National Alzheimer's Project Act (NAPA)

The information that follows was included as an attachment to an email submitted by the public.

For more information about NAPA, visit the NAPA website at:

http://aspe.hhs.gov/nationalalzheimers-project-act



increasing disclosure of dementia diagnosis

Divergence Between Common Perceptions About Dementia Diagnosis and Published Data

Physicians have cited many barriers to diagnosing dementia, including doubts about the value of diagnosis given limited treatment options, concern over risk of misdiagnosis, and lack of knowledge of local dementia support services.⁷ However, based on published data, perceptions that disclosure of dementia diagnosis is not preferred or causes psychological distress among individuals and family members should be challenged.

A majority of patients want to know if they have Alzheimer's Disease (AD)

A recent 5-country survey examining public attitudes about AD found that more than 80% of all adults (N=2,678) and 89% of US adults (N=639) responded that if they had memory or confusion symptoms, they would go to a doctor to determine if the cause was AD. This US finding is consistent with previously published reports over the last 2 decades. 10,11

Diagnosis does not cause psychological stress in most patients and their families

Physician conjecture that a dementia diagnosis may lead to depression or even suicide has been reported. ¹² Empirical findings on the issue are primarily limited to retrospective or review studies in populations with comorbid depression, a well-known risk factor for suicide. ^{13,14} To examine psychological stress, Carpenter and colleagues evaluated 90 individuals and their companions before a dementia evaluation and after dementia disclosure using the Geriatric Depression Scale (GDS) and the State-Trait Anxiety Inventory (STAI). ¹⁵

- No clinically significant changes were noted in depressive symptoms in either the persons diagnosed with dementia or their companion (Figure 1).
- Anxiety decreased or remained unchanged after diagnostic feedback for most groups (Figure 2).



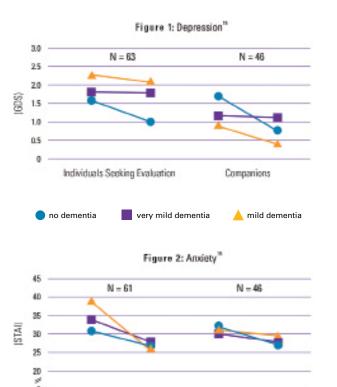
In gaining knowledge and developing a treatment plan, individuals may realize that they can take an active role in managing the illness, enhancing a sense of self-efficacy where before they might have felt helpless.⁴

99

Most family members appreciate the benefits of diagnosis

Connell and colleagues surveyed 178 adults who had a family member with AD.

- More than 75% of family members rated the following benefits of diagnosis as being very or extremely important:
 1) let family know what was wrong with relative;
 2) allowed family to get information about AD;
 and 3) allowed family to plan for the future.
- Only 6% of all respondents strongly agreed that "it is easier to not know what the diagnosis is."

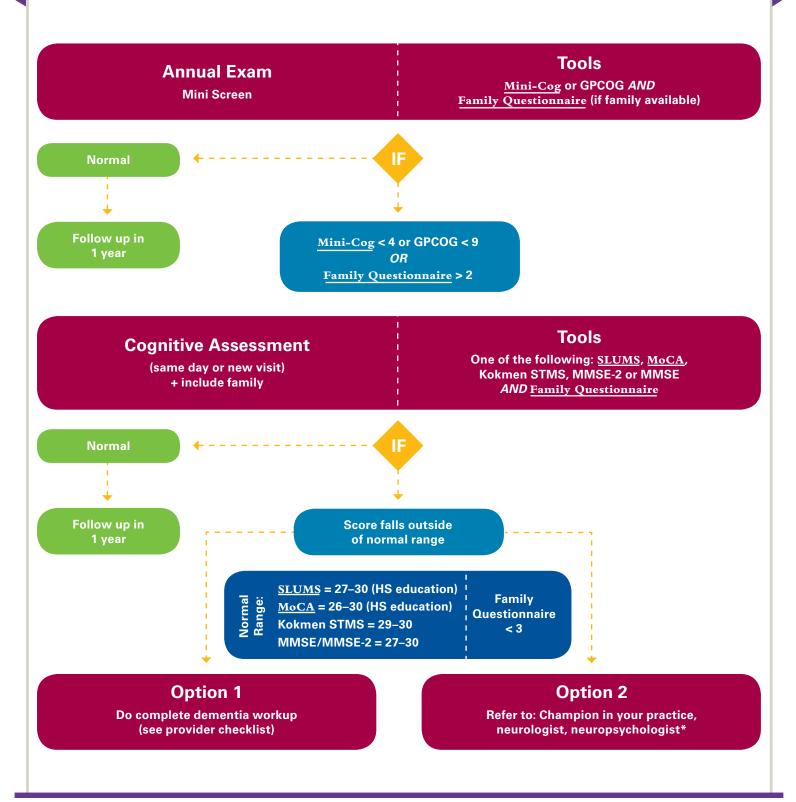


Individuals Seeking Evaluation

Companions

cognitive impairment identification

flow chart





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*Neuropsychological evaluation is typically most helpful for differential diagnosis, determining nature and severity of cognitive functioning, and the development of an appropriate treatment plan. Testing is typically maximally beneficial in the following score ranges:

SLUMS = 18-27 MoCA = 19-27 Kokmen STMS = 19-33 MMSE/MMSE-2 = 18-28

provider checklist

dementia work-up

Follow these diagnostic guidelines in response to patient failure on cognitive screening (e.g., Mini-cog) or other signs of possible cognitive impairment.

Hi	story and Physical			
	(Alzheimer's Association Family Questionnaire may assist) associated behavioral, medical or psychosocial issues	and edica	any tion	Assess mental health (consider depression, anxiety, chemical dependency) Perform neurological exam focusing on focal/lateralizing signs, vision, including visual fields, and extraocular movements, hearing, speech, gait, coordination, and evidence of involuntary or impaired movements
Di	iagnostics			
1.	☐ CBC, lytes, BUN, Cr, Ca, LFTs, Glucose		uropsych Indicated diagnosis, and/or de Typically	Ing RI when clinically indicated nological testing in cases of early or mild symptom presentation, for differential determination of nature and severity of cognitive functioning, velopment of appropriate treatment plan maximally beneficial in the following score ranges: MoCA 19-27; 18-27; MMSE 18-28 ^A
Di	iagnosis			
M	ild Cognitive Impairment Mild deficit in one cognitive function: memory, executive, visuospatial, language, attention Intact ADLs and IADLs; does not meet criteria for dementing the content of the co			Third most common type of dementia primarily affecting individuals in their 50s and 60s EITHER marked changes in behavior/personality OR language
ΑI	zheimer's disease			variant (difficulty with speech production or loss of word meaning)
	Most common type of dementia (60–80% of cases) Memory loss, confusion, disorientation, dysnomia, impaire judgment/behavior, apathy/depression ementia with Lewy Bodies/Parkinson's dementia			Relatively rare in pure form (6-10% of cases) Symptoms often overlap with those of AD; frequently there is relative sparing of recognition memory
	Second most common type of dementia (up to 30% of cases Hallmark symptoms include visual hallucinations, REM sldisorder, parkinsonism, and significant fluctuations in cognitions in cognitions.)	еер	1	
Fa	nmily Meeting			
	Include family care partners Review intervention checklist for Alzheimer's disease and			Refer to Alzheimer's Association (800.272.3900/alz.org. mnnd) or Senior LinkAge Line (800.333.2433/minnesotahelp.info)

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alzheimer's \bigcap association°

intervention checklist

for alzheimer's disease and related dementias

Diagnostic Uncertainty & Behavior Management	Refer to specialist as needed ☐ Neurologist (dementia focus, if possible) ☐ Geriatric Psychiatrist	☐ Geriatrician☐ Memory Disorders Clinic		
Counseling, Education,	Link to community resources	۵		
Support & Planning	☐ Alzheimer's Association 24/7 Helpline: 800.272.3900 alz.org/mnnd	☐ Senior LinkAge Line [®] 800.333.2433 MinnesotaHelp.info [®]		
	☐ Provide Taking Action Workbook	•		
Stimulation/Activity/ Maximizing Function	Daily mental, physical, & social actival Provide Living Well Workbook ² (for concrete recommendations)	vity Adult day services		
	Sensory aids (hearing aids, pocket t	Sensory aids (hearing aids, pocket talker, glasses, etc.)		
	Driving	Financial/Legal		
Safety	☐ Counsel on risks; "At the Crossroads" publication ³ ; refer for driving test or report to DMV as indicated	_		
	Medication Management ☐ Family oversight or public health nurse / home care	Note: Individuals with dementia are vulnerable adults and may be at a higher risk for elder abuse.		
	Complete advanced care plan			
Advanced Care Planning	☐ Refer to advanced care planning facilitator within system ☐ Encourage completion of healthcare directive forms ⁴⁻⁶			
	Memory	Avoid/Minimize		
Medications	 Donepezil, rivastigmine patch and galantamine 	• Anticholinergics, hypnotics and narcotics		
	☐ Memantine (mid-late stage)	• Antipsychotics (not to be used		
	Mood & Behavior ☐ SSRIs or SNRIs	in Lewy Body dementia)		

^AStructured Mental Status Exam

1. Montreal Cognitive Assessment (MoCA)

☐ Public domain: www.mocatest.org/

☐ Sensitivity: 90% for MCI, 100% for dementia

☐ Specificity: 87%

2. St. Louis University Mental Status (SLUMS)

☐ Public domain: http://medschool.slu.edu/ agingsuccessfully/pdfsurveys/slumsexam_05.pdf

☐ Sensitivity: 92% for MCI, 100% for dementia

☐ Specificity: 81%

3. Mini-Mental Status Exam (MMSE)

☐ Copyrighted: www4.parinc.com/ Products/Product.aspx?ProductID=MMSE

☐ Sensitivity: 18% for MCI, 78% for dementia

☐ Specificity: 100%

Note: This instrument is **not a preferred tool** in memory loss assessment. Accumulating evidence shows it is significantly less sensitive than both the MoCA and SLUMS in identifying MCI and early dementia.

Intervention Checklist

1. Taking Action Workbook

www.alz.org/mnnd/documents/2010_Taking_ Action_e-book(1).pdf

2. Living Well Workbook

http://www.alz.org/documents/mndak/alz_living_well_workbook_2011v2_web.pdf

3. At the Crossroads: Family conversations about Alzheimer's disease, dementia & driving www.thehartford.com/alzheimers

4. Minnesota Healthcare Directive

http://www.mnaging.org/en/Advisor/ HealthCareDirective.aspx

5. Five Wishes

www.agingwithdignity.org/forms/5wishes.pdf

6. Honoring Choices Minnesota

www.metrodoctors.com

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