



Daughters of
Charity Service



Supporting Persons with Intellectual Disability and Dementia: Quality Dementia Care Standards

A Guide to Practise

McCarron, M & Reilly, E. 2010



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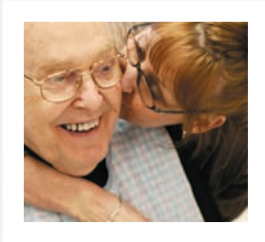
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BACKGROUND AND CONTEXT



A dramatic shift in the age profile of persons with Intellectual Disability in Ireland and elsewhere, from a younger to an older population, has reinforced awareness of new and emerging challenges. There is now general agreement that the level of Alzheimer's dementia (AD) in persons with Down syndrome (DS) exceeds that of the general population, occurring at a prevalence of 2% in persons aged 30–39 years, 9.4% in persons aged 40–49, 36.1% in persons aged 50–59, and 54.5% in persons aged 60–69 (Prasher, 1995).

Dementia is already a critical issue for the Daughters of Charity Service and, given the age profile of the population, it will continue to be an increasing concern in the years ahead. Of particular concern is the consequence of the numbers of people with Down syndrome over the age of 35 years (the age when their risk for dementia begins) who are currently served; in a prospective 12-year longitudinal follow-up of 80 persons with Down syndrome, 64 (83%) developed dementia, with a mean age of dementia diagnosis of 55.1 years (McCarron et al 2009).

These standards:

- have been developed to support and enhance high-quality person-centred care for persons throughout the continuum of dementia, and they identify the essential elements that need to be in place to ensure a consistent quality approach to persons with dementia.
- outline what a person with dementia and their family members and carers can expect from the Daughters of Charity Service in terms of support and quality of care, and encapsulate a positive vision for the delivery of support for persons with dementia.

This vision reflects the fact that the experience and outcomes for people living and dying with dementia is highly dependent on, and strongly influenced by, skilled and sensitive caregiving. The standards take into account that each individual with dementia is unique, and that their experience of dementia will be very individual – governed not only by their identified needs and life biography but also by their cultural values and religious and spiritual beliefs.



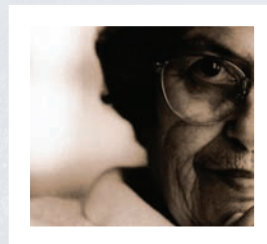
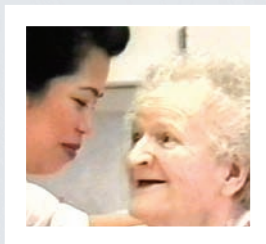
DEVELOPMENT OF THE STANDARDS

The standards reflect the central mission of the Daughters of Charity Service, and taken together they outline the key components necessary to support optimal living and end-of-life care for persons with dementia. They are based on best practice nationally & internationally for persons with dementia, and are strongly influenced by the *National Quality Standards: Residential Services for People with Disabilities* (HIQA, 2009); *Draft National Quality Standards for Residential Care Settings for Older People* (HIQA, 2007); *Draft Quality Standards for End-of-Life Care in Hospitals* (2009); *Professional Guidance for Nurses Working with Older People* (An Bord Altranais, 2009); *Dementia Quality Standard* (National Institute for Health and Clinical Excellence, 2009).

CONSULTATION WITH KEY STAKEHOLDERS

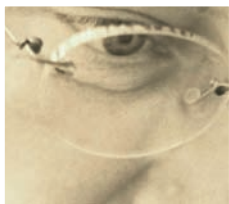
Building on the above guidance documents, development of these standards included a comprehensive consultation process which involved meetings with service users, families, and staff at all levels within the organisation. Comments and suggestions from service users have been incorporated and have helped inform this final version of the standards.

Families: Families were invited who had previous experience of supporting a family member with dementia within the organisation. Their experiences, expertise and reflections were gathered, and comments and suggestions received have informed this final version of the standards. In summary, families in general welcomed what they called '*excellent and important standards which were very complete*'. Families saw the need for continuity of staffing as critical: '*It ensures continuity for Anne's crucial and very delicate needs at this end stage of her life, and allowed a constant flow of communication between all staff caring for her...It eliminates gaps in care.*'



Service Users: Given the age demographics of clients in the Daughters of Charity Service, and the high incidence of dementia with increasing age, particularly in persons with Down syndrome, many service users will have experienced their friend or peer living through the continuum of dementia from diagnosis to death. A purposeful sample of 15 clients was invited to take part in a one-to-one interview. Pseudonyms have been used to protect confidentiality. For the majority of people interviewed, remaining in their own home or usual care setting was very important. 'I would like to stay here, this *is my home, everybody knows me*' (Mary). This was echoed by other service users: 'I will not live anywhere else but here with my friends' (Ann); 'I want to stay here with my friends, with the staff who know me well' (Patricia). In contrast, others had a desire to return to their original home and to their family members: 'Go home to Sligo to my family' (Pauline); 'Down at home with X and my family'.

A number of service users had also experienced their friend or peer being moved, often because it was no longer considered feasible to give care with safety or with comfort within the home. When asked if this were to happen what would be important to them, a number of useful insights emerged which helped to further inform the standards. 'I would like my own room, with my own pictures and photos' (Mary); 'I would like to take all my own clothes and my TV, and my friends to visit' (Pauline); 'bring all my own gear and all my friends to visit' (Geraldine); 'my friends to ring me' (Ann).



Service users were encouraged to talk about what they felt would be important for 'new staff' to know about them, and what might help this process. From service users' perspectives, life story books appeared to be familiar and important. *'I would like them to look at my life story books' (Ann); 'I will tell them and show them my books' (Pauline); 'I would show them my book of favourite things and they would know' (Veronica); 'I want them to know I like sweets, music and dancing' (Liz); 'It would be important to me that new staff learn how to talk to me . . . learn to know what I am saying.'*

Format:

The standards are grouped together under six main categories to reflect the dimensions and central underpinnings of holistic, person-centred dementia care. They are intended to be considered together and are highly dependent on each other. Standards consist of standard statements, and indicators and criteria for assessing evidence. The indicators and criteria for assessing evidence offer a guide for achieving quality dementia care outcomes, and should be seen as indicative rather than prescriptive.

This document and its companion documents for staff at the Daughters of Charity Service – namely, The Strategic Plan for Dementia and Memory Clinic Protocol – are only one element of the many things that need to happen to improve the lives of people with intellectual disability living with dementia and their caregivers.

Standard 1: Appropriately Trained Staff and Service Development

People with dementia receive care and support from staff who have the prerequisite knowledge and skills to perform their role effectively.



Standard 1: Appropriately Trained Staff and Service Development

Standard Principle: People with dementia receive care and support from staff who have the prerequisite knowledge and skills to perform their role effectively.

Criteria/Standard	Process	Sources of Evidence
1.1 Staff education: People with dementia receive care and support from staff appropriately trained in dementia care.	Training needs analysis undertaken within the service to identify training and education requirements of all staff members supporting persons with dementia.	<ul style="list-style-type: none"> Evidence of training needs analysis.
	A comprehensive, structured, in-service education programme developed.	<ul style="list-style-type: none"> Evidence of educational programme.
	Ongoing in-service education offered to all staff supporting persons with dementia; this training is consistent with their roles and responsibilities.	<ul style="list-style-type: none"> Record of calendar of educational opportunities. Records of attendance at various types of training, e.g. formal classroom, onsite, telephone. Individualised care plan demonstrates staff awareness and knowledge of contemporary practice in dementia care. Evidence that there is a key worker system in place and that the philosophy of care is compatible with person-centred care.
	Educational and reading materials are available in all areas supporting persons with dementia.	<ul style="list-style-type: none"> Evidence of education folders.

Appropriately Trained Staff and Service Development

Criteria/Standard	Process	Sources of Evidence
	The service promotes interdisciplinary teamwork, care discussion and review.	<ul style="list-style-type: none"> Record of the number of consensus and multidisciplinary team meetings.
	Information is available to staff in relation to upcoming dementia-related events, such as educational seminars and conferences.	<ul style="list-style-type: none"> Record of the number of staff who have attended dementia-related events.
	Post graduate education is encouraged and supported which is consistent with staff roles and responsibilities.	<ul style="list-style-type: none"> Record of the number of staff who have undertaken postgraduate education.
1.2 Peer education: Peers are offered education and training in dementia which is appropriately tailored to meet their specific needs and learning styles.	Ongoing in-service education is available to peers who are supporting their friend with dementia; this training is tailored to their learning styles and level of comprehension and understanding.	<ul style="list-style-type: none"> Appropriate educational resources and materials. Records of peer training.
1.3 Family education: Family members are offered information in relation to dementia care.	Seminars on ageing and dementia are offered to family members.	<ul style="list-style-type: none"> Record of family educational seminars. Record of family meetings.
	Family members are encouraged and supported to attend relevant interdisciplinary team meetings, and care discussion and review.	<ul style="list-style-type: none"> Record of interdisciplinary team meetings.



Standard 2: Memory Assessment Service



All people with intellectual disability have access to a memory assessment service specialising in baseline screening, dementia assessment and diagnosis in persons with intellectual disability.

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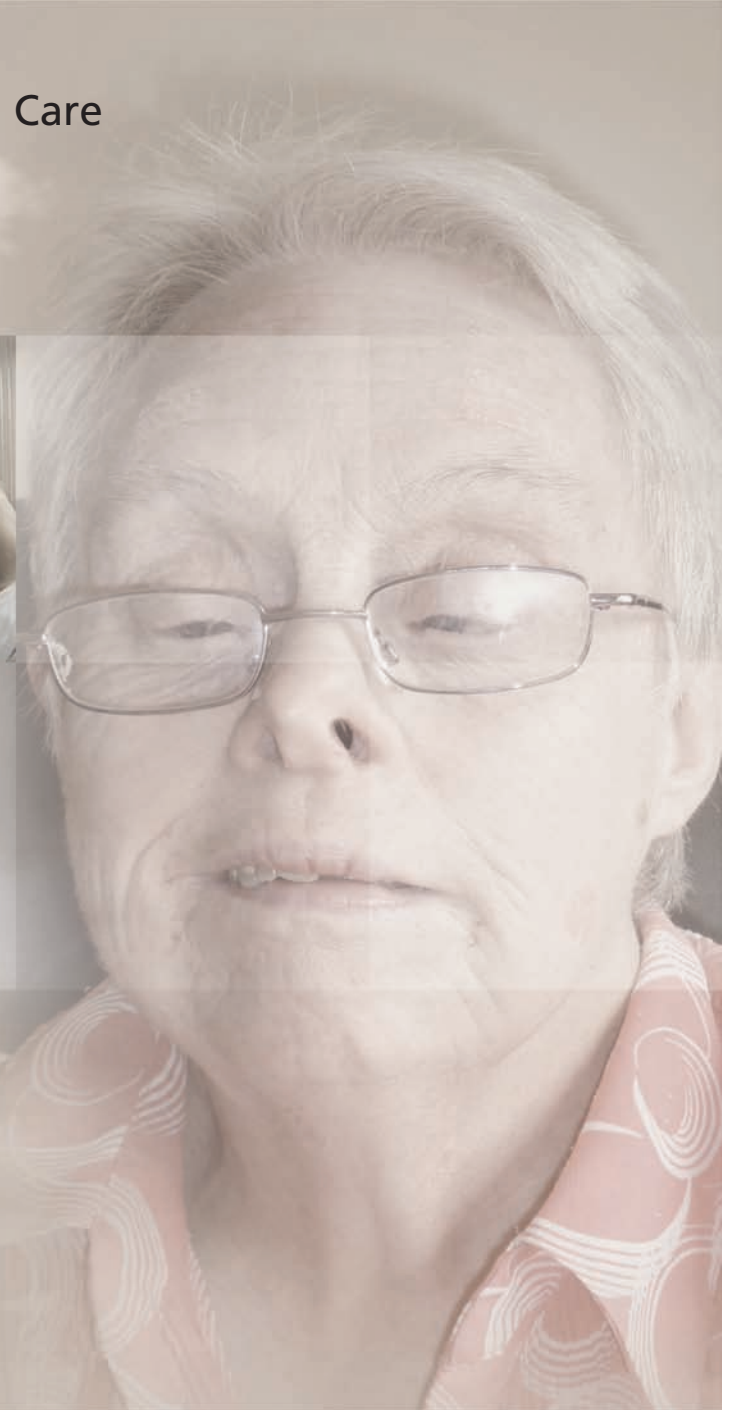
Criteria/Standard	Process	Sources of Evidence
2.1 Specialist memory clinic model: A systematic, services-wide approach to baseline screening, dementia identification, diagnosis and treatment, operationalised through a Specialist Memory Clinic Model.	Establishment and resourcing of memory clinic. Dedicated key staff with specialist knowledge in dementia diagnosis in persons with intellectual disability, to oversee and co-ordinate the day-to-day administration and activities of the memory clinic.	<ul style="list-style-type: none"> ■ Evidence of dedicated key staff with specialist knowledge in dementia diagnosis in persons with intellectual disability to oversee and co-ordinate the day-to-day administration and activities of the memory clinic. ■ Evidence of key multidisciplinary staff to support activities of the clinic.
	Development of a comprehensive screening and diagnostic protocol.	<ul style="list-style-type: none"> ■ Record of comprehensive memory clinic protocol.
	A clear referral pathway to memory clinic is developed.	<ul style="list-style-type: none"> ■ Evidence of clear documented structures regarding referral. ■ Record of number of people referred.
	All persons at age of risk of dementia are offered annual baseline screening and assessment.	<ul style="list-style-type: none"> ■ Record of the number of people screened and assessed for dementia on an annual basis.
	All persons referred to the memory clinic will be reviewed within one month.	<ul style="list-style-type: none"> ■ Record waiting times.
	Regular consensus meetings with staff, family, and members of the multidisciplinary team.	<ul style="list-style-type: none"> ■ Record of consensus meetings.

Memory Assessment Service

Criteria/Standard	Process	Sources of Evidence
<p>2.2 Comprehensive diagnostic work-up: All persons are offered a full range of services to aid diagnosis, including neuro-imaging and referral to mainstream generic dementia services if required.</p>	<p>All persons are offered full comprehensive diagnostic work-up, including neuro-imaging if it is considered that this procedure will not cause undue distress to the person. Procedures in place to refer for additional consultation to key experts in the generic dementia field if required.</p>	<ul style="list-style-type: none"> ■ Evidence of comprehensive diagnostic work up.
<p>2.3 Structured education programme in dementia recognition: All staff are offered a structured education programme to assist them to recognise changes and symptoms of dementia in persons with intellectual disability; this training is consistent with their roles and responsibilities.</p>	<p>Ongoing in-service education is available to all staff to assist them to recognise change and symptoms of dementia in persons with intellectual disability; this training is consistent with their roles and responsibilities.</p>	<ul style="list-style-type: none"> ■ Evidence of key experts to facilitate training. ■ Evidence of a calendar of educational opportunities. ■ Records of attendance of all staff. ■ Records of various types of training, e.g. formal classroom, onsite, telephone. ■ Evidence during the assessment process that staff demonstrate awareness of critical dementia type changes.



Standard 3: Health and Personal Care



Each person with dementia is encouraged and supported by staff to participate in their own personal care at whatever level they are capable of. The person's preferences, privacy, dignity, and well-being are key principles which underpin all care activities.

Standard 3: Health and Personal Care

Standard Principle: Each person with dementia is encouraged and supported by staff to participate in their own personal care at whatever level they are capable of. The person's preferences, privacy, dignity, and well-being are key principles which underpin all care activities. Optimum physical and mental health is promoted in partnership between the person, their carers, family and health care team.

Criteria/Standard	Process	Sources of Evidence
3.1 Care culture: Each person with dementia is encouraged and supported to participate in their own personal care to whatever level they are capable of.	Assessments of the person's strengths and needs in global day-to-day activities of living are carried out on a regular basis. Each person has a named key worker. Each individual is given adequate time and is not overwhelmed by either rushed care or demands which exceed their ability. During all personal care activities, each person's preferences, privacy and dignity are protected. Each person has a single room/private place in which most of their personal care takes place. When shared facilities exist, the person's privacy is protected using curtains or a screen.	<ul style="list-style-type: none"> ■ Individualised care plan demonstrates staff awareness and knowledge of contemporary practice in dementia care. ■ Protocols are in place to ensure that personalised care plans have a named key worker. ■ Record of Annual Assessment using Daily Living Skills Questionnaire (DLSQ). ■ Evidence of single rooms/private area, curtains, screens.
3.1.1 Dressing-Supportive choice: Each person is offered supportive choice in what to wear.	Each person is supported to choose their own clothing.	
	Personal dress style and preferences are acknowledged and supported; family and staff who know the person well are consulted if necessary.	<ul style="list-style-type: none"> ■ Life biography including knowledge of the person's personal tastes; preferences are evidenced in the person's individualised care plan.
3.1.2 Empowerment: Each person is empowered to dress to whatever level they are capable of, and supported in taking care of their personal clothing.	Dressing task is broken down and clothing is laid out to reflect the person's strengths and needs.	<ul style="list-style-type: none"> ■ Evidence in the individual person-centred care plan.

Health and Personal Care

Criteria/Standard	Process	Sources of Evidence
	The person is given adequate time and not overwhelmed by either rushed care or demands which exceed their ability.	<ul style="list-style-type: none"> ■ Evidence of person-centred vs. task-centred care. ■ Evidence of well-being versus ill-being.
	<p>Each person has their own personal wardrobe.</p> <p>Personal clothes are clearly labelled if appropriate and if the person wishes.</p> <p>The person's key worker has responsibility for ensuring that the person's clothes are not lost or unkempt.</p>	<ul style="list-style-type: none"> ■ Evidence of personal clothes which are well kept. ■ Record of named key worker.
3.2 Oral hygiene: The person's oral and dental condition are healthy.	<p>The person's ability to manage oral hygiene is assessed and recorded on an ongoing basis.</p> <p>Personalised tooth brushes, denture cartons and accessories are discreetly labelled and are accessible to the person.</p>	<ul style="list-style-type: none"> ■ Record of regular review. ■ Evidence of individualised care plan.
	<p>The key worker is responsible for ensuring that regular oral hygiene is maintained and the person is supported to carry out frequent oral hygiene and denture care.</p> <p>Regular schedule with reminding if necessary.</p> <p>Task is broken down into steps which reflect the person's strengths and needs.</p>	<ul style="list-style-type: none"> ■ The person's oral and dental condition is healthy. ■ Observation: The person is supported and encouraged to brush teeth and attend to oral care after each meal.
	The person is offered a yearly dental check-up, or more often if necessary.	<ul style="list-style-type: none"> ■ Record of dental appointment and annual review.

Health and Personal Care

Criteria/Standard	Process	Sources of Evidence
3.3 Diet and nutrition: A balanced nutritious diet is offered which reflects the person's food preferences.	A balanced daily menu is offered, and key members of the multidisciplinary team are available to assess for special dietary requirements.	<ul style="list-style-type: none"> Record of daily menu. Evidence of assessment by dietician.
	The care team is aware of each person's likes, dislikes, and food and drink preferences.	<ul style="list-style-type: none"> Evidence of the use of life story documentation and individualised Care Plan.
	The person is supported to maintain adequate food and fluid intake, and staff are knowledgeable and vigilant about nutritional needs and requirements.	<ul style="list-style-type: none"> Record of fluid and food intake if appropriate.
	Weight is monitored and the person is offered screening for indications of malnutrition on a monthly basis, or more regularly if indicated.	<ul style="list-style-type: none"> Record of nutritional screening and assessment by dietician using recognised screening tools, e.g. the 'Malnutrition Universal Screening Tool' (MUST). Evidence of weight recorded in individual care plan.
3.3.1 Supported choice: Each person is given supported choice of what they would like to eat or drink, and is encouraged to feed at whatever level they're capable of.	There is access to a snack-making area.	<ul style="list-style-type: none"> Evidence of dedicated snack-making area.
	A picture menu is offered daily to each person if appropriate.	<ul style="list-style-type: none"> Evidence of picture menus.

Health and Personal Care

Criteria/Standard	Process	Sources of Evidence
	<p>The person's ability to feed themselves is assessed on an ongoing basis.</p>	<ul style="list-style-type: none"> Record of annual assessment using DLSQ, or more often if indicated.
	<p>Personalised eating and drinking utensils are available as per assessed need.</p> <p>Expert swallow assessment is offered to persons with advanced dementia.</p>	<ul style="list-style-type: none"> Evidence of multidisciplinary team assessment by occupational therapist and/or speech and language therapist.
<p>3.4 Continence: Each person is supported and encouraged to use toilet facilities at whatever level they are capable of.</p>	<p>Ongoing assessment of continence and personal toileting routines established. Prompts and reminders are used to cue the person.</p> <p>Aids and appliances are used as indicated.</p> <p>Good visual access to toilet areas.</p> <p>Individualised continence programmes are designed as per assessed need.</p>	<ul style="list-style-type: none"> Evidence of a regular toileting routine. Record of person's continence programme. Evidence of hand rails and other aids and appliances. Evidence of signage and environmental cues.
<p>3.4.1 Bowel elimination: Each person is supported to maintain regular bowel elimination.</p>	<p>Record the person's normal bowel habits.</p> <p>Support normal bowel elimination and prevent constipation by establishing a regular routine, ensuring adequate fluids, fibre and exercise.</p>	<ul style="list-style-type: none"> Record bowel elimination if appropriate. Evidence of adequate diet. Record of activity menu and daily exercise programme if appropriate.

Health and Personal Care

Criteria/Standard	Process	Sources of Evidence
3.5 Bathing/showering: Each person is supported and encouraged to maintain their personal hygiene to whatever level they are capable of.	<p>Assess level of support required</p> <p>Record the person's preferences with respect to bathing or showering.</p> <p>Establish the person's preferred time for bathing/showering.</p> <p>Never force the person to have a bath or shower; if the person refuses, try again later.</p> <p>Use object of reference to orientate the person to the activity.</p> <p>If the person resists bathing or showering and becomes distressed, consider other means, such as bed bath.</p>	<ul style="list-style-type: none"> ■ Individualised care plan demonstrates staff awareness and knowledge of contemporary practice in dementia care. ■ Evidence of regular assessment and review.
	<p>Ensure the person is given adequate time and is not overwhelmed by either rushed care or demands which exceed their ability.</p>	
3.5.1 Dignity and privacy: There is respect at all times for the person's right to dignity and privacy.	<p>Ensure the person is never left exposed, and is draped with a towel when necessary.</p>	
	<p>Ensure there is minimal intrusion of personal space, and that staff members assisting with activities such as bathing are not disturbed except in extreme cases.</p>	
3.5.2 Personal safety: Ensure the safety of the person.	<p>There is a thermometer available to check water temperature, and temperature controls on taps if necessary or if the person is at risk.</p>	<ul style="list-style-type: none"> ■ Evidence of risk assessment and bath thermometer.

Health and Personal Care

Criteria/Standard	Process	Sources of Evidence
	The person is not left unsupervised in bathroom and level of supervision reflects both level of Intellectual Disability and stage of dementia.	<ul style="list-style-type: none"> Record of ongoing review and assessment.
3.6 Sleep: Each person is supported to achieve optimal sleep and rest.	Establish the person's usual bedtime and sleeping routine. Consult with family and/or staff who know the person well.	<ul style="list-style-type: none"> Evidence of individualised bedtime routine recorded in the person's care plan.
	<p>Establish a consistent bedtime routine that reflects the person's preferences and habits.</p> <p>Offer quiet activities if the person is unable to sleep.</p> <p>Record and review sleep pattern, and monitor to ensure that each person is achieving optimal sleep and rest.</p>	<ul style="list-style-type: none"> Record of individualised bedtime routine. Evidence of alternative quiet activities. Evidence that sleep pattern is recorded and reviewed regularly if appropriate.
	Avoid stimulants such as caffeine. Promote a calm environment. Keep noise levels to a minimum. Use subdued lighting.	<ul style="list-style-type: none"> Facilities for dim lighting are available. Evidence of a quiet environment with minimal disturbance.
	Night sedation is used as a last resort and only after all other approaches have been implemented.	<ul style="list-style-type: none"> Drug MPARS. Evidence in nursing documents and reports. Record of regular medication review in conjunction with documentation of behaviour and side effects.

Health and Personal Care

Criteria/Standard

3.7 **Medication management:** That each person's medication is managed safely and correctly.

Process

The prescription of psychotropic medication is only made following appropriate health and risk assessment, and when alternative management strategies have not been effective and there is continued evidence that the person is distressed. Medication is regularly reviewed and assessed in conjunction with observational documentation of behaviours and side effects. Clear protocols are available in relation to the use of PRN medications.

Sources of Evidence

- Record of regular medication review.
- Record of comprehensive assessment to establish generating or aggravating factors contributing to distress or behaviours that challenge.
- Record of alternative non-pharmacological management strategies.
- Record of protocol on the use of PRN medication.

Standard 4: Communication and Behaviour



*The personhood
and well-being of the
person is maintained
through effective
communication
approaches.*

Standard 4: Communication and Behaviour

Standard principle: The personhood and well-being of the person is maintained through effective communication approaches. People with dementia who develop non-cognitive symptoms that cause them distress or behaviours that challenge are offered an assessment at an early opportunity to establish generating and aggravating factors.

Criteria/Standard	Process	Sources of Evidence
4.1 Effective communication strategies and dementia: Effective and person-centred communication is an explicit component of the philosophy of care.	All staff receive education on person-centred communication and dementia.	<ul style="list-style-type: none"> Record of staff education and training.
	The person's usual means of communication, indicating signs of well-being and/or ill-being are clearly documented in the individual's person-centred plan.	<ul style="list-style-type: none"> The person's care plan identifies usual means of communication.
4.1.1 Communication challenges: The common communication challenges experienced by the person with dementia are understood and acknowledged by staff and family/peers.	All staff receive education in the common communication challenges experienced by the person across the continuum of dementia.	<ul style="list-style-type: none"> Details of training programmes, including content, on common communication problems such as aphasia, dysphasia, paraphasia, and echolalia. Record of attendance.
	Staff are not only encouraged to reflect on what the person with dementia is attempting to communicate, both verbally and non verbally, but also to reflect on what they themselves are expressing through their words and non-verbal cues such as posture and body language.	<ul style="list-style-type: none"> Record staff education and training. Observation. The person appears happy and not distressed.

Communication and Behaviour

Criteria/Standard	Process	Sources of Evidence
4.1.2 Enabling communication strategies: Staff use enabling communication strategies.	<p>No unwanted stimuli or noise.</p> <p>Short, understandable words.</p> <p>Right position physically – make eye contact.</p> <p>Uses gestures to help the person understand.</p> <p>Staff point, demonstrate and use objects of reference to help the person get the meaning.</p> <p>Staff slow down, allow time for message to “sink in”. Take time – even when in a hurry!</p> <p>AVOID “You are wrong” messages.</p>	<ul style="list-style-type: none"> ■ Observation. ■ Record of staff training and education.
4.1.3 Creative arts: Creative arts are used to support the person to express feelings, experiences and needs, and to maintain relationships and develop new ones.	<p>Life history knowledge is used to provide opportunities for communication.</p> <p>Occupational, recreational, arts and sensory stimulation activities are used with the person to facilitate self-expression.</p>	<ul style="list-style-type: none"> ■ Person-centred care plan. ■ Life story books. ■ Record of completed activity and recreational programmes such as sing-songs, reminiscence, art, etc. ■ Record of completed sensory activity programmes such as Sonas.
	The staff uses age-appropriate communication aids, e.g. flash cards, signage, photographs, picture boards, object of reference, etc.	<ul style="list-style-type: none"> ■ Record of communication aids and evidence of materials. ■ Observation.
	The staff use approaches such as reality orientation and validation therapy to facilitate communication	<ul style="list-style-type: none"> ■ Record of education for staff in communication strategies, including reality orientation and validation approaches. ■ Individualised care plans identify alternative communication strategies.

Communication and Behaviour

Criteria/Standard	Process	Sources of Evidence
<p>4.2 Non-cognitive symptoms and behaviours that challenge: People with dementia who develop non-cognitive symptoms that cause them significant distress, or who develop behaviours that challenge, are offered assessment at the earliest opportunity to establish generating or aggravating factors.</p>	<p>People who develop non-cognitive symptoms that cause them distress, or who develop behaviors that challenge, are offered an assessment.</p> <p>Interventions to reduce distress and improve behaviors are individually developed and reviewed regularly. A multidisciplinary team is available to support this process.</p>	<ul style="list-style-type: none"> ■ Evidence of assessment. ■ Evidence that individually tailored care plans, that help carers and staff address the behavior that challenges, are recorded in the notes and reviewed regularly.
	<p>The staff use the person's life story to help understand their behaviour and to identify possible ways of meeting their needs.</p>	<ul style="list-style-type: none"> ■ Evidence of life story documentation.
	<p>The person is assessed for possible pain and treated accordingly.</p>	<ul style="list-style-type: none"> ■ Record of pain assessment.
<p>4.3 Ageing in place: Every effort is made to support the person to remain in the home of their choice, in their community with their family and friends.</p>	<p>Additional supports in terms of staffing and environmental modifications are provided if possible and within the context of available resources. Clinical support is offered to persons with dementia and their caregivers in the home setting.</p> <p>Education is offered to all caregivers to support them in this role.</p> <p>The comfort and safety of the person with dementia is paramount and requires careful monitoring and vigilance. If the environment outstrips its capacity to give care with comfort or safety, procedures are in place to source more appropriate accommodation.</p>	<ul style="list-style-type: none"> ■ Evidence of an ageing-in-place philosophy. ■ Record of transfers and duration and stage of dementia. ■ Record of staffing and environmental changes. ■ Evidence of clinical support. ■ Record of education.

Communication and Behaviour

Criteria/Standard	Process	Sources of Evidence
4.4 Transitioning: The period of transition from one part of the service/care setting to another is acknowledged to be a difficult time for the person with dementia, their carers/staff, family and peers.	The person with dementia, their family/peers and staff are prepared in advance for the transition.	<ul style="list-style-type: none"> Record of pre-admission assessment and meetings.
	<p>The preferences of the person with dementia are acknowledged, and every effort is made to match care setting with the person's wishes, needs and life biography.</p> <p>Site visit to new home/setting is offered and facilitated.</p> <p>The person is supported in bringing valued personal items, such as items of furniture, bed linen, TV, etc. to new care setting.</p>	<ul style="list-style-type: none"> Evidence of multidisciplinary team meetings. Site brochure is available. Procedures are in place to support site visits. Evidence of personal items.
4.4.1 Settling in: Procedures are in place to support the introduction of the person with dementia to their new home/setting, with a process in place to support people when relationships change.	<p>Short visits to new home/setting are offered and facilitated.</p> <p>The staff has an awareness and knowledge of the role of the family/peers and friends in the person's life, and facilitates their involvement.</p>	<ul style="list-style-type: none"> Evidence of site visits. Life story book Opening visiting. Evidence of events such as parties, family days, community outings, etc.
	The person is encouraged and supported to maintain valued relationships with family, peers and community through organised events, telephone calls, letters, cards, outings to places of significance.	<ul style="list-style-type: none"> Evidence of maintenance of relationships, for example number of visits, telephone calls, outings, etc.



Standard 5:
Promoting Well-Being and
Social Connectedness



*Each person with dementia is
supported to maintain
relationships with those who
are important to them in
their family, home/service,
and local community*

Standard 5: Promoting Well-Being and Social Connectedness

Standard principle: Each person with dementia is supported to maintain relationships with those who are important to them in their family, home/service, and local community.

Criteria/Standard	Process	Sources of Evidence
5.1 Maintaining relationships: Each person with dementia is supported to maintain relationships with family, friends and peers.	Family members, friends and peers are encouraged to visit and participate in the person's life.	<ul style="list-style-type: none"> ■ Person-centred plan. ■ Life story book. ■ Evidence of visits.
	There is a quiet and private space for family members and friends.	<ul style="list-style-type: none"> ■ Private areas.
	Relatives and significant others are encouraged and supported to take their family member out on trips or to previous home. Decisions guided by the person's health status and wishes.	<ul style="list-style-type: none"> ■ Transport and support staff available. ■ Evidence of trips and outings.
5.1.1 Support previous established relationships: Efforts are used to maintain and support previous established relationships.	If the person with dementia has lived most of their adult life in another setting, such as a community home, staff and peers are encouraged to visit and keep in contact by phone, letter, visits, etc. and to remember key events such as birthdays.	<ul style="list-style-type: none"> ■ Person-centred plan. ■ Key worker is responsible for supporting the person with dementia to maintain relationships.
	Social events and valued life activities are organised which help people come together, for example parties, family events, sports, music, etc.	<ul style="list-style-type: none"> ■ Menu of valued life activities. ■ Programme of events distributed to family and friends. ■ Space and dedicated staff to support this programme.

Promoting Well-Being and Social Connectedness

Criteria/Standard	Process	Sources of Evidence
5.1.2 Preferences and lifelong interests: Activities reflect the person's choices, preferences and lifelong interests.	The person with dementia, their relatives and important others are consulted to help identify meaningful valued life experiences, including close relationships, interests and hobbies.	<ul style="list-style-type: none"> ■ Life story book. ■ Photographs and memorabilia. ■ Music preferences etc.
5.1.3 Activities across the continuum of dementia: Activities are reviewed and adapted across the continuum of dementia and reflect the person's strengths and needs.	Staff and key workers recognise that sensory, cognitive and functional capabilities vary according to the stage of the dementia; care approaches and interventions reflect this.	<ul style="list-style-type: none"> ■ Person-centred plan. ■ Opportunities to highlight strengths and likes.
	All staff and family respect the person's right to personal space and time alone if they wish.	<ul style="list-style-type: none"> ■ Personal space such as individual bedroom, sitting room etc.



Standard 6: Supporting Persons with Advanced Dementia: Addressing Palliative and End-of-Life Care Needs



Each person with dementia receives care that is appropriate to his/her needs and wishes and every effort is made to optimise the person's quality of life by providing the best possible palliative and end-of-life care.

Standard 6: Supporting Persons with Advanced Dementia: Addressing Palliative and End-of-Life Care Needs

Standard principle:: Each person with dementia receives care that is appropriate to his /her needs and wishes and every effort is made to optimise the person’s quality of life by providing the best possible palliative and end-of-life care. The person with dementia their peers, family and staff are viewed as a single unit of care with appropriate supports to address their collective needs.

Criteria/Standard	Process	Sources of Evidence
6.1 A palliative care approach: A palliative care approach guides and underpins care for persons with advanced and terminal dementia.	<p>All staff and family are educated in the philosophy and principles of delivering a palliative care approach to the person.</p> <p>Staff education should be relevant to their particular role within the MDT, and should provide them with the skills required for communicating with persons with dementia, peers, colleagues and families, in what can often be challenging circumstances.</p>	<ul style="list-style-type: none"> Evidence of education of family, peers and staff, including appropriate postgraduate education.
	<p>Families, staff and advocates are involved in the development of end-of-life care planning.</p>	<ul style="list-style-type: none"> Evidence of family, advocate and staff involvement through regular meetings. Evidence of written and agreed care plan for end-of life preferences.
	<p>End-of-life care plans are known and operationalised. Efforts are made to clarify issues related to the person’s end-of-life wishes and agreed plan, in order to avoid any misunderstandings by staff or family.</p>	

Supporting Persons with Advanced Dementia: Addressing Palliative and End-of-Life Care Needs

Criteria/Standard	Process	Sources of Evidence
<p>6.2 Liaison with specialist palliative services: Liaison with specialist palliative services for expert support, guidance, advice, input on complicated symptom management, end-of-life decision-making, or loss and grief support.</p>	<p>Staff are encouraged to seek advice and reassurance, when necessary, from specialist palliative care services regarding end-of-life symptom management.</p>	<ul style="list-style-type: none"> ■ Formal agreement and memorandum of understanding with St. Francis Hospice, Raheny.
<p>6.2.1 Advanced care planning and shared decision-making: End-of-life plans are responsive to the person's needs, values and expressed preferences, and take into account spiritual and religious beliefs and cultural needs.</p>	<p>Every effort should be made to enhance the person's ability to participate in decisions affecting their care.</p> <p>Where the person is not able to make decisions about care and treatment due to pre-morbid disability and dementia, there is an appointed person – i.e. advocate, key worker or family member – responsible for their care.</p> <p>Every effort should be made to determine their values, beliefs and wishes, and to include them when possible to guide in decision-making, particularly in relation to the end of life.</p>	<ul style="list-style-type: none"> ■ Person-centred plan. ■ Accessible information on dementia. ■ Named key worker. ■ Agreed plan for end-of-life care. ■ Regular meetings to review care based on changing needs. ■ Independent advocate where necessary.
<p>6.2.2 Decision-making on issues concerning end-of-life care: The person's family and staff who are significant to the person have opportunities to discuss and participate in decision-making on issues concerning end-of-life care.</p>	<p>Family members and staff receive information about palliative care options, approaches to decision-making and symptom management, such as pain, nutrition and hydration, terminal agitation, infections, secretions, constipation and any other symptoms associated with terminal disease and its management.</p>	<ul style="list-style-type: none"> ■ Evidence of family meetings. ■ Palliative care intervention guidelines. ■ Ongoing and regular review in the context of disease severity. ■ Good clinical support in terms of MDT input. ■ Specialist palliative care expertise is available if required.

Supporting Persons with Advanced Dementia: Addressing Palliative and End-of-Life Care Needs

Criteria/Standard	Process	Sources of Evidence
<p>6.3 Pain and symptom management: The person is comfortable and free from pain.</p>	<p>Key staff receive education on pain assessment and management. The person is assessed regularly for any indications of pain or discomfort.</p> <p>Key worker and care team are aware of longstanding conditions that predispose the person to pain e.g. arthritis, gastric reflux, constipation.</p>	<ul style="list-style-type: none"> ■ Staff education. ■ Pain assessment tool. ■ Specialist palliative care expertise is available to advise on pain management if required.
<p>6.4 Palliative sedation: Palliative sedation therapy (PST) should be used as an option of last resort when other treatments to relieve suffering and distress in the person who is imminently dying have failed.</p>	<p>Palliative sedation therapy (PST) is used to relief intolerable suffering. Multi-dimensional assessment to determine symptom refractoriness and suffering should be carried out by experienced professional caregivers.</p> <p>The complete PST process should be carefully monitored and documented, including, aim, type and doses of drugs; depth and duration of sedation; and relief of distress achieved.</p> <p>Additional support and consultation with specialist palliative care should be available.</p> <p>The effects of PST on the person's comfort should be assessed daily.</p> <p>Attention should be paid to distress and sedation levels, as well as the needs of family and staff caregivers.</p>	<ul style="list-style-type: none"> ■ Evidence of linkage with specialist palliative care. ■ Clear records of assessment, monitoring and treatment outcomes. ■ Evidence of appropriately trained and skilled professional care-givers.
<p>6.5 Psychological, emotional and spiritual care: The psychological, emotional and spiritual needs of the person with advanced dementia are respected.</p>	<p>Support and the presence of significant staff members is planned so that the person with dementia is supported through death and does not die alone.</p>	<ul style="list-style-type: none"> ■ Someone present with the person at all times.

Criteria/Standard	Process	Sources of Evidence
	Efforts are made to ensure that significant others are present during the person's dying and at their death.	<ul style="list-style-type: none"> ■ Private space available. ■ Regular contact with family & friends. ■ Peers are supported to spend time with the person.
	The person is in a comfortable environment where it is possible to give care with dignity and comfort at the end of life.	<ul style="list-style-type: none"> ■ The environment is suitably equipped for staff to deliver end-of-life care. ■ Appropriate skilled staff.
	The person's spiritual and religious beliefs are supported and respected.	<ul style="list-style-type: none"> ■ Person-centred plan documentation. ■ Support of key worker. ■ Pastoral care or Chaplaincy service.
6.5.1 Place of care: The person's preferred place of care should be established and every effort made to accommodate this where possible. This preference should be revisited to ensure that it meets the needs of the person with respect to comfort & safety.	<p>The person's preferred place of care should be established, and every effort made to accommodate this where possible.</p> <p>If this is not possible, an alternative care setting should be identified and discussed with the person themselves if appropriate, with their family, staff and peers.</p>	<ul style="list-style-type: none"> ■ Person-centred plan. ■ Needs assessment and MDT meeting prior to any decision to transfer. ■ Information on care options in brochures or site visit.
6.6 Pastoral care, and loss and grief support: The person is given bereavement support in accordance with their understanding of their decline in health and well-being. Bereavement support for family, peers and staff.	<p>Opportunities are given to the person to express grief reactions as they decline and in their final days. Family and staff are facilitated in grieving.</p> <p>When the person dies, opportunities are provided for peers, family and staff to express grief and develop and participate in funeral rituals.</p>	<ul style="list-style-type: none"> ■ Pastoral care, and loss & grief support. ■ Opportunities to pay last respects. ■ Participation in funeral rituals.

Criteria/Standard	Process	Sources of Evidence
	<p>Dignity, respect and bereavement support continues to be provided to the family, staff and peers after the death of the person.</p> <p>Formal opportunities are given to staff for debriefing and evaluation of the end-of-life care given to the person</p>	<ul style="list-style-type: none">■ Remembrance events, anniversaries, family days.■ Bereavement companionship is provided for peers through a structured programme, for example 'Seasons of Growth'.■ Bereavement counselling is available to staff and peers if required.■ Pastoral care or Chaplaincy service. Debriefing meeting.

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