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Building Post-Diagnostic Dementia Support Guidelines for People with an Intellectual Disability: Voices of Experience.

Brief Report





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Foreword



As the longevity of people with an intellectual disability has increased, health problems associated with ageing have become more evident. One such health concern is a higher prevalence and earlier onset of dementia among people with an intellectual disability compared to the general population. This is particularly apparent in people with Down syndrome.

Given the higher prevalence and early onset of dementia, it is critical for quality of life and wellbeing that best-practice post-diagnostic dementia supports are resourced and available for people with an intellectual disability.

There are existing international statements and recommendations on post-diagnostic dementia supports for people with an intellectual disability, with an acknowledged need for further refinement and specification to better support families and other carers. Model of Care for Dementia in Ireland (Begley et al., 2023) has been designed for the general population, but the need for further work and guidelines specifically for people with an intellectual disability living with dementia is also acknowledged. Critically, there is a need to gather and include input from people with an intellectual disability, and their caregivers, on the kind of supports that they would like to have or consider necessary.

The guidelines here are intended to address these gaps in available and proposed models for care. They are presented as a necessary first step, and will require resources and training for successful implementation, as well as accessible materials for - and continuing input from - families, staff carers and people with intellectual disabilities themselves.

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Introduction

Among adults with an intellectual disability in Ireland aged 40 plus, estimates have been that 31.1% live at home with family, 9.7% live independently, 34.6% live in a community group home, 17.1% live in a residential setting and 7.65% live in another residential setting (Hourigan et al., 2017). This is different from the experience of the general population where many more live in their family homes or independently. As a population at heightened risk for dementia, this therefore means that people with an intellectual disability are likely to require different structuring or management of supports. They are also more likely to face disruptions, such as moving from one setting to another, rather than necessarily receiving appropriate supports to help them to age in a place of their choice (Cleary & Doody, 2017; Manji & Dunn, 2010; Sheth, 2019; Watchman, 2008). Environmental and other supports will assist people to age in a place of their choice, particularly those with intellectual disabilities living independently or in their family home. The COVID-19 pandemic brought such challenges for people with an intellectual disability and their families into greater focus (McCarron et al., 2021; McCausland et al., 2021). The guidelines here, developed during the pandemic, were thoughtful about addressing these additional issues.

A process was undertaken to develop practice guidelines for post-diagnostic dementia supports for people with an intellectual disability in Ireland by: (a) examining the current landscape of post-diagnostic care at a national level; (b) considering barriers to access; (c) incorporating existing best practices; and (d) giving due consideration of the day-to-day experiences and recommendations of people with an intellectual disability living with dementia and of their families/carers.

Most critically, work on these guidelines began by considering how best-practice guidelines for post-diagnostic dementia support for people with an intellectual disability were informed by an understanding of: (a) the lived experience of post-diagnostic dementia for people with an intellectual disability; and (b) post-diagnostic supports offered in existing intellectual disability services.

The creation of the guidelines is the first step; their implementation, the securing of needed resources and the evaluation of the care to be provided, will be the next challenges. The guidelines are intended to provide a roadmap for these next steps.





Project Aim

The aim of the project was to develop accessible best-practice guidelines for post-diagnostic dementia supports for people with an intellectual disability in Ireland.

Project Objectives

- Objective 1:** To scope the current landscape of post-diagnostic dementia support services for people with an intellectual disability.
- Objective 2:** To identify current recommendations of best practice in post-diagnostic dementia supports nationally and internationally.
- Objective 3:** To identify the post-diagnostic supports currently available to people with an intellectual disability, at a national level, upon receiving a diagnosis of dementia.
- Objective 4:** To understand the current lived experience of post-diagnostic dementia supports for people with an intellectual disability and their carers following a dementia diagnosis.
- Objective 5:** To understand what post-diagnostic dementia supports people with an intellectual disability and their families would like to have.
- Objective 6:** To develop detailed descriptions of exemplars of best practice in Ireland from intellectual disability services with dedicated post-diagnostic supports.
- Objective 7:** To develop usable, useful, and practical best practice guidelines for post-diagnostic support for people with an intellectual disability.

Work packages

To address the aims and objectives, a series of work packages was undertaken:

Work Package 1	Work Package 2	Work Package 3	Work Package 4	Work Package 5
<p>(a) A scoping review of international research literature on post-diagnostic dementia supports.</p> <p>(b) Focus group interviews with people providing post-diagnostic dementia supports.</p>	<p>Survey instrument completed by key staff in services across Ireland, identified through the National Federation of Voluntary Service Providers network and the Health Service Executive.</p>	<p>Qualitative interviews with people with an intellectual disability and dementia, their families, and staff carers working directly in the provision of post-diagnostic supports.</p>	<p>Qualitative interviews with staff carers, management and family members in services identified as exemplars of best-practice post-diagnostic dementia supports.</p>	<p>Triangulation of the data from Work Packages 1-4 to inform guidelines for post-diagnostic dementia supports for people with an intellectual disability.</p>



Methodology

To achieve the work packages and support the subsequent development of guidelines, the project employed a multistage, mixed methods methodology, comprising both qualitative and quantitative methods that utilised a scoping review, qualitative interviews and a quantitative online survey, which in turn informed further qualitative research interviews.

This research project received ethical approval from the Trinity College Dublin Faculty of Health Sciences Research Ethics Committee on 1st June 2021 (REF: 210307). Where required, local ethical approval was obtained from six of the services participating/involved in recruitment for this research project. To support data protection and ensure compliance with General Data Protection Regulation (GDPR) and Health Research Regulations 2018 (previously the Data Protection Act 2018 [Section 36(2)] [Health Research] Regulations 2018), a Data Protection Impact Assessment (DPIA) was completed for the study, and this was reviewed and approved by the Data Protection Office at Trinity College Dublin. Permission was also granted from the The Health Research Consent Declaration Committee (HRCDC).

Appropriate quantitative and qualitative analysis approaches were utilised to analyse and interpret the data in each work package. Summated findings from the work packages were considered by an expert panel that included families and persons with intellectual disability. This occurred using a facilitated collective intelligence format. The finding of each of the work packages, along with the outcomes of the expert panel consultations, were triangulated to inform key points that then formed the basis of Post-Diagnostic Dementia Support Guidelines for People with an Intellectual Disability (McCarron et al., 2023)

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Findings

There were key findings across the five work packages which then cumulatively informed the development of the guidelines. A summary of the findings from each of the work packages is presented as follows:

Work Package 1

(a). Scoping review

The aim of Work Package 1 was to identify the current guidelines, evidence and recommendations on post-diagnostic care for people with an intellectual disability nationally and internationally. International literature on post-diagnostic dementia supports for people with an intellectual disability was reviewed using a systematic search. Based on the analysis of this literature, the key themes generated by the authors were: ageing in place; interventions/therapies; environmental supports; the role of the family; end-of-life/palliative care; and staff supports and training. The thematic findings of the scoping review of post-diagnostic supports are available in Dennehy et al. (2022).

Ageing in place

- Experience changes or disruption to their accommodation
- Lack of facilitation for ageing in place
- Lack of consideration for the person's wishes and interests

Interventions/Therapies

- Cognitive stimulation therapy: music therapy: life stories; dementia care mapping; home environment adaptations, reminiscence therapy, music, activity planner, namaste and pet therapy

Environmental supports

- Dementia-inclusive design
- Access to adaptive equipment, considerations for lighting, visual cues and auditory stimulation
- Compensatory strategies and environmental modifications



Work Package 1

The role of the family

- Reduction of caregiver burden
- “Strategy toolboxes”
- Care pathways and services are stressful to negotiate
- Focus on longstanding disability rather than recent diagnosis of dementia

End-of-Life/Palliative Care

- Increased relocation occurs
- Involvement in planning for individual end-of-life care
- Collaboration of specialist services
- Co-ordination of care
- Supporting the person through death

Staff supports and training

- Carers may not have access to specific education or training
- Training that supports the development of skills in accessible communication, meaningful one-to-one interactions and adjusting to changing care needs

Although the quality of the 42 articles was generally moderate to high, a sizeable number of studies did not evidence consideration of the role of the researcher and their relationship with the participant.

(b). Qualitative Interviews

The aims of these research interviews were to gather information on participants' (mainly services' staff from multiple professions) experiences of: (a) what post-diagnostic supports they have found most useful; (b) what supports or changes to supports they would find most beneficial; and (c) whether there were particular barriers to best practice in care provision. Best practices were reported to be multi-component practices; there were also many additional factors that impact on supports, and there were a number of concepts and values that underpin those practices. The five themes and related subthemes developed during data analysis were:



Work Package 1

- (1) **Foundational concepts underpinning post-diagnostic support.** Sub-themes: a) Enabling empowerment and inclusivity, b) actively sustaining a good life, c) establishing and maintaining person-centredness, d) establishing and maintaining meaningful connections.
- (2) **Pre-requisites of post-diagnostic support.** Sub-themes: a) Knowledge of the person and changes over time, b) appropriate diagnosis and communication of diagnosis, c) care pathways.
- (3) **Infrastructure and personnel components of post-diagnostic support.** Sub-themes: a) integrated organisation and structure, b) collaborative teams of skilled personnel, c) support of those providing care.
- (4) **Process components of post-diagnostic support.** Sub-themes: a) advance care planning, b) ageing in place of choice, c) environmental supports, d) working with and supporting families/carers, e) meaningful engagement, f) psychosocial interventions, g) a good death.
- (5) **Factors impacting on post-diagnostic support.** Sub-themes: a) resourcing, b) availability of supports across geographical regions, c) attitudes and understanding, d) current policy landscape.

To summarise, participants proposed that adequate resourcing for supports was a facilitator, and its absence was a barrier for best-practice post-diagnostic dementia supports. The obtaining of such resources required proactive advocacy particularly where there are a number of people at risk of, or experiencing, dementia. The availability of supports and associated resources was described as variable across different geographical regions, although the establishment of the National Intellectual Disability Service (NIDMS) and the roll out of the proposed satellite services was highlighted as a positive development in reducing disparities. Attitudes towards people with an intellectual disability and people with dementia were also discussed as a factor influencing post-diagnostic support; the importance of avoiding stigma and fear was highlighted or thinking that “nothing can be done” for a person with dementia. Finally, policy statements, both at a national and local level, were identified as influencing post-diagnostic supports, although the enactment of such policies was identified as a challenge in a context of limited or variable resourcing.



Work Package 2

An online survey investigated dementia supports for people with intellectual disability in services across Ireland to address the aim of Work Package 2 which was to understand the current landscape of post-diagnostic support for people with an intellectual disability.

Key findings from the online survey of services included:

- Services across all of the nine Community Health Organisations (CHO) regions in Ireland participated.
- A majority of service responses (69%) indicated that the services were supporting both people with Down syndrome aged over 30, and people with an intellectual disability without Down syndrome aged over 60; two high-risk groups for dementia.
- Most service responses indicated they always had a dementia care plan after a diagnosis of dementia, although 11.9% said this was not the case.
- Twenty-six service responses indicated that a person within the service had been transferred to a nursing home, with the most common reasons for this being “residence not equipped for level of care needed”. For most services, transfers occurred when the person was showing advanced signs of dementia.
- For services providing supports in residential/group homes, the environmental adaptations/supports most likely to be reported as available in all settings were: floor surfaces non-slip (68.3%), personal objects situated where people can see them (75.6%), access to a quiet/peaceful space if they want to have quiet time (58.5%), and expertise available to support environmental modifications (58.5%).
- For day services, the environmental adaptations/supports most likely to be reported as available in all settings were downstairs bathrooms available (68.9%), floor surfaces non-slip (62.2%), and grab bars and other safety tools (60%).
- The most commonly indicated barriers to providing quality dementia care to persons in residential or group homes were: lack of funding (83%), physical environment not dementia capable (70.2%), and not the right skill mix amongst staff (61.7%).
- The most commonly indicated barriers to providing quality dementia care to persons living independently or with family were: physical environment not dementia capable (79.4%), ageing/health needs of family caregivers (76.5%), family caregivers overwhelmed (70.6%), and safety/increasing nursing care needs (67.6%).



Work Package 2 (continued)

Although the importance of advanced care planning was highlighted in Work Package 1 interviews as well as in Model of Care for Dementia in Ireland (Begley et al., 2023), there were services who reported that they did not have a plan to support people across the continuum of dementia. Most services did indicate that the provision of dementia supports had been discussed with the person, their family, and staff. Furthermore, although a plan may have been in place, and discussed with all relevant parties including the person with dementia (e.g., around ageing in place of choice), this did not guarantee the plan would be followed (e.g., persons were reported as moving from a community group home back into residential care and/or to a nursing home, even though this went against their plan). Future research is required on the extent to which plans are implemented.

Notwithstanding the importance of ageing in place as highlighted in the literature (e.g. Cleary & Doody, 2017; Iacono et al., 2014), 26 service responses indicated that a person with a diagnosis of dementia had been transferred to a nursing home. This usually happened when a person was showing advanced signs of dementia, but also occurred during early signs of dementia. The most common reason for transfer to a nursing home was that the residence was not equipped for the level of care needed. It would appear that staffing issues (e.g., the availability of waking night staff, and lack of appropriate skill mix) were a related problem.

Consistent with key themes from our scoping review (e.g., environmental supports, staff supports and training; as well as our interviews from Work Package 1), the most commonly indicated barriers to providing quality dementia care to persons in residential or group homes were lack of funding, the physical environment not being dementia capable, and not the right skill mix amongst staff. Similarly, the most commonly indicated barriers for people living independently or with family were the physical environment not being dementia capable, as well as safety/increasing nursing care needs, ageing/health needs of family caregivers, and family caregivers being overwhelmed. Finally, in response to an open-ended question on what resources would allow people with intellectual disability to age in place, environmental adaptations and funding/resourcing were the most frequently cited factors. These points on the physical environment not being dementia capable and environmental adaptations are consistent with the findings that the most common reported reason for transfer to a nursing home was that the residence was unequipped for the required level of care.

Finally, the results indicate that although many post-diagnostic dementia supports are being provided by services, there are (a) gaps in terms of training/skill mix of staff; (b) a lack of funding to provide best-practice supports; and (c) a particular need to create living environments that have the necessary adaptations/aids to support people with intellectual disability and dementia ageing in their place of choice.

The most commonly indicated barriers to providing quality dementia care to persons in residential or group homes were lack of funding, a physical environment that was not dementia-capable, and a lack of appropriately skilled staff.



Work Package 3

The aim of Work Package 3 was to understand the lived experience of accessing and using post-diagnostic dementia supports from the perspective of people with dementia, as well as family members and staff carers supporting people with an intellectual disability and dementia. This work package also aimed to understand future post-diagnostic supports that participants would like to have.

The work package positioned the voice of the person with an intellectual disability and dementia at the centre of the analysis and drew core themes accordingly. The additional accounts of family carers, family members, and professional carers were valuable voices to enhance and support the voices and perspectives of the people with an intellectual disability and dementia. The four themes and related subthemes developed during thematic analysis of the qualitative interviews (n=12) are summarised in Figure 1.



Figure 1
Summary of the four themes and related subthemes developed during thematic analysis of the qualitative interviews (n=12) in Work Package 3.

- 1) **Being me.** A sense of self through connection and valued life pursuits. Subthemes: a) The importance of community and socialising, b) Connection through familiarity, c) Activities and hobbies.
- 2) **Meeting the social and personal needs of the person.** Subthemes: a) Creative and compassionate solutions in care, b) Good communication is key to good care, c) Familiarity in care is the foundation of a good life with dementia.
- 3) **Formal processes that support people with dementia and intellectual disability.** Subthemes: a) Multidisciplinary supports across the dementia journey, b) Satisfaction with the support in place.
- 4) **Challenges in supporting persons who are living with dementia and an intellectual disability** Subthemes: a) Challenges when support is not available, b) The impact of caring on carers, c) The need for appropriate and timely information and training.



Work Package 3 (continued)

People with an intellectual disability and dementia reported depending on familiar people to adhere to their preferences across the trajectory of dementia, and finding comfort in knowing the person who is caring for them. They also spoke of the importance of having social connections and access to hobbies and interests which were connected to a sense of agency and feeling valued. Connecting to the local community, knowing people, and being known, play a significant role in maintaining a person's self-identity. Upholding the familiar in the lives of people with an intellectual disability and dementia was noted by all participants to be an important goal. The loss of familiarity was equated with the loss of a sense of independence and life skills.

Professional carers spoke of the importance of access to multi-disciplinary teams, and family members expressed their satisfaction with the supports that have been made available. However they noted the geographical disparity in the availability of support for people with an intellectual disability and dementia. All participants spoke about a lack of information, training and supports. Family carers noted that there is no clear signposting to information, training, or funding and highlighted the financial burden. They experience sleep deprivation, hypervigilance, neglect of their personal health and burnout. They were also concerned that their low energy affects the person in their care along with their general quality of life. Family carers, professional carers, and family members suggested that there is a great need for improved support and information. It was also reported by family carers that they received significantly less information and support than professional carers, and expressed isolation, high-stress levels, and neglected health issues, as a result. There was agreement that care should be provided in an equitable way, and those being supported in the community should be supported to the same extent as those living within settings such as community group homes provided by disability services.

Connecting to the local community, knowing people, and being known, play a significant role in maintaining a person's self-identity. Upholding the familiar in the lives of people with an intellectual disability and dementia was noted by all participants to be an important goal. The loss of familiarity was equated with the loss of a sense of independence and life skills.



Work Package 4

The aim of Work Package 4 was to identify best-practice approaches to post-diagnostic care from specialist intellectual disability service providers. Interviews were held with staff and management (n=7), and family members (n=2) of people with an intellectual disability receiving specialist dementia services/supports at ID services. Participants were asked to describe key components of specialist care for people living with dementia in their organisation. The added value in this work package is the elaboration on the provision of care for people living with intellectual disability and dementia, the key components and prerequisites of good dementia care, the challenges that are encountered in delivering and sustaining good care, and the vision for future support.

The three themes and related subthemes developed during thematic analysis of the qualitative interviews (n=9) are summarised in Figure 2.



Figure 2
Summary of the three themes and related subthemes developed during thematic analysis of the qualitative interviews (n=9) in Work Package 4.

1. **Post-Diagnostic Supports: Current good care practises.** Subthemes: a) Working as a team, b). Approaches to care, c). Interventions changing lives.
2. **Sustaining good care.** Subthemes: a) Parity in access to support b) The complexity of intellectual disability and dementia c), The importance of familiar carers with requisite skills.
3. **Strengthening post-diagnostic supports** Subthemes: a) Supporting and resourcing specialist intellectual disability staff who have prerequisite skills and knowledge in dementia care, b) Funding needs for the future, c) Collaboration and information sharing.

Equitable post-diagnostic support was identified as requiring a focus on ensuring enough trained personnel to support the growing number of people with an intellectual disability and dementia. Access to funding was reported as needing to be possible, available and timely to ensure support is proactive. Parity is needed across the continuum of care, particularly for people living with family; and collaboration across all stakeholders is a foundational requirement for the future of support for people with an intellectual disability and dementia. A common theme inherent throughout the narrative was the need for collaboration between intellectual disability services and general community service and health care organisations which if developed, could enable clearer paths to planning, funding and training for the future of post-diagnostic supports for everyone with an intellectual disability and dementia.



Work Package 5

Guidelines for post-diagnostic support

The final stage in this study is the development of practical post-diagnostic guidelines that are evidence and research informed, and yet offer practical assistance to the person, family and other carers. The results from the various qualitative interviews and quantitative findings from the online survey were triangulated and integrated using a joint display in order to incorporate the findings from work packages 1-4. A collective intelligence workshop was convened with an international panel of experts and additional ideas from formal meetings with the Expert Advisory Panel further informed the development of the guidelines. The guidelines represent best practices of care and support across the continuum of dementia care for people with an intellectual disability and dementia.

There are 33 standards, which sit within five pillars of post-diagnostic support, with the person with an intellectual disability (ID) and dementia always at the centre. The five pillars of post-diagnostic support are interconnected, highly dependent on each other and must be considered in their entirety. With this in mind, each pillar is accompanied by a statement of purpose to support understanding and provide context. Next, individual standards associated with each pillar are dynamic, evidenced-based and can be added to, amended or subtracted as needs change or as evidence evolves.

The standards developed from the work packages were also considered and developed in ways that ensured that they were consistent with and aligned 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 Quality Authority (HIQA). They were also influenced by Model of Care for Dementia in Ireland (Begley et al., 2023), meaning they are focused upon a defined set of interventions determined to improve dementia care.





Five Pillars of Post Diagnostic Support

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

Pillar 2. Build awareness, understanding and skills

Pillar 3. An enabling infrastructure

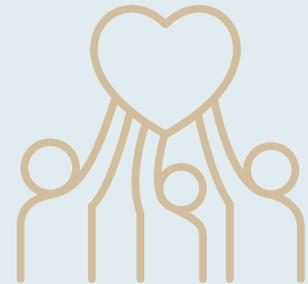
Pillar 4. A sense of place and community

Pillar 5. Promoting Autonomy, Enablement and Health



Pillar 1

To live one's best life with dementia



Pillar 2

A sense of place and community



Pillar 5

Promoting autonomy, enablement, and health



Pillar 4

An enabling infrastructure



Pillar 3

Build awareness, understanding, and skills





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 a life of their choosing, maximise their independence and ability to participate meaningfully in their communities

Standard Guidelines

- 1.1 Sensitive reflect on and try to understand the person's perspective, how they are coping with the diagnosis and work with the person addressing questions and/or concerns.
- 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.
- 1.3 Ensure the communication environment facilitates meaningful conversations, through respectful, sensitive, person-centred, and total communication approaches.
- 1.4 Ensure the physical environment enables the person to contribute, promoting a sense of belonging, well-being, confidence, and safety, supporting self-management.
- 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.
- 1.6 Ensure there is relationship continuity with consistency of staff caregivers, stability in the living environment and flexibility to accommodate fluctuating abilities.



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 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 Guidelines

- 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.
- 2.2 Support the person in maintaining and/or making desired changes in familiar relationships and social connections and networks.
- 2.3 Work to create dementia-inclusive local communities to build and maintain connectedness and relationships.
- 2.4 Utilise compassionate, tailored and timely supports to assist the person to live in their desired home.
- 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.
- 2.6 Develop and implement care plans to maintain a sense of place, home and community.
- 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.



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 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 Guidelines

- 3.1 Build awareness of the increased risk of dementia in people with Down syndrome.
- 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.
- 3.3 Ensure the person living with dementia is provided with timely and appropriate information.
- 3.4 Provide information and skills building for family carers.
- 3.5 Provide timely, tailored, appropriate and accessible information on dementia to peers.
- 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.
- 3.7 Build a collaborative learning culture, that includes the person, their family, health and social care professionals.



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.

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 Guidelines

- 4.1 Enhance and develop collaboration, cross-sectoral working and creative problem solving to support an enabling dementia care infrastructure.
- 4.2 Develop pathways of care that are clear and support integration.
- 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.
- 4.4 Ensure the person living with dementia is supported to engage in meaningful life pursuits that bring joy.
- 4.5 Build coping capacity and resilience amongst staff family and peers to help prevent and/or address compassion fatigue, burnout, unresolved grief and loss.



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 Guidelines

- 5.1 Allow adequate time for the person to process information, avoid outpacing and rushing care which risks overwhelming and distressing the person.
- 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.
- 5.3 Support the person to maintain a personal bathing and hygiene routine that respects and is grounded in personal preferences and lifelong habits.
- 5.4 Conduct regular health assessment and monitor, prevent and treat co-morbid health conditions.
- 5.5 Take an individualised and preventive approach to dental care.
- 5.6 Conduct regular nutritional assessment to ensure good nutrition, meal enjoyment and safety.
- 5.7 Ensure the non-cognitive symptoms of dementia (NCSD) are understood and responded to appropriately and in ways that minimise distress for the person.
- 5.8 Offer end-of-life care that responds to and meets a person's physical, social, spiritual and psychological needs.



A process guideline has been developed to accompany each standard statement to provide practical tips on evidence-based approaches that operationalise the standards contained within each of the five pillars. The full post-diagnostic support guidance, including the five pillars, accompanying standards and process guidelines, can be found in the following document: Post-Diagnostic Dementia Support Guidelines for People with an Intellectual Disability (McCarron et al., 2023) <https://doi.org/10.25546/106622>





Conclusion

There are existing national and international statements and recommendations on post-diagnostic dementia supports for people with an intellectual disability, albeit with an acknowledged need for further refinement and specification. Model of Care for Dementia in Ireland (Begley et al., 2023), which provided guidelines for the general population, was a beginning point for guidelines specifically for people with an intellectual disability and dementia. That said, the approach here was different and inclusive. Often consensus guidelines are developed by small groups of experts, reflecting professional perspectives only. Instead, this project began with a central desire to gather and include input from people with an intellectual disability themselves, and from their family and staff caregivers, on the kind of supports that they would like to have and/or consider necessary. It was hoped the project would benefit even further from experiences of what does and what does not work in post-diagnostic care, given that Ireland has providers that offer such care, and disciplines and universities developing such capacity. Including policy makers and system administrators helped gather a greater breadth of perspectives and offered opportunities to grapple with resources and other challenges to be balanced with what was valued. Finally, while being written for Ireland, the guidelines included international perspectives to influence solutions to this care dilemma in other countries. The guidelines began with building upon wishes and desires and known successful care, and then addressed gaps in available and proposed models for care; an innovative and inclusive approach to guidelines development.

Gathering qualitative and quantitative data from a variety of stakeholders across Ireland, accumulating that data, and applying mixed method analysis, anchored the guidelines in evidence. It also ensured that all voices were considered, with a purposeful inclusion of the voices, insights and desires of individuals with intellectual disabilities themselves. Using a collective intelligence workshop approach to translating data into useful and measurable guidelines ensured the thoughtful emergence of guidance.

There were limitations. The inclusion of policymakers, providers and professional groups always risks that existing assumptions and resource concerns may overly influence the outcomes. Here the methodology was designed to be wary for influence and to amplify other voices. Indeed, the collective intelligence workshops deliberately sought to question the emerging findings, not just to endorse them. Similarly, embedding the guideline development within Model of Care for Dementia in Ireland (Begley et al., 2023), which was focused on the general population, highlighted where care for persons with intellectual disabilities and dementia may and should be integrated within general dementia care. It also helped identify where greater prominence for the unique needs of people with intellectual disabilities should be considered. A potential limitation is that consideration of some innovations may have been more difficult or missed because of the tacit acceptance of a pragmatic context of overall dementia care. This was not evident in the deliberations: the range of voices, innovation testimonials by individual providers, and the voices of carers and of people with intellectual disabilities, all challenged current dementia care; while international experts brought in other ideas and perspectives. The emphasis on supporting ageing in place, and statements from many rejecting traditional institutional models, reinforced an emphasis on innovation throughout the guidance.

Implementation of the guidelines, ensuring there are needed resources and evaluating the care to be provided will present new challenges. The guidelines will be a roadmap for addressing these next steps.



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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.

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 well-being, 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 well-being 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.

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, or specialised dementia homes and day services. Pathways of care involve the coordination of various healthcare professionals, resources, and support systems to ensure the appropriate and comprehensive care of individuals with dementia.



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 well-being. 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.

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.



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.

List of abbreviations

CHO	Community Health Organisations
DPIA	Data Protection Impact Assessment
DSiDC	Dementia Services Information and Development Centre
GDPR	General Data Protection Regulation
HSE	Health Service Executive
HIQA	Health Information and Quality Authority
ID	Intellectual disability
NCS D	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





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