Avoid the Care Crisis!

Strategies to Anticipate and Plan for Increased Care Needs of Older Adults

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Disclosure

- My husband works for a tech company involved in the in home care giving space

A Consult Clinic Referral

- 86 yo male with moderate stage dementia (MoCA 17/30), HTN, HFrEF, AF, CKD Stage 3b, constipation, prior CVA
- Ambulatory but increasingly high risk for falls and does fall
- Full IADL dependence, starting to need help with ADLs (laying out clothes, reminders for showers…)

IADLs
Medications
Meals/Cooking
Shopping
House Work
Transportation
Finances
Appointments/Calendars
Communication (phone, email…)

ADLs
Dressing
Grooming
Bathing
Toileting
Transferring
Feeding

A Consult Clinic Referral

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- Ambulatory but increasingly high risk for falls and does fall
- Full IADL dependence, starting to need help with ADLs (laying out clothes, reminders for showers…)
- Lives with:
  - Partner/Spouse: 85 yo female, weight 102 lbs

  or
  - Adult Child: 56 yo son, has three kids, works full time

  or
  - No one

Objectives

- Review strategies to anticipate functional needs
- Review approach to conversation about increased care support
- Compare and Contrast different approaches to increased care support
- Understand resources for navigating transitions to higher levels of care

Why is Care Planning Hard?

Uncertainty in…

What the patient will need help with

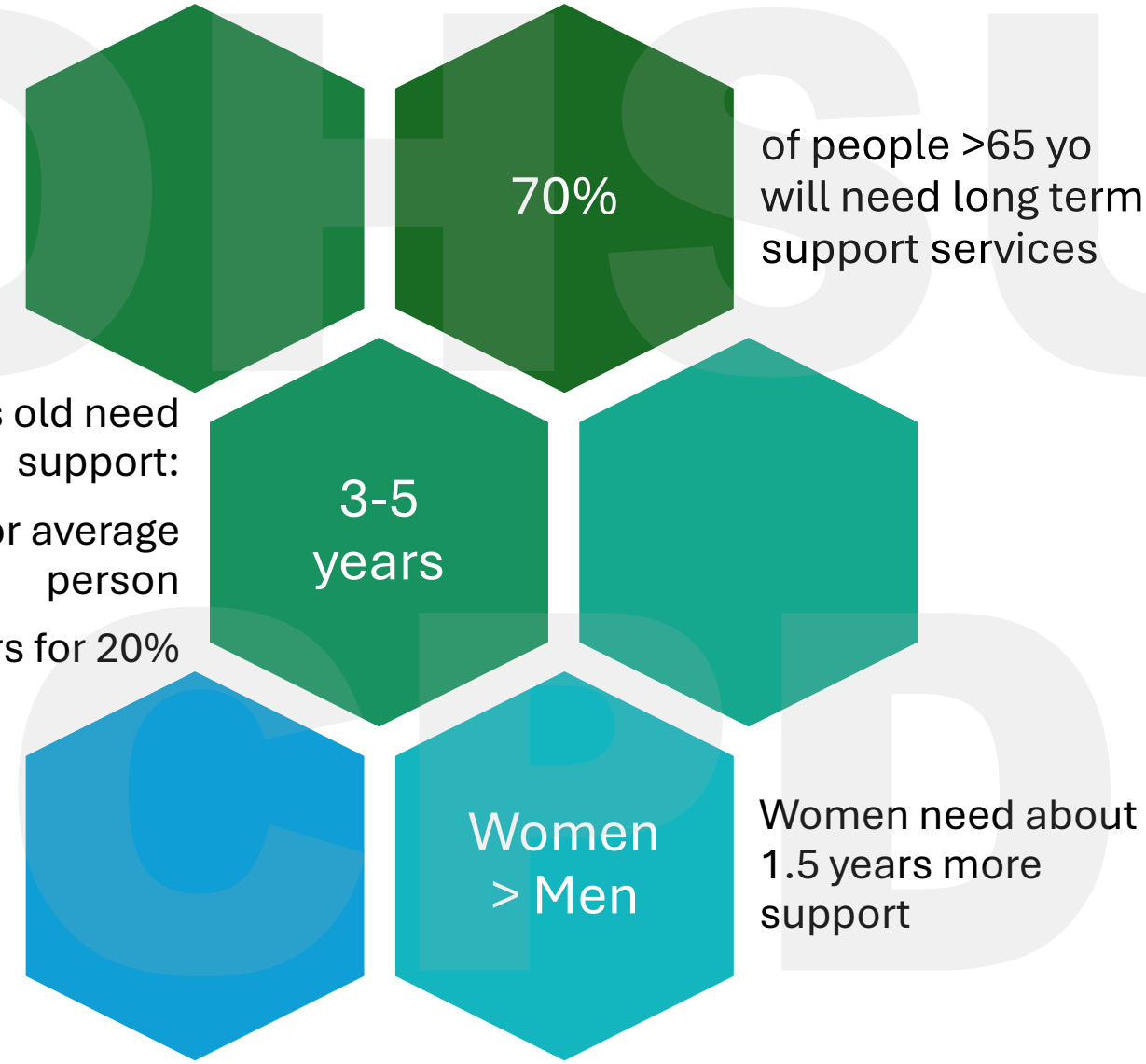
When the patient will need that help

How do they want the help to look

How to have this (often sensitive) conversation

What (realistic) options (will) exist to meet their needs

Background Statistics



ADRC
Aging and Disability Resource Connection of OREGON

Tools for Timeline and Needs Prediction

- ADRC of Oregon Questions
- FAST: Functional Assessment Staging Tool
- CFS: Clinical Frailty Scale
- FIM: Functional Independence Measure
- ePrognosis

Minimal Assistance to Stay Home

- Can you walk without assistance and without falling?
- Do you sometimes need reminders to bathe, dress, groom, take medications or keep doctors' appointments?
- Do you need help to prepare meals and do housework?
- Do you have some trouble remembering things?
- In case of an emergency, would you need help?

Significant Assistance to Stay Home or Facility

- Do you need regular reminders to get dressed, groom yourself, eat, take medications, etc.?
- Are you sometimes incontinent?
- Do you need help to set up your bath?
- Do you need help preparing meals and doing household chores?
- Do you need reminders to do social things?
- Do you sometimes have problems remembering things? Are you sometimes confused?
- In case of an emergency, would you need help?

Maximum Assistance to Stay Home or Facility

- Do you need help to move from your bed to a wheelchair?
- Do you require help to bathe, dress, groom and take medications?
- Do you need reminders and/or help to eat?
- Do you need encouragement to be in social activities or one-on-one visits?
- Do you need someone to help you in social activities or one-on-one visits?
- Do you require incontinence supplies and help using them?
- Do you need 24-hour help?
- Do you require services such as skilled nursing, physical therapy, occupational therapy or speech therapy?
- In case of an emergency, would you need help?

ADRC
Aging and Disability Resource Connection of OREGON

FAST: Functional Assessment Staging Tool

Stage	Stage Name	Characteristic
1	Normal Aging	No deficits whatsoever
2	Possible Mild Cognitive Impairment	Subjective functional deficit
3	Mild Cognitive Impairment	Objective functional deficit interferes with a person's most complex tasks
4	Mild Dementia	IADLs become affected, such as bill paying, cooking, cleaning, traveling
5	Moderate Dementia	Needs help selecting proper attire
6a	Moderately Severe Dementia	Needs help putting on clothes
6b	Moderately Severe Dementia	Needs help bathing
6c	Moderately Severe Dementia	Needs help toileting
6d	Moderately Severe Dementia	Urinary incontinence
6e	Moderately Severe Dementia	Fecal incontinence
7a	Severe Dementia	Speaks 5-6 words during day
7b	Severe Dementia	Speaks only 1 word clearly
7c	Severe Dementia	Can no longer walk
7d	Severe Dementia	Can no longer sit up
7e	Severe Dementia	Can no longer smile
7f	Severe Dementia	Can no longer hold up head

FAST: Functional Assessment Staging Tool

FAST Stage	(1) None	(2) Very MCI	(3)MCI	(4)Early	(5)Mod	(6)Mod/Sev	(7)V.Sev
Score			**MoCA:** 19-25 **MMSE**: 26-30	**MMSE**: 21-25	**MMSE** 11-20		**MMSE:** 0-10
Expected Changes	NO subjective or objective changes	Patient may complain about misplacing things, **subjective** work difficulty *(not evident to others)*	Friends, famiåly, coworkers may start to notice changes. NO TRUE FUNCTIONAL DEFICIT	**Beginning to have functional impact (predominantly IADL).** **You may observe:** Missing bills, overdrawing accounts, skipping meds, double meds, minor driving accidents, trouble with complex planning *(ex planning dinner party)* **You may see subtle behavioral changes:** social withdrawal, mood changes, apathy	**Beginning to have ADL impact** **You may observe:** help getting dressed due to difficulty making choice and cueing to remember steps, disorientation to date/place, getting lost in familiar places **You may observe more profound behavioral changes:** delusions, agitation, aggression, restlessness, anxiety, wandering… **May be difficult to remain at home**	**Progressive ADL impact + increasing behavioral changes** **You may observe:** Starting to forget family, altered sleep wake cycle, wandering, personality changes, worse ADLs (clothes > bathe > toileting mechanics > UI > FI)	**Continued loss of ADLs, end stage disease** **You may observe:** Continued loss of ADLs (1-5 words/day > unintelligible > non-ambulatory > can't sit > can't smile > can't hold head up. **Common Complications:** pressure sores, infections, aspiration, contractures **Qualifies for Hospice**
Years (since onset of symptoms)	Preclinical		Time Zero	1-3 years	2-8 years		6-12 years

Progression of Alzheimer's Dementia

Early

Moderate/Severe

Very Severe

CFS: Clinical Frailty Scale

Clinical Frailty Scale*

1 **Very Fit** – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.

2 **Well** – People who have **no active disease symptoms** but are less fit than category 1. Often, they exercise or are very **active occasionally**, e.g. seasonally.

3 **Managing Well** – People whose **medical problems are well controlled,** but are **not regularly active** beyond routine walking.

4 **Vulnerable** – While **not dependent** on others for daily help, often **symptoms limit activities.** A common complaint is being "slowed up", and/or being tired during the day.

5 **Mildly Frail** – These people often have **more evident slowing,** and need help in **high order IADLs** (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.

6 **Moderately Frail** – People need help with **all outside activities** and with **keeping house.** Inside, they often have problems with stairs and need **help with bathing** and might need minimal assistance (cuing, standby) with dressing.

7 **Severely Frail** – **Completely dependent for personal care**, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).

8 **Very Severely Frail** – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.

9. **Terminally Ill** - Approaching the end of life. This category applies to people with **a life expectancy <6 months**, who are **not otherwise evidently frail.**

Scoring frailty in people with dementia

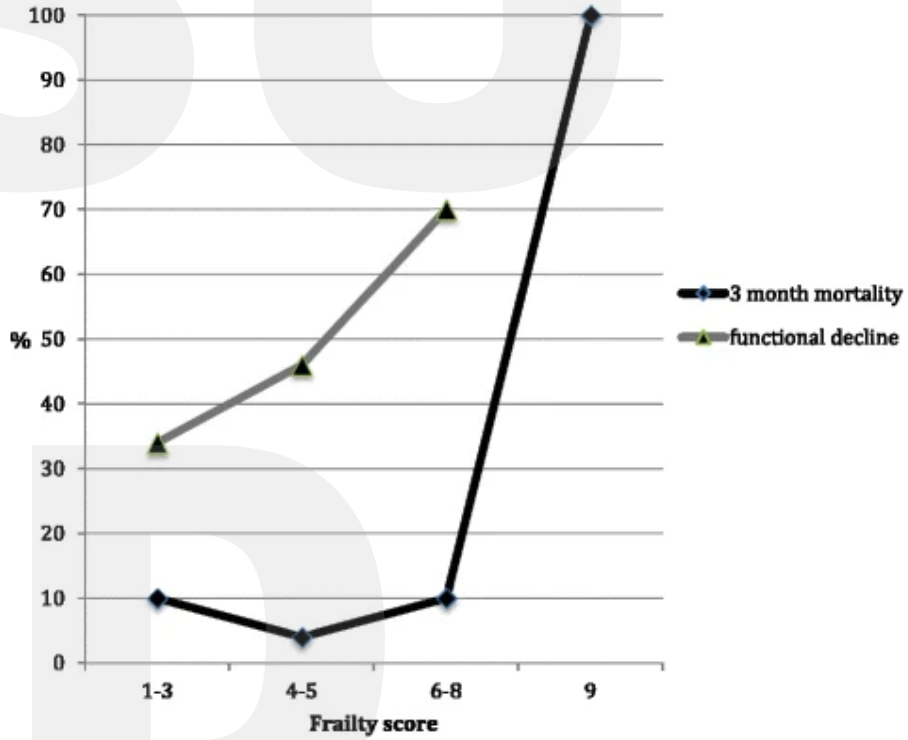
The degree of frailty corresponds to the degree of dementia. Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia**, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In **severe dementia**, they cannot do personal care without help.

* 1. Canadian Study on Health & Aging, Revised 2008.
2. K. Rockwood et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005;173:489-495.

DALHOUSIE UNIVERSITY *Inspiring Minds*

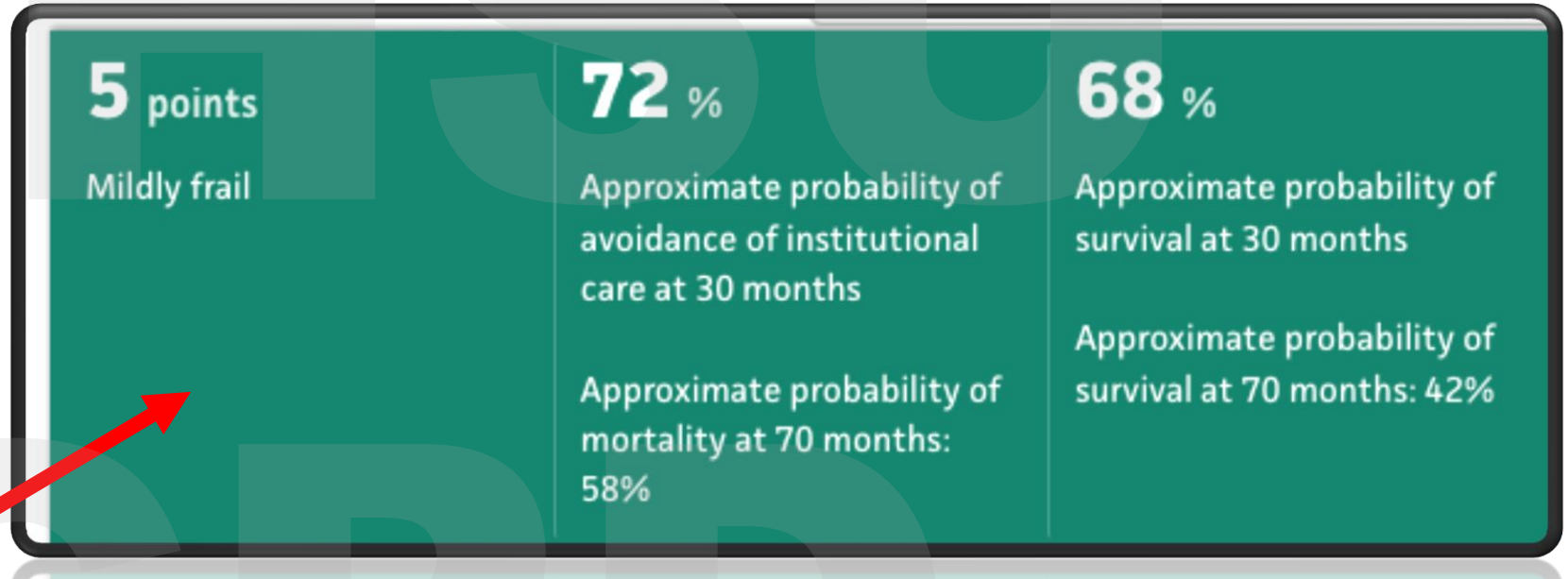


y-axis (%) = (number of patients experiencing outcome/total)x100

Gregorevic, 2016

CFS through MD Calc

Robust, active, energetic, well motivated and fit; they commonly exercise regularly and are in the most fit group for their age	+1
Without active disease, but less fit than people in category 1	+2
Disease symptoms are well controlled compared with those in category 4	+3
Although not frankly dependent, these people commonly complain of being "slowed up" or have disease symptoms	+4
With limited dependence on others for instrumental activities of daily living	**+5**
Help is needed with both instrumental and non-instrumental activities of daily living	+6
Completely dependent on others for the activities of daily living, or terminally ill	+7



FIM: Functional Independence Measure

Validated tool to assess a disability And need for assistance with ADLs

- 30-45 min to administer
- In person, chart review, phone interview…

- Motor: self-care, sphincter control, transfers, and locomotion
- Cognitive: communication and social cognition

- **6-7 points:** No helper
- **3-5 points:** Helper--modified dependence
- **1-2 points:** Helper -- complete dependence

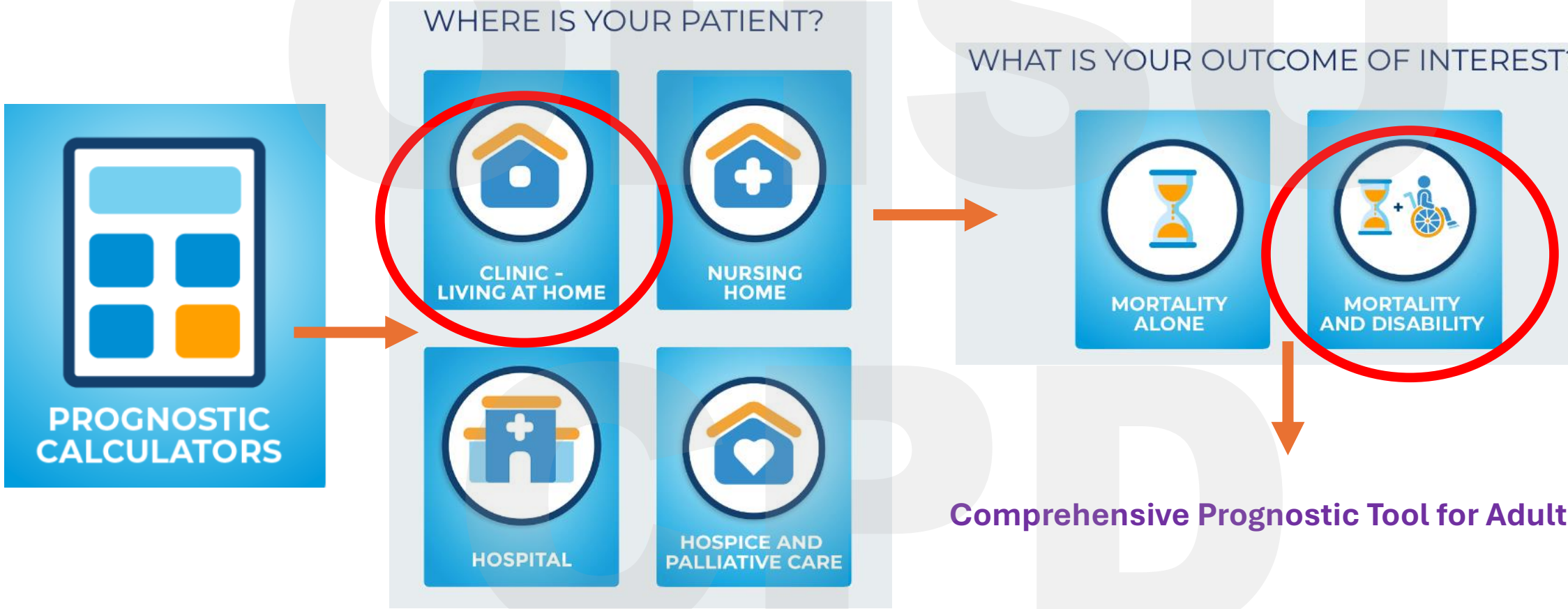
FIM Level	Description
7. Complete Independence	**No helper. No assistive device (AD). Timely. Safe**
6. Modified Independence	**No helper** May require AD that pt manages. May require more time (3x nl). Pt assumes all safety considerations
5. Supervision/Set Up	**Hands OFF Helper** Helper providers standby assistance (cues, coaxing, prompts, set up), but does not do hands on help (other than giving AD). Helper assumes safety considerations.
4. Minimal Assistance	**Hands ON Helper** Pt expends >75% of effort. Helper is hands on (touching, guiding, contact guard, incidental, steadying)
3. Moderate Assistance	**Pt > Helper** Pt expends 50-74% effort. Helper provides more than occasional assist, but <50%.
2. Maximal Assistance	**Helper > Pt** Pt expends between 25-49% of the effort. Helper does more than 50% activity.
1. Total Assistance	**Basically all Helper** Pt expends < 25% of the effort, pt does not do the activity or needs 2 or more helpers.

Burden of Care Rule of Thumb

FIM Item Average	FIM Total Score	Care Need Hours/Day	Discharge Site/Care Support Considerations
6	110	0-0.25	Home Alone or IL
5.5	100	0.25-1 hour	
5	90	1	Home with Assist
4.5	80	2	Home with Assist or ALF, HH services
4	70	3	Home, SNF, AFH with 24-hour Assistance
3	60	4	
	40		
	<40		24-hour Assistance

SeniorMatrix 2007
UDS for Medication Rehabilitation

ePrognosis.com



Comprehensive Prognostic Tool for Adults >70 !

ePrognosis

Enter the Variables…

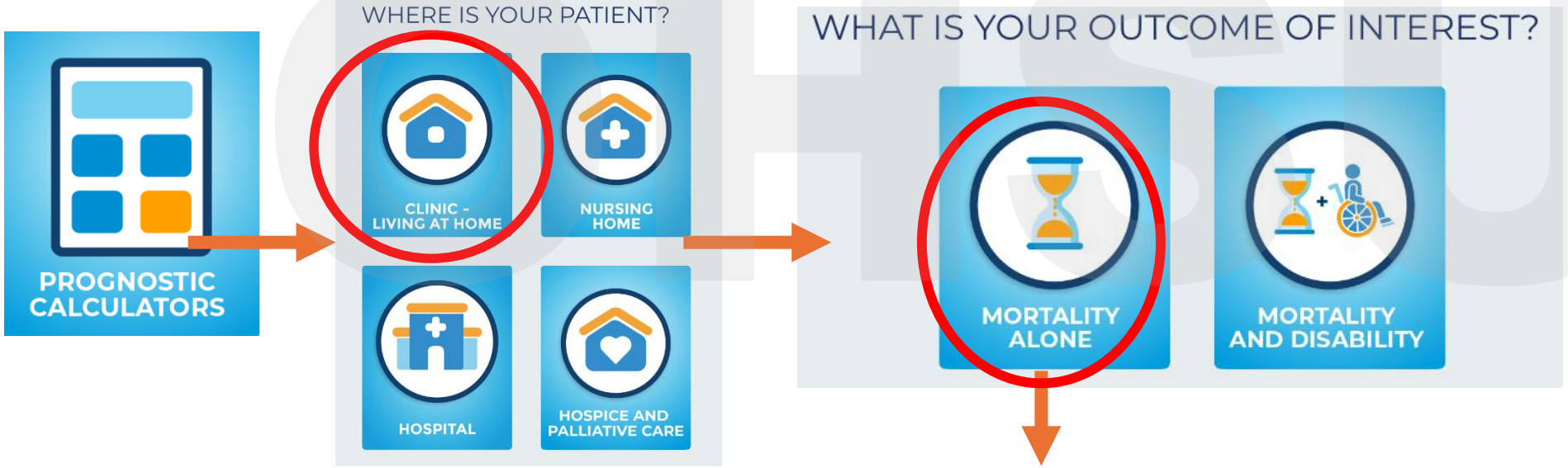
- Age
- Sex
- BMI
- Smoking Status
- Living alone/with others
- Difficulty eating
- **Difficulty preparing hot meals**
- **Difficulty managing money**
- **Difficulty pushing large objects**
- Difficulty walking several blocks
- **HTN**
- **Hx heart problems**
- **Hx stroke**
- Hx (non skin) cancer
- Hx lung disease

	Mortality		ADL Disability*		Walking Disability**	
	YOUR PATIENT	AVERAGE FOR AGE	YOUR PATIENT	AVERAGE FOR AGE	YOUR PATIENT	AVERAGE FOR AGE
5-year risk	76%	46%	52%	34%	28%	19%
10-year risk	99%	80%	81%	61%	52%	38%
14-year risk	100%	94%	90%	73%	64%	48%
Compare to others your patient's age your patient's risk at 10 year is:	Higher than average		Higher than average		Higher than average	

*ADL Disability: Needing help or unable to do 1 of the 5 ADLS

** Walking Disability: Needing help or unable to walk across the room

… but our patient has Dementia?



Mortality Risk Calculator for Community Dwelling Older Adults with Dementia

For a patient with these characteristics, the predicted probability of death equals:	
1 year	20%
2 years	41%
5 years	82%
10 years	99%
Median predicted time to death (25th to 75th percentile)	2.6 years (1.3 - 4.5 years)

Objective 2: Review approach to conversation about increased care support

Keep the Patient in the Driver Seat…

… and start early!

https://uknow.uky.edu/sites/default/files/styles/uknow_story_image/public/externals/b70a550b8d93d9e9e2c9451f9dedb449.jpg

The Preferred Conversation…

- **Normalize**

"The time comes when all of us need more care…"

- **Give them the Control**

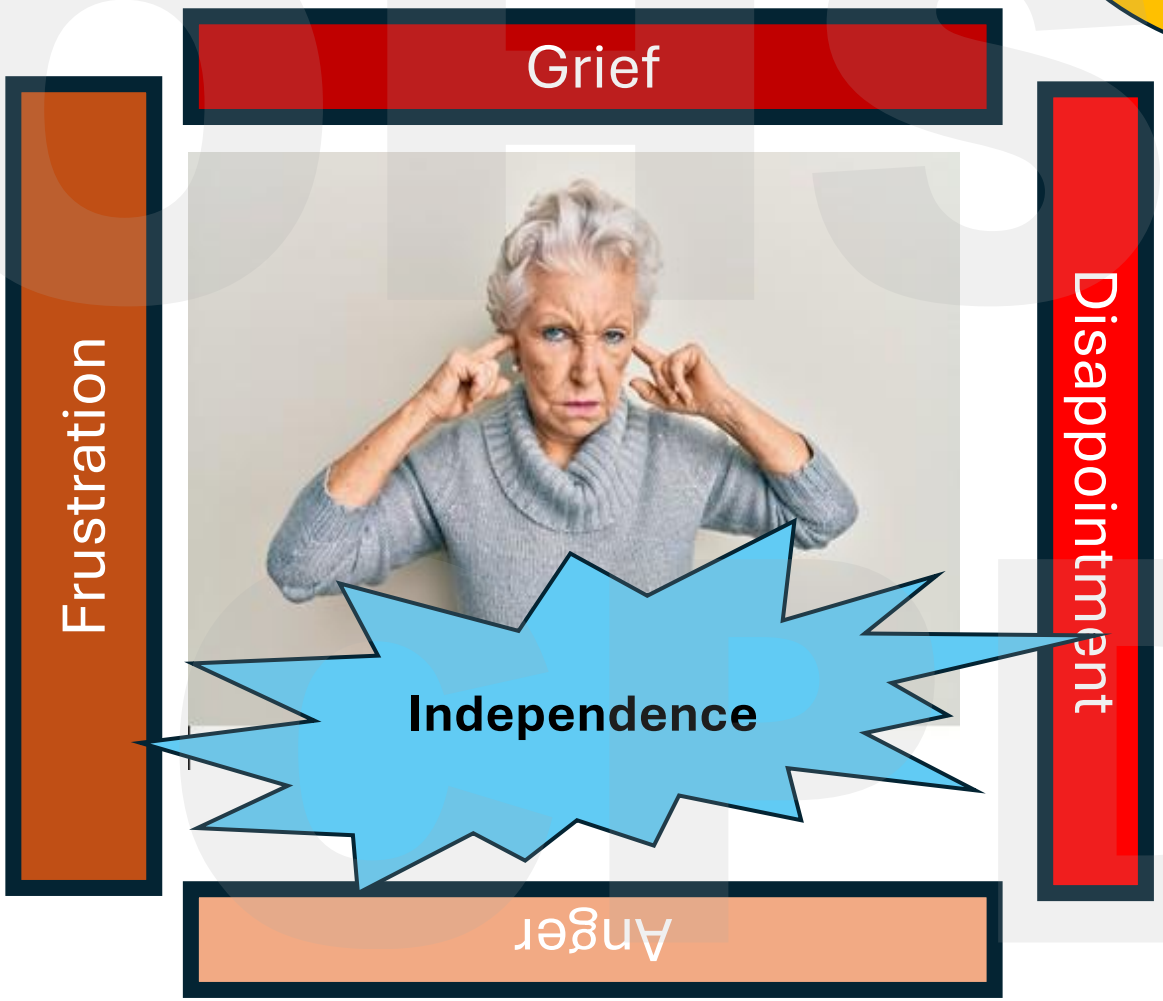
"There are a lot of ways people can receive more care, I'd love to explore with you about how you would like to receive more care when that time comes…"

- **Remember, Start Early!**

"The good news is we have time to explore the logistical considerations around some of your preferences. Also, that gives us some time to observe for how sooner or far you may start to need more help with certain daily tasks"

***EXTRA PSA: for pt's with cognitive changes, all the more reason to engage them while they can still advocate for their preferences!*

Crisis Mode!


Grief
Frustration
Disappointment
Anger
Independence


Blah blah… time to move… blah blah

The Power of Control: Crisis Mode

Can't Control

What disease may happen

How function will change in the future

Loss of independence

That people will need more help/support

Can Control!

How help is received

The pace that we one starts to receive cares

How much time we have to find the right fit

Care Planning “Homework”

1) Clarify preferences

How you would like to receive more care when that time comes?

(increased care at home, move in with adult child or friend? Move to a higher level of care like an assisted living facility or long term care facility or adult family home?)

1) When will it be time?

List clear/explicit things/changes to monitor for that will help you and your family know when it is time to move increase care/support

(ex: you have made some medication errors, you are requiring help with toileting or getting dressed, you are starting to have new or worrisome behavioral issues)

Have the conversation that day (if needed) or can give ”homework” as time allows.

PLAN YOUR LIFESPAN

Long term goals

People can live with Alzheimer's disease for years without needing help. Alzheimer's disease progresses differently for different people. It is important that if you ever need more help, people know your ultimate goal when it comes to your future.

- [ ] I am open to having someone help me in my home if it means I can stay there longer.
- [ ] I would like to move in with:

  Name of person
- [ ] My goal is to remain in my home as long as it is safely possible.
- [ ] I am willing to move into a senior community.

https://www.planyourlifespan.org

What should I say?

Jane shares how she discussed her long-term care plans with a loved one and finding the right person to share your plans with.

Conversation Starters

1

"I went through this website (Plan Your Lifespan) and have been answering some questions about planning for my future health care. I wanted to share my answers with you to see if you have any thoughts."

2

"I know it is hard to think about me or Mom getting Alzheimer's, but it is important to me that we start to talk about the health care needs we might have in the future."

3

"I was thinking about what happened with (Aunt Martha) and it made me think that I want to be prepared in case that happens to me."

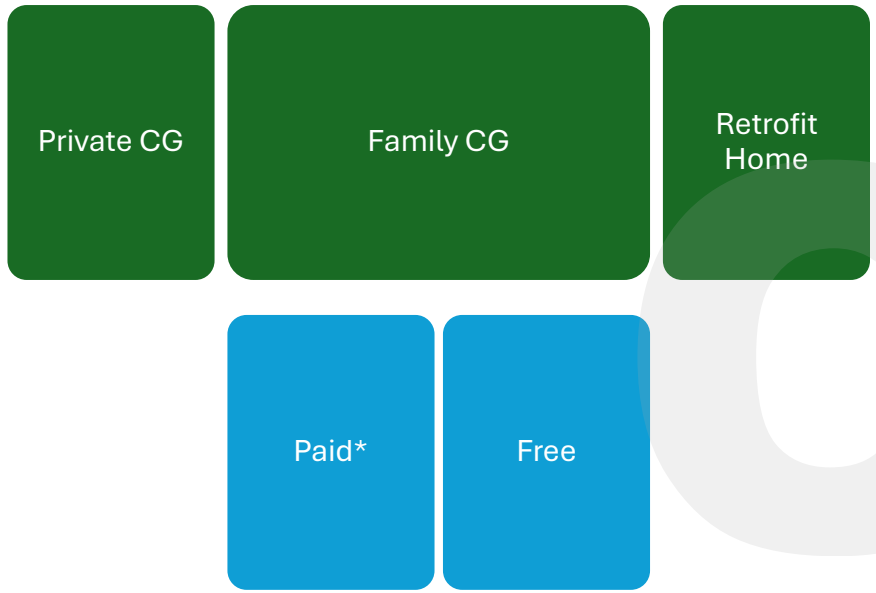
4

"I know right now, I'm doing okay... but there's always a chance something could happen and it's scary. I'd like to talk about what I may need in the future so we're both prepared."

Objective 3: Compare and Contrast different approaches to increased care support

Ways to Get More Help

Home



*Medicaid, VA, HCBS

Considerations:

Who would you prefer care from?

Who is capable of giving that care?

Who and what can you afford to pay for?

Some Benefits to Moving…

Increased socialization and sense of community

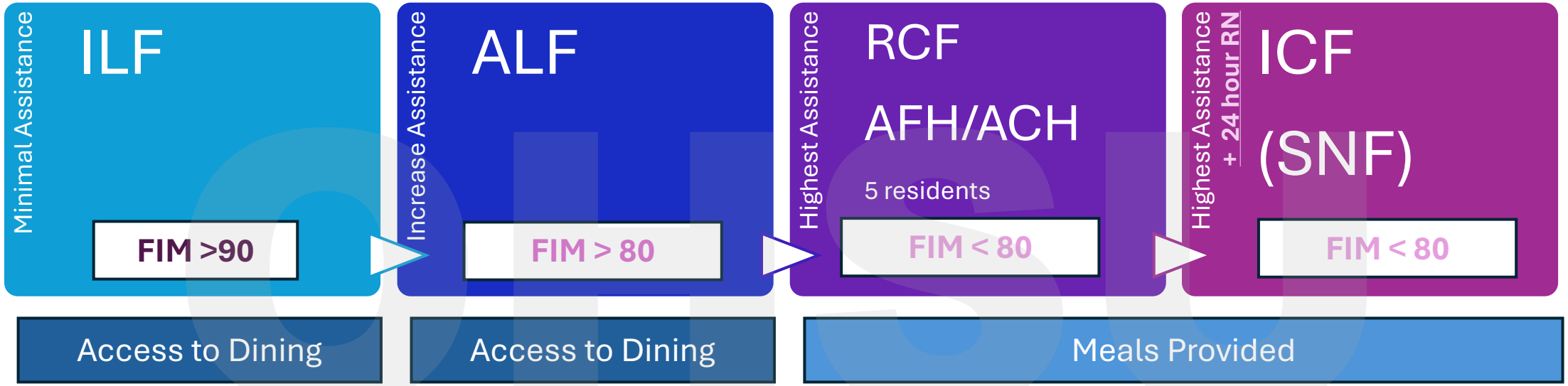
Less IADL burden (“you’ve earned the right to not cook and clean!”)

Physical and Cognitive Enrichment Activities

Partner = Partner again (NOT caregiver)

… and for, some with cognitive changes, the earlier you move, the better the adjustment


Minimal Assistance
ILF
FIM >90
Increase Assistance
ALF
FIM > 80
Highest Assistance
RCF
AFH/ACH
5 residents
FIM < 80
Highest Assistance
+ 24 hour RN
ICF
(SNF)
FIM < 80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Access to Dining
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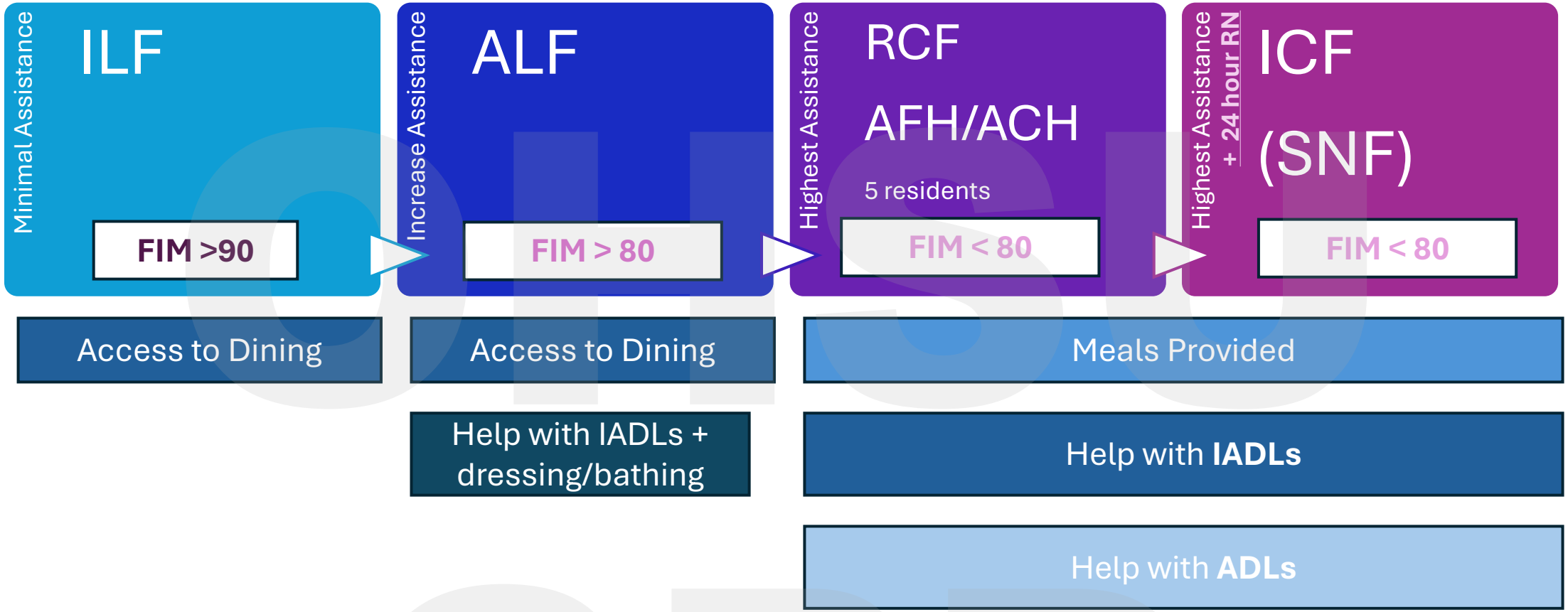
Meals Provided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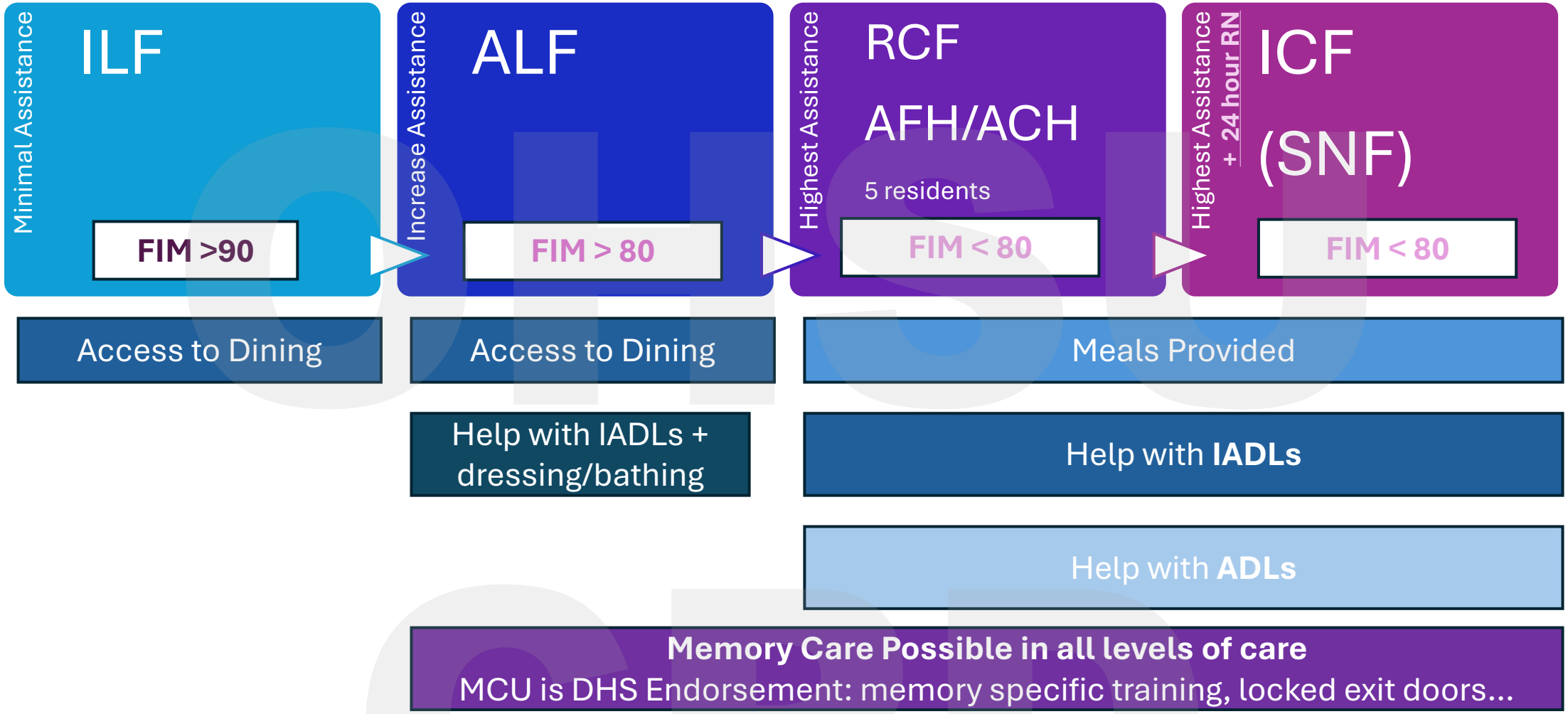
Meals Provided
Help with IADLs + dressing/bathing
Help with IADLs
Help with ADLs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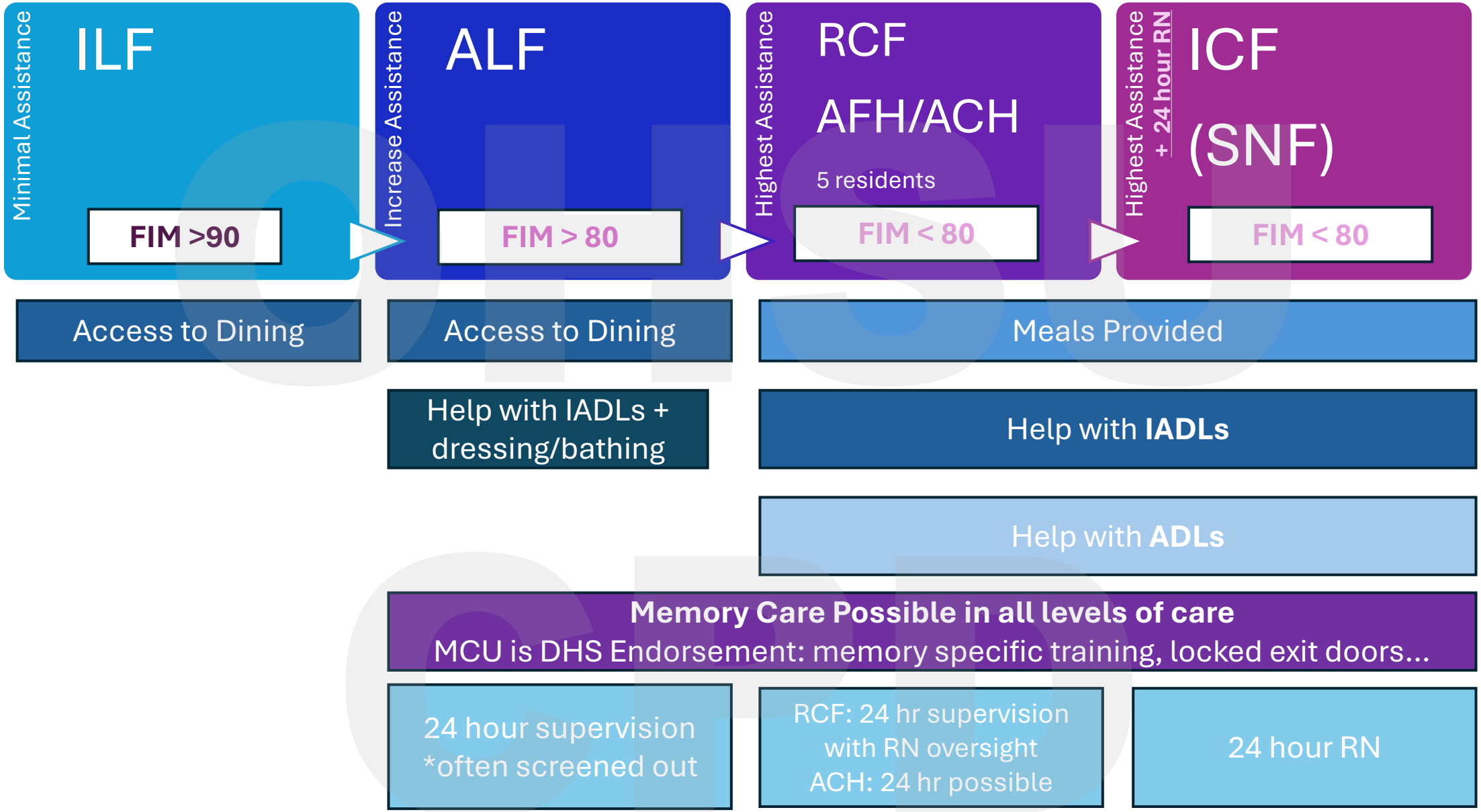
Memory Care Possible in all levels of care
MCU is DHS Endorsement: memory specific training, locked exit doors...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Memory Care Possible in all levels of care
MCU is DHS Endorsement: memory specific training, locked exit doors...
24 hour supervision
*often screened out
RCF: 24 hr supervision with RN oversight
ACH: 24 hr possible
24 hour RN

Access to Dining

Access to Dining

Meals Provided

Help with IADLs + dressing/bathing

Help with **IADLs**

Help with **ADLs**

Memory Care:
~$5,000/month

Memory Care Possible in all levels of care
MCU is DHS Endorsement: memory specific training, locked exit doors...

24 hour supervision
*often screened out

RCF: 24 hr supervision with RN oversight
ACH: 24 hr possible

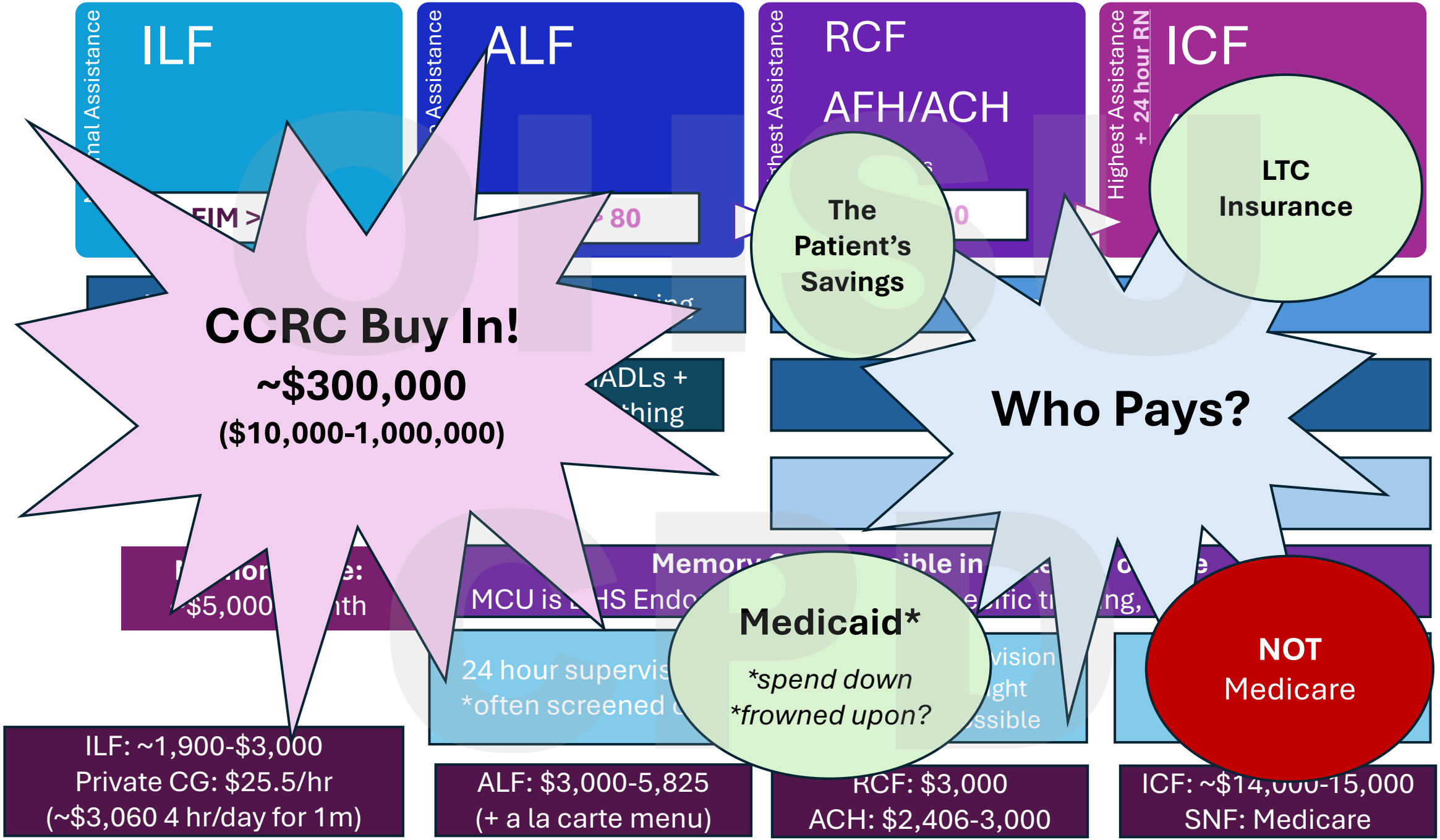
24 hour RN

ILF: ~1,900-$3,000
Private CG: $25.5/hr
(~$3,060 4 hr/day for 1m)

ALF: $3,000-5,825
(+ a la carte menu)

RCF: $3,000
ACH: $2,406-3,000

ICF: ~$14,000-15,000
SNF: Medicare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+ 24 hour RN
CCRC Buy In!
~$300,000
($10,000-1,000,000)
The Patient's Savings
LTC Insurance
Who Pays?
Medicaid*
*spend down
*frowned upon?
NOT Medicare
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How Much Will Services Cost?

Genworth

Calculate the Cost of Care in your area

ENTER AND SELECT CITY, STATE OR ZIP CODE

Oregon

Compare Location

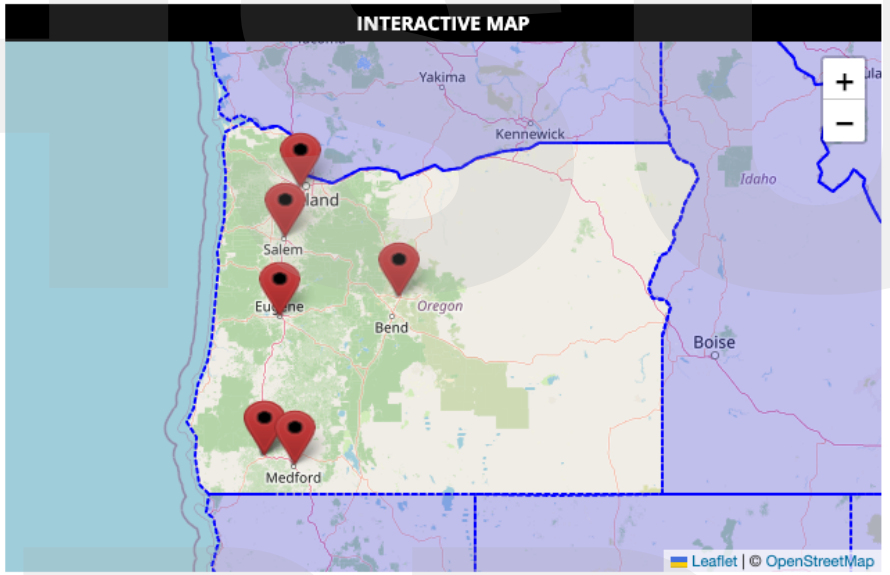
SELECT COST BY PERIOD

HOURLY | DAILY | MONTHLY | ANNUAL

CALCULATE FUTURE COST

2023 2033 2043 2053 2063 2073

Reset



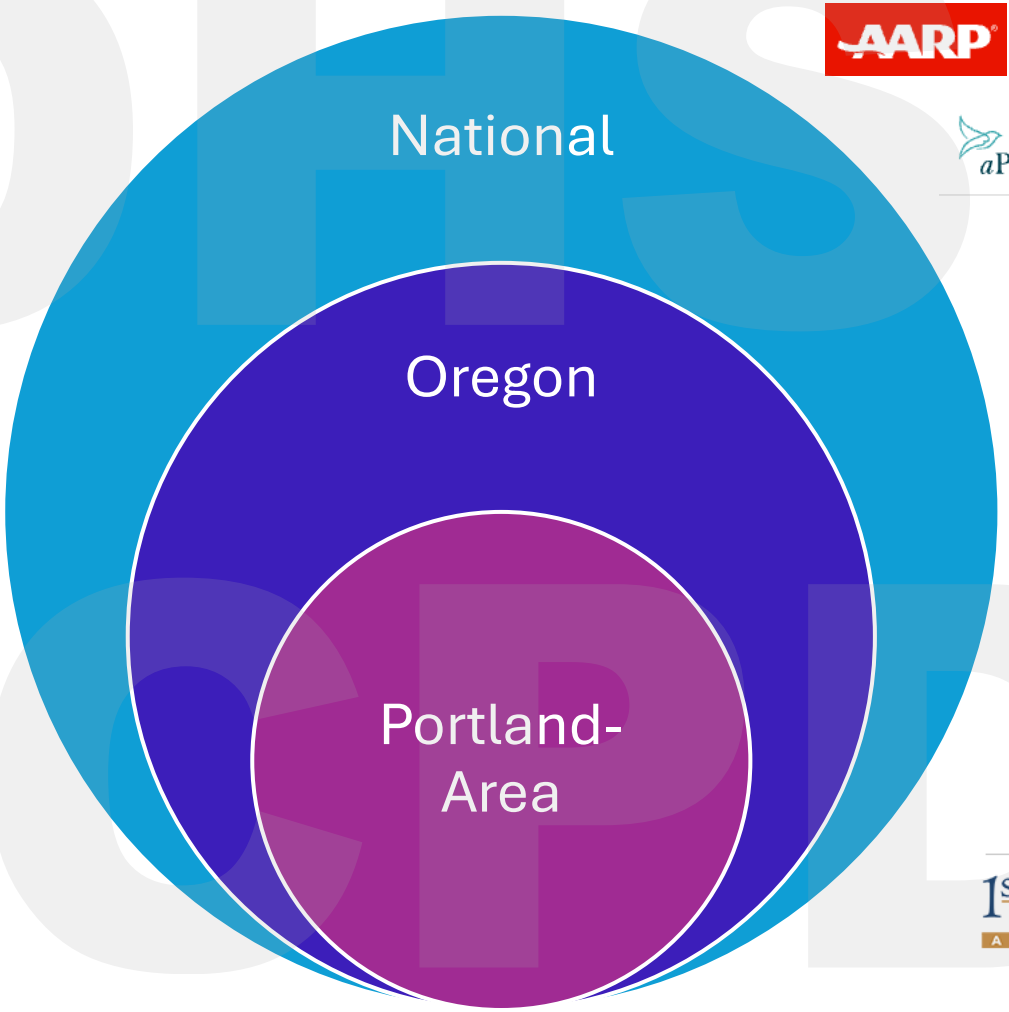
Annual Median Costs: *Oregon - State* (2023)

In-Home Care		Community and Assisted Living		Nursing Home Facility	
Home Maker Services[1]	$84,656	Adult Day Health Care[3]	$50,180	Semi-Private Room[5]	$175,018
Change Since 2022[2]	9%	Change Since 2022[2]	20%	Change Since 2022[2]	4%
Home Health Aide[1]	$60,632	Assisted Living Facility[4]	$69,900	Private Room[5]	$182,500
Change Since 2022[2]	No Change	Change Since 2022[2]	No Change	Change Since 2022[2]	11%

https://www.genworth.com/aging-and-you/finances/cost-of-care

Objective 4: Understand resources for navigating decisions around higher levels of care

Who Can Help!?



AARP

nco national council on aging 75 YEARS
CELEBRATING A LEGACY OF IMPACT

aPlaceforMom

ADRC
Aging and Disability
Resource Connection
of OREGON

RIGHT FIT
Senior
Living Solutions

1ST CHOICE
ADVISORY SERVICES

OSRAA
Oregon Senior
Referral Agency Association

Explore your options

Learn about resources, services and facilities in Oregon.

Search for resources

Find resources and services available in your local area.

Connect with your local ADRC

Contact your local ADRC if you have questions or would like to talk with someone in person about your situation. Staff are available to help you. You can also learn more about the ADRC of Oregon and view our data dashboard here.

Connect now

Plan and prevent

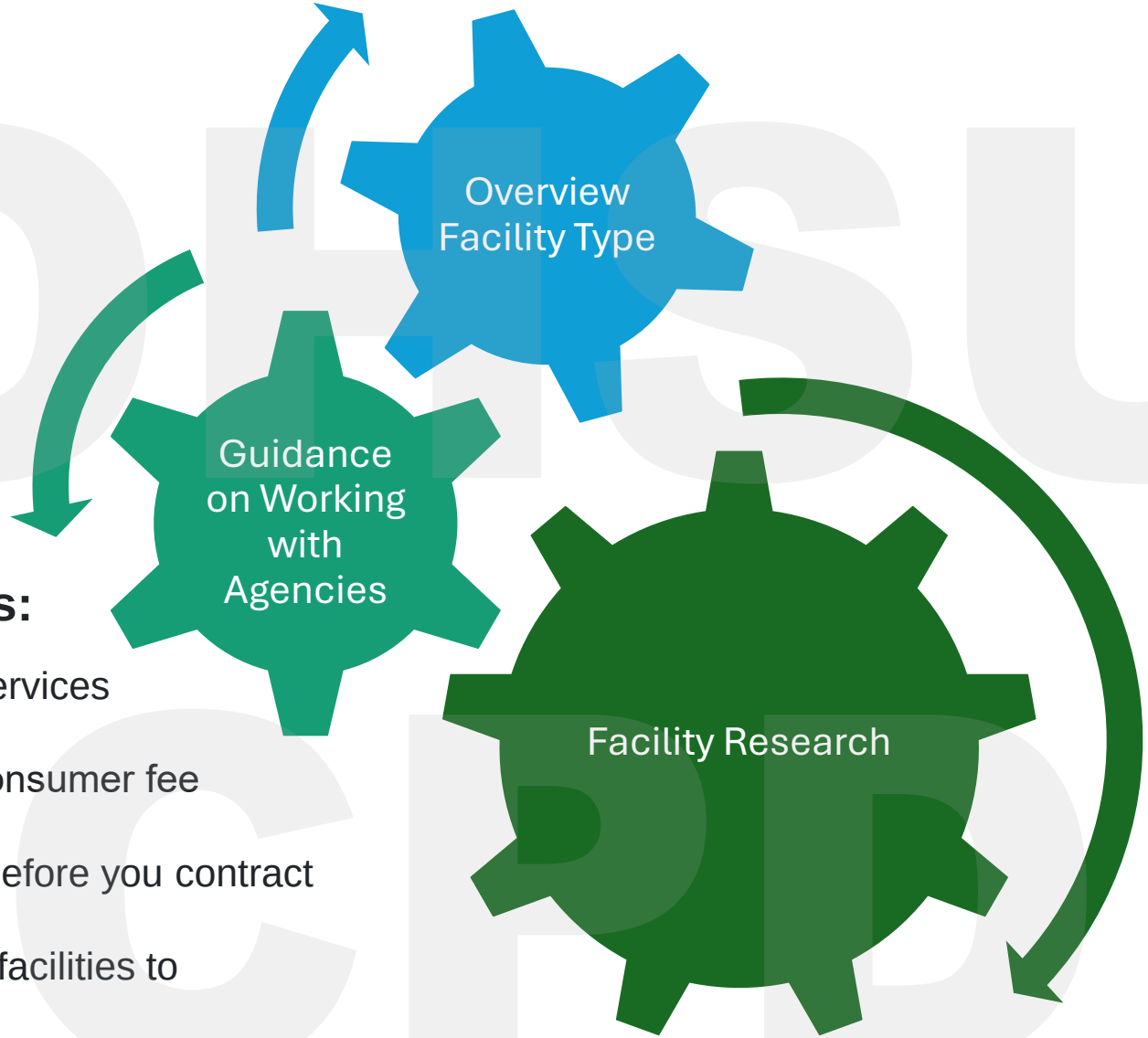
Access information, tools and guidance to help you plan for future needs before they arise.

Learn more

ADRC
Aging and Disability Resource Connection of OREGON

In your Community	In your Home	In a Facility	Alzheimer's

• Adult Day Programs
• Meal Assistance
• Senior Centers
• Transportation Services
	• Home Health Care
	• Personal Care Services
	• House Maker and Chore Services
	• Meal Delivery
		• **Adult Care Homes**
		• **Assisted Living & Residential Care**
		  • **Memory Care Communities**
		• **Nursing Facility**
			• In Home
			• Adult Day Centers
			• Residential Care
			• Care for the Caregiver
			  • Activities
			  • Communication
			  • Behavior
			  • Care giver support



Tips and Considerations:

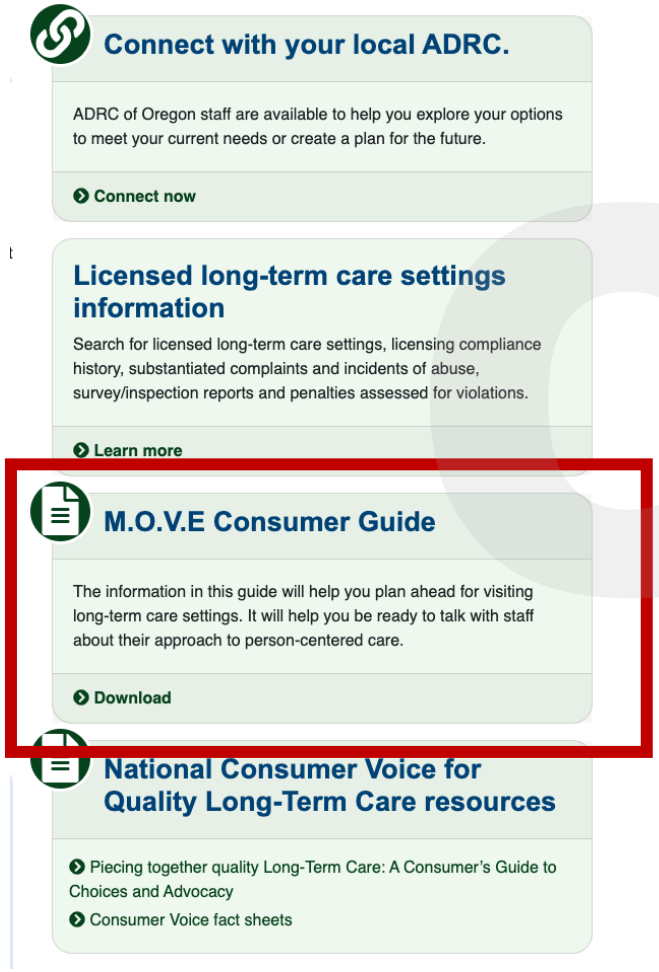
- Find out how it is paid for its services
- Inquire about finder's fee vs consumer fee
- Clarify the agencies services before you contract
- Clarify how they decide which facilities to represent
- Ask whether or not the agency goes with you for facility visits or gives you a list to visit on your own

Uniform Disclosure Statement

State Survey Evaluation

Complaints and Regulatory Actions

Ombudsman Office

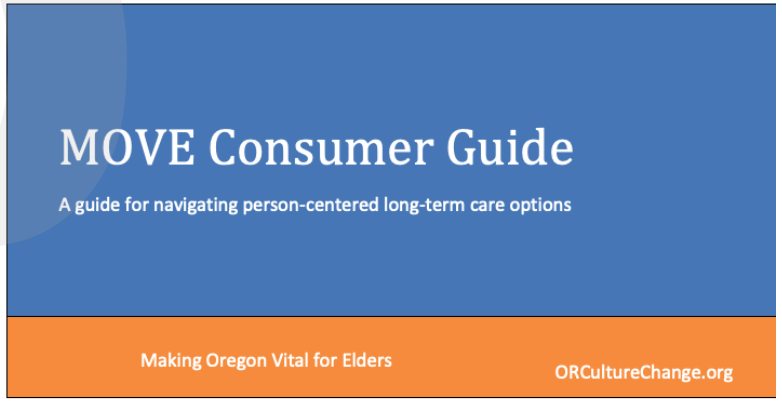


MOVE: Making Oregon Vital for Elders

Consumer Guide

- What is Important TO the Person
- What is Important FOR the Person
  - ADLS
  - Health Conditions
  - Cognitive Functioning
- Person Center Care Questions for Facility
- Questions for Residents and Other Family
- Trust your Senses

MAKING OREGON VITAL FOR ELDERS



Connect with your local ADRC.

ADRC of Oregon staff are available to help you explore your options to meet your current needs or create a plan for the future.

Connect now

Licensed long-term care settings information

Search for licensed long-term care settings, licensing compliance history, substantiated complaints and incidents of abuse, survey/inspection reports and penalties assessed for violations.

Learn more

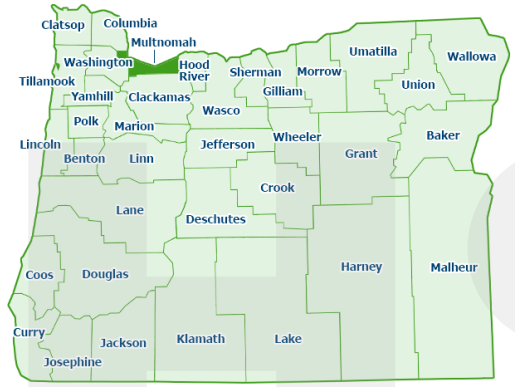
M.O.V.E Consumer Guide

The information in this guide will help you plan ahead for visiting long-term care settings. It will help you be ready to talk with staff about their approach to person-centered care.

Download

National Consumer Voice for Quality Long-Term Care resources

- Piecing together quality Long-Term Care: A Consumer's Guide to Choices and Advocacy
- Consumer Voice fact sheets



ADRC Contact Information

Multnomah county ADRC offices

Multnomah County Aging, Disability and Veterans Services (MCADVS)

Serves older adults and people 18+ with disabilities

Tel: 503-988-3646

adrc@multco.us

209 SW 4th Street Portland, OR, 97204

Independent Living Resources (ILR: Offering Peer-Based Disability Services)

Serves people of all ages with disabilities

Tel: 503-232-7411

Fax: 503-232-7480

adrc@ilr.org

1839 NE Couch Street Portland, OR, 97232

Find adult foster/care* homes in your local area

ZIP or county

Go

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Learn more

Guide to Oregon Adult Foster Homes

The information in this guide will help you learn more about Oregon's adult foster homes.

Download

Summary

- There is no crystal ball, but there ARE tools to quantify and anticipate functional needs
- Loss if independence is always hard, BUT starting early and emphasizing where the patient has control helps promote effective conversations
- In general, more care = more money, but truly understanding levels of care is confusing…
- … So don’t be shy to ask for help. There are MANY resources and experts here to help you and your patients/families

Thank you!

Neukam@ohsu.edu