User Manual

Caregiver Support-Staging Approach

Dementia Alignment Assessment Form

National Task Group on Intellectual Disabilities and Dementia Practices

Changing Thinking! Project

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National Task Group
on Intellectual Disabilities
and Dementia Practices

User Manual for the Caregiver Support-Staging Approach Assessment Form

Introduction

The **Caregiver Support-Staging Approach Assessment Form** is designed to help you, as an intake worker, assess a family caregiver's support-stage in relation to and involvement in caring for an adult with an intellectual or other developmental disability affected by dementia. This tool aligns with the **CMS GUIDE Model**, ensuring that caregiving support is tailored to the caregiver's capacity and the beneficiary's evolving needs.

Understanding the caregiver's current support-stage in their caregiving journey **allows Navigators to recommend appropriate resources, educational materials, and support services, facilitating a structured approach to dementia care**. The intersection of the nature of the caregiver's role and investment as a caregiver and the caregiver's subjective and objective expressions of understanding the nature and impact of dementia and caregiving responsibilities will help you in framing a dementia care plan that is practically useful and effective.

Purpose of the Form

This assessment form is used to:

- Determine the **caregiver's current support-stage needs in 'dealing with'** the presence of dementia in providing care.
- Identify **challenges** the caregiver faces supporting an adult with the condition.
- Guide **personalized interventions** and approaches to improve caregiving effectiveness.
- Support **ongoing evaluation and care planning to meet needs** for both the caregiver and the beneficiary.

Instructions for Use

Step 1: Gather Caregiver and Beneficiary Information

Before assessing the caregiver's support-stage, collect basic information:

- **Caregiver's Name & Contact Information**
- **Caregiver's Age and Relationship to Beneficiary**
- **Beneficiary's Name, Age & Dementia Diagnosis**

- **Stage of Dementia (if known)**
- **Other information required by agency**

This information aids Navigators contextualize the responses and ensure appropriate support and follow-up.

Step 2: Identify the Caregiver Role and Nature of Involvement

Purpose

This section helps define the caregiver's specific role and involvement in providing support to the beneficiary. Understanding the type of caregiving relationship ensures that appropriate services, education, and resources can be offered. Use this Step to consider the nature of the role and relationship of the caregiver to the beneficiary with an intellectual or other developmental disability and dementia.

Instructions for Completion

- Review each caregiving role below carefully.
- Select **the role(s) that best describes the caregiver's main caregiving role/situation.**
- If multiple roles apply, check all that are relevant.
- If none of the roles listed match the caregiver's situation exactly, select **"Other"** and provide a brief description.

Caregiver Role Options

☐ 1. **Primary Parent** Caregiver. (direct care of son or daughter in family home).

☐ 2. **Primary Sibling** Caregiver. (direct care of co-residing sister / brother).

☐ 3. **Primary Other Family** Caregiver (direct care, aunt/uncle/cousin, etc., co-residing)

☐ 4. **Secondary Family Caregiver** (supportive care by parent, sibling or other relative; for relative with ID living independently or with residential services)

Specify relationship _____

☐ 5. **Other Non-Kin Caregiver** (relationship, living arrangement, care provided).

Specify: Relationship, living arrangement, care provided. _____

☐ 6. **Sole Caregiver** (Handles all caregiving responsibilities alone in the shared home)

☐ 7. **Collaborative Caregiver** (Shares caregiving with a spouse, other relative or friend)

8. Other (specify): _____

Choose this option if none of the roles adequately describes the caregiver's situation and provide a brief explanation. For example, the caregiver may have been assigned to this function within the GUIDE program.

Step 3: Using the Caregiver Support-Stage Form to Assess the Caregiver's Current Support Needs

The form focuses on the caregiver's needs and includes a series of statements that are associated with the **four caregiving support-stages** that reflect differing levels of involvement and adaptations to caregiving for the beneficiary. Consider the statements in the four support-stages placing a checkmark beside each one that is relevant to the caregiver's situation.

1. **Diagnostic Support-Stage**

In general, the caregiver is concerned over signs of decline or increased memory loss and seeking help with an explanation for the changes.

□ Seeks help to understand cognitive/functional changes
□ Engaged in diagnostic process
□ Wants more information when diagnosis provided
□ Hesitant about next steps or acknowledging diagnosis

Recommended Actions: Provide information on dementia signs and co-occurring conditions to the caregiver and beneficiary, encourage involvement in diagnostic evaluations, and offer emotional support.

Outcomes: Validating suspicions, tracking behavior and function, engagement in assessment and diagnostic process and obtaining a diagnosis for the change(s).

2. **Explorative Phase**

In general, the caregiver is aware of and is accepting the beneficiary's diagnosis and considering support options.

□ Wants more information on dementia care strategies
□ Notes challenges with behavioral change or symptoms
□ Is exploring resources/services
□ Unsure as to how to plan for future or emergencies

Recommended Actions: Educate on disease progression and associated conditions, introduce supplementary support for behavioral concerns and support networks, and help with future planning.

Outcomes: Better understanding of disease, its progressive nature and understanding of strategies to address symptoms. Future plans (advance directive, health care proxy) for care, end-of-life care and emergency situations are formulated with involvement of beneficiary if they may still be able to participate.

3. **Adaptive Phase**

In general, the caregiver is actively adjusting caregiving practices, with the use of daily practical strategies, adjusting caregiving routines, and managing symptoms.

□ Trialing new strategies to manage symptoms
□ Requires ongoing support for behavior/cognition changes
□ Has developed self-care strategies
□ Seeking support for anticipatory grief/loss

Recommended Actions: Provide training on alternative strategies to address cognitive and behavioral symptoms of dementia, assist with practical strategies for daily living, and evaluate caregiver stress.

Outcomes: Home modifications made, routines and tasks adapted to reflect changes, service adaptations made to accommodate caregiver needs, respite instituted, coping with changes, better quality of life

4. **Closure Support-Stage**

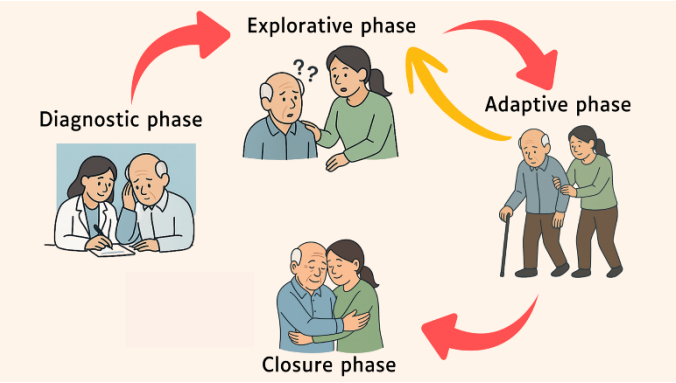
In general, the caregiver may feel relief, satisfaction past concerns were dealt with. Yet other new and immediate concern(s) may emerge to be addressed and resolved.. The caregiver is carrying on with the new or additional caregiving tasks. Alternatively, a caregiver is now addressing advanced dementia care, transitioning out of caregiving, or coping with post-caregiving grief.

□ Received timely practical support; concerns resolved
□ Needs guidance on legal/financial/emotional issues
□ Follows beneficiary's end-of-life plan
□ Seeking support for grief/loss

Recommended Actions: Schedule follow-up, support transitions to end-of-life, connect with grief counseling, and connect to post-caregiving resources.

Outcomes: Setting located for advanced care as needed, supportive palliative and hospice care services engaged, end-of-life decisions are respected, celebration of life rituals held, caregiver reflection on experiences and caregiver reflection on experience, grief and finding a meaningful way forward in their life.

Instructions For Use of the Form



Following the caregiver interview, **review and select the statements** that most accurately reflect the caregiver's current experience. **Map each selected statement** to its corresponding caregiving support-stage (Diagnostic, Explorative, Adaptive, or Closure) using the column headers provided in the form. This process supports a structured approximation of the caregiver's current support-stage.

It is important to recognize that caregiving stages are not strictly linear (Figure). Caregivers may exhibit characteristics across multiple phases or shift between stages as circumstances evolve. Nonetheless, **identifying the predominant phase offers critical insight** for assessing caregiver capacity, aligning services, and informing care planning. These findings should be integrated into the interdisciplinary team meeting to support a comprehensive and responsive dementia are plan. When appropriate, and with sensitivity to the caregiver's readiness, this staging framework may also be used to facilitate collaborative discussion with the caregiver to ensure alignment of recommended supports with their current needs and capacities.

Step 4: Identify Caregiver Needs and Support Plan

This section captures specific **challenges** the caregiver faces and helps determine

from. Caregiver needs may be objective or subjective.

- Examples of **objective needs** include information on signs/symptoms, understanding changes, determining daily routines, adapting the home environment.
- Examples of **subjective needs** include a profound sense of loss, difficulties with long term planning, feeling overwhelmed by care demands, isolated and abandoned.

Talking with the caregiver about their perceptions and their priorities will help identify plans to meet their needs. For example:

- Additional information or education on dementia progression and care strategies.
- Home adaptations.
- Self-care to prevent social isolation, personal mental and physical health.
- Counseling or mental health support for stress reduction.
- Respite care options.
- Financial or legal planning assistance.

Step 5: Establish Next Steps (Follow-up Actions)

The final section outlines **specific actions** to support the caregiver, such as:

- Distributing educational materials
- Connecting caregivers to support groups
- Providing referral and access to training and clinical supports
- Assisting with long-term care planning including an emergency plan should they be unable to provide care
- Scheduling follow-up assessments

Step 6: Navigator Notes & Recommendations

Based on the assessment, the Navigator can provide recommendations for:

- Addressing immediate support needs
- Making referrals to specialized services
- Identifying needed additional evaluations or follow-ups

This ensures that the caregiver receives continuous guidance as dementia progresses.

Step 7: Form Completion

Signing and dating the form to document the assessment and track caregiver progress over time.

Best Practices for Completing the Form

- **Use a conversational approach** to ease any stress or hesitation the caregiver may feel.
- **Encourage honesty** and validate the caregiver's experiences—dementia care is an evolving process.
- **Reassess periodically** since a caregiver's role and needs will change as dementia progresses.
- **Tailor recommendations** to the caregiver's unique circumstances and needs, including cultural, emotional, and logistical factors.
- **Provide the caregiver with your contact information**

Some Situation Examples and Staging

Caregiver Stage: Explorative Phase - This caregiver is actively trying to manage dementia-related changes while experiencing mounting stress and limited support. The

Situation Example #1 – Home-Based Primary Caregiver

Mary, a 61-year-old woman with an intellectual disability, lives at home with her 71-year-old stepmother, who is her primary caregiver. Mary's father, who had vascular dementia, was recently moved to a memory care center after a debilitating stroke and has since passed away. Mary's cognitive and behavioral decline over the past year—including obsessive behaviors, distress with routine changes, and withdrawal from community activities—has made caregiving increasingly complex. Mary's stepmother, originally hoping for an active retirement with her stepdaughter, is now managing intensive care needs alone. She struggles with isolation and limited options, especially as Mary resists leaving the home. With limited respite care from a neighbor, she is now considering the next steps after being referred to the local medical center's GUIDE program.

case illustrates a need to help Mary explore her options for easing the caregiving demands.

Caregiver Stage: Closure Phase

Situation Example #2 – Secondary Caregiver

Jonathan, a 53-year-old man with Down syndrome and Alzheimer's disease, was cared for at home by his aging adoptive parents (ages 89 and 93) without outside support. As his condition progressed, they sought residential care, eventually placing him in a group home for older adults. Though staff lacked dementia-specific training, his parents remained closely involved—monitoring care, advocating after an adverse medication reaction, and keeping in touch with him on a weekly basis. Jonathan has since experienced rapid decline, becoming nonverbal, non-ambulatory, and fully dependent. His parents continue to navigate the emotional and practical demands of late-stage dementia, actively engaged in his care despite their own health limitations.

This situation reflects caregivers grappling with advanced dementia, loss, and the emotional toll of long-term advocacy, while coordinating ongoing support in a facility-based setting.

Situation Example #3 – Sibling Caregivers

Rodrigo, a 57-year-old man with autism and intellectual disability, lived independently for nearly a decade after his parents' passing, supported mild financially and emotionally by his two older sisters. He maintained a rich social life and independence until his late-40s, when behavioral and mood changes began to emerge. These changes gradually intensified, leading to a recent diagnosis of dementia by their primary care physician. Rodrigo now lives with his two older sisters, who provide daily supports and direction. They arranged to have him become a Medicare beneficiary due to his disability. They have noted worsening symptoms, including hallucinations and verbal aggression, and are uncertain about how to manage his evolving needs. Concerned about the implications of the diagnosis but committed to keeping him at home, they have been referred to the local GUIDE program for support.

Caregiver Stage: Explorative/Adaptive Phase
This situation reflects caregivers transitioning from the recognition of behavioral changes to actively seeking help to manage the symptom. Information, support services, and guidance on disease progression , symptoms and care planning are required.

Note

The **Caregiver Support-Stage Assessment Form** is an essential tool in the GUIDE Model toolkit, helpful for supporting caregivers of adults with intellectual disabilities and dementia. By systematically assessing **where caregivers are on their journey**, Navigators can **deliver timely and relevant resources**, ultimately improving both caregiver well-being and the quality of dementia care provided to the beneficiary.

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Appendix: Caregiver Support-Staging Assessment Form

Caregiver Support–Staging Assessment Form

Navigator/Assessor Name:	Date of Assessment:

Beneficiary Information

Beneficiary Name	Case #
Beneficiary Age	Stage of Dementia
Confirmed Dementia Diagnosis □ Yes □ No	Special needs

Caregiver Information

Caregiver Name	Case #
Caregiver Age	Relationship to Beneficiary
Contact Information	

Caregiver Roles & Involvement (check all that apply and note)

□ Primary Parent Caregiver (direct care in family home)

□ Primary Sibling Caregiver (direct care, co-residing)

□ Primary Other Family Caregiver (aunt/uncle/cousin, co-residing)

□ Secondary Family Caregiver (supportive care; relative with ID living independently) – Specify:

□ Other Non-Kin Caregiver – Specify relationship/living arrangement:

□ Sole Caregiver (handles all responsibilities alone)

□ Collaborative Caregiver (shares responsibilities with others)

Caregiver Support-Staging Assessment

Check statements that best describe the caregiver's current situation. Discuss priorities with the caregiver.

- 1. **Diagnostic Support Stage** (seeking validation)

  □ Seeks help to understand cognitive/functional changes
  □ Engaged in diagnostic process
  □ Wants more information when diagnosis received
  □ Hesitant about next steps or acknowledging diagnosis

- 2. **Explorative Support Stage** (accepting diagnosis)

  □ Wants more information on dementia care strategies
  □ Notes challenges with behavioral change or symptoms
  □ Is exploring resources/services
  □ Unsure as to how to plan for future or emergencies

- 3. **Adaptive Support Stage** (managing symptoms)

  □ Trialing new strategies to manage symptoms
  □ Requires ongoing support for behavior/cognition changes
  □ Has developed self-care strategies
  □ Seeking support for anticipatory grief/loss

- 4. **Closure Support Stage** (redefining next steps)

  □ Received timely practical support; concerns resolved
  □ Needs guidance on legal/financial/emotional issues
  □ Following beneficiary's end-of-life plan
  □ Seeking support for grief/loss

Caregiver Needs & Support Plan

Identified urgent challenges, required actions, and helpful resources.

- Urgent/current challenges facing the caregiver?
- Support stage alignment with their priorities? Actions needed?
- Resources or services that could help short- and long-term?
- Follow-up needed? □ Yes □ No Frequency: _____

Next Steps (check all that apply and note actions to be undertaken)

□ Provide educational materials on dementia care

□ Refer for specific services/supports

□ Connect caregiver with support groups or counseling

□ Assist with planning future care transitions

□ Schedule a follow-up assessment

□ Other: _____

Navigator Notes & Recommendations

Navigator Signature:		Date:	

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