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

Guidelines for Trainers and Educators
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Introduction and Background

This guideline has been developed to support education providers to adopt a standardised approach to Dementia education in all undergraduate and postgraduate health and social services professionals’ educational preparation.

The guidance is based on Promoting Excellence – A framework for all health and social services staff working with people with dementia and their families and carers. The guidance outlines core curricular content and also provides links to a range of supporting educational resources that have been mapped against the various levels of Promoting Excellence.

It is hoped that together with a range of initiatives being taken forward as part of Scotland’s National Dementia Strategy, this guidance will make a significant contribution to meeting the aspiration of the strategy to put Scotland at the forefront of personalised and person centred support and care for people with dementia and their families and carers.¹²

Why is Dementia support and care so important in Scotland?

Dementia is a condition that can be caused by a number of progressive illnesses that affect memory, thinking, behaviour and the ability to perform everyday activities. Alzheimer’s disease is the most common type of dementia. Other types include vascular dementia, dementia with Lewy bodies and fronto-temporal dementia. Dementia is a significant issue for people in Scotland. It is a condition which changes the lives of those diagnosed and of those close to them. There is a recognition that, despite much good work, there are critical challenges and important gaps which must be addressed if people are to receive the services they need.

In 2010 the Scottish Government launched Scotland’s National Dementia Strategy. The aim of the strategy is to deliver world class dementia care and treatment in Scotland, ensuring that people with dementia and their families are supported in the best way possible to live well with dementia. One of the primary actions identified by the strategy was to improve staff skills and knowledge in health and social care settings;

“We must ensure that health and social care professionals, mainstream local services and communities across Scotland understand dementia and are encouraged to play a part in making a difference in the lives of people with the illness.”

Henry Simmons
Chief Executive Alzheimer Scotland
Scotland’s National Dementia Strategy ³

The national picture of dementia in Scotland

There are 5.2 million people in Scotland and just over a million aged 65 and over. The number of people in Scotland aged 65 and over will increase 21% by 2016, and 62% by 2031. There will be a 38% rise in people aged 85 by 2016 and a 144% rise by 2031.⁴

Dementia mainly affects older people; in 2012 approximately 84,000 people have dementia in Scotland, 3,500 of whom are under the age of 65. After age 65, the likelihood of developing dementia roughly doubles every five years.⁵ Consequently, the number of people with dementia in Scotland is expected to rise to 164,000 by 2036.⁶

Alzheimer Scotland estimates that the costs associated with dementia are £1.7 billion per annum. Of that cost, at least £600 or £700 million is the cost of care and treatment services provided by the NHS and local government. In fact more is spent on dementia in the UK than on cancer, heart disease and stroke put together. The remainder is the contribution made by carers.⁷⁸

The current situation in relation to dementia support and care

As the population in Scotland ages, this will be reflected in increasing use of the acute care setting (general hospitals and accident and emergency departments) by people with dementia, who are at an increased risk of physical health problems. Research has shown that 50% of people over 70 admitted to general hospitals as an emergency have some cognitive impairment. Additionally, it is estimated that people with dementia over 65 years of age are currently occupying up to 25% of hospital beds at any time. In Scotland, up to 30% of all people admitted to medical wards are described as having significant memory problems but, of this group, only 30% will have a diagnosis of dementia. Many older people admitted to general hospital will have symptoms but no formal diagnosis of dementia. Around 70% of people living in care homes have varying degrees and types of dementia.¹¹¹²
Figures such as these indicate that the likelihood of health and social care staff coming into contact or working directly with people with dementia and their families and carers was never greater and is likely to increase in future. This together with recently identified issues around dementia support and care within hospitals, care homes and in the community suggests that considerable development in the knowledge and skills of the health and social care workforce in relation to dementia support and care is essential.\textsuperscript{13 14 15 16}

**Aspirations for the future of dementia support and care in Scotland**

Scotland’s National Dementia Strategy promotes a new approach to dementia support and care which aims to shift engagement with people with dementia away from service led provision towards an outcomes focused approach with an emphasis on living well with a diagnosis of dementia. This promotes the view that people can live well with dementia if they receive the right support, build on their own personal resources, natural support systems and wider community based resources, and are empowered not to see dementia exclusively in terms of deficits. This approach is consistent with national policy priorities which seek to engage people using services through personalisation, enablement and an assets approach to health.\textsuperscript{17 18 19}

In supporting the implementation of the strategy the Scottish Government charged The Mental Welfare Commission to develop *Standards of Care for Dementia in Scotland: Action to support the change programme, Scotland’s National Dementia Strategy*.\textsuperscript{20}

The standards were developed to help all people with dementia and their families and carers understand their rights and how to ensure that they receive the support they need to stay well, safe and listened to. They apply to people living in their own homes, care homes or hospitals, especially general hospitals. Alongside the standards, NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC) 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.\textsuperscript{21}

The standards should be used in conjunction with Promoting Excellence in order to ensure continuous improvement in dementia support and care. If the ambitions of Scotland’s National Dementia Strategy are to be realised it is critical that Higher Education Institutions and other education providers afford opportunities for current and future health and social services staff to develop the knowledge and skills described in the framework. By using the framework to inform the content of the vocational and professional undergraduate and post graduate education and training, education providers can support future health and social services staff to make an informed and positive contribution when supporting people with a diagnosis of Dementia and their families and carers.

Promoting Excellence is structured to reflect levels of knowledge, skills and behaviours specific to the worker’s role in relation to dementia.

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.

Promoting Excellence p7
Within the framework it is recognised that the knowledge and skills and behaviour of staff may need to be adapted or changed to reflect where the person with dementia and their families and carers are in their dementia journey.

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.
Core Curricular Content

It is recognised that many elements of the knowledge and skills outlined in the *Promoting Excellence* knowledge and skills framework may already be incorporated generically into health and/or social services training and education courses and therefore it will be possible to embed them into existing learning. What is important is that these generic elements are recognised as being equally applicable to people with dementia as to any other health and social service users.

In reflecting current demographic trends, of equal relevance for undergraduate and postgraduate health and social services professionals’ educational preparation, is the specific dementia related knowledge described in the framework. These have been grouped within these guidelines to reflect domains of core curricular content which may be applicable at all, or any stage of the person’s dementia journey. It is hoped that this along with the listed resources will assist educators in designing programmes, courses, modules and classes for students preparing for a future career within health and social services.

Dementia Informed Practice Level

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.

This level requires a basic generalised knowledge and understanding about dementia, and its impact on the lives of people with dementia and their families and carers.

A DVD called Informed about *Dementia - Improving Practice* has been produced to support students and staff who require the knowledge and skills described in *Promoting Excellence* for the ‘Dementia Informed Practice Level’. The knowledge and skills demonstrated in this DVD can be used to inform students and staff how to respond in practical situations and circumstances. Content includes recognition of the impact of dementia, person centred support, communication, risk enablement, responding to stress and distress and support for people with dementia to maintain their quality of life throughout their journey.
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.

A specific learning resource - Dementia Skilled Improving Practice has been developed to help staff and students develop skills to support people with dementia, their families and carers. In addition to this other useful resources to support the knowledge and skills that health and social care staff will require have been grouped to reflect domains of core curricular content. These domains are grouped below, with a description of what students should know and understand for each domain, and a link to key learning resources to help develop this knowledge and understanding.

Students would be expected to have the knowledge and skills described in Promoting Excellence for the ‘Dementia Informed Practice Level’.

Guidance for Scottish Vocational Qualification (SVQ) assessors, other educators, trainers and operational managers to accompany Dementia Skilled Improving Practice is also available here.

Understanding Dementia

Students should have a sound understanding of the signs and symptoms commonly associated with different types of dementia. They should understand that dementia is a progressive condition that can have a variety of underlying causes. Additionally, students should be aware of the importance of an early diagnosis and be able to recognise the different stages of the dementia journey and the different ways that people with dementia and their families and carers will experience this.

Students should understand that fundamental to a person centred approach to dementia are the concepts of equality, diversity and inclusion and should be able to recognise the diversity of people who are affected by the condition.

They should be able to recognise the impact of dementia on the person’s communication skills and the importance of their own communication skills in supporting the person with dementia and their families and carers. Students should also be able to reflect on the range of influences on the health and well-being of the person with a diagnosis of dementia and how a diagnosis can impact on the person and their family and carers:

- stages of the dementia journey
- importance of keeping well and having a healthy lifestyle
- common signs, symptoms and causes of dementia
- depression and delirium

- diversity of people with dementia
- progression of the condition
- the impact of finding out its dementia for people with dementia and their families and carers
- communication and dementia
- impact of dementia on physical, emotional and psychological health and wellbeing.

Supporting Information for the Understanding Dementia domain.
Promoting person-centred outcomes for people with dementia and their families and carers

Students should understand person-centred approaches to dementia which recognise and utilise the individual’s strengths and abilities to enhance quality of life. They should recognise that individuals have unique values, personal history and personality and that each person with dementia has an equal right to dignity, respect, and to participate fully in their environment. Students should understand outcomes based approaches that emphasise the strengths, capacity and resilience of individuals, builds upon their natural support systems and wider community based resources. They should understand partnership approaches to working with people with dementia and their families and carers through personalisation, enablement and an assets approach to health and wellbeing. Students should know how a range of approaches and services can promote independence and a positive quality of life for people with dementia:

- socially inclusive approaches to dementia
- quality of life outcomes for people with dementia and their families
- recognising that people with dementia have rights
- person centred practice in working with people with dementia
- recognising and building on the strengths and abilities of the person with dementia
- personalisation and self-directed support to promote independent living
- the use of tele-healthcare to promote independent living
- the use of assistive and innovative technology to promote independent living.

Supporting information for the Promoting person centred outcomes for people with dementia and their families and carers domain.

Physical, psychological and emotional wellbeing of people with dementia

Students should understand the potential health and well-being opportunities and risks for people with dementia and the importance of remaining as fit and healthy as possible for people with dementia and their families and carers. They should know the factors that can influence health and well-being, including the negative and positive outcomes of hospitalisation, care at home or long term care. Students should understand the importance of developing person centred practice which recognises pain and responds appropriately to behavioural distress. Moreover, students should understand the concept of the anticipatory care planning approach to palliative care and it’s application to care for people with dementia:

- range of approaches across the dementia journey to maintaining health and wellbeing
- approaches to working with individuals with dementia
- specific health conditions associated with dementia
- recognising and responding to pain and behavioural distress
- slips, trips and falls and falls prevention
- anticipatory care planning and risk enablement
- palliative care approaches.

Supporting Information for the Physical, psychological and emotional wellbeing of people with dementia domain.
Legislation, policy, rights, and protection

Students should have a broad understanding of current key legislation, policies and procedures relating to working with people with dementia. They should be aware of the importance and implications of implementing local safeguarding policy and procedure. Students should be familiar with concepts of balancing risk and risk enablement and have understanding of the categories of harm and abuse and of the actions required to support the safety and well-being of people with dementia and their families and carers:

- principles and key provisions of relevant policy and legislation
- supporting rights and choices
- categories of risk
- signs and symptoms of neglect, harm or abuse
- adult safeguarding and protection procedures
- risk assessment and enablement strategies
- equality issues for people with dementia.

Supporting resources for the Legislation, policy, rights, and protection domain

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<td>Dementia Care Standards 2011</td>
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<td>Charter of rights for people with dementia 2009</td>
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Valued lives, relationships and community connections

Students should understand the importance of personal and community supports and networks that are available to people with dementia. They should understand the role of activity and engagement in promoting independence and in all aspects of a person with dementia’s quality of life.

Students should understand the benefits and challenges for the person with dementia of continuing to be actively involved in community life. Furthermore, they should understand the value and processes involved in Life Story Work for people with dementia and their families and carers:

- Support networks and therapeutic connections
- Strengths based approaches to maintaining and developing skills, roles and relationships
- The role of activities in promoting independence
- Spirituality, sexuality and cultural needs
- Active engagement in community life
- Range of approaches to environmental challenges for people with dementia
- Life story work.

Supporting Resources for the Valued lives, relationships and community connections domain

Supports and services for managing change

Students should recognise the value of local professional, specialist and community services available for people with dementia and their families and carers. Additionally, they should understand their own role in the provision of information and signposting to these supports. Students should also recognise the range of treatments and therapeutic interventions that can enhance quality of life for people with dementia at different stages of their journey. Students should also understand their own role in supporting carers and friends of people with dementia:

- cognitive stimulation, multi-sensory and therapeutic activities
- range of community services and supports
- accessing counselling and professional therapeutic support
- memory support methods and approaches
- support role of families, carers and friends
- peer and group support

Supporting resources for Supports and services for managing change domain
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 following section describes the core curricular content at ‘Enhanced Dementia Practice Level’. Links to appropriate, quality assured and relevant resources are provided at the end of each domain. These resources are recommended in addition to those for the ‘Dementia Skilled Practice Level’.

Students and staff would be expected to already demonstrate a broad and integrated knowledge and a critical understanding of the core curricular content described in Promoting Excellence for the ‘Enhanced Dementia Practice Level’ in addition to those aspects covered within the ‘Dementia Skilled Practice Level’.

Understanding Dementia

Students should have a sophisticated knowledge and understanding of bio-psychosocial perspectives of dementia and how these can inform support and care for people with dementia and their families and carers across the dementia journey. Additionally students should recognise how these perspectives can impact on the lived experience of people with dementia and their families and carers and influence their own approach to practice:

Biomedical perspectives
- demography, prevalence and incidence
- genetics, economics, pathology
- treatment options including pharmacology - overview
- limitations of the medical model

Psychological Perspectives
- personhood and person centred perspectives
- concepts of self
- asset based approaches

Social Perspective
- discrimination, stereotypes and stigma
- discourses around social inclusion and exclusion
- social disability model
- cultural influences

Supporting Information for the Understanding Dementia domain

Promoting person-centred outcomes for people with dementia and their families and carers

Students should have a broad and integrated knowledge of socially inclusive approaches to dementia. They should also demonstrate critical understanding of the principles, techniques, policy and guidance available to support person centred practice. Additionally, students should be able to apply this knowledge to support people with dementia and their families and carers, to achieve their desired outcomes throughout their journey.

Students should recognise that person centred care is a holistic philosophy across the continuum of services which takes into account the specific needs of each person. They should value and incorporate into practice the unique experiences, needs and strengths of the person with dementia and their families and carers.

Students should understand that the ultimate goal of person centred care is to create partnerships with people with dementia and their families and carers and other services and supports that will lead to the best outcomes and enhance the quality of life and the quality of care for people with dementia:

- Quality of life domains
- Users perceptions of quality of life
- The lived experience of dementia
- Supporting others in the implementation of person centred principles and practice
- Barriers to accessing services and supports
- Service models and indicators of good practice
• Implementation of policy, guidance and practices that can enhance person centred care and independent living at all stages of the dementia journey:
  – personalisation
  – self-directed care
  – co-production
  – person centred planning
  – telecare, assistive and innovative technology
  – advance planning
  – advance decisions, choice and dying well

Supporting information for the Promoting person centred outcomes for people with dementia and their families and carers domain

Physical, psychological and emotional wellbeing of people with dementia

Students should recognise the importance of quality interactions with health and social care services and their impact on the experiences of people with dementia and their families and carers at all stages of their journey. They should understand their own role in promoting and supporting physical, psychological and emotional health and wellbeing.

Students should have a detailed knowledge and understanding of a range of assessment and therapeutic interventions for people with dementia. Additionally they should be able to apply their knowledge and skills in communication to ensure that complex, stressful or traumatic situations are addressed with sensitivity and empathy:

Assessment
  • objective of assessment
  • collaborative approaches to assessment
  • single shared assessment
  • person centred approaches to assessment
  • impact of social and cultural influences on assessment
  • timely diagnosis
  • strengths based approaches to assessment of physical, psychological and emotional health needs
  • assessment of environmental impact

Interventions
  • dementia specific psychometric, age appropriate, psychological and physical health assessments
  • evidence based screening tools to assess cognition, memory, orientation, verbal and perceptual skills
  • range of assessment tools to support good nutrition, skin care, continence and pain management

  • treatment of depression and delirium.
  • early intervention
  • anticipatory care planning
  • collaborative and integrated approaches to intervention
  • health promotion and self management approaches to physical, psychological and emotional health and wellbeing
  • impact of hospitalisation
  • pharmacological interventions and treatment
  • national and local guidance on medication relevant to people with dementia.
  • poly-pharmacy and covert medication
  • evidence based psychological interventions and therapies for people with dementia and their families and carers
  • psychological and psychosocial skills
  • interventions regarding environmental influences on health and wellbeing
Behavioral Distress (formerly known as challenging behaviour)

- common types, causes and triggers for distressed behaviour
- complex behavioural changes that can indicate that people with dementia are distressed
- range of psychological, psychosocial and environmental interventions which can ease behavioural distress

Anticipatory care planning and wider approaches to palliative care

- advance planning
- supporting people with dementia in making decisions about interventions for health, wellbeing, present and future
- the complexity associated with the progression of dementia and the signs and symptoms associated with end of life
- current best practice guidance, frameworks, standards, legislation, policy and tools to support palliative care, end of life care and death
- implementation of advance planning
- the psychological and emotional effects of dying which can affect a person with dementia and their family and carers
- spiritual support and end of life care
- bereavement support for carers

Supporting Information for the Physical, psychological and emotional wellbeing of people with dementia domain

Legislation, policy, rights, and protection

Students should have a critical understanding of relevant current key legislation policies and procedures relating to working with people with dementia. They should be able to apply and/or contribute to the implementation of relevant legislative provisions, national and local policy and procedure in relation to promoting rights choices for people with dementia and safeguarding their wellbeing. Additionally, students should understand the importance of working in partnership with other professionals and with people with dementia and their carers in ensuring that people’s rights and safety are paramount. Students should be able to critically analyse and evaluate the relationship between concepts of risk and risk enablement. Students should also be able to articulate all these concepts to a range of audiences, including people with dementia and their families and carers:

- principles and key provisions of relevant policy and legislation
- informed consent and confidentiality.
- power of attorney, guardianship and advocacy
- implications and actions where no power of attorney is appointed
- principles of determining capacity in any given situation
- advance planning, advance directives, personal statements, living wills
- implications of refusal of treatment

Supporting resources for the Legislation, policy, rights, and protection domain

Valued lives, relationships and community connections

Students should be able to actively apply the knowledge and skills relating to this domain at Dementia Skilled Practice Level. They should be able to utilise and implement practices that support people with dementia to maintain valued lives, relationships and community connections at all stages of their journey. Additionally, students should be able to critically analyse and evaluate complex situations in order to assess levels of support and provide appropriate interventions. Students should also understand the importance of working in partnership with other staff involved in the provision of health and social care, other community supports and networks and people with dementia and their families and carers, in order to facilitate the maintenance and/or development of supportive networks and connections:

- assistive and innovative technology
- life story work
- risk enablement
- risk assessment and management
- environmental adaptations

Supporting Resources for the Valued lives, relationships and community connections domain
Supports and services for managing change

Building on the knowledge and skills described at Dementia Skilled Practice Level students should recognise the value of integrated and streamlined approaches to care and support at all stages of the dementia journey. They should be able to operate in a way that utilises partnership approaches, involving the person with dementia and their families and carers and other health and social care professionals. Where referral to other services and supports is required they should understand the relevance of knowing and utilising a range of specialists and services within their own or partner organisations and within the wider community. Students should also recognise the value of carer and family supports for people with dementia and the importance of information, assessment and support for their health and well being:

- integrated working practices
- referral mechanisms
- community and service assets mapping
- peer support and support groups- principles and practice
- accessible information
- carer assessment

Supporting resources for Supports and services for managing change domain
Expertise in Dementia Practice Level

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.

Staff undertaking learning programmes at ‘Expertise in Dementia Practice Level’ would be expected to demonstrate extensive and detailed knowledge and understanding of dementia.

Programmes designed to meet the knowledge, skills and behaviours described at this level will focus on specific elements of dementia support and care. Consequently, they will be specialised in nature and therefore out with the scope of this guidance.
The listed resources and links are not exhaustive and have been gathered from international sources and as such may refer to some concepts and legislation directly pertinent to their own national context. It is important, therefore, that they are used in relation to the current Scottish context.

Information correct at October 2011.

Further resources are available on the Dementia Managed Knowledge Network and on the NES website.

10. Goldberg S E; Whittamore K H; Harwood R H; Bradshaw L E; Gladman J R F; Jones R G; The prevalence of mental health problems among older adults admitted as an emergency to a general hospital. Age and Ageing 2011