# Managing Stages of Dementia in People with I/DD (Adapted from Dr. Philip McCallion, 2016)

| **STAGE and** **Characteristics** | **Care Environment Recommendations** | **Day Programming Recommendations** | **Day to Day Care Recommendations** | **Communication Recommendations** |
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| **Early Stage**Preferably from an established and measured baseline and always in comparison to the person’s prior functioning and behaviors, there are noticeable and increasing changes in:* memory
* ability to find their way
* confusion with familiar tasks and situations
* increased frustration and changes in personality

Problems with walking and gait may become noticeable.Particularly for persons with Down syndrome, there may be late onset epilepsy.  | Supply lighting to avoid shadows and disperse direct sunlight with curtains or tinted glass. Label cupboards and needed utensil and care products with visual cues.Provide safe storage for kitchen tools, liquids and powders (not food) using discreetly locked cabinets. Install shut-off switches on appliances.Ensure that valued activities may continue in kitchens and there is independence in bathrooms by making needed supplies visually available. | Adjust daily routines.Move from large group to small group activities.Focus on things known, activities previously valued, modifications to activities to reduce demands and using familiar materials.Improve signage to support way finding.Support safety by providing safe places and safe activities. | Adjust daily routines to be less demanding but supporting continued participation.Offer help rather than “doing for.”Give extra time and limit range of choices so that independence may still be supported.Install devices to ease use (e.g., grab bars, raised toilet seats, water temperature regulators).Review and adjust medications as needed.Provide memory aids to assist with wayfinding, remembering chores, activities, and basic skills. | Use simple, direct language.Let the person teach you their attention span.Different words and other information.Avoid talking for and filling in words.Allow time for processingIntroduce topic, summarize, details.Summarize and rephrase.Reminisce.Allow to express feelings.Express support and caring.Repeat important messages.Use memory aides.Give specific instructions and information before it is needed. |
| **Middle Stage**Increased loss of abilities and often increases in challenging behaviors.Memory loss becomes more pronounced, as does disengagement with familiar and preferred activities. Increases in agitation, restlessness, repetitive talk/questioning, falls, pacing, wandering and shadowing of others. Hallucinations/ delusions and sundowning for some. Co-morbid health conditions increase. | Change lighting to avoid glare as well as sudden changes in lighting levels.Reduce reflective surfaces (e.g., floor surfaces should not be buffed/waxed to produce shine).Avoid patterned flooring and table surfaces.Arrange furniture with rounded versus sharp edges that is sturdy, simple and versatile. Ensure contrast between furniture color and floors and walls.Use color and contrast to create visual cues or reduce attention to specific areas throughout the home.Reduce visibility of exits, cupboards and areas with increased safety challenges. Replace standard showers or tubs with walk-in models.Install electronic alert systems so caregivers know when someone has left the home or install door opening prevention devices (where not a needed exit). | Multi-sensory in approach – both stimulating and calming.Supports existing skills and memories rather than teaches new things.Tailored to the likes/dislikes and previous experiences of the consumers.Reminiscence, trips in the community, walks, simple exercise, massage, snoezelen, horticulture, pottery, art, music, aromatherapy, hair/make-up/personal grooming (activity, not training!), offered by staff trained in dementia issues.Electronic alert systems so caregivers know when someone has left the program area or install door opening prevention devices (where not a needed exit). | Reduce safety and wayfinding challenges. Increase assistance with personal care, nutrition, safety and supervision but seek opportunities to maintain even limited choice.Routine monitoring AND treatment of co-morbid health conditions.Particular attention to additional assistance with toileting and other hygiene/personal care activities so that dignity and personhood are supported.Attention to facilitating continued valued relationships with family, friends and staff. | Speak only when visible.Use the person’s name and your name.Avoid - “Do you know who I am?”Use overemphasis, gestures, facial expressions and pointing to familiar objects.Make sure you have been understood.Wait for the person to respond.If the person does not respond - repeat once.Use a different, simpler way rather than repeating over and over.Use people’s names not “he” or “she.”Maintain predictable routine.Implement familiar activities.Label things.Don’t take it personally.Listen and repeat.Ask person to repeat.Encourage and praise.Use all available cues.Avoid sudden changes in topic.Avoid long complex sentences. |
| **Advanced Stage**Complete loss of self-care and communication skills and the person becomes increasingly immobile. Memory and skills loss becomes severe deterioration. Seizures, swallowing, difficulties and respiratory and breathing problems increase  | Attention to lifting needs including related equipment to preserve caregiver as well as the individual’s safety and comfort.As mobility becomes more impaired, changes to environment and use of adaptive equipment to ensure that valued activities and experiences previously found stimulating are still possible. | Often provided where the person lives to reduce need for transportation but should include outdoors activities if desired by the person.Focused on making the person as comfortable as possible utilizing massage, snoezelen, art, music, aromatherapy, hair/make-up/personal grooming, offered by staff trained in dementia issues and in comfort care including monitoring for discomfort and/or distress. | Care is best when it reflects what is known about the person’s wishes for their final days and when comfort and continued quality of life are emphasized. Also support of the people the person cares about will add to their sense of comfort.Continued attention to assistance with toileting and other hygiene / personal care activities so that dignity and personhood are supported.Routine monitoring AND treatment of co-morbid health conditions.Increased nursing care and prevention of secondary conditions and problems from malnutrition and dehydration and/or aspiration. | Speak only when visible.Use his/her name.Give your own name.Speak low, affectionate, subdued.Overemphasize when speaking and use gestures, facial expressions; smile.Speak slow and clear.Assume person is hearing.Do not speak as if person is not in room.Keep talking even if no response.Use touch.Respond to seemingly meaningless speech.Watch non-verbals.Listen to music, read aloud.Always say goodbye. |