



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



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







Acknowledgement

We would like to extend our thanks to the Scottish Dementia Working Group for their permission to use quotes in this framework from their DVD *Through our eyes, a life with dementia* and all the people who contributed to making the DVD.

© Crown copyright 2011

You may re-use this information (excluding logos and images) free of charge in any format or medium, under the terms of the Open Government Licence. To view this licence, visit http://www.nationalarchives.gov.uk/doc/open-government-licence/ or e-mail: psi@nationalarchives.gsi.gov.uk.

Where we have identified any third party copyright information you will need to obtain permission from the copyright holders concerned.

This document is available from our website at www.scotland.gov.uk.

ISBN: 978-1-78045-194-7

The Scottish Government St Andrew's House Edinburgh EH1 3DG

Produced for the Scottish Government by APS Group Scotland DPPAS11594 (06/11)

Published by the Scottish Government, June 2011

Contents

Page 1: Background and Purpose of the NES/SSSC 'Promoting Excellence' Fra	ramework
---	----------

D 0	- 1 · 1	1	1	
Page 2:	The evidence	and principle	es underpinning	The Framework
1 466 2.	THE CVIGCITE	and principle	23 011aci pii ii ii i	CITC I TUITIC VVOIT

- Page 4: How the framework should be used
- Page 6: The structure of the Framework
- Page 12: The Dementia Informed Practice level
- Page 17: The Dementia Skilled Practice level
- Page 28: The Enhanced Dementia Practice level
- Page 56: The Expertise in Dementia Practice level
- Page 71: References and links to supporting resources

What I would say to the professionals is that - you can pull me back, give me my life back and pull me into the light. And by the same token, ignorance, arrogance, couldn't care less, you can shove me down into the darkness and just cast me away. I can't do it. I need your help to do it.

Background and purpose of the NES/SSSC 'Promoting Excellence' framework

In June 2010, the Scottish Government launched Scotland's National Dementia Strategy. NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC) then developed Promoting Excellence: A framework for health and social services staff working with people with dementia, their families and carers to support delivery of the aspirations and change actions outlined in the strategy.

The NES/SSSC Promoting Excellence framework details the knowledge and skills all health and social services staff should aspire to achieve in relation to the role they play in supporting people with a diagnosis of dementia, and their families, and carers. The NES/SSSC framework has been designed in a way that recognises the existence of various sector (and professional group) specific standards and frameworks, for example: the NHS Knowledge and Skills Framework: the Social Services Continuous Learning Framework and the National Occupational Standards for Health and Social Care.

- ► This framework supplements these existing frameworks.
- ➤ This framework applies to *all* health and social services staff who have contact with, and provide support, care, treatment and services for people who have dementia, and their families and carers
- This framework is aspirational and future focussed meaning it is not a just a description of what we do now it is what we aspire to do in the future to support delivery of the aspirations and change actions outlined in Scotland's National Dementia Strategy.
- This framework details the knowledge and skills that will inform new ways of working for *all* health and social services staff to ensure we enable people with dementia, and their families and carers, to maximise their rights, choices and health and wellbeing at all stages of their unique dementia journey.

The evidence and principles underpinning the framework

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

The development of the framework was informed by a number of activities including:

- Evidence, best practice guidance and literature reviews;
- Reviews of existing competency frameworks:
- Links being made with wider UK Dementia work programmes;
- Stakeholder consultation and engagement.

Of most importance is that the framework is underpinned by values and principles that reflect what people with dementia, and their families and carers have said are most important to them.

The framework places a great emphasis on peoples' rights and was developed alongside the development of *Standards* of *Care for Dementia in Scotland* led by the Mental Welfare Commission for Scotland. The standards and this framework are based on *The Charter of Rights for People with Dementia and their Carers in Scotland*.

Later sections of the framework signpost the key references and supporting resources that informed the development of the framework and will support its delivery.

How the framework should be used

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

The framework should be used at a personal, service provider and organisational level in a number of 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, 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 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 defines the knowledge, skills and behaviours specific to the worker's role in relation to dementia. Rather than being hierarchical, the levels are concerned with levels of responsibility in relation to working with people with dementia which will vary greatly across organisations and sectors. Each level defines the expertise, specific to their role in relation to dementia, that a worker must have, rather than in relation to their seniority within the organisation or their profession.

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

The 'Dementia Skilled Practice Level' describes the knowledge and skills required by all staff that have direct and/or substantial contact with people with dementia and their families and carers.

The 'Enhanced Dementia Practice Level' outlines the knowledge and skills required by health and social services staff that have more regular and intense contact with people with dementia, provide specific interventions, and/or direct/manage care and services.

The 'Expertise in Dementia Practice Level' outlines the knowledge and skills required for health and social care staff who by virtue of 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 each level are constructed in *an incremental way*, for example staff that operate at the 'Dementia Enhanced Practice' level would also possess the knowledge and skills, attitudes and behaviours described at all preceding levels. Given the scope of the workforce across health and social services this framework does not identify specific health and social services staff roles in relation to the framework domains. Each individual staff member and their employer must take responsibility in ensuring they correctly interpret and apply the content and aspirations of the framework to their role in relation to working with people with dementia, their families and carers.

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

Stages of the Dementia Journey

There is well documented evidence that dementia has a recognised pathway of progression and the framework has incorporated this as the needs of a person with dementia, and their family and carers will be different at different stages of the condition. Whilst acknowledging the life changing impact, challenges and difficulties that often surround receiving a diagnosis of dementia; the framework recognises that receiving a diagnosis is not the starting place. Striving to prevent the onset of dementia and the maintenance of good health and maximising wellness, are general ambitions for all of us in an ageing and health conscious society and there are specific actions for workers involved in the delivery of dementia services and care settings in this regard.

The 4 Stages of the 'dementia journey' identified in the framework are:

- ➤ Keeping well, prevention, and finding out it's dementia
- Living well
- Living well with increasing help and support
- ▶ End of life and dying well

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

There is a growing body of research on quality of life indicators for people with dementia. Research from the Alzheimer's Society¹ (2010) states that it is perfectly possible to maintain a good quality of life following a diagnosis of dementia and that the domains that feature in generic quality of life measures may be of as much relevance to people with dementia as the more dementia-specific domains in health related quality of life measures. The framework incorporates quality of life (OoL) outcome indicators developed from a review of the literature. These are an integral part of the framework and are intended to encourage workers and services to consider the impact and end result of the support, care, interventions and treatments they provide against these indicators. The diagram on page 10 shows how the OoL indicators map against the Standards of Care for Dementia in Scotland domains

¹ Alzheimer's Society/Mental Health Foundation (2010) My name is not dementia. London. Alzheimer's Society

Since your diagnosis you are much busier and much more active than you were before

(Family Member)

Standards of Care for Dementia in Scotland

- ▶ I have the right to a diagnosis.
- ▶ I have the right to be regarded as a unique individual and to be treated with dignity and respect.
- I have the right to access a range of treatment and supports.
- I have the right to end of life care that respects my wishes.
- I have the right to be as independent as possible and be included in my community.
- I have the right to have carers who are well supported and educated about dementia.

Knowledge and Skills Framework QoL Outcome Indicators

- ▶ People with dementia have access to a timely and accurate diagnosis of dementia.
- People with dementia feel empowered and enabled to exercise rights and choice, maintain their identity and to be treated with dignity and equity.
- People with dementia maintain their best level of physical, mental, social and emotional wellbeing.
- ▶ People with dementia have access to individuals, groups and organisations that can support their spiritual or personal beliefs and reflect their cultural wishes.
- ▶ People with dementia have access to quality services and can continue to participate in community life and valued activities.
- People with dementia feel safe and secure and are able to be as independent as possible.
- ▶ People with dementia are able to maintain valued relationships and networks, and have the opportunity to develop new ones both personal and professional.
- People with dementia, their families, friends and carers, have access to the information, education and support that enhances the wellbeing of the person with dementia and those that support them.

•• 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.

DEMENTIA INFORMED PRACTICE LEVEL

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

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

Dementia Informed Practice Level

Across all stages of the dementia journey

Outcome

People with dementia

maintain their identity

and to be treated with

feel empowered and

enabled to exercise

rights and choice,

dianity and eauity.

What workers know (knowledge)

- Appreciate that people with dementia, their families and carers are still able to have 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 person-centred support in relation to people with dementia.
- Understand the importance of recognising, enhancing and supporting the strengths and abilities of people with dementia.
- Understand the benefits of continued engagement in life's 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 workers are able to do (capability/skill/ability)

Interact with people with dementia, their families and carers. in a way that recognises their wishes and priorities.

Interact with people with dementia in a person-centred way that recognises and utilises their unique strengths and abilities

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

Dementia Informed Practice Level

Across all stages of the dementia journey

Outcome

People with dementia have access to a timely and accurate diagnosis of dementia.

What workers know (knowledge)

- ➤ Knowledge of how to access local community information and services that can provide information and support for people with dementia and their families and carers
- Awareness of the common signs and symptoms of dementia, e.g. memory problems, confusion and communication difficulties.
- ➤ Knowledge of a range of communication methods to suit people who are experiencing confusion, memory or communication difficulties.
- ▶ Understand that diversity, equality and inequality issues impact, the experience and support needs of people with dementia (for example people from different cultural and ethnic groups, people with learning disabilities and younger people).

- Provide relevant information or signpost to an appropriate person, or service, to enable people with dementia to access chosen community services and activities
- Recognise when a person appears to be experiencing confusion, memory or communication difficulties.
- Communicate in a way and at a pace that takes account of difficulties associated with dementia.
- Communicates in a way that recognises individual needs and diversity and the potential impact of memory difficulties and confusion

Dementia Informed Practice Level

Across all stages of the dementia journey

Outcome

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

What workers know (knowledge)

- ▶ Understand the potential physical, social and environmental hazards and risks to the safety and wellbeing of people with dementia.
- Understand the effects of the symptoms of dementia can mean that people may need support, or environmental adjustment, to maintain active engagement in community life and valued activities.
- Awareness of the potential effects that the symptoms of dementia can have on a person's behaviours, relationships, and activities and how this can affect mood.
- Knowledge of how to respond to a person with dementia who is distressed.
- Understands the effects of stigma and fear of stigma associated with dementia.

- Recognise when the physical or social environment could compromise the health and safety of people who are experiencing confusion and memory problems.
- 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.
- Recognises when a person with dementia, their family or carers appear to be disressed, identify areas of concern, and respond appropriately.
- Engage with people with dementia in a way that recognises the negative impact of stigma and discrimination.

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

Dementia Informed Practice Level

Across all stages of the dementia journey

Outcome

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

What workers know (knowledge)

- Understand that people with dementia may be at risk of experiencing neglect, harm or abuse – physical, sexual, psychological and financial.
- Understand that legislation exists to protect the rights of people with dementia and safe guard them against any potential risk or harm.
- Awareness of local adult protection protocol and policy.
- Awareness of the benefits of risk enablement in giving people choice and control.

- Recognise when a person with dementia is experiencing neglect, harm or abuse.
- Take appropriate action according to organisational procedures when a person with dementia may be experiencing neglect, harm or abuse.
- Support the person with dementia to take risks that provide opportunities and benefits for them.

DEMENTIA SKILLED PRACTICE LEVEL

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

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

Dementia Skilled Practice Level

Stage in the dementia journey Keeping well, prevention and finding out it's dementia

Outcome

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

What workers know (knowledge)

- Appreciate that people with dementia have a right to continued engagement in life's roles and relationships.
- Understand the importance of supportive networks and/or therapeutic connections for people with dementia, their families and carers.
- Awareness of the benefits for people with dementia to engage in activities as a means of maintaining their independence and enriching their lives.
- Understand the importance of maintaining the spiritual and cultural aspects of life for the person with dementia, their family and carers.
- Understand that the effects of dementia can mean that people may require support or environmental adjustment to maintain active engagement in community life and valued activities.
- Understand that the environment incorporates physical, cultural and social aspects that can impact on the experience of people with dementia.

- Support and encourage the person with dementia to develop new roles, skills and relationships.
- Support and encourage the person with dementia to maintain their chosen activities, social life and/or work and community involvement.

- Provide information or signpost to services including those that reflect the person's spiritual and cultural wishes.
- Make environmental adjustments to suit the individual requirements of the person with dementia.

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

Dementia Skilled Practice Level

Stage in the dementia journey Keeping well, prevention and finding out it's dementia

Outcome

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

What workers know (knowledge)

- ➤ Knowledge of the different types of dementia and the particular implications and impact on the person, their family and carers.
- ➤ Knowledge of a range of effective communication techniques and strategies to suit people who are affected by memory difficulties or confusion
- Awareness of local professional and community services and specialists, who can provide assessment, advice and support for memory problems.
- Understand the potential impacts of a diagnosis of dementia on people and their families and carers
- Knowledge of local professional, specialist and community and voluntary resources that provide services such as counselling, psychological or pharmacological supports, peer and group support.

- Respond appropriately to the diverse range of challenges that people with dementia may experience that reflect the impact of specific types of dementia
- Adapt communication to meet the individual needs of the person with dementia.
- Communicate respectfully and sensitively, with the person with dementia, giving consideration to the potential impact of memory difficulties or confusion.
- Support people to access services that address memory issues.
- Support the person with dementia to access emotional support, counselling or specialist psychological therapies.
- Support the person with dementia to access pharmacological treatments to alleviate distress and support mental wellbeing.

Dementia Skilled Practice Level

Stage in the dementia journey Keeping well, prevention and finding out it's dementia

Outcome

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

What workers know (knowledge)

- ➤ Knowledge of the types of health behaviours that can support physical health and contribute to prevention of certain types of dementia.
- Awareness of the principles and key provisions of legislation such as the Human Rights Act (1998), Mental Health (Care and Treatment) (Scotland) Act (2003) Adults with Incapacity Act (2000), Adult Support and Protection Act (2007) and the Equalities Act (2010).

- ▶ Provide people with a range of information about strategies and healthy lifestyle behaviour that can reduce the likelihood of developing some types of dementia
- Use legislative frameworks to support the person with dementia to exercise their rights and choices.
- Support people with dementia in risk enablement by contributing to risk assessment and management.
- Contribute to the assessment and support of people with dementia who may be experiencing neglect, harm or abuse.

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

Dementia Skilled Practice Level

Stage in the dementia journey

Living well with dementia

Outcome

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

What workers know (knowledge)

- Knowledge of the services and supports which can help people with dementia to maintain valued activities, social engagement and inclusion.
- ▶ Understand that stigma and the impact of dementia may lead to social isolation and withdrawal from previously valued social connections and activities.
- ▶ Understand how telehealthcare and assistive and innovative technology, can positively support and promote the independence and quality of life for people with dementia
- ➤ Knowledge of how to safely use tele-health and assistive and innovative technology to support the person with dementia, when appropriate to role.

- Provide information and access to supports for risk enablement and maintaining independence, such as telehealthcare.
- Utilise assistive technology where appropriate to promote people's independence and quality of life.

Dementia Skilled Practice Level

Stage in the dementia journey

Living well with dementia

Outcome

People with dementia, their families, friends and carers, have access to the information, education and support that enhances the wellbeing of the person with dementia and those that support them.

What workers know (knowledge)

- ➤ Knowledge of the impact of the progression of dementia on the physical, emotional and psychological health and wellbeing of the person with dementia their families and carers.
- Understand the impact of the environment on the safety and wellbeing of the person with dementia
- Understand the ways in which the impact of environmental challenges can result in frustration and distress
- Awareness of the benefits of cognitive stimulation in maintaining people's independence and alleviating frustration and distress.
- Awareness of the range of multi sensory, therapeutic and recreational activities that promote wellbeing and independence.

What workers are able to do (capability/skill/ability)

Engage with the person with dementia, their families and carers in a warm and empathic manner when responding to frustrations and distress.

- ➤ When appropriate to role engage with the person with dementia in undertaking informal cognitive stimulation activities
- ≥ Encourage and support the person with dementia to participate in therapeutic and recreational activities.

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.

Dementia Skilled Practice Level

Stage in the dementia journey

Living well with dementia

Outcome

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

What workers know (knowledge)

- ▶ Understand the benefits to the person with dementia in undertaking life story work in relation to sense of self and value both now and the future.
- ▶ Understand how life story work can be used to communicate with the person with dementia and engage them in meaningful interactions and activities.
- ▶ Understand the value to families and carers of recording a life story in order to maintain the sense of the person and their relationships.

What workers are able to do (capability/skill/ability)

Use the person's life story to support their engagement in meaningful activities relating to their interest and abilities.

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

Dementia Skilled Practice Level

Stage in the dementia journey

Living well with increasing help and support

Outcome

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

What workers know (knowledge)

- Understand 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.
- Understand 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 might face people with dementia, their families and carers, as their dementia progresses.
- Knowledge of a range of methods of communication with people with dementia who may be experiencing increasing difficulties with their memory and life skills.

- ➤ Work with the person with dementia, their family and carers to maximise their ability to participate in decisions and choices.
- ➤ Work with the person with dementia in a way that attends to their previously expressed choices, wishes and desires.
- Support the person with dementia to maintain their valued personal and community connections.
- Support the person with dementia, their family and carers to access counselling or psychological therapies that can support and enhance intimate relationships or build coping skills.
- Use communication strategies that take into account the individual progression and variable nature of dementia.

Dementia Skilled Practice Level

Stage in the dementia journey

People with dementia

feel safe and secure

and are able to be

as independent as

possible.

Living well with increasing help and support

Outcome

What workers know (knowledge)

- Understand that people with dementia are more at risk of issues that might impact on their physical health, for example, becoming dehydrated, malnourished or have continence issues.
- Knowledge of how to use a range of aids and adaptations to assist with eating and drinking and continence.
- Understand the particular risk people with dementia have to falling because of visual impairment.
- Understand that people with dementia may have a reduced ability to communicate physical illness, pain and mental distress.
- Understand that acute hospital admission may have a negative impact on the experience and outcomes for people with dementia.
- Understand the range of anticipatory and preventative measures that can be put in place to prevent hospital admission for people with dementia

What workers are able to do (capability/skill/ability)

Provide direct support in eating and drinking, when appropriate to role, to ensure the person maintains good nutrition and hydration.

- Recognise when a person with dementia may be at risk of falls and take appropriate action.
- Monitor changes and deteriorations in the person's physical and mental health and take appropriate action.

Report changes that may compromise the person's health and wellbeing and /or safety and security.

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

Dementia Skilled Practice Level

Stage in the dementia journey

End of life and dying well

Outcome

What workers know (knowledge)

➤ Knowledge of the specific palliative and end of life care needs of people with dementia.

What workers are able to do (capability/skill/ability)

Contribute to the palliative and end of life care of people with dementia. The goal of palliative care is the achievement of the best quality of life for people and their families.

(World Health Organisation)

ENHANCED DEMENTIA PRACTICE LEVEL

The **Enhanced Dementia Practice Level** outlines the knowledge and skills required by health and social care workers who have more regular and intense contact with people with dementia, provide specific interventions, and/or direct and manage care and services for people with dementia.

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

Enhanced Dementia Practice Level

Stage in the dementia journey Keeping well, prevention and finding out it's dementia

Outcome

People with dementia have access to a timely and accurate diagnosis of dementia.

What workers know (knowledge)

- Understand the evidence base, strategies and health and wellbeing promoting behaviours that may help prevent some forms of dementia
- Understand the complex issues that need to be addressed and explored by people, their families and carers facing a potential diagnosis of dementia.
- Detailed knowledge of the different types of dementia and the implications and support needs for the person on receiving a diagnosis.
- Detailed knowledge of the differences between dementia and other physical and mental health problems, in particular delirium, depression.
- ➤ Knowledge of a range of evidence based screening tools which may be used to measure cognition in people with dementia.

- Raise public awareness of the strategies and health and wellbeing promoting behaviours that may help prevent some forms of dementia
- Support people to explore the benefits and risks in receiving a diagnosis of dementia.
- Discuss sensitively with the person with dementia their options in relation to referral to memory clinics and specialist services.
- Use basic screening tools to assess memory, orientation, verbal and perceptual skills.
- Use and interpret feedback from evidence based screening tools for measurement of cognition.

Stage in the dementia journey Keeping well, prevention and finding out it's dementia

Outcome

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

What workers know (knowledge)

- Detailed knowledge of local services and specialists, their roles and functions and the services they offer for assessment and advice on memory problems.
- Understand the potential impact of a diagnosis of dementia on relationships, roles and expectations.
- Understand the potential impact of a diagnosis of dementia on a diverse range of people including people from range of ethnic and cultural groups, people with learning disabilities and younger people.
- Knowledge of the increased risk of developing dementia for people with learning disabilities.

- 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.
- Ascertain the information and education needs of the person with dementia, their families and carers and provide or signpost as appropriate.
- ▶ 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 with dementia and people with a learning disability are supported to access chosen services in an equitable way.

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

Enhanced Dementia Practice Level

Stage in the dementia journey Keeping well, prevention and finding out it's dementia

Outcome

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

What workers know (knowledge)

- Understand the concept of an outcomes focussed approach in dementia care, treatment and support.
- Understand the importance of identifying and focusing on outcomes that are important to the person with dementia.
- ➤ Knowledge of evidence based, solution focussed psychological interventions to address the impact of diagnosis on the wellbeing of people with dementia, their families and carers

- Engage with the person with dementia to establish the outcomes that are important to them, and support them to prioritise and achieve these outcomes.
- Maintain a positive and solution focussed approach which encourages and supports the person with dementia, their family and carers to build on their strengths and abilities.
- Provide advice and education for the person with dementia, their family and carers about the management of their own health and wellbeing.

Stage in the dementia journey Keeping well, prevention and finding out it's dementia

Outcome

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

What workers know (knowledge)

- Understand the potential risk of social isolation that can follow a diagnosis of dementia,
- Understand the importance for people with dementia, their families and carers, to continue to engage in socially included roles, relationships and activities that support their independence and wellbeing.
- Understand the importance of peer and community support for people with dementia, their families and carers.
- Understand the importance of people maintaining the spiritual and cultural aspects of life following a diagnosis of dementia.

What workers are able to do (capability/skill/ability)

Work to maximise social inclusion by supporting people with dementia, families and carers, to access community organisations and supports and continue to engage in meaningful activity.

Engage with the person, their family and carers, to find out how their spiritual and cultural beliefs can be supported and harnessed to maintain their valued quality of life.

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

Enhanced Dementia Practice Level

Stage in the dementia journey Keeping well, prevention and finding out it's dementia

Outcome

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

What workers know (knowledge)

- Understand the human and legal rights of people with dementia to make decisions and to take risks in the context of their own lives.
- Detailed knowledge of the principles and key provisions of legislation such as the Human Rights Act (1998), Mental Health (Care and Treatment) (Scotland) Act (2003) Adults with Incapacity Act (2000), Adult Support and Protection Act (2007) and the Equalities Act (2010).

- 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 to safeguard the best interests of people with dementia, families and carers
- Sensitively work with the person to Identify the elements of Advanced Planning which they wish to undertake.

Stage in the dementia journey Keeping well, prevention and finding out it's dementia

Outcome

What workers know (knowledge)

- Detailed knowledge and understanding of health promotion and its impact on the progression of dementia.
- ▶ Understand the impact and potential losses associated with a diagnosis of dementia and the range of possible reactions, including emotional distress.
- ➤ Knowledge and understanding of the causes and signs of stress and distress for the person with dementia, their family and carers.
- ➤ Knowledge of the signs of common mental and physical health problems for people with dementia, families and carers.
- Knowledge of local services that provide specialist psychological interventions and therapies.

What workers are able to do (capability/skill/ability)

- Actively support the person with dementia to access physical health assessments, treatments and services to maintain or improve their physical health.
- Identify and respond sensitively to verbal and non verbal cues from the person with dementia, their families and carers that may indicate psychological distress.
- Recognise when a person with dementia, their families and carers, are experiencing anxiety and/or depression and make referral to specialists when necessary.

People with dementia

maintain their hest

level of physical.

mental, social and

emotional wellbeing.

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

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

Enhanced Dementia Practice Level

Stage in the dementia journey

Living well with dementia

Outcome

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

What workers know (knowledge)

- ▶ Understand the importance of existing and new, natural community resources that can provide support for people with dementia, their families and carers, to maintain a valued and socially included quality of life.
- Understand the concepts of person-centred care and personalisation and the implications for how services and individual support is delivered
- Knowledge and understanding of self directed support and how this can be enabled and maximised to support people with dementia.

- Contribute to practices which build on and expand natural community resources for people with dementia, their families and carers.
- ➤ Facilitate the development of new and supportive networks and connections, e.g. peer support, group support and virtual and internet supports.
- ➤ Contribute to practices that enable the person with dementia to actively find the right solutions for them, and to choose and access any services they receive including the use of self directed support.

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

Enhanced Dementia Practice Level

Stage in the dementia journey

Living well with dementia

Outcome

What workers know (knowledge)

- ▶ Understand the principles, approaches and practices that promote outcomes focussed approach to dementia care, treatment and support.
- Understand the importance of, and approaches and methods that should be used to measure the impact of dementia support against outcomes.

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

- Understand how environmental adaptations, assistive and innovative technology and tele-healthcare can enhance the quality of life of the person with dementia.
- ➤ Knowledge of the range of assistive and innovative technologies available that support independent living and the evidence base for their use.

- Adopt an outcomes based approach, building on peoples existing capabilities, when assessing the support needs of people with dementia, families and carers.
- Undertake person-centred assessments, focussed on the outcomes for the person with dementia.
- Evaluate the impact of the support provided to people, their families and carers in a way that actively involves them and informs continuous improvements.
- ≥ Enable people with dementia to address the environmental issues that may provide challenges to their safety and quality of life.

Stage in the dementia journey

People with dementia

maintain their hest

level of physical,

mental, social and

emotional wellbeing.

Living well with dementia

Outcome

What workers know (knowledge)

- When appropriate to role, understand how to sensitively undertake a range of dementia specific psychometric, age appropriate, mental and physical health assessments.
- Nowledge of how to interpret the results of assessment and how to feed back results sensitively.
- ➤ Knowledge of a range of responses to assessment results including referral to specialists, self-directed support and carer's assessments.
- ➤ Knowledge of the range of strategies that maximise the strengths and wellbeing of the person with dementia to engage in self management and self help.
- ➤ Knowledge of the range of physical conditions that can be associated with the different types of dementia, e.g. visual difficulties, vascular conditions.

What workers are able to do (capability/skill/ability)

Discuss findings of assessments sensitively and empathically and promote access to appropriate services and specialists for further advice and support.

- Use appropriate psychological and psychosocial skills to work with the person with dementia, their family and carers.
- Work sensitively with the person, their family and carers to recognise when additional assistance may be required.

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 also no life.

Stage in the dementia journey

People with dementia

have access to avality

continue to participate

in community life and

services and can

valued activities

Living well with dementia

Outcome

What workers know (knowledge)

- Knowledge of evidence based psychological interventions and therapies for people with dementia, their families and carers.
- Understand the possible causes of personal or family distress linked to the emotional impact of the symptoms of dementia.
- Understand the processes involved in adapting to changes in sense of self, relationships and roles.
- Knowledge of specialist services that can provide therapy, support and self-help techniques.
- Knowledge of the range of pharmacological interventions that may enhance memory.

- ➤ Support the person with dementia to access physical, cognitive, psychological and emotional support, treatments and specialist services including self help resources.
- Provide support and interventions to assist the person with dementia to maintain existing cognitive skills and devise strategies to cope with reducing cognitive ability.
- When appropriate to role, provide the person with dementia, their family and carers with counselling or psychological therapies that can support and enhance intimate relationships or build coping skills.
- Raise awareness of the potential benefits of pharmacological interventions that may enhance memory and when appropriate to role monitor the impact on the person.

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

Enhanced Dementia Practice Level

Stage in the dementia journey

Living well with dementia

Outcome

What workers know (knowledge)

- ▶ Understand the emotional complexities in relation to future planning for the person with dementia, families and carers.
- ➤ Knowledge of how to empathically engage with people facing difficult and potentially distressing decisions involved in advanced planning.

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

➤ Knowledge of how to sensitively support people in the creation of a life story which form the basis for understanding their cultural, spiritual and personal history, and supports the implementation of their present and future wishes and choices

- Recognise and interpret cues that indicate when the person with dementia is ready to embark on advance planning.
- Sensitively engage in difficult conversations that may be upsetting to the person with dementia, their family and carers.
- Sensitively and empathically 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
- ➤ 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 in the dementia journey

Living well with dementia

Outcome

People with dementia and their families, friends and carers, have access to the information, education and support that enhances the wellbeing of the person with dementia and those that support them.

What workers know (knowledge)

- Understand how legislation can contribute to person-centred planning for people with dementia.
- Knowledge of the appropriate current legislation on informed consent and confidentiality.
- ➤ Knowledge of the elements of the relevant legislation that can support people with dementia, e.g. power of attorney, guardianship and 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.

- Actively support the person with dementia, their family and carers, to exercise their rights, entitlements and choices.
- Provide information and guidance for people with dementia, their families and carers, regarding legal aspects of advance planning in relation to welfare and finance.
- ▶ Provide information for the person with dementia, their family and carers, about the ongoing implications for them of legislation regarding informed consent, guardianship, power of attorney and advocacy.
- Engage with families and carers as equal and expert partners in care and support.

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

Enhanced Dementia Practice Level

Stage in the dementia journey

Living well with dementia

Outcome

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

What workers know (knowledge)

- Understand that respite and short breaks are key support intervention to maximise carer's contribution and enhance the person with dementia wellbeing.
- Understand the importance and opportunities of risk enablement in the promotion of independent living for people with dementia.
- Nowledge of evidence based approaches and techniques for assessing neglect and abuse and appropriate responses.

- Encourage and support the person with dementia, their family and carers, to identify respite 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 the person with dementia to assess risk, including areas of potential neglect and abuse.

Stage in the dementia journey

Living well with increasing help and support

Outcome

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

What workers know (knowledge)

- ▶ Understand the importance of continued engagement in valued relationships and meaningful activities, for people with dementia, as their condition progresses.
- Knowledge and recognition of the need to balance dependence and interdependence to maximise social inclusion.

- ➤ Knowledge of human rightsbased and adult protection legislation and how to apply appropriate measures and safeguards for people with dementia
- Understand how legislation can contribute to person-centred planning and maximise a person with dementia's ability to communicate their decisions.

- ➤ Work in partnership in a way that reflects diversity of people with dementia, their families and carers to positively and constructively respond to their specific situation.
- Support families and carers of people with dementia in working through the life and relationship changes which 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 the person with dementia and challenge any discriminatory practices that may compromise the person's right to dignity respect and safety.
- ▶ Proactively ensure that the person with dementia is supported to exercise their rights and choices or their previously determined choices are upheld wherever possible.

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

Enhanced Dementia Practice Level

Stage in the dementia journey

Living well with increasing help and support

Outcome

legislation on informed consent, confidentiality and advance planning and the implications for the person with dementia, their families and carers.

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

➤ Knowledge of the principles of determining capacity in any given situation.

What workers know

Understand the requirements

of appropriate current

(knowledge)

- Knowledge of a range of communication tools and techniques that can support the person with dementia in their decision making.
- Knowledge of how potentially reducing capacity in the person with dementia can impact on their ability to effectively communicate their choices, wishes and needs

- Actively support the person 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.
- Ascertain whether the person with dementia has a guardian or attorney appointed.
- Refer for assessment when no guardian or attorney has been appointed.
- Actively support the person with dementia to maximise their ability to communicate their needs wishes and desires.

Stage in the dementia journey

People with dementia

maintain their hest

level of physical,

mental, social and

emotional wellbeing.

Living well with increasing help and support

Outcome

Understand the contribution that can be made to quality of life of the person with

(knowledge)

What workers know

- life of the person with dementia, by timely gathering of personal details and information from all sources, for example families, carers and friends.
- Understand how physical health problems can particularly impact people with dementia and influence the progression of dementia.
- Knowledge of the distinguishing signs of dementia, depression and delirium and appropriate responses and treatment options.

- ➤ Work in partnership with the person with dementia, their family and carers, 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 health needs and observe for changes and deteriorations in the persons health.
- Promote and maintain the person's current abilities and strengths related to health.
- Instigate and/or involve others in providing the most appropriate treatment for depression and delirium.

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

Enhanced Dementia Practice Level

Stage in the dementia journey

People with dementia

have access to quality

continue to participate

in community life and

services and can

valued activities.

Living well with increasing help and support

Outcome

(knowledge)

What workers know

- Aware of national and local guidance relating to use of medication for people with dementia.
- ▶ Understand the specific pharmacological issues relating to people with dementia in responding to both physical and psychological needs, including poly-pharmacy and covert medication.
- Understand the range of assessment and interventions that support the maintenance of physical health.
- Understand how dementia can affect people's continence and the interventions that can be used to support this.
- Understand the particular environmental and individual physical and cognitive issues for people with dementia that can intensify the possibility of slips, trips and falls.
- ▶ Understanding of the impact of the physical environment on the quality of life of the person with dementia as their conditions progresses.

- ➤ Where medication use is indicated ensure it adheres to national and local guidance relevant to people with dementia.
- Sensitively use a range of assessment tools to support good nutrition, skin care, continence and pain management for people with dementia.
- Maintain the person with dementia's dignity through use of individualised prompts to maintain continence.
- Work with the person with dementia, their family and carers, and other agencies to make adaptations to the physical environment that can promote independence and minimise the amount of help required.

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

Enhanced Dementia Practice Level

Stage in the dementia journey

Living well with increasing help and support

Outcome

What workers know (knowledge)

➤ Knowledge of the range of assistive and innovative technologies available that support independent living, and the evidence base for their use.

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

- Understand the range of environmental and personcentred approaches which can prevent behavioural distress and promote wellbeing for people with dementia.
- ▶ Understand the complex behavioural changes and their causes that indicate people with dementia are distressed.

- Use signage, lighting and familiar objects to maximise orientation and reduce confusion.
- Assess need and engage with assistive and innovative technology, where appropriate, such as pressure mats or door alarm to maintain the person's independence.
- Support and enable the person with dementia to remain active and mobile.
- Engage in implementing best practice in environmental adaptations can contribute to the privacy and safety of people with dementia.
- Take a person-centred approach to assessing distressed behaviour which may be perceived as challenging.
- Use a range of assessment strategies to identify changes in the person with dementia's emotional wellbeing.

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

Enhanced Dementia Practice Level

Stage in the dementia journey

Living well with increasing help and support

Outcome

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

What workers know (knowledge)

▶ Understand that changes in behaviour can be responded to with appropriate interventions based on a knowledge of the person with dementia.

What workers are able to do (capability/skill/ability)

- Recognise changes in emotional wellbeing in the person with dementia.
- Use knowledge of the person with dementia in responding to their expression of stress and distress.

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

- Detailed knowledge and understanding that distressed behaviours perceived as being challenging are often an expression of unmet needs.
- Dunderstand the range of psychological, psychosocial and environmental interventions which can ease behavioural distress.
- ▶ Understand the range of multisensory stimulation, recreational activities and combined therapies that promote wellbeing and alleviate distress in people with dementia

Proactively intervene to support the person with dementia, their family and carers to manage stress and avert distress.

Creatively use a combination of different levels of intervention, based on individual needs, to promote wellbeing and alleviate distress.

Stage in the dementia journey

End of life and dying well

Outcome

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

What workers know (knowledge)

- Nowledge of the complexity associated with the progression of dementia and the signs and symptoms associated with end of life.
- ➤ Knowledge of best practice and a range of approaches to gathering information from people with dementia, their families and carers at end of life stage.
- Knowledge of the implications of advance planning 'power of attorney', guardianship, advance directives including any regarding refusal of treatment.
- Knowledge and understanding of the legal and policy position regarding resuscitation in relation to people with dementia.

What workers are able to do (capability/skill/ability)

Ascertain whether advance planning has been undertaken and is recorded.

- Use the person with dementia's advanced plan relating to their choices for palliative end of life care.
- In the absence of an advanced plan work with families and carers to ensure the person with dementia's choices for palliative end of life care are met.

Get rid of the stereotypical images they have of people with dementia and how dementia affects people because it affects everybody differently.

(Family Member)

Stage in the dementia journey

End of life and dying well

Outcome

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

What workers know (knowledge)

- ▶ Understand the importance of keeping carers and families well informed about options at this stage.
- Understand the need may arise to advocate on behalf of carers in relation to implementing the wishes of the person with dementia.
- ▶ Understand the requirement to remain up to date with changes to best practice guidance, legislation and policy regarding palliative care, end of life care and death and implement this in relation to end of life care for people with dementia.

- ▶ Recognise that there can be potential conflicts between the person and family and carers wishes, and seek expert advice when this occurs.
- Communicate and listen in a sensitive manner when discussing difficult and complex end of life concerns with people with dementia, their families and carers

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

Enhanced Dementia Practice Level

Stage in the dementia journey

End of life and dying well

Outcome

What workers know (knowledge)

- ➤ A thorough knowledge and understanding of palliative care standards, frameworks and tools to help support good palliative care and how to use them with people with dementia.
- Understand possible additional distress may manifest in behavioural symptoms which require sensitive responses.
- Understand the importance of constant review and observation for changes in condition, signs and symptoms.
- ▶ Understand the need to assess pain thoroughly, how to distinguish between chronic and acute pain and that dementia impairs the persons' ability to articulate/describe their pain.
- ▶ Understand when to seek specialist dietetic services, support and guidance from colleagues.
- Understand the need to support physical wellbeing of the person with dementia as far as possible at end of life.

What workers are able to do (capability/skill/ability)

- Use a range of assessment tools and techniques to carry out assessment and review appropriately and consistently including assessment of pain both chronic and acute and all needs over and above dementia.
- Explore 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.

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

Stage in the dementia journey

End of life and dying well

Outcome

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

What workers know (knowledge)

- Understand the importance of spiritual support at the end of life for some people with dementia, their families and carers.
- Understand the psychological and emotional effects of dying which can affect a person with dementia, their family and carers.
- Awareness of when there is a need to continue bereavement support for carers.
- ▶ Understand the range of psychological, pharmacological and community supports for carers and family members which can assist with loss, coping skills and the maintenance of mental health and wellbeing.

- Support people with dementia, their families and carers to meet their spiritual needs.
- Encourage, enable and involve carers, so far as desired and appropriate, in assisting in the provision of care for the person with dementia.
- Support families and carers of people with dementia to seek social and/or psychological supports as appropriate.
- ▶ 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 services workers who by virtue of their role or practice setting play an expert specialist role in the care, treatment and support of people with dementia.

Expertise in Dementia Practice Level

Stage in the dementia journey Keeping well, prevention and finding out it's dementia

Outcome

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

What workers know (knowledge)

- ≥In-depth knowledge of positive approaches to enable and support people to be empowered to exercise rights and choices.
- Comprehensive understanding of the impact that discrimination and stigma may have on the life of the person with dementia, their family and carers.
- Advanced understanding of the value of person-centred approaches in therapeutic relationships and communication.
- Comprehensive understanding of the impact that a diagnosis of dementia can have on person's identity and emotional wellbeing.
- Comprehensive understanding of the impact of a diagnosis of dementia on peoples' families, wider social networks and relationships.

- Promote awareness of the person'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.
- Use a range of person-centred assessment approaches to assist in making a diagnosis of dementia, when appropriate to role
- Use specialist psychological and psychosocial skills to support the person to manage receiving a diagnosis in as positive a way as possible.

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

Expertise in Dementia Practice Level

Stage in the dementia journey Keeping well, prevention and finding out it's dementia

Outcome

People with dementia have access to a timely and accurate diagnosis of dementia.

What workers know (knowledge)

- Understand how diversity (e.g. age, gender and ethnic group) can influence the presentation of dementia.
- Understand how people from diverse backgrounds and cultures may understand and respond to a diagnosis of dementia.
- Comprehensive knowledge and understanding of the particular impact of a diagnosis for younger people with dementia.
- Comprehensive understanding of the equality and diversity, issues that should be considered in relation to receiving a diagnosis of dementia and post diagnostic support.
- Comprehensive understanding of how access to appropriate services and support can be enabled in a way that respects diversity and challenges inequalities.
- Comprehensive knowledge of how to assess the wide range of requirements of people with dementia including younger people and those with a learning disability.

What workers are able to do (capability/skill/ability)

- Demonstrate empathy and respect when supporting the person, their family and carers through the diagnosis process in a way that values diversity.
- Adopt a person-centred approach to sensitively communicate a diagnosis in a way that responds to the unique needs and situation of the person, their family and carers.
- 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, e.g. people with a learning disability.

Adapt assessment approaches to reflect the diversity of people who may receive a diagnosis of dementia.

Expertise in Dementia Practice Level

Stage in the dementia journey Keeping well, prevention and finding out it's dementia

Outcome

People with dementia, their families, friends and carers, have access to the information, education and support that enhances the wellbeing of the person with dementia and those that support them.

What workers know (knowledge)

- ➤ Knowledge of the increased risk of developing dementia for people learning disabilities understanding of the complex interaction that results.
- ➤ Knowledge of the range of changes in behaviour and communication that can signify dementia in a person with learning disabilities.
- Expert knowledge of specific neuropsychological assessment tools and techniques to assist in diagnosis appropriate to role.
- Expert knowledge of the range of pharmacological interventions that may enhance memory.

- Adopt a person-centred approach to regular assessment and review of people with learning disability to ensure accurate and timely diagnosis when dementia is present.
- When appropriate to role undertake specific neuropsychological assessments.
- When appropriate to role discuss with the person the benefits and implications of pharmacological interventions that may enhance memory.
- ➤ When appropriate to role sensitively engage with the person and their family in monitoring and reviewing the impact of pharmacological interventions.

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

Expertise in Dementia Practice Level

Stage in the dementia journey

Living well with dementia

Outcome

What workers know (knowledge)

Comprehensive knowledge of the concepts of person-centred care and personalisation, and the implications for practice, service design and delivery.

- People with dementia have access to quality services and can continue to participate in community life and valued activities.
- ▶ In-depth understanding of the need for citizen leadership, user and carer expertise and participation in creating systems and services which 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.

- Support and enable the person with dementia to find the right solutions for them and actively design and select the services they require.
- Contribute to the development of practices and services which meet the individual needs of people with dementia.
- Provide expert advice on strategies to adapt lifestyle that supports continued engagement in communities, employment, relationships and social networks.
- Support and encourage all staff to adopt attitudes and practices that values the importance of existing natural community resources in supporting people with dementia.
- Demonstrates leadership in shaping service design and delivery that reflects co-production, participation, empowerment, enablement and community capacity building.

If we're having problems, then no matter how far on we are in our dementia, we deserve the problem to be challenged and an answer to be found if at all possible.

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

Expertise in Dementia Practice Level

Stage in the dementia journey

Living well with dementia

Outcome

What workers know (knowledge)

➤ Comprehensive knowledge and understanding of the principles, processes, implications and procedures involved in utilising self-directed support.

- People with dementia are able to maintain valued relationships and networks, and have the opportunity to develop new ones both personal and professional.
- ➤ Knowledge of the principles and options for the application of outcomes-based approaches including a joint outcomes approach for people with dementia, their families and carers.
- ➤ 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.
- ▶ In-depth knowledge of personcentred and relationship focussed approaches to dementia care and support, e.g. the Senses Framework.

What workers are able to do (capability/skill/ability)

- When appropriate to role, support the person with dementia, their family and carers, to understand and make informed choices about self directed support.
- Support the person with dementia, their family and carers to access self directed support if desired.
- Promote the use of an outcomes based approach which builds on people with dementia's existing capabilities when assessing the support needs of people with dementia.

■ Use person-centred and empathic approaches to assessment, treatment and support for people with dementia.

Expertise in Dementia Practice Level

Stage in the dementia journey

Living well with dementia

Outcome

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

What workers know (knowledge)

- Comprehensive understanding of the relationship between dementia, depression and delirium.
- Expert knowledge of the range of options and interventions that support people with dementia who are experiencing anxiety and depression.
- Expert knowledge of the complexity of co-morbidity in dementia.
- Thorough understanding of evidence based approaches which can enhance psychological, social and physical wellbeing.
- Comprehensive understanding of how stress may impact people with dementia and their families and carers and how to support people to manage this.
- ➤ Knowledge of the pharmacological treatment of dementia and the impact on the person with dementia.

- Instigate and involve others in providing the most appropriate treatment for depression and delirium in people with dementia.
- Provide role appropriate social, emotional and psychological support and interventions to help people with dementia, and their families and carers, address issues such as anxiety or depression.
- Draw on a range of different social, psychological and psychosocial approaches to provide support appropriate to the person with dementia.
- When appropriate to role provide expert advice on pharmacological interventions that support emotional wellbeing.

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

Expertise in Dementia Practice Level

Stage in the dementia journey

Living well with dementia

Outcome

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

What workers know (knowledge)

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

- ➤ 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 the person with dementia to support them to enhance their coping skills and strategies to address memory changes.
- 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 adaptations are made to the physical and social environment to support people with dementia where they live or work.

Expertise in Dementia Practice Level

Stage in the dementia journey

Living well with dementia

Outcome

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

What workers know (knowledge)

- Comprehensive understanding of the particular environmental and individual physical and cognitive issues for people with dementia that can intensify the possibility of slips, trips and falls.
- Expert knowledge of the range of measures that can contribute to the safety and privacy of people with dementia, including prevention of falls, without compromising their right to dignity or independence.
- Expert knowledge of the different perceptions of risk and the range of approaches to the management of risk.
- Understand the reasons and rationale behind an aversion some may have to risk and risk taking.

- Make recommendations regarding the various ways in which the environment and environmental adaptations can contribute to the person's privacy and safety.
- ▶ Make recommendations regarding environmental design, including signage to assist the person with dementia to be orientated and independent.
- Act as a source of expert advice on the benefits of risk enablement in supporting the person with dementia to have choice and control.
- Apply flexible and responsive approaches to eliminating risk aversion.

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

Expertise in Dementia Practice Level

Stage in the dementia journey

Living well with dementia

Outcome

People with dementia and their families, friends and carers, have access to the information, education and support that enhances the wellbeing of the person with dementia and those that support them.

What workers know (knowledge)

- Expert understanding of advance planning processes for example, advanced statements, power of attorney and planning and end of life care.
- Expert understanding of the sensitivities associated with advance planning processes for a person with dementia, their family and carers.

- Support people with dementia and their families and carers to engage in advance planning.
- Provide support and advice to services and professionals involved in supporting people with dementia, their families and carers to engage in advance planning.

Expertise in Dementia Practice Level

Stage in the dementia journey

Living well with increasing help and support

Outcome

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

What workers know (knowledge)

- Comprehensive knowledge, understanding and synthesis of rights-based legal, ethical and professional guidance to inform practice in relation to dementia.
- Comprehensive understanding of the principles of assessment of capacity for people with dementia and the underpinning evidence and legislation.
- Expert knowledge in the application and understanding of the legislation, guidance and policy in all pertinent areas, including ethical decision making in relation to people with dementia.
- Expert knowledge and in-depth understanding of impact of dementia on communication.
- Expert knowledge and skill to individually tailor evidencebased psychological or pharmacological interventions relevant to people with dementia.

- 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 peoples' rights and choices.
- Actively promote ethical decision making in relation to people with dementia.
- Respond expertly to the diversity of communication challenges experienced by the person with dementia.
- When appropriate to role individually tailor evidence based psychological or pharmaceutical interventions relevant to people with dementia.
- When appropriate to role modify and adapt social, psychological and psycho-social interventions and evaluate effectiveness for the person with dementia

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

Expertise in Dementia Practice Level

Stage in the dementia journey

People with dementia

maintain their hest

level of physical,

mental, social and

emotional wellbeing.

Living well with increasing help and support

Outcome

What workers know (knowledge)

- ➤ Knowledge and understanding of the theory behind evidence based cognitive stimulation and rehabilitation approaches and best practice for use.
- Expert knowledge of the benefits of multi sensory stimulation, recreational activities and use of combined therapies.
- ▶ In-depth knowledge of the sources of stress and distress and the approaches and evidence based interventions to support people who cannot communicate their needs
- ➤ Knowledge of approaches which promote multidisciplinary assessment and interventions to support people with dementia with distressed behaviours perceived to be challenging.

- Engage the person with dementia in activities to maximise and improve their memory such as cognitive stimulation and cognitive rehabilitation
- Act as a source of expert advice and guidance in sensory stimulation, recreational activities and use of combined therapies.
- Expertly use person-centred interventions to support people with dementia who are stressed or distressed.
- Promote and lead on multidisciplinary assessment and interventions to support people with dementia with distressed behaviour that may be perceived as challenging.

Expertise in Dementia Practice Level

Stage in the dementia journey

Living well with increasing help and support

Outcome

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

What workers know (knowledge)

- Comprehensive knowledge of a range of person-centred approaches to support people with dementia who have unmet needs or whose ability to communicate needs is compromised.
- Understand the importance of partnership working in the provision of support, care and services for people with dementia, their families and carers.
- Expert knowledge of the opportunities and challenges in implementing an outcomes based approach to provision of support for people with dementia, their families and carers.

- Actively promote personcentred responses to people with dementia with unmet needs or 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 in implementing outcomes focussed practices and services for people with dementia, their families and carers, to drive continuous improvements.

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

Expertise in Dementia Practice Level

Stage in the dementia journey

End of life and dying well

Outcome

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

What workers know (knowledge)

- Expert knowledge of the specific palliative care and end of life care needs for people with dementia.
- Expert knowledge of legal, ethical and human rights issues relevant to people with dementia at the end of life.
- Expert knowledge and understanding of the complexity of interactions and potential conflicts that arise which may compromise the wishes of the person with dementia.

- Provide expert advice on meeting the specific needs of people with dementia to promote comfort and dying well.
- Act as a source of expert advice on legal, ethical and human rights issues relevant to people with dementia at the end of life.
- Act as a source of expertise in conflict resolution relating to decision making and compliance with the wishes of the person with dementia.

References and links to supporting resources

This is an indicative list and will be subject to constant updating via the webbased interactive version of *Promoting Excellence* that will be available by the end of 2011.

Alzheimer Scotland is the leading dementia organisation in Scotland and campaigns for the rights of people with dementia and their families and provides an extensive range of innovative and personalised support services. See www.alzscot.org

Alzheimer's Society/Mental Health Foundation (2010) 'My name is not Dementia'. London. Alzheimer's Society. This report outlines the quality of life indicators people with Dementia have defined as most important to them.

See http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=1339

Alzheimer Scotland (2010) **Let's get personal – personalisation and dementia**. Edinburgh. Alzheimer Scotland. This report outlines findings of research into personalisation and direct payments for people with dementia and a guide to self-directed support.

See http://www.atdementia.org.uk/newsStory.asp?page_id=281

Cross Party Group on Alzheimer's (2009) **The Charter of Rights for People with Dementia and their Carers in Scotland** Edinburgh. Alzheimer Scotland. *The Charter has been key in shaping Promoting Excellence and the Dementia Care Standards*. See http://www.dementiarights.org/

Department of Health (2010) 'Nothing Ventured, Nothing Gained': risk guidance for dementia. A useful resource that provides guidance to promote risk enablement for people with Dementia.

See http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets

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

Dementia Services Development Centre, University of Stirling. The Centre provides comprehensive dementia education and training, consultancy and research services. See www.dementia.stir.ac.uk

Joint Improvement Team (JIT). Hosted by the Scottish Government JIT works directly with local health and social care partnerships across Scotland to provide practical support and additional capacity to partnerships.

For general information, about JIT see http://www.jitscotland.org.uk/about/what-is-jit/

For personal outcomes focussed approaches see http://www.jitscotland.org.uk/action-areas/talking-points-user-and-carer-involvement

For the wider Reshaping Care for Older People agenda see http://www.jitscotland.org.uk/action-areas/reshaping-care-for-older-people/

Mental Welfare Commission for Scotland. The Commission 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 including 'Remember I'm still Me' and 'Dementia; Decisions for Dignity' See http://www.mwcscot.org.uk/mwc_home/home.asp

NHS Education for Scotland is a special health board, responsible for supporting NHS services by developing and delivering education and training for those who work in NHSScotland.

For general information about NES see http://www.nes.scot.nhs.uk/

For specific information about NES Mental Health work see http://www.nes.scot.nhs.uk/initiatives/mental-health

The Scottish Dementia Working Group is an independent group run by people with dementia in Scotland. See http://www.sdwg.org.uk/

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

Scottish Dementia Working Group (2010) **Through our eyes, a life with dementia DVD.** The DVD is intended primarily for use as a training and awareness-raising tool amongst professionals at all levels within the health and social care sectors working in Dementia Care.

See http://www.sdwg.org.uk/videos/through-our-eyes-a-life-with-dementia/

Scottish Government (2010) **Scotland's National Dementia Strategy**. Edinburgh. SGHD. The Strategy outlines the Scottish Government's vision for transforming Dementia support and services alongside the key change actions that will enable this.

See http://www.scotland.gov.uk/Resource/Doc/324377/0104420.pdf

Scottish Social Services Council is responsible for raising standards in the Scottish social service workforce including registering people who work in the social services and regulating and promoting their education and training. See http://www.sssc.uk.com/

Social Care Institute for Excellence Dementia Gateway includes a range of quality an accessible educational resources to support the development of staff who work with people with dementia in nursing, residential or domiciliary settings. See http://www.scie.org.uk/publications/dementia/index.asp



© Crown copyright 2011

This document is available from our website at www.scotland.gov.uk.

ISBN: 978-1-78045-194-7

Produced for the Scottish Government by APS Group Scotland DPPAS11594 (06/11)