



**Health
Information
and Quality
Authority**

An tÚdarás Um Fhaisnéis
agus Cáilíocht Sláinte

Guidance on Dementia Care for Designated Centres for Older People

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About the Health Information and Quality Authority

The Health Information and Quality Authority (HIQA) is the independent Authority established to drive high quality and safe care for people using our health and social care services. HIQA's role is to promote sustainable improvements, safeguard people using health and social care services, support informed decisions on how services are delivered, and promote person-centred care for the benefit of the public.

The Authority's mandate to date extends across the quality and safety of the public, private (within its social care function) and voluntary sectors. Reporting to the Minister for Health and the Minister for Children and Youth Affairs, the Health Information and Quality Authority has statutory responsibility for:

- **Setting Standards for Health and Social Services** – Developing person-centred standards, based on evidence and best international practice, for those health and social care services in Ireland that by law are required to be regulated by the Authority.
- **Supporting Improvement** – Supporting health and social care services to implement standards by providing education in quality improvement tools and methodologies.
- **Social Services Inspectorate** – Registering and inspecting residential centres for dependent people and inspecting children detention schools, foster care services and child protection services.
- **Monitoring Healthcare Quality and Safety** – Monitoring the quality and safety of health and personal social care services and investigating as necessary serious concerns about the health and welfare of people who use these services.
- **Health Technology Assessment** – Ensuring the best outcome for people who use our health services and best use of resources by evaluating the clinical and cost effectiveness of drugs, equipment, diagnostic techniques and health promotion activities.
- **Health Information** – Advising on the efficient and secure collection and sharing of health information, evaluating information resources and publishing information about the delivery and performance of Ireland's health and social care services.

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| Subject: | Care of people with dementia in residential services for older people | | |
| Audience: | Providers of services for older people in designated centres | | |
| Standards and regulations relevant to this guide include: | | | |
| Standard | No. | Regulation | No. |
| National Standards for Residential Care Settings for Older People in Ireland Revised December, 2015 | All Standards | Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People) Regulations 2013 | 5, 6 7, 8, 9, 10, 11, 15, 16, 17. |

1. Introduction

The framework for the regulation of residential services for older people consists of the Health Act 2007 as amended, the Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People) (Amendment) Regulations 2016 and the National Standards for Residential Care Settings for Older People in Ireland Revised (2016). This guidance for dementia care in residential centres for older people has been developed to guide service providers in the provision of high quality, safe and effective care for residents with dementia.

The number of people with dementia in Ireland is estimated at just over 40,000¹, with numbers expected to treble over the next 30 years as population ageing continues. The prevalence of dementia increases almost exponentially with age, nearly doubling every 5 years from the age of 65 years onwards. Early onset dementia in those under 65 accounts for 8.6% of all people with dementia and the majority are young men. There are approximately 700 people in Ireland with Down's Syndrome and dementia. The majority of people with dementia live in the community with 4.6% living in residential care (Cahill et al, 2012).

The guide explains concepts and signposts some of the available resources that may help service providers to meet regulations and implement standards. It will help you to identify the regulations, standards and good practice relevant to your service. Please note other requirements relevant to a particular service may not be addressed here. This document is current at the time of printing. Please check www.hiqa.ie for the latest version or for more information on your requirements as a provider of residential services.

1.1 What is dementia?

Dementia is a collective term used to describe the problems that people with various underlying brain disorders or damage can have with their memory, judgement, reasoning, problem-solving skills, language, thinking, communication and social

¹ Taken from a research review for Ireland's Dementia Strategy, Cahill et al (2012)

skills. Alzheimer's disease is the best known and most common disorder under the umbrella of dementia. Other types of dementia include; vascular, Lewy body, fronto-temporal, Korsakoff's Syndrome and Creutzfeld-Jacob dementia. The different types of dementia are described in Appendix 1.

1.2 Why is dementia care important?

As our population ages, it is expected that the numbers of people with dementia will increase including those who live in residential services. People with dementia should be able to experience joy, comfort, meaning and growth in their lives.

The quality of life of older people living in residential care depends on the quality of the relationships they have with care staff and ancillary staff working in the service. Optimal care occurs within a social environment that supports the development of healthy relationships between staff, family and residents.

Good dementia care involves an assessment of a resident's strengths and abilities, care planning and provision, strategies for addressing behavioural and psychological symptoms and signs of dementia, communication changes and an appropriate staffing skill mix.

Each person with dementia is unique and has a different range of abilities and need for support, which change over time as the disease progresses. Residential care staff can determine how best to serve each resident by knowing as much as possible about each resident's life story, preferences and abilities. Good dementia care involves using this information to develop "person-centred" care, which is designed to ensure that services are tailored to each individual's circumstances.

1.3 Aims of effective dementia care

The aims of effective dementia care are to:

- ensure that staff provide person-centred dementia care based on a thorough knowledge of residents, their abilities and their needs
- help staff and available family provide best care to residents by working with them to achieve optimal functioning and a high quality of life
- have staff use a flexible approach to care which aims to prevent problems before they occur by adapting care strategies to meet the changing conditions of people with dementia.

2. Health and social care needs

Each person with dementia is unique, having a different set of abilities and requirements for support which can change over time as the disease progresses. Care planning involves using information about the resident to develop a person-centred care plan that is designed to ensure that services are tailored to each residents' circumstances, including strategies for communication and addressing any behavioural and psychological signs and symptoms.

3.1 Assessment

A holistic assessment of the resident's abilities and background is necessary to provide care and assistance that is tailored to the resident's needs. A holistic assessment includes understanding a resident's:

- cognitive health
- physical health
- physical functioning
- behavioural and psychological symptoms and signs of dementia
- medication needs
- sensory capabilities
- decision-making capacity
- communication abilities
- personal background
- cultural preferences
- spiritual needs and preferences
- intimacy and sexuality needs
- emotional and social needs.

Assessments acknowledge that the resident's functioning may vary at different periods during the day. Thorough assessment includes obtaining verbal information directly from residents and from family and advocates when possible. Family members and advocates can help to develop a 'life story' of the resident, offering

information about a resident's life experiences, preferred daily routines and general personal preferences. Staff can also learn about the resident by observing the resident's reaction to various approaches to care.

If assessment identifies the need for consultation or assessment by medical professionals (geriatrician, psycho-geriatrician), health and social care professionals or other professionals, a timely referral should be made and followed up. Obtaining the most current information about any advance care planning or wishes², enduring power of attorney, wardship, as well as information about a resident's preferences regarding future healthcare events and end of life care helps to ensure that the resident's wishes are honoured.

3.2 Care planning

Personalised care for people with dementia involves placing the resident at the centre of the care process and adapting any supports to their individual needs. A person-centred approach to care can also help to avoid unnecessary hospital admissions and has been found to reduce agitation in people with dementia living in residential care.

Care plans are based on assessment of the resident's life history, social and family circumstance and preferences, as well as their physical and mental health needs and current level of functioning and abilities. The care plan should be endorsed by the resident and or their key family member or advocate, as appropriate.

Staff should promote and maintain the independence, including mobility of residents with dementia. It is important for care plans to address activities of daily living (ADLs) that maximise independent activity, enhance function, adapt and develop skills and minimise the need for support. When writing care plans, the individual needs for residents with different types of dementia should be addressed. Effective care planning includes a resident and their family or advocate when appropriate, and

² Note while residents have the capacity for decision making they have a right to review and revise any advance care plans or wishes.

the multidisciplinary team, which includes nurses and care staff who regularly interact with the resident.

Care plans are formally reviewed in line with the changing needs of the resident with dementia and any timelines set out in relevant legislation. Care plans are up-to-date and flexible enough to adapt to daily changes in a resident's needs and wishes. When all staff involved in a resident's care are familiar with the care plan, they are better equipped to provide appropriate, consistent care to the resident.

Care plans:

- are discussed and developed with the resident, and their family or advocate where appropriate, and the multidisciplinary team
- assist the resident to maintain their sense of identity and includes them in decision-making whenever possible builds on the residents abilities and includes strategies, such as physiotherapy or occupational therapy, to help the resident to complete their daily routines and maintain their functional abilities for as long as possible
- include consistency in staffing rotations to ensure continuity of care
- include a process for review of medications which is in line with any legislative requirements and takes account of the individual assessed needs of the resident
- include support for people, to go at their own pace and participate in activities they enjoy. Care is planned on the basis of improving the resident's functioning, building on strengths and lifestyle preferences but also being mindful of risks and discussing realistic safe care options with residents
- include flexibility to accommodate fluctuating abilities
- include assessment and care planning advice for independent toileting skills; if incontinence occurs all possible causes should be assessed and relevant treatments tried before concluding that it is permanent
- includes assessment and review for all medications

- takes into account the layout and design of the environment to aid the resident with independent functioning. Environmental modifications and assistive technologies may facilitate this with the advice from an occupational therapist. This may include physical exercise, with assessment and advice from a physiotherapist when necessary.

Aspects of care which are particularly relevant to people with dementia include:

- communication and decision-making
- food and fluid consumption
- medication management
- acute changes in behaviour and or mental state
- pain
- falls
- behavioural and psychological signs and symptoms of dementia
- palliative care philosophy and approach to end of life
- social engagement.

Some residents with dementia, who have difficulty communicating, may try to communicate through different behavioural or emotional actions. Observation of residents for signs of agitation or mood changes may indicate a desire to communicate or an underlying problem that the resident cannot verbalise. Care planning should include strategies for sensory impairment and language barrier's where necessary.

Resources about health and social care needs:

1. Alzheimer Society of Canada. *Guidelines for Care: Person-centred care of people of people with dementia living in care homes*. Framework. Ontario: Alzheimer Society of Canada; 2011.
2. Cahill, S, O'Shea, E and Pierce, M. [Future Dementia Care in Ireland – Sharing the Evidence to Mobilise Action](#). Dublin: Dementia Services Information and Development Centre; 2011.
3. Cahill, S, Diaz-Ponce A, Coen, R, & Walsh, C., *The Under detection of Cognitive Impairment in Nursing Homes in the Dublin area: The Need for on-going Cognitive Assessment*. *Age and Ageing*, 39, 1, 2010, 128 – 130.
4. Department of Health. *Strengthening assessment and care planning – Dementia practice guidelines for HACC assessment services*. Victoria: Department of Health; 2012.
5. Health Information and Quality Authority. [Guidance on Intimate Care](#). Dublin: Health Information and Quality Authority; 2013.
6. Health Information and Quality Authority. [Guidance for designated centres. Intimacy and Sexual Relationships](#). Dublin: Health Information and Quality Authority; 2013.
7. Irish Hospice Foundation. [A Guide to Symptom Control at End of Life in Advanced Dementia](#). Dublin: Irish Hospice Foundation; 2014.
8. Irish Hospice Foundation. [Planning for the Future Project. Initiating 'End of Life' Discussions for People with Dementia](#). Dublin: Irish Hospice Foundation; 2013.
9. Irish Hospice Foundation. [Supporting Families at End of Life](#). Dublin: Irish Hospice Foundation; 2013.
10. Irving, K and McGarrigle, L. *Expert Policy Paper Series 2012 - Integrated Care Pathways for People with Dementia - Exploring the Potential for Ireland and the forthcoming National Dementia Strategy*. Dublin: Dublin City University and the Alzheimer Society of Ireland; 2012.
11. National Institute for Health and Clinical Excellence. *Dementia – Supporting people with dementia and their carers in health and social care* (NICE clinical guideline 42): London: National Institute for Health and Clinical Excellence; 2006.

12. National Institute of Clinical Excellence. *Quality standard for supporting people to live well with dementia (NICE Quality Standard 30)*. London: NICE; 2013.
13. [Rowland Universal Dementia Assessment Scale](#) (RUDAS).
14. The Alzheimer's Association. *Dementia Care Practice – Recommendations for Assisted Living Residences and Nursing Homes*. Chicago: The Alzheimer's Association: 2009.
15. The International Longevity Centre – UK (ILC - UK). The last taboo. [A guide to dementia, sexuality, intimacy and sexual behaviour in care homes](#). London: The International Longevity Centre – UK (ILC - UK); 2011.
16. Food for the brain – [Cognitive function test](#)
17. The IPA Complete Guides to Behavioural and Psychological Symptoms of Dementia (BPSD) – Specialists Guide is a comprehensive compilation of eight modules detailing the presentation and causes of BPSD, constructive guidance on pharmacological and non-pharmacological treatment interventions, and information on caregiver education and support.
This guide is especially instructive for geriatric mental healthcare specialists: physicians, nurses, psychologists, occupational therapists, social workers and others. There are eight modules; an introduction to BPSD, clinical issues, etiology, role of family caregivers, non-pharmacological treatments, pharmacological management, cross-cultural and transnational considerations and long-term care. Each module includes an in-depth discussion and analysis of its subject area and concludes with a reference and recommended reading list. Find out more [here](#). (Note: Membership of the IPA is required to access these documents, however, non members of the IPA can purchase these documents via the IPA website).

Please note: This list is not exhaustive. It is not intended as anything other than a useful aide memoir for providers and more up to date information may have superseded this.

3. Residents rights, dignity and consultation

The current strategic approach to positive and active aging and healthy living for older people is set out by the National Positive Aging Strategy (2013), the Healthy Ireland Strategy (2013) and the Irish National Dementia Strategy (2014).

The national disability policy and legislation may also be relevant for certain groups of older people. The National Positive Aging Strategy is underpinned by the UN Principles for Older Persons. The UN Principles for Older Persons are independence, care, self-fulfilment and dignity. Although the UN Principles serve as a useful guide when developing national policy, there are no binding obligations on states to implement them.

Aside from the equality legislation and the Health Act 2007 and Regulations, there is no explicit mention of the specific rights of older people in Irish legislation. There are, however, two pieces of legislation, one relatively recent (the Nursing Homes Support Scheme Act 2009 and subsequent Regulations) and the Assisted Decision Making (Capacity) Act 2015, which deal with issues impacting directly on many, though not all, older people.

Older people with dementia have an inherent dignity, value and personhood which remains with them throughout the whole course of the disease and should be respected at all times. It is important that staff caring for people with dementia see the person and not the condition and residents are listened to and their perspectives and choices are honoured.

The values, beliefs, cultural and spiritual backgrounds of people with dementia and their families should be incorporated into the planning and delivery of care. It is important that people with dementia and their families are consulted with and

supported to participate in care and decision-making at the level they choose, regardless of their level of cognitive or physical impairment.

The right to self-determination of all persons with dementia, no matter where they are in the disease progression should be respected. The right of residents with dementia to decline admission to residential care, treatment and/or care is respected. This means ensuring that choices are provided, the person's wishes are taken into consideration, and their consent obtained. As dementia progresses, it may become increasingly difficult to obtain fully informed consent from people with dementia. However, it is always possible to involve them in the decision-making process to some extent, keeping them informed, asking and/or finding out from others about their preferences taking into account previously expressed wishes. Dissent must also be respected.

Having a positive culture of consultation, communication and sharing of information in residential centres for older people promotes the involvement of residents and their families and can help residents to maintain their identity and foster good-quality, person-centred care in centres. Everyone's contribution should be recognised and valued and all stakeholders need to be given the opportunity to be involved in decisions that affect them.

Resources about Residents rights, dignity and consultation:

1. Alzheimer Europe. [Caring for someone with dementia](#).
2. Department of Health. [The Irish National Dementia Strategy](#). 2014. Dublin: The Department of Health.
3. The Alzheimer Society of Ireland. Human Rights and Older People in Ireland. Dublin: 2013.
4. Age Action Ireland. [Overview of the Human Rights of Older People in Ireland](#).

Additional resources to be published

Health Information and Quality Authority. Guidance for providers of Health and social care services: Communicating in plain English 2015. Dublin: Health Information and Quality Authority

This list is not exhaustive. It is not intended as anything other than a useful aide memoir for providers and more up to date information may have superseded this.

4. Suitable staffing

Staff and volunteers should understand that dementia is not a normal part of ageing. Understanding the symptoms and prognosis of dementia enables staff to meet the needs of residents with dementia under their care.

Staff in residential services need education, support and supervision, appropriate to their role, that empowers them to tailor their care to the needs of residents and recognises problem-solving approaches to providing care.

Staff and volunteers in residential services should be aware of the signs, symptoms and disabilities associated with dementia and know how to seek further advice and assistance on how to effectively support a resident who is experiencing difficulty with: memory, communication, recognition and co-ordination, orientation, changes in behaviour, judgement and completion of daily life skills.

Staff should also be aware of other conditions (such as urinary tract infections, acute respiratory chest infection, vitamin deficiency etc.) that may impact on a resident's memory, orientation and behaviour and seek appropriate medical support for investigation and diagnosis.

Effective initial and ongoing staff training addresses:

- the provision of person-centred care
- dementia, including the progression of the disease, memory loss, and behavioural/psychological signs and symptoms
- strategies for communication to address sensory/cognitive impairment and language barriers
- a variety of techniques for understanding and approaching behavioural/psychological signs and symptoms, including alternatives to restraints

- the appropriate use of restraints to ensure that restrictive procedures are always legitimate, safe and minimal
- an understanding of the role of the family
- information on how to address specific aspects of care (e.g., pain, food and fluid, social engagement)
- culturally sensitive training which addresses issues affecting older people from culturally and linguistically diverse backgrounds
- emotional wellbeing of staff as they deal with their own emotional reactions to the decline of residents over time and eventual death.

The staffing skill mix should ensure that residents with dementia have sufficient support to complete their health and personal care routines and to participate in the daily life of the service. Continuity of staffing helps to promote the quality of the relationships between staff, residents and advocates.

Staff should acknowledge and accept a resident's experience and should not ignore a resident's report of an event or his or her feelings and thoughts.

Resources concerning staffing:

1. [Alzheimer Europe. Caring for someone with dementia.](#)
2. Department of Health 2010. Nothing ventured, nothing gained: risk guidance for dementia.
3. [Dr Suzanne Cahill, Ana Diaz. The priorities of older people with a cognitive impairment.](#)
4. One day workshops provided by the Irish Hospice Foundation.
5. HIQA, Restraint Procedures Guidance
6. The Royal College of Physicians in Ireland provide online courses, such as the [delirium module](#).
7. NHS education for Scotland. [Promoting psychological wellbeing for people with dementia and their carers.](#)
8. Scottish social services council, NHS education for Scotland: [Dementia Skilled - Improving Practice](#).

9. Scottish Social Services Council. [Enhanced dementia practice for social workers](#).
10. The Alzheimer Society of Ireland, [Memory checklist](#)
11. The Alzheimer's society of Ireland. [Resources for carers](#).
12. The European Delirium Association, 2009. [A complex intervention for delirium in care homes for older people; Final report Summary](#).
13. University of Tasmania: Wicking Dementia Research and Education Centre. (Understanding Dementia is a Massive Open Online Course (MOOC). It is a free 9-week course which provides an opportunity to engage with the perspectives of an international community. Understanding Dementia is designed to be accessible and appealing to people from diverse backgrounds including: health professionals, community and residential facility support staff, health policymakers and social scientists. The course imparts knowledge to improve quality of life across the trajectory of dementia for people with the condition, their families and their carers. Expressions of Interest can be registered at <https://oer.utas.edu.au>

Please note: This list is not exhaustive. It is not intended as anything other than a useful aide memoir for providers and more up to date information may have superseded this.

5. The environment

The design of the physical environment is increasingly recognised as an important aid in the care of people with Alzheimer's disease and other dementias³ and is regarded as a therapeutic resource to promote wellbeing and functionality among people with dementia. Person-centred care is enhanced by an environment that is conducive to a lifestyle as close as possible to that of being at home. People living with dementia who live in a residential centre need the same amount of space as if they were living at home. The environment in a residential centre must be monitored to provide acceptable levels of noise and stimulation. Freedom and choice of movement through the centre should be possible. Areas of quiet space for reflection and interaction with others are also important.

The physical environment can encourage and support independence while promoting safety. The optimal environment feels comfortable and familiar, as a home. It is important to provide easy, safe and secure access to the outdoors while maintaining a safe environment. Designing facilities to support people with a reduced level of cognitive function is practical and achievable. Accommodation for people living with dementia should⁴:

- compensate for disability
- maximise independence, reinforce personal identity, and enhance self esteem/confidence
- demonstrate care for staff
- be orientating and understandable
- welcome relatives and the local community
- control and balance stimuli.

³ Day et al (2000)

⁴ Marshall (2001) reviewed the international literature on principles for designing dementia specific facilities summarised elements that became a consensus of views

Design features that should be incorporated in a facility, to provide quality accommodation for people living with dementia include:

- small size, in terms of the numbers of people accommodated in a dementia specific unit
- familiar building style, that is, domestic and home like
- plenty of scope for ordinary activities (unit kitchens, washing lines, garden sheds)
- unobtrusive inclusion of safety features
- rooms for different functions that are equipped with furniture and fittings familiar to the age and generation of the residents
- a safe outside space
- single rooms - big enough for a reasonable amount of personal belongings
- good signage and multiple cues where possible, e.g. sight, smell, sound
- use of objects rather than colour for orientation
- enhancement of visual access
- control of stimuli, especially noise.

These design features should be considered in the design of dementia friendly residential services and should include all the rooms and areas that form part of the residential service. It is important to recognise that some quite small changes that can have a major impact on improving accessibility for people with dementia. For example, clear signs and lighting can be done at minimal cost, whereas other changes will involve some investment. National Services Scotland, Health Facilities Scotland provides an example of a checklist of features (highlighted in reference 2 below).

Resources: This list is not exhaustive. It is not intended as anything other than a useful aide memoir for providers and more up to date information may have superseded this.

1. Edgerton EA, Richie L. (2010) [Improving Physical Environments for Dementia Care: Making Minimal Changes for Maximum Effect. Annals of Long-Term Care: Clinical Care and Aging 2010;18\[5\]:43-45](#)

2. National Services Scotland. (2007) Dementia Design Checklist, [Design checks for people with dementia in healthcare premises. Version 1](#). Health Facilities Scotland

The Centre for Excellence in Universal Design has ten booklets on the subject of '[Building for Everyone: A Universal Design Approach](#)' available to download for free from their website. The booklets cover elements such as the external environment, entrances and horizontal circulation, internal environment, sanitary facilities, facilities in buildings, building types, building management and planning and policy. They promote the concept and philosophy of Universal Design and encourage developers, designers, builders and building managers to be innovative and think creatively about solutions that meet the needs of all building users.

Universal Design places human diversity at the heart of the design process so that buildings and environments can be designed to meet the needs of all users. It therefore covers all persons regardless of their age or size and those who have any particular physical, sensory, mental health or intellectual ability or disability. It is about achieving good design so that people can access, use, and understand the environment to the greatest extent and in the most independent and natural manner possible, without the need for adaptations or specialised solutions

Additional resources to be published about the environment

Additional information is available at the Dementia Services Development Centre DSDC, University of Stirling, Scotland <http://dementia.stir.ac.uk/> (DSDC is an international centre of knowledge and expertise dedicated to improving the lives of people with dementia).

The Centre for Excellence in Universal Design (CEUD) www.universaldesign.ie at the National Disability Authority (NDA) has completed the following documents which will be available in Q1 of 2015:

'Research for Dementia and Home Design in Ireland looking at New Build and Retro-Fit Homes from a Universal Design approach; Key Findings and Recommendations' Report.

'Universal Design Guidelines - Dementia Friendly Dwellings for People with Dementia, their Families and Carers'.

This work was undertaken with The Dementia Services Information and Development Centre at St James Hospital, Dublin and the School of Social Work and Social Policy Trinity College Dublin and TrinityHaus construction research Centre, Trinity College Dublin

6. Resources

This list is not exhaustive. It is not intended as anything other than a useful aide-memoir for providers and more up to date information may have superseded this.

An Bord Altranais. *Professional Guidance for Nurses Working with Older people*. Dublin: And Bord Altranais; 2009.

Anne D. Basting. 2009 *Forget Memory: Creating Better Lives for People with Dementia*. Baltimore, MD: Johns Hopkins University Press, 2009.

Basting, A. *Forget Memory: Creating Better Lives for People with Dementia*. Baltimore, MD: Johns Hopkins University Press, 2009.

Bobersky, A. and Cahill, S. (2011) 'Family caregivers' experience of placing their relatives with dementia in Specialist Dementia Care Units', *Irish Journal of Medical Science*, 180(1), pp. 324-5.

Cahill, C, O'Shea, E and Pierce, M. [Creating Excellence in Dementia Care: A Research Review for Ireland's National Dementia Strategy](#). 2012.

Cahill, S, Diaz-Ponce, A, Cohen, F and Walsh, C. *The under detection of cognitive impairment in nursing homes in the Dublin area. The need for on-going cognitive assessment*. *Age Ageing* (2010) 39 (1): 128-131.

Day K, Carreon D, Stump C. 2000 The Therapeutic Design of Environments for People with Dementia: A review of the Empirical Research. *The Gerontologist* Vol: 40 No. 4 397-416.

Department of Health (2011) *Towards a Restraint Free Environment in Nursing Homes*. Dublin: The Stationary Office.

Department of Health. *Healthy Ireland – A Framework for Improved Health and Wellbeing 2013 – 2015*. Dublin: The Stationery Office; 2013.

Department of Health. *Positive Aging Starts Now - National Positive Aging Strategy*. Dublin: The Stationery Office; 2013.

Health Act 2007 (as amended). Dublin: The Stationery Office; 2007.

Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People) Regulations 2013.

Health Information and Quality Authority. National Standards for Residential Care Settings for Older People in Ireland. Dublin: Health Information and Quality Authority; Revised December, 2015

Marshall, M. 2001 Environment: how it helps to see dementia as a disability in Care Homes and Dementia (ed S. Benson) The Journal of Dementia Care Vol: 6, Issue: 1, pp15-17

UN General Assembly, [Universal Declaration of Human Rights, 10 December 1948, 217 A](#) (III), (accessed 3 December 2014)

United Nations 1991. United Nations Principles for Older Persons.

List of useful web resources:

1. [Dementia Services Information and Development Centre](#), Dublin, Ireland
2. [Department of Health – Victoria](#), Australia
3. [International Psychogeriatric Association](#) (IPA).
4. [Irish Hospice Foundation](#).
5. NHS Education for Scotland. [An Educational Resource](#).
6. [Support and Advocacy Services for Older People](#) (SAGE)
7. Social Care Institute for Excellence – [Dementia Gateway](#)
8. The Alzheimer's society of Ireland. [Support for Health Care Professionals](#).
9. The Dementia elevator. Support for Health Care Professionals.

Please note: The Health Information and Quality Authority is not responsible for external website content.

Appendix 1: Types of dementia

Alzheimer's disease

Alzheimer's disease is the most common and well-known cause of dementia. It is recognised by the build up of protein on the brain which forms plaques and tangles that impact on how the brain functions. In general with Alzheimer's disease, changes are gradual over time and the illness may last several years. Memory loss is often one of the first symptoms of this disease; however, there are a range of early signs and symptoms including getting stuck for words, misplacing things regularly, losing track of time, changes in mood and behaviour and difficulty in finding the way, even in familiar places. In the early stages of the disease, changes may be slight; however, as the illness progresses, the changes become greater.

Vascular dementia

Vascular dementia is the second most common type of dementia and it occurs when the blood supply to the brain is damaged. There are two main types of vascular dementia; one caused by stroke and the other by small vessel disease.

Multi-infarct dementia is a type of vascular dementia that is caused by repeated small strokes. Very often small strokes have no impact on the person, hence the effects of the stroke are not evident. However, the person may get worse quite suddenly and then not change again until the next stroke happens. As a result, the progression of this dementia is often described as happening in steps rather than steady gradual changes, such as in Alzheimer's disease. People with vascular dementia will often have difficulty concentrating and communicating. People with vascular dementia may have memory problems, but this may not be the first symptom. Depression is a common feature of multi-infarct dementia.

Lewy body dementia

Lewy body dementia is a type of dementia that shares characteristics with both Alzheimer's disease and Parkinson's disease. Like Alzheimer's disease symptoms progress gradually over several years. The person with Lewy body dementia experiences many of the signs and symptoms of Alzheimer's disease. Other

symptoms experienced by the person with Lewy body dementia include; muscle stiffness, trembling of the limbs and a shuffling gait. Hallucinations may also be experienced and normal sleep patterns are often disturbed.

Fronto – temporal dementia

Fronto-temporal dementia, including Picks Disease, is a rare type of dementia. During the early stages, a person's memory may be fine but their personality, behaviour and language skills can change. This dementia often causes a loss of insight and so the person may say and do things at the wrong time and in the wrong place. The progression of this dementia is unpredictable and in the later stages symptoms are similar to those of Alzheimer's disease.

Korsakoff's Syndrome

Korsakoff's syndrome is a brain disorder usually associated with heavy alcohol consumption over a long period. Although Korsakoff's syndrome is not strictly speaking a dementia, people with the condition experience loss of short-term memory. Korsakoff's syndrome is caused by lack of thiamine (vitamin B1), which affects the brain and nervous system. People who drink excessive amounts of alcohol are often thiamine deficient. This is because:

- many heavy drinkers have poor eating habits and their diet does not contain essential vitamins
- alcohol can interfere with the conversion of thiamine into the active form of the vitamin (thiamine pyrophosphate)
- alcohol can inflame the stomach lining, cause frequent vomiting and make it difficult for the body to absorb the key vitamins it receives. Alcohol also makes it harder for the liver to store vitamins.

Korsakoff's syndrome is part of a condition known as Wernicke-Korsakoff syndrome. This consists of two separate but related stages: Wernicke's encephalopathy followed by Korsakoff's syndrome. However, not everyone has a clear case of Wernicke's encephalopathy before Korsakoff's syndrome develops.

Creutzfeldt-Jacob Dementia

Creutzfeldt-Jacob disease (CJD) is the most common human form of a group of rare, fatal brain disorders known as prion diseases. Prion diseases, such as Creutzfeldt-Jacob disease, occur when prion protein (which is found throughout the body but whose normal function isn't yet known) begins folding into an abnormal three-dimensional shape. This shape change gradually triggers prion protein in the brain to fold into the same abnormal shape. Through a process scientists don't yet understand, mis-folded prion protein destroys brain cells. Resulting damage leads to rapid decline in thinking and reasoning as well as involuntary muscle movements, confusion, difficulty walking and mood changes.

Down's syndrome and dementia

As they age, those affected by Down syndrome have a greatly increased risk of developing a type of dementia that's either the same as or very similar to Alzheimer's disease. As with all adults, advancing age also increases the chances a person with Down syndrome will develop Alzheimer's disease. Because people with Down syndrome live, on average, 55 to 60 years, they are more likely to develop younger-onset Alzheimer's (Alzheimer's occurring before age 65) than older-onset Alzheimer's (Alzheimer's occurring at age 65 or older). Autopsy studies show that by age 40, the brains of almost all individuals with Down syndrome have significant levels of plaques and tangles, abnormal protein deposits considered Alzheimer's hallmarks. Despite the presence of these brain changes, not everyone with Down's syndrome develops Alzheimer's symptoms.

Appendix 2: Dementia projections 2011-2046

Estimated number and projected growth in the number of people with dementia in Ireland by age group, 2011-2046

| Age group | 2011 | 2016 | 2021 | 2026 | 2031 | 2036 | 2041 | 2046 |
|--------------|--------|--------|--------|--------|--------|---------|---------|---------|
| 30-59 | 2,866 | 2,935 | 2,934 | 2,869 | 2,854 | 2,864 | 2,889 | 2,991 |
| 60-64 | 1,200 | 1,301 | 1,449 | 1,615 | 1,738 | 1,906 | 2,044 | 1,896 |
| 65-69 | 2,776 | 3,287 | 3,827 | 4,020 | 4,485 | 4,876 | 5,315 | 5,645 |
| 70-74 | 4,604 | 5,532 | 7,013 | 7,442 | 8,367 | 9,378 | 10,211 | 11,188 |
| 75-79 | 7,475 | 8,213 | 11,298 | 12,560 | 14,055 | 15,928 | 17,968 | 19,692 |
| 80-84 | 10,958 | 12,265 | 16,099 | 17,868 | 22,348 | 25,364 | 29,102 | 33,196 |
| 85+ | 17,970 | 21,260 | 25,595 | 31,085 | 40,195 | 52,512 | 64,654 | 77,549 |
| Total | 47,849 | 54,793 | 68,216 | 77,460 | 94,042 | 112,828 | 132,182 | 152,157 |

Note: Estimates for 2011 based on Census of Population 2011. Projections for 2016 to 2041 based on CSO (2013) Population and Labour Force Projections, 2016-2014, Stationery Office, Dublin, Table 3, page 40 and EuroCoDe (2009) Age and gender specific dementia prevalence rates. (Source: Pierce, M. et al. (forthcoming). Prevalence and Projections of Dementia in Ireland, 2011. Genio Ltd., Mullingar).

Appendix 3: Estimates of number of people with dementia in Ireland, 2011

| Age groups | Total Population (Census 2011) | | Persons with dementia (estimated using EuroCoDe (2009) age/gender-related dementia prevalence rates) | | | |
|-------------|--------------------------------|-----------|--|------------------|--------|-------------------------|
| | Men | Women | Men | Women | Total | % of defined population |
| 30-59 years | 953,715 | 959,396 | 1907 ¹ | 959 ¹ | 2,866 | 0.15% |
| 60-64 years | 109,869 | 108,917 | 220 | 980 | 1,200 | 0.55% |
| 65-69 years | 86,298 | 87,340 | 1,553 | 1,223 | 2,776 | 1.60% |
| 70-74 years | 63,476 | 67,714 | 2,031 | 2,573 | 4,604 | 3.51% |
| 75-79 years | 46,631 | 55,405 | 3,264 | 4,211 | 7,475 | 7.33% |
| 80-84 years | 28,423 | 41,690 | 4,121 | 6,837 | 10,958 | 15.63% |
| 85-89 years | 13,591 | 26,296 | 2,841 | 7,494 | 10,335 | 25.91% |
| 90-94 years | 4,155 | 10,722 | 1,213 | 4,761 | 5,974 | 40.16% |
| 95+ | 740 | 2,912 | 240 | 1,421 | 1,661 | 45.48% |
| Total | 1,306,898 | 1,360,392 | 17,390 | 30,459 | 47,849 | 1.79% |

Source: CSO (2011) Census of Population – Profile 2: Older and Younger: An Age profile of Ireland Tables 7A-7C, pp. 47-49; Persons with dementia estimated by application of EuroCoDe gender/age-specific prevalence rates.

Notes: As EuroCoDe does not specify early onset prevalence rates, EURODEM early onset dementia prevalence rates were used instead. (Source: Pierce, M. et al. (forthcoming). Prevalence and Projections of Dementia in Ireland, 2011. Genio Ltd., Mullingar).

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