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Post-Diagnostic Dementia Support Guidelines for People with an Intellectual Disability





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List of abbreviations

DSiDC	Dementia Services Information and Development Centre
GPS	Global Positioning System
HSE	Health Service Executive
HIQA	Health Information and Equality Authority
ID	Intellectual disability
MDT	Multi-Disciplinary Team
NALA	National Adult Literature Agency
NCSd	Non-cognitive symptoms of dementia
NIDMS	National Intellectual Disability Memory Service
PPI	Public and Patient Involvement
UN CRPD	United Nations Convention on the Rights of Persons with Disabilities





Introduction

Increased longevity for people with an intellectual disability, for many, means a longer enjoyed life with those they care for, and who care for them. But for some, health challenges associated with ageing become more evident. One such health concern is a higher prevalence and earlier onset of dementia among people with an intellectual disability, particularly those with Down syndrome as compared to the general population. Yet, the optimisation of health, wellbeing, and enjoyment of and engagement in life is both possible and a right, if best-practice post-diagnostic dementia supports are properly understood, resourced, and made available with people with an intellectual disability.

To advance this agenda, usable, useful, and practical best-practice guidelines for post-diagnostic support for people with an intellectual disability are needed. Therefore, a project was designed to (1) examine the current landscape of post-diagnostic care in Ireland; (2) consider barriers to access; (3) incorporate existing best practices; and (4) give due consideration to the experiences being described and the recommendations provided by people with an intellectual disability living with dementia and by their families and carers. The core research team also identified national and international experts in the field of post-diagnostic dementia supports for people with an intellectual disability to form an expert advisory panel who, together with people with an intellectual disability and family carers, offered further guidance to advance the project aim.

A large amount of data and testimony were gathered and analysed using a multistage mixed methods framework with five work packages. These work packages involved 1) a scoping review and focus group interviews; 2) a survey of key staff in services; 3) qualitative interviews with people with an intellectual disability and dementia, their families, and staff carers; 4) this informed a further quantitative online survey and further qualitative research interviews of people identified as exemplars of best-practice post-diagnostic dementia support provision and 5) and finally, findings from work packages 1-4 were triangulated and considered through a collective intelligence workshop convening international experts and national stakeholders to inform the creation of guidelines for post-diagnostic dementia supports for people with an intellectual disability. The findings identified the current national availability of services, the challenges which are encountered in accessing and receiving support, and important concepts and life-enhancing areas for consideration to ensure that people with an intellectual disability have the opportunity to live well after a dementia diagnosis. (For more detailed information see: Building Post-Diagnostic Dementia Support Guidelines for People with an Intellectual Disability: Voices of Experience. Brief Report. (McCarron et al. 2024). <https://doi.org/10.25546/106621>)

The final stage in this study was the development of practical post-diagnostic guidelines that were evidence and research informed, and yet offered practical assistance to the person, their family and other carers. The guidelines represent best practices of care and support across the continuum of dementia care for people with an intellectual disability and dementia.





Guidelines for post-diagnostic support

There are five pillars of post diagnostic support with 33 accompanying standards, with the person with an intellectual disability (ID) and dementia always at the centre.

These pillars are:

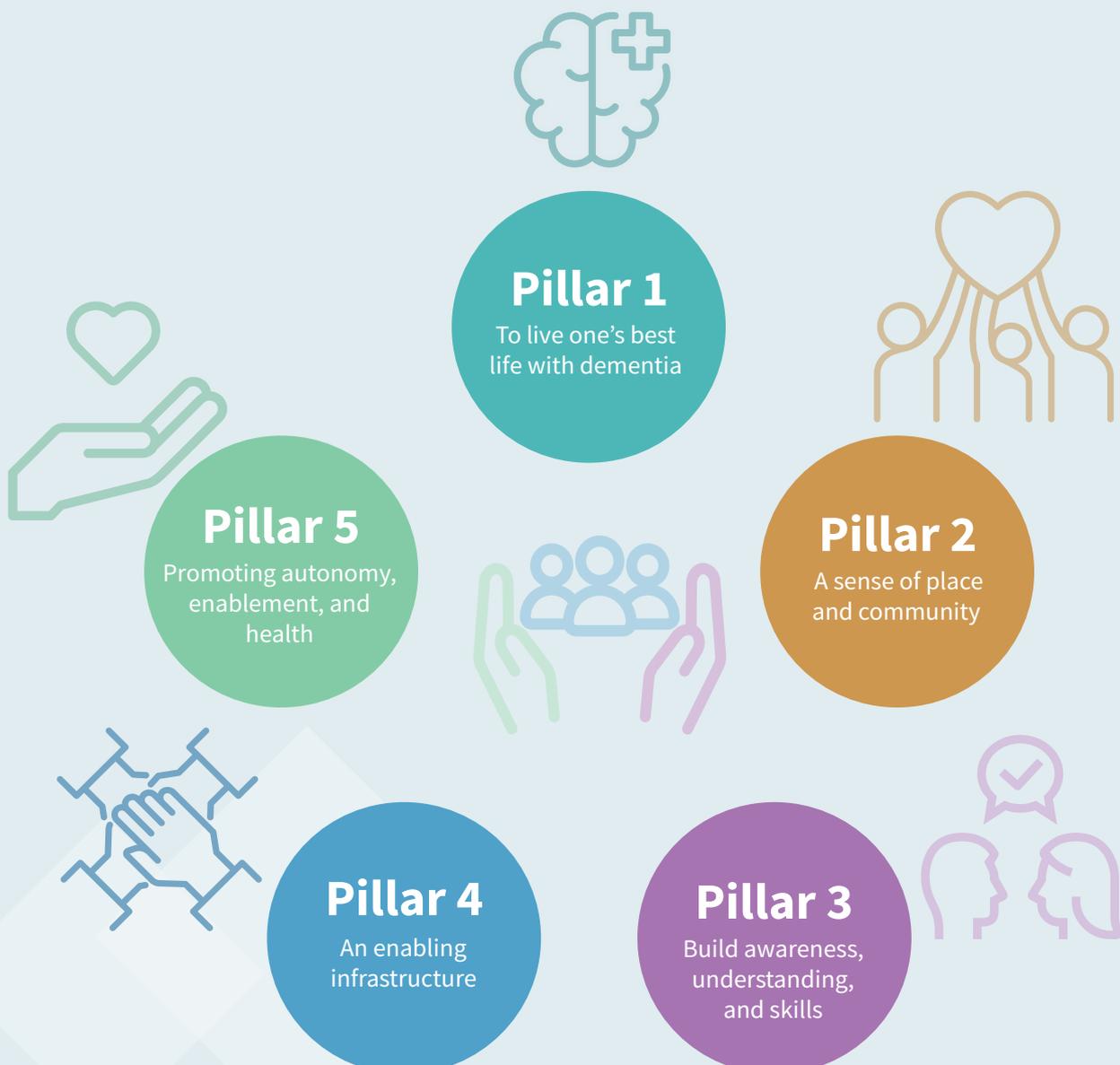
Pillar 1. To live one's best life with dementia

Pillar 2. A sense of place and community

Pillar 3. Build awareness, understanding and skills

Pillar 4. An enabling infrastructure

Pillar 5. Promoting autonomy, enablement and health





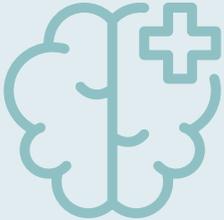
Key points about the 5 pillars of diagnostic support

- The five pillars of post diagnostic support are interconnected, highly dependent on each other, and must be considered in their entirety.
- Each pillar is accompanied by a statement of purpose to support the understanding of, and provide a context for, the pillar.
- The standards associated with each pillar are dynamic, evidenced-based and can be added to, amended or removed as needs change or as evidence evolves.
- Each standard statement is accompanied by a process guideline structured in a manner to give some practical tips on evidence-based approaches in operationalising each of the standard statements. Useful links are provided throughout.
- The standards are consistent and align with the [United Nations Convention on the Rights of Persons with Disabilities](#) (UN CRPD) and to a range of existing audit and quality improvement frameworks such as those indicated by the Health Service Executive (HSE) and Health Information and Equality Authority (HIQA).
- The Post-Diagnostic Dementia Support Guidelines for People with an Intellectual Disability support the Model for Dementia Care in Ireland (Begley et al., 2023) by focusing on a defined set of interventions determined to improve dementia care.





Pillar 1: To live one’s best life with dementia



This pillar is underpinned by the understanding that wellbeing and quality of life can be enjoyed throughout the continuum of dementia, and is best created and sustained through supportive environments, social connections, and total communication approaches.

Those who support the person living with dementia must begin with an understanding of the life enjoyed and the life desired by the person, and use a strength-based, creative, and compassionate approach to support that person to live a life of their choosing. People living with dementia have the right to exercise choice, for example, to be on their own or spend time with others. Person-centred, reasonable adjustments will support the person to lead a life of their choosing, and maximise their independence and ability to participate meaningfully in their communities.

Standard Guideline	Process
<p>1.1 Sensitive reflect on, and try to understand, the person’s perspective and how they are coping with the diagnosis. Work with the person to address questions and/or concerns.</p>	<p>Informal conversations can be guided by the AFIRM approach (Stirling et al., 2011). https://figshare.utas.edu.au/ndownloader/files/40913123</p> <p>Acknowledge the person’s concerns and questions.</p> <p>Find out what the person knows and understands.</p> <p>ImmEDIATE concern is responded to by providing information in an accessible format.</p> <p>Respond to additional questions or concerns within the scope of your role.</p> <p>Meeting offered to discuss additional concerns with relevant members of the Multi-Disciplinary Team (MDT).</p>



Standard Guideline	Process
<p>1.2 Establish how the person wants to live their life, respecting and supporting the individual to exercise self-determination, experience a sense of control, and to live the life of their choosing.</p>	<p>Encourage and facilitate the person in expressing their will and preferences, especially how they would like support/care to be delivered.</p> <p>For example:</p> <ul style="list-style-type: none">■ Respect the person's sense of agency in how they wish to live.■ Be culturally sensitive, pay attention and give respect to the person's traditions and life experiences.■ Use a strengths-based approach to develop an individualised support plan in partnership with the person that facilitates and empowers functional and social independence.■ Document the progression of dementia, including any changes in personality or behaviour as well as any changes in assistance required to support functional and social independence. The care plan should then be reviewed and adapted accordingly.■ Ask the person who they would like to have involved in their circle of support and future care planning, for example, a family member, friend/ peer, and or/ familiar staff.
<p>1.3 Ensure the communication environment facilitates meaningful conversations, through respectful, sensitive, person-centred, and total communication approaches.</p>	<p>Communicate in an inclusive and respectful manner, call the person by their preferred name and pay attention to your own tone of voice, body language and posture.</p> <p>Understand that the person may be more alert or communicative at different times of the day and use these moments for meaningful interaction.</p> <p>Find out how best to support the person to understand information and use the communication techniques and supports that work for the person, including multi-modal approaches.</p> <p>For example:</p> <ul style="list-style-type: none">■ Make eye contact, sit at the same level as the person, or lower, listen carefully to both the spoken word and nonverbal cues.■ Provide sufficient time for the person to process information and respond.



Standard Guideline	Process
	<ul style="list-style-type: none"> ■ Adapt to the person’s communication strengths as they change across the continuum of dementia. ■ Provide alternative or additional means to support communication, for example, develop easy read materials, a communication passport, personal social stories, and assistive technology. ■ Structure conversations around topics that the person is interested in and likely to enjoy. ■ Use everyday encounters such as cooking meals, assisting with personal care, gardening etc. as a tool and opportunity to facilitate meaningful communication. ■ Avoid criticising, correcting, or trying to orientate the person to your reality. Instead, validate the feelings inherent in the message. ■ Connect with the person rather than correct. ■ Assess hearing and eyesight on a regular basis and support the person where required in wearing their hearing aids and glasses as prescribed.
<p>1.4 Ensure the physical environment enables the person to contribute, promoting a sense of belonging, well-being, confidence, and safety, supporting self-management.</p>	<p>Modify the environment to help reduce and keep stress to a minimum.</p> <p>Help a person know what to expect and navigate spaces by making the environment predictable, familiar, safe, and neither over-stimulating or under-stimulating.</p> <p>For example:</p> <ul style="list-style-type: none"> ■ Have seating strategically placed throughout the environment and ensure where the person is seated maximises the opportunity to connect with and engage in what’s happening in the home. ■ Modify the layout and décor to give a better sense of home, using personalised photographs, artefacts, furniture etc. ■ Kitchen appliances, fridge, microwave, dishwasher will be easier accessed by the person if they are visible and not integrated <p>Additional information: http://tinyurl.com/iridisApp</p>



Standard Guideline	Process
<p>1.5 Ensure the social environment supports meaningful connections with family, friends and important others in the person's life, promoting a sense of wellbeing.</p>	<p>Use a strengths-based approach to maintain normality and support the person to engage with others in the normal rhythm of life.</p> <p>For example:</p> <ul style="list-style-type: none">■ Encourage and support desired participation in chosen activities by providing social cues and environmental supports.■ Build on the person's lifelong interests and create space for the person to engage and experience new opportunities.■ Provide opportunities for the person to work with others, assisting at whatever level they are capable of in pursuits such as meal preparation, laundry and wash-up, and to contribute to gardening and other important life activities and interests <p>See also Pillar 2: A Sense of Place and Community.</p>
<p>1.6 Ensure there is relationship continuity with consistency of staff caregivers, stability in the living environment and flexibility to accommodate fluctuating abilities.</p>	<p>Ensure that the person living with dementia and their caregiver has access to a key worker/care coordinator to offer support, advice, and signposting, throughout their journey from diagnosis to end of life.</p> <ul style="list-style-type: none">■ Ensure that there is consistency in staff caregivers, with a named staff member working in partnership with the person and family, advocating for and with the person, and enabling the person to live the life of their choosing.■ Ensure there is adequate time to build trust and form a therapeutic relationship.■ Prioritise and value relationships of importance to the person as the basis for relationship-centred care. It is through knowing the person that caregivers can truly understand the individual and their world.■ Understand that human security is a fundamental human right.



Pillar 2: A sense of place and community



This pillar is underpinned by the importance of knowing people and being known within one's community.

The maintenance of the individual's personhood and life skills requires an emphasis on living in their community, and being able to continue social connections, lifelong interests, and hobbies. Intellectual disability care providers must ensure that if a person living with dementia has to change or move between any settings or services, there is attention by all care partners to future planning, communicating and working with each other. The joint aim is to support a seamless transition and appropriately coordinated supportive interventions to enable the person to adapt to and cope within the changed environment.

Standard Guideline	Process
<p>2.1 Build a sense of place and community where the person can contribute, and where their identity, dignity, sense of belonging and self-worth are upheld.</p>	<p>Use the established personal history and social stories to identify and then access the places and community connections that are valued by the person.</p> <p>For example:</p> <ul style="list-style-type: none"> ■ Establish with the person the social connections they value and want to preserve, and those they no longer enjoy or wish to continue. ■ Create and offer opportunities for new social connections. ■ Develop a plan to maintain links to the places, communities, and community activities the person wishes to continue, and revisit this plan frequently to ensure it is responsive to the person's changing wishes and abilities.
<p>2.2 Support the person in maintaining and/or making desired changes in familiar relationships and social connections and networks.</p>	<p>Within the relationships and social connections important to the person, support their decisions around things they would like to do, including a decision to not participate.</p> <p>For example:</p> <ul style="list-style-type: none"> ■ Identify, in partnership with the person, the supports they require to maintain familiar relationships and document these in the person's care plan. ■ Support family and friends' active involvement in the life of the person. ■ As dementia progresses, find creative adaptations to maintain social connections, and make reasonable accommodations to the layout of social spaces to be less challenging to the person, and more familiar.



Standard Guideline	Process
	<ul style="list-style-type: none"> ■ Identify and facilitate opportunities to bring the community to the person, when the person is increasingly challenged in accessing their community. ■ Introduce technology to empower the person in maintaining functional and social independence. <p>www.understandtogether.ie/get-support/memory-technology-resource-rooms/</p>
<p>2.3 Work to create dementia-inclusive local communities to build and maintain connectedness and relationships.</p>	<p>Contribute to creating local dementia-friendly/inclusive communities that are supportive of people with an ID and dementia.</p> <p>For example:</p> <ul style="list-style-type: none"> ■ Locate or create peer group gatherings which support social connectedness, cognitive stimulation and physical activity. ■ Access dementia cafés and similar resources, and work with these organisations to ensure accessibility for people with ID and dementia. <p>www.understandtogether.ie</p> <p>https://dementiacafe.ie/</p>
<p>2.4 Utilise compassionate, tailored and timely supports to assist the person to live in their desired home.</p>	<p>Provide information about available and accessible supports to assist the person to continue living in their desired home.</p> <p>In partnership with the person and/or their caregiver, facilitate in-home and out-of-home respite, where desired, to enhance quality of life for everyone.</p> <p>alzheimer.ie/service/dementia-adviser</p> <p>www.hse.ie/eng/home-support-services</p>



Standard Guideline	Process
<p>2.5 If the person has to move from their home or care setting, care transitions must be planned, with relationship building, and working in partnership to ensure a smooth and seamless transition.</p>	<p>Recognise that undesired, un-needed and poorly planned home changes can impact on the person’s wellbeing and quality of life.</p> <p>Involve and listen to the person in any decisions about where they are going to live. The person should be at the centre of planning at all stages. https://www.decisionsupportservice.ie</p> <p>Should a person move from their usual place of residence/ home, take a dementia inclusive approach and plan how support staff/family/peers will maintain connectedness and relationships.</p> <p>Consider how well the person will interact with others in the proposed home to further reduce the potential for stress for the person or for others living there.</p> <p>Consider innovative ways for the new care team to get to know the person, build trust and form a therapeutic relationship.</p> <p>For example:</p> <ul style="list-style-type: none">■ Support brief periods of respite/short visits prior to the move.■ Have familiar staff or family provide support in the new home during the first weeks.■ Use an assigned key support worker to better build relationships.■ Minimise the use of short-term agency staff.
<p>2.6 Develop and implement care plans to maintain a sense of place, home and community.</p>	<p>Should the person transition to a new care setting, the care plan should transition with them.</p> <p>For example:</p> <ul style="list-style-type: none">■ Consider what is important to the person in terms of places visited, people seen, activities engaged in, and pleasures enjoyed.■ Pursue specific strategies to continue such pursuits and enjoyments in the place desired, rather than see changing needs as requiring movement to new settings.



Standard Guideline	Process
<p>2.7 Actively maintain the person's desired activities to support the normal day-to-day rhythm of life and ensure there are stimulating things to look forward to which bring joy.</p>	<p>Ensure carers are familiar with the person's preferences, tastes and interests when arranging activities.</p> <p>Develop and offer a personalised menu of flexible choices that engage the person in meaningful life pursuits, reflective of the person's expressed preferences, and changing needs.</p> <p>As preferred activities and hobbies become more difficult for the person, explore necessary adaptations to better respond to changing abilities and needs before considering stopping valued activities.</p> <p>For example:</p> <ul style="list-style-type: none">■ Explore new activities. Consider well-established cognitive stimulation and psychosocial interventions such as music therapy, the arts, physical activity, and horticulture and gardening.■ Celebrate the seasons and major events throughout the year and use these as an opportunity to bring joy and help the person to remember and experience the world around them, for example, birthdays, anniversaries, national holidays.■ Use resources such as personalised menus of life-enhancing activities or weekly activity planners to facilitate planning and sharing/continuity of information. <p>www.understandtogether.ie/Training-resources/Helpful-Resources/Publications/Weekly-Activity-Planner-for-people-with-dementia-families-and-carers.pdf</p> <p>www.tcd.ie/tcaid/assets/pdf/nidms%20brochures/menuoflifeenhancingpursuitsNIDMS.pdf</p>



Pillar 3: Building dementia awareness, understanding, and skills



This pillar is underpinned by an understanding that diagnosis of dementia in people with an intellectual disability is often complex due to pre-existing intellectual impairment, communication challenges, frequent staff changes, high levels of physical and mental health co-morbidities, hyperpolypharmacy, and environmental influences. In addition, some people with ID, particularly those with Down syndrome are at higher risk of developing dementia with an earlier age of onset. This cumulative complexity across multiple domains magnifies difficulties in both dementia diagnosis and post diagnostic care. Support from a range of professions with diverse skills will therefore be required to support diagnosis and address changing needs across the continuum of dementia.

People with an ID are entitled to timely assessment for memory concerns, treatment and post diagnostic support in the same way as any other citizen.

Every person’s experience of living with dementia will be unique, and their needs for supports will be different. Carers and those in the person’s circle of support must be positioned to support the person and have the prerequisite knowledge and skills to deliver competent person-centred care. They need to know how, and where, to access relevant supports and training, and must build a collaborative network with other carers and supports.

Standard Guideline	Process
<p>3.1 Build awareness of the increased risk of dementia in people with Down syndrome.</p>	<p>Identify relevant groups who would benefit from being more informed.</p> <p>Build dementia awareness campaigns targeted to a range of stakeholders.</p>
<p>3.2 Ensure timely access to a dedicated memory assessment service with specific expertise in supporting people with an ID who are at risk of dementia and/or have memory concerns.</p>	<p>Arrange access to a dedicated MDT with the expertise to communicate effectively with the person, and the competence to support assessment, a full diagnostic work up, consensus diagnosis and communication of a diagnosis. This will form the basis to advance the process of post diagnostic support and related planning.</p>



Standard Guideline	Process
<p>3.3 Ensure the person living with dementia is provided with timely and appropriate information.</p>	<p>People with an ID who are having an assessment for a memory impairment should be offered the opportunity to receive their diagnosis in a timely and appropriate manner.</p> <p>Allow sufficient time to communicate the diagnosis sensitively to the person in a respectful, gradual and individualised manner.</p> <p>The person also has a right not to receive a diagnosis if they so choose. Their choice should be ascertained at the start of the assessment and should be checked throughout the process.</p> <p>In preparing to communicate the diagnosis, explore the person's perspectives and understanding, integrate family and/or staff caregivers as per the person's wishes, focus on quality of life, and planning for the future.</p> <p>The process should take into account the person's pre-existing intellectual impairment and their level of understanding.</p> <p>Use multi-modal communication approaches such as text, vocalisation, images, gestures to ensure information provided is accessible and understandable.</p> <p>Format information in accordance with National Adult Literacy Agency (NALA) guidance (www.nala.ie).</p> <p>For example:</p> <ul style="list-style-type: none">■ The easy-read guidelines from the National Intellectual Disability Memory Service (NIDMS) can be used: www.tcd.ie/tcaid/research/NIDMSbrochures.php.■ Support and check that the person understands the information given.■ Arrange a follow-up appointment for 2-4 weeks later to address any additional questions and /or concerns.■ Provide the person with contact details should they need additional support such as NIDMS or other relevant local supports. www.tcd.ie/tcaid/research/NIDMS.php.



Standard Guideline	Process
<p>3.4 Provide information and skills building for family carers.</p>	<p>Provide education to increase knowledge and skills building for family members which is relevant and dementia stage appropriate.</p> <p>For example:</p> <ul style="list-style-type: none">■ Information on the increased risk of dementia in people with Down syndrome.■ early signs of dementia, the importance of comprehensive diagnostic work up, timely assessment and diagnosis, and post diagnostic support.■ skills and confidence in sensitive, supportive care.■ the understanding that people can live well with dementia.■ multi-modal communication approaches and strategies to maintain the functional and social independence of the person.■ strategies to equip carer/supporter to recognise, prevent and effectively manage the non-cognitive symptoms of dementia.■ the use of pleasant and meaningful activities as a means to engage and connect with the person.■ strategies to maintain health, wellbeing, functional and social independence of the person.■ local resources, support groups, dementia advisors and other specialist services such as the NIDMS.■ education on coping strategies to maintain their own wellbeing including stress management.■ support services, such as peer supports, financial assistance and counselling if needed/desired.
<p>3.5 Provide timely, tailored, appropriate and accessible information on dementia to peers/friends.</p>	<p>Provide accessible education and skills-building for peers/friends to empower them to support their friends and increase their knowledge.</p> <p>For example:</p> <ul style="list-style-type: none">■ growing older, brain health, the ageing brain, memory problems and dementia.



Standard Guideline	Process
	<ul style="list-style-type: none"> ■ skills and confidence in sensitive and supportive care to their friend/peer living with dementia. ■ death and grief. ■ coping strategies to maintain their own wellbeing including stress management. ■ support services, such as peer supports, financial assistance and counselling if needed/desired. <p>The information that is given should be appropriate and cognisant of pre-existing level of intellectual impairment and be provided in an accessible format in accordance with NALA guidance.</p> <p>Useful resources include:</p> <p>Down's Syndrome Scotland: <i>Let's Talk About Dementia</i>. www.dsscotland.org.uk/wordpress/wp-content/uploads/2016/02/Lets-Talk-About-Dementia-final-version-05.08.15.pdf</p> <p>Dodd, K. et al. (2005). <i>About Dementia For People with Learning Disabilities</i>. Bild. www.bild.org.uk/product/about-dementia</p>
<p>3.6 Provide education and skills building for health and social care professionals ensuring that they have the knowledge and skills to perform their role effectively.</p>	<p>Provide education and skills-building for health and social care professionals that is:</p> <ul style="list-style-type: none"> ■ consistent with their roles and responsibilities, and designed to increase their knowledge, confidence, skills and competence in sensitive, supportive dementia care. <p>(For example, the masterclasses on intellectual disability and dementia from TCAID: www.tcd.ie/tcaid/research/nidmsmasterclass.php and Trinity College Dublin's School of Nursing and Midwifery's postgraduate courses: https://nursing-midwifery.tcd.ie/postgraduate/.)</p> <ul style="list-style-type: none"> ■ grounded in the principles of person-centred care and the application of related principles in the day-to-day care and support of the person.



Standard Guideline	Process
	<ul style="list-style-type: none"> ■ offering a strong focus on communication approaches and strategies to maintain functional and social independence of the person. ■ equipping staff to recognise, prevent and effectively manage the non-cognitive symptoms of dementia. healthservice.hse.ie/filelibrary/non-cognitive-symptoms-of-dementia-guidance-document.pdf ■ emphasising the use of pleasant and meaningful activities as an opportunity to engage and connect with the person. ■ encouraging the application of person centred non-pharmacological/ psychosocial approaches and multicomponent interventions to avoid and address responsive behaviours. ■ designed with a built-in evaluation of the impact of education programs on dementia awareness, understanding, staff practices and outcomes for the person living with dementia.
<p>3.7 Build a collaborative learning culture that includes the person, their family, health and social care professionals.</p>	<p>Promote a culture of collaboration, relationship building, knowledge exchange and shared learning.</p> <p>For example:</p> <ul style="list-style-type: none"> ■ Ensure the voice and experience of all stakeholders is heard and respected. ■ Target relevant information about the complexity of dementia for people with an ID to specific roles/groups. ■ Provide regular information and bespoke training to stakeholder groups. ■ Ensure information is presented in an accessible and engaging manner that supports active learner involvement and meets the stakeholder’s existing level of understanding, learning and skill requirements.



Pillar 4: An enabling infrastructure



This pillar is underpinned by the understanding that the infrastructure, environment and resourcing should support the person with dementia to lead a life that has meaning and value.

In such an environment a range of interventions are available that support functional and social independence in the context of changing need. Lack of meaningful things to do may lead to worsening of symptoms and impaired quality-of-life.

Appropriate structures and necessary resources, when combined with respect for the personhood of the individual, will support choice, safety and quality of life and care for all stakeholders.

Therefore, the person living with dementia should have access, when needed, to relevant dedicated services regardless of their place of residence. An enabling infrastructure supports caregivers to give care with comfort and with safety, creating a positive environment for all.

Standard Guideline	Process
<p>4.1 Enhance and develop collaboration, cross-sectoral working and creative problem solving to support an enabling dementia care infrastructure.</p>	<p>Work collaboratively to address the inequities in access to supports for people with an ID and dementia.</p> <p>Improve collaboration, cross working and creative problem solving and partnerships between intellectual disability services, general ageing services, hospitals, primary care, specialist dementia and hospice services.</p> <p>Consider and reflect in policy and practice how unique post-diagnostic dementia support needs will be met by respecting:</p> <ul style="list-style-type: none"> ■ the person’s pre-existing and current intellectual impairment and abilities. ■ early age of dementia onset. ■ cumulative complexity across multiple domains including pre-existing physical and mental health comorbidities. ■ reduced social networks and the criticalness of longstanding relationships with staff and family. <p>Investigate how dementia supports for the general population can accommodate and be adapted for people with an ID.</p> <p>Continuously evaluate and improve the effectiveness of post-diagnostic supports by seeking feedback from people with an ID and dementia, caregivers and other stakeholders.</p> <p>Share examples of excellence and innovations in dementia infrastructure and services.</p> <p>McCarron M., et al. (2013) <i>Achieving Quality Environments for Person Centred Dementia Care</i>. Trinity College Dublin. https://www.tcd.ie/tcaid/research/AchievingQualityEnviornmentsforPersonCentredDementiaCare.pdf</p>



Standard Guideline	Process
<p>4.2 Develop pathways of care that are clear and support integration.</p>	<p>Conduct a community mapping exercise of supports available.</p> <p>For example:</p> <ul style="list-style-type: none"> ■ Identify, signpost and provide timely and relevant information to support the person and their caregiver to navigate needed resources across the continuum of dementia. ■ Where support and service gaps are identified, evidence-based business plans to address needs should be developed.
<p>4.3 Conduct an organisational audit of home and community hubs, day and other services to ensure the environment is dementia inclusive and supports the needs of those living with dementia.</p>	<p>Build enabling environments and implement changes to physical infrastructure to support inclusion, increase empowerment, wellbeing and self-worth.</p> <p>Ensure the environment is designed to create opportunities for the person to succeed, is failure free and stress free, and supports functional and social independence.</p> <p>Utilise an environmental audit tool to identify potential barriers, for example: dta.com.au/resources/environmental-design-resources/</p> <p>Address environmental barriers/challenges by ensuring;</p> <p>For example:</p> <ul style="list-style-type: none"> ■ Bathroom, bedroom, kitchen and living areas are easily visible and accessible. ■ Adequate lighting with signage and objects is strategically placed to aid wayfinding and orientation. ■ Assistive technology is utilised with tailored, ethical and person-centred interventions co-designed to promote functional and social independence. ■ Personal items are visible, organised and within reach, but clutter is avoided. ■ Outside gardens are inviting, visible, accessible, safe with space to be alone or with others as desired. ■ Follow guidance on low-cost renovations that will enable continued care in the person's home. <p>(See standard 1.4 for additional advice)</p> <p>universaldesign.ie/built-environment/building-for-everyone</p> <p>www.alzheimers.org.uk/get-involved/dementia-friendly-communities/organisations/dementia-friendly-environment-checklist</p> <p>https://www.citizensinformation.ie/en/housing/housing-grants-and-schemes/housing-supports-for-older-people-and-people-with-disabilities/housing-adaptation-grant-for-people-with-disability/</p>



Standard Guideline	Process
<p>4.4 Ensure the person living with dementia is supported to engage in meaningful life pursuits that bring joy.</p>	<p>Provide access to day programs and community hubs that offer cognitive stimulation, social connectedness and physical activity.</p> <p>Provide programs that combine both sensory stimulating and sensory calming activities.</p> <p>Tailor programs to individual likes, comfort levels and previous experience.</p> <p>Signpost the person/caregivers to a range of individual and group based physical activity opportunities within their community.</p>
<p>4.5 Build copng capacity and resilience amongst staff, family and peers to help prevent and/or address compassion fatigue, burnout, unresolved grief and loss.</p>	<p>Support those providing care and friendship and ensure they have resources to support themselves in terms of their own wellbeing. Offer family, peers and staff carers tailored and appropriate resources, time, and support to maintain their own quality of life and health.</p> <p>For example:</p> <ul style="list-style-type: none">■ Provide skills training for caregivers on self-care techniques, making self-care a priority, and help caregivers recognise that compassion fatigue is not a weakness.■ Offer emotional support through counselling and peer group meetings to address the risk of stress and isolation.■ Provide support for peers, family members and staff caregivers who are grieving for the person with dementia.■ Ensure there is both space and time to debrief and process emotions around the progression, and end of life.■ Maintain a care team adequate in size, with the prerequisite knowledge and skills to support the changing care requirements of the person across the continuum of dementia.■ Ensure there is flexibility in the care team to accommodate fluctuating needs, and that the person and staff are adequately supported and not overwhelmed.



Pillar 5: Promoting autonomy, enablement, and health



This pillar is underpinned by the importance of placing the person at the centre of their care, promoting autonomy and enablement meeting changing needs and preferences with compassion and creativity over the course of dementia. Such an approach will increase the likelihood that the person can live well and die well with dementia.

Successful and sensitive post diagnostic supports include reasonable adjustments to care that: meet the person’s needs and personal preferences; promote health, functional and social independence and quality of life; and minimise distress. Planning for the future and making key decisions on end-of-life care is important for every person living with dementia and will optimise comfort and reduce distress for the person and their caregivers.

Standard Guideline	Process
<p>5.1 Allow adequate time for the person to process information. Avoid outpacing and rushing care, which risks overwhelming and distressing the person.</p>	<p>Emphasise the importance of maintaining self-identity and wellbeing in the provision of care.</p> <p>Assess, at least on an annual basis, the person’s strengths and changing needs, and adapt supports as required to help maintain functional and social independence.</p> <p>Avoid outpacing and ensure the person is given adequate time and is not overwhelmed by rushed care or demands that exceed their abilities.</p>
<p>5.2 Provide reasonable adjustments to care that will empower and support the individual’s personal preferences in dress and grooming style, helping the person to feel confident and good about themselves.</p>	<p><i>Document:</i> the person’s dress style and grooming preferences and understand that the maintenance of these desires is essential to the person’s sense of self, identity, and personal wellbeing.</p> <p><i>Simplify choices:</i> Keep wardrobes free of excess clothing and ensure there is good lighting.</p> <p><i>Organise the process:</i> Lay out clothing on a non-patterned background in the order that each item should be put on. Recognise that the person may have difficulty in starting a task and may require a prompt.</p> <p><i>Ignore mistakes:</i> If mistakes are made, for example, by putting something on the wrong way round – be sensitive, mirror the right way and tactfully assist the person.</p>



Standard Guideline	Process
<p>5.3 Support the person to maintain a personal bathing and hygiene routine that respects and is grounded in personal preferences and lifelong habits.</p>	<p>Establish and record the person's lifelong hygiene habits and preferences, such as a bath or shower, or their preferred time i.e., morning or before going to bed.</p> <p>Ensure bathing areas are warm, clean, and welcoming with all items ready: toiletries, towels, clothes.</p> <p>Never leave a person who is confused alone in the shower or bathroom.</p> <p>Check with the person that the water temperature is comfortable. Be aware that the person may be less sensitive to extremes of hot or cold.</p> <p>Adapt the bathroom/shower area to support continued independence, and ensure the safety and comfort of both the person and caregiver e.g., install and use non-slip mats, an assisted bathtub, hoists, grab rails etc.</p> <p>Recognise that the person may be uncomfortable receiving assistance with such an intimate activity and respect the person's dignity and their right to privacy.</p> <p>For example:</p> <ul style="list-style-type: none">■ Be sensitive, do not leave the person exposed unnecessarily, use large bath towels, and discourage others from entering the bath/shower area.■ If two carers are required to bath/shower the person, include the person in any conversation between carers, acknowledging their presence.■ Use bathing time as an opportunity for a therapeutic activity, using lighting, smells and soft music to help the person relax and respecting their personal preferences.
<p>5.4 Take an individualised and preventive approach to dental care.</p>	<p>Offer the person regular dental assessment and include a preventative and dental care plan in the overall care plan.</p> <p>For example:</p> <ul style="list-style-type: none">■ Monitor for dental decay, tooth pain/sensitivity and gum disease.■ Record the person's ability to manage oral hygiene/denture care and provide support as required.■ Keep mouth and lips hydrated, support and offer regular fluids, and use lip moisturisers as required.



Standard Guideline	Process
<p>5.5 Conduct regular nutritional assessment to ensure good nutrition, meal enjoyment and safety.</p>	<p>Engage the person in planning the menu and in meal preparation.</p> <p>Offer a balanced diet, with appropriate portions, respecting food preferences and flexibility in timing of meals.</p> <p>Ensure that the person is positioned properly and is alert during meals.</p> <p>Create a social occasion around mealtimes by encouraging and providing opportunities for the person to share mealtimes with family and friends.</p> <p>Modify noise levels which can quickly raise stress and create a sense of added confusion, disconnectedness and distress for the person.</p> <p>Use place settings to create contrasts, serve one course at a time and introduce adapted cutlery and tableware as required to support continued independence.</p> <p>Introduce nutritious finger foods if the person can no longer use cutlery such as: cheese cubes, small sandwiches, small pieces of chicken, sliced fruits and vegetables, potato wedges, chicken strips, etc.</p> <p>If the person requires oral nutrition support such as modified food, use a food mould and do not mix different foods together.</p> <p>As dementia progresses, monitor for swallowing difficulty and request a swallow assessment by an appropriate member of the MDT when changes are noted.</p> <p>www.indi.ie/images/Nutrition_and_Dementia_Booklet_March_2021_Update.pdf</p> <p>https://alzheimer.ie/wp-content/uploads/2018/11/ASI-Eating-well-with-Dementia_-website_2017.pdf</p>



Standard Guideline	Process
<p>5.6 Ensure the non-cognitive symptoms of dementia (NCSD) are understood and responded to appropriately and in ways that minimise distress for the person.</p>	<p>Consider responsive behaviour as a form of communication and try to understand the meaning behind the behaviour.</p> <p>Identify, monitor and address environmental, physical health and psychosocial factors that may increase the likelihood of the person with dementia experiencing NCSD and responsive behaviours.</p> <p>Be alert and assess for unmet needs that may influence the behaviours being observed, for example:</p> <ul style="list-style-type: none"> ■ pain ■ hunger or thirst ■ need to use the bathroom ■ lack of privacy ■ lack of meaningful activities and boredom ■ desire to walk ■ social isolation <p>Be aware and accommodate the person’s lowered threshold to stress and understand that there may be feelings of lack of control over one’s environment that may heighten anxiety.</p> <p>Be alert and assess for:</p> <ul style="list-style-type: none"> ■ a misfit with the environment and/or the people who are living there ■ poor communication approaches ■ rushed care, which risks overwhelming the individual ■ demands that exceed abilities ■ loud sounds and ambient background noise <p>Monitor and document antecedents, or what happened to cause distress or a responsive behaviour, and take proactive steps to avoid or reduce this happening in the future.</p> <p>Provide safe spaces indoors and outdoors for the person to walk and exercise.</p> <p>Provides cues to encourage rest periods such as strategic seating, rummage boxes, etc.</p> <p>Avoid confrontations, don’t try to reason or correct, validate the feelings inherent in the message.</p> <p>Use empathy, model calm behaviour in your words, voice and posture.</p>



Standard Guideline	Process
<p>5.7 Offer end-of-life care that responds to and meets a person’s physical, social, spiritual and psychological needs.</p>	<p>Care for the person at an advanced stage of dementia should be based on a palliative approach and involve a palliative care service if indicated.</p> <p>Sensitively discuss advanced care plans with the person and/or their designated decision-maker, and honour and respect the values of the person, their will and preferences, and ensure their wishes are clearly documented in their overall plan of care.</p> <p>Treatment and care should be provided as per the person’s care plan and should be revisited on a regular basis and following any significant change in health condition or circumstance.</p> <p>Ensure staff have adequate skills and competencies to support good end-of-life care and peaceful dying including an understanding of:</p> <ul style="list-style-type: none"> ■ The importance of a peaceful and familiar environment. ■ The sustenance of relationships with people significant to the person who is dying being present at end of life. ■ Symptom management including pain, nutrition, hydration & antibiotics. ■ Comfort measures that address personal hygiene, mouth care, difficulty with breathing, skin care, bowel care, mobilisation, personal support. ■ Knowing where and how to access additional professional expertise for help and support should it be needed. ■ Spiritual and psychosocial support that acknowledges pending death, supports inclusive decision-making, prepares the person, families, peers, and staff for last days and addresses last wishes. <p>(McCarron, M., et al. (2017). ‘He’d mind you, you mind him.’ Experiences of end of life care for people with an intellectual disability as perceived by staff carers. Dublin: Trinity Centre for Ageing and Intellectual Disability, School of Nursing and Midwifery, Trinity College Dublin. https://www.tcd.ie/tcaid/research/endoflifepublications/ReportExperiencesofendoflife.pdf</p> <p>tcd.ie/tcaid/research/endoflifepublications</p> <p>Stancliffe, R.J., Wiese, M. Y., McCallion, P., & McCarron, M. (Eds.). (2022). End of life and people with intellectual and developmental disability. Contemporary issues, challenges, experiences and practice. Palgrave Macmillan. https://link.springer.com/book/10.1007/978-3-030-98697-1</p> <p>hospicefoundation.ie/i-need-help/i-want-to-think-ahead</p> <p>https://hospicefoundation.ie/other/ihf-launch-seven-guidance-documents-improve-palliative-care-people-dementia/</p>



References

Begley E., Gibb M., Kelly G., Keogh F., & Timmons, S. (2023). Model of care for dementia in Ireland. Tullamore: National Dementia Office. Link to full version: www.hse.ie/eng/services/publications/olderpeople/model-of-care-for-dementia-in-ireland.pdf; Link to the easy-read version: <https://www.hse.ie/eng/services/publications/olderpeople/dementia-model-of-care-easy-read.pdf>; Link to plain English summary version: www.hse.ie/eng/services/publications/olderpeople/dementia-model-of-care-summary.pdf

Dodd, K., Turk, V., & Christmas, M. (2005). About Dementia For People with Learning Disabilities. Bild.

Down's Syndrome Scotland. Let's talk about dementia. <https://www.dsscotland.org.uk/wordpress/wp-content/uploads/2016/02/Lets-Talk-About-Dementia-final-version-05.08.15.pdf>

McCarron, M., Allen, A.P., Buttery, N., Dennehy, H., Kennelly, S., Corr, C., Dunne, P., Daly, L., McCallion, P., & McGlinchey, E. (2024). Building post-diagnostic dementia support guidelines for people with an intellectual disability: Voices of experience. swso Brief Report. Dublin: Trinity Centre for Ageing and Intellectual Disability, School of Nursing and Midwifery, Trinity College Dublin. <https://doi.org/10.25546/106621>

McCarron, M., Reilly, E., & Dunne, P. (2013) Achieving quality environments for person centred dementia care. Trinity College Dublin. <https://www.tcd.ie/tcaid/research/AchievingQualityEnviornmentsforPersonCentredDementiaCare.pdf>

Stancliffe, R.J., Wiese, M. Y., McCallion, P., & McCarron, M. (Eds.). (2022). End of life and people with intellectual and developmental disability. Contemporary issues, challenges, experiences and practice. Palgrave Macmillan. <https://link.springer.com/book/10.1007/978-3-030-98697-1>

Stirling C., Andrews S., McInerney F., Toye C., M Ashby., & Robinson A. (2011) Talking about dementia and dying: A discussion tool for aged care residential facility staff. Hobart: Print Press. <https://figshare.utas.edu.au/ndownloader/files/40913123>





Glossary of terms (in alphabetical order)

Advanced Care Plans: Advanced care plans, also known as Advance Healthcare Directives, is a legally-binding document that allows you to state what treatments you would refuse or request if you cannot express your choices at a later time—for example, if you are injured in an accident, or become very ill. They provide guidance to healthcare providers and loved ones regarding the person's desired medical interventions, treatments, and end-of-life care. An Advance Healthcare Directives also allows you to appoint someone you trust to be your Designated Healthcare Representative—to advocate for you and uphold your choices.

Assistive Technology: Assistive technology refers to devices, tools, or technologies designed to assist individuals with disabilities or impairments in performing tasks, improving their independence, and enhancing their quality of life. In the context of dementia, assistive technology can include devices like reminder systems, GPS trackers, or simplified communication aids to support the person's daily functioning.

Care Plans: Care plans are comprehensive, personalised documents that outline the specific needs, goals, and preferences of an individual receiving care. They are created collaboratively between the person, their family, and healthcare professionals and serve as a guide for providing consistent and appropriate care. Care plans address various aspects of the person's wellbeing, including medical, social, emotional, and cognitive needs.

Circle of Support: A circle of support refers to a network of family members, friends, professionals, and other individuals who provide support, guidance, and care to someone with a particular condition or disability. In the context of dementia, the circle of support helps to ensure the wellbeing and quality of life of the person with dementia by providing emotional support, assistance with daily activities, and coordinating care and resources.

Dementia: Dementia is a general term used to describe a decline in cognitive abilities (such as memory, thinking, and reasoning) that is severe enough to interfere with daily functioning. It is characterised by a progressive and irreversible loss of brain function and is often associated with ageing. Dementia affects multiple cognitive domains and can have significant impacts on memory, language, attention, and problem-solving abilities.

Human security is a human right. It refers to the security of people and communities, as opposed to the security of countries or states. Human security recognises that there are several dimensions related to feeling safe, such as freedom from fear, freedom from want, and freedom from indignity.

Intellectual Disability: Intellectual disability refers to significant limitations in intellectual functioning (such as reasoning, problem-solving, and learning) and adaptive behaviour. It is usually present from childhood and affects an individual's ability to function independently in daily life. Intellectual disability is characterised by below-average intellectual functioning and limitations in adaptive skills, such as communication, self-care, and social skills.

Non-Cognitive Symptoms of Dementia: Non-cognitive symptoms of dementia encompass a range of behavioural and psychological symptoms that can occur in individuals with dementia. These symptoms include agitation, depression, anxiety, sleep disturbances, hallucinations, delusions, changes in appetite or behaviour, and other emotional and behavioural changes not directly related to cognition.

Pathways of Care: Pathways of care refer to the different routes or options available for delivering healthcare and support services to individuals with dementia. This may include home-based care, assisted living facilities,



Person-Centred Care: Person-centred care is an approach to caregiving that focuses on the individual's unique needs, preferences, and goals. It involves actively involving the person with dementia in decision-making, tailoring care plans to their individuality, and promoting their autonomy, dignity, and wellbeing. Person-centred care recognises and respects the person's values, cultural background, and personal choices in all aspects of their care.

Post-Diagnostic Supports: Post-diagnostic supports refer to the services and interventions provided to individuals and their families after a diagnosis of dementia. These supports can include education about the condition, counselling, access to resources and support groups, and assistance in navigating the healthcare.

Psychosocial Interventions: Psychosocial interventions are therapeutic approaches that focus on addressing the psychological and social aspects of a person's well-being. They aim to improve mental and emotional health, promote social engagement, and enhance overall quality of life. In the context of dementia, psychosocial interventions can include cognitive stimulation therapy, reminiscence therapy, behaviour management techniques, and support groups for both individuals with dementia and their caregivers.

Relationship-Centred Care: Relationship-centred care emphasises the importance of building meaningful and supportive relationships between healthcare professionals, individuals with dementia, their peers, and families. It recognises the role of relationships in promoting well-being and focuses on fostering trust, respect, effective communication, and collaboration among all involved. Relationship-centred care actively involves the person with dementia, their family and caregivers in decision-making and care planning, and tailoring care to their unique needs and preferences.

Respite: Respite refers to a temporary break or relief provided to caregivers of individuals with dementia. It allows caregivers to take time for themselves, recharge, and attend to their own needs while their loved one receives temporary care from trained professionals or other support services. Respite can be provided in various forms, such as in-home respite care, adult day programs, or short-term stays in specialised dementia care facilities.

Responsive Behaviours: Responsive behaviours, also known as challenging behaviours, are behavioural or emotional responses exhibited by individuals with dementia. These behaviours can include agitation, aggression, wandering, restlessness, repetitive actions, resistance to care, and other behaviours that may be difficult for caregivers to manage. Responsive behaviours are often a communication of unmet needs, pain, discomfort, or frustration, and require understanding, patience, and appropriate interventions to address them effectively.

Sense of Belonging: Sense of belonging refers to the feeling of being connected, accepted, and valued within a social group or community. For individuals with dementia, maintaining a sense of belonging is important for their well-being and quality of life. It involves creating inclusive and supportive environments where individuals feel accepted and respected, fostering social connections and meaningful relationships, and promoting active engagement and participation in activities and community life.

Sense of Place: Sense of place refers to an individual's subjective and emotional attachment to a specific location or environment. In the context of dementia care, it relates to creating a familiar and supportive environment for individuals with dementia that promotes feelings of comfort, security, and familiarity. Enhancing the sense of place can involve incorporating personal belongings, familiar objects, and familiar routines into the person's living environment to create a sense of familiarity and reduce disorientation.



Strengths-Based Approach: A strengths-based approach focuses on identifying and utilising an individual's strengths, abilities, and resources to promote their wellbeing and maximise their potential. In the context of dementia care, it involves recognising and building upon the remaining abilities, interests, and skills of individuals with dementia rather than focusing solely on their limitations. A strengths-based approach fosters a positive and empowering environment that supports autonomy, independence, and dignity.

Total Communication: Total communication is an approach that involves using a combination of communication methods and strategies to effectively communicate with individuals with dementia who may have difficulty expressing themselves verbally. It includes verbal communication, non-verbal cues, gestures, facial expressions, touch, visual aids, and other forms of communication to convey messages, facilitate understanding, and promote meaningful interactions. Total communication aims to meet the individual's communication needs and preferences while promoting engagement and connection.





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