

PROMOTING EXCELLENCE 2021

A framework for all health and social services staff working
with people with dementia, their families and carers

in partnership with:



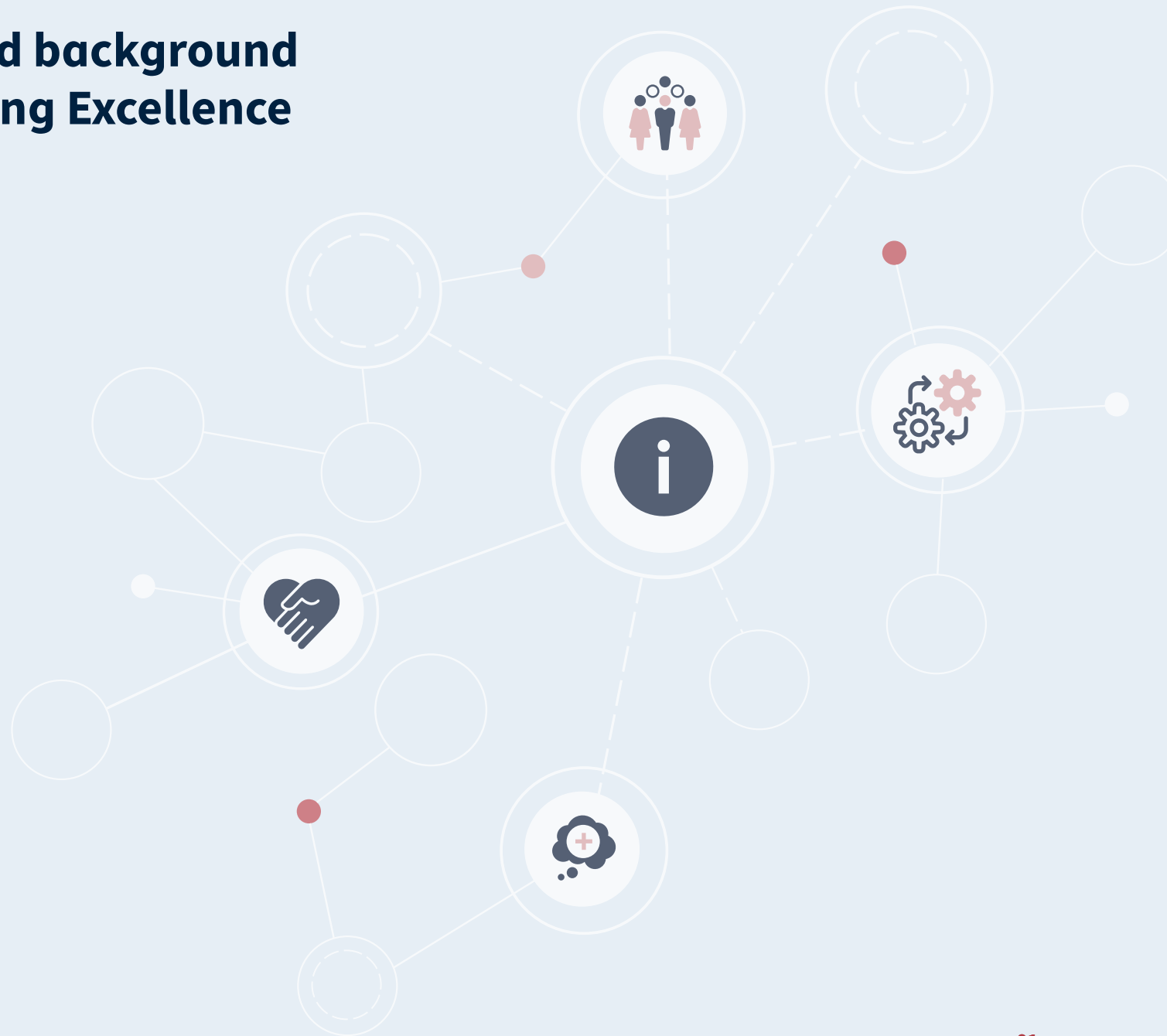
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Introduction and background to 2021 Promoting Excellence framework



Introduction

In June 2010, the Scottish Government launched Scotland's first National Dementia Strategy. In 2011, NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC) developed *Promoting Excellence: a framework for all health and social services staff working with people with dementia, their families and carers* to support the strategy and implementation of *The Standards of Care for Dementia in Scotland* (2011).

Since then, the Scottish Government has published **two** further dementia strategies, the most recent covering the years 2017 to 2020. Consultation on a fourth strategy was planned for the start of 2020 before the onset of COVID-19. The Scottish Government will now publish a National COVID-19 Dementia Transition and Resilience Plan to respond to the on-going challenges around the impact of the pandemic on people with dementia and to continue to build on and extend national action in the 2017-2020 strategy, including in the key area of post-diagnostic support.

On-going implementation of Promoting Excellence will remain a key part of our national work on dementia, including in response to the current public health challenge, and is complemented by the national dementia AHP framework, *Connecting People, Connecting Support*.

The wider national policy context has also changed and progressed since 2011, including the integration of health and social care, the roll out of self-directed support and the legislation which expands support and entitlements for carers.

The Promoting Excellence framework *reflects the actions, priorities and commitments of the dementia strategies* and on-going national activity on dementia. NES and the SSSC have been active since 2011 in supporting the four levels of the framework in practice, including the development of:

- **core educational** resources
- **training programmes;** and
- **developing leaders and infrastructures** to support implementation.

The 2011 Promoting Excellence framework was ground-breaking as Scotland's first national workforce development framework. It set high aims for the care and support of people with dementia, their families and carers.

This 2021 version reflects progress made since 2011, such as:

- **new research on preventing dementia**, new ways to support people across their dementia journey (*including the Scottish Government's national commitment on post-diagnostic support effective since 2013*), and what works best for people with dementia, their families and carers;
- **new laws**, including the Carer's Rights (Scotland) Act; and
- **new human rights-based** Standards for Health and Social Care.

The purpose and structure of the 2021 version of the framework has not been changed. What has changed are some of the knowledge and skills statements in the framework levels and domains sections.

The purpose of the framework

The framework sets out the knowledge and skills all health and social care staff should achieve in their roles in supporting people with dementia, their families and carers. It works alongside other standards and frameworks, such as the NHS Knowledge and Skills Framework, the Social Services Continuous Learning Framework and the National Occupational Standards for Health and Social Care. The framework also has relevance and applicability to other sectors, such as housing.

The Promoting Excellence framework:

- **adds** to these existing frameworks;
- **applies to all health and social care staff** who have contact with, and provide support, care, treatment and services for, people living with dementia, their families and carers;
- **is future-focused**, meaning it is not just a description of what we do now — it is also what we aspire to do in the future to support the changes outlined in Scotland's national dementia strategies; and

- **sets out the knowledge and skills needed for new ways of working** for *all* health and social care staff to help people with dementia, their families and carers to maximise their rights, choices, and health and wellbeing at all stages of their own dementia journey.

The evidence and principles for the framework

The original 2011 framework was based on a number of activities, including:

- **gathering evidence, best practice guidance and reviews** of research and reports;
- **reviewing** competency frameworks;
- **making links** with wider UK dementia work programmes;
- **consulting with a wide range of people** with an interest in care and support for people with dementia, their families and carers.

This 2021 version has used similar activities. Experts, including people living with dementia, their families and carers, have been involved in developing this version of the framework. We acknowledge their contribution in **Appendix II**.

The most important thing is that the framework is based on the **values and principles that people with dementia, their families and carers have said are most important to them.**

The framework highlights and supports the primacy of people's rights. These are based on The Charter of Rights for People with Dementia and their Carers in Scotland and The Standards of Care for Dementia in Scotland. The key resources used to develop the framework are shown in **Appendix I**.

How the framework should be used





The framework should be used at a *personal, service provider and organisational level* in several ways, and for a range of purposes. This will be achieved:

- **By individual staff members** (*in conjunction with their appropriate generic and/or professional frameworks and guidance*) to help them fully understand the values base and knowledge and skills expected of them to fulfil their responsibilities in delivering excellence in dementia care, support and treatment.
- **By individual staff members, alongside their managers/supervisors**, to identify and explore their strengths and any gaps in knowledge and skills in relation to the role they are performing. It will allow both to identify and take action to address any development needs to deliver the aspirations set out in this framework.
- **By providers of services commissioned by health or social care** to ensure people with dementia receive care, treatment and support of the highest quality that meets the standards.
- **By organisations** to ensure staff have the necessary knowledge and skills to meet the needs of people with dementia, their families and carers, and to plan staff development activities to reflect the aspirations set out in the framework.
- **By organisations** to identify any staff development needs to support delivery of the Standards of Care for Dementia in Scotland.
- **By education and training providers** to inform the content of the education and training they provide and shape the design and delivery of future-focussed vocational and professional undergraduate and post-graduate education and training.
- **By people with dementia, their families and carers** to ensure they are aware of and can exercise their rights and entitlements for excellence in the support, care and treatment they should expect to receive.

The structure of the framework

Levels of knowledge and skills

Each level sets the specific knowledge and skills specific staff need based on their role rather than their position in the organisation, or their profession.

			
<p>The Dementia Informed Practice Level provides the baseline knowledge and skills required by <i>all</i> staff working in health and social care settings, including in a person’s own home.</p>	<p>The Dementia Skilled Practice Level describes the knowledge and skills required by all staff who have direct and/or substantial contact with people with dementia, their families and carers.</p>	<p>The Enhanced Dementia Practice Level outlines the knowledge and skills required by health and social care staff who have more regular and intense contact with people with dementia, provide specific interventions, and/or direct and co-ordinate care and services for people with dementia. <i>The knowledge and skills outlined at this level become increasingly role and context specific.</i></p>	<p>The Expertise in Dementia Practice Level outlines the knowledge and skills required for health and social care staff who, through their role and practice setting, play an expert specialist role in the care, treatment and support of people with dementia. <i>The knowledge and skills outlined at this level become increasingly role and context specific.</i></p>

The knowledge and skills outlined at each level follow on from each other. For example, **staff who operate at the Dementia Enhanced Practice Level would also have the knowledge and skills, attitudes and behaviours described at the levels before.**

Roles in health and social care differ, so the framework does not point out any specific health and social care staff roles in the domains. Each staff member and their employer must make sure they understand and work to the content of the framework as it relates to their role when working with people with dementia, their families and carers.

Stages of the dementia journey

Dementia follows a well-recognised pathway of progression.

The framework uses the pathway as a structure, although we understand that the needs of people with dementia, their families and carers *will be different at different stages*, and that the dementia journey will be *unique* for each person.

Receiving a diagnosis of dementia is not the starting place for the framework. Helping to prevent the onset of dementia, and supporting people to keep good health and wellness, are also vital. A targeted public health approach to dementia risk reduction and prevention has a specific focus in national work on dementia from 2021 led by Brain Health Scotland, which is funded by the Scottish Government and hosted by Alzheimer Scotland.

The four stages of the dementia journey identified in the framework are:



**Keeping well,
prevention,
and finding out
it's dementia**



**Living well
with dementia**



**Living well with
increasing help
and support**



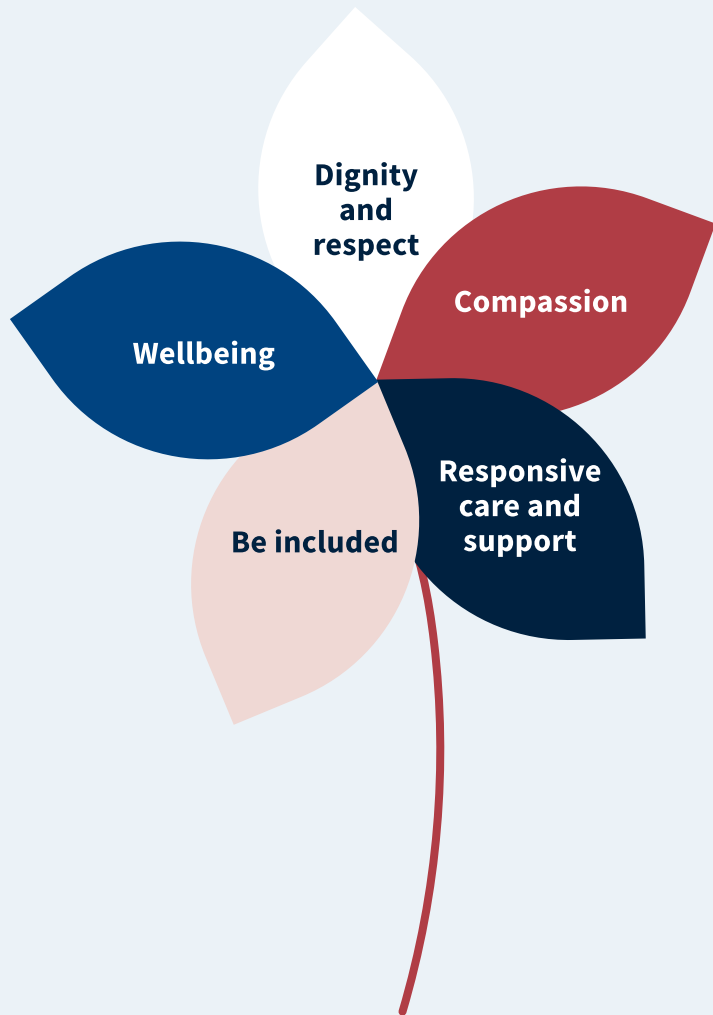
**End of life and
dying well**

Quality of life outcome indicators for people with dementia, their families and carers

Work done by the Alzheimer's Society in 2010 showed that **people can have a good quality of life following a diagnosis of dementia**, and that the domains in general quality of life measures are as relevant to people with dementia as more dementia-specific domains. The views of people with dementia, their families and carers on the relevance of the quality of life outcome indicators developed for the original 2011 Promoting Excellence framework were sought through a recent consultation. With some small changes, these were still found to reflect the views of people living with dementia, their families and carers.

The quality of life outcome indicators are at the heart of the framework and encourage staff and services to think about the impact and end results of the support, care, interventions and treatments they provide against these indicators. The quality of life outcome indicators reflect the new Standards for Health and Social Care and their underpinning principles.

Health and Social Care Principles



Health and Social Care Standards



Quality of Life Outcome Indicators**01**

People with dementia have access to a timely and accurate diagnosis of dementia that includes high-quality support before, during and after their diagnosis

02

People with dementia feel empowered and enabled to exercise rights and choice, maintain their identity and be treated with dignity and equity.

03

People with dementia have access to individuals, groups and organisations that can support their spiritual or personal beliefs and reflect their cultural wishes.

04

People with dementia have access to quality services and can continue to participate in community life and valued activities.

05

People with dementia maintain their best level of physical, mental, social and emotional wellbeing.

06

People with dementia feel safe and secure and are able to be as independent as possible.

07

People with dementia are able to maintain valued relationships and networks and have the opportunity to develop new ones, both personal and professional.

08

People with dementia, with their families, friends and carers, have access to the information, education and support that promotes their rights and enhances their wellbeing.

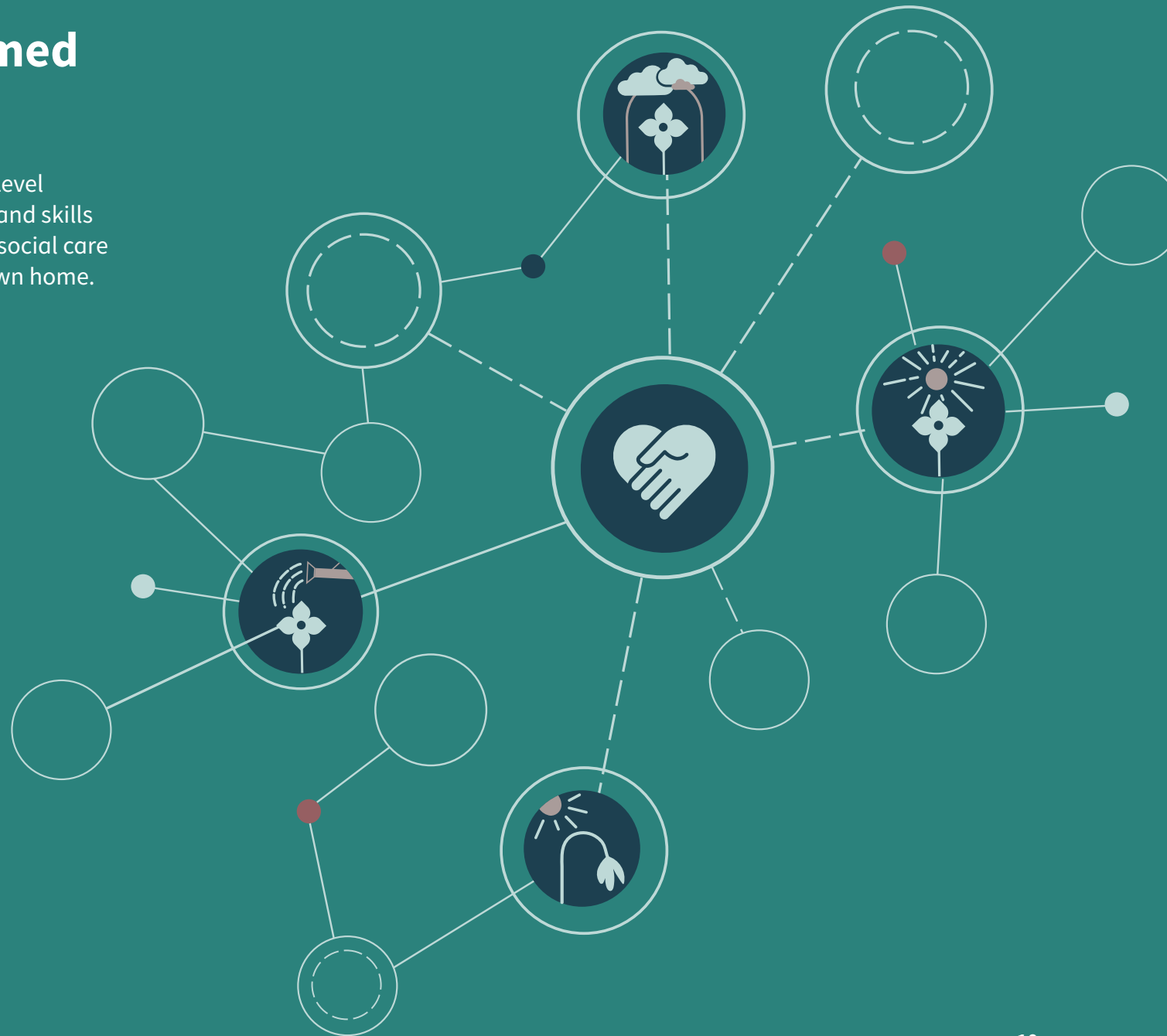


Once the word dementia comes into a conversation, people more or less dismiss you. They think you have no views, no thoughts of your own; you can't speak for yourself, you can't do things for yourself and you have a very, very difficult job persuading these people to listen to you, to take you seriously and to get help of any manner or kind, because they're very dismissive. All of a sudden, you become useless. This is not the case.

A person living with dementia

Dementia Informed Practice Level

The Dementia Informed Practice Level provides the baseline knowledge and skills required by all staff in health and social care settings, including in a person's own home.



Stage**Across all stages of the dementia journey****What staff know (knowledge)**

- Appreciate that people with dementia, their families and carers are able to live well and maintain a quality of life valued by them.
- Understand that a good and valued quality of life should reflect the priorities of the person with dementia, their family and carers.
- Understand what is meant by the term rights-based, person-centred support in relation to people with dementia.
- Understand that legislation exists to support carers in their role.
- Understand the importance of recognising, enhancing and supporting the strengths and abilities of people with dementia.
- Understand the benefits of continued engagement in life roles and relationships, and that people with dementia have a right to be supported to achieve this.
- Understand that people with dementia have the right and ability to develop new skills and make the most of new opportunities.

What staff are able to do (skills)

- Interact with people with dementia, their families and carers in a way that recognises and respects their rights, wishes, priorities and needs.
- Interact with people with dementia in a person-centred way that recognises and utilises their unique strengths and abilities.
- Contribute to supporting people with dementia and their families to explore and engage in new opportunities.

Stage**Across all stages of the dementia journey****What staff know (knowledge)**

- Know how to access local community information and services that can provide information and support for people with dementia, their families and carers.
- Understand some of the common difficulties people with dementia may experience, such as memory problems, confusion, communication, perception and sensory changes.
- Know how to communicate with people who are experiencing confusion, memory or communication difficulties.
- Know about potential different and supplementary tools, techniques and methods that people with dementia may use to enhance communication.
- Understand that diversity, equality and inequality issues impact on the experience and support needs of people with dementia (for example, people from different cultural and ethnic groups, lesbian, gay, bisexual and transgender people, people with learning disabilities, younger people and people with disabilities).
- Know how existing and emerging technologies can enable people with dementia to live well.

What staff are able to do (skills)

- Provide relevant information or signpost to an appropriate person or service to enable people with dementia to access chosen community services, supportive technology and activities.
- Recognise when a person appears to be experiencing confusion, memory or communication difficulties.
- Communicate in a way that suits and responds to people's strengths and needs, using their preferred tools and technology if required.
- Communicate in a way that recognises individual needs and diversity and the potential impact of memory difficulties and confusion.

Stage	Across all stages of the dementia journey
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What staff know (knowledge)	What staff are able to do (skills)
<ul style="list-style-type: none"> • Understand the potential physical, social and environmental hazards and risks to the safety and wellbeing of people with dementia. • Appreciate when the physical or social environment can compromise the health and safety of people who are experiencing confusion and memory problems. • Understand that people with dementia, their families and carers need support for changes at different stages of the dementia journey. • Understand that the changes people with dementia experience can mean that they may need support, or environmental adjustment, to live well and remain engaged in community life and valued activities. 	<ul style="list-style-type: none"> • Support people who appear confused or are experiencing problems with their memory to manage situations where the environment is challenging or presents risks to them. • Support people to live well with dementia at any stage of their dementia journey by ensuring that their wishes, needs and priorities are continually revisited.

Stage**Across all stages of the dementia journey****What staff know (knowledge)**

- Understand that people with dementia may have a range of other health problems/conditions that influence their support needs.
- Understand how the changes experienced by people with dementia can have an effect on their behaviour, relationships and activities, and that this can affect their mood.
- Understand how the environment circumstances/situation/context can have an effect on people with dementia.
- Know how to respond in a supportive and sensitive way to a person with dementia who is distressed.
- Understand the effects of stigma and fear of stigma associated with dementia.

What staff are able to do (skills)

- Identify areas of concern and respond appropriately to people with dementia, their families and carers who appear distressed.
- Engage with people with dementia in a respectful, person-centred way to negate the impact of stigma and discrimination.



It's time to remove the stigma around dementia. It's an illness just like cancer or diabetes but there is still a fear and misunderstanding about dementia.



A person living with dementia

02

People with dementia feel empowered and enabled to exercise rights and choice, maintain their identity and be treated with dignity and equity.

Quality of Life Outcome Indicator

Stage	Across all stages of the dementia journey
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What staff know (knowledge)	What staff are able to do (skills)
<ul style="list-style-type: none"> • Understand that people with dementia may be at risk of experiencing neglect, harm or abuse – including physical, sexual, psychological and financial. • Understand that legislation exists to protect the rights of people with dementia and safeguard them against any potential risk or harm. • Know about local adult protection protocols and policies. • Understand the benefits of risk enablement in giving people choice and control. 	<ul style="list-style-type: none"> • Recognise when a person with dementia is experiencing neglect, harm or abuse. • Take appropriate action according to organisational procedures when concerned that a person with dementia may be experiencing neglect, harm or abuse. • Contribute to supporting people with dementia to take positive risks that provide opportunities and benefits for them.

Dementia Skilled Practice Level

The Dementia Skilled Practice Level describes the knowledge and skills required by all health and social services staff who have direct and/or substantial contact with people who have dementia.



Stage**Keeping well, prevention and finding out it's dementia****What staff know (knowledge)**

- Appreciate that people with dementia have a right to continued engagement in life's roles and relationships.
- Appreciate the importance of supportive networks and/or therapeutic connections for people with dementia, their families and carers.
- Appreciate that people with dementia can continue in employment with support and reasonable adjustments.
- Appreciate the benefits for people with dementia of engaging in activities as a means of maintaining their independence and enriching their lives.

What staff are able to do (skills)

- Support and enable people with dementia to develop new roles, skills and relationships.
- Support and enable people with dementia to maintain their chosen activities, social life and community involvement.
- Support people with dementia to continue in employment and signpost/refer to appropriate support services if required.
- Provide information and signpost to relevant services, including those that reflect the person's spiritual and cultural wishes.

Stage

Keeping well, prevention and finding out it's dementia



What staff know (knowledge)

- Understand the types of health behaviours that can support physical health and contribute to prevention of certain types of dementia.
- Appreciate the short- and long-term benefits for people with dementia of remaining active and, where possible, increasing their physical activity and following a healthy diet.
- Appreciate the potential benefits to self-esteem of mental stimulation, education and knowledge sharing for people with dementia.
- Recognise the importance of maintaining the spiritual and cultural aspects of life for people with dementia, their families and carers.

What staff are able to do (skills)

- Enable people to access and explore a range of information about strategies and healthy lifestyle behaviour that can reduce the likelihood of developing some types of dementia.
- Work alongside people with dementia to support them to remain active, engage in physical activity and follow a healthy diet.
- Support people with dementia to access opportunities to engage in education and knowledge-sharing.
- Support people to maintain the spiritual and cultural aspects of life.



People with dementia shouldn't be dismissed just because they have dementia, because we're asking for things and doing things that nobody has done and asked for before.

A person living with dementia

07

People with dementia are able to maintain valued relationships and networks and have the opportunity to develop new ones, both personal and professional.

Quality of Life Outcome Indicator

Stage**Keeping well, prevention and finding out it's dementia****What staff know (knowledge)**

- Appreciate that the effects of dementia can mean that people may require support or environmental adjustment to maintain meaningful engagement in community life and valued activities.
- Appreciate that the environment incorporates physical, cultural and social aspects that can impact on the experience of people with dementia, their families and carers.
- Understand the different types of dementia and the particular implications and impact on the person, their family and carers.
- Recognise the differences between dementia and other physical and mental health problems, particularly delirium and depression.

What staff are able to do (skills)

- Contribute to making environmental adjustments, including the use of enabling technology, to suit the individual requirements and needs of people with dementia.
- Respond appropriately to the diverse range of issues that people with dementia may experience that reflect the impact of specific types of dementia.
- As part of a multi-disciplinary team, provide appropriate support, treatment and management in response to the recognition of delirium and depression.

Stage**Keeping well, prevention and finding out it's dementia****What staff know (knowledge)**

- Understand a range of effective communication techniques and strategies to suit people who are affected by memory difficulties or confusion.
- Understand how a range of augmentative and alternative communication can support people with dementia to express themselves.
- Know and understand the range of local professional and community services and specialists who can provide assessment, advice and support for memory problems.
- Understand the anxiety and uncertainty that people can experience before, during and following a diagnosis of dementia.
- Understand and appreciate the potential impact of a diagnosis of dementia on people, their families and carers and their wider network.

What staff are able to do (skills)

- Adapt communication to meet the individual strengths and needs of people with dementia.
- Communicate respectfully and sensitively with people with dementia in a personalised way, giving consideration to the potential impact of memory difficulties or confusion.
- When appropriate, communicate with people with dementia using their preferred augmentative and alternative methods.
- Support people to access services and specialists who can provide assessment, advice and support for memory problems.
- Respond sensitively using person-centred approaches to support people through the diagnosis of dementia.

Stage**Keeping well, prevention and finding out it's dementia****What staff know (knowledge)**

- Understand that the way staff support people through a diagnosis of dementia will have a lasting impact on their wellbeing.
- Understand the range of local professional, specialist and community and voluntary resources that provide services such as counselling, psychological or pharmacological supports, and peer and group support.
- Understand how technology can enable connectedness, communication, autonomy and independence.
- Have awareness of the principles and key provisions of relevant adult support and protection and equalities legislation.
- Have critical knowledge of local guidelines and protocols to respond to neglect and abuse.

What staff are able to do (skills)

- Support people with dementia to access emotional support, counselling or psychological therapies and interventions to promote mental wellbeing.
- Contribute to supporting people with dementia to access enabling technology.
- Use the principles of legislative frameworks to support people with dementia to exercise their rights and choices.
- Contribute to the assessment and support of people with dementia who may be experiencing neglect, harm or abuse.

Stage

Living well with dementia



What staff know (knowledge)

- Appreciate that stigma and the impact of dementia can lead to social isolation and withdrawal from previously valued social connections and activities.
- Understand the concepts of risk and risk enablement in relation to supporting people with dementia, their families and carers.
- Appreciate the potential of enabling technology to positively support and promote independence and quality of life for people with dementia.
- Recognise the diverse range of services and supports that help people with dementia to maintain valued activities, social engagement and inclusion.
- Understand the impact of the environment on the safety and wellbeing of people with dementia.
- Know how to use a range of enabling technology safely to support people with dementia, their families and carers.

What staff are able to do (skills)

- Challenge any signs or actions that stigmatise people with dementia.
- Contribute to enabling people with dementia to take considered risks to maximise their opportunities.
- Work with people to support them to understand risk enablement and risk.
- Take an individualised approach to risk by acknowledging that dementia affects people in different ways.
- Using person-centred approaches, utilise a range of enabling technologies to positively support and promote independence and quality of life for people with dementia.

Stage**Living well with dementia****What staff know (knowledge)**

- Understand the impact of the progression of dementia on the physical, emotional and psychological health and wellbeing of people with dementia, their families and carers.
- Understand the impact the progression of dementia may have on relationships, including sexuality and intimacy.
- Appreciate that people with dementia have a right to be sexually active.
- Understand the models, concepts and underlying causes of stress and distress in dementia.
- Appreciate the range of multi-sensory, therapeutic and recreational activities that promote wellbeing and independence.

What staff are able to do (skills)

- Engage with people with dementia, their families and carers in a warm and empathic manner that takes account of the progression of dementia on their health and wellbeing.
- Work with people with dementia, their families and carers in a way that supports and respects their right to engage in sexual and intimate relationships.
- Utilise detailed knowledge of the person to recognise when they are at risk of becoming distressed.
- Identify areas of concern and potential triggers for stress and distress for people with dementia, their families and carers and respond appropriately.
- Support people to engage in activities and experiences which they find meaningful and valued.

Stage**Living well with dementia****What staff know (knowledge)**

- Appreciate the importance of getting to know the person, both in the present and the past, using a range of approaches, including life-story work and reminiscence.
- Appreciate how life-story work can positively facilitate a person's sense of self and self-value and inform future planning.
- Appreciate how life-story work and reminiscence can be used to communicate with people with dementia and engage them in meaningful and valued interactions, activities and experiences.
- Understand the value to families and carers of recording a life story to maintain the sense of person and their relationships.
- Appreciate the benefits of engaging in life-story work for families and carers.
- Appreciate the role of emerging technology in providing a creative means of exploring, compiling and recording life stories.

What staff are able to do (skills)

- Use a range of approaches, including life-story work and reminiscence, to get to know the person and support their engagement in meaningful and valued activities relating to their interests, abilities and experiences.
- Work with families, carers and the person to compile and record their life story in their preferred format, including the use of emerging technology.

Stage**Living well with increasing help and support****What staff know (knowledge)**

- Appreciate that people with dementia have the right to continue to be actively involved in all decisions that help them to live well with dementia.
- Understand the requirements of formal assessment of capacity under the terms of the legislation.
- Appreciate the benefits of ongoing and supportive relationships to the health and wellbeing of people with dementia, their families and carers.
- Understand the range of challenges that people with dementia, their families and carers might face as their dementia progresses.
- Identify when people with dementia, their families and carers are experiencing barriers to accessing support for physical, social or psychological difficulties.
- Know about a range of methods of communication with people with dementia who may be experiencing increasing difficulties with their memory and life skills.

What staff are able to do (skills)

- Work with people with dementia, their families and carers to maximise their ability to participate in decisions and choices.
- Contribute to formal assessment of capacity to enable people to achieve their expressed choices, wishes and desires.
- Support people with dementia to maintain their valued personal and community connections.
- Work with the person, family and carers to manage or challenge barriers to accessing support.
- Support and signpost the person with dementia, their family and carers to access counselling or psychological therapies that can enhance coping skills and maintain intimate relationships.
- Assess the person's preferred approach to communication, taking account of the individual progression and variable nature of dementia, and use this in all interactions with the person.

Stage**Living well with increasing help and support****What staff know (knowledge)**

- Appreciate that people with dementia are more at risk of developing changes that might impact on their physical health, such as becoming dehydrated and/or malnourished, or having continence problems.
- Recognise when previous psychological trauma has occurred, and that people will react and respond differently.
- Appreciate that a person might feel distressed or even re-traumatised in certain situations if they are reminded in some way of past trauma.
- Understand that for some people with dementia, previous trauma can impact on mental health and wellbeing and on physical health and relationships with others.
- Recognise that through engagement in life-story work and reminiscence, a person with dementia may recall and share previous physical and psychological traumatic experiences.

What staff are able to do (skills)

- Provide direct support in eating, drinking and continence, when appropriate to role, to promote physical wellbeing.
- Use local protocols and procedures to obtain informed consent to share information to facilitate the team and enable them to respond in a trauma-informed manner.
- Provide support, including personal care, in a way that reflects trauma-informed practice.

Stage**Living well with increasing help and support****What staff know (knowledge)**

- Understand the complexity of experiencing multiple illnesses for people with dementia.
- Recognise that people with dementia who also have frailty are at risk of adverse outcomes that include dramatic changes in their physical and mental wellbeing after an apparently minor health event, such as an infection or the introduction of new medication.
- Understand that people with dementia may have a reduced or changed ability to communicate physical illness, pain and mental distress.
- Understand that people who know the person well may recognise unique and individual signs that indicate the person is in pain or distress.
- Have knowledge of how pain assessment tools can help establish when a person with dementia is in pain, particularly when communication is compromised.
- Understand that a person-centred approach, working with family and carers, is required to identify when a person with dementia is experiencing pain.

What staff are able to do (skills)

- Work as part of a multi-disciplinary team to support people with dementia who have a range of co-morbid conditions.
- Working as part of the multi-disciplinary team, adopt a strengths-based approach to holistically assess people's physical and mental health needs, and monitor changes and deteriorations in their health.
- Working as part of the multi-disciplinary team, contribute to person-centred assessment of pain and monitor and report any changes in the person that may suggest they are experiencing pain and discomfort.

Stage**Living well with increasing help and support****What staff know (knowledge)**

- Understand the particular environmental and individual physical and cognitive issues for people with dementia that can intensify the possibility of slips, trips and falls.
- Understand that visual impairment and perceptual changes can increase the risk of slips, trips and falls for people with dementia.
- Know how to use a range of aids, adaptations, techniques and technological solutions to support independence.
- Understand the range of anticipatory and preventative measures, including consideration of technology, that can be put in place to prevent hospital admission for people with dementia.
- Understand that when hospital admission is necessary, potential solutions are available to improve the experience and outcomes for people with dementia.
- Understand that open and frequent communication with people with dementia, their families and carers during acute hospital admissions can reduce anxiety and distress and promote partnership-working.

What staff are able to do (skills)

- Recognise when people with dementia may be at risk of slips, trips and falls and take appropriate action/utilise the most appropriate solution in line with the multi-disciplinary assessment and care plan.
- Implement a range of appropriate changes and adaptations to support people with dementia.
- Working as part of the multi-disciplinary team, implement anticipatory and preventative measures to support people with dementia to remain in their familiar environment.
- Work in partnership with families and carers as an integral part of the assessment and care-planning and delivery process when the person is in hospital.

Stage**End of life and dying well****What staff know (knowledge)**

- Understand the interdependence of the physical, psychological, emotional and spiritual care needs of a person with dementia, their family and carers in relation to palliative and end of life care.
- Understand the importance of values, beliefs and communication in the delivery of person-centred palliative and end of life care for people with dementia, their families and carers.
- Understand that anticipatory care plans or advance plans should help inform decisions relating to the person's needs, wishes and choices to support dying well.
- Understand the complexities of decision-making and the legal and ethical framework necessary to ensure the wishes of the person with dementia are heard and respected.

What staff are able to do (skills)

- Work as part of the multi-disciplinary team and in partnership with the family and carers to provide palliative and end of life care that reflects the unique needs, wishes and choices of the person with dementia.
- Working as part of the multi-disciplinary team and in partnership with the family and carers, ensure the wishes of the person with dementia are heard and reflected in the care and support provided, which takes account of relevant legal and ethical frameworks.

**Stage****End of life and dying well****What staff know (knowledge)**

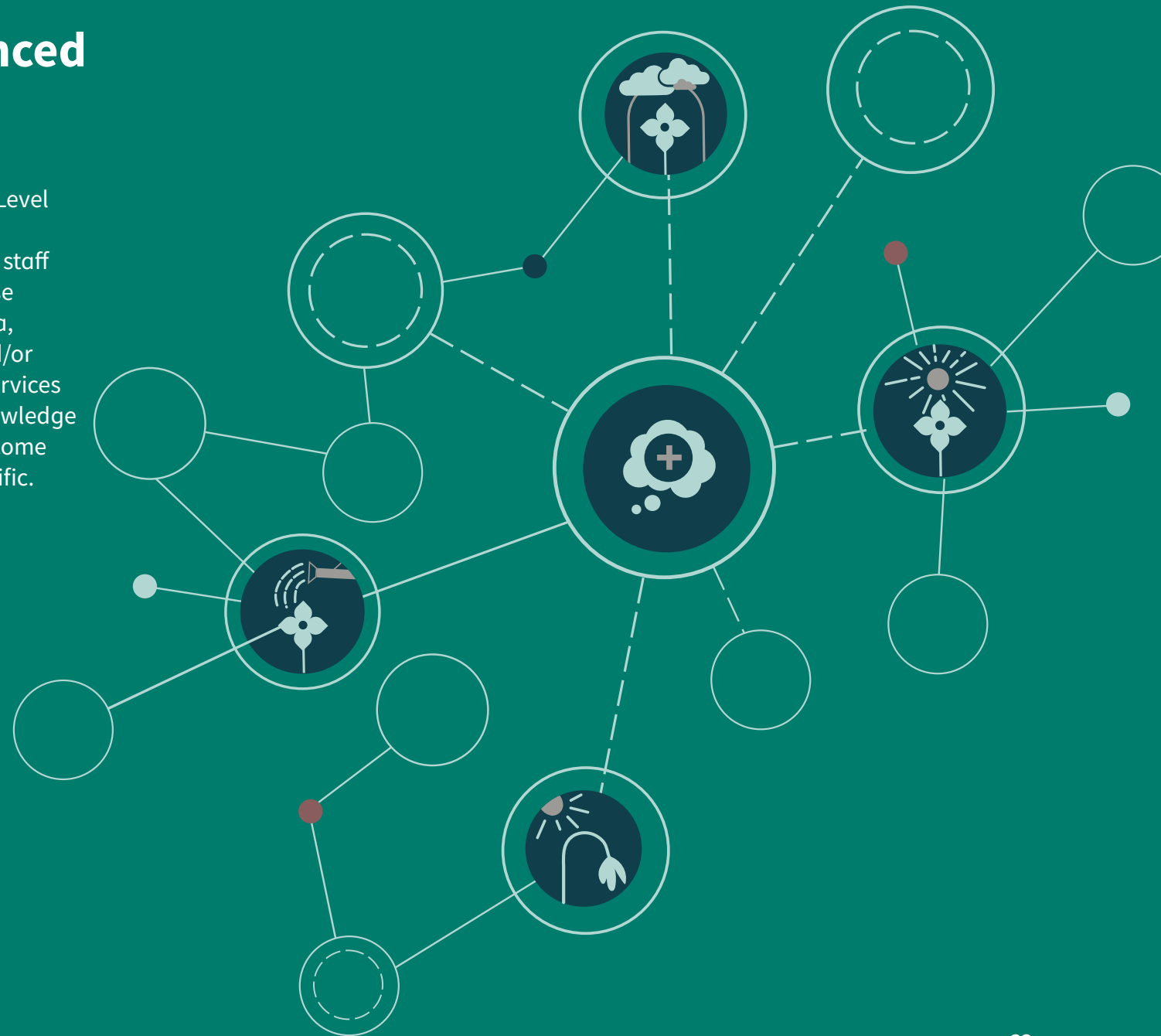
- Understand the specific needs of people with dementia and promote comfort and dying well.
- Recognise the changes that indicate that a person with dementia is nearing the end of their life.
- Appreciate the important role and support needs of family, carers and friends, including after the death of the person with dementia.

What staff are able to do (skills)

- Work as part of the multi-disciplinary team to provide person-centred care that promotes comfort through palliative and end of life care.
- Respond appropriately when changes indicate that a person is nearing the end of their life.
- Contribute as part of the multi-disciplinary team to supporting family, carers and friends, including following the death of the person with dementia.

Dementia Enhanced Practice Level

The Enhanced Dementia Practice Level outlines the knowledge and skills required by health and social care staff who have more regular and intense contact with people with dementia, provide specific interventions, and/or direct and co-ordinate care and services for people with dementia. The knowledge and skills outlined at this level become increasingly role and context specific.



Stage**Keeping well, prevention and finding out it's dementia****What staff know (knowledge)**

- Critically evaluate and apply the evidence base that may help prevent some forms of dementia.
- Appreciate the complex issues that need to be addressed and explored by people, their families and carers facing a potential diagnosis of dementia.
- Have detailed knowledge of the different types of dementia and the implications for the support needs of the person on receiving a diagnosis.
- Have detailed knowledge about how to prevent and minimise deterioration in people's health following a diagnosis of dementia.

What staff are able to do (skills)

- Raise public awareness of the strategies that promote health and wellbeing and may help prevent some forms of dementia.
- Support people to explore and consider the benefits and risks of receiving a diagnosis of dementia.
- Discuss sensitively with the person with dementia their options in relation to referral to memory clinics and specialist services.



It is important to have high-quality integrated support from the point of diagnosis rather than waiting for a crisis that can have a long-term impact on the health and wellbeing of the person with dementia and their families and carers.

Family member

01

People with dementia have access to a timely and accurate diagnosis of dementia that includes high-quality support before, during and after their diagnosis

Quality of Life Outcome Indicator

Stage**Keeping well, prevention and finding out it's dementia****What staff know (knowledge)**

- Have detailed knowledge of the differences between dementia and other physical and mental health problems, particularly delirium, anxiety and depression.
- Have knowledge of a range of evidence-based screening tools that may be used to assess cognition (memory, orientation, language, praxis, perceptual skills and executive function) in people with dementia.
- Have detailed knowledge of local services and specialists, their roles and functions, and the services they offer for assessment and advice on memory problems.
- Appreciate the impact and potential losses associated with a diagnosis of dementia and the range of possible reactions, including emotional distress.
- Appreciate the potential impact of a diagnosis of dementia on relationships, roles and expectations.

What staff are able to do (skills)

- When required, support treatment and management of delirium, anxiety and/or depression.
- Use screening tools to assess memory, orientation, language, praxis, perceptual skills and executive function.
- Interpret feedback from evidence-based screening tools.
- Refer to the most appropriate professional or service as required for specialist in-depth assessment and/or treatment.
- Encourage the person to talk through concerns and fears and prioritise issues following a diagnosis of dementia.
- Identify and respond sensitively to the verbal and non-verbal cues from the person with dementia, their family and carers, that may indicate psychological distress.
- Ascertain the education needed by the person with dementia, their family and carers following a diagnosis and provide information or signpost as appropriate.

Stage**Keeping well, prevention and finding out it's dementia****What staff know (knowledge)**

- Appreciate that a person may need time to adjust to a diagnosis of dementia.
- Appreciate the importance of promoting hope for a person receiving a diagnosis of dementia, their family and carers.
- Appreciate the potential impact of a diagnosis of dementia on a diverse range of people, including those from a range of ethnic and cultural groups, people with learning disabilities and younger people.
- Recognise the risk of people with learning disabilities developing dementia.

What staff are able to do (skills)

- Adopt a person-centred approach, as part of the multi-disciplinary team, to supporting a person receiving a diagnosis that reflects the pace necessary to allow them to adjust.
- Communicate sensitively and empathetically, promoting hope while focusing on positive elements of how people with dementia can live well.
- If appropriate to role, contribute to regular assessment and review of people with learning disabilities to ensure accurate and timely diagnosis of dementia.
- Ensure that all people with dementia, including younger people and people with learning disabilities, are supported to access chosen services in an equitable way.

Stage**Keeping well, prevention and finding out it's dementia****What staff know (knowledge)**

- Have detailed knowledge of outcomes-focused approaches in dementia care, treatment and support.
- Appreciate the importance of identifying and focusing on outcomes that are important to the person with dementia.
- Have detailed knowledge of evidence-based, solution-focused psychological interventions to assess the impact of diagnosis on the wellbeing of people with dementia, their families and carers.
- Critically evaluate the evidence base relating to the short- and long-term benefits for people living with dementia to remain active and, where possible, increase their physical activity and follow a healthy diet.
- Appreciate the importance of supporting people to maintain their independence and live well, including through the use of existing and emerging technologies.
- Appreciate the supportive actions that can enable people with dementia and their families and carers to engage in education or knowledge-sharing.

What staff are able to do (skills)

- Engage with the person with dementia to establish and assess the outcomes that are important to them and support them to prioritise and achieve them.
- Maintain a positive and solution-focused approach that encourages and supports people with dementia, their families and carers to build on their strengths and abilities.
- Provide advice and education for people with dementia about the short- and long-term benefits of remaining active and, where possible, increasing their physical activity and following a healthy diet.
- Provide advice and education for people with dementia, their families and carers about the management of their own health, wellbeing and independence, including how technology can help maintain their quality of life.
- Work to maximise opportunities for people with dementia and their families and carers to engage in education and knowledge-sharing.



I'm trying to create a dementia-friendly community. I'd like a dementia-friendly world, but I'll start with my community.



A person living with dementia

03

People with dementia have access to individuals, groups and organisations that can support their spiritual or personal beliefs and reflect their cultural wishes.

Quality of Life Outcome Indicator

Stage

Keeping well, prevention and finding out it's dementia**What staff know (knowledge)**

- Appreciate the potential risk of social isolation that can follow a diagnosis of dementia.
- Understand the importance for people with dementia, their families and carers of continuing to maintain their chosen activities, social life and community involvement.
- Appreciate the importance of peer and community support for people with dementia, their families and carers.
- Appreciate the importance of people maintaining the spiritual and cultural aspects of life following a diagnosis of dementia.
- Critically understand the human and legal rights of people with dementia to make decisions and take risks in the context of their own lives.
- Have detailed knowledge of the principles and key provisions of relevant adult protection, and equalities legislation.

What staff are able to do (skills)

- Work to maximise social inclusion by supporting people with dementia, their families and carers to access community organisations and supports and continue to engage in meaningful activity.
- Engage with people with dementia, their families and carers to find out how their spiritual and cultural beliefs can be supported and harnessed to adjust to their diagnosis and maintain their valued quality of life.
- Actively support people with dementia, their families and carers to understand the legal frameworks that support choice and decision-making.
- Apply the principles and key provisions of legislation to safeguard people with dementia.
- Identify the complexities associated with dementia that may have legal and ethical implications, and act in a way that is of benefit to the person with dementia, their families and carers.

Stage

Keeping well, prevention and finding out it's dementia**What staff know (knowledge)**

- Have knowledge of how to work sensitively and empathetically alongside people with dementia to support them to identify and record their priorities for the future.
- Recognise the complexities for people with dementia in planning for times when they have reducing capacity and when making decisions regarding end of life care.
- Have detailed knowledge and understanding of health promotion and its impact on the progression of dementia.
- Have knowledge of the signs of common mental and physical health problems for people with dementia, their families and carers.
- Have knowledge of local services that provide specialist psychological interventions and therapies.
- Have detailed knowledge and understanding of the underlying causes and signs of stress for the person with dementia, their family and carers.

What staff are able to do (skills)

- Using advanced communication skills, sensitively work with people with dementia to identify and record their priorities for the future and the elements of advanced planning they wish to undertake.
- Ensure that planning for the future is at a pace that suits the person with dementia, their family and carers.
- Actively support people with dementia to access physical and mental health assessments, treatments and services to maintain or improve their health and wellbeing.
- Recognise and respond appropriately when a person with dementia, their family and carers are experiencing anxiety and/or depression and, if necessary, make referral to specialist services.
- Use a range of preventative and proactive strategies to reduce the likelihood of the person with dementia becoming stressed or distressed.
- Adopt a holistic approach to responding to a person with dementia who is stressed or distressed.

Stage**Living well with dementia****What staff know (knowledge)**

- Appreciate how existing and new natural community resources and opportunities can enable people with dementia, their families and carers to maintain a valued and socially included quality of life.
- Have detailed knowledge about the concepts of person-centred care and personalisation, and the implications for how services and individual support is delivered.
- Have a well-informed understanding of how self-directed support can be enabled and maximised to support people with dementia, their families and carers in creative and personalised ways.
- Have detailed knowledge of personal outcomes-focused approaches and how they can enable the delivery of creative person-centred support for people with dementia.

What staff are able to do (skills)

- Practise in a way that builds on and expands the natural community resources that can support people with dementia, their families and carers.
- Facilitate the development of new and creative supportive networks and connections that enable new learning and experiences.
- Practise in a way that enables people with dementia actively to find the right solutions for them and to choose and access any services they receive, including the use of self-directed support.
- Apply personal outcomes-focused approaches to working with people, building on their existing capabilities, when assessing the support needs of people with dementia, their families and carers.

Stage**Living well with dementia****What staff know (knowledge)**

- Have detailed knowledge of the approaches and methods that should be used to measure the effectiveness and impact of support against people's personal outcomes.
- Have detailed knowledge of the range of evidence-informed assistive and innovative technologies available that can support people in independent living.
- Appreciate how environmental adaptations, assistive and innovative technology, and technology-enabled care can enhance the quality of life of a person with dementia, their family and carers.
- Have detailed knowledge of approaches to working with people in assessing how the use of technologies will support people to live well.

What staff are able to do (skills)

- Work with people as equal partners to undertake person-centred assessments focused on personal outcomes for people with dementia, their families and carers.
- Engage people with dementia, their families and carers in frequently assessing the usefulness of any support or intervention.
- Use appropriate approaches and methods to evaluate the impact of the support provided to people, their families and carers in a way that actively involves them and informs continuous improvements.
- Support people to understand and make informed choices about how to choose technologies that might best support them, and how they can be accessed.
- Support people to adapt their environment to maintain their independence and enhance their safety and quality of life.



People should be allowed to take a certain amount of risk. You've got to be allowed to stumble and fall occasionally. You've got to be encouraged to take yourself out of the comfort zone. Where there's no nothing, there's no life.

A person living with dementia

06

People with dementia feel safe and secure and are able to be as independent as possible.

Quality of Life Outcome Indicator

Stage

Living well with dementia



What staff know (knowledge)

- Critically understand the legal, moral and ethical issues, including capacity and consent, surrounding opportunities, challenges and dilemmas associated with technology-enabled care in supporting people with dementia.
- Critically understand the concept of risk enablement and person- and family-centred risk-enablement approaches to promote people's independence and quality of life.
- When appropriate to role, understand how to sensitively undertake a range of dementia-specific and age-appropriate psychometric mental and physical health assessments.
- Know how to interpret the results of assessment and how sensitively to feed back the results and consequences.
- Have knowledge of the range of potential responses to assessment results, including referral to specialist services, self-directed support and carers' assessments.

What staff are able to do (skills)

- Adopt a person-centred approach to assess and identify technological solutions that will enhance quality of life and independence for a person with dementia. Ensure that the technological solutions put in place take account of legal, moral and ethical considerations.
- Work in partnership with people with dementia, their families and carers to consider and support informed decisions about risk-enablement approaches.
- Select and sensitively undertake a range of assessments and interpret results to promote health and wellbeing for people with dementia.
- Sensitively and empathetically discuss and explore findings of assessments with people with dementia, their families and carers to inform future decisions and plans.

Stage

Living well with dementia



What staff know (knowledge)

- Have enhanced knowledge of the range of physical, cognitive, psychological and emotional changes and health problems that can be associated with different types of dementia.
- Have knowledge of the range of strategies that can maximise the strengths and abilities of people with dementia that will enable them to enhance their own health and wellbeing.
- Have detailed knowledge of the range of evidence-based psychological interventions and therapies to support people with dementia, their families and carers to live well.

What staff are able to do (skills)

- Enable access to appropriate services and specialists for further advice and support to promote health and wellbeing for people with dementia, their families and carers.
- Support people with dementia to access physical, cognitive, psychological and emotional support.
- Apply appropriate psychological and psychosocial skills to work with people with dementia, their families and carers to promote their health and wellbeing.
- Work sensitively with people with dementia, their families and carers to recognise when additional assistance may be required.
- Provide support and interventions to assist people with dementia to develop strategies to compensate for diminishing cognitive ability and improve or maintain abilities and skills.

Stage**Living well with dementia****What staff know (knowledge)**

- Appreciate the role of creative and imaginative community experiences that people may choose to support them in living well — for example, engagement in the arts (including music), environmental and outdoor activities, and multi-species animal-assisted opportunities for learning.
- Appreciate that people with dementia, their families and carers have the potential to build on their strengths and undertake new and valued opportunities and learning together, and how this can have a positive impact on relationships.
- Appreciate the multiple possible causes of personal or family distress linked to the emotional impact of dementia.
- Appreciate the complex processes people may experience when adapting to changes in sense of self, relationships and roles.

What staff are able to do (skills)

- Work with people to explore and maximise opportunities to undertake new creative and imaginative experiences to build on their existing skills and interests and develop new learning.
- Work with people with dementia, their families and carers to identify, and enable them to engage in, activities and opportunities that bring fun and joy to their lives.
- Using advanced communication skills, provide people with dementia, their families and carers with counselling or psychological therapies/interventions that can support and enhance intimate relationships and/or build resilience and coping strategies.



People with dementia should have equality of access to health care and treatment the same as everyone else and not be discriminated against because of their diagnosis.

Family member

08

People with dementia, with their families, friends and carers, have access to the information, education and support that promotes their rights and enhances their wellbeing.

Stage**Living well with dementia****What staff know (knowledge)**

- Have detailed knowledge about the range of local services, and statutory, voluntary and peer-support services available that can provide support, interventions and therapy.
- Have detailed knowledge of the range of pharmacological interventions that may enhance people's memory, including benefits and unwanted side-effects.

What staff are able to do (skills)

- Work with people with dementia, their families and carers to enable them to make informed choices about what support best suits their situation and enables their access to services and support.
- Ensure that people have the information they need to make informed choices about pharmacological interventions that may enhance memory, including consideration of benefits and unwanted side-effects.
- Work with people with dementia, their families and carers to monitor and assess the impact of pharmacological interventions on people with dementia and take any action needed to initiate a review.

Stage**Living well with dementia****What staff know (knowledge)**

- Appreciate the potential emotional complexities that could be associated with future planning for people with dementia, their families and carers.
- Appreciate how to engage empathetically in meaningful and timely conversations as part of advance planning.
- Have detailed knowledge of how sensitively to support people in the creation of a life story that informs understanding of their cultural, spiritual and personal history, and supports implementation of their present and future wishes and choices.

What staff are able to do (skills)

- Recognise and interpret cues that indicate when the person with dementia is ready to embark on advance planning.
- As part of advance planning, sensitively engage in meaningful and timely conversations with the person with dementia, their family and carers.
- Sensitively and empathetically support the person with dementia to make plans and identify their priorities for the future, including their wishes regarding times when reducing capacity and end of life issues need to be addressed.
- Support the person with dementia, their family and carers to record any advance decisions and future plans.
- Work sensitively with people with dementia, their families and carers to support them in developing a life story that reflects and promotes their wishes and choices.

Stage**Living well with dementia****What staff know (knowledge)**

- Appreciate how legislation can contribute to person-centred planning for people with dementia.
- Know how to apply the appropriate current legislation on informed consent and confidentiality.
- Have a detailed understanding of the elements of the relevant legislation that can support people with dementia, such as proxy decision-making or advocacy.
- Appreciate the role of families and carers who support people with dementia and their right to assessment and support to promote their own health and wellbeing.
- Appreciate that families and carers are equal and expert partners in care and support.

What staff are able to do (skills)

- Actively support people with dementia, their families and carers to exercise their rights, entitlements and choices.
- Work with people with dementia, their families and carers to provide guidance and support their understanding of the legal aspects of advance planning in relation to welfare and finance.
- Work with people to enhance their understanding of the ongoing implications of elements of legislation, including informed consent, proxy decision-making and advocacy.
- Facilitate families and carers to access assessment and support that promotes their own health and wellbeing.
- Engage and work with families and carers as equal and expert partners in care and support.



I have a diagnosis of dementia
and I like a challenge.
Each day is a fascination.

A person living with dementia

02

People with dementia feel empowered and enabled to exercise rights and choice, maintain their identity and be treated with dignity and equity.

Stage**Living well with dementia****What staff know (knowledge)**

- Appreciate that short restorative breaks are key support interventions to maximise carers' contributions and enhance the wellbeing of people with dementia, their families and carers.
- Have detailed knowledge of the range of restorative break options available.
- Appreciate the importance and opportunities of risk enablement in the promotion of independent living for people with dementia.
- Have detailed knowledge of evidence-based approaches and techniques for recognising and assessing neglect and abuse.
- Have critical understanding of legislation and national and local guidelines and protocols that respond to neglect and abuse.

What staff are able to do (skills)

- Encourage and support people with dementia, their families and carers to identify restorative and short-break interventions that meet their individual needs.
- Support people with dementia in risk enablement through involvement in risk assessment and management.
- Work with people with dementia to assess risk, including areas of potential neglect and abuse.
- Take appropriate action that reflects legislation and national and local guidelines and protocols to prevent and respond to people who are experiencing neglect and abuse.

Stage**Living well with increasing help and support****What staff know (knowledge)**

- Recognise diversity of people with dementia, their families and carers.
- Appreciate the importance of continued engagement in valued relationships and meaningful activities for people with dementia as their dementia progresses.
- Appreciate the need to balance people's dependence and interdependence to maximise social inclusion.
- Have detailed knowledge of human rights-based and adult protection legislation and how to apply appropriate measures and safeguards for people with dementia.
- Appreciate how legislation can contribute to person-centred planning and maximise the ability of people with dementia to communicate their decisions.

What staff are able to do (skills)

- Work in partnership in a way that reflects the diversity of people with dementia, their families and carers to respond positively and constructively to their specific situation.
- Support families and carers of people with dementia in working through the life and relationship changes that occur as dementia progresses.
- Utilise the social network and spiritual supports familiar to the person to maintain contact with their own community, family, friends and carers.
- Actively promote dignity and respect for people with dementia and challenge any discriminatory practices that may compromise their right to dignity, respect and safety.
- Proactively ensure that people with dementia are supported to exercise their rights and choices, or their previously determined choices are upheld wherever possible.

Stage**Living well with increasing help and support****What staff know (knowledge)**

- Appreciate the requirements of appropriate current legislation on informed consent, confidentiality and advance planning, and the implications for the person with dementia, their family and carers.
- Appreciate the principles of determining capacity and how to apply these in any given situation.
- Have detailed knowledge of a range of tools and techniques, including augmentative and alternative communication methods, that can support the person with dementia in their decision-making.
- Appreciate how diminishing capacity in the person with dementia potentially can impact on their ability to effectively communicate their choices, wishes and needs.

What staff are able to do (skills)

- Actively support people with dementia, their families and carers to implement legal aspects regarding informed consent, confidentiality and advance planning.
- Actively seek the person's consent before any intervention is carried out and at intervals commensurate with the intervention.
- When appropriate to role, contribute to assessment of capacity.
- Ascertain whether the person with dementia has appropriate substitute decision-making arrangements in place relevant to the situation and intervention, and ensure they are actioned.
- Take appropriate action where the person with dementia has no guardian or attorney appointed.
- Actively support people with dementia to maximise their ability to communicate their needs, wishes and desires using their preferred method of communication.

Stage**Living well with increasing help and support****What staff know (knowledge)**

- Appreciate the contribution that can be made to the quality of life of people with dementia by the timely gathering of personal details and information from all sources, such as families, carers and friends.
- Have a detailed understanding of how concurrent physical and mental health problems can impact on people with dementia and influence the progression of their dementia.
- Appreciate the complexities co-morbid conditions present for people with dementia.
- Have a detailed understanding of the concept and consequences of frailty and how these can impact on people with dementia.
- Appreciate that people with dementia who also have frailty are at risk of adverse outcomes that include dramatic changes in their physical and mental wellbeing after an apparently minor event that challenges their health, such as an infection or the introduction of new medication.

What staff are able to do (skills)

- Work in partnership with people with dementia, their families, carers and friends to gather pertinent information to support the promotion of the best quality of life.
- Adopt a strengths-based approach to holistically assessing the person's physical and mental health needs and monitor changes and deteriorations in their health.

Stage**Living well with increasing help and support****What staff know (knowledge)**

- Know how to apply strengths-based approaches to support people with dementia to maintain their physical and mental health and wellbeing.
- Have detailed knowledge of the distinguishing signs of depression and delirium in people with dementia and how to initiate appropriate responses, support and treatment options.
- Have critical knowledge of environmental and cognitive issues for people with dementia that can increase the risk of slips, trips and falls.
- Appreciate how visual impairment and perceptual changes can increase the risk of falls for people with dementia.

What staff are able to do (skills)

- Promote and maintain people's current abilities and strengths related to physical and mental health and wellbeing.
- Instigate and/or involve others in providing the most appropriate treatment for depression and delirium.
- When required and appropriate to role, use critical thinking skills to identify and implement the most appropriate interventions and treatment for depression and delirium.
- Undertake a holistic assessment of the potential cognitive and visual changes that may place the person at risk of slips, trips and falls.
- Monitor and document the risk of slips, trips and falls for people with dementia.
- Respond appropriately to mitigate risk and promote safety, independence and wellbeing.

Stage**Living well with increasing help and support****What staff know (knowledge)**

- Have detailed knowledge of national and local guidance relating to use of medication for people with dementia.
- Have detailed knowledge of the specific pharmacological issues relating to people with dementia in responding to both physical and psychological needs, including polypharmacy and covert medication.
- Have detailed knowledge of the range of assessment tools and interventions that support the maintenance of physical health.
- Appreciate how dementia can affect people's continence and understand the interventions that people can use to support continence management.

What staff are able to do (skills)

- Where medication use is indicated, ensure it adheres to national and local guidance relevant to people with dementia.
- Sensitively use critical thinking in conjunction with a range of assessment tools to support good nutrition, skin care, continence and pain management for people with dementia.
- Use a range of assessment tools and interventions that support the maintenance of physical health.
- Ensure that the dignity of people with dementia is maintained through use of individualised prompts to maintain continence.

Stage

Living well with increasing help and support



What staff know (knowledge)

- Appreciate the particular environmental and individual physical and cognitive issues for people with dementia that can intensify the possibility of slips, trips and falls.
- Appreciate both the positive and negative impacts of the physical environment on the quality of life of people with dementia as their dementia progresses.
- Have detailed knowledge of the evidence-based assistive and innovative technologies available that support and enhance independent living.
- Have knowledge of best practice in environmental adaptations that can contribute to independence, wellbeing, privacy and safety of people with dementia.

What staff are able to do (skills)

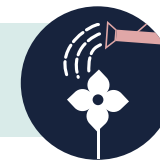
- Work with people with dementia, their families and carers and other agencies to assess what adaptations to the physical environment would help promote independence and minimise the amount of support required.
- Where appropriate, assess needs and engage with assistive and innovative technology to enhance people's independence.
- Use signage, lighting and familiar objects to maximise orientation and reduce confusion.
- Support and enable people with dementia to remain active and mobile.
- Support people with dementia, their families and carers to access assistive and innovative technologies that support safety and enhance their independence.
- Support people with dementia, their families and carers to use technology to enable them to continue with outdoor activities.

Stage**Living well with increasing help and support****What staff know (knowledge)**

- Have a detailed understanding of the range of environmental and person-centred approaches that can reduce and alleviate stress, prevent distress and promote wellbeing for people with dementia.
- Have a detailed understanding of the complex behavioural changes and their causes that indicate people with dementia are distressed.
- Have detailed knowledge of multi-disciplinary approaches to prevention of distress and promotion of psychological wellbeing.

What staff are able to do (skills)

- Engage in implementing best practice in environmental adaptations and person-centred approaches that can reduce and alleviate stress, prevent distress and contribute to the privacy and safety of people with dementia.
- Use a range of assessment strategies and tools to identify changes in the emotional wellbeing of people with dementia.
- Recognise changes in emotional wellbeing in people with dementia.
- Assist people with dementia, their families, carers and wider networks to identify how to maintain psychological wellbeing and prevent stress and distress.
- Contribute to a multi-disciplinary approach to prevention of distress and promotion of psychological wellbeing.
- Take a person-centred approach as part of a multi-disciplinary team to assess the potential causes of distressed behaviours.
- Contribute to a multi-disciplinary approach in how to respond to distress, understanding various models that can inform a comprehensive assessment.

Stage**Living well with increasing help and support****What staff know (knowledge)**

- Appreciate the potential for people with dementia affected by trauma to experience distress when memories of the trauma are triggered by circumstances/relationships/situations that bear some similarity to previous trauma.
- Appreciate the importance of providing safety and building trust, giving choice and control, and engaging collaboratively with people with dementia to reduce the likelihood of triggering trauma-related distress.
- Appreciate that changes in behaviour can be responded to with appropriate approaches and interventions based on a detailed knowledge of the person with dementia.

What staff are able to do (skills)

- Apply approaches/interventions consistent with trauma-informed practice and effective safety and stabilisation techniques, where applicable.
- Use knowledge of the person with dementia to tailor responses to their expression of stress and distress.

Stage**Living well with increasing help and support****What staff know (knowledge)**

- Have detailed knowledge and understanding of how distressed behaviour can be an expression of unmet needs.
- Have detailed knowledge and understanding of the range of psychological, psychosocial and environmental interventions that can prevent or ease distress.
- Have detailed knowledge and understanding of the range of multi-sensory stimulation, recreational activities and combined therapies that promote wellbeing and can prevent or alleviate distress in people with dementia.

What staff are able to do (skills)

- Use proactive and preventative strategies to support the person with dementia, their family and carers to remain stress-free and reduce the likelihood of distressed behaviour arising.
- Creatively use a combination of appropriate interventions, based on individual needs, to promote wellbeing and prevent and alleviate distress.



Good communication is crucial in supporting a person with dementia to live well and exercise their right to make decisions and also needs to include their family and carers.

Family member

03

People with dementia have access to individuals, groups and organisations that can support their spiritual or personal beliefs and reflect their cultural wishes.

Quality of Life Outcome Indicator

Stage**End of life and dying well****What staff know (knowledge)**

- Appreciate the importance of communication in the delivery of person-centred palliative and end of life care for people with dementia.
- Have detailed knowledge of best practice in a range of approaches to gathering information from people with dementia, their families and carers at end of life.
- Critically evaluate the evidence base, frameworks, standards and tools that underpin delivery of person-centred palliative and end of life care for people with dementia.
- Have critical understanding of the interdependence and complexity of physical, psychological, emotional and spiritual care needs of people with dementia, their families and carers in relation to palliative and end of life care.

What staff are able to do (skills)

- Sensitively use advanced communication skills to gather information to support the person with dementia, their family and carers to promote person-centred palliative and end of life care that reflects their values and beliefs.
- Use a range of holistic assessment tools and techniques to assess the physical, psychological, emotional and spiritual needs of the person with dementia, their family and carers in relation to palliative and end of life care.

Stage**End of life and dying well****What staff know (knowledge)**

- Appreciate the importance of values and beliefs in the delivery of person-centred palliative and end of life care for people with dementia.
- Understand when to seek specialist support and guidance from colleagues to address the specific physical, psychological, emotional and spiritual care needs of a person with dementia.
- Appreciate the important role of family, carers and friends in the provision of palliative and end of life care of people with dementia.
- Understand the importance of involving families and carers and keeping them well informed about options.
- Appreciate when action is needed to advocate on behalf of families and carers in relation to implementing the wishes of the person with dementia.

What staff are able to do (skills)

- Provide person-centred care that promotes comfort through palliative and end of life care.
- Encourage, enable and involve families and carers, so far as desired and appropriate, in assisting in the provision of care for the person with dementia.
- Engage in meaningful and timely conversations, communicating and listening in a sensitive manner when discussing complex end of life concerns with people with dementia, their families and carers.
- Support families and carers to be informed about options and involved in decisions.
- Practise in a way that is sensitive to, respects and responds to potential conflicts between the wishes of the person, their family and carer, and seek expert advice when this occurs.

Stage

End of life and dying well



What staff know (knowledge)

- Have detailed knowledge of pain assessment and how to distinguish between chronic and acute pain, including an appreciation that dementia impairs the person's ability to articulate/describe their pain.
- Appreciate the importance of constant review and observation for changes in condition, signs and symptoms.
- Have critical knowledge of pharmacological and non-pharmacological interventions/therapies to prevent and alleviate stress and distress.
- Appreciate that possible additional distress may manifest in behavioural symptoms that require sensitive responses.

What staff are able to do (skills)

- Use critical thinking in conjunction with a range of assessment tools to identify and respond to acute and chronic pain.
- Explore and assess unexplained changes in behaviour or signs of distress and intervene appropriately.
- Consider both pharmacological and non-pharmacological interventions/therapies and implement appropriately and in line with any preferences the person with dementia may have articulated.

Stage**End of life and dying well****What staff know (knowledge)**

- Have detailed knowledge of the indicators that suggest the person with dementia is nearing the end of their life.
- Appreciate the requirement to remain up to date with changes to best practice guidance, legislation and policy regarding palliative care and end of life care.
- Critically analyse the legal and ethical framework necessary to ensure the wishes of the person with dementia are heard.
- Understand how to apply the implications of advance plans, advance directives and proxy decision-makers on treatment, interventions and care, including expressed refusals.
- Have detailed knowledge and understanding of the legal and policy position regarding resuscitation in relation to people with dementia.

What staff are able to do (skills)

- Respond appropriately when changes indicate that a person is nearing the end of their life.
- Provide support that meets the specific needs of people with dementia to promote comfort and dying well.
- Ascertain whether advance planning has been undertaken and is recorded.
- Use the person with dementia's advance plan and advance directive and confer with proxy decision-makers relating to their choices for palliative and end of life care.
- In the absence of an advance plan, advance directive and proxy decision-makers, work with families and carers to ensure the person with dementia's choices for palliative and end of life care are met.

Stage

End of life and dying well



What staff know (knowledge)

- Appreciate the support needs of family, carers and friends, including after the death of the person with dementia.
- Appreciate the importance of spiritual support at the end of life for some people with dementia, their families and carers.
- Appreciate the psychological and emotional effects on families, carers and friends when the person with dementia dies.
- Have detailed knowledge of the range of psychological, pharmacological and community supports for carers and family members that can assist with loss, coping skills and the maintenance of mental health and wellbeing.
- Recognise when there is a need to continue bereavement support for carers and have knowledge of the different approaches this might involve.

What staff are able to do (skills)

- Provide support for family, carers and friends, including following the death of the person with dementia.
- Meet the specific psychological, emotional and spiritual needs of the person with dementia and promote comfort and dying well.
- Provide psychological and emotional support for families and carers when the person with dementia dies.
- Support families and carers of people with dementia to access social/psychological and pharmacological supports as appropriate.
- Identify when families and carers of people with dementia require referral for specialist assessment or intervention related to their loss.
- Provide ongoing support, guidance and advice for carers and families, including after the death of the person with dementia.

Expertise in Dementia Practice Level

The Expertise in Dementia Practice Level outlines the knowledge and skills required for health and social care staff who, through their role and practice setting, play an expert specialist role in the care, treatment and support of people with dementia. The knowledge and skills outlined at this level become increasingly role and context specific.



Stage**Keeping well, prevention and finding out it's dementia****What staff know (knowledge)**

- Have in-depth knowledge of positive approaches to enable and support people to be empowered to exercise rights and choices.
- Have comprehensive understanding of the impact that discrimination and stigma may have on the life of people with dementia, their families and carers.
- Have advanced understanding of the value of person-centred approaches in therapeutic relationships and communication.
- Have knowledge and critical understanding of a range of person-centred assessment approaches to diagnosing dementia.

What staff are able to do (skills)

- Promote awareness of people's right to exercise choice, social inclusion and citizenship.
- Challenge any discrimination and stigma people with dementia may face within health and social care services and their wider communities.
- Support people to exercise their rights if they experience discrimination and stigma.
- Sensitively undertake pre-diagnostic counselling with the person to ascertain whether they wish to proceed with investigations that may result in a diagnosis.
- Support the person to include others they wish to be part of the diagnostic process.

Stage**Keeping well, prevention and finding out it's dementia****What staff know (knowledge)**

- Have comprehensive understanding of the impact and potential losses associated with a diagnosis of dementia and the range of possible reactions, including emotional distress.
- Have comprehensive understanding of the impact that a diagnosis of dementia can have on a person's identity and emotional wellbeing.
- Appreciate how promoting hope can contribute to people's positive adjustment to a dementia diagnosis.
- Have comprehensive understanding of the impact of a diagnosis of dementia on people's families, wider social networks and relationships.

What staff are able to do (skills)

- When appropriate to role, assess a person's capacity to consent to cognitive screening or neuropsychological testing.
- Use a range of person-centred assessment approaches and tools to assist in making a diagnosis of dementia, when appropriate to role.
- Using advanced communication skills, sensitively and empathetically communicate a diagnosis of dementia to the person and their family that responds to their unique needs and situation.
- Recognise the verbal and nonverbal cues from people with dementia, their families and carers that may indicate psychological distress.
- Provide psychological and psychosocial support for people and their families when receiving a diagnosis of dementia.
- Identify and respond when a person becomes distressed following a diagnosis of dementia and requires a specific psychological intervention.



No one should have a diagnosis alone, it's a major, life-changing diagnosis that is scary for the person, but also for their family.



Family member

01

People with dementia have access to a timely and accurate diagnosis of dementia that includes high-quality support before, during and after their diagnosis

Quality of Life Outcome Indicator

Stage**Keeping well, prevention and finding out it's dementia****What staff know (knowledge)**

- Have comprehensive understanding of the supportive actions that can enable people with dementia and their families and carers to engage in education or knowledge-sharing.
- Appreciate how a person's background and culture can influence how they present with dementia.
- Understand how people from diverse backgrounds and cultures may understand and respond to a diagnosis of dementia.
- Have comprehensive knowledge and understanding of the particular impact of a diagnosis of dementia for younger people.
- Have comprehensive understanding of the equality and diversity issues that should be considered in relation to receiving a diagnosis of dementia and in post-diagnostic support.

What staff are able to do (skills)

- Promote, influence and lead the development of accessible sources for education and knowledge-sharing for people with dementia and their families and carers.
- Demonstrate empathy and respect when supporting the person, their family and carers through the diagnosis process in a way that values diversity.
- Challenge, and take steps to address, any inequalities in access to early diagnosis and post-diagnostic support that may be experienced in relation to diversity, including for people with learning disabilities or younger people with dementia.

Stage**Keeping well, prevention and finding out it's dementia****What staff know (knowledge)**

- Have comprehensive understanding of how access to appropriate services and support can be enabled in a way that respects diversity and challenges inequalities.
- Have comprehensive knowledge of how to assess the wide range of requirements of people with dementia, including younger people and those with learning disabilities.
- Have critical knowledge of the increased risk of developing dementia for people with learning disabilities.
- Have critical understanding of the complex interaction between learning disabilities and dementia.
- Have knowledge of the range of changes in behaviour and communication that can indicate dementia in a person with learning disabilities.
- Have expert knowledge of the strengths and limitations of specific neuropsychological assessment and diagnostic tools and techniques, when appropriate to role.

What staff are able to do (skills)

- Adapt assessment approaches to reflect the diversity of people who may receive a diagnosis of dementia.
- Adopt a person-centred approach to regular assessment and review of people with learning disabilities to ensure accurate and timely diagnosis when dementia is present.
- When appropriate to role, undertake specific neuropsychological assessments.

Stage**Keeping well, prevention and finding out it's dementia****What staff know (knowledge)**

- Have expert knowledge of the range of pharmacological interventions that can enhance memory.
- Have expert knowledge of the differences between dementia and other physical and mental health problems, particularly delirium and depression.
- Have expert knowledge of the short- and long-term benefits for people living with dementia of remaining active and, where possible, increasing their physical activity and following a healthy diet.

What staff are able to do (skills)

- When appropriate to role, sensitively engage with people and their families in monitoring and reviewing the impact of pharmacological interventions.
- Using advanced communication skills and when appropriate to role, discuss with people the benefits and implications of pharmacological interventions that can enhance memory.
- Provide appropriate assessment and interventions to address other physical and/or mental health problems where identified.
- Work in partnership with specialist colleagues to provide physical and mental health support to people and families when required
- When appropriate to role, provide expert advice on the short- and long-term benefits for people with dementia of remaining active and, where possible, increasing their physical activity and following a healthy diet.

Stage**Living well with dementia****What staff know (knowledge)**

- Have comprehensive knowledge of the concepts of person-centred care and personalisation, and the implications for practice, service design and delivery.
- Have in-depth understanding of the need for citizen leadership, user and carer expertise and participation in creating systems and services that meet the individual needs of people with dementia.
- Understand the principles and roles of co-production, participation, empowerment, enablement and community capacity-building in promoting independence.

What staff are able to do (skills)

- Support and enable people with dementia, their families and carers to find the right solutions for them and actively design and select the services they require.
- Promote, influence and lead innovative and creative practices and services that meet the individual needs of people with dementia.
- Provide expert advice on strategies to adapt lifestyles that support continued engagement in communities, employment, relationships and social networks.
- Promote a culture that supports all staff to adopt attitudes and practices that value the importance of existing natural community resources in supporting people with dementia.
- Demonstrate leadership in shaping service design and delivery that reflects co-production, participation, empowerment, enablement and community capacity-building.

Stage**Living well with dementia****What staff know (knowledge)**

- Have comprehensive knowledge and understanding of the principles, processes, implications and procedures involved in accessing and utilising self-directed support.
- Have detailed knowledge of outcomes-focused approaches, including a joint outcomes approach for people with dementia, their families and carers.
- Have knowledge of a range of methodologies for delivering, measuring and monitoring outcomes to ensure that the needs and wishes of people with dementia, their families and carers are met.
- Have in-depth knowledge of up-to date evidence-based approaches to person-centred and relationship-focused assessment, treatment and support for people with dementia.

What staff are able to do (skills)

- When appropriate to role, support people with dementia, their families and carers to understand and make informed choices about self-directed support.
- Support people with dementia, their families and carers to access self-directed support if desired.
- When assessing the support needs of people with dementia, promote outcomes-focused approaches that build on their existing strengths and capabilities.
- Support people with dementia, their families and carers to achieve their expressed outcomes.
- Promote and use person-centred and relationship-focused approaches to assessment, treatment and support for people with dementia.

Stage**Living well with dementia****What staff know (knowledge)**

- Have comprehensive understanding of the relationship between dementia, depression and delirium.
- Have expert knowledge of the complexity of co-morbidity in dementia.
- Have a thorough understanding of evidence-based approaches that can enhance psychological, social and physical wellbeing.
- Have expert knowledge of the range of options and interventions that support people with dementia who are experiencing anxiety and depression.
- Have comprehensive understanding of how stress can impact on people with dementia, their families and carers.
- Have detailed knowledge of how to support people with dementia, their families and carers to prevent stress and manage and minimise it when it occurs.

What staff are able to do (skills)

- When appropriate to role, lead and/or contribute to the development of up-to-date evidence-based practice in providing the most appropriate treatment for depression and delirium in people with dementia.
- Support others in the delivery of up-to-date evidence-based practice in providing the most appropriate treatment for co-morbidity in dementia.
- Provide social, emotional and psychological support and interventions to assist people with dementia, their families and carers to manage difficulties such as anxiety or depression.
- Draw on a range of different social, psychological and psychosocial approaches to provide support appropriate to people with dementia, their families and carers.

Stage**Living well with dementia****What staff know (knowledge)**

- Have detailed knowledge of the pharmacological treatment of dementia and the potential impact on people with dementia.
 - Have expert knowledge of evidence-based psychological interventions and therapies for people with dementia, their families and carers.
 - Appreciate the possible causes of personal or family distress linked to the emotional impact of the symptoms of dementia.
-
- Have expert knowledge of how evidence-based assistive and innovative technology and technology-enabled care can enhance the quality of life of people with dementia.
 - Have expert knowledge of the legal, moral and ethical issues, challenges and dilemmas of technology-enabled care in supporting people to live well with dementia.

What staff are able to do (skills)

- When appropriate to role, provide expert advice on pharmacological interventions that support emotional wellbeing.
 - Provide expert support and provide a range of non-pharmacological interventions to assist people with dementia to maintain existing cognitive skills and devise strategies to cope with reducing cognitive ability.
 - Using expert communication skills, provide expert support in the provision of counselling or psychological therapies that can support and enhance intimate relationships or build coping skills.
-
- Ensure that staff and services use evidence-based practice in the use of assistive and innovative technology and technology-enabled care.
 - Ensure that provision of technology-enabled care takes account of legal, moral and ethical considerations, including capacity and consent.



We want to stay active and in the community as long as possible. We're not stupid, we know we have a condition and we know our condition progresses and that many of us will get to that stage where we'll need home care support and may go into a home.

A person living with dementia

04

People with dementia have access to quality services and can continue to participate in community life and valued activities.

Quality of Life Outcome Indicator

Stage**Living well with dementia****What staff know (knowledge)**

- Have expert understanding of the specific interpersonal and relationship issues that may impact on people with dementia, their families and carers.
- Have expert knowledge of the self-help strategies that enable people with dementia to deal with memory changes and enhance their memory.
- Have expert knowledge of the range of approaches and adaptations, including technological solutions, that can enhance people's home environment to promote physical safety, emotional security and privacy.
- Have comprehensive understanding of the concept of a dementia-friendly environment.

What staff are able to do (skills)

- Work with the person, their family and carers in responding to complex interpersonal and relationship issues associated with dementia.
- Provide expert advice to other practitioners on responding to complex interpersonal issues associated with dementia.
- Work with people with dementia to support them to enhance their coping skills and strategies to compensate for their memory difficulties and/or reductions in other cognitive areas.
- Provide dementia-specific expert advice, education and guidance on enhancing the physical and social environment to ensure physical safety and emotional security.
- Assess, audit, review and, where necessary, ensure that adaptations are made to the physical and social environment to support people with dementia where they live or work.

Stage**Living well with dementia****What staff know (knowledge)**

- Have comprehensive understanding of the environmental, physical and cognitive issues for people with dementia that can increase the risk of slips, trips and falls.
- Have expert knowledge of the range of measures that can contribute to the safety of people with dementia, including prevention of falls, without compromising their right to dignity or independence.
- Have expert knowledge of different perceptions of risk and the range of approaches to risk enablement.
- Appreciate the reasons and rationale behind the aversion some people may have to risk and risk-taking.

What staff are able to do (skills)

- Make recommendations regarding the various ways in which the environment and environmental adaptations can contribute to people's physical safety, emotional security and privacy.
- Make recommendations regarding environmental design to assist people with dementia to be orientated and independent.
- Act as a source of expert advice on the benefits of risk enablement in supporting people with dementia to have choice and control.
- Apply flexible and responsive approaches to supporting people, including staff, families and carers, to recognise that risk-enabling approaches can result in positive benefits for people with dementia.

Stage**Living well with dementia****What staff know (knowledge)**

- Have expert understanding of advance planning, taking into consideration any substitute decision-making arrangements that are in place.
- Have expert understanding of the sensitivities associated with advance planning conversations and processes for people with dementia, their families and carers.
- Have expert knowledge of evidence-based approaches and techniques for assessing neglect and abuse.
- Have critical knowledge of legislation, national and local guidelines, and protocols to respond to neglect and abuse.

What staff are able to do (skills)

- Support people with dementia, their families and carers to engage in advance planning, including palliative and end of life care.
- Provide support and advice to services and professionals involved in supporting people with dementia, their families and carers to engage in advance planning.
- Provide support and advice to services, professionals and people with dementia in relation to assessing risk, including areas of potential neglect and abuse.
- Take appropriate action that reflects legislation, national and local guidelines, and protocols to safeguard people, to prevent neglect and abuse, and respond to people who are concerned about or experiencing neglect and abuse

Stage**Living well with increasing help and support****What staff know (knowledge)**

- Have comprehensive knowledge, understanding and synthesis of rights-based legal, ethical and professional guidance to inform practice in relation to supporting people with dementia, their families and carers.
- Have comprehensive understanding of the principles of assessment of capacity for people with dementia and the underpinning evidence and legislation.
- Have expert knowledge in the application and understanding of the legislation, guidance and policy, including ethical decision-making in relation to people with dementia.

What staff are able to do (skills)

- Act as a source of expert advice when informed consent may be compromised.
- Sensitively carry out assessments to inform consent and capacity where this may be compromised in relation to people's rights and choices.
- Actively promote ethical decision-making in relation to people with dementia.
- Support staff to understand and apply legislation, guidance and policy, including ethical decision-making.

Stage**Living well with increasing help and support****What staff know (knowledge)**

- Have expert knowledge and in-depth understanding of the impact of dementia on communication.
- Have expert knowledge of advanced communication approaches to support people with dementia whose communication is compromised, including augmentative and alternative methods.
- Appreciate that people with dementia have the right to communication equipment and the support they need to use it where communication is compromised.
- Have expert knowledge on how to individually tailor evidence-based psychological or pharmacological interventions to provide best outcomes for people with dementia.

What staff are able to do (skills)

- Using advanced communication skills, support people with dementia whose communication is compromised.
- Ensure that services and staff are able to support people with dementia whose communication is compromised through provision of communication equipment and the support they need to use it.
- Share expertise to support staff to develop advanced communication skills.
- When appropriate to role, individually tailor evidence-based psychological or pharmacological interventions to provide best outcomes for people with dementia.
- When appropriate to role, modify and adapt social, psychological and psychosocial interventions.
- Monitor and evaluate the effectiveness of social, psychological and psychosocial interventions for people with dementia.

Stage**Living well with increasing help and support****What staff know (knowledge)**

- Have comprehensive understanding of the specific ways in which physical health problems can impact on people with dementia and influence the progression of dementia.
- Have expert knowledge of the complexities of living with co-morbid conditions for people with dementia.
- Have expertise in the concept and consequences of frailty and how these can impact on people with dementia.
- Have expert knowledge of how people with dementia who also have frailty are at risk of adverse outcomes that include dramatic changes in their physical and mental wellbeing after an apparently minor event that challenges their health, such as an infection or the introduction of new medication.
- Have critical understanding that strengths-based approaches support people with dementia to maintain their physical and mental health and wellbeing.

What staff are able to do (skills)

- Adopt/promote/provide expert advice on strengths-based approaches to holistically assess people's physical and mental health needs and monitor for changes and deteriorations in their health.
- Lead multi-disciplinary approaches to promoting and maintaining people's current abilities and strengths related to physical and mental health and wellbeing.

Stage**Living well with increasing help and support****What staff know (knowledge)**

- Have knowledge and understanding of the theory behind evidence-based cognitive stimulation therapy (CST) and cognitive rehabilitation approaches and best practice for use.
- Have expert knowledge of the benefits of multi-sensory stimulation, recreational activities and use of combined therapies.
- Have in-depth knowledge of the potential sources of stress and distress and evidence-based approaches to prevent and manage this.
- Have knowledge of approaches that promote holistic collaborative assessment and interventions to support people with dementia who are stressed or distressed.
- Have critical knowledge of best-practice guidance and evidence relating to working with people affected by trauma and how this can cause distress for people with dementia.
- Have in-depth knowledge and understanding of potential trauma triggers in the dementia service context and how this can lead to re-traumatisation.

What staff are able to do (skills)

- Engage people with dementia in a range of meaningful activities to maximise and improve their memory, such as cognitive rehabilitation.
- Act as a source of expert advice and guidance on sensory stimulation, recreational activities and use of combined therapies.
- Expertly assess and formulate person-centred interventions as part of a multi-disciplinary team to support people with dementia who are stressed or distressed.
- Lead and promote holistic, collaborative assessment and interventions to support people with dementia who are stressed or distressed, ensuring involvement of people with dementia, their families and carers.
- Develop and support trauma-informed systems and procedures within services to address the immediate safety needs of people with dementia affected by trauma and recognise and reduce risk of re-traumatisation.



It is essential to include the family when the person with dementia is in a stressful situation as they may be the best person to help their loved one feel supported.

Family member

05

People with dementia maintain their best level of physical, mental, social and emotional wellbeing.

Quality of Life Outcome Indicator

Stage**Living well with increasing help and support****What staff know (knowledge)**

- Have comprehensive knowledge of a range of person-centred approaches to support people with dementia whose ability to communicate their needs is compromised.
- Appreciate the importance of partnership-working in the provision of support, care and services for people with dementia, their families and carers.
- Have expert knowledge of the opportunities and challenges in implementing an outcomes-focused approach to supporting people with dementia, their families and carers.
- Appreciate the concepts of person-centred care and personalisation, and the implications for how services and individual support is delivered.

What staff are able to do (skills)

- Actively promote person-centred responses to people with dementia whose ability to communicate their needs is compromised.
- Actively liaise with partners in care to promote best practice in dementia care.
- Act as a source of expert advice on designing, developing and delivering outcomes-focused approaches, practices and services for people with dementia, their families and carers.
- Evaluate the impact of services and support provided to people, their families and carers in a way that actively involves them and informs continuous improvements.

Stage**Living well with increasing help and support****What staff know (knowledge)**

- Have knowledge and critical understanding of self-directed support and how this can be enabled and maximised to support people with dementia.
- Have expert knowledge of the range of the evidence-based assistive and innovative technologies available that can support independent living.
- Have expert knowledge of the legal, moral and ethical issues, challenges and dilemmas of technology-enabled care in supporting people to live well with dementia.

What staff are able to do (skills)

- Contribute to practices that enable people with dementia to actively find the right solutions for them and access any services they choose, including the use of self-directed support.
- Ensure that service provision utilises a range of evidence-based assistive and innovative technologies to support people with dementia to maximise independent living.
- Act as a source of expert advice on assessment and identification of technological solutions that will enhance quality of life and independence for people with dementia.
- Ensure that services and staff take legal, moral and ethical considerations, including capacity and consent, into account when technological solutions are put in place.

Stage**End of life and dying well****What staff know (knowledge)**

- Have critical understanding of the importance of comprehensive and effective communication within and across teams in the delivery of person-centred palliative and end of life care for people with dementia.
- Have expert knowledge of the evidence base, frameworks, standards and tools that underpin delivery of person-centred palliative and end of life care for people with dementia.
- Have expert knowledge of the interdependence and complexity of physical, psychological, emotional and spiritual care needs of a person with dementia, their family and carers in relation to palliative and end of life care.
- Have expert knowledge of the importance of values and beliefs in the delivery of person-centred palliative and end of life care for people with dementia.

What staff are able to do (skills)

- Lead the co-ordination of palliative and end of life care utilising advanced communication skills within and across teams.
- Provide expert advice and support to others to use a range of holistic assessment tools and techniques to assess the physical, psychological, emotional and spiritual needs of the person with dementia, their family and carers in relation to palliative and end of life care.
- Provide specialist support and guidance for colleagues to address specific physical, psychological, emotional and spiritual care needs of the person with dementia.
- When appropriate to role, lead the co-ordination of palliative and end of life care.

Stage**End of life and dying well****What staff know (knowledge)**

- Have expert understanding of the role of family, carers and friends in the provision of palliative and end of life care for people with dementia.
- Have expert knowledge on how to communicate sensitive information relating to death and dying to families and carers.
- Appreciate the importance of involving families and carers and keeping them well informed about options.
- Have expert knowledge and understanding of the complexity of interactions and potential conflicts that arise which may compromise the wishes of the person with dementia.

What staff are able to do (skills)

- Ensure that services and staff encourage, enable and involve families and carers, so far as desired and appropriate, in assisting in the provision of care for the person with dementia.
- Promote a service culture that supports staff to engage in meaningful and timely conversations, communicating and listening in a sensitive manner when discussing complex end of life concerns with people with dementia, their families and carers.
- Support families and carers to be informed about options and involved in decisions.
- Act as a source of expertise in conflict resolution relating to decision-making and compliance with the wishes of the person with dementia.
- Promote a service culture that supports staff to advocate on behalf of families and carers in relation to implementing the wishes of the person with dementia.

Stage**End of life and dying well****What staff know (knowledge)**

- Have expert knowledge of assessment, prevention and management of chronic and acute pain.
- Have expert knowledge of pharmacological and non-pharmacological interventions/therapies to prevent and alleviate stress and distress.
- Understand that possible additional distress may manifest in behavioural symptoms that require sensitive responses.
- Have expert knowledge in identifying and responding to the progression from palliative care, to end of life care, to the last days of life.

What staff are able to do (skills)

- Act as an expert and source of advice on the assessment, prevention and management of chronic and acute pain.
- Ensure that staff implement appropriate management of pain in line with any preferences the person with dementia may have articulated.
- Ensure that unexplained changes in behaviour or signs of distress are fully explored and assessed.
- Act as an expert source of information on both pharmacological and non-pharmacological interventions/therapies.
- Provide expert advice and support to others to enable them to understand and respond to the changing needs of the person with dementia as they progress through palliative care, to end of life care and to the last days of life.
- Provide expert advice on meeting the specific needs of people with dementia to promote comfort and dying well.

Stage**End of life and dying well****What staff know (knowledge)**

- Have expert knowledge of legal, ethical and human rights relevant to people with dementia at the end of life.
- Have in-depth knowledge of current best practice guidance, legislation and policy regarding palliative care and end of life care.
- Have expert knowledge and understanding of the legal and policy position regarding resuscitation in relation to people with dementia.
- Have expert knowledge and understanding of the support needs of family, carers and friends, including after the death of the person with dementia.

What staff are able to do (skills)

- Act as a source of expert advice on legal, ethical and human rights issues relevant to people with dementia at the end of life.
- Ensure that services reflect current best practice guidance, legislation and policy regarding palliative care and end of life care.
- Promote a service culture that supports staff to provide appropriate support for family, carers and friends, including following the death of the person with dementia.
- Promote a service culture that supports staff to access support, if required, related to issues associated with palliative care in dementia.
- Be an agent of change within services to improve the palliative care service for people with dementia, their families and carers.

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Appendix I

Links to supporting organisations, resources and frameworks

- **Age Scotland** is Scotland's national charity supporting people over the age of 50, Age Scotland works to improve people's lives and promote their rights and interests.
- **Alzheimer Scotland** is the leading dementia organisation in Scotland. It campaigns for the rights of people with dementia and their families and provides an extensive range of innovative and personalised support services.
- **Alzheimer Scotland Centre for Policy and Practice** is a centre of excellence for advancing dementia policy and practice through education, applied research and social enterprise.
- **Together in Dementia Everyday (TIDE)** is a UK wide involvement network of carers, former carers and health and care professionals who are working together to build a better future for carers of people living with dementia.
- **Dementia Engagement and Empowerment Project** is the UK network of dementia voices. DEEP consists of around 100 groups of people with dementia – groups that want to change things.
- **The Care Inspectorate Hub** contains several dementia resources and reports.

- **The Carers Scotland Act (2016)**
- **The Charter of Rights for People with Dementia and their Carers in Scotland** has been key in shaping Promoting Excellence and the Dementia Care Standards.
- **Connecting People, Connecting Support** outlines how the role of allied health professionals is being transformed to support people with dementia, their families and carers.
- **Dementia Circle** provides a range of information about how people living with dementia can use technology to help them remain independent.
- **Focus on Dementia** is part of Health Care Improvement Scotland's iHub and undertakes a number of improvement programmes to support implementation of Scotland's dementia strategies.
- **Life Changes Trust** is a charity that invests in and supports the empowerment and inclusion of three groups: young people with experience of being in care, people living with dementia and unpaid carers of those with dementia.
- **The Mental Welfare Commission for Scotland** is an independent organisation working to safeguard the rights and welfare of everyone with a mental illness, learning disability or other mental disorder. The commission has produced Standards of Care for People with Dementia and other important reports.
- **How Can Positive Risk Taking Help Build Dementia Friendly Communities?**
A report published by the Joseph Rowntree Foundation in 2014.
- **NES Transforming Psychological Trauma Knowledge and Skills Framework and Related Resources.**
- **The National Dementia Carers Action Network (NDCAN)** is a national campaigning and awareness-raising group for carers of people with dementia. NDCAN was formed in 2011 and exists to make the voices of carers heard and raise awareness of the issues impacting on carers.
- **NHS Education for Scotland (NES)** is a special health board, responsible for supporting NHS services by developing and delivering education and training for those who work in NHSScotland.
- **Specific information about NES dementia work and learning resources.**

- **Palliative and End of Life Care Framework: enriching and improving experience and associated resources.** Published jointly by NES and the Scottish Social Services Council to promote a consistent, inclusive and flexible approach to learning and development on palliative and end of life care for the health and social service workforce.
- **Scottish Social Services Council information and resources about personal outcomes-focused approaches.**
- **The Scottish Dementia Working Group** is an independent group run by people with dementia in Scotland.
- **Self Directed Support Scotland** has information and resources about self-directed support in Scotland,
- **Scotland's Digital Health and Care Strategy: enabling, connecting and empowering.** Published by the Scottish Government in 2018.
- **Scottish Social Services Council** is responsible for raising standards in the Scottish social service workforce, including registering people who work in social services and regulating and promoting their education and training.
- **Scottish Social Services Council range of learning resources.**
- **Social Care Institute for Excellence Dementia Gateway** includes a range of quality and accessible educational resources to support the development of staff who work with people with dementia in nursing, residential or domiciliary settings.
- **Remember ... The Deaf Dementia Experience in Scotland ... A Toolkit for All.** The toolkit is for British Sign Language users who are deaf and have dementia and those who are caring for a family member with dementia, as well as for care staff supporting people who are deaf with dementia.
- **The Technology Charter for People Living with Dementia in Scotland** has been written in partnership with people living with dementia to drive change and raise public and professional awareness of how technology can make a difference to the lives of those living with dementia in Scotland.

Appendix II

Acknowledgements

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