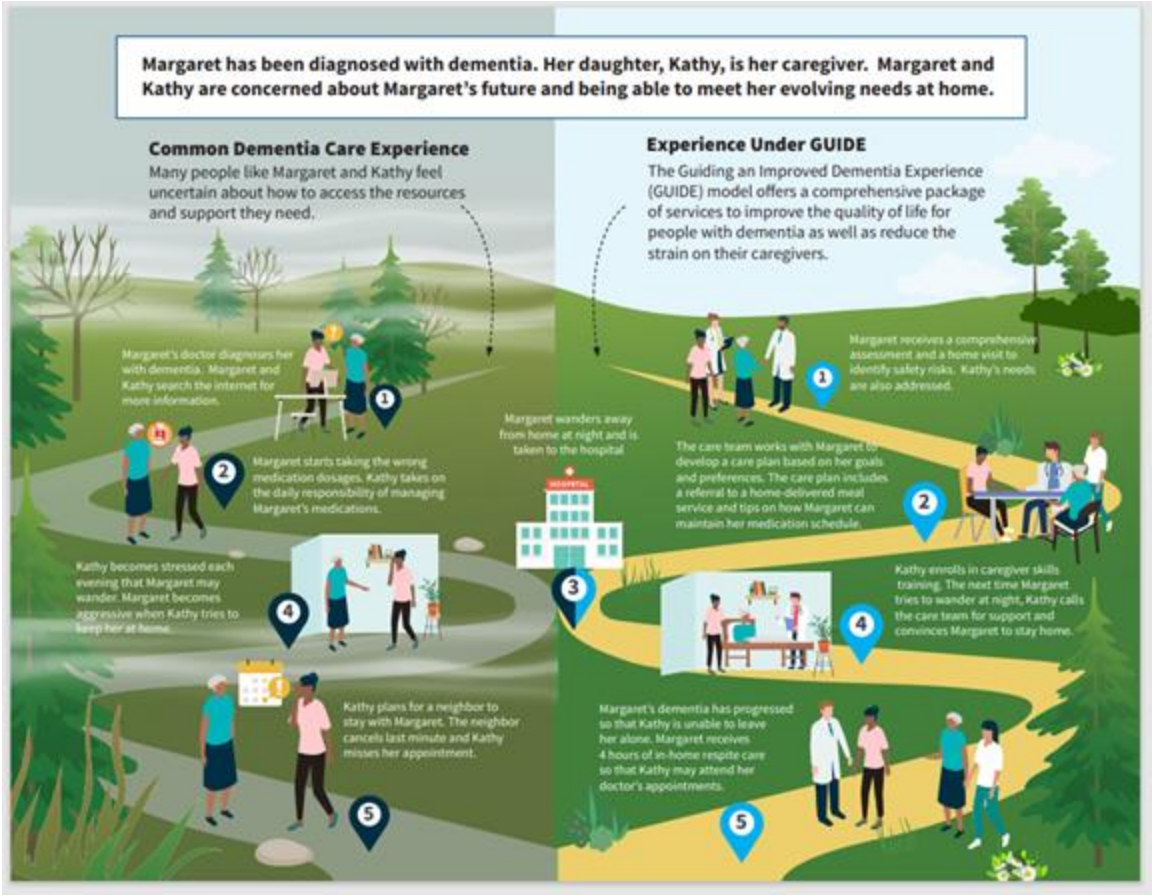
GUIDE to Quality, Reimbursement and Innovation

Guiding an Improved Dementia Experience Model (GUIDE)

Goals:

- Focus on dementia care management
- Improve quality of life for people living with dementia (PLWD)



Education for our Workforce

- The status quo is not working
- Focus on retention instead of turnover
- Consider staff to acuity
- A trained and supported staff will excel
- The leader sets the tone, establishes the culture, and impacts quality of care and quality of life for residents/clients and the staff
- Evaluate systems and progress routinely for continuous improvement

Didactic Presentation Q&A

Location Poll

NHPCO

Case Study Presentation:

Situation

Sue is a young, dynamic 61year old female. She lives at home with her husband Joe, who is 68 years old.

Over the past 10 months, Sue has increasingly been irritable, with short term memory lapses and occasional statements that reflect possible hallucinations ("Why is the plumber on our roof?") ("I think we should talk to the landlord" - they live in their own house). She was diagnosed with Lewy Body dementia last month by her PCP

Sue has private insurance, while Joe is under Medicare coverage

Sue recently fell, and is complaining of left hip pain, but refuses to see the orthopedic specialist recommended by their primary care provider (PCP)

Joe has advanced Chronic Obstructive Pulmonary Disease (COPD, 50-pack year smoking history), on supplemental oxygen and recent finding of lung nodules. Joe has been seeing the palliative care team for past 15 months.

Background

- Sue has a past medical history (PMH) of DM 2, weight gain, depression and HTN. She has questionable medication adherence, but Joe is often able to convince her to take her medications and manage her blood sugar.
- Sue has a recent foot wound, for which she is provided wound care by the home care nurse
- The home care agency also provides hospice care, so Sue's nurse is often pulled to see other patients at short notice.
- Sue does not like it when her nurse reschedules a visit and Sue often reacts negatively, at which time Joe steps in with problem solving strategies
- Joe has missed a few medical appointments of his own and is overdue to see his palliative care team. Joe verbalizes caregiver fatigue
- Sue and Joe's son lives in California (visits annually for Thanksgiving) and daughter lives in London

Assessment

- What assessments would benefit Sue, in order to complete a comprehensive care plan?
  - Physical (including mental)
  - Psychosocial (food, transportation, utilities)
  - Health beliefs
  - Health literacy
  - Goals of Care Conversations
  - Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADLs)
  - What else?

- Who / which disciplines would be responsible for completing those assessments?

- What assessments need to be done for Joe?
- What comprehensive assessments do they both/ the family benefit from?
- How is Joe's role changing/ will change?
- How can the health insurance issues be navigated?

Discussion and Recommendations

Discussion and Recommendations

- Provide as much consistency as possible for Sue as she navigates her trajectory across the dementia lived experience
- Management of Sue's chronic disease needs to remain a focus, but the context and intensity of chronic disease management may change as her condition progresses
- The PCP remains as the quarterback of the larger healthcare team due to the unique advantage of having a longitudinal relationship with the patient family (read as positive trust, communication and the potential for collaborative decision making)
- Joe needs support, in his own unique way, for his own unique issues
- Disparities could still be in the backdrop – focus on assessments, ongoing care plan updates and individual patient/ family needs

Teamwork....Teamwork...Teamwork..... Patient/ spouse/ children/ friends and other supports/ PCP/ interdisciplinary care team/ the broader community around Sue where she lives and was thriving in.

Key Takeaways

- Dementia is a syndrome with a constellation of symptoms related to cognitive decline; most common cause is Alzheimer's
- Dementia Care Practice Recommendations include 56 based recommendations across 10 areas
- Person centered care involved recognizing and maintaining the self across the disease continuum, including creating opportunities to support a sense of self through meaningful relationships, activities and by eliciting values, preferences and choice
- When describing the situation of a patient with end stage dementia, paint a detailed picture of the patient to demonstrate the changes that occur as they may not be as obvious as large changes in weight or functional status.
- Compared to caregivers of patients with non-dementia related diagnoses, caregivers of patients with dementia-related diagnoses have higher levels of stress, are more isolated and have felt a sense of relief after the patient dies
- When caregiving for persons with dementia, literacy, language, and cultural sensitivity are key factors for a successful and high-quality experience.
- Prepare and educate persons living with dementia and their family caregivers about common transitions in care
- Provide a thorough orientation and training program for new staff, as well as ongoing training
- Develop systems for collecting and disseminating person-centered information

References

- www.alz.org
- www.alz.org/qualitycare
- www.nhpco.org
- www.ihi.org
- https://www.cms.gov/priorities/innovation/innovation-models/guide
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- https://www.nationalacademies.org/our-work/the-quality-of-care-in-nursing-homes

Session Evaluation and Certificate of Completion

- Your feedback is valuable as we plan upcoming sessions! Please complete the Project ECHO Best Practices in Dementia Care Post-Session Evaluation as well as the final Project ECHO Best Practices in Dementia Care Miniseries Evaluation
- Project ECHO sessions are not accredited for continuing education, but we are able to offer a confirmation of completion for participants who attend at least five live sessions and complete all session evaluations as well as a final miniseries evaluation. Please reach out to projectecho@nhpco.org if you would like a certificate of completion.

Additional Information

NHPCO Project ECHO webpage:

https://www.nhpco.org/regulatory-and-quality/quality/projectecho/

For more information:

projectecho@nhpco.org