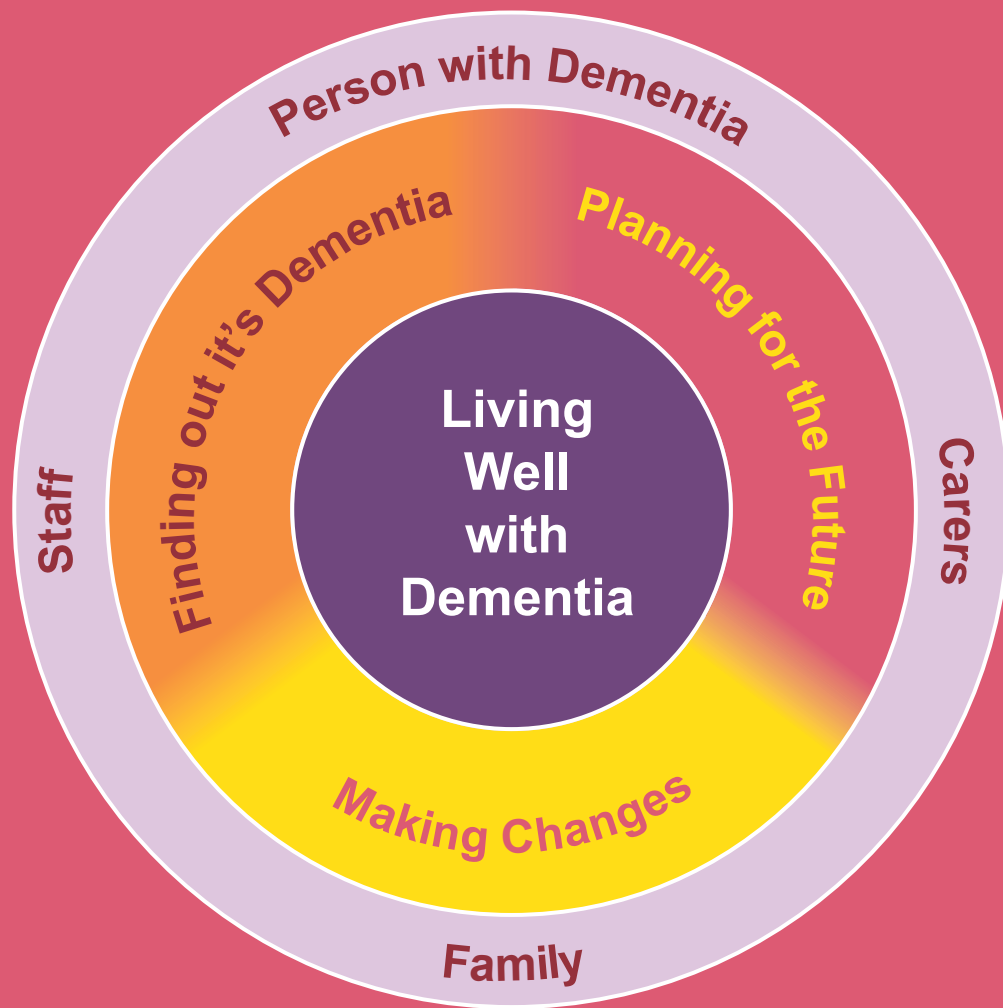


The Dementia Learning and Development Framework



Supporting health and social care staff to deliver better care to people living with a dementia, their families and carers

September 2016

Contents

	Page
Acknowledgements	5
Forewords	6
Background and Introduction	8
Tiers within Thematic Subject Areas.....	10
Structure of the Framework	11
Values and Principles Underpinning the Framework	12
The Journey of Dementia	13
Thematic Design of the Framework	15
Theme 1 Dementia Awareness	17
Theme 2 Communication	21
Theme 3 Receiving a Diagnosis of Dementia	27
Theme 4 Person-Centred and Relationship-Centred Dementia Care	31
Theme 5 Promoting Physical, Psychological and Social Well-being in Dementia Care...	35
Theme 6 Holistic Approach to the Management of Dementia Care	39
Theme 7 Promoting Enabling Environments	43
Theme 8 Legal and Ethical Considerations in Dementia Care	47
Theme 9 Equality, Cultural Diversity and Inclusion in Dementia Care	51
Theme 10 Palliative Care in Dementia/End of Life Dementia Care	55
Theme 11 Working in Partnership with Families and Carers	59
Theme 12 Research and Evidence-based Practice in Dementia Care	63
Theme 13 Leadership in Transformational Dementia Care	67
Glossary	70
Bibliography	71
Appendices:	
1. Membership of Groups	72
2. Frameworks and Important Links	79
3. Self Assessment Tool	80



Acknowledgements

The development of the Dementia Learning and Development Framework was steered by an expert group (Appendix 1a) and we are extremely grateful to the members of this group for generously giving of their time, expertise and support throughout the development process.

A series of regional workshops were held to identify the thematic subject areas which were considered to be central to the content of this Framework. Thanks to those organisations and individuals who were represented at the stakeholder workshops (Appendix 1b) and also to those who contributed electronically through the virtual reference group (Appendix 1c).

A special thanks is due to those people living with a dementia, their family members and carers, whose contribution to this work has been both invaluable and enlightening.

We wish to acknowledge the financial support from the Delivering Social Change Dementia Signature Programme which was funded jointly by the NI Executive and Atlantic Philanthropies.

Dementia Learning and Development Framework Creatlach Foghlama agus Forbartha Néaltraithe

Foreword/Réamhrá

As the Minister with responsibility for the health and social care for the people of the North of Ireland I am delighted to have this opportunity to show my support for this new and important document The Dementia Learning and Development Framework.

The number of people living with a dementia in the North has been steadily increasing over recent years and will continue to do so into the foreseeable future. This increase provides both challenges and opportunities for everyone working in health and social care.

The production of this framework is part of the outworking of one of the Executive's Delivering Social Change (DSC) Signature Programmes. The Dementia Signature Programme is jointly funded by the Executive's DSC Fund and the Atlantic Philanthropies. This particular DSC project was launched in 2014 and aims to transform the design and delivery of dementia services in order to improve the quality of care for people living with dementia and their carers. The DSC initiative recognises it is vital that we have a well trained health and social care workforce to deliver high quality care for people with dementia.

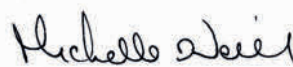
This framework sets out the knowledge and skills that Health and Social Care staff, across both the public and private sectors, will require in order to interact and respond sensitively to the needs of people with dementia. Training of health and social care staff is needed to ensure that those working with people with dementia

have the right knowledge and skills to do their job well, to challenge the stigma that exists around dementia, and to improve communication skills with people with dementia.

It is the culmination of considerable efforts by staff working within dementia services, academics and regulators. The views of those living with dementia and their carers have been vital to its development.

It will allow individual staff and their managers to assess their training needs and those of their staff team/profession and will enable educationalists to design and deliver more effective training programmes.

The longer term benefits will be enhanced quality of life, improved care and treatment for people living with dementia and their carers and higher standards of service delivered by a more competent and professional workforce.



Michelle O'Neill MLA
Minister for Health
An tAire Sláinte



Foreword

I was diagnosed 7 years ago with dementia and from the beginning I knew this was going to be a long unknown journey. It took 3 years for the overall diagnosis and in this time I researched all I could about dementia and how it can affect the life of an individual and their families.

I started to volunteer and soon became a champion for dementia, giving assistance and advice to anyone on this journey. I wanted to make a change and remove the stigma attached to dementia as well as wanting to raise awareness amongst professionals.

I was delighted to be part of the group which came together to develop the Dementia Learning and Development Framework. This group consisted of a wide range of individuals from health and social care as well as, local charities, university academics, carers and people with dementia who had already received a diagnosis.

Whilst availing of health and social care services, I met many dedicated and caring staff who wanted to help but would benefit from additional support and training. This Framework is an excellent way forward and will be a key driver in training all health and social care staff at all levels thus ensuring a high quality service is delivered to all those with a dementia.

I feel empowered and humbled to know that this Framework is now going to make major changes to the way dementia is perceived. We can now be assured that we will continue to build upon good practice already in place and ensure that all those with a dementia receive the highest standard of care and support to help them on their journey.



Liz Cunningham
Expert by Experience



Background and Introduction

Context

There are a growing number of people living with a dementia and this is recognised as a major social, economic and health care challenge. It is estimated that there are currently 20,000 people living with a dementia in Northern Ireland of whom approximately 13,000 have a confirmed diagnosis. It is thought that as many as 1,000 people living with a dementia are under the age of 65 years. (DHSSPS, 2011; Alzheimer's Society 2015) Projections suggest that 23,000 people will be living with a dementia by 2017 and this number is expected to rise to 60,000 by 2051.

Following an extensive public consultation process the Regional Strategy "Improving Dementia Services" was published in November 2011 and set out a holistic model for supporting people living with a dementia (DHSSPS, 2011).

The strategy contained 44 recommendations categorised under 7 themes including:

- Raising awareness;
- Promoting early assessment and diagnosis; and
- Supporting people with a dementia and their caregivers.

Integral to the development of the themes of the Regional Strategy was the necessity for training and education, both general and specialist, across all staff levels and sectors of health and social care services.

The presence of a trained and competent health and social care workforce is essential if we are to challenge the stigma that exists around dementia. The provision of a structure for dementia specific training and education is important in order to

ensure that all staff working within health and social care across the statutory, voluntary and independent sectors have the skills and knowledge they require. This should enable them to recognise and respond appropriately to the unique needs of a person living with a dementia and their carers to provide an effective, person-centred service.

It is important for staff to be mindful of the fact that it is not only older people that experience dementia, but that younger people and people with learning disability can be affected, e.g. people with Down syndrome.

Consideration should be given to the different needs of those being trained with particular emphasis being placed on Section 75 groups to ensure training materials are accessible in all relevant formats.

Development of The Framework

The Dementia Learning and Development Framework was set in motion following an extensive regional scoping exercise which collated information on the type and volume of training currently available to staff in the region. The exercise included an examination of the cost and accessibility of training programmes and existing levels of accreditation.

This Framework was also informed by best practice guidance and literature reviews, reviews of other frameworks and a programme of consultation and engagement with key stakeholders from June 2015 until January 2016. This included people living with a dementia, carers, professionals, academics and regulators who represented a range of agencies and professions.

Purpose of The Dementia Learning and Development Framework

This Framework outlines the core themes in terms of the knowledge and skills that health and social care staff require in order to interact and respond sensitively to the needs of people living with a dementia, their families and carers.

It should be used to:

- help identify the relevant expertise and skills of staff who come into contact or work directly with people living with a dementia, their families and carers.
- assist staff and their employers or managers to:-
 - (i) recognise gaps in their knowledge and skills
 - (ii) facilitate the planning of on-going training and development needs
 - (iii) prepare for career progression
- inform the commissioning, development and provision of appropriate continuing education and training programmes.

The Self Assessment Tool has been included to assist managers and staff to rate their knowledge against thematic subject areas. (Appendix 3)

This Framework is designed to be read and used in conjunction with other relevant health and social care documents, including legislation, codes of practice, competency frameworks, action plans and strategies. (Appendix 2)

Scope of The Dementia Learning and Development Framework

A greater number of staff are employed in the delivery of health and social care services than in any other sector. Many of these staff have direct involvement in the care, treatment and support offered to people living with a dementia, their families and carers. As well as those who provide direct care, there are many more support staff who also come into contact with people living with a dementia across a range of primary, secondary and acute care settings.

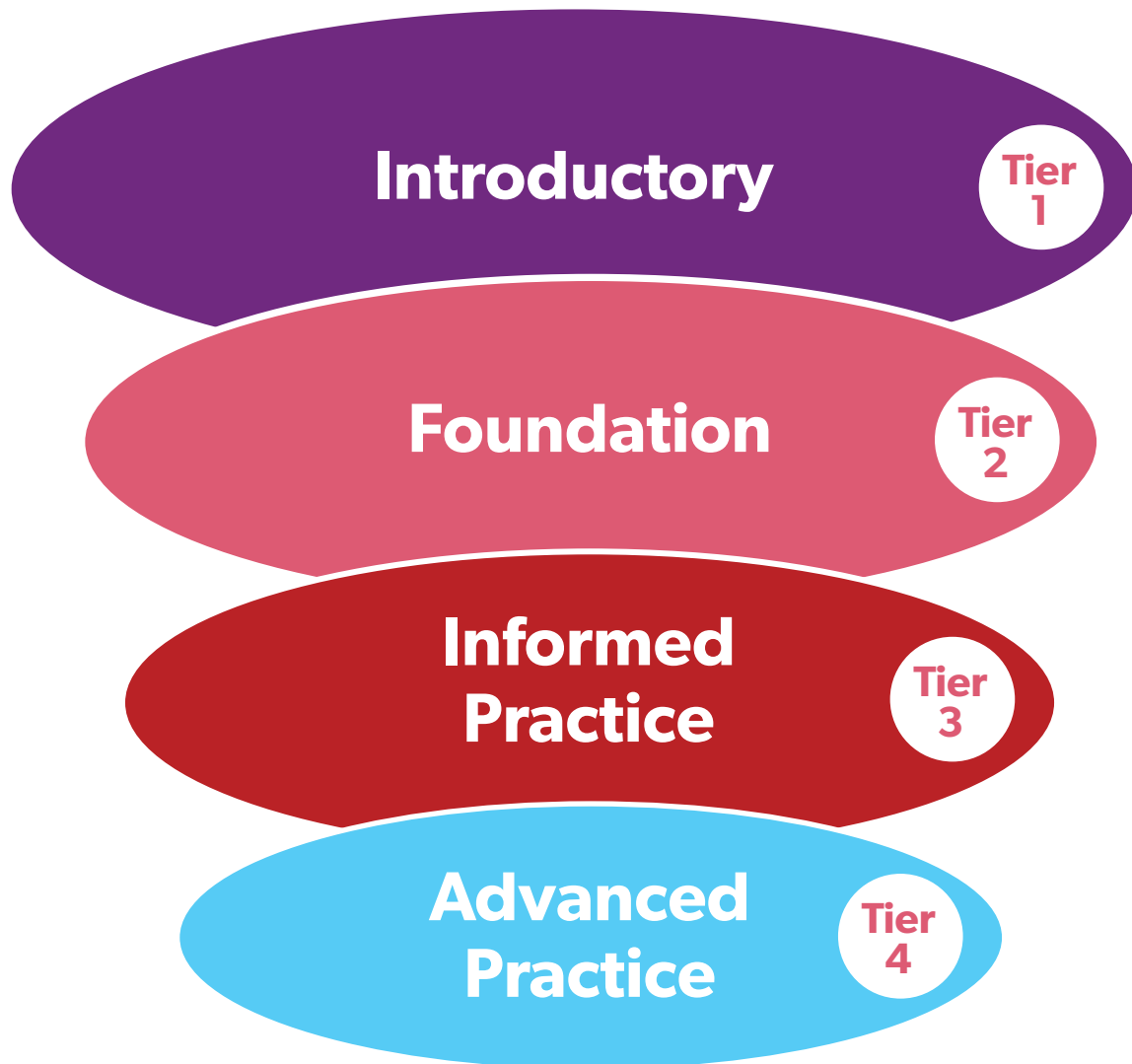
This Framework has been designed to support all health and social care staff to deliver better care to people living with a dementia, their families and carers regardless of the settings in which they work or their current level of expertise or experience of working with people living with a dementia.

The Framework is applicable to employers and educational organisations who provide training to health and social care staff and students.

This should support these organisations to:

- standardise the content of education in dementia care to ensure consistency in standards and approach;
- guide the focus and aims of dementia training;
- encourage continuing professional and vocational development;
- improve the quality and availability of dementia education;
- enhance the experiences of people living with a dementia, their families and carers.

Tiers within Thematic Subject Areas



Structure of the Framework

Health and social care staff will have different learning needs commensurate with their role and involvement in the care process. Therefore, this Framework has been structured under four incremental Tiers, each of which defines the knowledge and skills specific to roles and responsibilities of staff. It is recognised that the Tiers are not necessarily based on seniority of role within an organisation or a profession.

It should be noted that health and social care staff working at Tier 2 will possess the knowledge and skills of Tier 1. In the same way staff working at Tiers 3 and Tier 4 will also possess the knowledge and skills of Tiers 1 and 2.

Tiers

Tier 1 - Introductory

The first Tier of the Framework, termed Introductory, is universally relevant to all health and social care staff. This Tier provides a baseline level of dementia knowledge for every person who works in health and social care settings. This level of knowledge should be the minimum standard across all grades of staff.

This may include staff in reception areas, administration, support services e.g. domestic, catering, security or portering, dementia friends and families as well as informal carers.

Tier 2 - Foundation

The second Tier, termed Foundation, builds on the Introductory level by ensuring staff have knowledge that will enable them to understand the needs of people living with a dementia and provide better quality care. This Tier is generally aimed at all registered and non registered health and social care staff with expertise in a non dementia environment or who are involved in any aspect of care for a person living with a dementia.

Tier 3 - Informed Practice

This Tier, termed Informed Practice, is aimed at health and social care staff working within specialist dementia settings or who come into contact with a high proportion of people living with a dementia. These staff will undertake holistic assessments, develop and initiate a range of therapeutic interventions, review care and support plans and lead in the delivery of person-centred and relationship-centred dementia care.

Tier 4 - Advanced Practice*

This final Tier, Advanced Practice, targets specialist health and social care staff who are working at an advanced level of expertise. These health and social care staff will act as role models in dementia care, playing a key role in leadership and assisting in driving forward improvements in dementia research

*Nurses who practice at an advanced level should meet the requirements outlined in the Advanced Nursing Practice Framework: Supporting advanced nursing practice in Health and Social Care Trusts (DHSSPS, 2014)

Values and Principles Underpinning the Framework

This Framework is underpinned by values and principles that reflect the expressed views and opinions of people living with a dementia, their families and carers with regard to the care and treatment they expect to receive.

At the core of this Framework are the principles that people living with a dementia, their families and carers have the right to be treated with privacy, dignity and respect; have their human rights upheld and independence promoted; be

involved in decision making; to receive safe care and treatment from staff who are suitably qualified, competent and well motivated to undertake their roles.

In essence these values and principles are the foundation stones of all care provided by health and social care staff to all patients, residents, service users and carers. As such these values and principles underpin each Theme and Tier implicitly.



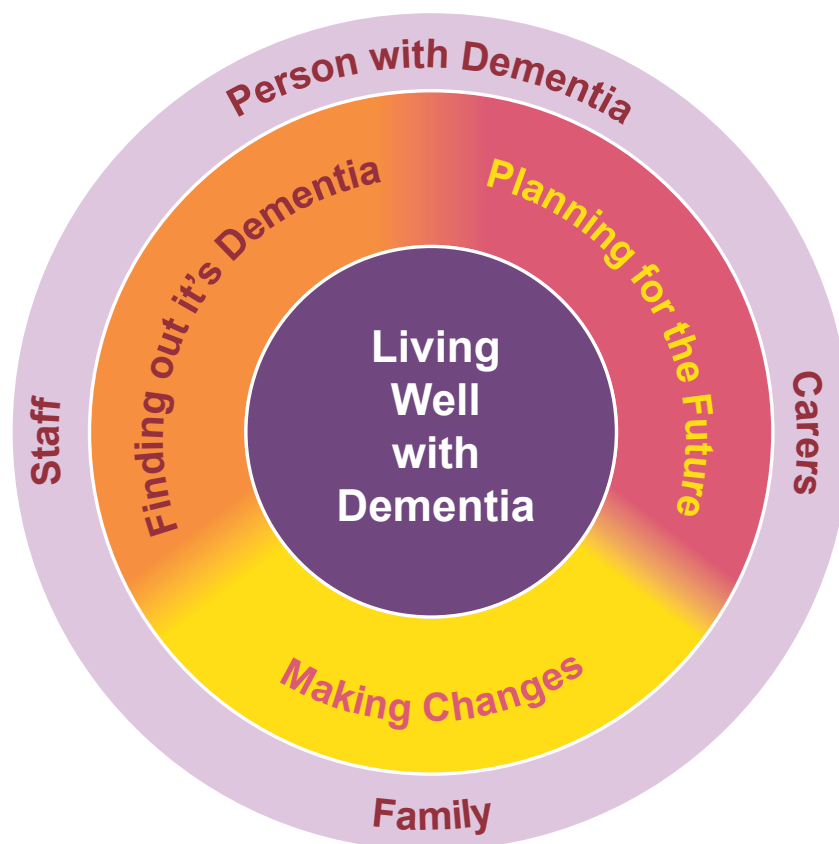
The Journey of Dementia

This Framework presents an illustrative model which encapsulates the value base for all encounters with people living with a dementia, their families and carers. It is based on the concept that living with a dementia is not a linear journey nor indeed one where people fit into clinical categories such as early, middle or late stages of dementia. In fact people will enter the journey at different stages.

This model reflects the ethos of the Dementia Learning and Development Framework by recognising the importance

of collaboration between the person living with a dementia, their families and carers as well as health and social care staff throughout the person's journey.

At the centre of the model is the key objective that the Framework strives to ensure that the person living with a dementia, their families and carers, can live well with dementia. The key points in a person's journey pertains to finding out it's dementia, making changes and planning for the future.



The Journey of Dementia (continued)

(i) Living Well with Dementia

Living Well with Dementia focuses on what an individual can do as opposed to what they cannot. Living with a dementia may change the future plans of the person but dementia does not change who that person is. Importantly, living with a dementia should not stop the person doing the things they enjoy but they may need some support to do them in a slightly different way.

Promotion of 'Living Well with Dementia' is at the heart of this Framework and underpins the three other strands - Finding out it's Dementia, Making Changes and Planning for the Future.

(ii) Finding out it's Dementia

Globally there is a drive to increase rates of diagnosis for people with a dementia. While it must be acknowledged that not everyone will wish to receive a diagnosis there are a number of people living with the condition who do wish to know their diagnosis. Unfortunately, there are a number of barriers which impede a timely diagnosis which include:

- inability to recognise early symptoms
- delays in carrying out diagnostic tests
- medical reluctance in the absence of treatment
- family members concern about the impact on the person (DOH, 2001; DOH, 2005; Vernooij-Dassen, 2005; Iliffe et al, 2009; Mitchell 2013a; 2013b)

Providing a timely diagnosis to people living with a dementia is important to enable them to have access to information

about their condition, decide on their treatment options and importantly enable future planning. Due to the progressive nature of the condition it is important that diagnosis is timely for those people who wish to receive it.

(iii) Making Changes

While there is currently no cure for dementia, extensive empirical research exists with regard to lifestyle changes which can affect the lived experience of people living with a dementia. Lifestyle changes are often designed to improve a person's life through the maintenance of independence and management of symptoms to enable the continuation of their lifestyle.

Making changes in a timely manner e.g. adaptations to a person's living environment or the administration of medication may help people living with a dementia to retain their independence for as long as possible and exercise their rights, choices and care preferences.

(iv) Planning for the Future

Planning for the Future is essential throughout the person's journey with a dementia. It is particularly important given that a person's cognitive function is likely to decline as the dementia progresses.

Future planning provides an opportunity for people living with a dementia to express their preferences and inform decision making should they no longer be able to do so. This can extend to decisions regarding enduring power of attorney, advance care-planning and financial affairs.

Thematic Design of the Framework

The Framework is presented in 13 thematic subject areas:

1. Dementia Awareness
2. Communication
3. Receiving a Diagnosis of Dementia
4. Person-Centred and Relationship-Centred Dementia Care
5. Promoting Physical, Psychological and Social Well-being in Dementia Care
6. Holistic Approach to the Management of Dementia Care
7. Promoting Enabling Environments
8. Legal and Ethical Considerations in Dementia Care
9. Equality, Cultural Diversity and Inclusion in Dementia Care
10. Palliative Care in Dementia/End of Life Dementia Care
11. Working in Partnership with Families and Carers
12. Research and Evidence-based Practice in Dementia Care
13. Leadership in Transformational Dementia Care

Each thematic subject area is comprised of:

- A **Context** Statement
- Statements by People **Living with a Dementia**
- **Target** Audience
- **Knowledge** - Learning Outcomes
- **Skills** - Learning Outcomes
- **Recommended Reading** - Guidance and/or Legislation



Theme 1

Dementia Awareness

Context

The number of people who are affected by a dementia is continuing to rise with conservative estimates suggesting that this will treble over the next 35 years.

Dementia is and should continue to be a key priority for the entire health and social care workforce. This is because any member of staff in any setting may come into contact with someone who is affected by a dementia. Having a broad awareness of dementia can facilitate the health and social care workforce to provide appropriate needs led support and direct people to specialist services where necessary.

Ultimately this should improve the quality of the health and social care interaction as well as the service received by people with a dementia, their families and carers.

This theme refers to the knowledge and skills required to enhance the level of understanding that society has about dementia.

“We all need to recognise that with dementia, more awareness will lead to reduced stigma in our society and a general acceptance of the condition.”

“I need people to realise what it is like for me living with a dementia; I find it frustrating when people are not fully aware how I feel on a daily basis”.

“Ignorance and lack of awareness makes us frustrated, then we feel depressed”.

Target Audience - Tiers 1 - 4

Knowledge

Learning Outcomes - Tier 1

- Know what is meant by the term dementia.
- Recognise that dementia is an umbrella term for a number of conditions which includes Alzheimer's disease.
- Describe the prevalence of dementia in society.
- Identify that dementia is not a normal part of ageing.
- Recognise that as many as 50% of people who live with dementia may not have a formal diagnosis.
- Explain why receiving a diagnosis of dementia is important.
- Recognise that each person living with dementia is a unique individual.

Skills

Learning Outcomes - Tier 1

- Demonstrate how to communicate effectively and sensitively with people living with a dementia, their families and carers.
- Demonstrate how to seek guidance from other staff for appropriate dementia advice, support or information.

Recommended Reading

- Alzheimer's Disease International. (2012) *World Alzheimer Report 2012: Overcoming the stigma of dementia*. Alzheimer's Disease International: London
- Alzheimer's Society. (2015) *Dementia Today and Tomorrow: A New Deal for People with Dementia and Their Carers*. Deloitte Centre for Health Solutions: London
- Alzheimer's Society/NHS. *The Dementia Guide: Living Well after Diagnosis*. www.alzheimers.org.uk
- Alzheimer's Society/Royal College of Nursing. *This Is Me*. www.alzheimers.org.uk
- Alzheimer's Society. (Updated 2014) *What is dementia?* www.alzheimers.org.uk
- Andrews, J. (2015) *Dementia: The One-Stop Guide: Practical advice for families, professionals and people living with dementia and Alzheimer's Disease*. Profile Books: London
- (Eds) Bamford, S.M. Holley-Moore, G. and Watson, J. (2014) *A Compendium of Essays: New Perspectives and Approaches to Understanding Dementia and Stigma*. ILC-UK London
- Burdett Trust for Nursing: Barbara's Story: The Sequel. (25 Sept 2013) *Nursing Standard*, Vol. 28, Issue 4, p 10
- Dementia Together NI. (2016) *Are You Worried About Dementia?* Health and Social Care Board, Public Health Agency: Belfast
- Dementia Together NI. (2016) *The Early Stages of Dementia*. Health and Social Care Board, Public Health Agency: Belfast
- Dowds, Lizanne, McParland, Patricia, Devine, Paula, Gray, Anne Marie. (2012) *Attitudes to and knowledge of Dementia in Northern Ireland*. University of Ulster and Queen's University: Belfast
- Kerr, D. (2007) *Understanding learning disability and dementia: Developing effective interventions*. London: Jessica Kingsley Publishers.
- Skladzien, Dr Ellen, Bowditch, Katherine, Rees, Glenn. (Oct 2011) *National Strategies to Address Dementia*. Alzheimer's: Australia
- The All-Party Parliamentary Group on Dementia. (2012) *Unlocking Diagnosis – The Key to Improving the Lives of People with Dementia*. The Stationery Office: London
- Van Gorp, Baldwin and Vercruyssen, Tom. (February 2012) *Frames and counter-frames giving meaning to dementia: A framing analysis of media content in Social Science and Medicine*, 74 (2012) 1274-1281
- Watchman, K, Kerr, D. & Wilkinson, D. (2010) *Supporting Derek*. York: Joseph Rowntree Foundation.
- World Health Organization and Dementia Disease International. (2012) *Dementia: A Public Health Priority*. World Health Organization: Geneva
- www.hellobrain.eu/
- www.freedemliving.com/
- www.nidirect.gov.uk/dementia



Theme 2

Communication

Context

People living with a dementia may face challenges with communication because of the clinical manifestations of the condition. Importantly, a person's level of ability may change at different periods throughout any given day and also as their dementia progresses.

The additional needs of disabled people and those from ethnic minority backgrounds with a dementia may require staff to have an enhanced level of communication i.e. knowledge and skills.

Consideration of both verbal and non-verbal communication is important within dementia care.

People living with a dementia may exhibit certain 'behaviours' that are incorrectly perceived to be a symptom of the condition but in fact these are actually important forms of communication.

Throughout the dementia journey, consideration should also be given to timely communication with family members or carers of people living with a dementia.

This theme refers to the knowledge and skills required to actively engage with people living with a dementia.

"We need people to be open with us – it is about us and we deserve to know. I can still think for myself and it's really important for me to know what's going on in my life. I'm still a person".

"Communication in Dementia is key to ensure our needs are understood and met".

Target Audience - Tiers 1 - 4

Knowledge

Learning Outcomes - Tier 1

- List the methods of interacting and listening to people living with a dementia to make them feel valued and involved.
- Identify the skills and attitudes required to communicate effectively.
- Recognise the factors that act as enablers and barriers to effective engagement with people living with a dementia, their families and carers.
- Recognise the role and value of families and carers as collaborative partners in supporting the person living with a dementia to achieve positive outcomes.
- Examine how the behaviour of others may have a direct impact on the behaviour displayed by a person living with a dementia.
- Recognise that distressed behaviour is a form of communication.
- Recognise that a person's mood and feeling may affect their behaviour.
- Recognise and appreciate the impact of distressed behaviour and provide the appropriate intervention in accordance with assessed need.
- Explain the importance of non-verbal communication and understand the importance of life-story information and how this can facilitate communication.
- Identify that people living with a dementia, their families and carers require access to timely and relevant information appropriate to their needs.
- Recognise the key components of therapeutic relationships which takes account of individual differences, capabilities and needs to ensure safe, effective and non-discriminatory communication.
- Give examples of the range of multi-agency organisations and individuals working with people living with a dementia and those caring for them.
- Define the roles within a multi-disciplinary team.

Learning Outcomes - Tier 2

- Discover that the ability to communicate is often compromised in a person living with a dementia.
- Recognise and minimise barriers to support effective communication e.g. use of hearing aids or reading glasses.
- Identify how to adapt the style of communication to the needs and abilities of people living with a dementia who do not communicate verbally.
- Identify why effective communication is particularly important in multidisciplinary and multi-agency working.
- Define the referral pathways between services which provide support to people living with a dementia.

Skills

Learning Outcomes - Tier 3

- Evaluate and appreciate that the person living with a dementia may have reduced ability to articulate their physical health needs e.g. relating to pain, anxiety or depression.
- Establish that any behaviour is a form of communication.
- Consider the many different ways in which people communicate and how these may be influenced by ill health, disability and other factors and be able to recognise and respond effectively when a person finds it difficult to communicate.

Learning Outcomes - Tier 4

- Analyse when people are anxious or in distress and respond effectively, using therapeutic principles, to promote their well-being, manage personal safety and resolve conflict.
- Compare approaches which promote multidisciplinary assessment and interventions to support people living with a dementia with distressed behaviours perceived to be challenging.

Learning Outcomes - Tier 1

- Demonstrate a person-centred approach to sensitively communicate with a person living with a dementia, their families and carers in all aspects of communication.
- Identify appropriate tone of communication used with someone living with a dementia and their choice of words.
- Recognise the various forms of communication and appreciate the appropriate method to apply within the presenting circumstances.
- Recognise that not all people living with a dementia have difficulty with communication but that it may be beneficial to communicate in a more concise manner using non-complex language.
- Demonstrate active listening skills and be able to check for understanding.
- Identify environmental issues when communicating with a person living with a dementia e.g. crowded areas and excessive noise.
- Omit the use of stigmatising language e.g. 'challenging behaviour', 'wanderer', 'sufferer' or 'demented'.
- Demonstrate that all communication with a person living with a dementia is appropriate. Speak in a clear, concise, slow manner, maintaining eye contact at all times and allow the person extra time if necessary.

Skills (continued)

Learning Outcomes - Tier 2

- Recognise the fact that families and carers may be more familiar with the 'behaviours' exhibited by a person living with a dementia and what these may mean.
- Pay close attention to body language, touch, tone of voice and facial expression.
- Give examples of a range of communication skills and technologies to support person-centred care and enhance quality and safety. Information must be shared in a language and manner that allows people to make informed choices.
- Identify when language, interpretation or other communication support is needed and know how to obtain it.
- Demonstrate an ability to engage through meaningful interactions and activities.
- Consider the use of visual aids, memory boxes and life-history information to enhance communication experiences in dementia care.
- Identify how people living with a dementia, their families and carers can be involved in collaborative decision making about their care based on life story work such as "My Life My Way".
- Analyse and evaluate information to support multidisciplinary/multi-agency decision making.

Learning Outcomes - Tier 3

- Decide how to maximise the ability of the person living with a dementia to communicate their needs, wishes and desires.
- Interpret communication and listen in a sensitive manner when discussing difficulties and complex care concerns with the person living with a dementia, their families and carers.
- Develop the ability to support other professionals to ensure appropriate and timely referrals.

Learning Outcomes - Tier 4

- Support leadership in promoting effective communication in all aspects of care delivered in health and social care settings.
- Evaluate and ensure that the communication needs of those living with a dementia are at the forefront in the development of all practices and services.
- Appraise communication strategies and negotiation techniques to achieve best outcomes respecting the dignity and human rights of all concerned.

Recommended Reading

- Hawkes, D, Hingley, D, Wood, S and Blackhall, A. (2015) Evaluating the VERA framework for communication. *Nursing Standard*, Sept 9, 30, (2), pp. 44-48
- Killick, J, and Allan, K. (2006) The Getting Through Initiative: inside the interactions. *Journal of Dementia Care*, 14, (2), March, pp. 27-29. Hawker Publications Ltd: Australia
- Paul, N. & Mehrhoff, J (2015). Descriptive analysis: Survey of Direct and Indirect Interventions for Persons with Dementia-based communication disorders. *Perspectives on Neurophysiology and Neurogenic Speech and Language Disorders*, 25, pp 125-141
- Powell, J. (2000) *Care to Communicate: Helping the older person with dementia*. Hawker Publications Ltd: Australia
- RCSLT (2013), *Resource Manual for Commissioning and Planning Services for Speech, Language and Communication Needs, LCN*; Dementia www.rcslt.org/about/docs/slcn_resource_manual
- Sedgewick, R and Belfast Health and Social Care Trust. (2014) *Communicating Effectively with a Person Living with a Dementia*. Public Health Agency and Dementia Together NI: Belfast
- Swaffer, K. (2014) Dementia: Stigma, Language and Dementia Friendly, *Dementia*, 13, (6), pp. 709-716
- The Dementia Engagement and Empowerment Project (DEEP) (2014) *Dementia words matter: Guidelines on language about dementia*. Centre for Ageing Research and Development in Ireland: Ireland
- Vasse, E, Vernooij-Dassen, M, Spijker, A, Rikkert, M. O, and Koopmans, R. (2010) A systematic review of communication strategies for people with dementia in residential and nursing homes, *International Psychogeriatrics* 22, (2), pp. 189-200
- Watson, B, Aizawa, L.D, Savundranayagam, M.Y, & Orange, J.B (2012). Links among Communication, Dementia and Caregiver Burden, *Canadian Journal of Speech-Language Pathology and Audiology*, 36, 4, pp 276-283



Theme 3

Receiving a Diagnosis of Dementia

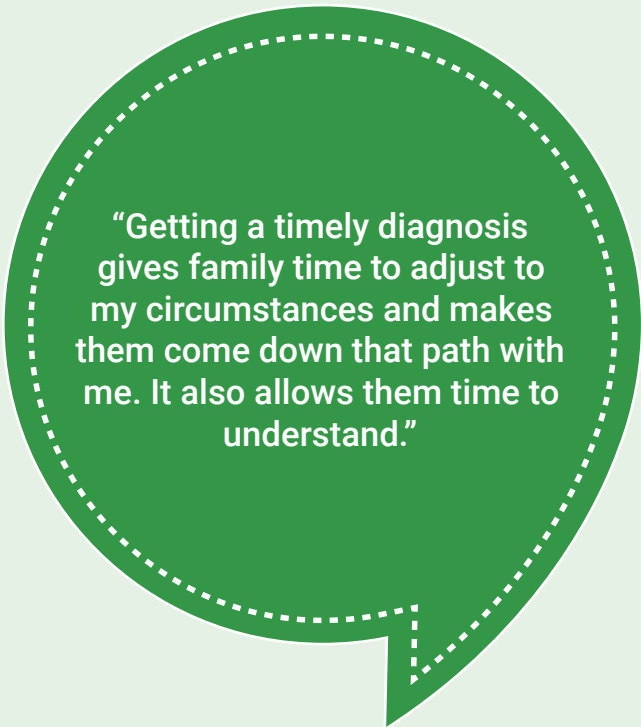
Context

Timely diagnosis of dementia has been outlined as a priority for a number of years in both local and national policy guidance. Currently less than half of people who live with a dementia actually receive a diagnosis.

Receiving a timely diagnosis of dementia is essential as it provides people with information about their condition, supportive options and potential treatments which can arrest the progression of dementia and improve quality of life. How this is delivered also has an impact on the person's well-being and their ability to cope post diagnosis.

While the diagnosis of dementia is currently carried out by a clinician with specialist skills, all health and social care staff have an important role in being able to recognise possible symptoms of dementia, provide support and direct or refer people to specialist services.

This theme refers to the knowledge and skills required to support people living with symptoms of dementia as well as their families and carers throughout the diagnostic stages of their journey.



“Getting a timely diagnosis gives family time to adjust to my circumstances and makes them come down that path with me. It also allows them time to understand.”

Target Audience - Tiers 1 - 4

Knowledge

Learning Outcomes - Tier 1

- Recognise that not all people who live with a dementia have a diagnosis.
- Establish the needs and impact of diagnosing younger people (under the age of 65) living with a dementia.

Learning Outcomes - Tier 2

- Define the most common types of dementia and their underlying causes.
- Establish the needs of people with learning disabilities being diagnosed with a dementia.
- Identify the most common symptoms of dementia.
- Apply the Memory Services National Accreditation Programme as per Royal College of Psychiatrists.
- Recognise why timely diagnosis of dementia is important.
- Demonstrate awareness of the supportive networks that exist outside of a hospital setting e.g. Alzheimer's Society, Age NI, Dementia Navigators, Carers NI and Dementia NI.

Learning Outcomes - Tier 3

- Evaluate local demographic population figures for dementia and have the leadership ability to ensure capacity and demand is balanced in the provision of memory clinics.
- Plan innovative ways to deliver evidence-based diagnosis service.
- Compare the presentation, prevalence and stages of the more common types of dementia.
- Assess national and international developments in dementia diagnosis.
- Outline the rare types of dementia.
- Develop an awareness of the needs of a person living with a dementia who have other co-morbidities.
- Articulate that diagnosing dementia is a sensitive issue and the person has a right to know their diagnosis. However, there are occasions where the person may not wish to know their diagnosis or their family may be reluctant for them to be told.
- Employ and use post-diagnosed services available for people living with a dementia, their families and carers.

Learning Outcomes - Tier 4

- Evaluate local demographic population figures for dementia and have the leadership ability to ensure capacity and demand is balanced in the provision of memory clinics.
- Plan innovative ways to deliver evidence-based diagnosis service.
- Assess national and international developments in dementia diagnosis.

Skills

Learning Outcomes - Tier 1

- Demonstrate sensitivity to people's needs and wishes during any interaction.

Learning Outcomes - Tier 2

- Recognise the need to refer or direct a person to specialist services if required.
- Explain the need for referral or investigation to the person with symptoms of dementia, their families and carers in a sensitive manner.

Learning Outcomes - Tier 3

- Differentiate between different types of dementia, delirium, depression and other conditions that may present similar symptoms.
- Employ a comprehensive assessment for dementia utilising appropriate investigations and tools that are scientifically tested and approved for use.
- Demonstrate how to collaborate with multidisciplinary healthcare professionals throughout the diagnostic process and thereafter.
- Organise discussions of advance care planning.
- Support people who are diagnosed with young onset dementia through specialist advice, direction and services.
- Support people who live with learning disability and are diagnosed with a dementia through specialist advice, direction and services.

Learning Outcomes - Tier 4

- Evaluate and participate in research and scientific trials.

Recommended Reading

- All Party Parliamentary Group on Dementia. (2012) *Unlocking Diagnosis: The Key to Improving the Lives of People with Dementia*: England
- Iliffe, S, Robinson, L, Brayne, C, Goodman, C, Rait, G, Manthorpe, J. and Ashley, P. (2009) Primary care and dementia: 1, diagnosis, screening and disclosure. *International Journal of Geriatric Psychiatry*, Sept, 24 (9), pp. 895-901
- Milne, A. (2010) Dementia screening and early diagnosis: The case for and against. *Health Risk and Society*, 12, (1), pp. 65-76
- Mitchell, G, McCollum, P. and Monaghan, C. (2013) The personal impact of disclosure of a dementia diagnosis: a thematic review of the literature, *British Journal of Neuroscience Nursing*, 9, (5), pp. 223-228
- Mitchell, G, McCollum, P. and Monaghan, C. (2013) Disclosing a Diagnosis of Dementia: A Background to the Phenomenon, *Nursing Older People*, 25, (10), pp. 16-21
- Mitchell, H. (2012) *Coping with Young Onset Dementia: Perspectives of Couples and Professionals*. Doctoral Thesis. Cardiff University: Cardiff
- Robinson, L, Gemski, A, Abley, C, Bond, J, Keady, J, Campbell, S, Samsi, K. and Manthorpe, J. (2011) The transition to dementia individual and family experiences of receiving a diagnosis: A review. *International Psychogeriatrics*, Feb, 23, (7), pp. 1026-43
- Sansoni, J, Duncan, C, Grootemaat, P, Capell, J, Samsa, P, Westera, A. (2016) Younger Onset Dementia: A Review of the Literature to Inform Service Development, *American Journal of Alzheimer's Disease and other Dementias: America* (Epub ahead of print)



Theme 4

Person-Centred and Relationship-Centred Dementia Care


Context

Person-centred care is advocated consistently throughout current policy and practice. It is about the consideration of the whole person during their illness, including not only their physical needs, but also their psychological, social and spiritual needs. The term is, therefore, synonymous with 'holistic' care.


In dementia care, Professor Tom Kitwood highlighted the importance of building meaningful relationships as the foundation of person-centred care in dementia services. In essence, person-centred care is premised on the values of individuality, respect, dignity, independence, choice, rights and partnership.

While person-centred care has been established for some time, practitioners and policy writers have begun to identify the associated need for relationship-centred care in the pursuit of holistic care.

This theme refers to the knowledge and skills required to foster meaningful relationships with people living with a dementia, their families and carers.



"Having person-centred care means we are treated and cared for as individuals. We can receive the quality care we are entitled to thus allowing us to live well with dementia."



"We need to see a friendly face; it is reassuring for us and lifts our morale."

Target Audience - Tiers 1 - 4

Knowledge

Learning Outcomes - Tier 1

- Recognise that people who live with a dementia must be treated with the same courtesy and respect as other people.
- Define the important contribution of family members and carers of the person living with a dementia.

Learning Outcomes - Tier 2

- Explain the principles of person-centred dementia care i.e. the human value of people living with a dementia regardless of age or cognitive impairment and those who care for them.
- Recognise the individuality of people living with a dementia, their unique personality and life experiences and how this impacts on their response to dementia.
- Recognise the importance of the perspective of the person living with a dementia.
- Examine the importance of 'personhood' in dementia care and how this can enhance or diminish a person's level of well-being.
- Summarise the role of families and carers in the care and support of people living with a dementia.
- Examine the importance of relationships and interactions with others to the person living with a dementia and their potential for promoting well-being.

Learning Outcomes - Tier 3

- Determine the value of person-centred care and relationship-centred care in therapeutic relationships and communication.
- Modify person-centred and relationship-centred approaches in the management and delivery of services.
- Outline how to incorporate person-centred and relationship-centred approaches in the management and development of services.
- Question how person-centred and relationship-centred concepts impact on how support and services are delivered.
- Appraise the importance of inter-agency and professional working in order to promote an enabling environment and culture.

Learning Outcomes - Tier 4

- Compare how different models are used to operationalise person-centred and relationship-centred care for people living with a dementia and how these can be reflected in decision making, planning and service delivery.
- Analyse the evidence for the effectiveness of different psychosocial approaches in different situations.
- Analyse the tensions in implementing person-centred and relationship-centred approaches.

Skills

Learning Outcomes - Tier 1

- Recognise that every person living with a dementia is a unique individual.
- Demonstrate how to communicate in a way that displays respect for the individual, their families and carers.

Learning Outcomes - Tier 2

- Demonstrate how people living with a dementia should be part of the decision making process in relation to their journey e.g. current and future care preferences.
- Recognise that knowledge of a person's life history can help in forming meaningful relationships with a person living with a dementia.
- Explain how to communicate in a way that does not undermine the person living with a dementia e.g. by avoiding labelling terminology such as "challenging behaviour".
- Recognise that a person living with a dementia may need to be supported by their families or carers in relation to complex decision making.
- Give examples of how to facilitate people living with a dementia to make non-complex decisions e.g. the choice of what to eat or drink.

Learning Outcomes - Tier 3

- Apply person-centred and relationship-centred approaches in the management and delivery of care.

Learning Outcomes - Tier 4

- Analyse and evaluate how person-centred and relationship-centred approaches affect the culture of the workplace.

Recommended Reading

- Brooker, D. (2006) *Person-centred dementia care: making services better*. Jessica Kingsley Publishers: London
- Brooker, D. Latham, I (2E) (2015) *Person-centred dementia care: making services better with the VIPS framework*. Jessica Kingsley Publishers: London
- Cahill, S, O'Shea, E. and Pierce, M. (2012) *Creating Excellence in Dementia Care. A Research Review for Ireland's Dementia Strategy*. National University of Ireland: Galway
- De Rynck, P, Rondia, K. and Van Gorp, B. (2012) *I am still the same person: An invitation to communicate differently about Alzheimer's Disease and related illnesses*. The European Foundations' Initiative on Dementia. www.nef-europe.org
- Dewing, J. (2008) Personhood and dementia: revisiting Tom Kitwood's ideas. *International Journal of Older People Nursing*, 3, (1), pp. 3-13
- Erol, R. Brooker, D. and Peel, E. (2015) *Woman and Dementia: a Global research review*. Alzheimer's Disease International: Worcester
- Goldsmith, M. (1996) *Hearing the Voice of People with Dementia: Opportunities and Obstacles*. Jessica Kingsley Publishers: London
- Kitwood, T. (1997) *Dementia Reconsidered: The Person Comes First*. Open University Press: Buckingham
- McDermott, S. (2015) *10 Helpful hints for when a person with dementia has to go to hospital*. Dementia Services Development Centre: Stirling
- McGreevy, J. (2015) Dementia and the person-centred care approach. *Nursing Older People*, 27, (8), pp. 27-31
- Marshall, M. (2005) *Perspectives on Rehabilitation and Dementia*. Jessica Kingsley Publishers: London
- Marshall, M. and Allan K. (eds) (2006) *Dementia: Walking not Wandering – Fresh Approaches to Understanding and Practice*: Hawker Publications Ltd: London
- Mitchell, G. and Agnelli, J. (2015) Person-centred care for people with dementia: Kitwood reconsidered, *Nursing Standard*, Oct 14, 30, (7), pp. 46-50
- NHS Institute for Improvement and Innovation (2012) *Care Homes Programme Capturing and Understanding the Experience of People Living with Dementia: An improvement guide*. NHS Institute for Innovation and Improvement, University of Warwick Science Park: Warwick
- Nolan, M, Brown, J, Davies, S, Nolan, J. and Keady, J. (2006) *The Senses Framework: Improving Care for Older People Through a Relationship-Centred Approach*. Getting Research into Practice (GRiP) Report No 2. University of Sheffield: Sheffield
- Taggart, W and Southern Health and Social Care Trust. (2014) *Eating, Drinking and Swallowing: A guide for a person living with a Dementia*. Public Health Agency and Dementia Together NI: Belfast

Theme 5

Promoting Physical, Psychological and Social Well-being in Dementia Care

Context


Dementia is caused by gradual changes within the structure of the brain. There are many types of dementia and most types cause the brain cells to breakdown and die more quickly than normal. While there is still much unknown about dementia, recent evidence suggests that there are a number of lifestyle factors that may increase a person's risk of developing a dementia.

Supporting people to live well with a dementia as well as their families and carers is at the heart of this Learning and Development Framework. While there are a number of factors that are important, the

most important to living well is a person's level of well-being.

A person's well-being may be determined by their physical health as well as psychological, social and spiritual needs. Consideration of these needs are important in attaining and sustaining well-being for people living with a dementia, their families and carers.

This theme refers to the knowledge and skills required to facilitate people to live well with a dementia.



"Dementia affects me and my loved ones. Their health and well-being is vital so that they can help and support me when I need it."

Target Audience - Tiers 1 - 4

Knowledge

Learning Outcomes - Tier 1

- Recognise that while dementia is not a normal part of ageing, growing older does increase the risk of developing dementia.
- Describe the lifestyle factors that may increase the risk of developing certain types of dementia.
- Select specialised crockery and adaptive cutlery to ensure people living with a dementia maintain their independence during mealtimes.
- Show the importance of meaningful activity and be aware of how to facilitate this.

Learning Outcomes - Tier 2

- Identify how genetic links can play a role in the development of some dementias.
- Explain how people with learning disabilities, particularly Down syndrome are at an increased risk of developing a dementia.
- Describe the importance of maintaining good physical and mental health through nutrition, exercise, relaxation and social engagement.
- Recognise the individual's specific needs e.g. nutrition, swallowing, medication, sleep or elimination needs.
- Recognise the individual's specific needs e.g. oral health, pain relief and personal care.
- Give examples of helping a person living with a dementia to maintain their independence.
- Explain how families and carers have a unique role in supporting the person living with a dementia.
- Describe the importance of a positive dining experience and its link to nutrition.
- Recognise how the use of relaxation techniques or medications may help if the person is not able to sleep.
- Recognise the impact of delirium, depression and anxiety as they are likely to diminish a person's level of well-being.
- Identify triggers that may cause a person living with a dementia to become distressed.
- Compare non-pharmacological approaches in the alleviation of distress in people living with a dementia.
- Give examples of support services for signposting to health promotion information.

Learning Outcomes - Tier 3

- Articulate the importance of contributory factors such as diet, alcohol consumption, exercise and smoking in relation to the increased risk of developing certain types of dementia.
- Demonstrate ability to refer to other agencies for support and assessment regarding relevant health promotion services.
- Appraise strategies for long term behavioural changes.

- Compare and implement health improvement strategies that will delay or reduce the onset of certain types of dementia.
- Outline the impact on well-being when a person receives a diagnosis.
- Articulate the importance of timely support, counselling and follow up.
- Compare therapeutic interventions that can enhance well-being.
- Predict the range of coping strategies that promote well-being for both the person living with a dementia, their families and carers.

Learning Outcomes - Tier 4

- Contrast the range of services and interventions that will continue to promote well-being as the person moves through the dementia journey.
- Analyse the evidence base that supports the different interventions and techniques either non-pharmacological or pharmacological.
- Appraise the key drivers and policies which influence strategic dementia service development.
- Evaluate the development of health improvement strategies.

Skills

Learning Outcomes - Tier 1

- Demonstrate how to communicate the health promotion message associated with risk reduction for certain types of dementia.

Learning Outcomes - Tier 2

- Recognise the appropriate action in relation to a person's changing physical needs e.g. gait, fatigue, dehydration, infection or fall.
- Describe how to liaise with multidisciplinary healthcare professionals if needed e.g. a dietitian if the person is losing weight.
- Explain how to support the person to maintain their personal appearance and their nutritional needs.
- Discuss how to support the person living with a dementia to maintain and express their individuality that addresses their culture, language, sexual orientation and spiritual needs.
- Demonstrate how to include families and carers in all discussions regarding care and treatment.
- Identify delirium, depression and anxiety and assess or refer to an appropriate practitioner.
- Identify and respond to any change in behaviour and refer for assessment.

Learning Outcomes - Tier 3

- Devise an active role in health promotion by providing information and advice.
- Analyse and employ behavioural change strategies or techniques that would reduce risk and potentially delay the onset and severity of certain types of dementia.
- Evaluate the effectiveness of health promotion activities.
- Plan to develop and disseminate health promotion information and advice.

Skills (continued)

- Determine when someone requires support and information.
- Assess need for and offer emotional support and counselling when diagnosis is being communicated.
- Employ a range of services for families and carers that will promote well-being as people come to terms with dementia at any stage of the journey.
- Network effectively with multi-agency organisations following an assessment of need.
- Devise a care package from diagnosis to the end of life stage that will promote well-being.

Learning Outcomes - Tier 4

- Recognise and disseminate new and evidence-based practice developments.
- Design and implement a range of interventions and techniques that may enhance well-being and be able to evaluate their effectiveness.

Recommended Reading

- Alzheimer's Society (Updated 2015) *Am I at risk of developing dementia?* www.alzheimers.org.uk
- Alzheimer's Society (Reviewed 2012) *Washing and bathing.* www.alzheimers.org.uk
- Alzheimer's Society (Reviewed 2015) *Dressing.* www.alzheimers.org.uk
- Alzheimer's Society (Reviewed 2013) *Eating and drinking.* www.alzheimers.org.uk
- Andrews, J. (2013) Maintaining continence in people with dementia, *Nursing Times*, 109, (27), pp. 20-21
- Banerjee, S. (2013) Good news on dementia prevalence – we can make a difference, *The Lancet*, 382, (9902), pp. 1384-1386
- Bauer, M, Nay, R, Tarzia, L, Fetherstonhaugh, D, Wellman, D. and Beattie, E. (2014) We need to know what's going on: Views of family members toward the sexual expression of people with dementia in residential aged care, *Dementia*, Sept, 13, (5), pp. 571-585
- Gibson, F. (2011) *Reminiscence and Life story work: A Practical guide.* Jessica Kingsley Publishers: London
- Lourida, I, Soni, M, Thompson-Coon, J, Purandare, N, Lang, I, Ukoumunne, O. and Llewellyn, D. (2013) Mediterranean diet, cognitive function, and dementia: A systematic review, *Epidemiology*, Jul, 24 (4), pp. 479- 489
- Moran, J.A., Rafii, M.S., Keller, S.M., Singh, B.K. & Janicki, M.P. (2013). The national task group on intellectual disabilities and dementia practices consensus recommendations for the evaluation and management of dementia in adults with intellectual disabilities. *Mayo Clinic Proceedings*, 88(8), 831–840
- Norton, S, Matthew, F, Barnes, D, Yaffe, K. and Brayne, C. (2014) Potential for primary prevention of Alzheimer's disease: an analysis of population-based data, *The Lancet Neurology*, 13, (8), pp. 788-794
- Reinhard, G and Colleagues. (2014) *A Guide to Psychosocial Interventions in Early Stages of Dementia*, The British Psychological Society: Leicester.
- Reinhard, G and Colleagues. (2014) *Clinical Psychology in the Early Stage Dementia Care Pathway.* The British Psychological Society: Leicester.
- Sheard, D. M. (2007) *Being; An Approach to Life and Dementia.* Alzheimer's Disease Society: London
- Sheard D. M. (2008) *Enabling: Quality of Life: an evaluation tool.* Alzheimer's Society: London

Theme 6

Holistic Approach to the Management of Dementia Care

Context

There are a number of common symptoms that are associated with dementia. These may include short-term memory loss, difficulty finding the right words, behavioural or personality changes, disorientation and reduced independence.

While there is currently no cure for dementia, there are a number of non-pharmacological and pharmacological interventions which can be employed to assist with the management of symptoms. Similarly, less formalised types of art, music making and creative activities can be beneficial.

A holistic approach to the management of dementia will improve quality of life and enable the person to live better with a dementia.

This theme refers to the knowledge and skills required to support people living with a dementia to overcome symptoms using non-pharmacological and pharmacological approaches.

“Sometimes we need interventions such as medication or complementary therapies to help us live life as independently and comfortably as possible.”

Target Audience - Tiers 2 - 4

Knowledge

Learning Outcomes - Tier 2

- Identify the common symptoms associated with different types of dementia and how these change through the different stages.
- Describe the current recommended cognitive enhancing medications for dementia, their main benefits and risks of cognitive enhancing medication.
- Describe the importance of non-pharmacological interventions in dementia care such as cognitive stimulation therapy, music or art therapy and be aware that any intervention should be therapeutic.
- Explain the main classes of medication that are used in dementia care e.g. antidepressants, anxiolytics, antipsychotics, analgesia and sedatives.
- Explain how oral medication may not always be best for the person living with a dementia.
- Recognise that undiagnosed pain is common in dementia and this can manifest as distress.
- Discuss how over prescription of antipsychotic medication is common.
- Describe how antipsychotic medication should only ever be used under the supervision of an appropriately qualified medical officer.
- Examine the issues around poly-pharmacy for people living with a dementia.

- Demonstrate the importance of recording and reporting side effects of medication.

Learning Outcomes - Tier 3

- Explain the importance of reminiscence and helping people living with a dementia to create memory boxes.
- Examine non-pharmacological cognitive enhancing treatments.
- Predict when cognitive enhancing medication should be commenced and discontinued.
- Explain that cognitive enhancing medication is only appropriate for use in some types of dementia.
- Consider the contra-indications of prescribing a combination of medication e.g. antipsychotic medications and anxiolytic medications.
- Undertake a professionally relevant and accredited prescribing course.

Learning Outcomes - Tier 4

- Analyse new and emerging non-pharmacological and pharmacological interventions that may be used to enhance the well-being of people living with a dementia.
- Evaluate national and international developments in research regarding symptom management.

Skills

Learning Outcomes - Tier 2

- Administer medication if your role dictates and review safely and appropriately in partnership with people living with a dementia.
- Select an appropriate and validated pain assessment tool to establish if a person is in pain.
- Select an appropriate and validated depression assessment tool to establish if a person may be depressed.
- Select an appropriate and validated delirium assessment tool to establish if a person has a delirium.
- Select an appropriate and validated behavioural assessment tool.
- Summarise the legislation around Duty of Care and Best Interests.
- Apply best practice guidance on restrictive interventions.
- Organise regular pain assessments in people living with a dementia and take the appropriate action.
- Consider and initiate cognitive stimulation exercises.

Learning Outcomes - Tier 4

- Teach other care staff to deliver non-pharmacological interventions in practice.
- Evaluate and influence randomised clinical trials and be able to take part in local and/or national studies.

Learning Outcomes - Tier 3

- Employ non-pharmacological approaches in practice e.g. reality orientation, validation, reminiscence and a range of therapies i.e. music, pet, doll and horticultural.
- Review of prescribed medications, including cognitive enhancers, antipsychotic medications and determine if these need to be prescribed.
- Liaise with multidisciplinary team members to ensure that symptom management of dementia is maintained.

Recommended Reading

- Bidewell, J. and Chang, E. (2011) Managing dementia agitation in residential aged care, *Dementia*, Aug, 10, (3), pp. 299-315
- Brooker, D. & Duce, L. (2000) Well-being & activity in dementia: A comparison of group reminiscence therapy, structured goal directed group activity and unstructured time. *Aging & Mental Health*, 4, (4), pp. 354-358
- Cohen-Mansfield, J. (2005) Non-pharmacological interventions for persons with dementia, *Alzheimer's Care Quarterly*, 6, (2), pp. 129-145
- Delirium experience - www.youtube.com/watch?v=A-ILLP8Me0E
- De Rynck, P. Rondia, K. and Van Gorp, B. (2011) *I am still the same person. An invitation to communicate differently about Alzheimer's Disease and related illnesses*. The European Foundations' Initiative on Dementia: Belgium
- Dodd, K & Bush, A (2013) Quality Outcome Measure for Individuals with Dementia (QOMID). Accessible from http://dcp-ld.bps.org.uk/dcp-ld/useful-links-and-info/useful-linksand-info_home.cfm.
- Duffy, F (2016) Look at all of me; a Clear model for dementia care. *The Journal of Dementia Care*, 22(3), 27-30
- Gibson, F. (2005) *Reminiscence with People with Dementia*. Ulster University: Belfast
- James, I, Mackenzie, L, Pakrasi, S. et al (2008) Non-pharmacological treatments of challenging behaviour. *Nursing Residential Care*, 10, (5 and 6), pp. 228-32 and pp. 290-2
- Jones, S. and Mitchell, G. (2015) Assessment of pain and alleviation of distress for people living with a dementia, *Mental Health Practice*, 18, (10), pp. 32-36
- Killick, J. and Allen, K. (2001) *Communication and the Care of People with Dementia*. Open University Press: Buckingham
- McAlpine, C. (2014) *Think frailty and delirium – the Scottish approach* www.bgs.org.uk/index.php/component/content/article/303-newsletter/3118-nlaug14-think-frailty-and-delirium
- Mitchell, G. and Agnelli, J. (2015) Non-pharmacological approaches for alleviating distress in dementia care, *Nursing Standard*, Nov, 25, 30 (13), pp. 38-44.
- Mitchell, R. and Chapman, A. (2007) *Dementia Skill Starters: Booklet 6. Understanding the Importance of Life Story Work*. Dementia Services Development Centre: Stirling
- Mullan, M. and Killick, J. (2001) *Responding to Music*. Dementia Services Development Centre: Stirling
- Prasher, V.P, Adams, C. & Holder R. (2003) Long-term safety and efficacy of donepezil in the treatment of dementia in Alzheimer's disease in adults with Down syndrome: open-label study. *International Journal of Geriatric Psychiatry*, 8, 549-51.
- SCIE (2004) Dignity in Care <http://www.scie.org.uk/publications/guides/guide15/factors/choice/>
- Volkmer, A. (2013) *Assessment and Therapy for Language and Cognitive Communication in Dementia and Other Progressive Diseases*: J & R Press.

Theme 7

Promoting Enabling Environments

Context

People living with a dementia should be encouraged to maintain their independence for as long as possible. Due to the clinical manifestations of dementia, coupled with any other underlying conditions, people who live with dementia may have sight, mobility or hearing impairments. For example, people living with a dementia may need more light to overcome certain visual difficulties or they may not be able to differentiate between certain colours. In relation to reduced hearing, often as a result of growing older, there may be a need for a quieter environment in order to hear and comprehend.

These impairments can negatively impact on the person living with a dementia particularly if the environment has not been considered from the perspective of someone living with a dementia. Through promoting an enabling environment, either at home, in the community or in a hospital setting, this should remove or avoid any matters which could further impair people living with a dementia.

This theme refers to the knowledge and skills required to promote the use of environmental and technological aids which facilitate people living with a dementia to live well.

“Simple changes to my home and the places I go to means that I’m able to live comfortably and feel safe in my environment. A lack of knowledge of people in places like hospitals, clinics, public places is very frustrating for me as people aren’t aware of how to support and deal with people like me.”

Target Audience - Tiers 1 - 4

Knowledge

Learning Outcomes - Tier 1

- Recognise that some people living with a dementia may have sensory impairments.
- Recognise that some people living with a dementia may become disorientated to their current time and place and may need signposted or accompanied to their destination.
- Describe the importance of good lighting and clutter free environments.

Learning Outcomes - Tier 2

- Recognise that some people living with a dementia will experience decline in vision due to the ageing eye.
- Explain the importance of signage in dementia care e.g. signs that direct people to where the nearest bathroom is and the importance of environmental design i.e. flooring, use of colours and lighting.
- Examine how positive risk is advocated in dementia care and people living with a dementia should be facilitated, where possible, to engage in modes of life which they enjoy.
- Discuss how because of disorientation, people living with a dementia may not be familiar in their environment but this might be helped by personalisation e.g. personal memorabilia such as photographs which are recognisable or personal memory boxes.
- Define the benefits and limitations of assistive technology in dementia care.
- Describe the roles of multidisciplinary team members who can advise on equipment, assistive technologies or adaptations e.g. an occupational therapist.

Learning Outcomes - Tier 3

- Give examples of the types of assistive technologies that are available in relation to communication aids e.g. daily living aids, vision and reading aids, environmental aids and ergonomic aids.
- Summarise the range of agencies involved in promoting an enabling environment and be able to signpost to these agencies for specific support.
- Compare the key legislation relevant to mental capacity, deprivation of liberty, equality and human rights.
- Discuss the ethical dilemmas in the environment that may present obstacles in practice.
- Consider best practice in environmental design.
- Analyse specific risk assessment and management tools that can be applied to identify and manage environmental risks acknowledging this is the person's own home or preferred way of living.
- Contrast the reasons and rationale behind risk taking or risk aversion.

Learning Outcomes - Tier 4

- Evaluate policy direction on assistive technologies and environmental design.
- Appraise national and international evidence base around promoting safe enabling environments and managing associated risks.

Skills

Learning Outcomes - Tier 1

- Demonstrate how to make basic changes to the environment to benefit people living with a dementia e.g. ensuring areas have appropriate lighting (natural and/or artificial) and that 'way finding' signs are in place for direction.
- Recognise when people require help with mobility or require assistance with access or restriction to access.

Learning Outcomes - Tier 2

- Identify ways to adapt the physical environment to suit a person's changing needs on their journey in dementia.
- Outline how to support families and carers to modify their environment to support safe environments and benefit the person living with a dementia.

Learning Outcomes - Tier 3

- Develop and lead on the introduction of assistive technology to support self-care and meaningful activity.
- Support and provide dementia specific expert advice, education and guidance on technology which enhances the physical and social environment.
- Demonstrate ability to manage and take "therapeutic risks" within the appropriate environment, whilst working safely and ethically.
- Apply flexible and responsive approaches to eliminating risk aversion.

Learning Outcomes - Tier 4

- Design and influence policy direction within the environment.
- Formulate evidence and evaluate thresholds that promote safety within an on-going therapeutic context.
- Justify and influence the planning and provision of supportive environments at a strategic level.

Recommended Reading

- Alzheimer's Society (2011) *Support, Stay, Save, Care and Support of People with Dementia in Their Own Homes*. Alzheimer's Society: London
- Andrews, J. and Cunningham, C. (2010) *10 Helpful Hints for Dementia Design at Home: Practical Design Solutions for Carers Living at Home with a Person Who Has Dementia*. Dementia Services Development Centre: Stirling
- Davis, S, Byers, S, Nay, R. and Koch, S. (2009) Guiding design of dementia friendly environments in residential care settings: Considering the living experiences. *Dementia*, May, 8, (2), pp. 185-203
- Fleming, R. and Purandare, N. (2010) Long-term care for people with dementia: environmental design guidelines. *International Psychogeriatrics*, 22, (7), pp. 1084-1096
- Fleming, R, Goodenough, B, Low, L, Chenoweth, L. and Brodaty, H. (2014) The relationship between the quality of the built environment and the quality of life of people with dementia in residential care, *Dementia*, May, 13, (3), pp. 289-425
- Lee, S, Chaudhury, H. and Hung, L. (2014) Exploring staff perceptions on the role of the physical environment in dementia care setting, *Dementia*, May, 13, (3), pp. 289-425
- Martin, S, Kelly, G, Kernohan, G, McCreight, B. and Nugent, C. (2007) *Smart home technologies for health and social care support* (Review) The Cochrane Collaboration. John Willey and Sons Ltd: London, Issue 1, Journal Article no. CD006412
- O'Shea, E, Manning, E, Ross, E, McErlean, S, Timmons, S. (2015). *Northern Ireland Audit of Dementia Care in Acute Hospitals 2015*: Northern Ireland Audit of Dementia Steering Committee and Advisory Group, Murphy Print and Design: Killarney, Ireland
- Pollock, A. and Fuggle, L. (2013) Designing for dementia: creating a therapeutic environment. *Nursing & Residential Care*, 15, (6), pp. 438-442
- Rahman, S. (2014) *Living Well With Dementia: The Importance of the Person and the Environment for Well-being*. Radcliffe Publishing: London

Theme 8

Legal and Ethical Considerations in Dementia Care

Context

Staff working with people living with a dementia must be fully aware of their Duty of Care as they may be required to help make decisions where people are unable to make decisions on their own. This will include putting emphasis on capacity, ability and autonomy to empower their decision making to the best of their ability.

Duty of Care is about acting in the best interest of others and not acting or failing to act in ways that result in harm. In dementia care, this is likely to include ethical issues such as the need to balance a person's safety with their need for independence, making decisions about their ability to consent to treatment and recognising that the views of the person living with a dementia may sometimes conflict with the opinions of family members.

People living with a dementia may also be vulnerable to situations where they could suffer neglect, harm or exploitation. In recent years a number of high profile cases have highlighted distressing examples where there have been failings in the Duty of Care as documented in the Francis Report (2013) and the Cavendish Review (2013). These reports serve to highlight the vital importance of staff raising concerns and acting on them before it is too late. Therefore, health and social care staff must be able to recognise and address any areas of concern and have the confidence to speak out when required.

This theme refers to the knowledge and skills required to provide care in a legal and ethical way for people living with a dementia.

“On occasions we need our family and friends to make decisions on our behalf when we are unable to make these decisions. They have to act in our best interests to ensure we are looked after safely.”

Target Audience - Tiers 1 - 4

Knowledge

Learning Outcomes - Tier 1

- Recognise the rights and choices of people living with a dementia, their families and carers.
- Recognise own responsibility to refer on any concerns of harm or risk and the need for supportive decision making.

Learning Outcomes - Tier 2

- Identify ethical dilemmas that may present in practice.
- Identify Duty of Care and how this contributes to safe practice.
- Recognise that people living with a dementia may experience fluctuations in their ability to make decisions.
- Identify recommended action to take if a person living with a dementia lacks mental capacity.
- Recognise how Best Interest decisions are made for those who lack mental capacity.
- Identify local legislation and policy relevant to mental capacity, deprivation of liberty, equality and human rights including the Adult Safeguarding Prevention and Protection in Partnership Policy 2015.
- Identify the professional codes of practice with regard to information recording, handling, confidentiality, informed consent and disclosure.
- Identify restrictive practices and its application in the care planning process including recording, implementing and review.

Learning Outcomes - Tier 3

- Compare the roles and responsibilities of the different agencies involved in safeguarding investigations and the importance of sharing safeguarding information with relevant agencies.
- Recognise the options available when informed consent can be compromised.
- Explain advance decisions and how these can impact on care preferences.
- Explain advance directives and how these can impact on care preferences.
- Illustrate knowledge of the Adult Safeguarding Prevention in Partnership Policy July 2015.

Learning Outcomes - Tier 4

- Illustrate knowledge of national and international policy developments in health with respect to mental health and older people's services.

Skills

Learning Outcomes - Tier 1

- Demonstrate ability to communicate concerns.

Learning Outcomes - Tier 2

- Communicate effectively about proposed treatment or care to enable people living with a dementia to make informed choices as far as possible.
- Recognise neglect, abusive or exploitative practice and how to raise concerns to the Adult Safeguarding Teams.

- Demonstrate accountability and responsibility for own professional judgement and actions and work within professional boundaries and scope of practice.
- Identify unsafe practice and take appropriate action.
- Consider own beliefs and values and reflect on how these may influence care giving.
- Outline the values, customs, spiritual beliefs and practices of individuals/groups to exercise culturally competent practice.
- Report and record activities in line with professional guidelines and local policies.
- Complete visible and sequential recording of events.
- Demonstrate ability to recognise and report any concerns.
- Demonstrate ability to appropriately challenge health care practices which could compromise the safety, privacy or dignity of the person living with a dementia.
- Apply sensitive and emotional intelligence in dealing with the issue whilst it is being investigated.

Learning Outcomes - Tier 4

Learning Outcomes - Tier 3

- Demonstrate ability to initiate Safeguarding alerts and referrals.
- Demonstrate ability to implement legislation such as: Human Rights Act 1998, The Mental Health (Northern Ireland) Order 1986, Disability Discrimination Act 1995, Health and Personal Social Services (Northern Ireland) Order 1972, The Carers and Direct Payments Act (NI 2002), Mental Capacity Act (Northern Ireland) 2016 (when enacted), to support people with a dementia.
- Demonstrate ability to communicate and report concerns.
- Demonstrate ability to communicate and co-operate with the Adult Safeguarding Team.

Recommended Reading

- Alzheimer's Society (2014) *Deprivation of Liberty Safeguards*. Alzheimer's Society: London
- Department of Health (2009) (2E) *Reference guide to consent for examination or treatment*. Department Of Health: London
- Department of Health (2014) *Care and support statutory guidance: Issued under the Care Act 2014*. Department Of Health: London
- DHSSPS (2015) *Adult Safeguarding Prevention and Protection in Partnership Policy*. Department of Health, Social Services and Public Safety and Department of Justice: Belfast
- DHSSPS (2003) *Good Practice in Consent. Consent for examination, treatment or care: A handbook for the HPSS*. Department of Health, Social Services and Public Safety: Belfast
- Nuffield Council on Bioethics (2009) *Dementia: Ethical Issues*. Nuffield Council on Bioethics: London



Theme 9

Equality, Cultural Diversity and Inclusion in Dementia Care

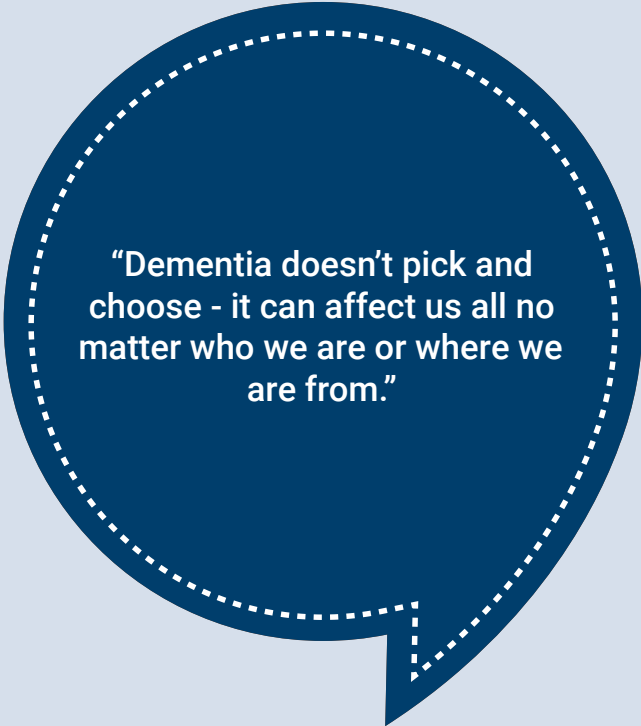
Context

Treating all people living with a dementia as equal partners in care is an important enabling factor in relation to living well. Equality is of particular importance in dementia care for people living with younger onset dementia, learning disability and dementia or people with a dementia from the LGBT community, ethnic minorities and the traveller community.

Essentially dementia affects people from all cultural and ethnic backgrounds. A good awareness of how issues of cultural diversity can differentially

impact on people affected with a dementia is important. This includes acceptance of their condition within their family or wider community as well as their ability to access services or early diagnosis.

This theme refers to the knowledge and skills required to support people living with a dementia from different cultural and ethnic backgrounds.



“Dementia doesn’t pick and choose - it can affect us all no matter who we are or where we are from.”

Target Audience - Tiers 1 - 4

Knowledge

Learning Outcomes - Tier 1

- Appreciate that all people regardless of age, disability, culture, sexual orientation, gender identity or ethnic background should be treated with respect and dignity.
- Recognise family diversity and cultural variations.
- Identify access to a range of support services i.e. Interpreters.

Learning Outcomes - Tier 2

- Recognise age, cultural diversity and equality issues and how these may impact on people living with a dementia.
- Recognise that all people from different cultures may have different approaches to living with a dementia.
- Recognise the stigma that is often associated with dementia and help overcome this.
- Recognise the prevalence of younger onset dementia and its impact on their families.
- Consider the impact of dementia on people who live with learning disabilities.
- Understand that people living with a dementia whether younger, older or learning disabled will have individual interests and hobbies.
- Recognise the importance of reducing stigma in any person living with a dementia, regardless of age, gender, sexual orientation, culture or marital status.

- Consider the impact of dementia on families and carers who are from different cultural backgrounds.
- Consider the impact of dementia on younger family members or carers.

Learning Outcomes - Tier 3

- Consider the impact that discrimination and stigma may have on the person living with a dementia, their families and carers.
- Consider legislation relevant to equality, diversity and human rights.
- Examine the importance of cultural diversity throughout advance care planning.
- Examine the impact that health inequalities and social deprivation have on the emotional well-being and mental health of people living with a dementia.

Learning Outcomes - Tier 4

- Recognise how practice can compromise as well as promote a person's right to dignity, respect and safety.

Skills

Learning Outcomes - Tier 1

- Demonstrate sensitivity to differences in family diversity and cultural variation.
- Demonstrate ability to refer to appropriate support services.

Learning Outcomes - Tier 2

- Demonstrate ability to carry out assessments and care planning sensitively, particularly around issues pertaining to cultural diversity, disabilities, gender and sexual orientation.
- Demonstrate ability to deliver care that is based on individual needs and is person-centred.
- Demonstrate ability to actively challenge and discourage any discriminatory practice that may compromise a person's right to dignity, respect or safety.
- Demonstrate cognisance of spiritual beliefs.

Learning Outcomes - Tier 3

- Give examples of local policies and procedures pertaining to equality, diversity and cultural diversity.
- Apply practices that positively engage with and respect cultural diversity.

Learning Outcomes - Tier 4

- Demonstrate ability to lead practice and create an organisational culture that values and respects the cultural diversity of individuals.

Recommended Reading

- Alzheimer's Society (2013) All Party Parliamentary Group on Dementia. *Dementia does not Discriminate: The Experience of Black, Asian and Minority Ethnic Communities* Alzheimer's Society: London
- Alzheimer's Society (2012) *Supporting Lesbian, Gay and Bisexual people with dementia*. Alzheimer's Society: London
- Botsford, J. and Harrision-Dening, K. (2015) *Dementia, Culture and Ethnicity*. Jessica Kingsley Publishers: London
- British Psychological Society (April 2015) *Dementia and People with Intellectual Difficulties: Guidance on the Assessment, Diagnosis, Interventions and Support of People with Intellectual Difficulties who Develop Dementia*. British Psychological Society: Leicester
- British Psychological Society & Royal College of Psychiatrist (2015). *Dementia and people with learning disabilities: Guidance on the assessment, diagnosis, treatment and support of people with learning disabilities who develop dementia*. Leicester: British Psychological Society.
- Harris, P. and Keady, J. (2009) Selfhood in younger onset dementia: Transitions and testimonies, *Aging and Mental Health*, 13, (9), pp. 437-444
- Hughes, C J, (2013) "Y" feel me? How do we understand the person with dementia, SAGE: London
www.dem.sagepub.com/content/early/2013/04/16/1471301213485374
- McDonnell, E. and Ryan, A. (2013) *The Experience of Sons Caring for a Parent with Dementia*.
- Mitchell, H. (2012) *Coping with Young Onset Dementia: Perspectives of Couples and Professionals*. Doctoral Thesis. Cardiff University: Cardiff
- Northamptonshire Healthcare, (2010) *Dementia Care Pathway for People with a Learning Disability*, British Psychological Society: Leicester
- Peel, E, McDaid, S, *Over the Rainbow - Lesbian, Gay, Bisexual and Transgender People and Dementia Project Summary Report (2015)*, University of Worcester: Worcester
www.dementiavoices.org.uk/wp-content/uploads/2015/03/Over-the-Rainbow-LGBTDementia-Report.pdf
- Public Health Agency (2014), *See Me, Hear Me, Know Me - Guidelines to support the needs of Older Lesbian, Gay, Bisexual and Transgender people in nursing, residential, and day care settings and those who live at home and receive domiciliary care*, <http://www.publichealth.hscni.net/publications/see-me-hear-me-know-me%E2%80%99-guidelines>
- Truswell, D. (2013) *Black and minority ethnic communities with dementia: Where are we now?* Race Equality Foundation: London
- Watchman K. (2003) Critical Issues for Service Planners and Providers of Care for People with Down's syndrome and Dementia, *British Journal of Learning Disabilities*, 31, pp. 81 – 84.

Theme 10

Palliative Care in Dementia/ End of Life Dementia Care

Context

Dementia is considered as a progressive, incurable condition. Palliative Care is “an approach that improves the quality of life” of people and their families facing the issues associated with life limiting conditions (WHO, 2002). Therefore all people living with a dementia are entitled to well planned, good quality, timely palliative care.

Currently there is still a widely held belief that palliative care should only be considered in the final months of life but in fact current best practice evidence suggests that it should be considered as close to diagnosis as possible to enable the person living with a dementia to contribute to their future care preferences.

‘End of life is the period of time during which an individual’s condition deteriorates to the point where death is either probable or would not be an unexpected event within the ensuing 12 months, however, a specific timescale cannot always be applied’ (DHSSPS 2010).

In relation to end of life care, care staff should carefully consider the person’s physical, psychological, social and spiritual needs. Importantly, palliative care does not cease when a person passes away as supportive bereavement care should always be afforded to the person’s family and carers.

This theme refers to the knowledge and skills required to actively support people living with a dementia, their families and carers, to plan their future care as well as fulfil end of life wishes.

“I need to understand what this involves and what my options are. I want to make sure my personal needs and wishes are met when I reach this stage of my life. I need to be able to plan this with my family and that everyone is aware of my final wishes.”

Target Audience - Tiers 1 - 4

Knowledge

Learning Outcomes - Tier 1

- Recognise the range of communication strategies.

Learning Outcomes - Tier 2

- Recognise that the terms palliative care and end of life care are different.
- Recognise that people living with a dementia will require palliative care and/or end of life care.
- Recognise that commencement of palliative care discussions should take place at an early stage when the person living with a dementia is likely to have a higher degree of mental capacity.
- Recognise appropriately validated tools to inform holistic patient assessment.
- Determine how advance care plans or advance directives are recorded.
- Recognise the importance of shared communication between the multidisciplinary team, the person living with a dementia, their families and carers.
- Recognise the cultural, spiritual and religious differences associated with death.

Learning Outcomes - Tier 3

- Recognise supportive frameworks that are utilised for breaking bad news.
- Recognise that all staff have a Duty of Care to family members of a person who passes away.
- Identify appropriate supportive services available (statutory and voluntary) e.g. All Ireland Institute of Hospice and Palliative Care 'Hub' and be able to articulate on how to access these.

Learning Outcomes - Tier 4

- Recognise regional and national strategic drivers with regards to both dementia and palliative care.

Skills

Learning Outcomes - Tier 1

- Demonstrate sensitive and effective verbal and non-verbal communication skills with people living with a dementia, their families and carers.
- Recognise the individual's specific needs e.g. nutrition, swallowing, medication, sleep or elimination needs.

Learning Outcomes - Tier 2

- Recognise indicators suggestive of when a person is likely to be nearing end of life.
- Use appropriate validated tools to inform holistic assessment.
- Support people living with a dementia to fulfil their spiritual, cultural and religious needs.
- Demonstrate use of relevant frameworks for breaking bad news.
- Describe how to support and facilitate families and carers who wish to remain with the person nearing end of life.
- Anticipate the spiritual, cultural and religious needs of a person nearing end of life.

Learning Outcomes - Tier 3

- Understand, develop and progress advance care plans.
- Demonstrate the use of sensitive communication to the person living with a dementia, their families and carers about future care preferences.
- Apply supportive palliative care frameworks that have been utilised in dementia care.
- Organise family conferences and update the person living with dementia, their families and carers about their management of care on a regular basis.
- Recognise when a person is likely to be in the end of life phase.
- Recognise that hospitalisation is not always appropriate for people living with a dementia.

Learning Outcomes - Tier 4

- Demonstrate appropriate leadership skills to influence provision of quality, palliative and end of life care.
- Demonstrate understanding of the change process and how you could enable change in practice.
- Demonstrate effective communication and dissemination of knowledge and information to others that will promote positive outcomes for people with a dementia, their families and carers.

Recommended Reading

- Arcand, M, Brazil, K, Nakanishi, M, Nakashima, T, Alix, M, Desson, J, Morello, R, Belzile, L, Beaulieu, M, Hertogh, C, Toscani, F. and van der Steen, J. (2013) Educating families about end-of-life care in advanced dementia: Acceptability of a Canadian family booklet to nurses from Canada, Japan and France, *International Journal of Palliative Nursing*, 19, (2), pp. 67-74
- Brazil, K, Brink, P, Kaasalainen S, Kelly ML, McAiney, L. (2012) Knowledge and perceived competence among nurses caring for the dying in long-term care homes, *International Journal of Palliative Nursing*, 18, (2), pp. 77-83
- CARDI Grants Programme: Research Brief (2012) *Medication Use in Patients with Dementia at End of Life*, www.cardi.ie
- Dempsey, L, Dowling, N, Larkin, P, Murphy, K. (2015) The unmet palliative care needs of those dying with dementia. *International Journal of Palliative Care Nursing*, 21, (3): pp. 126-33
- DHSSPS (2010) *Living Matters, Dying Matters. A Strategy for Palliative and End of Life Care in Adults in Northern Ireland*. DHSSPS: Belfast
- DHSSPS (2013) *Guidelines for palliative and end of life care in nursing homes and residential care homes*, GAIN Guidelines, DHSSPS: Belfast.
- Harrison-Dening, K, Jones, L and Sampson, E. (2011) Advance care planning for people with dementia: A review, *International Psychogeriatric*, 23, (10), pp. 1535-1551
- Kovach, C. (ed) (1997) *Late Stage Dementia Care. A Basic Guide*. Taylor and Francis: USA
- Mitchell, G, Agnelli, J, McGreevy, J, Diamond, M, Roble, H, McShane, E. and Strain, J. (2016) Optimum delivery of palliative and end-of-life care for people living with dementia in care home settings, *Nursing Standard* (in press)
- NIPEC (2011) *Palliative and End of Life care Competency Assessment Tool*. HSCB: Belfast
- Pace, V, Treloar, A, Scott, S (2011) *Dementia from advanced disease to bereavement*. Oxford University Press: Oxford
- The National Council for Palliative Care (2012) *How Would I Know? What Can I Do? How to help someone with dementia who is in pain or distress*. The National Council for Palliative Care: London.
- Volicer, L (2013) Palliative Care in dementia. *Progress in Palliative Care*, 21,(3) pp. 146-150, Taylor and Francis Online

Theme 11

Working in Partnership with Families and Carers


Context

A large proportion of support and care that people living with a dementia receive is actually undertaken by their families and carers. Family members and carers of people who live with a dementia often report high levels of stress, depression and social isolation.

Often family members reluctantly relinquish part of their caring role when the needs of the person living with a dementia become too much or if their own health deteriorates. Health and social care staff have a role in enabling and empowering families and carers throughout the journey of dementia to ensure that they are well

informed regarding the condition, available training and support as well as actual service provision. Importantly, family and carers should be considered as equal partners, alongside the person living with a dementia and the healthcare professional team in the pursuit of person-centred and relationship-centred care.

This theme refers to the knowledge and skills needed to support family members and carers affected by dementia in a practical and holistic way.



“Carers need and deserve so much help and support... we could not live without them.”

Target Audience - Tiers 1 - 4

Knowledge

Learning Outcomes - Tier 1

- Appreciate that families and carers have an important role throughout the dementia care journey.

Learning Outcomes - Tier 2

- Accept that families and carers are likely to have specialist knowledge about the person living with a dementia that will help in the delivery of care.
- Understand the importance of developing partnerships with family members and carers.
- Examine the impact of caregiving on family members and carers.
- Recognise the complexity and diversity of family relations.
- Recognise the needs of families or carers may not always be met.
- Recognise the impact caring has on younger people.

Learning Outcomes - Tier 3

- Examine legislation relevant to families and carers.
- Examine methods of assessment of carers needs.
- Recognise the potential for conflict and ethical dilemmas which can occur.

Learning Outcomes - Tier 4

- Critically appraise international initiatives and best practice guidelines in empowering and involving carers.

Skills

Learning Outcomes - Tier 1

- Demonstrate respect and understanding.

Learning Outcomes - Tier 2

- Communicate compassionately with family and carers throughout the person's journey.
- Involve families and carers in decision making where appropriate.

Learning Outcomes - Tier 3

- Explain to families or carers how to access supportive networks e.g. The Alzheimer's Society, Age NI, Dementia NI, Dementia Navigators and Carers NI.
- Show family members and carers how they contribute to the decision making process.
- Assess a family member or carer's psychological and practical needs.
- Articulate to carers where to access further support around legal issues e.g. Enduring Power of Attorney.

Learning Outcomes - Tier 4

- Articulate to carers where to access international forums and training opportunities.

Recommended Reading

- Andrews, J, and House, A (2009) *10 Helpful Hints for Carers – Practical Solutions for Carers Living with people with Dementia*, Dementia Services Development Centre: Stirling
- Cahill, S. and Moore, V. *Cognitive Impairment and Dementia: A Practical Guide to Daily Living for Family Care Givers*. Trinity College: Dublin,
- Cahill, S. and O’Cahen Y, D. *Specialist Care Units for People with Dementia in Ireland: A Guide for Family Care Givers and Health Service Professionals*. The Dementia Services Information and Development Centre. St James’s Hospital: Dublin.
- Dementia Services Development Centre (2015) *10 Helpful Hints for When a Person with Dementia has to go to Hospital*, Dementia Services Development Centre: Stirling
- Dementia Services Development Centre (2010) *10 Helpful Hints for Dementia Design at Home, Practical design solutions for carers living at home with someone who has dementia*, Dementia Services Development Centre: Stirling
- Etters, L, Goodall, D. and Harrison, B. (2008) Caregiver burden among dementia patient caregivers: A review of the literature, *Journal of the American Association of Nurse Practitioners*, 20, (8), pp. 423-428
- Newbronner, L, Chamberlain, R, Borthwick, R, Baxter, M. and Glendinning, C (2013) *A Road Less Rocky: Supporting Carers of People with Dementia*. Carers Trust: London
- Ryan, A, Taggart, L, Truesdale-Kennedy, M. and Slevin, E. (2014) Issues in caregiving for older people with intellectual disabilities and their ageing family carers: A review and commentary, *International Journal of Older People Nursing*, 9, (3). pp. 217-226
- Thomas, P, Lalloue, F, Preux, P, Hazif-Thomas, C, Pariel, S, Inscale, R, Belmin, J. and Clement, J. (2006) Dementia patients caregivers quality of life: the PIXEL study, *International Journal of Geriatric Psychiatry*, 21, (1), pp. 50-56



Theme 12

Research and Evidence-based Practice in Dementia Care


Context

The Prime Minister's Challenge on Dementia (2015) asserted that "boosting research in dementia care will also require more of the nurses, allied health professionals, social work and other care professionals who lead and deliver care, to be trained to become researchers, able to lead research on issues that matter most to patients and carers, and to deliver results into clinical practice". (DOH, 2015).

The development of dementia services and care can only come about through on-going research, practice development, service evaluation and audit.

Importantly, these findings must be disseminated widely to improve the care experience and to assist in the development of dementia services.

This theme refers to the knowledge and skills that are needed to develop dementia care practice through the use of evidence-based practice and research.



"More research is essential; we really need to get a cure for dementia."

Target Audience - Tiers 2 - 4

Knowledge

Learning Outcomes - Tier 2

- Articulate service development processes and evidence-based practice e.g. data collection, audit, user involvement and research.
- Evaluate the service on an on-going basis and contribute to evidence-based practice with regard to the mental health and well-being of people living with a dementia their families and carers.
- Evaluate service developments and delivery in relation to the mental health and well-being of people living with a dementia, their families and carers.

Learning Outcomes - Tier 3

- Critically evaluate the service on an on-going basis and contribute to evidence-based practice with regard to the mental health and well-being of a person living with a dementia, their families and carers.
- Critically evaluate service developments and delivery in relation to the mental health and well-being of a person living with a dementia, their families and carers.
- Distinguish the difference between service evaluation and empirical research in dementia.
- Consider people living with a dementia, their families and carers who may wish to contribute to service evaluation and empirical research in dementia.

Learning Outcomes - Tier 4

- Critique systematic research methods and be able to facilitate evidence-based practice.
- Collect the range of evidence that informs decision making, care practice and service delivery.
- Recognise approaches to evaluation of services or measuring service impact.
- Recognise the ethical processes involved in conducting and participating in empirical research.
- Recognise the importance of continuing professional development to ensure the methods used are robust, valid and reliable.

Skills

Learning Outcomes - Tier 2

- Demonstrate ability to access research and use information systems.
- Use and evaluate evidence-based practice to enhance care and services provided with regard to the emotional well-being and mental health of people living with a dementia.
- Collate data and information in relation to people living with a dementia to support service improvements.
- Develop a culture of learning and development with regard to the mental health and well-being of people living with a dementia.
- Initiate and manage practice or service development regarding the emotional well-being and mental health of a person living with a dementia, their families and carers, taking account of relevant research, clinical guidelines and policy.

Learning Outcomes - Tier 4

Learning Outcomes - Tier 3

- Participate in or facilitate service evaluation and empirical research in the workplace.
- Contribute to and generate research to inform evidence-based practice with regard to the mental health and well-being of a person living with a dementia, their families and carers.
- Apply continuous quality improvement approaches to identify gaps and develop services that are evidence-based and meet organisational or governmental priorities.
- Disseminate research in relation to mental health and well-being of a person living with a dementia, their families and carers.
- Disseminate international service evaluations or empirical research findings in written reports or by verbal presentations.
- Show skills in systematic research methods and be able to facilitate and evaluate evidence-based practice.
- Critique the range of evidence that informs decision making, care practice and service delivery.
- Develop new approaches to the evaluation of services for the measuring of service impact.
- Analyse and respond to the ethical issues and processes involved in conducting and participating in empirical research.
- Undertake continuing professional development to ensure the methods used are robust, valid and reliable.

Recommended Reading

- Babbie E (2007) *The Practice of Social Research*, California: Wadsworth
- Bowling A (2009) *Research Methods in Health (3rd Ed)*, Buckingham: Open University Press
- Bryman A (2012) *Social Research Methods*, New York: Oxford University Press
- Cahill, S, O'Shea, E. and Pierce, M. (2012) *Creating Excellence in Dementia Care A Research Review for Ireland's Dementia Strategy*. University of Ireland: Galway
- Creswell JW & Plano Clark VL (2011) *Designing and Conducting Mixed Methods Research*, London: Sage Publications.
- Dodd, K. (2014). Staff knowledge and training. In K. Watchman (Ed.) *Intellectual disability and dementia: Research into practice*. Jessica Kingsley Publishers. London.
- Gelling, L. (2015a) Stages in the research process, *Nursing Standard*, 29, (27), pp. 44-49
- Gelling, L. (2015b) Qualitative research, *Nursing Standard*, 29, (30), pp. 43-47
- Gelling, L. and Engward, H. (2015) Planning a research project, *Nursing Standard*, 29, (28), pp. 44-48
- Nolan, M, Ryan, T, Enderby, P. and Reid, D. (2002) Towards a more inclusive vision of dementia care practice and research, *Dementia*, 1, (2), pp. 193-211
- O'Shea, E, Manning, E, Timmons, Dr S, Ross, E. and McErlean, S. (2015) *The Northern Ireland Audit of Dementia Care in Acute Hospitals*. HSCB/PHA: Belfast.
- Punch KF (2006) *Developing Effective Research Proposals*, London: Sage
- de Siún, A, O'Shea, E, Timmons, S, McArdle, D, Gibbons, P, O'Neill, D, Kennelly, S. and Gallagher, P (2014) *Report of the Irish National Audit of Dementia Care in Acute Hospitals*, University College Cork: Cork.
- Taylor BJ, Killick C & McGlade A (2015) *Understanding and Using Research in Social Work*, London: Sage
- Thyer B (Ed) (2010) *The Handbook of Social Work Research Methods (2nd Ed)*, Thousand Oaks, CA: Sage
- Watson, R. (2015) Quantitative research, *Nursing Standard*, 29, (31), pp. 44-48

Theme 13


Leadership in Transformational Dementia Care

Context

People who occupy positions of leadership are important within the arena of dementia care as they can provide, motivate, direct and help by utilising best practice into their teams.

This theme refers to the knowledge and skills that are required to help healthcare professionals lead positive change within dementia care.

These people, usually leaders within an organisation or senior managers, should have an understanding about the organisational landscape and strategic direction as well as the latest developments in dementia policy and best practice guidelines.



“Inspirational leaders in health and social care settings should help make positive changes thus promoting dementia friendly environments for us all”

Target Audience - Tiers 3 - 4

Knowledge

Learning Outcomes - Tier 3

- Explain quality assurance mechanisms and measures.
- Compare different models of mentoring and coaching team members to become leaders in dementia care.

Learning Outcomes - Tier 4

- Appraise the key drivers and policies which influence national and international legislation.
- Critique and compare evidence-based research, innovations and developments in dementia care.
- Identify the importance of quality assurance.
- Integrate good leadership in practice.
- Facilitate the provision of good leadership in practice.

Skills

Learning Outcomes - Tier 3

- Produce quality assurance reports.
- Facilitate other members of the team to become leaders in dementia care.

Learning Outcomes - Tier 4

- Consider new evidence-based approaches and challenge poor practice.
- Critique a range of methods and select the most appropriate way to measure quality assurance.
- Facilitate other staff with a view to developing leaders in dementia care across the organisation.
- Develop and train team members to maximise their competence within dementia care.
- Collaborate with other agencies in order to maximise support and quality of care afforded to people living with a dementia, their families and carers.

Recommended Reading

- Bass, B.M. (1985) *Leadership and Performance*, FreePress: New York
- Covey, S. (2006) *The 7 habits of highly effective people*, Simon and Schuster: New York
- Department of Health (2009) *Living Well With Dementia – A National Dementia Strategy*, The Stationery Office: London
- DHSSPS (2011) *Improving Dementia Services in Northern Ireland: a regional Strategy*, DHSSPS: Belfast
- Hodge, S. and Orrell, M (eds) (2010) (2E) *Memory Services National Accreditation Programme (MSNAP): Standards for Memory Services, Assessment and Diagnosis*, Royal College of Psychiatrists: Doncaster
- Holland, A.J., Hon, J., Huppert, F.A., Stevens, F. & Watson, P. (1998). Population-based study of the prevalence and presentation of dementia in adults with Down's syndrome. *British Journal of Psychiatry*, 172, 493–8. 102
- Janicki, M.P. & Dalton, A.J. (2000). Prevalence of dementia and impact on intellectual disability services. *Mental Retardation*, 38, 276–88
- Marshall, E. (2010) *Transformational Leadership in Nursing: From Expert Clinician to Influential Leader*, Springer Publishing Company, New York
- National Institute for Clinical Excellence (NICE) (2011) *A NICE–SCIE Guideline on supporting people with dementia and their carers in health and social care*. National Clinical Practice Guideline Number 42, HMSO: London
- NICE Quality Standard 30: (2013) *Supporting People to Live Well with Dementia*, NICE: Manchester



Glossary

DHSSPS	Department of Health, Social Services and Public Safety
DOH	Department of Health
HPSS	Health and Personal Social Services
H&SCT	Health and Social Care Trust
LGBT	Lesbian, Gay, Bisexual and Transgender
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
NIPEC	Northern Ireland Practice and Education Council
NISCC	Northern Ireland Social Care Council
NMC	Nursing and Midwifery Council
RCN	Royal College of Nursing
SCIE	Social Care Institute for Excellence
VERA	Validation, Emotion, Reassurance, Activity
WHO	World Health Organisation

Bibliography

- Alzheimer's Society (2015) *Demography of Dementia*. Alzheimer's Society: London
- Cavendish, C. (2013) *The Cavendish Review: An independent review into healthcare assistants and support workers in the NHS and social care settings*. London: Department of Health
- Department of Health (DOH) (2015) *Prime Minister's Challenge on Dementia 2020*. London: Stationery Office
- Department of Health (DOH) (2001) *National Service Framework for Older People: Modern Standards and Service Models*. London: Stationery Office
- Department of Health (DOH) (2005) *Everybody's Business*. London: Stationery Office
- Department of Health, Social Services and Public Safety (DHSSPS) (2011) *Improving Dementia Services in Northern Ireland: A Regional Strategy*. DHSSPS: Belfast
- Department of Health, Social Services and Public Safety (DHSSPS) (2010) *Living Matters, Dying Matters. A Strategy for Palliative and End of Life Care in Adults in Northern Ireland*. DHSSPS: Belfast
- Iliffe, S, Robinson, L, Brayne, C, Goodman, C, Rait, G, Manthorpe, J. and Ashley, P. (2009) Primary care and dementia: 1, diagnosis, screening and disclosure. *International Journal of Geriatric Psychiatry*, Sept, 24 (9), pp. 895-901
- Mitchell, G, McCollum, P. and Monaghan, C. (2013a) 'The personal impact of disclosure of a dementia diagnosis: a thematic review of the literature', *British Journal of Neuroscience Nursing*, 9, (5), pp. 223-228
- Mitchell, G, McCollum, P. and Monaghan, C. (2013b) 'Disclosing a diagnosis of dementia: A background to the phenomenon', *Nursing Older People*, 25, (10), pp. 16-21.
- The Mid Staffordshire NHS Foundation Trust Public Inquiry (2013) *(Francis) Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry: Executive Summary*. London: Stationery Office
- Vernooij-Dassen, M, Moniz-Cook, E, Woods, R, De Lepeleire, J, Leuschner, A, Zanetti, O, de Rotrou, J, Kenny, G, Franco, M, Peters, V, Iliffe, S. and the INTERDEM group (2005) Factors affecting timely recognition and diagnosis of dementia across Europe: from awareness to stigma, *International Journal of Geriatric Psychiatry*, 20, pp. 377-386
- World Health Organisation (WHO) (2002), *Definition of Palliative Care*. World Health Organisation: Geneva

Appendix 1a

Membership of the Expert Steering Group

Mr Seamus McErlean, Co-chair of the Dementia Strategy Implementation Group and Social Care Commissioning Lead, (Older People and Adults), Health and Social Care Board

Mrs Eleanor Ross MBE, Co-chair of the Dementia Strategy Implementation Group and Nurse Consultant, Public Health Agency

Ms Lorna Conn, Project Manager, Dementia Together NI, Health and Social Care Board

Ms Teresa McGarvey, Project Officer (Training), Dementia Together NI, Health and Social Care Board

Miss Thelma Swann, Business Support Manager, Dementia Together NI, Health and Social Care Board.

Mrs Joanne Agnelli, Dementia Services Quality Manager, Four Seasons Health Care

Mrs Sarah Penney, Dementia Lead, Belfast Central Mission and Research Fellow, Ulster University

Ms Marsha Tuffin, Head of Dementia Innovation, Abbeyfield and Wesley Housing Association

Mr Gary Mitchell, Dementia Care Advisor, Four Seasons Health Care

Appendix 1b

Membership of the Stakeholder Group

Joanne Agnelli	Four Seasons Health Care
Joan Boylan	Homecare Independent Living
Jean Byrne	Clinical Education Centre, Allied Health Professions
Lyn Campbell	Carers NI
Frances Cannon	Northern Ireland Practice and Education Council
Lorna Conn	Health and Social Care Board
Tara Collins	Dementia NI
David Cundy	Social Care Institute for Excellence
Liz Cunningham	Expert by Experience
Philip Cunningham	Carer
Michael Currie	Bryson Charitable Group
Siobhan Donaghy	Southern Health and Social Care Trust
Susan Foster	Northern Ireland Hospice
Robert Hagan	Ulster University, Social Work
Marc Harvey	Northern Health and Social Care Trust
Nathalie Hastings	Alzheimer's Society
Louise Henry	North West Regional College
Pamela Holmes	Social Care Institute for Excellence
Colin Hughes	Queen's University, Mental Health Nursing
Sean Hughes	Dementia Services Development Centre
Amanda Jackson	Northern Ireland Medical and Dental Training Agency
Meta Keenan	Northern Ireland Social Care Council
Roisin Keown	South Eastern Health and Social Care Trust
Liz Laird	Ulster University, Nursing
Melanie Legg	Marie Curie Cancer Care
Audrey Lockhart	Reminiscence NI
Majella Magee	Western Health and Social Care Trust
Natalie Magee	Belfast Health and Social Care Trust
Suzanne Martin	Ulster University, Allied Health Professions
Maureen McCloskey	Western Health and Social Care Trust, Social Services Training Unit
Alison McCullough	Royal College of Speech and Language Therapists
John McErlane	Expert by Experience

Membership of the Stakeholder Group

Seamus McErlean	Health and Social Care Board
Teresa McGarvey	Health and Social Care Board
Linzi McIlroy	Royal College of Nursing
Sharon McIlroy	Kirk House Residential Care Home
Carole McKenna	NI Practice and Education Council
Clare McVeigh	Northern Ireland Hospice
Gary Mitchell	Four Seasons Health Care
Lorna Montgomery	Queen's University, Social Work
Debbie Mooney	Southern Health and Social Care Trust
Maria Mullan	Age NI
Siobhan Murphy	Clinical Education Centre
Jean Nugent	Queen's University, School of Nursing and Midwifery
Geraldine Patterson	Southern Health and Social Care Trust, Social Services Training Unit
Sarah Penney	Belfast Central Mission/Ulster University
Eleanor Ross	Public Health Agency
Moira Scanlon	Learning Disability, NSHCT
Michelle Simpson	Sense
Heather Sleator	Regulation and Quality Improvement Authority
Daphne Stevenson	Reminiscence NI
Toni Strawbridge	Fold Group
Marsha Tuffin	Abbeyfield and Wesley Housing Association

Appendix 1c

Membership of the Virtual Reference Group

Philip Adamson	South Eastern Health and Social Care Trust
Lorna Akroyd	Western Health and Social Care Trust
Brenda Arthurs	South Eastern Health and Social Care Trust
Dawn Arthurs	Domestic Care NI
Michael Bagood	Spa Nursing Homes
Emma Bailie	Beacon Well-being, NIAMH
Philip Bartley	Northern Health and Social Care Trust
Dawn Beckett	Dementia NI
Gillian Bingham	Belfast Health and Social Care Trust
Alison Bloomer	Belfast Health and Social Care Trust
Rema Borland	Belfast Health and Social Care Trust
Danny Branniff	South Eastern Health and Social Care Trust
Dr Sarah Bravey	Clinical Psychologist, Northern Health and Social Care Trust
Dr R Brazil	Consultant Psychiatrist, Southern Health and Social Care Trust
Caroline Brogan	Belfast Health and Social Care Trust
Ashley Brown	Northern Health and Social Care Trust
Sarah Browne	South Eastern Health and Social Care Trust
Maureen Browne	Northern Health and Social Care Trust
Mary Burke	Southern Health and Social Care Trust
Fidelma Carolan	Unison
Gillian Carr	Inspire Well-being, NIAMH
Sandra Carroll	Homecare Independent Living
Catherine Casey	Northern Health and Social Care Trust
Damian Cassidy	Kilcreggan Homes
Ann Marie Coen	Dublin College University
Sharon Colhoun	Springlawn House Care Home
Caroline Crawford	Presbyterian Church in Ireland, Council of Social Witness
Donna Curley	Southern Health and Social Care Trust
Ashley Curry	Belvedere Private/Residential Care Home
Catriona Curry	South Eastern Health and Social Care Trust
Sue Curry	Larchwood Care Home
Una Cushnahan	Health and Social Care Board
Eileen Dealey	Western Health and Social Care Trust
Ailish Devlin	Marina Care Home
Marie Devlin	Apex Housing Association
Maureen Devlin	Southern Health and Social Care Trust
Janet Dickson	Southern Health and Social Care Trust

Membership of the Virtual Reference Group

Donna Dillon	South Eastern Health and Social Care Trust
Rosemary Dilworth	Priory Health Care Group
Olivia Doak	All Season Home Care Services
Jean Donaghy	Western Health and Social Care Trust
Catherine Donnelly	Speech and Language Therapist, Belfast H&SCT
Linda Dornan	South Eastern Health and Social Care Trust
Dr Frances Duffy	Northern Health and Social Care Trust
Lee Edmonds	South Eastern Health and Social Care Trust
Karen Edwards	Phoenix Clinic and Resource Centre
Retha Erasmus	Parkdean Nursing Home
Heather Finlay	Department of Health Social Services and Public Safety NI
Geraldine Fleming	Health and Social Care Board
Oonagh Galway	Belfast Health and Social Care Trust
Helen Gault	Northern Health and Social Care Trust
Julie Geoghegan	Bryson Charitable Group
Esther Gishkori	Southern Health and Social Care Trust
May Gordon	Presbyterian Church in Ireland
Dr Damian Gormley	Southern Health and Social Care Trust
Diane Gracey	Mears Group
Alan Graham	Conard Care
Elizabeth Graham	Northern Health and Social Care Trust
Oonagh Grant	Glencarron Nursing Home
Sandra Gray	Belfast Health and Social Care Trust
Jane Greene	Southern Health and Social Care Trust
Barbara Gregg	Health and Social Care Board
Deirdre Harkin	Western Health and Social Care Trust
Louise Harte	Bardan Cottage Residential Home
Karen Harvey	Northern Health and Social Care Trust
Nichola Hayes	Western Health and Social Care Trust
Gerry Heatley	Praxis Care
Linda Hook	The Salvation Army
Louise Hughes	NI Association for Mental Health
Agnes Jainar	Bryansburn Nursing Home
Julie Jess	South Eastern Health and Social Care Trust
Carole Johnston	Northwick House Residential Care Home
Paula Kealy	Macmillan Cancer Care
Denise Keegan	Presbyterian Church in Ireland, Council of Social Witness

Membership of the Virtual Reference Group

Julie Kinkaid	South Eastern Health and Social Care Trust
Laura Kelly	Strule Erne Day Care
Ann Keppler	Collegeland Nursing Home
Margaret Kolbohm	Drapersfield House Private Nursing Home
Rosalind Kyle	Belfast Health and Social Care Trust
Diane Laverty	NIAMH Well-being Centre
Geraldine Lavery	North West Regional College
Amanda Leitch	Health and Social Care Consultant
Deirdre Lewis	Northern Health and Social Care Trust
Maria Loughran	Northern Health and Social Care Trust
Sabrina Lynch	The Derry Engaging and Empowering Dementia Project
Feargal Lynn	Rowandale Residential Home
Jennifer MacAuley	South Eastern Health and Social Care Trust
Mary MacDonnell	Advanced Community Care
Tony McAllister	South Eastern Health and Social Care Trust
Patricia McCaffrey	Southern Health and Social Care Trust
Sean McCartan	Northern Health and Social Care Trust
Emma McCay	South Eastern Health and Social Care Trust
Gillian McCorkell	Western Health and Social Care Trust
Michael McCormick	Southern Health and Social Care Trust
Victoria McCullough	Positive Futures
David McDowell	Belfast Health and Social Care Trust
Kathleen McGoldrick	Southern Health and Social Care Trust
Maureen McKeague	Derg Valley Care
Bronagh McKeown	Southern Health and Social Care Trust
Sam McMahan	South Eastern Health and Social Care Trust
Angela McVeigh	Southern Health and Social Care Trust
Tracey McVeigh	South Eastern Health and Social Care Trust
Gemma McWilliams	Quality Care Services Limited
Jillian Martin	Belfast Health and Social Care Trust
Cathy Mawhinney	Southern Health and Social Care Trust
Bernie Michaelides	Western Health and Social Care Trust
Joanne Minay	Southern Health and Social Care Trust
Connie Mitchell	Aughnacloy House Care Home
Debbie Mooney	Southern Health and Social Care Trust
Deborah Moore	Limetree House
Mandy Moore	Belfast Health and Social Care Trust

Membership of the Virtual Reference Group

Eilish Morris	Apex Housing Association
Gillian Mullan	Western Health and Social Care Trust
Mary Murdock	Belfast Health and Social Care Trust
Genevieve Murphy	Macmillan Cancer Support
Elaine Nelson	Southern Health and Social Care Trust
Katie Niblock	South Eastern Health and Social Care Trust
Pat Nugent	Southern Health and Social Care Trust
Margaret O’Kane	South Eastern Health and Social Care Trust
Martha O’Kane	Milesian Manor Nursing Home
Kathy Peacock	Belfast Health and Social Care Trust
Joanne Quinn	Western Health and Social Care Trust
Chris Ramrachia	Benbradagh Care Home
Francis Rice	Southern Health and Social Care Trust
Mark Roberts	Southern Health and Social Care Trust
Linda Robinson	Age NI
Margaret Robinson	Staff Nursing Agency
Trish Rockett	Belfast Metropolitan College
Maggie Ross	South Eastern Health and Social Care Trust
Sheelagh Ross	Northern Health and Social Care Trust
Valerie Rutherford	Rylands Private Nursing Home
Ann Scott	South Eastern Health and Social Care Trust
Maureen Serplus	Northern Health and Social Care Trust
Catherine Sheeran	Southern Health and Social Care Trust
Pauline Shepherd	Independent Health Care Providers
Dawn Smyth-Sargent	Admiral Care Services (NI) Ltd
Sally-Anne Stacey	Breffni House Residential Care Home
Wilma Steele	Presbyterian Church in Ireland, Council of Social Witness
Emma Stinson	Southern Health and Social Care Trust
Geraldine Teague	Health and Social Care Board
Paula Thompson	South Eastern Health and Social Care Trust
Jacqueline Toner	Southern Health and Social Care Trust
Roisin Toner	Southern Health and Social Care Trust
Pamela Topping	Pamela Topping Design
Heather Trouton	Southern Health and Social Care Trust
Lisa Watt	Southern Health and Social Care Trust
Linda Wray	Presbyterian Church in Ireland, Council of Social Witness

Appendix 2

Frameworks and Important Links

Competency Frameworks to be referred to in conjunction with the Dementia Learning and Development Framework:

- Adult Safeguarding Prevention and Protection in Partnership Policy (DHSSPS 2015) and Associated Training Framework (draft)
- Competence Assessment Tools for Ward Sisters, Charge Nurses and Team Leaders (NIPEC 2010 and 2012)
- Mental Capacity Bill and Principles Framework (NI Assembly 2015) (draft)
- Guidance on Mandatory Training for Providers of Care in Regulated Services (RQIA 2012)
- Healthcare Leadership Model (NHS Leadership Academy 2013)
- Induction Standards for Social Care Workers (NISCC November 2015)
- Knowledge and Skills Framework (DOH 2004)
- Learning Disability Service Framework (DHSSPS 2012)
- Medical Leadership Framework (NHS Leadership Academy and Academy of Royal Colleges 2010)
- Nurses who practice at an advanced level should meet the requirements outlined in the Advanced Nursing Practice Framework: Supporting advanced nursing practice in Health and Social Care Trusts (DHSSPS, 2014)
- Palliative Care Framework (Revised Service Framework for Respiratory Health and well-being (DHSSPS 2015)
- Post Qualifying Framework: A Resource for Occupational Therapists (College of Occupational Therapists 2006)
- Professional in Practice (NISCC 2014)
- Quality 2020 An Attributes Framework for Health and Social Care (DHSSPS 2014)
- Regulated Qualifications Framework (RQF 2017)
- Service Framework for Older People (DHSSPS 2013)
- Skills for Care and Development (Sector Skills Council)
- See also Social Work Research and Continuous Improvement Strategy for Northern Ireland (Health and Social Care Board, 2015) <http://www.hscboard.hscni.net/our-work/social-care-and-children/swresearch/>

This list is not exhaustive and its purpose is to assist with individual self-directed learning, self-evaluation and development.

Self Assessment Tool

Rating Scale for Thematic Subject Areas

SD = Substantial Development Required

WD = Well Developed

MD = Moderate Development Required

NA = Not Applicable

THEME 1

DEMENTIA AWARENESS

Rating Scale

Tier	Knowledge		SD	MD	WD	NA
1	1.1	Know what is meant by the term dementia.				
1	1.2	Recognise that dementia is an umbrella term for a number of conditions which includes Alzheimer's disease.				
1	1.3	Describe the prevalence of dementia in society.				
1	1.4	Identify that dementia is not a normal part of ageing.				
1	1.5	Recognise that as many as 50% of people who live with dementia may not have a formal diagnosis.				
1	1.6	Explain why receiving a diagnosis of dementia is important.				
1	1.7	Recognise that each person living with dementia is a unique individual.				
Tier	Skills		SD	MD	WD	NA
1	1.1	Demonstrate how to communicate effectively and sensitively with people living with a dementia their families and carers.				
1	1.2	Demonstrate how to seek guidance from other staff for appropriate dementia advice, support or information.				

THEME 2

COMMUNICATION

Rating Scale

Tier	Knowledge		SD	MD	WD	NA
1	1.1	List the methods of interacting and listening to people living with a dementia to make them feel valued and involved.				
1	1.2	Identify the skills and attitudes required to communicate effectively.				
1	1.3	Recognise the factors that act as enablers and barriers to effective engagement with people living with a dementia, their families and carers.				
1	1.4	Recognise the role and value of families and carers as collaborative partners in supporting the person living with a dementia to achieve positive outcomes.				
1	1.5	Examine how the behaviour of others may have a direct impact on the behaviour displayed by a person living with a dementia.				
1	1.6	Recognise that distressed behaviour is a form of communication.				
1	1.7	Recognise that a person's mood and feeling may affect their behaviour.				
2	2.1	Discover that the ability to communicate is often compromised in a person living with a dementia.				
2	2.2	Recognise and minimise barriers to support effective communication e.g. use of hearing aids or reading glasses.				
2	2.3	Identify how to adapt the style of communication to the needs and abilities of people living with a dementia who do not communicate verbally.				
2	2.4	Recognise and appreciate the impact of distressed behaviour and provide the appropriate intervention in accordance with assessed need.				
2	2.5	Explain the importance of non-verbal communication and understand the importance of life-story information and how this can facilitate communication.				
2	2.6	Identify that people living with a dementia, their families and carers require access to timely and relevant information appropriate to their needs.				
2	2.7	Recognise the key components of therapeutic relationships which takes account of individual differences, capabilities and needs to ensure safe, effective and non-discriminatory communication.				

THEME 2

COMMUNICATION

Rating Scale

Tier	Knowledge		SD	MD	WD	NA
2	2.8	Give examples of the range of multi-agency organisations and individuals working with people living with a dementia and those caring for them.				
2	2.9	Define the roles within a multidisciplinary team.				
2	2.10	Identify why effective communication is particularly important in multidisciplinary and multi-agency working.				
2	2.11	Define the referral pathways between services which provide support to people living with a dementia.				
3	3.1	Evaluate and appreciate that the person living with a dementia may have reduced ability to articulate their physical health needs e.g. relating to pain, anxiety or depression.				
3	3.2	Establish that any behaviour is a form of communication.				
3	3.3	Consider the many different ways in which people communicate and how these may be influenced by ill health, disability and other factors and be able to recognise and respond effectively when a person finds it difficult to communicate.				
4	4.1	Analyse when people are anxious or in distress and respond effectively, using therapeutic principles, to promote their well-being, manage personal safety and resolve conflict.				
4	4.2	Compare approaches which promote multidisciplinary assessment and interventions to support people living with a dementia with distressed behaviours perceived to be challenging.				

THEME 2

COMMUNICATION

Rating Scale

Tier		Skills	SD	MD	WD	NA
1	1.1	Demonstrate a person-centred approach to sensitively communicate with a person living with a dementia, their families and carers in all aspects of communication.				
1	1.2	Identify appropriate tone of communication used with someone living with a dementia and their choice of words.				
1	1.3	Recognise the various forms of communication and appreciate the appropriate method to apply within the presenting circumstances.				
1	1.4	Recognise that not all people living with a dementia have difficulty with communication but that it may be beneficial to communicate in a more concise manner using non-complex language.				
1	1.5	Demonstrate active listening skills and be able to check for understanding.				
1	1.6	Identify environmental issues when communicating with a person living with a dementia e.g. crowded areas and excessive noise.				
1	1.7	Omit the use of stigmatising language e.g. 'challenging behaviour', 'wanderer', 'sufferer' or 'demented'.				
1	1.8	Demonstrate that all communication with a person living with a dementia is appropriate. Speak in a clear, concise slow manner maintaining eye contact at all times and allow the person extra time if necessary.				
2	2.1	Recognise the fact that families and carers may be more familiar with the 'behaviours' exhibited by a person living with a dementia and what these may mean.				
2	2.2	Pay close attention to body language, touch, tone of voice and facial expression.				
2	2.3	Give examples of a range of communication skills and technologies to support person-centred care and enhance quality and safety. Information must be shared in a language and manner that allows people to make informed choices.				
2	2.4	Identify when language, interpretation or other communication support is needed and know how to obtain it.				

THEME 2

COMMUNICATION

Rating Scale

Tier	Skills		SD	MD	WD	NA
2	2.5	Demonstrate an ability to engage through meaningful interactions and activities.				
2	2.6	Consider the use of visual aids, memory boxes and life-history information to enhance communication experiences in dementia care.				
2	2.7	Identify how people living with a dementia, their families and carers can be involved in collaborative decision making about their care based on life story work such as “My Life My Way”.				
2	2.8	Analyse and evaluate information to support multidisciplinary/multi-agency decision making.				
3	3.1	Decide how to maximise the ability of the person living with a dementia to communicate their needs, wishes and desires.				
3	3.2	Interpret communication and listen in a sensitive manner when discussing difficulties and complex care concerns with the person living with a dementia, their families and carers.				
3	3.3	Develop the ability to support other professionals to ensure appropriate and timely referrals.				
3	4.1	Support leadership in promoting effective communication in all aspects of care delivered in health and social care settings.				
4	4.2	Evaluate and ensure that the communication needs of those living with a dementia are at the forefront in the development of all practices and services.				
4	4.3	Appraise communication strategies and negotiation techniques to achieve best outcomes respecting the dignity and human rights of all concerned.				

THEME 3

RECEIVING A DIAGNOSIS OF DEMENTIA

Rating Scale

Tier		Knowledge	SD	MD	WD	NA
1	1.1	Recognise that not all people who live with a dementia have a diagnosis.				
2	2.1	Define the most common types of dementia and their underlying causes.				
2	2.2	Identify the most common symptoms of dementia.				
2	2.3	Recognise why timely diagnosis of dementia is important.				
2	2.4	Demonstrate awareness of the supportive networks that exist outside of a hospital setting e.g. Alzheimer's Society, Age NI, Dementia Navigators, Carers NI and Dementia NI.				
3	3.1	Compare the presentation, prevalence and stages of the more common types of dementia.				
3	3.2	Outline the rare types of dementia.				
3	3.3	Develop an awareness of the needs of a person living with a dementia who have other co-morbidities.				
3	3.4	Articulate that diagnosing dementia is a sensitive issue and the person has a right to know their diagnosis. However, there are occasions where the person may not wish to know their diagnosis or their family may be reluctant for them to be told.				
3	3.5	Employ and use post-diagnosed services available for people living with a dementia, their families and carers.				
3	3.6	Establish the needs and impact of diagnosing younger people (under the age of 65) living with a dementia.				
3	3.7	Establish the needs of people with learning disabilities being diagnosed with a dementia.				
3	3.8	Apply the Memory Services National Accreditation Programme as per Royal College of Psychiatrists.				
4	4.1	Evaluate local demographic population figures for dementia and have the leadership ability to ensure capacity and demand is balanced for provision of memory clinics.				
4	4.2	Plan innovative ways to deliver evidence-based diagnosis service.				
4	4.3	Assess national and international developments in dementia diagnosis.				

THEME 3

RECEIVING A DIAGNOSIS OF DEMENTIA

Rating Scale

Tier	Skills		SD	MD	WD	NA
1	1.1	Demonstrate sensitivity to people’s needs and wishes during any interaction.				
2	2.1	Recognise the need to refer or direct a person to specialist services if required.				
2	2.2	Explain the need for referral or investigation to the person with symptoms of dementia, their families and carers in a sensitive manner.				
3	3.1	Differentiate between different types of dementia, delirium, depression and other conditions that may present similar symptoms.				
3	3.2	Employ a comprehensive assessment for dementia utilising appropriate investigations and tools that are scientifically tested and approved for use.				
3	3.3	Demonstrate how to collaborate with multidisciplinary healthcare professionals throughout the diagnostic process and thereafter.				
3	3.4	Organise discussions of advance care planning.				
3	3.5	Support people who are diagnosed with young onset dementia through specialist advice, direction and services.				
3	3.6	Support people who live with learning disability and are diagnosed with a dementia through specialist advice, direction and services.				
4	4.1	Evaluate and participate in research and scientific trials.				

THEME 4

PERSON-CENTRED AND RELATIONSHIP-CENTRED DEMENTIA CARE

Rating Scale

Tier	Knowledge		SD	MD	WD	NA
1	1.1	Recognise that people who live with a dementia must be treated with the same courtesy and respect as other people.				
1	1.2	Define the important contribution of family members and carers of the person living with a dementia.				
2	2.1	Explain the principles of person-centred dementia care i.e. the human value of people living with a dementia regardless of age or cognitive impairment and those who care for them.				
2	2.2	Recognise the individuality of people living with a dementia, their unique personality and life experiences and how this impacts on their response to dementia.				
2	2.3	Recognise the importance of the perspective of the person living with a dementia.				
2	2.4	Examine the importance of 'person-hood' in dementia care and how this can enhance or diminish a person's level of well-being.				
2	2.5	Summarise the role of families and carers in the care and support of people living with a dementia.				
2	2.6	Examine the importance of relationships and interactions with others to the person living with a dementia and their potential for promoting well-being.				
3	3.1	Determine the value of person-centred care and relationship-centred care in therapeutic relationships and communication.				
3	3.2	Modify person-centred and relationship-centred approaches in the management and delivery of services.				
3	3.3	Outline how to incorporate person-centred and relationship-centred approaches in the management and development of services.				
3	3.4	Question how person-centred and relationship-centred concepts impact on how support and services are delivered.				

THEME 4

PERSON-CENTRED AND RELATIONSHIP-CENTRED DEMENTIA CARE

Rating Scale

Tier	Knowledge		SD	MD	WD	NA
3	3.5	Appraise the importance of inter-agency and professional working in order to promote an enabling environment and culture.				
4	4.1	Compare how different models are used to operationalise person-centred and relationship-centred care for people living with a dementia and how these can be reflected in decision making, planning and service delivery.				
4	4.2	Analyse the evidence for the effectiveness of different psychosocial approaches in different situations.				
4	4.3	Analyse the tensions in implementing person-centred and relationship-centred approaches.				
Tier	Skills		SD	MD	WD	NA
1	1.1	Recognise that every person living with a dementia is a unique individual.				
1	1.2	Demonstrate how to communicate in a way that displays respect for the individual, their families and carers.				
2	2.1	Demonstrate how people living with a dementia should be part of the decision making process in relation to their journey e.g. current and future care preferences.				
2	2.2	Recognise that knowledge of a person’s life history can help in forming meaningful relationships with a person living with a dementia.				
2	2.3	Explain how to communicate in a way that does not undermine the person living with a dementia e.g. by avoiding labelling terminology such as “challenging behaviour”.				
2	2.4	Recognise that a person living with a dementia may need to be supported by their families or carers in relation to complex decision making.				
2	2.5	Give examples of how to facilitate people living with a dementia to make non-complex decisions e.g. the choice of what to eat or drink.				
3	3.1	Apply person-centred and relationship-centred approaches in the management and delivery of care.				
4	4.1	Analyse and evaluate how person-centred and relationship-centred approaches affects the culture of their workplace.				

THEME 5

PROMOTING PHYSICAL, PSYCHOLOGICAL AND SOCIAL WELL-BEING IN DEMENTIA CARE

Rating Scale

Tier	Knowledge		SD	MD	WD	NA
1	1.1	Recognise that while dementia is not a normal part of ageing, growing older does increase the risk of developing dementia.				
1	1.2	Describe the lifestyle factors that may increase the risk of developing certain types of dementia.				
2	2.1	Identify how genetic links can play a role in the development of some dementias.				
2	2.2	Explain how people with learning disabilities, particularly Down syndrome are at an increased risk of developing a dementia.				
2	2.3	Describe the importance of maintaining good physical and mental health through nutrition, exercise, relaxation and social engagement.				
2	2.4	Recognise the individual’s specific needs e.g. nutrition, swallowing, medication, sleep or elimination needs.				
2	2.5	Recognise the individual’s specific needs e.g. oral health, pain relief and personal care.				
2	2.6	Give examples of helping a person living with a dementia to maintain their independence.				
2	2.7	Explain how families and carers have a unique role in supporting the person living with a dementia.				
2	2.8	Describe the importance of a positive dining experience and its link to nutrition.				
2	2.9	Select specialised crockery and adaptive cutlery to ensure people living with a dementia maintain their independence during mealtimes.				
2	2.10	Show the importance of meaningful activity and be aware of how to facilitate this.				
2	2.11	Recognise how the use of relaxation techniques or medications may help if the person is not able to sleep.				
2	2.12	Recognise the impact of delirium, depression and anxiety as they are likely to diminish a person’s level of well-being.				
2	2.13	Identify triggers that may cause a person living with a dementia to become distressed.				

THEME 5

PROMOTING PHYSICAL, PSYCHOLOGICAL AND SOCIAL WELL-BEING IN DEMENTIA CARE

Rating Scale

Tier	Knowledge		SD	MD	WD	NA
2	2.14	Compare non-pharmacological approaches in the alleviation of distress in people living with a dementia.				
2	2.15	Give examples of support services for signposting to health promotion information.				
3	3.1	Articulate the importance of contributory factors such as diet, alcohol consumption, exercise and smoking in relation to the increased risk of developing certain types of dementia.				
3	3.2	Demonstrate ability to refer to other agencies for support and assessment regarding relevant health promotion services.				
3	3.3	Appraise strategies for long term behavioural changes.				
3	3.4	Compare and implement health improvement strategies that will delay or reduce the onset of certain types of dementia.				
3	3.5	Outline the impact on well-being when a person receives a diagnosis.				
3	3.6	Articulate the importance of timely support, counselling and follow up.				
3	3.7	Compare therapeutic interventions that can enhance well-being.				
3	3.8	Predict the range of coping strategies that promote well-being for both the person living with a dementia, their families and carers.				
4	4.1	Contrast the range of services and interventions that will continue to promote well-being as the person moves through the dementia journey.				
4	4.2	Analyse the evidence base that supports the different interventions and techniques either non-pharmacological or pharmacological.				
4	4.3	Appraise the key drivers and policies which influence strategic dementia service development.				
4	4.4	Evaluate the development of health improvement strategies.				

THEME 5

PROMOTING PHYSICAL, PSYCHOLOGICAL AND SOCIAL WELL-BEING IN DEMENTIA CARE

Rating Scale

Tier	Skills		SD	MD	WD	NA
1	1.1	Demonstrate how to communicate the health promotion message associated with risk reduction for certain types of dementia.				
2	2.1	Recognise the appropriate action in relation to a person’s changing physical needs e.g. gait, fatigue, dehydration, infection or fall.				
2	2.2	Describe how to liaise with multidisciplinary healthcare professionals if needed e.g. a dietitian if the person is losing weight.				
2	2.3	Explain how to support the person to maintain their personal appearance and their nutritional needs.				
2	2.4	Discuss how to support the person living with a dementia to maintain and express their individuality that addresses their culture, language, sexual orientation and spiritual needs.				
2	2.5	Demonstrate how to include family and carers in all discussions regarding care and treatment.				
2	2.6	Identify delirium, depression and anxiety and assess or refer to an appropriate practitioner.				
2	2.7	Identify and respond to any change in behaviour and refer for assessment.				
3	3.1	Devise an active role in health promotion by providing information and advice.				
3	3.2	Analyse and employ behavioural change strategies or techniques that would reduce risk and potentially delay the onset and severity of certain types of dementia.				
3	3.3	Evaluate the effectiveness of health promotion activities.				
3	3.4	Plan to develop and disseminate health promotion information and advice.				
3	3.5	Determine when someone requires support and information.				
3	3.6	Assess need for and offer emotional support and counselling when diagnosis is being communicated.				

THEME 5

PROMOTING PHYSICAL, PSYCHOLOGICAL AND SOCIAL WELL-BEING IN DEMENTIA CARE

Rating Scale

Tier	Skills		SD	MD	WD	NA
3	3.7	Employ a range of services for families and carers that will promote well-being as people come to terms with dementia at any stage of the journey.				
3	3.8	Network effectively with multi-agency organisations following an assessment of need.				
3	3.9	Devise a care package from diagnosis to the end stage of life that will promote well-being.				
4	4.1	Recognise and disseminate new and evidence-based practice developments.				
4	4.2	Design and implement a range of interventions and techniques that may enhance well-being and be able to evaluate their effectiveness.				

THEME 6

HOLISTIC APPROACH IN THE MANAGEMENT OF DEMENTIA CARE

Rating Scale

Tier	Knowledge		SD	MD	WD	NA
2	2.1	Identify the common symptoms associated with different types of dementia and how these change through the different stages.				
2	2.2	Describe the current recommended cognitive enhancing medications for dementia, their main benefits and risks of cognitive enhancing medication.				
2	2.3	Describe the importance of non-pharmacological interventions in dementia care such as cognitive stimulation therapy, music or art therapy and be aware that any intervention should be therapeutic.				
2	2.4	Explain the main classes of medication that are used in dementia care e.g. antidepressants, anxiolytics, antipsychotics, analgesia and sedatives.				
2	2.5	Explain how oral medication may not always be best for the person living with a dementia.				
2	2.6	Recognise that undiagnosed pain is common in dementia and this can manifest as distress.				
2	2.7	Discuss how over prescription of antipsychotic medication is common.				
2	2.8	Describe how antipsychotic medication should only ever be used under the supervision of an appropriately qualified medical officer.				
2	2.9	Examine the issues around polypharmacy for people living with a dementia.				
2	2.10	Demonstrate the importance of recording and reporting side effects of medication.				
3	3.1	Explain the importance of reminiscence and helping people living with a dementia to create memory boxes.				
3	3.2	Examine non-pharmacological cognitive enhancing treatments.				
3	3.3	Predict when cognitive enhancing medication should be commenced and discontinued.				
3	3.4	Explain that cognitive enhancing medication is only appropriate for use in some types of dementia.				
3	3.5	Consider the contra-indications of prescribing a combination of medication e.g. antipsychotic medications and anxiolytic medications.				
3	3.6	Undertake a professionally relevant and accredited prescribing course.				
4	4.1	Analyse new and emerging non-pharmacological and pharmacological interventions that may be used to enhance the well-being of people living with a dementia.				
4	4.2	Evaluate national and international developments in research regarding symptom management.				

THEME 6

HOLISTIC APPROACH IN THE MANAGEMENT OF DEMENTIA CARE

Rating Scale

Tier	Skills		SD	MD	WD	NA
2	2.1	Administer medication if your role dictates and review safely and appropriately in partnership with people living with a dementia.				
2	2.2	Select an appropriate and validated pain assessment tool to establish if a person is in pain.				
2	2.3	Select an appropriate and validated depression assessment tool to establish if a person may be depressed.				
2	2.4	Select an appropriate and validated delirium assessment tool to establish if a person has a delirium.				
2	2.5	Select an appropriate and validated behavioural assessment tool.				
2	2.6	Summarise the legislation around Duty of Care and Best Interests.				
2	2.7	Apply best practice guidance on restrictive interventions.				
3	3.1	Employ non-pharmacological approaches in practice e.g. reality orientation, validation, reminiscence and a range of therapies i.e. music, pet, doll and horticultural.				
3	3.2	Review of prescribed medications, including cognitive enhancers, antipsychotic medications and determine if these need to be prescribed.				
3	3.3	Liaise with multidisciplinary team members to ensure that symptom management of dementia is maintained.				
3	3.4	Organise regular pain assessments in people living with a dementia and take the appropriate action.				
3	3.5	Consider and initiate cognitive stimulation exercises.				
4	4.1	Teach other care staff to deliver non-pharmacological interventions in practice.				
4	4.2	Evaluate and influence randomised clinical trials and be able to take part in local and/or national studies.				

THEME 7

PROMOTING ENABLING ENVIRONMENTS

Rating Scale

Tier	Knowledge		SD	MD	WD	NA
1	1.1	Recognise that some people living with a dementia may have sensory impairments.				
1	1.2	Recognise that some people living with a dementia may become disorientated to their current time and place and may need signposted or accompanied to their destination.				
1	1.3	Describe the importance of good lighting and clutter free environments.				
2	2.1	Recognise that some people living with a dementia will experience decline in vision due to the ageing eye.				
2	2.2	Explain the importance of signage in dementia care e.g. signs that direct people to where the nearest bathroom is and the importance of environmental design i.e. flooring, use of colours and lighting.				
2	2.3	Examine how positive risk is advocated in dementia care and people living with a dementia should be facilitated, where possible, to engage in modes of life which they enjoy.				
2	2.4	Discuss how because of disorientation, people living with a dementia may not be familiar in their environment but this might be helped by personalisation e.g. personal memorabilia such as photographs which are recognisable or personal memory boxes.				
2	2.5	Define the benefits and limitations of assistive technology in dementia care.				
2	2.6	Describe the roles of multidisciplinary team members who can advise on equipment, assistive technologies or adaptations e.g. an occupational therapist.				
3	3.1	Give examples of the types of assistive technologies that are available in relation to communication aids e.g. daily living aids, vision and reading aids, environmental aids and ergonomic aids.				

THEME 7

PROMOTING ENABLING ENVIRONMENTS

Rating Scale

Tier	Knowledge		SD	MD	WD	NA
3	3.2	Summarise the range of agencies involved in promoting an enabling environment and be able to signpost to these agencies for specific support.				
3	3.3	Compare the key legislation relevant to mental capacity, deprivation of liberty, equality and human rights.				
3	3.4	Discuss the ethical dilemmas in the environment that may present obstacles in practice.				
3	3.5	Consider best practice in environmental design.				
3	3.6	Analyse specific risk assessment and management tools that can be applied to identify and manage environmental risks acknowledging this is the person’s own home or preferred way of living.				
3	3.7	Contrast the reasons and rationale behind risk taking or risk aversion.				
4	4.1	Evaluate policy direction on assistive technologies and environmental design.				
4	4.2	Appraise national and international evidence base around promoting safe enabling environments and managing associated risks.				

THEME 7

PROMOTING ENABLING ENVIRONMENTS

Rating Scale

Tier	Skills		SD	MD	WD	NA
1	1.1	Demonstrate how to make basic changes to the environment to benefit people living with a dementia e.g. ensuring areas have appropriate lighting (natural and/or artificial) and that 'way finding' signs are in place for direction.				
1	1.2	Recognise when people require help with mobility or require assistance with access or restriction to access.				
2	2.1	Identify ways to adapt the physical environment to suit a person's changing needs on their journey in dementia.				
2	2.2	Outline how to support families and carers to modify their environment to support safe environments and benefit the person living with a dementia.				
3	3.1	Develop and lead on the introduction of assistive technology to support self-care and meaningful activity.				
3	3.2	Support and provide dementia specific expert advice, education and guidance on technology which enhances the physical and social environment.				
3	3.3	Demonstrate an ability to manage and take "therapeutic risks" within the appropriate environment, whilst working safely and ethically.				
3	3.4	Apply flexible and responsive approaches to eliminating risk aversion.				
4	4.1	Design and influence policy direction within the environment.				
4	4.2	Formulate evidence and evaluate thresholds that promote safety within an on-going therapeutic context.				
4	4.3	Justify and influence the planning and provision of supportive environments at a strategic level.				

THEME 8

LEGAL AND ETHNIC CONSIDERATIONS IN DEMENTIA CARE

Rating Scale

Tier	Knowledge		SD	MD	WD	NA
1	1.1	Recognise the rights and choices of people living with a dementia, their families and carers.				
1	1.2	Recognise own responsibility to refer on any concerns of harm or risk and the need for supportive decision making.				
2	2.1	Identify ethical dilemmas that may present in practice.				
2	2.2	Identify Duty of Care and how this contributes to safe practice.				
2	2.3	Recognise that people living with a dementia may experience fluctuations in their ability to make decisions.				
2	2.4	Identify recommended action to take if a person living with a dementia lacks mental capacity.				
2	2.5	Recognise how Best Interest decisions are made for those who lack mental capacity.				
2	2.6	Identify local legislation and policy relevant to mental capacity, deprivation of liberty, equality and human rights including the Adult Safeguarding Prevention and Protection in Partnership Policy 2015.				
2	2.7	Identify the professional codes of practice with regard to information recording, handling, confidentiality, informed consent and disclosure.				
2	2.8	Identify restrictive practices and its application in the care planning process including recording, implementing and review.				
3	3.1	Compare the roles and responsibilities of the different agencies involved in safeguarding investigations and the importance of sharing safeguarding information with relevant agencies.				
3	3.2	Recognise the options available when informed consent can be compromised.				
3	3.3	Explain advance decisions and how these can impact on care preferences.				
3	3.4	Explain advance directives and how these can impact on care preferences.				
3	3.5	Illustrate knowledge of the Adult Safeguarding Prevention in Partnership Policy July 2015.				
4	4.1	Illustrate knowledge of national and international policy developments in health with respect to mental health and older people's services.				

THEME 8

LEGAL AND ETHNIC CONSIDERATIONS IN DEMENTIA CARE

Rating Scale

Tier		Skills	SD	MD	WD	NA
1	1.1	Demonstrate ability to communicate concerns.				
2	2.1	Communicate effectively about proposed treatment or care to enable people living with a dementia to make informed choices as far as possible.				
2	2.2	Recognise neglect, abusive or exploitative practice and how to raise concerns to the Adult Safeguarding Teams.				
2	2.3	Demonstrate accountability and responsibility for own professional judgement and actions and work within professional boundaries and scope of practice.				
2	2.4	Identify unsafe practice and take appropriate action.				
2	2.5	Consider own beliefs and values and reflect on how these may influence care giving.				
2	2.6	Outline the values, customs, spiritual beliefs and practices of individuals/groups to exercise culturally competent practice.				
2	2.7	Report and record activities in line with professional guidelines and local policies.				
2	2.8	Complete visible and sequential recording of events.				
3	3.1	Demonstrate ability to communicate and report concerns.				
3	3.2	Demonstrate ability to communicate and co-operate with the Adult Safeguarding Team.				
3	3.3	Demonstrate ability to recognise and report any concerns.				
3	3.4	Demonstrate ability to appropriately challenge health care practices which could compromise the safety, privacy or dignity of the person living with a dementia.				
3	3.5	Apply sensitive and emotional intelligence in dealing with the issue whilst it is being investigated.				
4	4.1	Demonstrate ability to initiate safeguarding alerts and referrals.				
4	4.2	Demonstrate ability to implement legislation such as: Human Rights Act 1998, The Mental Health (Northern Ireland) Order 1986, Disability Discrimination Act 1995, Health and Personal Social Services (Northern Ireland) Order 1972, The Carers and Direct Payments Act (NI 2002), Mental Capacity Act (Northern Ireland) 2016 (when enacted), to support people with a dementia.				

THEME 9

EQUALITY, CULTURAL DIVERSITY AND INCLUSION IN DEMENTIA CARE

Rating Scale

Tier	Knowledge		SD	MD	WD	NA
1	1.1	Appreciate that all people regardless of age, disability, culture, sexual orientation, gender identity or ethnic background should be treated with respect and dignity.				
1	1.2	Recognise family diversity and cultural variations.				
1	1.3	Identify access to a range of support services i.e. Interpreters.				
2	2.1	Recognise age, cultural diversity and equality issues and how these may impact on people living with a dementia.				
2	2.2	Recognise that all people from different cultures may have different approaches to living with a dementia.				
2	2.3	Recognise the stigma that is often associated with dementia and help overcome this.				
2	2.4	Recognise the prevalence of younger onset dementia and its impact on their families.				
2	2.5	Consider the impact of dementia on people who live with learning disabilities.				
2	2.6	Understand that people living with a dementia whether younger, older or learning disabled will have individual interests and hobbies.				
2	2.7	Recognise the importance of reducing stigma in any person living with a dementia, regardless of age, gender, sexual orientation, culture or marital status.				
2	2.8	Consider the impact of dementia on families and carers who are from different cultural backgrounds.				
2	2.9	Consider the impact of dementia on younger family members or carers.				
3	3.1	Consider the impact that discrimination and stigma may have on the person living with a dementia, their families and carers.				
3	3.2	Consider legislation relevant to equality, diversity and human rights.				
3	3.3	Examine the importance of cultural diversity throughout advance care planning.				
3	3.4	Examine the impact that health inequalities and social deprivation have on the emotional well-being and mental health of people living with a dementia.				
4	4.1	Recognise how practice can compromise as well as promote a person's right to dignity, respect and safety.				

THEME 9

EQUALITY, CULTURAL DIVERSITY AND INCLUSION IN DEMENTIA CARE

Rating Scale

Tier	Skills		SD	MD	WD	NA
1	1.1	Demonstrate sensitivity to differences in family diversity and cultural variation.				
1	1.2	Demonstrate ability to refer to appropriate support services.				
2	2.1	Demonstrate ability to carry out assessments and care planning sensitively, particularly around issues pertaining to cultural diversity, disabilities, gender and sexual orientation.				
2	2.2	Demonstrate ability to deliver care that is based on individual needs and is person-centred.				
2	2.3	Demonstrate ability to actively challenge and discourage any discriminatory practice that may compromise a person’s right to dignity, respect or safety.				
2	2.4	Demonstrate cognisance of spiritual beliefs.				
3	3.1	Give examples of local policies and procedures pertaining to equality, diversity and cultural diversity.				
3	3.2	Apply practices that positively engage with and respect cultural diversity.				
4	4.1	Demonstrate ability to lead practice and create an organisational culture that values and respects the cultural diversity of individuals.				

THEME 10

PALLIATIVE CARE IN DEMENTIA/END OF LIFE DEMENTIA CARE

Rating Scale

Tier	Knowledge		SD	MD	WD	NA
1	1.1	Recognise the range of communication strategies.				
2	2.1	Recognise that the terms palliative care and end of life care are different.				
2	2.2	Recognise that people living with a dementia will require palliative care and/or end of life care.				
2	2.3	Recognise that commencement of palliative care discussions should take place at an early stage when the person living with a dementia is likely to have a higher degree of mental capacity.				
2	2.4	Recognise appropriately validated tools to inform holistic patient assessment.				
2	2.5	Determine how advance care plans or advance directives are recorded.				
2	2.6	Recognise the importance of shared communication between the multidisciplinary team, the person living with a dementia, their families and carers.				
2	2.7	Recognise the cultural, spiritual and religious differences associated with death.				
3	3.1	Recognise supportive frameworks that are utilised for breaking bad news.				
3	3.2	Recognise that all staff have a Duty of Care to family members of a person who passes away.				
3	3.3	Identify appropriate supportive services available (statutory and voluntary) e.g. All Ireland Institute of Hospice and Palliative Care “Hub” and be able to articulate on how to access these.				
4	4.1	Recognise regional and national strategic drivers with regards to both dementia and palliative care.				

THEME 10

PALLIATIVE CARE IN DEMENTIA/END OF LIFE DEMENTIA CARE

Rating Scale

Tier		Skills	SD	MD	WD	NA
1	1.1	Demonstrate sensitive and effective verbal and non-verbal communication skills with people living with a dementia, their families and carers.				
2	2.1	Recognise indicators suggestive of when a person is likely to be nearing end of life.				
2	2.2	Use appropriate validated tools to inform holistic assessment.				
2	2.3	Support people living with a dementia to fulfil their spiritual, cultural and religious needs.				
3	3.1	Understand, develop and progress advance care plans.				
3	3.2	Demonstrate the use of sensitive communication to the person living with a dementia, their families and carers about future care preferences.				
3	3.3	Apply supportive palliative care frameworks that have been utilised in dementia care.				
3	3.4	Organise family conferences and update the person living with dementia, their families and carers about their management of care on a regular basis.				
3	3.5	Recognise when a person is likely to be in the end of life phase.				
3	3.6	Recognise that hospitalisation is not always appropriate for people living with a dementia.				
3	3.7	Recognise the individual's specific needs e.g. nutrition, swallowing, medication, sleep or elimination needs.				
3	3.8	Recognise the individual's specific needs e.g. oral health, pain relief and personal care.				
3	3.9	Demonstrate use of relevant frameworks for breaking bad news.				
3	3.10	Describe how to support and facilitate families and carers who wish to remain with the person nearing end of life.				
3	3.11	Anticipate the spiritual, cultural and religious needs of a person nearing end of life.				
4	4.1	Demonstrate appropriate leadership skills to influence provision of quality, palliative and end of life care.				
4	4.2	Demonstrate understanding of the change process and how you could enable change in practice.				
4	4.3	Demonstrate effective communication and dissemination of knowledge and information to others that will promote positive outcomes for people with a dementia, their families and carers.				

THEME 11

WORKING IN PARTNERSHIP WITH FAMILIES AND CARERS

Rating Scale

Tier	Knowledge		SD	MD	WD	NA
1	1.1	Appreciate that families and carers have an important role throughout the dementia care journey.				
2	2.1	Accept that families and carers are likely to have specialist knowledge about the person living with a dementia that will help in the delivery of care.				
2	2.2	Understand the importance of developing partnerships with family members and carers.				
2	2.3	Examine the impact of caregiving on family members and carers.				
2	2.4	Recognise the complexity and diversity of family relations.				
2	2.5	Recognise the needs of families or carers may not always be met.				
2	2.6	Recognise the impact caring has on younger people.				
3	3.1	Examine legislation relevant to families and carers.				
3	3.2	Examine methods of assessment of carer’s needs.				
3	3.3	Recognise the potential for conflict and ethical dilemmas which can occur.				
4	4.1	Critically appraise international initiatives and best practice guidelines in empowering and involving carers.				
Tier	Skills		SD	MD	WD	NA
1	1.1	Demonstrate respect and understanding.				
2	2.1	Communicate compassionately with family and carers throughout the person’s journey.				
2	2.2	Involve families and carers in decision making where appropriate.				
3	3.1	Explain to families or carers how to access supportive networks e.g. The Alzheimer’s Society, Age NI, Dementia NI, Dementia Navigators and Carers NI.				
3	3.2	Show family and carers how they contribute to the decision making process.				
3	3.3	Assess a family member or carer’s psychological and practical needs.				
3	3.4	Articulate to carers where to access further support around legal issues e.g. Enduring Power of Attorney.				
4	4.1	Articulate to carers where to access international forums and training opportunities.				

THEME 12

RESEARCH AND EVIDENCE-BASED PRACTICE IN DEMENTIA CARE

Rating Scale

Tier	Knowledge		SD	MD	WD	NA
2	2.1	Articulate service development processes and evidence-based practice e.g. data collection, audit, user involvement and research.				
2	2.2	Evaluate the service on an on-going basis and contribute to evidence-based practice with regard to the mental health and well-being of people living with a dementia, their families and carers.				
2	2.3	Evaluate service developments and delivery in relation to the mental health and well-being of people living with a dementia, their families and carers.				
3	3.1	Critically evaluate the service on an on-going basis and contribute to evidence-based practice with regard to the mental health and well-being of a person living with a dementia, their families and carers.				
3	3.2	Critically evaluate service developments and delivery, in relation to the mental health and well-being of a person living with a dementia, their families and carers.				
3	3.3	Distinguish the difference between service evaluation and empirical research in dementia.				
3	3.4	Consider people living with a dementia, their family and carers who may wish to contribute to service evaluation and empirical research in dementia.				
4	4.1	Critique systematic research methods and be able to facilitate evidence-based practice.				
4	4.2	Collect the range of evidence that informs decision making, care practice and service delivery.				
4	4.3	Recognise approaches to evaluation of services or measuring service impact.				
4	4.4	Recognise the ethical processes involved in conducting and participating in empirical research.				
4	4.5	Recognise the importance of continuing professional development to ensure the methods used are robust, valid and reliable.				

THEME 12

RESEARCH AND EVIDENCE-BASED PRACTICE IN DEMENTIA CARE

Rating Scale

Tier	Skills		SD	MD	WD	NA
2	2.1	Demonstrate ability to access research and use information systems.				
2	2.2	Use and evaluate evidence-based practice to enhance care and services provided with regard to the emotional well-being and mental health of people living with a dementia.				
2	2.3	Collate data and information in relation to people living with a dementia to support service improvements.				
2	2.4	Develop a culture of learning and development with regard to the mental health and well-being of people living with a dementia.				
3	3.1	Participate in or facilitate service evaluation and empirical research in the workplace.				
3	3.2	Contribute to and generate research to inform evidence-based practice with regard to the mental health and well-being of a person living with a dementia, their families and carers.				
3	3.3	Apply continuous quality improvement approaches to identify gaps and develop services that are evidence-based and meet organisational or governmental priorities.				
3	3.4	Disseminate research in relation to mental health and well-being of a person living with a dementia, their families and carers.				
3	3.5	Initiate and manage practice or service development regarding the emotional well-being and mental health of a person living with a dementia, their families and carers, taking account of relevant research, clinical guidelines and policy.				
4	4.1	Disseminate international service evaluations or empirical research findings in written reports or by verbal presentations.				
4	4.2	Show skills in systematic research methods and be able to facilitate and evaluate evidence-based practice.				
4	4.3	Critique the range of evidence that informs decision making, care practice and service delivery.				
4	4.4	Develop new approaches to the evaluation of services for the measuring of service impact.				
4	4.5	Analyse and respond to the ethical issues and processes involved in conducting and participating in empirical research.				
4	4.6	Undertake continuing professional development to ensure the methods used are robust, valid and reliable.				

THEME 13

LEADERSHIP IN TRANSFORMATIONAL DEMENTIA CARE

Rating Scale

Tier	Knowledge		SD	MD	WD	NA
3	3.1	Explain quality assurance mechanisms and measures.				
3	3.2	Compare different models of mentoring and coaching team members to become leaders in dementia care.				
4	4.1	Appraise the key drivers and policies which influence national and international legislation.				
4	4.2	Critique and compare evidence-based research, innovations and developments in dementia care.				
4	4.3	Identify the importance of quality assurance.				
4	4.4	Integrate good leadership in practice.				
4	4.5	Facilitate the provision of good leadership in practice.				
Tier	Skills		SD	MD	WD	NA
3	3.1	Produce quality assurance reports.				
3	3.2	Facilitate other members of the team to become leaders in dementia care.				
4	4.1	Consider new evidence-based approaches and challenge poor practice.				
4	4.2	Critique a range of methods and select the most appropriate way to measure quality assurance.				
4	4.3	Facilitate other staff with a view to developing leaders in dementia care across the organisation.				
4	4.4	Develop and train team members to maximise their competence within dementia care.				
4	4.5	Collaborate with other agencies in order to maximise support and quality of care afforded to people living with a dementia, their families and carers.				

Health & Social Care Board
12-22 Linenhall Street
Belfast BT2 8BS

Tel: 0300 555 0155
www.hscboard.hscni.net

Follow us on

