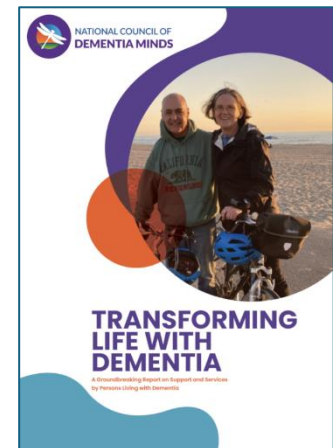


## ***Transforming Life with Dementia (2024)*** **FULL LIST OF RECOMMENDATIONS**

In 2024, the National Council of Dementia Minds (NCDM) conducted a groundbreaking needs assessment in which people living with dementia identified key information and services that individuals need during their first year after a diagnosis of dementia. As co-researchers in the project, we reviewed the current post-diagnosis support landscape and shared our stories to identify critical gaps and deficiencies in the resources and services available.

The primary product of that effort was ***Transforming Life with Dementia***, a report that recommends specific strategies for healthcare systems, care providers and policy makers to improve the health and wellness of persons living with dementia during this key period. This document accompanies that report and provides the full list of recommendations that were summarized in the report.

These recommendations were arrived at through a series of three focus group meetings, during which we identified critical gaps in support and resources for persons living with dementia.



In our initial meeting, we shared our experiences from diagnosis to one year afterward, laying the groundwork for understanding the existing landscape. Building on these insights, the second session focused on envisioning ideal support and resources to enhance quality of life post-diagnosis. During our final meeting, we refined recommendations generated from the previous session, ensuring accuracy and alignment with our collective experiences.

These 131 recommendations, crafted by 65 diverse individuals living with dementia, reflect our vision for a more supportive future for living well with dementia.

Please join us in championing meaningful change in dementia care and support by delving into these recommendations and taking decisive action today.

## RECOMMENDATION CATEGORIES

We categorized our findings into specific areas, each addressing different dimensions of the diagnosis experience and the subsequent need for information and resources. The number following each category indicates the number of recommendations within that specific category.

Stigma: 11

Social: 21

Emotional: 26

Medical: 53

Financial: 18

Legal: 2

## STIGMA

Living with dementia is clouded by harmful stereotypes and misconceptions that portray us as incapable or burdensome. These negative beliefs not only diminish our sense of self-worth but also affect how others perceive and interact with us. To break down these barriers, it's crucial to challenge stereotypes and educate society about the diverse experiences of people living with dementia. By fostering understanding and empathy, we can create a more inclusive and supportive community for all.

1. Launch initiatives to educate families and the public on the uniqueness of each individual's dementia experience, crucial for combating harmful stereotypes and promoting understanding, while also highlighting the reality of a fulfilling life after diagnosis.
2. Provide a curated list of trustworthy books and websites upon diagnosis, recognizing that discerning which ones are trustworthy is a daunting task. This information is crucial in empowering us with accurate information, essential for understanding and managing dementia effectively.
3. Guide individuals in accessing reliable online resources, including Facebook groups and YouTube channels tailored to specific dementia types, to assist in finding valuable information.
4. Facilitate the exchange of information among various dementia research and support groups to advance knowledge and improve outcomes.
5. Ensure that online resources offer accurate, positive, and personalized information to address the unique needs and challenges of dementia.
6. Recognize individuals diagnosed as lifelong learners to shift societal perceptions and promote continued education.
7. Provide a comprehensive series of videos covering various aspects of dementia and featuring individuals living well with the condition, both at the time of diagnosis and thereafter.

8. Ensure that videos accessible upon diagnosis provide informative and uplifting content, along with supplementary materials to enhance understanding.
9. Provide individuals recently diagnosed with dementia access to tailored written material and videos focusing on their specific dementia type, along with guidance to relevant resources.
10. Customize all provided resources to meet the individual needs of each person living with dementia, ensuring that peer support groups are specifically matched to preferences and characteristics.
11. Create a comprehensive guide for organizations on effectively structuring and facilitating peer support groups. This guide should encompass considerations such as age, gender, dementia type, care partner involvement, and disease stage to ensure tailored and effective support for all participants.

## SOCIAL

Building and maintaining social connections is crucial for living well and navigating life after receiving a dementia diagnosis. Effectively communicating our diagnosis to close relations and employers in a manner that fosters understanding and empowerment is essential. Through open and truthful sharing of our experiences, we aim to uphold our sense of identity and autonomy throughout our journey with dementia.

12. Encourage individuals living with dementia to engage in meaningful activities such as advocacy work, education, volunteering, and other pursuits. Emphasize the importance of finding joy and purpose in everyday activities, such as walking a dog, to rediscover meaning in life after diagnosis. Highlight that new opportunities and horizons exist for people living with dementia, reinforcing their continued significance and potential contributions to society.
13. Ensure individuals living with dementia have access to Zoom and receive support in utilizing this platform effectively, as well as other relevant technologies, recognizing their importance in accessing resources and enhancing quality of life, including fostering social connections with peers.
14. Develop a comprehensive conversation guide equipped with checklists to aid individuals newly diagnosed with dementia in communicating about the condition with employers, children, grandchildren (both minor and adult), family members, and friends.
15. Provide a written conversation guide for individuals living with dementia and their family members, covering essential topics like driving, cooking, general safety, and housing. This guide should provide practical recommendations and be tailored for self-study at home by individuals with dementia.
16. Develop informational resources for individuals newly diagnosed with dementia that emphasize the positive aspects of living well following a diagnosis, providing hope and inspiration for the journey ahead.

17. Provide comprehensive education for care partners and family members to understand the evolving changes in individuals living with dementia from the time of diagnosis, including guidance on preparing for future personality changes as the condition progresses.
18. Enhance care partner and family education programs to equip them with the skills and knowledge necessary to effectively communicate and deliver the diagnosis to individuals newly diagnosed with dementia.
19. Encourage doctors and other healthcare professionals to customize the delivery of information about dementia based on the current condition of the individual, rather than solely concentrating on the end stage of the disease.
20. Offer tailored classes or educational opportunities for individuals newly diagnosed with dementia and their care partners, ensuring that the information provided aligns with the varying degrees of acceptance and understanding. Adjust the flow of information to meet the unique needs of the person diagnosed, avoiding overwhelming or insufficient information that may increase stress levels for both parties.
21. Provide comprehensive website information, including dementia advocacy organizations led by individuals living with dementia as advocates, available services, and hotline contacts. Additionally, highlight organizations with stores offering products to support individuals living with dementia.
22. Develop diagnosis-specific websites centered on individuals living with dementia, prioritizing their needs and experiences over those of care partners. Ensure that these websites include information provided by advocacy associations that offer valuable resources applicable to various types of dementia.
23. Promote the use of identification cards or bracelets by individuals diagnosed with dementia to communicate their dementia type and pertinent information about medications or support requirements to others when outside their home environment.
24. Facilitate one-on-one peer support opportunities for individuals living with dementia, with a focus on persons who are newly diagnosed. Recognize that many of the newly diagnosed are still employed, necessitating flexible scheduling to accommodate their availability.
25. Establish dedicated peer support groups tailored to underrepresented communities, including African American and LGBTQ+ individuals, to ensure inclusive and culturally sensitive support networks.
26. Establish peer support groups that connect individuals newly diagnosed with dementia with others living with the condition, providing valuable information, and fostering hope for persons navigating a dementia diagnosis.
27. Establish peer support groups tailored for individuals living with dementia to actively learn and exchange strategies for coping and living well with the condition, emphasizing compensatory techniques and effective management strategies.
28. Organize peer support groups aimed at connecting individuals who have been living with dementia for five years or more, providing an opportunity for persons newly diagnosed to learn from their experiences and management strategies.

29. Establish peer support groups specifically tailored for individuals whose dementia has progressed, allowing them to connect with others facing similar challenges and gain insights into effective management strategies for the future.
30. Facilitate peer support groups where individuals can connect with others sharing the same diagnosis, enabling them to discuss and address specific issues related to their form of dementia in a supportive and understanding environment.
31. Create peer support groups that mirror the experiences of individuals newly diagnosed with dementia, ensuring participants share the same diagnosis and are at a similar point in their journey or slightly further along, to foster comfort and relatability among group members.
32. Refer individuals newly diagnosed with dementia to support groups consisting of members at the same stage in their dementia journey, excluding care partners from discussions to maintain focus on the needs of persons diagnosed with dementia.

## EMOTIONAL

Being newly diagnosed with dementia comes with a flood of emotions that we must navigate to live well with this condition. Seeking connections with support groups, healthcare professionals, and spiritual resources can greatly improve our day-to-day life and long-term perspective. It's crucial to find this support as soon as possible after diagnosis, as it significantly impacts not only our well-being but also that of our family.

33. Facilitate connections between individuals living with dementia and advocacy opportunities, encouraging active participation in social activities and information sharing.
34. Ensure that persons living with dementia and their families are referred to dementia-friendly and dementia-capable organizations with extensive experience and training, guaranteeing comprehensive support and services.
35. Ensure referrals to organizations that offer specialized support services tailored for persons with young-onset dementia, children, and care partners.
36. Initiate discussions about the benefits of physical therapy, occupational therapy, and speech therapy early after diagnosis to help individuals maintain motor skills and function. Therapists can assist in streamlining life and preserving functioning to the greatest degree possible, ultimately helping individuals and their families maintain normal routines.
37. Provide access to a dedicated coach or guide who can support the person living with dementia and their care partner in living their best life possible.
38. Ensure a coordinated interdisciplinary approach is established from the time of diagnosis, providing access to all necessary services tailored to the specific diagnosis. Address the common issue of individuals being told they are not "bad enough" to receive these services.
39. Establish a system where a social worker or case worker reaches out shortly after diagnosis to check on the individual's well-being and provide comprehensive support. This includes assistance with acceptance of the diagnosis, guidance on navigating challenges, and addressing individual needs such as understanding legal rights, accessing support groups, managing

finances, applying for government benefits, and coordinating medical care. Ensure this support is provided promptly after diagnosis to address immediate concerns and minimize anxiety.

40. Establish a dedicated case worker or coordinator for medical and clinical services to provide comprehensive support for individuals diagnosed with dementia. This service can be offered through various healthcare providers, including primary care doctors, neurologists, geriatricians, university health systems, palliative care clinics, and private care coordinator services. Ensure all team members have access to the electronic medical record (EMR) to enhance coordination of care. Centralize clinicians and related supports within one network to prevent complications and ensure seamless collaboration.
41. Provide a referral to a psychologist or counselor at the time of diagnosis to support individuals in coping with acceptance or the grieving process following the diagnosis of dementia. Ensure that the counselor has specific training or experience in working with people living with dementia and the grieving process. The referral should encompass the person living with dementia, care partners, and family members, though they may not attend the same sessions. Offer a written list of qualified clinicians to the person for their convenience.
42. Encourage individuals supporting persons living with dementia to consider each stage of receiving a diagnosis and the progression of the condition as opportunities for the individual to pivot. Providing support during each pivot for acceptance and, at times grieving, can significantly aid individuals navigating dementia diagnoses and progression. Viewing dementia as moments of life changes, rather than a new normal, has proven helpful for some individuals.
43. Offering a scientific and detailed overview of the distinct types of dementia, along with insights into potential future trajectories, may be appropriate for some individuals newly diagnosed.
44. Tailor information provided to individuals newly diagnosed with dementia, recognizing that while some may benefit from comprehensive insights into potential challenges and considerations for the end stage of the condition, others may prefer information focused solely on their current situation.
45. Provide individuals diagnosed with dementia with a curated list of recommended books tailored to their specific type of dementia, along with guidance on how to obtain them.
46. Introduce the ASAP concept—Acceptance, Socialization, Attitude, and Purpose—at the early stages of a dementia diagnosis to aid in managing emotions effectively.
47. Provide a stress management resource offering techniques such as meditation, breathing exercises, and other health practices to reduce fear, anxiety, and grief. This resource should be available for persons diagnosed and care partners to enhance their well-being and provide a sense of control.
48. Provide contact information for individuals with the same diagnosis at the time of diagnosis. Connecting with peers living well with dementia can greatly assist in navigating the early days post-diagnosis. This information should be furnished by the doctor's office, or a trusted entity should be referred to facilitate the contact.
49. Facilitate access to spiritual, religious, or philosophical groups for individuals living with dementia, as appropriate and according to their preferences and needs.
50. Provide a resource to connect individuals newly diagnosed with dementia and their care partners with peers sharing the same diagnosis, ideally locally. Both group and individual

connections serve similar and unique needs, each playing an important role in fostering hope for the future.

51. Facilitate opportunities for individuals newly diagnosed with dementia to share their experiences post-diagnosis. This sharing can provide them with purpose, hope, and new positive perspectives on their journey with dementia.
52. Collaborate with the Black Church to share information and increase resources available to the Black community, particularly regarding dementia support and services.
53. Establish culturally specific peer support groups composed of individuals who share similar values, providing a supportive environment tailored to the cultural needs of participants.
54. Refer individuals to age-appropriate and culturally specific peer support groups tailored to their diagnosis, emphasizing the purpose of these groups for education, advocacy, and peer mentoring. Encourage participation in groups consisting of individuals with the same diagnosis, as well as persons with different dementia diagnoses, to foster a diverse and supportive community.
55. Provide information about peer support groups at the time of diagnosis, including options for Zoom groups to accommodate individuals, especially individuals living in rural areas, where in-person meetings may be limited.
56. Provide comprehensive support group information that encompasses resources for both persons living with dementia and support groups tailored for care partners.
57. Facilitate access to a dependable resource for locating skilled care partners available for hire.
58. Encourage individuals newly diagnosed with dementia to organize a resource binder with categorized tabs for easy access to helpful information. Starting with a basic format, they can gradually add more resources over time as needed.

## **MEDICAL**

As individuals recently diagnosed with dementia, we face numerous challenges in accessing and navigating medical services. It is vital for both us and our healthcare providers to enhance our collaboration and understanding to ensure optimal care. This includes addressing the timing of diagnosis, sharing pertinent information, and managing the impact on both private and government benefits. Furthermore, we must prioritize strategies that empower us to live well with dementia and maintain hope for the future.

59. Advocate for the inclusion of people living with dementia in genetic research studies, ensuring their representation in scientific investigations.
60. Facilitate the exchange of information among various groups involved in dementia research and support efforts, including state organizations responsible for the development and implementation of a state's dementia service plans. Ensure that project reports and relevant findings are disseminated to stakeholders, including individuals living with dementia. Additionally, provide contact information for similar initiatives across the country to enhance accessibility and collaboration nationwide.

61. Encourage individuals living with dementia to share the final report generated from this grant project with all their physicians to foster understanding and awareness of dementia-related issues and advancements.
62. Advocate for policy changes with medical insurers to ensure that individuals newly diagnosed with dementia have access to clinicians such as occupational therapists, cognitive speech therapists, etc. These professionals can offer valuable assistance in adapting everyday living skills needed to thrive with dementia. This support should not be withheld until the individual's condition reaches a certain level of severity.
63. Share the names of highly recommended programs and individual clinicians who specialize in dementia care. Even if a person living with dementia is receiving care at a large, prestigious hospital or university, a detailed list of experienced and competent clinicians is essential. This resource should offer specific recommendations beyond generic referrals. Access to such information is crucial for all individuals living with dementia, especially individuals in rural areas facing greater challenges in finding specialized care.
64. Offer immediate guidance to individuals newly diagnosed with dementia on essential action steps related to diet, exercise, meditation, joining support groups, and improving sleep. These steps should be readily actionable and prioritized to facilitate prompt implementation and support well-being.
65. Ensure that individuals newly diagnosed with dementia are informed about the importance of discussing all medical and psychological conditions, as well as current medications, with their pharmacist. Requesting a thorough review for potential contraindications that could affect functioning is crucial. Additionally, consider seeking the expertise of a specialized pharmacist who utilizes genetic testing, if appropriate, to optimize medication management.
66. Facilitate timely referrals for individuals newly diagnosed with dementia to access various resources as needed, recognizing that support and services may vary over time as the condition progresses. Provide a comprehensive resource guide detailing appropriate referrals to request from healthcare providers and how to locate these resources. Emphasize the importance of an ongoing and adaptable approach, ensuring that support is provided at the appropriate stages of the dementia journey. This includes the establishment of a multidisciplinary team to address changing needs, with team members adjusting as necessary throughout the progression of dementia.
67. Ensure individuals newly diagnosed with dementia, including persons with young onset, are connected with services from a geriatrician or clinicians specializing in gerontology. These professionals can offer tailored support and referrals to address the unique challenges of dementia, promoting comprehensive care from the outset of the diagnosis.
68. Provide individuals with specific information about their dementia diagnosis, including its potential progression both in the short term and over the long term. Highlight the variability of symptoms and functioning, emphasizing that individuals may experience fluctuations in their condition on a day-to-day basis. This understanding is crucial for individuals newly diagnosed to navigate their journey with dementia effectively.
69. Identify and assemble an interdisciplinary team of clinicians and professionals to address the evolving needs of individuals with dementia as the condition progresses.



70. Develop and distribute a comprehensive list of questions, sourced from reputable dementia advocacy websites or organizations, to empower newly diagnosed individuals to have informed discussions with their doctors about their diagnosis and to facilitate effective communication with healthcare providers.
71. Establish a structured information dissemination process within healthcare settings, providing comprehensive details about the specific form of dementia at the time of diagnosis, with subsequent appointments dedicated to discussing clinical trials, supplements, and strategies for slowing progression. Ensure the information is sourced from trusted resources, minimizing the need for individuals diagnosed with dementia to seek information independently on the internet.
72. Compile and distribute a concise guide featuring contact details of Alzheimer's Disease Research Centers, highlighting their resources such as information on dementia types, clinical trials, research studies, available clinicians, and monthly public Zoom sessions. This initiative aims to streamline access to essential support and information for individuals and families dealing with dementia.
73. Develop and distribute a simple fact sheet for individuals newly diagnosed with dementia, outlining the different forms of dementia and related conditions, along with links to additional information specific to each form. This initiative aims to provide easily accessible and informative resources to support individuals navigating their diagnosis.
74. Develop and implement sensitivity training for doctors to enhance communication with individuals newly diagnosed with dementia. Train doctors to use carefully considered language and a pace conducive to comprehension when discussing the diagnosis and predicting the progression course. Highlight the significance of acknowledging the awareness and intellect of individuals living with dementia, fostering an environment where they feel respected and empowered during medical consultations.
75. Develop and implement comprehensive communication training for doctors regarding interactions with individuals living with dementia. Emphasize the importance of addressing the person with dementia directly, making eye contact, and allowing them the opportunity to respond before engaging with the care partner. Additionally, train doctors to recognize and respect the capabilities and competence of individuals with dementia, avoiding assumptions of incapacity. This initiative aims to foster respectful and inclusive communication practices, ensuring individuals with dementia are actively engaged and respected during medical consultations.
76. Implement a multidisciplinary approach for delivering a dementia diagnosis, involving professionals such as psychologists, social workers, nurse practitioners, and doctors. Ensure that the delivery of the diagnosis and addressing associated emotions is primarily handled by a psychologist, social worker, or other trained professional, with the doctor playing a supportive role. This approach aims to provide holistic and emotionally supportive care to individuals receiving a dementia diagnosis.
77. Offer individuals newly diagnosed with dementia the option to choose the professional who will deliver the diagnosis and address associated emotions, recognizing that a psychologist may not always be the preferred choice due to past trauma associated with neuro-psych testing. Ensure

availability of alternatives such as social workers, nurse practitioners, or other professionals trained in emotional support and counseling. This approach aims to empower individuals to select the most suitable support system tailored to their specific needs and experiences.

78. Develop and implement a structured program focused on teaching individuals newly diagnosed with dementia how to effectively build relationships with doctors and other professionals, with the goal of accessing increased resources and support. This program should provide guidance on communication strategies, advocacy techniques, and navigating healthcare systems to empower individuals to actively seek and utilize available resources and support networks.
79. Implement a structured approach for the initial discussion of a dementia diagnosis, focusing on providing a realistic yet hopeful narrative about the individual's condition. Ensure that the conversation includes a balanced description of what to expect in the future, highlighting the individual's remaining capabilities alongside challenges. Utilize simple and practical language to convey information effectively, fostering an environment of understanding and hope for the individual and their caregivers.
80. Establish a coordinated care model for dementia patients within medical practices, wherein a physician assistant or nurse, trained specifically in dementia care, collaborates closely with neurologists or family practice doctors. This clinician, employed by the doctor, will serve as a dedicated coordinator for dementia patients. The doctor will provide the diagnosis, while the appointed clinician disseminates detailed information regarding test results, diagnosis rationale, implications, and recommendations to patients and their families. This approach ensures comprehensive support at the time of diagnosis, particularly crucial for cognitively aware patients. Additionally, a social worker or psychologist affiliated with the clinic will promptly meet with patients to address immediate needs, including accessing information about the specific form of dementia, psychological adjustment strategies, support group referrals, and facilitating access to ancillary services. Recognizing the uniqueness of each patient's response, the process allows flexibility to accommodate individual needs and circumstances, ensuring optimal support and resource allocation during this critical period.
81. Develop and implement best practice guidelines in medical practices diagnosing dementia, where a designated staff member contacts the person newly diagnosed with dementia via phone or video chat within one week of diagnosis. This personalized contact ensures the patient is connected with essential resources, such as a social worker, to assist with financial and legal affairs, support group connections, and other recommended services or clinicians. Recognizing the overwhelming nature of online resources for the newly diagnosed, direct human interaction is prioritized. Additionally, at the initial appointment, comprehensive information should be provided to the newly diagnosed individual and their family, enabling them to return with prepared questions about their diagnosis. This structured approach aims to facilitate access to wrap-around care and support, helping patients navigate their new reality effectively. A follow-up office visit one month after diagnosis is recommended to discuss ongoing clinical needs and provide further guidance.
82. Establish a protocol where a psychologist or appropriately trained clinician delivers news of the diagnosis, imparts information about dementia, and outlines the path forward if the doctor lacks empathy or expertise in this area. Patients or their families should research the clinician's

practice to ensure a positive experience. It is essential for clinicians to possess specific experience or undergo training tailored to the patient's particular type of dementia, ensuring optimal support and guidance during the diagnostic process.

83. Develop and implement best practice guidelines for treating specific dementia diagnoses, incorporating a sequential timeline of essential tasks to be completed at each stage. Consider integrating this timeline into the electronic medical record (EMR) system to promote consistency and streamline implementation across healthcare providers. This initiative aims to enhance the quality of care by ensuring standardized procedures and timely interventions tailored to the needs of individuals with dementia.
84. Develop and disseminate best practice guidelines for diagnosing dementia, ensuring consistency and accuracy in the diagnostic process. These guidelines should outline standardized procedures and criteria to be followed by clinicians, acknowledging that a definitive diagnosis may require additional testing over time. Prioritize widespread adoption of these guidelines to promote uniformity across healthcare settings and enhance diagnostic accuracy. This initiative aims to address the current variability in diagnostic approaches, ultimately improving the quality of care for individuals undergoing evaluation for dementia.
85. Develop and implement a standardized communication protocol for doctors to inform individuals undergoing the diagnostic process for dementia about the anticipated duration, steps involved, and reasons for potential delays in reaching a definitive diagnosis. This protocol aims to proactively manage expectations, mitigate frustration, and alleviate stress associated with waiting for further diagnostic steps, ultimately enhancing the patient experience and well-being during this challenging period.
86. Establish a disease management protocol akin to those used for chronic conditions like diabetes, heart disease, or cancer, tailored specifically for individuals diagnosed with dementia. This protocol should encompass comprehensive care strategies, including regular assessments, personalized treatment plans, and multidisciplinary collaboration among healthcare professionals. Additionally, integrate education and support programs for individuals living with dementia, focusing on self-management skills, symptom recognition, and lifestyle modifications. By implementing a structured disease management protocol, akin to other chronic diseases, this initiative aims to optimize care delivery, improve patient outcomes, and enhance the overall quality of life for individuals living with dementia.
87. Develop and implement guidelines for doctors to refrain from advising individuals newly diagnosed with dementia to immediately "get their affairs in order" without a thorough understanding of the specific form of dementia and allowing time for processing the diagnosis. This precautionary measure aims to avoid unnecessary emotional distress and confusion. Simultaneously, provide written recommendations detailing the specific affairs and legal documents necessary for individuals to organize, such as wills, advance directives, and powers of attorney.
88. Offer individuals living with dementia the option to receive advice regarding affairs and legal matters from a counselor rather than solely from the doctor. Develop and implement a protocol where individuals can express their preferences for receiving such advice, ensuring they have access to the appropriate clinician based on their needs and preferences. This initiative aims to

enhance patient-centered care by respecting individual preferences and ensuring that advice regarding affairs and legal matters is delivered in a manner that best meets the needs of each person living with dementia.

89. Establish a new medical specialty dedicated solely to dementia, aimed at providing specialized care and expertise in managing the complexities of the condition. This specialty would involve the designation of "dementia doctors" whose practice focuses exclusively on dementia care. Each dementia doctor would be supported by a dementia coordinator who facilitates referrals to interdisciplinary teams for additional services as needed. This initiative aims to address the current challenges of finding healthcare providers with expertise in dementia and ensure individuals living with dementia receive comprehensive and specialized care tailored to their unique needs.
90. Develop a comprehensive written roadmap or flow chart for dementia, outlining essential information regarding testing, diagnostic milestones, criteria for diagnosis progression, treatment options, support referrals, legal affairs, and lifestyle adjustments. This tool will be presented in a simplified format at the time of diagnosis, providing basic information to the individual. Subsequent appointments, typically 2-6 months after diagnosis, will feature more detailed and individualized information tailored to the person's specific needs and current stage in the dementia journey. Additionally, the roadmap will include reminders for regular reviews to accommodate changes over time. It will offer alternative routes depending on individual needs, ensuring that individuals living with dementia understand their position on the roadmap and can navigate their journey effectively.
91. Develop a brief list of the top five questions for individuals to ask their doctor immediately following a dementia diagnosis. This concise resource will empower patients to seek essential information and engage in meaningful discussions with their healthcare providers about their condition and care options.
92. Implement a protocol for clinicians to maintain consistency in the terms used to identify specific forms of dementia. Should there be a need to introduce a new or more accurate term, clinicians must discuss the rationale behind the change with the person living with dementia. While dementia diagnoses can evolve over time, terminology should remain consistent, with changes only occurring after a clear explanation is provided. This protocol aims to promote clarity and understanding for individuals living with dementia regarding their condition and any associated terminology adjustments.
93. Establish guidelines for doctors to avoid withholding information from individuals with dementia under the pretext that the timing is inappropriate. It's essential to provide relevant information in a clear and compassionate manner, regardless of the perceived timing. Withholding information may exacerbate feelings of disorientation and hinder the individual's ability to adjust to their new reality. These guidelines aim to promote transparency and respect for the autonomy of individuals with dementia, ensuring they receive the information they need to navigate their diagnosis with dignity and understanding.
94. Implement a standard practice where, at the time of diagnosis, individuals receive a written document containing the name of the specific dementia diagnosis along with essential facts.

This document aims to provide clarity and serve as a reference point for individuals and their families as they navigate the initial stages of understanding and processing the diagnosis.

95. Establish a process to ensure that individuals diagnosed with dementia are provided with resources and guidance to find healthcare providers who possess knowledge and experience specific to their particular form of dementia. This process may include providing curated lists of healthcare professionals with expertise in different types of dementia, facilitating referrals to specialists, and offering guidance on questions to ask when seeking medical care.
96. Implement a structured nutritional education component during the six-month follow-up appointment after a dementia diagnosis. Provide individuals with information on healthy eating habits and foods that have been demonstrated to improve brain functioning.
97. Establish a protocol to ensure consistency in the information presented to individuals with dementia by all doctors involved in their care. Within the same health system, mandate that all doctors review the dementia diagnosis and related information to maintain uniformity in communication. For individuals seeing doctors outside the health system, provide written documentation of the dementia diagnosis and pertinent information to ensure consistency of information across healthcare providers.
98. Revamp the process for delivering a dementia diagnosis at doctor's appointments. After the diagnosis is presented by the doctor, accompany the patient and their family to a separate, comfortable room with a trained counselor or nurse practitioner who specializes in crisis intervention. Offer refreshments and provide a supportive environment. Screen a video about dementia that instills hope. Introduce informational books and discuss their potential usefulness. Offer resources such as websites specific to the diagnosis. If this cannot be done on the day of diagnosis, schedule an appointment within a week for this purpose. This approach aims to provide comprehensive support and resources to individuals and their families during the challenging period following a dementia diagnosis.
99. Encourage individuals living with dementia to prepare a list of their top three concerns or symptoms before follow-up appointments with their doctor after receiving the initial diagnosis. This practice ensures that the doctor addresses the most pressing issues and allows for more effective communication and treatment planning.
100. Develop and implement a standardized process to provide individuals diagnosed with dementia with comprehensive information about available treatments and strategies specific to their diagnosed form of dementia at the time of diagnosis.
101. Enhance education delivery at the time of diagnosis by providing a variety of learning resources, including textbooks, online courses, and reputable websites. Tailor the amount and type of education to the individual's preferences and readiness to receive information, ensuring access to diverse materials that suit their unique needs and learning styles.
102. Implement a protocol for doctors to recommend books about dementia, authored by or from the perspective of individuals living with the condition, to individuals newly diagnosed with dementia. This protocol ensures that patients receive valuable insights and perspectives from firsthand experiences, fostering empathy, understanding, and empowerment.
103. Establish a protocol for doctors to provide individuals diagnosed with dementia information about reputable websites specific to their diagnosed form of dementia during their visit. This

protocol ensures that patients have access to reliable online resources tailored to their condition, enabling them to access additional information, support, and resources as needed.

104. Implement sensitivity training for doctors to improve their listening skills and attentiveness to the information provided by patients during the diagnostic process. Emphasize the importance of carefully considering patient input, as it can significantly contribute to expediting the diagnostic journey.
105. Enhance the information provided by doctors or associated social workers, particularly when individuals are diagnosed with Mild Cognitive Impairment (MCI). Immediately share details about MCI being a potential precursor to Alzheimer's and other dementia diagnoses to facilitate proactive planning for living well with dementia. Providing comprehensive information about the possible future reality empowers individuals to make informed decisions about employment, including the possibility of continuing to work with or without accommodations. Additionally, this detailed information can significantly impact financial decision-making.
106. Provide pamphlets in doctor's offices outlining the steps individuals should take if they sense that they may be experiencing cognitive impairment. These materials should offer guidance on seeking appropriate medical evaluation and support services.
107. Establish a protocol for doctors to provide information about clinical trials to patients at the time of diagnosis and during follow-up visits. Doctors should proactively inform patients about ongoing clinical trials relevant to their condition, emphasizing the potential benefits and risks of participation. Additionally, doctors should recommend advocacy organizations as reliable resources for finding information about clinical trials.
108. Establish a protocol to provide individuals living with dementia with access to their test results, allowing them to understand their diagnosis and plan for the future effectively. This protocol should ensure that patients have the opportunity to review their test results in a clear and understandable format, with support from healthcare providers as needed.
109. Develop and implement targeted interventions to address the unique needs of people living with dementia in rural areas, where access to experienced clinicians and professionals is limited. These interventions may include telemedicine services, mobile clinics, and outreach programs to provide essential dementia care, support, and resources to rural communities. Collaborate with local healthcare providers, community organizations, and advocacy groups to establish networks and partnerships aimed at enhancing dementia care delivery in rural areas.
110. Implement a standardized practice of providing individuals with a written list of dementia-specific peer support groups during the doctor's appointment when newly diagnosed.
111. Ensure that dementia-specific support group information is provided during the doctor's appointment when the diagnosis is received. Emphasize the myriad benefits of support groups, including aiding adjustment to a new reality, learning to live better with dementia, navigating changing family dynamics, reducing feelings of isolation, and receiving legal and financial guidance. It's crucial that the support group aligns with the individual's diagnosis, age, and other relevant factors to maximize its effectiveness. Finding peers at a similar stage in their dementia journey is particularly important for fostering a sense of camaraderie and mutual understanding within the support group. This initiative aims to facilitate access to valuable peer support

resources for individuals diagnosed with dementia and their families, promoting emotional well-being and empowerment throughout their journey.

## **FINANCIAL**

Upon receiving a diagnosis, we are often encouraged to get our financial affairs in order, which is undoubtedly wise. However, this guidance must be provided thoughtfully and at the appropriate juncture. Understanding how the diagnosis impacts one's financial landscape is the first step, followed by navigating the interplay between employer benefits, private resources, and government assistance. A delay in addressing these matters can lead to adverse financial repercussions, underscoring the importance of timely action.

112. Establish a comprehensive resource provision process for individuals newly diagnosed with dementia after their initial doctor visit. Provide education and assistance in navigating both employer and private benefits, covering topics such as life insurance, disability insurance, long-term care insurance, and medical insurance. Ensure that individuals are informed about how their benefits may change post-diagnosis and how specific diagnostic information could impact their benefits. Encourage discussions with the employer's Human Resource Department to address any questions or concerns. It's essential to initiate this process in a follow-up visit to allow individuals time to process the diagnosis fully. Regular financial reviews at specific intervals are also recommended to accommodate changing perspectives and needs over time, considering the potential complications of disease progression.
113. Provide individuals who are newly diagnosed with dementia and are employed with resources and information regarding the Americans with Disabilities Act (ADA), as their diagnosis may impact their continued employment. This includes educating individuals about their rights under the ADA, accommodations available in the workplace, and the process for requesting accommodations from their employer. Additionally, offer guidance on navigating conversations with employers about their diagnosis and employment status.
114. Provide education to individuals living with dementia and their family members regarding the Family and Medical Leave Act (FMLA), emphasizing its potential to offer leave time from work for caregiving responsibilities related to dementia. Encourage them to explore their rights under FMLA and engage with their employers to discuss potential leave options available.
115. Develop a written resource for individuals living with dementia who are employed, focusing on supporting continued employment rather than termination/retirement. This resource should cover topics such as exploring part-time work options, accommodations available under the Americans with Disabilities Act (ADA), and how retirement may impact medical insurance coverage and expenses.
116. Develop a comprehensive resource to address various employment-related issues for individuals living with dementia, including communicating with supervisors, accessing supports or accommodations to facilitate continued employment, understanding employer benefit packages,

and exploring retirement options. Recognize that individuals may experience generalized anxiety following the initial diagnosis, which can complicate interactions with their employer.

117. Develop a comprehensive resource to guide individuals newly diagnosed with dementia in organizing their financial affairs. This resource should include information on legal considerations, employer benefits, government benefits, and long-term planning. Encourage separate reviews of each area as well as integrated discussions, as they are interconnected aspects of financial planning. Consider involving an elder law attorney to provide expertise and support throughout the process.
118. Provide guidance and support to newly diagnosed individuals and their families regarding potential changes in family roles, particularly in terms of financial responsibilities. Offer resources and assistance to facilitate open discussions within the family about how roles may shift and evolve in light of the diagnosis. Emphasize the importance of addressing financial responsibilities and planning collaboratively to ensure continuity and stability.
119. Develop a comprehensive resource to educate newly diagnosed individuals about recognizing fraudulent offers and predatory behavior from professionals, clinicians, and others serving people with dementia and their families. This resource should provide guidance on identifying warning signs, understanding common tactics used by scammers, and knowing how to report suspicious activity. Empower individuals to protect themselves and their families from exploitation by equipping them with the knowledge and tools needed to navigate potential scams and predatory behavior confidently.
120. Provide education and resources to individuals living with dementia and their care partners about managing medication expenses. Offer guidance on exploring different payment options, including Medicare, Medicaid, private insurance, and cash payments, to potentially save money on prescription drugs. Encourage individuals to research and compare pricing options.
121. Develop a dedicated resource to assist newly diagnosed individuals in obtaining benefits from their employer. Recognize that individuals may find this process challenging, particularly due to anxiety about their diagnosis and speaking with their employer. Provide guidance and support tailored to address these concerns, including tips for navigating discussions with employers, understanding available benefits, and advocating for their rights.
122. Implement a dedicated program to provide resources to individuals who are newly diagnosed with dementia and have served in the military. Offer educational materials and assistance in navigating the Department of Veterans Affairs (VA) and Veterans Administration (VA) services. Ensure that these resources are provided promptly after the first doctor visit to support individuals in accessing the benefits and support available to them as veterans.
123. Establish a resource program to provide newly diagnosed individuals without medical insurance with information and guidance regarding Affordable Care Act (ACA) plans and Medicaid eligibility. Offer comprehensive information on ACA plans available in their state, including coverage options and enrollment procedures. Additionally, provide details on Medicaid availability in respective states, outlining eligibility criteria and application processes.
124. Provide comprehensive information on government benefit programs such as Social Security Disability Insurance (SSDI), Medicaid, and Medicare to individuals living with dementia who are working, retiring, or retired. This support, coupled with emotional assistance from a social



worker or clinician at the time of diagnosis, will include details on benefit estimates, covered services, and the impact on employer benefits such as medical insurance. Additionally, highlight the doctor's role in expediting benefit approvals, ensuring timely access to necessary support.

125. Provide newly diagnosed individuals, after their first doctor's visit, with resources to educate and assist them in navigating government benefits. This education should cover various topics, including the application process, rules, appeal rights, required documentation, and the importance of timing in benefit applications and modifications. Emphasize the possibility of retroactive benefits and how to enroll in Medicare. Highlight the role and designation of Representative Payee. Provide information to newly diagnosed individuals about Supplemental Security Income (SSI) for low-income individuals or individuals who have never worked.
126. Educate newly diagnosed persons about the existence of State Health Insurance Assistance Program (SHIP) programs available in each state. These free services are designed to help individuals understand their Medicare coverage options specific to their state.
127. Inform individuals newly diagnosed with dementia about potential assistance available through their bank, leveraging existing relationships. Additionally, encourage them to seek support from the constituent services staff employed by their federal and state legislators. These staff members can offer guidance and assistance in navigating government benefit programs such as Social Security and Medicare.
128. Develop a comprehensive resource for individuals living with dementia, including individuals who have never worked, are currently employed, are nearing retirement, or are already retired. Provide detailed information on government benefit programs such as Social Security Disability Insurance (SSDI), Medicaid, and Medicare, including how these programs may affect employer benefits **such as** medical insurance. Offer in-depth guidance on program operations, covered services, application procedures, response times, and the appeal process.
129. Provide information on benefits to individuals newly diagnosed with dementia and consider discussing the option of utilizing an attorney to assist in obtaining benefits, while being mindful of the potential expenses involved.

## LEGAL

After receiving a diagnosis, we are frequently told to go home and get our legal affairs in order, which is indeed valuable advice. However, this guidance must be provided thoughtfully and at the right time. Understanding how the diagnosis affects one's legal standing is the initial step, followed by identifying areas requiring attention, such as wills, advance directives, and securing legal representation. Delays in this process can lead to complications, underscoring the urgency of taking timely action.

130. Offer referral or assistance with organizing legal affairs from the time of diagnosis for individuals newly diagnosed with dementia. This includes arranging wills, powers of attorney, advance directives, and locating an attorney, along with providing information about expected fees. Emphasize the importance of addressing legal matters early on, as disease progression may complicate these tasks. Recommend this assistance during a follow-up visit to allow time for

processing the diagnosis. Regular legal reviews should occur at specific intervals, considering changing perspectives, needs, and laws over time. Ideally, this support should be provided in conjunction with emotional or other forms of assistance from a social worker or clinician at the time of diagnosis. Understanding the role of an elder law attorney and finding one locally is crucial for effective legal planning.

131. Provide written information detailing how a person living with dementia may be deemed incompetent to handle their own affairs by a court of law. Present this information directly for the benefit of the person living with dementia, rather than their family members. Additionally, outline the potential legal process in the event of a dispute between family members or others and the person living with dementia regarding an incompetency determination by a court of law.



National Council of Dementia Minds (NCDM) is the nation's first 501c3 nonprofit organization founded and governed by persons living with dementia. Dedicated to ensuring that people with dementia have a powerful voice in both personal and public conversations, NCDM stands out by challenging stigma and offering hope-filled strategies and resources to support living well with dementia. This project was made possible thanks to support from the Michigan Health Endowment Fund.

*For more information, visit us online:*

[DementiaMinds.org](https://DementiaMinds.org)

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