

Good Work

A Dementia Learning and Development Framework for Wales

People are often unreasonable, irrational, and self-centered.

Forgive them anyway

If you are kind, people may accuse you of selfish, ulterior motives.

Be kind anyway

If you are successful, you will win some
unfaithful friends and some genuine enemies.

Succeed anyway

If you are honest and sincere people may deceive you.

Be honest and sincere anyway

What you spend years creating, others could destroy overnight.

Create anyway

If you find serenity and happiness, some may be jealous.

Be happy anyway

The good you do today, will often be forgotten.

Do good anyway

Give the best you have,
and it will never be enough.

Give your best anyway

Mother Theresa

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Introduction

Welsh Government and the NHS in Wales are committed to improving the health and well-being of everyone living in Wales. Dementia is not exclusively a condition that affects older people, although there is a strong link between older age and a diagnosis of dementia. As life expectancy increases, there will naturally be more older people and so more people with dementia. As a consequence, there is a growing need for the health and social care workforce to understand the issues involved in good dementia care and support. All workers need a solid awareness of dementia and the issues surrounding it to ensure that their approach supports people with dementia and carers to live well.

We also need to extend our thinking beyond just the health and social care workforce. Carers and other members of the community play a pivotal role in enhancing the well-being of people with dementia. The term 'carer' is used throughout this document and refers to people who provide unpaid care and / or support and could include family members, partners, neighbours or friends'. In 2015 there were estimated to be more than 370,000 carers in Wales, and Welsh Government is committed to improving the lives of carers of all ages (Welsh Government, 2015).

There are a number of initiatives across Wales being delivered by a range of education and training providers, including a large amount of in-house staff development; some being delivered through the third sector. All of the principles and learning and development topics outlined within the Framework are being applied in practice **somewhere** in Wales but this is not consistent, with pockets of good practice across Wales and elsewhere. We need to learn and build on this to spread the good practice everywhere. The Framework recognises that everyone is on a different journey in developing support for people with dementia and carers. However, the hope is that the Framework will enable their direction of travel to be consistent.

Policy context

Welsh Government is committed to providing support to people with dementia, carers and families. The *Social Services and Well-being (Wales) Act 2014* (*the Act*) provides overarching legislation that places co-production at the centre of the development and delivery of health and social care services across Wales. **Everyone**, adult or child, has a right to be heard as an individual; as a citizen, in shaping the decisions that affect them, and to exercise greater control over their day-to-day lives. Other principles that are central to the Act include the concept of helping people to maximise their own well-being, prevention and early intervention.

This parallels the approach to prudent healthcare (Public Health Wales, 2014) which NHS Wales is embracing, with its focus on achieving health and well-being with the public, patients and professionals as equal partners through co-production; caring for those with the greatest health need first, making the most effective use of all skills and resources; doing only what is needed and doing no harm, no more, no less; and reducing inappropriate variation using evidence-based practices consistently and transparently.

The National Dementia Vision for Wales (Welsh Government, 2011) highlights the support and advice recommended to anyone diagnosed with dementia. In April 2015, Professor Mark Drakeford, the Minister for Health and Social Services announced his priorities for dementia care in the year ahead and the steps that should be taken to support each of these:

- **Dementia risk reduction** - the revised *Dementia: Reduce your risk in 6 steps* guidance (Welsh Government, 2015c) sets out the lifestyle choices people can take to lessen the risk of developing dementia.
- **Dementia diagnosis rates** - taking action to improve dementia diagnosis rates in Wales, including extra training and support for the primary care and care home workforce.
- **Post-diagnostic support** - funding new support workers across Wales to help those who have received a dementia diagnosis.
- **Care in general hospital settings** - supporting the NHS Wales workforce to ensure they have the knowledge, skills and values they need to provide the best care and support for patients with dementia.

Recommendations have been identified within a number of reports published in Wales, for example *Trusted to Care* (Andrews and Butler, 2015) and *Learning from Trusted to Care* (Welsh Government, 2015). These reports, and the national audits of dementia undertaken by the Royal College of Psychiatrists in 2010 and 2012 cite a lack of dementia education and training as a key issue influencing standards of dementia care in Wales. These are reflected in the delivery plans that underpin *Together for Mental Health: A Strategy for Mental Health and Wellbeing in Wales* (Welsh Government, 2012).

Wales has strong systems in place to ensure quality and safety. Delivering Safe Care, Compassionate Care (Welsh Government, 2013) sets out the expectations that all services should be person centred and driven by their needs. This has committed Wales to ensure high quality, safe care whenever and wherever it is provided by:

- doing the right things well;
- knowing how well we are doing;
- being open and honest in all that we do;
- showing care, compassion and commitment;
- leading by example.

The Welsh Government Quality Delivery Plan for the NHS in Wales (2012 – 2016) (Welsh Government 2012a) sets out the clear vision for a quality-driven NHS Wales to achieve the triple aim of:

- providing the highest possible quality care and excellent experience;
- improving health outcomes and helping reduce inequalities;
- getting high value from all our services.

The Health and Care Standards (Welsh Government, 2015a) form the cornerstone of the overall quality assurance system within the NHS in Wales. Alongside the Framework for Assuring Service User Experience 2015 (Welsh Government, 2015b) it will help to ensure that people have positive first and lasting impressions, that they receive care in safe, supportive and healing environments, and that they understand and are involved in their care.

Access to services through the medium of Welsh is crucial to be able to deliver person-centred care and support for people living with dementia and carers whose first language is Welsh. This is supported by Welsh Government's commitment described in the *More than Just Words: Strategic Framework for Welsh Language Services in Health, Social Services and Social Care* (Welsh Government, 2012b), which requires that services can be delivered in Welsh without someone having to ask for it.

This comprehensive framework to support dementia learning and development across health and social care services, is built upon all of these foundational policy imperatives.



Vision for this Framework

This Framework is intended to support **what matters most** to the people of Wales as well as the spirit and requirements of Welsh policy, legislation and guidance regarding the care, support and empowerment of people with dementia, carers and the health and social care workforce.

Within Wales, our cultural and policy commitments to mutuality and solidarity requires us to consider the learning and development needs of everyone who is affected in some way by dementia. This includes people with dementia, carers, frontline staff, managers, commissioners, regulators, researchers, shopkeepers, next door neighbours... and so the list continues. This is an ambitious vision, but one that is required if we are to respond as effectively as possible, to the growing challenges that dementia poses to all of us. However, within these challenges lie opportunities to enable people with dementia to live as good a life as is possible, and to support carers and the health and social care workforce.

Person-centred care is at the heart of the vision and refers to ways of being and working that are focused on the intrinsic value, independence and well-being of individuals. It also recognises that meaningful relationships are as important as choice and control, which requires collaborative, relational and responsive ways of working (Patterson et al, 2011).

Who is this framework for and how to use it?

Whilst much of the content of this framework is aimed at the health and social care workforce, it is also intended to support people with dementia, carers and anyone who may come into contact with people with dementia. This is because quality of life for people with dementia and carers is influenced by a much wider range of people than just the health and social care workforce.

Overall, the aim of the Framework is to support people to freely, creatively and responsibly identify and address their own specific learning and development needs within the context of their lives and circumstances, wherever they happen to be.

The intention of the Framework is not to constrain people by providing an overly prescriptive list of who needs to know and do what. However, it does identify three broad groups of people; those who are **Informed**, those who are **Skilled** and those who are **Influencers**.

- | | |
|-----------------------|---|
| Chapter 1 | outlines some important underpinning values, which provide a foundation upon which everything else is built. |
| Chapter 2 | describes what is meant by the terms Informed, Skilled and Influencer. It also provides a summary of key learning and development topics and associated outcomes for Informed and Skilled people. |
| Chapter 3 | focuses on developing and sustaining organisational culture and systemic support that enables Informed and Skilled people to flourish and give their best. It also provides a summary of key learning and development topics and associated outcomes for Influencers. |
| The Appendices | provide links to resources and other associated support and guidance. |

Regarding health and social care service and workforce development, the Framework can be used to inform:

- The development of recognised qualifications;
- The development of recognised modules of training that respond to specific elements of this framework;
- The involvement of people with dementia, carers, families and the wider community;
- Continuing Professional Development (CPD) programmes;
- Recruitment processes;
- Appraisal and supervision systems;
- Feedback systems such as 360-degree review;
- Individual and group development processes such as Action Learning;
- Programmes of organisational development;
- Collaborative and partnership working.

All the activities above can also be applied to other parts of the system that impact on the lives of people with dementia and carers, including commissioners and regulators.



The Framework can also be used by people with dementia, carers and other significant people. In particular it can assist them to:

- Know their rights;
- Know what good care, support and services should look like;
- Be able to evaluate the quality of any care and support they receive;
- Know how they can contribute to the design and delivery of good care and support and understand the pivotal role they can play in this.

Finally, the wider community can also benefit from this Framework, firstly by engaging with and responding to the Informed person section, and secondly as a consequence of the Framework being applied by the health and social care workforce, for example in being more proactive in working with carers, families and communities.

What is dementia?

The Alzheimer's Society estimate that there are over 45,000 people with dementia in Wales and describe dementia as:

'A set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language. These changes are often small to start with, but for someone with dementia they have become severe enough to affect daily life. A person with dementia may also experience changes in their mood or behaviour.'

Dementia is caused when the brain is damaged by diseases, such as Alzheimer's disease or a series of strokes. Alzheimer's disease is the most common cause of dementia but not all dementia is due to Alzheimer's. The specific symptoms that someone with dementia experiences will depend on the parts of the brain that are damaged and the disease that is causing the dementia' (Alzheimer's Society).

However, whilst dementia is clearly a medical condition, people's **experience** of dementia varies widely. A well-used phrase coined by Tom Kitwood is 'when you have met **one** person with dementia, you have met **one** person with dementia'. In his book *Dementia Reconsidered* (Kitwood, 2007), he suggests that a person's experience of dementia depends on five things:

- Their neurological impairment.
- Their physical and mental health and medicines.
- Their biography (life story).
- Their personality.
- The way they are perceived and treated by others, i.e. social psychology.

This understanding of the need to focus on the **experience** of people with dementia and not just the disease, is at the heart of this learning and development framework. Whilst it is important to understand a person's neurological impairment and its effects, it is equally important to take into account and respond to their physical and mental health needs, their biography and personality. Most importantly, we also need to focus on how we perceive and treat people with dementia, because this is the thing over which we have the greatest control. The **approach** we take in the care and support of people with dementia and carers will play a vital role in either building or undermining their sense of well-being.



'Good work' - an introduction

The concept of 'good work' has developed out of the positive psychology movement, with a focus on meaning and purpose; building on strengths rather than pointing out deficits. Appreciative Inquiry (Cooperrider et al, 2003) is a practical methodology that can be used to promote this and is very much in tune with the spirit of the *Social Services and Well-being (Wales) Act 2014*. This suggests bringing out the best in everyone by focusing on their strengths and what matters to them in terms of promoting their well-being. Another key element in Welsh culture, social policy and legislation is recognition of the importance of mutuality and solidarity, where individual well-being cannot be separated out from the well-being of others. Research and practice development regarding 'good work' suggests three key elements, which have been chosen to underpin this framework. These resonate with what we know about how to bring out the best in people, often in complex, changing and difficult circumstances. The three elements are:

- Ethics – values based and getting to the heart of 'what matters' (**compassionate** practice)
- Excellence – technically competent and 'fit for purpose' (**competent** practice)
- Engagement – personally engaging and contextualised (**wise** practice)

These three elements apply not only to paid work, but also to a broader conceptualisation of work that includes volunteering and other ways of bringing benefit to others through what you do. This is consistent with what Edgar Cahn (2000) calls the 'core economy', and includes small acts of kindness which are such an important aspect of our common humanity.



Chapter 1: Ethics to support compassionate practice

Ethics and values form the cornerstone for this learning and development framework, and are fundamental in supporting **compassionate** practice. This framework suggests 5 key ethical considerations:

- Everyone matters.
- Everyone has something to contribute.
- Everyone is different.
- Everything matters and the 'normal' and the 'ordinary' are important.
- Every word matters - we must use positive and strengths-based terminology in supporting people with dementia.

The above are articulated within a range of codes of practice across health and social care in Wales.

1.1 Everyone matters and has a right to experience well-being

At the heart of this framework is recognition that **everyone** matters and that individual well-being is inherently linked to the well-being of others. Research and practice development in health and social care has identified the concept of 'enriched environments of learning and practice' (Nolan, et al 2006), within which people accessing services, carers and staff (practitioners and managers) **all** experience a sense of:

- **Security** – to feel safe and secure, not just physically but also psychologically
- **Continuity** – to feel that what we are doing in the present has links with our past
- **Belonging** – to feel 'part of things', maintaining existing relationships and forming new ones
- **Purpose** – to have valued goals to aim for and a feeling of 'I have a contribution to make'
- **Achievement** – being able to achieve goals and to feel satisfied with your efforts
- **Significance** – to feel that you 'matter', that your life has importance, and that other people recognise and value who you are.

Experiencing well-being is a **right** rather than an aspiration for everyone. This being the case, these six senses can be mapped against the Welsh Declaration of Human Rights for Older People (Welsh Government, 2014):

Sense of:	Declaration of Rights for Older People in Wales
Security	I have a right to safety, security and justice
Continuity	I have a right to be who I am
Belonging	I have the right to decide where I live, how I live and with whom I live
Purpose	I have freewill and the right to make decisions about my life
Achievement	I have the right to work, develop, participate and contribute
Significance	I have the right to be valued

It does not take much of a stretch of the imagination to think of a similar charter of rights for carers and staff (practitioners and managers), who can feel equally disempowered by some systems that control or exclude them or do not value what matters to them (Patterson et al, 2011). This can also relate to training that attempts to change people's values and attitudes. If strategies for training, development and improvement do not truly 'engage' and resonate with each learner, they may remain unchanged in terms of how they think, what they believe and hence, how they behave (Horton and Freire, 1990). This is one of the biggest challenges for many services and for those in a leadership role; changing people's hearts, minds and behaviours. These changes do not always need to be significant; it is often the small things in terms of how people behave that make the most difference.

This framework suggests an interdependent approach to well-being, which ensures that **everyone** is included:



The recognition of interdependence and the rights of **all**, requires us to understand the need for **negotiation** and **compromise**, words which do not sit comfortably with an individualistic and consumerist approach to care and support. However, these words lie at the heart of our understanding of community and family relationships. When these things are in place they contribute to developing mutual honesty and trust between people and this leads to effective collaborative working.

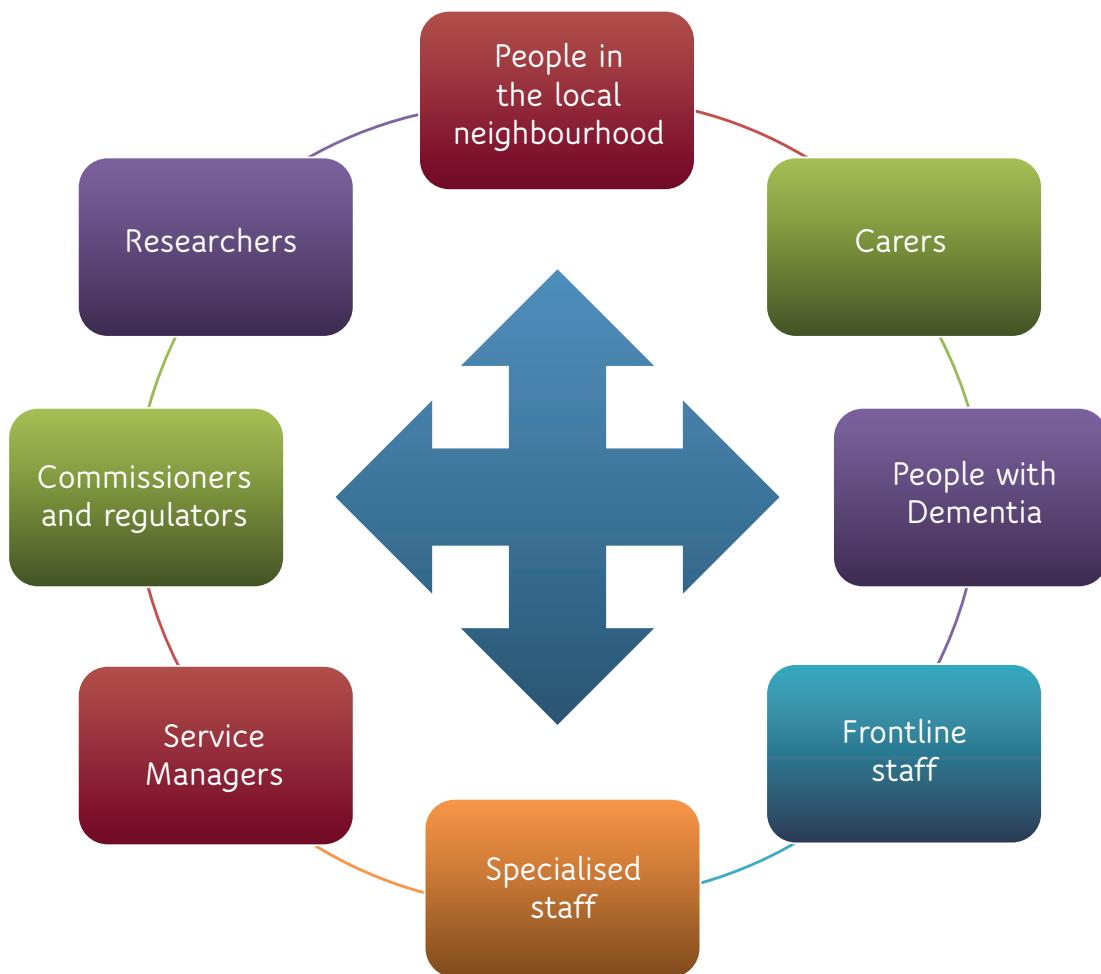
1.2 Everyone has something to contribute

Some learning and development frameworks are hierarchical, and imply that the people who matter most lie towards the top of the scale. They are usually highly qualified professionals and are rarely the person with dementia or a carer. Whilst recognising that knowledge progression can be a good thing, there is a danger that this can lead to an undervaluing of the **lived experience** of people with dementia, carers and frontline staff. Comments such as "I am **only** a care assistant" reflect this. This fails to recognise the fundamental importance and value of frontline practice, where tacit knowledge built up over years of experience can enable some staff to do the right thing, at the right time, for the right person, in the right way.

Such expertise is just as valuable as specialist knowledge, for example in assessment or service management. This is why the recruitment process is so important; identifying those people who have developed this learning and understanding, or who have the potential to grow and develop in line with the concepts and thinking expressed in this framework. This also links with concepts of Value Based Recruitment (Health Education England, 2014) which seeks to focus on the values of applicants rather than just their qualifications and experience.

This is also why carers and other significant people in the life of people with dementia need to be valued in terms of their experience and learning. In addition, the *Social Services and Well-being (Wales) Act 2014* enshrines the right of carers to have their own assessment so they can be provided with, or enabled to develop, their own support systems. This in turn means that they can give of their best alongside others, including the health and social care workforce.

This framework therefore suggests a **complementary** model of expertise, as indicated in the following diagram – each of these groups has something special to contribute. ‘Living well with dementia’ can only be realised when the expertise of each group is shared in what Smale et al (1993) would call an ‘exchange model’ of assessment, care and support planning.



1.3 Everyone is different

The old saying 'do unto others as you would have them do unto you' can be misapplied when taken literally, as we all have unique needs, interests and preferences. This is the reason why the promotion of person-centred approaches has been at the heart of previous and current strategies across social care and health. However, how people have applied this approach in terms of delivering training and direct work with individuals has not always been maximised.

Policies and procedures, for example in relation to dignified care, professional boundaries and risk management are designed to support creative and contextual decision making that acknowledges difference; not standardised responses.

1.4 Everything matters and the normal and the ordinary are important

The Joseph Rowntree Foundation (JRF) research programme *A Better Life* (Blood, 2013), identified how important it is for older people with high support needs to feel **normal** and no different to anyone else. Essentially they want a life on equal terms. The programme also identified the importance of the ordinary; often little things in the promotion of their well-being. However, the research suggested that this is something that services need to improve on – the **ordinary** is important and need not cost the earth!

'Often it is the simple things that bring the most pleasure (and the lack of them can bring a sense of sadness and loss) and services do not always seem to be very good at delivering 'the ordinary'. (Blood, 2013 p.13).

1.5 Every word matters - we must use positive and strengths based terminology in supporting people with dementia

Language, the system of words or signs that people use to express thoughts and feelings to each other is fundamental in shaping who we are and how we perceive other people.

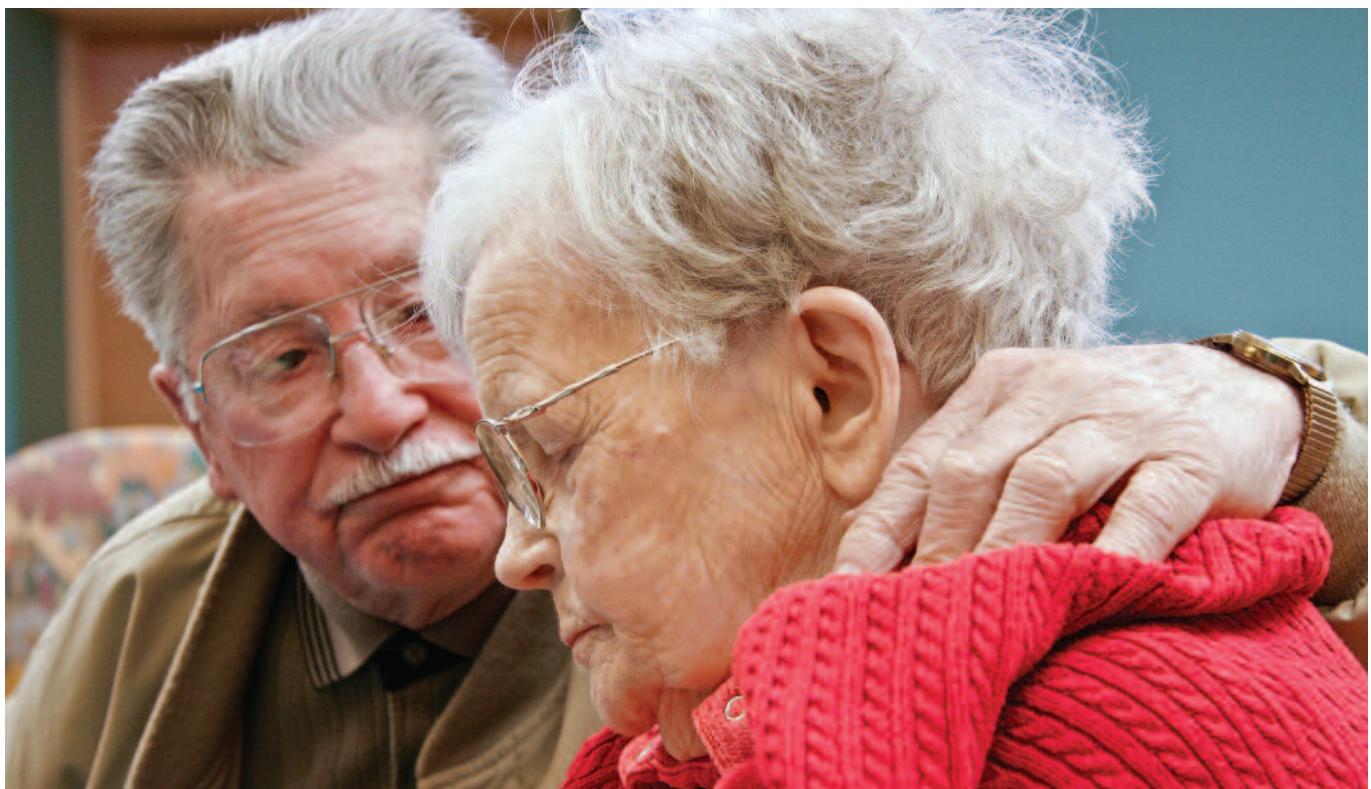
Across the UK, the terminology used in dementia care is often couched in terms of deficit and loss. For example, the 'elderly mentally infirm', 'sufferers', 'wanderers' people who are 'damaged' etc. Whilst dementia can have a devastating effect on people which must be acknowledged, it is also important to develop strengths based approaches to supporting people with dementia and carers. For this to happen, we need to use positive and strengths based terminology.

For example:

Negative and deficit based terminology	Positive and strengths based terminology
The frail elderly	Older people with high support needs
Elderly Mentally Infirm (EMI)	People with dementia
People suffering with dementia	People living with dementia
People afflicted by dementia	
Wandering	Walking
Dements	People with dementia
Feeders	People who need help with eating
36 (i.e. naming a care home resident by their room number)	Never a number!
Senile	Old
Not there	Still here
An empty shell	A person

1.6 Code of professional practice

The *Code of Professional Practice for Social Care* and the relevant codes of practice for health professions reflect the principles outlined above. These codes are fundamental, as they specify the expected standards and behaviours of all employees and professional groups. They clarify the positive essential elements of ethical, competent and effective practice.



Chapter 2: Excellence – to support *competent* practice

2.1 Taking an outcomes focus

Competence in supporting people with dementia and their carers requires a wide range of knowledge and skills tailored to the particular role of the person concerned. Each person within the system (see circle diagram on page 14) must bring their knowledge and skills to bear in promoting the well-being of people with dementia, carers and the people who support them. At the same time, they always need be checking out this understanding with other people in order to obtain a rounded view that values everyone's perspective and experience. Sometimes this may involve professionals (and others) re-evaluating their beliefs and perspectives. This may simply involve sometimes saying "I was wrong about that" and going on to listen and hear what the person is saying in order to fully understand their perspectives and views.

A key element in the promotion and evaluation of well-being within Welsh social policy is taking an outcome focused approach to practice, prioritising **what matters** to the people of Wales and **making a positive difference**, rather than just what we should know and do. Within this Framework we have mapped learning and development needs against the themes outlined in the *National Well-being Statement* (<http://gov.wales/docs/dhss/publications/150629wellbeingen.pdf>).



The *National Well-being Outcomes Framework* and the *NHS Outcomes and Delivery Framework* build on this Statement and will help drive the continual improvement in the health and wellbeing of the people of Wales.

This chapter sets out six learning and development topics under each of the eight well-being themes within the National Well-being Statement, making a total of 48 topics. It will be obvious to the reader that many of the topics relate to more than one theme, but our hope is that by structuring the chapter in this way, the primary focus will be on knowing and achieving the outcomes that people in Wales have identified as being important to them. This is underpinned by the need for people to receive support in the language of their choice, as set out in *More than Just Words: Strategic Framework for Welsh Language Services in Health, Social Services and Social Care* (Welsh Government, 2012).

Assumptions cannot be made about what people are able to achieve and one of the key messages in this framework is the need to know and understand the person in order that creative and responsive support strategies can be put in place.

2.2 Knowledge and skills

For the purpose of this Framework, we think it is helpful to identify three broad groups of people; Informed, Skilled and Influencer, on the understanding that each group could include people with dementia, carers, staff and others

Informed people

Informed people understand what dementia is and how it affects a person with dementia and those around them. They also understand how to communicate effectively. They should have clear understanding of the core principles of this Framework as set out in Chapter 1, the knowledge and skills associated with the Dementia Friends training programme in Wales, and essential communication skills.

The learning and development topics and associated learning outcomes for 'Informed' people are set out in Section 2.3 of this framework.

Skilled people

Skilled people are Informed but have also developed more detailed and comprehensive knowledge and skills across a range of key learning and development topics over time, according to their experience, role, interests and needs. For example, they could have spent an extended period of time providing care and support for people with dementia, or have engaged with further training, personal and professional development opportunities and organisational development activities. The learning and development topics for Skilled people are set out in Section 2.4 of this framework and are mapped against the well-being themes in the National Well-being Statement. Numerical levels of learning and skills associated with qualifications have not been identified within this framework.

Influencers

Influencers are people who are Informed, possibly Skilled and who also have a management, leadership and/or strategic role. It is not just managers who can be leaders, this can apply to anyone who is able to inspire, lead or influence others.

People may take on leadership roles at different times and in different circumstances. These people are critical in ensuring that others become Informed and/or Skilled over time. Most importantly they have a key role in ensuring that the service or activities they are responsible for deliver on the principle of Good Work and the 3Es (Ethics, Excellence, and Engagement). The area of Engagement is central to the role of the Influencer. The result is that people (typically the workforce) care about the work they do, find it meaningful and are empowered to give their best, which cannot be achieved through training alone. Influencers could be service or organisational managers, commissioners, regulators or dementia or carer activists. The learning and development topics and associated learning and development outcomes for Influencers are set out in Section 3.5 of this Framework under the Engagement chapter.

The remainder of this chapter sets out the key learning and development topics for Informed and Skilled people. Some people will have more expertise than others regarding the various topics according to their role, needs and interests. For example, a person with dementia or a carer may develop greater expertise than a social worker or nurse in some topics.

2.3 Learning and development topics for Informed people

BEING A DEMENTIA FRIEND

SUMMARY	LEARNING OUTCOMES The learner will:
Dementia is not a natural part of ageing	<ul style="list-style-type: none"> ■ Understand that dementia is not a natural part of growing old ■ Understand that certain lifestyle choices can increase the chance of getting dementia ■ Understand that living a healthy lifestyle can help prevent dementia
Dementia is caused by brain diseases	<ul style="list-style-type: none"> ■ Understand dementia is caused by a disease of the brain ■ Understand there are different types of dementia ■ Understand that dementia can affect different people in different ways
Dementia is not just about losing your memory	<ul style="list-style-type: none"> ■ Understand some of the key ways dementia can affect people ■ Be able to respond to people with dementia in ways that takes account of the apparent challenges they are facing
It is possible to live well with dementia	<ul style="list-style-type: none"> ■ Understand that people with dementia need to be supported to live life as fully as they are able

BEING A DEMENTIA FRIEND

SUMMARY	LEARNING OUTCOMES The learner will:
<p>Even when dementia progresses and starts to affect the individual to a greater degree, they can be supported to continue doing the things they enjoyed and carry on contributing. Even small things can be important, e.g. helping to wash up. Reminiscence, emotional and arts based activities are also important as they connect with parts of the brain that are last to be affected by the disease.</p>	<ul style="list-style-type: none"> ■ Understand that little things can be important in terms of people's quality of life ■ Support people with dementia to engage with everyday activities and meaningful relationships where possible
<p>There is more to the person than the dementia</p> <p>There is a danger that when someone develops dementia, this becomes the focus of what people see in them, not the person. As a result, some people might think that the person with dementia is 'no longer there', which is very harmful to the person who may be treated as an object not a person with a life history and current thoughts, feelings and desires. Tom Kitwood (1997) suggests we should focus on seeing 'a person with dementia', not 'a person with dementia'. He goes on to define personhood as: 'The standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust'</p>	<ul style="list-style-type: none"> ■ Understand the importance of seeing the person first and not the dementia ■ Understand the importance of personhood ■ Recognise the importance of value, trust and respect
<p>Effective communication is important to people with dementia</p> <p>It is important to adapt to the person, a person with dementia cannot adapt their communication for you. Understanding each individual's communication needs and preferences is critical in terms of effective support and enablement</p>	<ul style="list-style-type: none"> ■ Understand the importance of effective communication that responds to each individual's sense of reality, needs and preferences ■ Understand how the environment can impact on effective communication ■ Be aware of your own verbal and non-verbal communication and how this might impact on the person with dementia ■ Understand the important role that touch can play in communication ■ Understand the importance of active listening and allowing people time to respond ■ Understand that behaviour can be a way of communicating ■ Communicate in ways that best meets the needs and wishes of the person with dementia

"When the person with dementia is talking and their conversation goes from one thing to another, the person with them should just go with it, no matter if it makes sense or not." Tommy Dunne

2.4 Learning and development topics for Skilled people

WELL-BEING THEME: RIGHTS AND ENTITLEMENTS

SUMMARY	LEARNING OUTCOMES The learner will:
Current relevant legislation and guidance including rights	
<p>It is important to have a sufficient level of knowledge regarding relevant legislation, guidance and policy to be able to apply these in the context of people's lives and professional practice. Everyone should be familiar and work within the five principles of the <i>Mental Capacity Act 2005</i>, which are:</p> <p>Principle 1: A presumption of capacity – a person has a right to make their own decisions and must be assumed to have capacity to do so unless it is proved otherwise. This means that you cannot assume that a person cannot make a decision for themselves just because they have a particular medical condition or disability, e.g. dementia.</p> <p>Principle 2: People must be supported to make their own decisions – a person must be given all practicable help before anyone treats them as not being able to make their own decisions. This means you should make every effort to encourage and support people to make the decision for themselves. If lack of capacity is established, it is still important that you involve the person as far as possible in making decisions.</p> <p>Principle 3: Unwise decisions – people have the right to make decisions that others might regard as unwise or eccentric. You cannot treat a person as lacking capacity for this reason. Everyone has their own values, beliefs and preferences which may not be the same as those of other people.</p> <p>Principle 4: Best interests – anything done for or on behalf of a person who lacks mental capacity must be done in their best interests – and not in order to protect the agency or the interests of others at the expense of the person.</p> <p>Principle 5: Less restrictive option – someone making a decision or acting on behalf of a person who lacks capacity must consider whether it is possible to decide or act in a way that would interfere less with the person's rights and freedoms of action, or whether there is a need to decide or act at all. Any intervention should be weighed up in the particular circumstances of the case.</p> <p>Everyone should also be aware of and work within the <i>Declaration of Rights for Older people in Wales</i> as outlined in Section 1.1 of this Framework and the <i>Human Rights Act 1998</i>.</p>	<ul style="list-style-type: none"> ■ Know the key areas of legislation and guidance that are relevant to the care and support of people with dementia and carers (e.g. <i>Social Services and Wellbeing (Wales) Act 2014</i> and the <i>Mental Health (Wales) Measure 2010</i>) ■ Understand how legislation and guidance influence the rights, welfare and safety of people with dementia and carers ■ Know the five principles of the <i>Mental Capacity Act 2005</i> and their implications for practice ■ Understand the concept of mental capacity and how this impacts on people's ability to make informed decisions ■ Understand the concept of 'best interests' decision making and what this means from the perspective of people with dementia ■ Be able to work with people with dementia, carers and others in supporting their rights and entitlements, in accordance with legislation and guidance

WELL-BEING THEME: RIGHTS AND ENTITLEMENTS

SUMMARY	LEARNING OUTCOMES The learner will:
<p>Recognising and challenging discrimination</p> <p>Discrimination is the unjust or prejudicial treatment of different categories of people. It is important to be aware that many people (including people with dementia) are subject to discrimination and to be able to recognise and challenge this. Everyone should be aware of the protected categories under the <i>Equality Act 2010</i>, which are:</p> <ul style="list-style-type: none"> ■ age; ■ disability; ■ gender reassignment; ■ marriage and civil partnership; ■ pregnancy and maternity; ■ race; ■ religion or belief; ■ sex (gender); ■ sexual orientation. 	<ul style="list-style-type: none"> ■ Understand the concept of discrimination ■ Be able to reflect on how discrimination can impact on the lives of people with dementia and others ■ Be able to describe how legislation and guidance (including the <i>Equality Act 2010</i>) protect people from discrimination ■ Be able to demonstrate nondiscriminatory practice ■ Be able to recognise when discrimination is taking place and be able to report and/or challenge this as appropriate
<p>The prevention and delay of dementia onset</p> <p>People have a right to information that may enable them to make their own informed choices on their health, well-being and lifestyle. Whilst there is currently no cure for dementia, there are things that people can do to delay its onset. These include:</p> <ul style="list-style-type: none"> ■ eat a healthy diet; ■ maintain a healthy weight; ■ exercise regularly; ■ don't drink too much alcohol; ■ stop smoking (if you smoke); ■ make sure you keep your blood pressure at a healthy level. 	<ul style="list-style-type: none"> ■ Understand the concept of healthy living and how it relates to well-being ■ Understand the key areas related to healthy living that can delay the onset of dementia ■ Be able to provide information to people about healthy living and, where possible, act as a role model ■ Support people to access services, supports and facilities that can support them to live healthy lives
<p>Early support and access to information and services</p> <p>Without access to information, advice and early support, people with dementia and carers can struggle with knowing what to do for the best. This can be distressing and lead to uninformed decision making which may have a poor outcome.</p>	<ul style="list-style-type: none"> ■ Understand the fundamental importance of providing people with dementia and carers with good, timely information and advice throughout their journey with dementia

WELL-BEING THEME: RIGHTS AND ENTITLEMENTS

SUMMARY

LEARNING OUTCOMES The learner will:

Early support and access to information and services (continued)

Research suggests that people prefer issue-based information and advice (e.g. 'I am worried about being forgetful - what can I do?' or 'I need a break from caring') rather than descriptions of services (e.g. 'A guide to assessment and care management' or 'Respite care services'). People also need timely access to information and advice and do not usually engage with information in advance of need (Quinn et al 2003).

There is huge stigma around dementia and a fear that statutory services will 'take over', which can make people shy away from seeking help. Therefore, information, advice and support must be as informal and friendly as possible. This may encourage them to seek a diagnosis.

- Be able to provide information and advice that is relevant, accessible and timely
- Understand the importance of single points of contact and other methods that minimise the number of individuals people have to deal with

Diagnosis

Experiencing difficulties with memory and other cognitive abilities may be because of dementia, or down to other reasons such as poor sleep, low mood, medications (e.g. anti-cholinergic, antidepressants, benzodiazepines, anti-psychotics, opioids or other medical conditions, e.g. B12 deficiency, thyroid disorders and urinary tract infections). This uncertainty can be distressing for everyone involved. If someone has dementia, knowing which type of dementia is an important prerequisite to effective care and support planning.

Whilst a diagnosis of dementia can be devastating news, an explanation of what the problem is and what can be done about it can empower people and reduce some of the worry caused by uncertainty. Sensitivity is required in supporting, advising and assessing people in these situations.

- Understand the importance of effective early diagnosis and associated practical and emotional support
- Be able to facilitate access to effective and timely diagnosis
- Be able to facilitate access to associated practical and emotional support (see 'Impact of diagnosis on the person with dementia and everyone involved' Learning and Development topic on page 21)

Assessment, care and support planning and review

High quality assessment, care and support planning and review must focus on **what matters** to the person with dementia and carers, not just their clinical or care needs. They must also identify and focus on their strengths, draw on family and community resources and support as well as statutory services.

- Understand the cycle of assessment, care and support planning and review as outlined in statutory guidance

WELL-BEING THEME: RIGHTS AND ENTITLEMENTS	
SUMMARY	LEARNING OUTCOMES The learner will:
Assessment, care and support planning and review	
<p>A reablement approach to supporting people with dementia should run throughout all service provision: (http://www.ssiacymru.org.uk/home.php?page_id=8643)</p> <p>Research suggests that people highly value a relational, rather than procedural approach to assessment, care and support planning and review (Manthorpe et al 2008), ideally with the support of a designated care and support co-ordinator. Having to deal with too many different people can be distressing.</p> <p>The recording of assessments, care and support planning must comply with legislation and guidance, e.g. the <i>Social Services and Well-being (Wales) Act 2014</i> and the <i>Mental Health (Wales) Measure 2010</i>.</p>	<ul style="list-style-type: none"> ■ Understand the importance of person-centred and personal outcomes focused approaches to assessment, care and support planning and review ■ Be able to involve and fully engage all key people in the assessment, care and support planning and review processes ■ Understand the concept of reablement and why this is important in relation to assisting people with dementia to maximise their independence ■ Understand how a designated lead or key person can support the assessment, care and support planning and review process ■ Be able to record in clear and concise ways that are compliant with legislation and guidance

WELL-BEING THEME: PHYSICAL AND MENTAL HEALTH	
SUMMARY	LEARNING OUTCOMES The learner will:
Impact of diagnosis on the person with dementia and everyone involved	
<p>Receiving a diagnosis of dementia is a distressing experience for many individuals. It can also be upsetting for family and can impact on close relationships and personal circumstances.</p> <p>Dementia is not an easy diagnosis to make, especially in the early stages of the disease. In some cases symptoms develop over many years. It is not unusual therefore that a person may have had concerns for many years before consulting a GP.</p>	<ul style="list-style-type: none"> ■ Understand that the impact of the diagnosis will be a personal experience and will differ between individuals and within families ■ Understand equality and diversity issues that should be considered in diagnostic and post diagnostic support ■ Be able to engage people with dementia and carers in an empathic and supportive manner ■ Enable people with dementia and carers to adjust to living with the diagnosis by actively listening to their experiences and emotions

WELL-BEING THEME: PHYSICAL AND MENTAL HEALTH

SUMMARY

LEARNING OUTCOMES The learner will:

Impact of diagnosis on the person with dementia and everyone involved (continued)

In other cases, and depending on the type of dementia diagnosed, a person may have been subject to protracted tests and even earlier misdiagnosis especially in the case of rare or younger onset dementias. There are also rare cases of familial dementia that can be hereditary and genetic counselling may be required.

It is important therefore to recognise that the point of diagnosis is not the beginning or the end of the story for each newly diagnosed individual and family. However, it is the point at which sensitive access to relevant advice, information and support is essential in assisting the individual and significant others to come to terms with the initial emotional and subsequent practical and financial impact of a diagnosis of what is essentially a terminal disease with no current cure.

- Be able to refer people to relevant specialist services dependent upon individual circumstances and needs
- Be able to provide signposting and/or access to timely relevant advice, information and support
- Be able to support people with dementia and carers to plan for a future that is important to them
- Knowledge of the range of legal directives that people can make to help plan for their future care and wishes

Different types of dementia and their impact

Dementia is a global term used to describe the complex decline and impairment of mental functions, including memory, orientation, judgement, and language. Although there are over 100 different causes of dementia, the more common causes seen in Wales are Alzheimer's Disease, Vascular dementia and Dementia with Lewy Bodies. Rarer forms include Fronto-temporal dementia and Creutzfeldt-Jakob disease. Every dementia has distinct characteristics in clinical terms, as well as in how they impact on an individual's prognosis, abilities, and general health and wellbeing.

It is also not uncommon for individuals to have a vascular dementia and Alzheimer's Disease. Mixed presentations are common and provide further challenges to all involved. Each person diagnosed, will experience dementia in a unique way. Many people who are diagnosed are older and as such there are increased risks of other diseases and conditions that will impact upon the experience of dementia or vice versa.

- Understand the differences and commonalities between the major causes of dementia and how these may impact upon people with dementia and carers
- Be able to recognise and respond effectively and sensitively to the common symptoms and presentation of dementia such as memory, judgement, language and orientation, whatever the cause
- Understand memory impairment and its impact in dementia; i.e. the significance of short term memory in registering information and the 3 main categories of long term memory: Semantic memory (enabling the recall of facts), Episodic memory (recall of events and experiences and emotions) and Procedural memory (implicit memory linked to motor function such as signing our name, driving a car etc.)

WELL-BEING THEME: RIGHTS AND ENTITLEMENTS

SUMMARY	LEARNING OUTCOMES The learner will:
<p>Different types of dementia and their impact (continued)</p> <p>It is important to recognise that dementia is not a disease exclusive to old age. The diagnosis of young onset dementia can impact on people in different ways as they are often in employment and can have caring responsibilities towards children and parents.</p> <p>Younger people with learning disabilities are also at a higher risk of developing dementia as they approach mid-age. In particular it is estimated that over fifty percent of people with Down's syndrome will develop Alzheimer's disease when they are in their 60s. The specific needs of people with young onset dementia therefore need to be understood and addressed.</p>	<ul style="list-style-type: none"> ■ Recognise the difference between dementia and other physical and mental health conditions such as Delirium, Depression ■ Be aware of the conditions that people with dementia may have that could also impact upon the symptoms of dementia ■ Know that dementia is not a natural part of ageing and that it can also affect younger people and that their needs for support are often different to those of older people ■ Recognise the increased risk for people with learning disabilities of developing dementia and the difficulties that this can pose in symptom assessment, management and support
<p>Promoting physical health</p> <p>Health is defined by the World Health Organisation (WHO), as:</p> <p>'A state of complete physical, mental and social well-being and not merely the absence of disease'.</p> <p>The Welsh government approaches public health from an 'Holistic' perspective (www.publichealthnetwork.cymru)</p> <p>Whilst there are no current curative treatments for dementia, there is much that can be done to alleviate the distress of the disease and conditions that can compound symptoms.</p> <p>Physical health promotion for people living with dementia and their families is paramount. Supporting people, irrespective of their limitations, to achieve a state of physical well-being, through health assessment, promotion, activity and care can impact positively on the lived experience of dementia.</p>	<ul style="list-style-type: none"> ■ Understand the factors that contribute to individual physical health and how a person with dementia will need more support to maintain this ■ Understand the purpose and protocols for undertaking physical health assessments as appropriate to your role ■ Understand the importance of holistic and person centred assessment, planning and review ■ Be able to identify the necessity for further investigations and specialist interventions to support a person living with dementia and the carer/s to maintain optimum health ■ Enable a proactive approach to health promotion assisting the people with dementia and carers to access relevant services, activities and information

WELL-BEING THEME: PHYSICAL AND MENTAL HEALTH

SUMMARY

Early and continued physical health promotion interventions can also have a positive impact on the symptoms experienced and in some cases (e.g. Alcohol related Korsakoff's Syndrome) the progression of the dementia.

It is not uncommon for individuals living with dementia to experience a range of other physical conditions, particularly those that are age associated. It is therefore important to recognise that physical health needs may be complex and will change over time.

LEARNING OUTCOMES The learner will:

Promoting physical health (continued)

- Demonstrate an understanding of increasing risk factors associated with maintaining physical well-being particularly in the areas of physical care such as:
 - Management of infection
 - Nutrition - diet and fluid
 - Mobility and safe transfer
 - Continence promotion
 - Skin care and tissue viability
 - Oral health
 - Visual and auditory health
 - Sexual health
 - Sleep
 - Assessment and management of pain
- Awareness and understanding that the type of dementia itself can have an impact on physical abilities and well-being and that this state may be transient or more permanent. For example, visual perception difficulties, vascular conditions
- Understand the importance and legalities associated with the codes of practice of your own role in relation to physical health assessments, care planning, review and record keeping

Promoting mental health

Together for Mental Health: A Strategy for Mental Health and Wellbeing in Wales provides the basis for the Welsh Government approach to dementia care and makes a commitment to 'Supporting the optimum state of well-being right through to the end of life for older people and those with dementia.'

Mental health promotion aims to raise self-esteem, strengthen life and coping skills and improve emotional resilience, through access to appropriate support, education and information.

- Understand that mental health is a state of internal balance of many interacting factors, including, physical, psychological and biological that can be influenced by a number of personal experiences and the environment
- Have knowledge of your own professional protocols and tools for the assessment of mental health

WELL-BEING THEME: RIGHTS AND ENTITLEMENTS

SUMMARY	LEARNING OUTCOMES The learner will:
<p style="text-align: center;">Promoting mental health (continued)</p>	<ul style="list-style-type: none"> ■ Recognise the potential risks to mental health both covert (social isolation, relationship issues, maladjustment to diagnosis, personal losses experienced) and overt (clinical signs and symptoms of mental health issues) that a diagnosis of dementia can have on people with dementia and carers and be able to respond with appropriate support and or interventions ■ Have knowledge of the common psychotic symptoms that may in some cases manifest as a result of dementia and be able to support people with dementia and carers in the management of these symptoms ■ Be able to direct a person with dementia and the carer/s to relevant psychological therapies where indicated ■ Be able to proactively engage people with dementia and carers in activities that support independence and promote mental health
<p style="text-align: center;">Medication management</p>	<ul style="list-style-type: none"> ■ Understanding of the nature of pharmacological treatments for the symptoms of the most common dementias and their potential impact in terms of efficacy and side effects ■ Understand the principles of capacity and consent in relation to administering prescribed medications to a person diagnosed with dementia ■ Be able to refer to national, local and organisational guidance with regards to administration of and monitoring of prescribed medications and their side effects ■ Be aware of the risks associated with polypharmacy, particularly in older people, and seek appropriate advice where indicated
<p>The development and availability of medicines in our society aims to ease discomfort, treat disease and prolong life. Whilst prescribed medicines often have beneficial effects, there are also risks of adverse drug reactions (ICH, 1996). In particular, when a number of concurrent physical and or mental health conditions are being treated. In addition, older people and people with dementia and other long term conditions are at increased risk of adverse drug reactions.</p> <p>It is therefore incumbent upon all professionals to ensure compliance with national guidelines and codes of professional practice, ensuring that appropriate medication is provided and reviewed to meet individually assessed need (Jordan et al 2015). Also that there is timely, accessible and appropriate medicines monitoring, advice and information available.</p>	

WELL-BEING THEME: PHYSICAL AND MENTAL HEALTH

SUMMARY

LEARNING OUTCOMES The learner will:

Medication management (continued)

- Understand the principles of safe storage and disposal of medicines in line with your role
- Be cognisant of legal and professional practice guidance for the safe and appropriate handling of medications including, regular review, record keeping and reporting of side effects/adverse reactions or errors in administration
- Be able to support people with dementia and carers, to safely self-manage prescribed medication where possible
- Be aware of national and local guidance in relation to use of medication for the management of behavioural symptoms in dementia and its associated risks

Palliative and end of life care and support

The report, *Living and Dying with dementia in Wales; The Barriers*, (Alzheimer's Society and Marie Curie Cancer Care, 2015), calls for a far greater focus, in both policy and practice, on the terminal nature of dementia, and identifies areas for improvement specifically in Wales, whilst drawing on national developments and wider research.

It acknowledges that although historically, dementia has been rarely recognised as a terminal illness or cause of death, recent statistics are showing some increases in the reporting of death from dementia, but the numerous causes and very nature of dementia makes this difficult and impacts on the quality of care accessed and experienced by people dying from dementia and their families.

- Understand the specific palliative care needs and end of life protocols for people dying with dementia and carers
- Appreciate that palliative care approaches should commence at the point of diagnosis
- Understand the need to support physical (including environment), social, psychological and spiritual needs of people with dementia and carers
- Understand the legal and organisational policy in relation to resuscitation
- Recognise the importance of keeping carers informed throughout the process
- Have knowledge of palliative care and end of life services in the community e.g. Marie Curie, Bereavement Counselling etc.
- Appreciate the importance of Advance Directives that are in Wales, the only legally binding form of a person expressing their own situation specific views on care

WELL-BEING THEME: RIGHTS AND ENTITLEMENTS

SUMMARY	LEARNING OUTCOMES The learner will:
Palliative and end of life care and support (continued)	
<p>Palliative care relates to the care and support provided to people with dementia who have a terminal illness with no hope for a cure. It provides management of pain and physical symptoms as well as seeking to address spiritual, psychological, social, and practical needs, and aims to support people to live well with a terminal illness until they die.</p> <p>End of life care is the stage within palliative care, recognised as being the last 12 months of life, including the final days and hours of life. It provides support to people to help them to die with dignity and pain free.</p> <p>Greater awareness and understanding by health and social care professionals of the terminal nature of dementia is needed to ensure that palliative care protocols and practice are put in place.</p>	<ul style="list-style-type: none"> ■ Understand the limitations of 'proxy directives' or 'general values directives' in the absence of the legally binding Advance Directive and be able to support carers in this respect ■ Understand the concept and use of Lasting Power of Attorney ■ Be able to manage sensitively any conflict that may arise with families in the absence of any advance planning when it becomes the responsibility of professionals involved to make decisions in the best interests of the person with dementia ■ Understand that the person with dementia may not be able to communicate pain or distress and ensure that strategies are in place to minimise this risk

WELL-BEING THEME: SAFEGUARDING

SUMMARY	LEARNING OUTCOMES The learner will:
Positive risk taking	
<p>Risk taking must not be assumed to be a bad thing; it can result in good things happening. The achievement of meaningful quality of life requires an approach to risk-taking that has a primary focus on the achievement of positive outcomes and then explores and addresses the associated risks.</p> <p>Positive risk-taking is weighing up the potential benefits and harms of exercising one choice of action over another. It requires identifying the potential risks involved (i.e. good risk assessment) and developing plans and actions (i.e. good risk management) that reflect the positive potentials and stated priorities of the person with dementia (i.e. a strengths approach). It involves using available resources and support to achieve the desired outcomes, and to minimise any potential harmful outcomes (Morgan, 2013).</p>	<ul style="list-style-type: none"> ■ Understand the concept of positive risk taking and the implications for practice ■ Understand the concept of 'silent harms' and the implications for practice ■ Be able to identify ways in which positive risk taking can contribute to achieving good outcomes and quality of life of people with dementia and carers ■ Be able to demonstrate positive risk taking in partnership with people with dementia, carers and others

WELL-BEING THEME: SAFEGUARDING

SUMMARY

LEARNING OUTCOMES The learner will:

Positive risk taking (continued)

People with dementia can be subject to 'silent harms' (Clarke et al, 2011), when those who support them are risk-averse and preoccupied with physical safety, rather than the achievement of meaningful quality of life. This is unacceptable.

Collaborative rights informed decision making

The power imbalances within health and social care services can result in decisions being made with little reference to the views and preferences of people with dementia and carers. Even between professional groups, one profession may dominate over another when it comes to deciding what will be done, which can result in unbalanced decision making.

Research suggests that the best decisions are made as a result of dialogue (Escobar 2011), where differing perspectives and priorities are shared and explored. This results in negotiated and balanced decision making.

There are a number of 'contested territories' in supporting people with dementia, where different people will have different views as to what is right and acceptable (Clarke et al 2011). Decision making within 'contested territories' require a collaborative and rights informed approach.

Common 'contested territories' include:

- Relationships and friendships
 - Smoking
 - Going out
 - Domestic arrangements
 - Occupation and activity
- There are a number of techniques that can be used to support collective decision making. Positive risk-taking should be carefully considered, collaboratively agreed and recorded.

- Understand the importance and benefits of involving people, carers and a range of professionals in decision making in order to provide a fully 'rounded' view
- Understand the concept of 'contested territories' and the need to consider a range of views in making balanced decisions
- Understand how the rights of people with dementia and carers can inform balanced decision making
- Be able to contribute to collaborative decision making processes in a fair and balanced way that seeks to find a solution that is understood and owned by everyone
- Be able to record collaborative and rights-informed decision making in a clear and concise format

WELL-BEING THEME: SAFEGUARDING	
SUMMARY	LEARNING OUTCOMES The learner will:
Recognising signs and indicators of abuse	<ul style="list-style-type: none"> ■ Understand the different types of abuse and their effect on people ■ Understand the indicators of each different type of abuse ■ Understand how to report actual or suspected abuse ■ Be able to identify actual or potential abuse and report this as required ■ Understand the legal requirements, rights and protection of the workforce in relation to whistle-blowing
Statutory safeguarding procedures	<p>Everyone must understand the definition of 'adults at risk', i.e. someone who</p> <ul style="list-style-type: none"> ■ is experiencing or is at risk of abuse or neglect, and ■ has needs for care and support (whether or not the authority is meeting any of those needs), and ■ as a result of those needs is unable to protect himself or herself against the abuse or neglect or the risk of it. <p>Depending on the particular role of the person supporting someone with dementia, they must understand and follow the appropriate safeguarding responses in line with the <i>Social Services and Wellbeing (Wales) Act 2014</i> and associated guidance.</p> <ul style="list-style-type: none"> ■ Understand the term 'adults at risk' ■ Be able to identify potential and/or actual situations where people with dementia and carers are 'adults at risk' ■ Be able to make appropriate safeguarding responses regarding 'adults at risk', in accordance with legislation and guidance
Advocacy	<p>All practical steps must be taken to help an individual participate in decision-making even when these decisions are complex. If a person with dementia can no longer make complex decisions, it is likely that they can make day to day decisions. In general, once a person with dementia begins to lose capacity it is important that their carer, family or independent advocate are fully involved in making decisions about the person's treatment, care and support.</p> <ul style="list-style-type: none"> ■ Understand the concept and benefits of advocacy and the different types of advocacy ■ Understand when and why advocacy might be required in the care and support of people with dementia and carers

WELL-BEING THEME: SAFEGUARDING

SUMMARY	LEARNING OUTCOMES The learner will:
<p>However, it must also be recognised that carers and/or family do not always know what is in the best interests of the person with dementia, in which case the involvement of advocates may also be appropriate.</p> <p>Lasting Power of Attorney, advance decisions and advance statements by people with dementia, can ensure that their views and preferences are taken into account when they are less able to express themselves. People with dementia should be advised on these as early as possible, so they can make informed decisions about their future.</p>	<ul style="list-style-type: none"> ■ Be able to explain advocacy in order that people with dementia and carers are able to make an informed decision about its use ■ Be able to facilitate people with dementia and carers to access to advocacy support when needed ■ Understand the concept and benefits of Lasting Power of Attorney, advance decisions and advance statements and when they should be considered ■ Be able to support people with dementia and carers to set-up Lasting Power of Attorney, advance decisions and advance statements
<p>Careful and sensitive monitoring of people with dementia is able to balance the need for safety and security against their freedom and autonomy. For example, assistive technology that enables monitoring or tracking both indoors and outdoors, may support a person with dementia to remain in their own home, rather than be admitted to a care home. They can also provide peace of mind for carers.</p> <p>However there is a danger that monitoring can be used as a substitute for human contact, an invasion of privacy, and may be unnecessarily restrictive. Therefore, whenever a person with dementia is subject to monitoring, every effort must be made to do so in a manner that is least restrictive and there must be a clear rationale as to why it is in their best interests.</p>	<ul style="list-style-type: none"> ■ Understand the potential for assistive technology to enhance independence, safety and well-being ■ Understand how to ensure that decisions about the use of assistive technology are outcome-focused, inclusive, open and transparent ■ Understand the limitations and constraints of assistive technology ■ Understand the concept of 'least restrictive' option in relation to using electronic monitoring and tracking devices and the implications for practice ■ Be able to ensure that all decisions regarding the use of electronic monitoring and tracking technology are fully recorded and reviewed on a regular basis

WELL-BEING THEME: MEANINGFUL LIVING

SUMMARY	LEARNING OUTCOMES The learner will:
<p>Life story work</p> <p>Life story work is an activity which involves reviewing a person with dementia's past life events and developing a biography. Effective life story work goes beyond identifying a person's life history (e.g. where they went to school, where they worked) and focuses on the things that were and still are meaningful to people (for example, just because someone worked in a school kitchen all their life, does not mean they enjoy cooking).</p> <p>The benefits of meaningful life story work, include:</p> <ul style="list-style-type: none"> ▪ Being able to see the person behind the label or diagnosis; ▪ Enabling an individualised approach to assessment, care and support planning; ▪ Supporting the development of personalised living spaces; ▪ Building and strengthening relationships between people with dementia, carers and the people who support them; ▪ Enhancing communication and helping to understand and respond to particular behaviours. 	<ul style="list-style-type: none"> ■ Understand the wide-ranging benefits of meaningful life story work with people with dementia and carers ■ Be able to engage in meaningful life story work with people with dementia and carers ■ Be able to apply life story work in the design and delivery of care and care and support plans ■ Be able to apply life story work in the development of personalised living spaces and activities ■ Be able to use life story work to interpret and respond to behaviours that may be perceived as challenging ■ Be able to demonstrate a positive-risk taking approach in the use of life story work in practice
<p>Identifying the strengths of people with dementia and their 'ability to do'</p> <p>Whilst life story work plays a central role in supporting people with dementia, the aspirations listed above may not be achieved unless biographical understanding is matched with an understanding of a person with dementia's ability to do things. For example, someone may have loved gardening, but is no longer able to understand how to use a spade; in which case, it would be discouraging and unhelpful to send them out into a garden with a set of tools.</p> <p>Occupational Therapists have particular expertise in this area, but there are a range of fairly simple techniques that can be used by others to identify the sorts of things that people with dementia can do as their cognitive abilities decline. When this is understood, appropriate activities can be planned that are in tune with a person's biography.</p>	<ul style="list-style-type: none"> ■ Understand the importance of focusing on people's strengths and abilities in the design and delivery of care and support ■ Understand the concept of cognitive and functional ability and the implications for practice ■ Be able to assess cognitive and functional ability or work with other professionals who have expertise in this topic ■ Be able to combine life story work and cognitive and functional ability assessment in the design and delivery of care and support plans and /or associated activities

WELL-BEING THEME: SAFEGUARDING

SUMMARY

Neurological research and practical experience from around the world, has discovered that whilst people with dementia may experience difficulties with memory and reasoning, they are much more able to engage in emotional and artistic activities, as the parts of the brain that are involved in these activities remain intact throughout the course of the disease (Zeisel, 2012).

There is increasing evidence that people with dementia can engage meaningfully in all of the following activities:

- Playfulness and laughter
- Poetry
- Visual arts
- Drama
- Music and singing
- Food preparation and sharing
- Craft activities

Involving people with dementia in these activities can also benefit carers and staff, who are encouraged by the response and feel more able to support people with dementia in ways that are enjoyable and meaningful.

Walking is a normal, enjoyable and healthy activity for many people. People with dementia who like to walk must not be seen as 'wanderers' with the negative assumptions this brings. Whilst a person's safety is important, there are ways of supporting people with dementia to walk safely. Physiotherapists are able to offer advice and support.

Creative and meaningful activities

LEARNING OUTCOMES The learner will:

- Understand that parts of the brain associated with emotions and creativity are often the least affected by dementia
- Understand the important role that creativity can play in everyone's life
- Be able to support people with dementia to engage in a range of creative activities that build on their strengths and interests and promote their well-being
- Understand that people with dementia have the same right to walk as everyone else
- Be able to seek advice from specialists (e.g. physiotherapists) in supporting people with dementia to walk safely
- Be able to provide opportunities and a safe, accessible environment for people with dementia to walk, if they want to

Sensory stimulation

Whilst people in the later stages of dementia may be unable to engage in some of the activities listed above, they can continue to find enjoyment, meaning and purpose through the uses of their senses, i.e. sight, hearing, smell, taste and touch.

There are a range of activities that can be designed around these, including multi-sensory rooms (Snoezelen), aromatherapy, and sound stimulation (which can be as simple as listening to birdsong or the sound of the sea).

- Understand how all of the senses can play an important part in supporting the well-being of people with dementia
- Be able to use appropriate physical contact and touch in the care and support of people with dementia

WELL-BEING THEME: MEANINGFUL LIVING

SUMMARY	LEARNING OUTCOMES The learner will:
<p>Sensory stimulation (continued)</p> <p>The use of touch can be particularly important – from the simple act of holding hands or having your hair brushed, to holding or stroking a baby, a doll, an animal, an artefact, a soft toy or a piece of textured material.</p>	<ul style="list-style-type: none"> ■ Be able to use sensory-focused objects and activities in the care and support of people with dementia
<p>Adjusting to change and experiencing positive transitions</p> <p>We all experience change and transitions throughout our life. People with dementia and carers are subject to more change and transitions than most as the disease progresses and impacts on every aspect of their lives.</p> <p>Some carers can experience what has been called 'anticipatory grief' as they feel they are losing touch with the person they love. For other carers, dementia can bring them closer to the person with dementia as their relationship becomes less rational and more emotional.</p> <p>Supporting people with dementia and carers in adjusting to change and managing transitions is very important. Key transitions include:</p> <ul style="list-style-type: none"> ■ Changes in care and support settings ■ Changes in relationships ■ Changes in behaviour ■ Stopping driving ■ End of life 	<ul style="list-style-type: none"> ■ Understand the importance of change transitions in everyone's life ■ Understand the impact of change and transitions on people with dementia and carers, both positive and negative ■ Be able to support people with dementia and carers in adjusting to change and managing transitions; where possible, enabling them to retain a sense of security, continuity, belonging, purpose, achievement and significance ■ Understand the impact of grief and loss on people ■ Be able to support people with dementia and carers who are experiencing grief and loss
<p>Meaningful short breaks</p> <p>Respite care is the most asked for service by carers, but uptake is less than expected because all too often a 'one size fits all' approach can be distressing to people with dementia and leave carers feeling guilty (Arksey et al 2004).</p> <p>Caring relationships are complex and the well-being of people with dementia and carers is interdependent. Both people need to feel good about respite care when it is provided. Poorly designed respite can be counter-productive.</p>	<ul style="list-style-type: none"> ■ Understand the importance of short breaks to people with dementia and carers and how they can contribute to sustaining caring relationships ■ Understand that short breaks can be achieved through a range of different options that do not always involve separating carers and the people they support

WELL-BEING THEME: MEANINGFUL LIVING

SUMMARY

There is a growing awareness of the need to think more creatively about how to support caring relationships, out of which has arisen the concept of short breaks, which are tailored to individual needs. These can include respite at home, supported holidays, Shared Lives schemes and activities and services bought using Direct Payments.

LEARNING OUTCOMES The learner will:

Meaningful short breaks (continued)

- Understand that the well-being of people with dementia and carers is usually interdependent and that short breaks needs to address the preferences and needs of both
- Be able to involve people with dementia and carers in the design and delivery of personalised short breaks that are beneficial for both

WELL-BEING THEME: MEANINGFUL RELATIONSHIPS

SUMMARY

Person-centred care is a term that is often used, but poorly defined. As a result, it can mean different things to different people.

The Care Council for Wales published practice guidance in 2010 on the delivery of person-centred care, which suggests working to a clear definition of person-centred care as set out in the VIPS Framework (Brooker, 2007):

<http://www.ccwales.org.uk/edrms/100361/>

This definition encompasses four principles:

- **V** – a value base that asserts the absolute value of all human lives regardless of age or cognitive ability
- **I** – an individualised approach to care and support, recognising uniqueness
- **P** – understanding the world from the perspective of the person with dementia, and providing care and support that is in-tune with this
- **S** – providing a social environment that supports psychological needs

Having independent choice and control over our lives is of fundamental importance to all human beings. Research in care services has found that people who do not have choice and control have reduced quality of life and may not live as long as those who do (Knight et al, 2010).

LEARNING OUTCOMES The learner will:

Person-centred approaches

- Have a clear and comprehensive understanding of the principles that underpin person-centred care and support and how these can impact positively on the lives of people with dementia and carers
- Be able to demonstrate a person-centred approach to supporting people with dementia and carers within their own practice
- Understand the importance of choice and control in promoting the independence and well-being of people with dementia and carers
- Understand how aspirations, rights and decisions about choice and control contribute to the process of balanced risk taking
- Be able to provide opportunities for people with dementia and carers to make informed and meaningful decisions in their daily lives, in ways which promote their independence and well-being

WELL-BEING THEME: MEANINGFUL RELATIONSHIPS

SUMMARY	LEARNING OUTCOMES The learner will:
Interdependence and the management of relationships	
<p>Narrow interpretations of independence focus on people doing things for themselves, but this does not take into account that fact that we are social beings and relationships play a central role in our well-being (Valliant, 2012). The concept of interdependence (Nolan et al 2006) recognising this and suggests that the well-being of people with dementia, carers and the people who support them are deeply connected.</p> <p>All good support is founded in and reflects meaningful and rewarding relationships (Blood, 2013) and approaches towards professional boundaries that undermine the quality of relationships in health and social care services are unhelpful.</p>	<ul style="list-style-type: none"> ■ Understand the fundamental importance of relationships in supporting the well-being of people with dementia and carers ■ Understand that the well-being of people with dementia, carers and the people who support them is generally interdependent ■ Be able to develop meaningful and helpful working relationships with people with dementia and carers ■ Be able to manage the balance between professional boundaries and the need to establish meaningful and helpful relationships with people with dementia and carers
The interpretation of behaviour	
<p>People with dementia can behave in ways that other people can find challenging. There is a danger of seeing so called 'challenging behaviour' as coming from the person with dementia, which suggests that it something that needs to be controlled or managed.</p> <p>Applying the social model of disability, suggests that so called 'challenging behaviour' may be in response to something going wrong with the physical environment (e.g. a poorly lit, impersonalised room) or the social environment (e.g. the way people talk to or treat the person), rather than with the person. In this case, the focus of attention is on identifying what might be causing the behaviour and making appropriate changes to the physical and or social environment.</p> <p>Behaviour is best seen as a form of communication: to be interpreted and responded to, rather than something to be controlled or managed. Whilst withdrawing anti-psychotic medication may lead to worsening of neuropsychiatric symptoms (Ballard et al, 2015), the inappropriate and potentially harmful use of anti-psychotic medication to sedate people with dementia is unacceptable (Banerjee, 2009).</p>	<ul style="list-style-type: none"> ■ Understand the concept of behaviour as a form of communication ■ Understand the social model of disability, how it relates to understanding behaviour and the implications for practice ■ Be able to apply the social model of disability in addressing the physical and social environmental factors that may be contributing to how people with dementia behave in ways that might be perceived as challenging ■ Understand the limitations and problematic nature of over using antipsychotic medication, anti-depressants, anti-muscarinic or sedatives ■ Be able to use appropriate person-centred techniques in the care and support of people with dementia who behave in ways that might be perceived as challenging ■ Be able to support carers and other significant people in understanding and supporting people with dementia who behave in ways that might be perceived as challenging

WELL-BEING THEME: MEANINGFUL RELATIONSHIPS

SUMMARY

One of the most important aspects of supporting people with dementia and carers is to communicate effectively with them.

Communication is more than just spoken word and includes the use of body language and appropriate use of touch.

For people with dementia, this requires others to understand 'where they are coming from' and starting from there. As one person with dementia said "We know the feelings but we don't know the plot. Your smile, your laugh, and your touch are what we connect with" (Bryden 2005).

People have individualised preferences regarding communication and touch, which must be recognised and addressed. For example, some people like banter, whilst others don't and it must not be assumed that everyone likes a cwtch. When people with dementia use words that do not appear to make sense, it can be helpful to reflect on the emotional content of what they are saying. For example, if someone is constantly asking for their mother who has died, they may be seeking comfort.

People with dementia who speak a number of languages, may revert to using only their first language (e.g. Welsh). It is very important to understand and respond to this.

Effective communication

LEARNING OUTCOMES The learner will:

- Understand the critical importance of effective communication in the care and support of people with dementia, including the use of body language and touch
- Understand the importance of knowing people's language preferences and needs when communicating
- Be able to communicate effectively with people who have dementia, working to some of the principles set out in the 'Careful and sensitive communication is important to people with dementia' section on page 15 of this framework
- Be able to use words, touch and other forms of non-verbal communications in ways that are appropriate and effective in the care and support of people with dementia, taking into account their individual preferences
- Be able to support people with dementia and carers to communicate in the language of their choice

Gender identity and sexual orientation

Gender identity can be more complex than an assumed 'he' or 'she', and people's current self-identified gender may be different to that assigned at birth. It is important to consider how a person defines their own gender currently, and which terms they use to describe themselves.

As with culture, it is important not to make assumptions about lesbian, gay male, bisexual and transgender (LGBT) people. It is important to find out what matters to individual people.

- Understand the range of ways that people define their gender identity and sexual orientation and how this can change through time
- Be able to reflect on and recognise own values and beliefs regarding gender identity and sexual orientation
- Understand the importance of people with dementia and carers being able to express their gender identity and sexual orientation, if they want to

WELL-BEING THEME: MEANINGFUL RELATIONSHIPS	
SUMMARY	LEARNING OUTCOMES The learner will:
Gender identity and sexual orientation (continued)	<ul style="list-style-type: none"> ■ Be able to contribute to a nonstigmatising LGBT friendly environment that supports and enables people with dementia and carers to express their gender identity and sexual orientation, if they want to, without fear of discrimination ■ Be able to take an individualised approach in understanding and supporting LGBT people with dementia and carers
Intimacy and sexual relationships	<ul style="list-style-type: none"> ■ Understand that intimacy and sexual relationships can be important to all people, including people with dementia ■ Be able to support people with dementia to experience intimacy and sexual relationships in ways that balance the preferences, rights and well-being of everyone concerned

WELL-BEING THEME: COMMUNITY INCLUSION AND CONTRIBUTION

SUMMARY

Understanding 'community' and the five principles of coproduction in Wales

Community inclusion and services working in partnership with communities and community based organisations is a key theme within the *Social Services and Well-being (Wales) Act 2014*.

The term 'community' can be used within services (e.g. people living in, working in or visiting a care home can be seen as a community), or in terms of communities of interest (e.g. walking groups) or local neighbourhoods.

Co-production is an asset-based approach that enables citizens and professionals to share power and work together in equal partnerships, to create opportunities for people to access support when they need it and to contribute to social change (Public Health Wales / Co-production Wales, 2015).

Professionals supporting people with dementia and carers should work to the five principles of co-production in Wales, which are:

- Value all participants and take an asset-based approach
- Develop peer-support networks and social capital
- Focus on personal outcomes – what matters to individuals
- Build relationships of equality and reciprocity
- Work in partnership with the people who use our services, as catalysts for change

LEARNING OUTCOMES The learner will:

- Understand the concept and principles of co-production and what this means in practice
- Understand methods of delivering co-production
- Understand the concept of asset/strength based approaches to working with people and organisations, and the implications for practice
- Be able to identify and engage with opportunities to use co-productive approaches in the design and delivery of care and support for people with dementia and carers

Understanding, valuing and encouraging 'contribution'

Traditional models of care suggest one-way transactions, where people with dementia and carers are passive recipients of care and support provided by professionals (Cahn, 2000). Not only can this restrict choice and control for these people, but it can also undermine their sense of well-being.

- Understand the benefits of enabling and supporting people with dementia and carers to contribute and give, as well as to receive care and support

WELL-BEING THEME: COMMUNITY INCLUSION AND CONTRIBUTION

SUMMARY	LEARNING OUTCOMES The learner will:
<p>In general, people achieve a greater sense of well-being when they are in balanced reciprocal 'give and take' relationships (Fyrand, 2010). This needs to be recognised and addressed when supporting people with dementia and carers.</p> <p>When people with dementia and carers are encouraged to contribute to the design and delivery of support and to the well-being of others (including the professionals who may support them), there is evidence to suggest that they are more able to flourish (Andrews et al, 2015).</p>	<ul style="list-style-type: none"> ■ Be able to create opportunities for people with dementia and carers to use their interests, strengths and skills to contribute to improving their own lives and the lives of others
Supporting and working with families and other significant people	
<p>It is important to recognise that people with dementia and carers seldom exist in isolation; they are part of wider family, friend and community networks (Woods et al, 2008). Professionals need to recognise this and ensure that they take a family-centred and /or community-centred approach to working with people with dementia, carers and other significant people. For example, where a person with dementia lives in a care home, carers, family members and other significant people can be encouraged to become involved in the life and work of the care home in ways that are comfortable to them and in the best interests of their relative and other residents.</p>	<ul style="list-style-type: none"> ■ Understand the critical role that carers, families and other significant people have in the care and support of people with dementia ■ Understand how carers, families and other significant people can provide valuable information to inform assessment, care planning and review processes regarding people with dementia ■ Be able to actively involve and encourage carers, families and other significant people in appropriate aspects of the care and support of people with dementia, if they want to be involved ■ Be able to identify and address the care and support needs of carers in their own right
Supporting and working with Dementia Friendly Communities, Carer Friendly Communities and local neighbourhoods	
<p>A Dementia Friendly Community (DFC) is a local community initiative that focuses on stigma reduction and the inclusion of people with dementia in all aspects of family and community life. People living and working in the community, including children, are educated about dementia and know that a person with dementia may sometimes experience the world differently.</p>	<ul style="list-style-type: none"> ■ Understand the role that people living in the wider community play in the lives of people with dementia and carers ■ Understand the importance of giving people with dementia a voice in their community

WELL-BEING THEME: COMMUNITY INCLUSION AND CONTRIBUTION

SUMMARY	LEARNING OUTCOMES The learner will:
Supporting and working with Dementia Friendly Communities, Carer Friendly Communities and local neighbourhoods (continued)	
<p>In DFCs, people with dementia and carers feel supported by their community members whether they are at post offices, shops, banks, using transportation or enjoying activities out in the community.</p> <p>The development of DFCs is a central feature of the Ageing Well in Wales programme: http://www.ageingwellinwales.com/en/home</p> <p>Carer Friendly Communities (CFCs) are places where carers feel supported to look after their family or friends, and recognised as individuals with needs of their own.</p> <p>Whilst DFCs and CFCs are essentially grass roots organisations, they can be supported and encouraged by professionals working in health and social care services.</p> <p>People with dementia and carers who receive support from health and social care services may benefit from being involved in DFCs and CFCs and professionals should facilitate their engagement with them.</p>	<ul style="list-style-type: none"> ■ Be able to support people with dementia and carers to access community facilities and networks, both retaining and developing their links where possible ■ Be able to identify and engage with opportunities to inform and educate the wider community about some of the issues related to having dementia (as in the Dementia Friends initiative) or in being a carer
Supporting and working with volunteers	
<p>Volunteers can play a very important role in enriching the quality of life of people living with dementia and carers. Volunteers may support someone who does not receive any formal services, but may also 'add value' to health and social care services (e.g. in supporting the work of care homes and hospitals).</p> <p>Professionals need to understand how to value, support and encourage volunteers and volunteering.</p> <p>It is important to recognise the difference between formal volunteering (which usually requires registration with an agency and a DBS check, if supporting an individual) and informal volunteering (e.g. people from the community 'chipping-in' to communal activities and events in care homes) and be able to judge when each kind of volunteering is appropriate.</p>	<ul style="list-style-type: none"> ■ Understand the important part volunteers can play in the lives of people with dementia and carers ■ Understand the different types of volunteering and the associated, proportionate safeguards that need to be put into place ■ Be able to support the involvement and well-being of volunteers in the care and support for people with dementia and carers

WELL-BEING THEME: COMMUNITY INCLUSION AND CONTRIBUTION

SUMMARY	LEARNING OUTCOMES The learner will:
Intergenerational activities	
<p>Intergenerational activity brings together people of different ages (from young to old) in positive, planned activities designed to bridge gaps between generations. These activities are most beneficial for everyone concerned when they all have an opportunity to give as well as receive. For example, whilst older people in a care home may enjoy hearing children sing, they generally find their contact with children more rewarding when they feel they have something to give to them, which can include sharing their wisdom and stories.</p> <p>Intergenerational activities can also challenge discrimination, stigma and institutionalised health and social care services. Research has identified the benefits to older people of being involved in intergenerational activities (Park, 2014). Those involved in supporting people with dementia and carers should explore how to promote and facilitate intergenerational activities.</p>	<ul style="list-style-type: none"> ■ Understand the benefits intergenerational activities can have for all involved, whatever their age or abilities ■ Be able to identify, promote and support the development of intergenerational activities

WELL-BEING THEME: SOCIAL AND ECONOMIC WELL-BEING

SUMMARY	LEARNING OUTCOMES The learner will:
Cultural and language diversity	
<p>It is important to recognise and respond to the language and cultural needs of people with dementia and carers. This starts by finding out what matters to individual people, rather than making generalised assumptions about people from particular cultural backgrounds.</p> <p>Cultural competency requires:</p> <ul style="list-style-type: none"> ■ The valuing of diversity; ■ The capacity for cultural self-assessment (being aware of your own culture and language and how it shapes your thoughts and actions); ■ Knowledge of individuals' cultural and language background and how this relates to various aspects of their life; 	<ul style="list-style-type: none"> ■ Understand the concept of cultural background and how this shapes who we are ■ Understand the fundamental importance of language and how we use it to express who we are and communicate with others ■ Understand the importance of providing care and support in ways that respects and responds to the cultural and language needs and/or preferences of people with dementia and carers

WELL-BEING THEME: SOCIAL AND ECONOMIC WELL-BEING

SUMMARY	LEARNING OUTCOMES The learner will:
<p>Cultural and language diversity (continued)</p> <ul style="list-style-type: none"> ■ Awareness of and ability to explore the dynamics of difference, when people from different cultures and languages come together ■ An ability to adapt care and support to address all of the above in the promotion of well-being. 	<ul style="list-style-type: none"> ■ Be able to demonstrate cultural competency, i.e. the ability to respond to and support people with dementia and carers in ways that take account of their cultural background and associated preferences ■ Understand the status of the Welsh language and the active offer ■ Be able to support people with dementia and carers to express themselves in their preferred language (which for some people with dementia may be their first language, e.g. Welsh)
<p>Spirituality and faith</p> <p>The concept of spirituality is difficult to understand although there is an increasing acknowledgement that it plays an important part in our lives. There are two approaches to the definition of spirituality; both acknowledge a search for meaning. For some people a divine presence is central (faith); for others spirituality is a secular concept involving inner life and personal belief. Within health and social care services, questions of spirituality and faith should be included in assessment, care and support plans, as is often the case in palliative and end of life care services.</p>	<ul style="list-style-type: none"> ■ Understand the importance of spiritual and faith beliefs to individuals in helping them to make sense of the world and their place within it ■ Understand how an individual's spiritual and faith beliefs may impact on how care and support is provided and offered ■ Understand how an individual's spiritual and religious beliefs may impact on choices and decisions related to many aspects of daily life, death and dying ■ Be able to respond to and support people with dementia and carers in ways that value and respect their spirituality and faith

WELL-BEING THEME: SOCIAL AND ECONOMIC WELL-BEING

SUMMARY	LEARNING OUTCOMES The learner will:
<p>Employment can be a major concern to anyone affected by dementia, but will be of particular importance to people with young onset dementia, who may have families to support.</p> <p>Employers should provide appropriate support throughout the journey of a person with dementia. Health and social care professionals can provide advice and support to both employers and employees regarding this.</p> <p>People with dementia have reported negative reactions at work to their diagnosis, including bullying. Reducing the stigma attached to dementia would enable individuals to acknowledge and discuss any problems that they might have at work because of their dementia and enable employers to make reasonable adjustments to support their needs.</p> <p>As a person's dementia advances, employers and employees will require information, advice and guidance about finishing work.</p>	<ul style="list-style-type: none"> ■ Understand the importance that employment plays in the life of people with dementia and carers, particularly people with early onset dementia who are in paid employment ■ Be able to support people with dementia and carers to retain their employment ■ Be able to work collaboratively with employers and other social and health care professionals in the support of people with dementia and carers
<p>Access to financial benefits and entitlements</p> <p>People with dementia and carers can struggle to access their entitlements as a result of limited staff knowledge about financial benefits and entitlements or a failure to explore this in assessment processes. Health and social care professionals can provide appropriate advice and support with this.</p> <p>The financial impact of giving up work particularly affects people with early onset dementia who are more likely to have financial commitments and dependent children. Health and social care professionals should refer people to appropriate sources of financial information, advice and guidance.</p>	<ul style="list-style-type: none"> ■ Understand the importance of people with dementia and carers having full access to all their benefits and entitlements ■ Be able to support people with dementia and carers to access appropriate financial benefits and entitlements, including assistance with administration and referral to specialist advice and support services, as needed

WELL-BEING THEME: SOCIAL AND ECONOMIC WELL-BEING

SUMMARY	LEARNING OUTCOMES The learner will:
<p>Family and social networks</p> <p>Family and social networks are important to everyone. Such networks provide meaning and purpose to people's lives and support to help them travel through the ups and downs of life's journeys. Having good family and social networks can delay the onset of dementia (Frataglioni et al, 2000) and enable carers to carry on caring (Charlesworth et al, 2007).</p> <p>Professionals working in health and social care should support and strengthen the development of family and social networks in whatever way they can. The development of community based network organisations, e.g. Circles of Support is one way of achieving this:</p> <p>http://www.circlesnetwork.org.uk/home.asp?slevel=0z&parent_id=1</p>	<ul style="list-style-type: none"> ■ Understand the importance of existing and potential networks of support for people with dementia and carers ■ Be able to support people with dementia and carers in strengthening their family and social networks of support wherever possible, in order to maximise their well-being and complement any formal services that may be required
<p>Peer support and activism</p> <p>Whilst it is important to maintain a sense of personhood for people with dementia (Kitwood, 1997) through person-centred and relationship-centred approaches to support, there is growing recognition of the need to promote and support their citizenship (Bartlett and O'Connor, 2010).</p> <p>A citizenship approach focuses on issues such as social inclusion, sharing power, being involved and making things happen.</p> <p>People with dementia and carers are realising their citizenship through advocacy and peer support groups, lobbying and campaigning and their participation in research, e.g. the Scottish Dementia Working Group: http://www.sdwg.org.uk/</p> <p>People with dementia and carers need information about and access to these kinds of activities to support their citizenship. The Dementia Engagement and Empowerment Project (DEEP) is working across the UK to facilitate this:</p> <p>http://dementiavoices.org.uk/ as is the Alzheimer's Society Service User Review Panel in Wales.</p>	<ul style="list-style-type: none"> ■ Understand what is meant by a citizenship approach to supporting people with dementia and carers ■ Understand the benefits of peer support ■ Be able to encourage and facilitate the development of peer support for people with dementia and carers ■ Be able to actively support the involvement of people with dementia and carers in the design and delivery of any care, support, service or research, intended to assist them

WELL-BEING THEME: PHYSICAL ENVIRONMENT

SUMMARY	LEARNING OUTCOMES The learner will:
<p>Wherever a person with dementia is living, the environment should reflect and support who they are. It must include aspects of 'home' which are important to them, with a particular focus on possessions of emotional significance and interest to them. Well-designed living spaces will enhance a person with dementia's senses of security, continuity, belonging, purpose, achievement and significance.</p> <p>When people have a restricted living space and limited mobility, it is important to create an immediate environment that as far as possible, addresses all of the above. This requires attention to detail.</p> <p>Within care settings, the placement of 'interesting features' along communal paths and corridors and within individual communal rooms, can stimulate interest, promote memory and create a homely atmosphere.</p> <p>The availability of quiet spaces can be important for some people with dementia.</p>	<ul style="list-style-type: none"> ■ Understand the particular importance of the physical environment in supporting a sense of self and the emotional wellbeing of people with dementia ■ Be able to support the adaptation and development of the physical environment in order to make it most conducive in supporting the well-being of people with dementia ■ Understand the importance of quiet spaces for some people with dementia
<p>The environment needs to support the independence of people with dementia and ability to engage in meaningful living and meaningful relationships. This is best achieved using clear design that eliminates unnecessary complexity and design features that are familiar and recognisable (e.g. taps, toilet rolls and household items).</p> <p>The inclusion of settees as well as individual chairs in health and social care services can enable people to sit together if they want to and chairs arranged in clusters rather than lines can promote positive social interactions. Chairs along corridors enable people to stop and rest whilst going somewhere.</p> <p>Physical accessibility is important in both outdoor and indoor environments. There is a wide range of research-informed guidance on all of the above and more which should be read and applied (see Appendix 1: Resources).</p>	<ul style="list-style-type: none"> ■ Understand the part that furnishings and fittings play in maximising the independence, comfort and well-being of people with dementia ■ Understand issues related to safety in terms of the layout of rooms and how and where furniture and fittings are placed ■ Understand the importance of small design features in relation to enhancing the quality of life and independence of people with dementia ■ Be able to access and use good practice guidance in the design of physical environments for people with dementia

WELL-BEING THEME: PHYSICAL ENVIRONMENT

SUMMARY	LEARNING OUTCOMES The learner will:
<p>Visual accessibility is a very important and must be enhanced through:</p> <ul style="list-style-type: none"> ■ The maximisation of natural light – but with the potential to control it (e.g. with blinds); ■ A good level of lighting throughout the environment, and avoidance of sharp variations in lighting levels, e.g. excessive brightness and shadowed areas; ■ Avoidance of glossy finishes to floors and other surfaces that might cause glare or confusing reflections; ■ Good visual and colour contrast (i.e. surfaces, features and controls); ■ Things, e.g. paintings or sculptures to help people find their way around buildings or gardens; ■ Signs that are clear and understandable to the person; ■ Making important things that might be hidden and 'out of mind' clearly observable and accessible (e.g. food in a fridges or cupboards, which can be addressed by having a transparent doors). <p>Glass doors and other potential hazards need to be clearly marked or removed.</p> <p>A layout that enables people with dementia to observe activities without actually participating, can promote important social and sensory stimuli.</p> <p>It is also important to create an environment that minimises unnecessary background noise (e.g. a television that no one is watching).</p>	<p>Visual and other sensory accessibility</p> <ul style="list-style-type: none"> ■ Understand how environmental factors such as light and sound can impact both positively and negatively on the lives and well-being of people with dementia ■ Understand the importance of appropriate signage and other features that support the safety, independence and well-being of people with dementia ■ Be able to access and use good practice guidance regarding visual and other sensory accessibility for people with dementia
<p>There is a vast array of assistive technology that can be used to support the independence and well-being of people with dementia and carers.</p>	<p>Use of assistive technology to support independent living</p> <ul style="list-style-type: none"> ■ Understand how technology can be used to enhance the independence, safety and well-being of people with dementia and support carers

WELL-BEING THEME: PHYSICAL ENVIRONMENT

SUMMARY	LEARNING OUTCOMES The learner will:
<p>Use of assistive technology to support independent living (continued)</p> <p>Examples include:</p> <ul style="list-style-type: none"> ▪ automated prompts and reminders ▪ clocks and calendars ▪ medication aids ▪ locator devices – for things that often get lost ▪ communication aids, e.g. Skype, adapted phones ▪ safety devices, e.g. automatic lights, shut-off devises, fall sensors, phone call blockers ▪ safer walking devices, e.g. boundary alarms, location monitoring devices (see description under Safeguarding on page 34) ▪ automated prompts and reminders ▪ equipment for leisure, e.g. electronic games, interactive artefacts, digital photo frames etc. <p>Assistive technology should never be used as a substitute for important human contact. Careful ethical consideration is required before using it.</p> <p>Some products may not have been designed with the specific wants of the person with dementia in mind and, as a result, they may not achieve the required outcomes. Instead, it is expected that the person will adapt to the technology, not the other way round. Expecting the person with dementia to adapt, without listening to their views, can affect how keen they are to use the technology. This in turn will affect how successful it is.</p>	<p>The learner will:</p> <ul style="list-style-type: none"> ■ Understand that people with dementia benefit from the early introduction of assistive technology ■ Be able to work with other professionals and technology suppliers to assess and use technology in ways that promote the safety, independence and well-being of people with dementia and carers ■ Understand the limitations of technology; in particular, in relation to it not being a substitute to 'real' human contact ■ Understand that the use of assistive technology needs to be outcome focused, not technology led
<p>Outdoors and the natural environment</p> <p>The outdoors and natural environment can create an important multi-sensory experience for people with dementia, as well as having physical and mental health benefits. Some people may just want to feel the wind or sunshine on their face, whilst others might want to engage in outdoor activities that may be perceived as involving risk. This must never be ruled out.</p>	<p>The learner will:</p> <ul style="list-style-type: none"> ■ Understand and recognise the importance of the natural environment in providing sensory and aesthetic stimulation for people with dementia, that promotes their well-being

WELL-BEING THEME: PHYSICAL ENVIRONMENT

SUMMARY	LEARNING OUTCOMES The learner will:
Outdoors and the natural environment (continued)	
<p>For some people with dementia who are not able to access the outdoors and the natural environment, there are ways of bringing these to them (e.g. flowers in a room, bringing in animals to hold and stroke, having bird feeders outside windows). Low windows can make the outdoors more visible to people sitting in chairs.</p> <p>GPS locator systems and devices (e.g. linked to a mobile phone) can be used to support people with dementia who want to experience the outdoors on their own, but who do not want to get lost.</p> <p>Films and recordings from nature can provide a virtual natural environment indoors, for people with dementia who are unable to go out.</p>	<ul style="list-style-type: none"> ■ Understand the different ways in which people with dementia can be supported to experience the outdoors environment ■ Be able to facilitate opportunities for people with dementia to access the real or virtual natural environment within the context of positive risk-taking.
Health and safety	
<p>It is very important to recognise that there is a duty to ensure that the environment goes beyond providing a physically safe space and facilitates a sense of personal and psychological security.</p> <p>Health and safety guidelines (e.g. moving and handling, avoiding slips and trips etc.) are important for people with dementia, carers and staff in health and social care services and must be understood and applied.</p> <p>However, these guidelines must never be misapplied to the detriment of people (for example, the creation of a sterile and depersonalised living environment in the name of keeping people 'safe'). There are many myths about health and safety, which the Health and Safety Executive are keen to challenge:</p> <p>http://www.hse.gov.uk/myth/top10myths.htm</p>	<ul style="list-style-type: none"> ■ Understand how health and safety legislation and guidance places a responsibility on everyone to ensure that the safety of everyone concerned is fully considered within a balanced risk assessed process ■ Understand how the correct use of equipment can keep everyone safe whilst promoting the independence and well-being of people with dementia ■ Be able to identify and respond to potential and actual health and safety hazards in ways that promote the safety and well-being of everyone concerned ■ Be able to challenge and overcome health and safety myths within the context of good practice

Chapter 3: Engagement to support wise practice

Compassionate and technically **competent** practitioners are not the same as **engaged** practitioners. Engaged practitioners are compassionate and competent, but also feel good about what they do, and work within systems that are empowering, enabling them to make wise decisions about how they support people with dementia, carers and staff within in the context of their daily lives. As one recent study of professional practice suggests:

'Rather than a set of discrete knowledge and skills, professionalism may be better regarded as a meta-skill, comprising situational awareness and contextual judgement, which allows individuals to draw on the communication, technical and practical skills appropriate for a given professional scenario. The true skill of professionalism may not be so much in knowing what to do, but when to do it' (Morrow et al, 2014).

How we support this wise, reflective and responsive practice must lie at the heart of this framework. This includes a strong focus on the emotional well-being of frontline staff as well as people with dementia and carers, which will require:

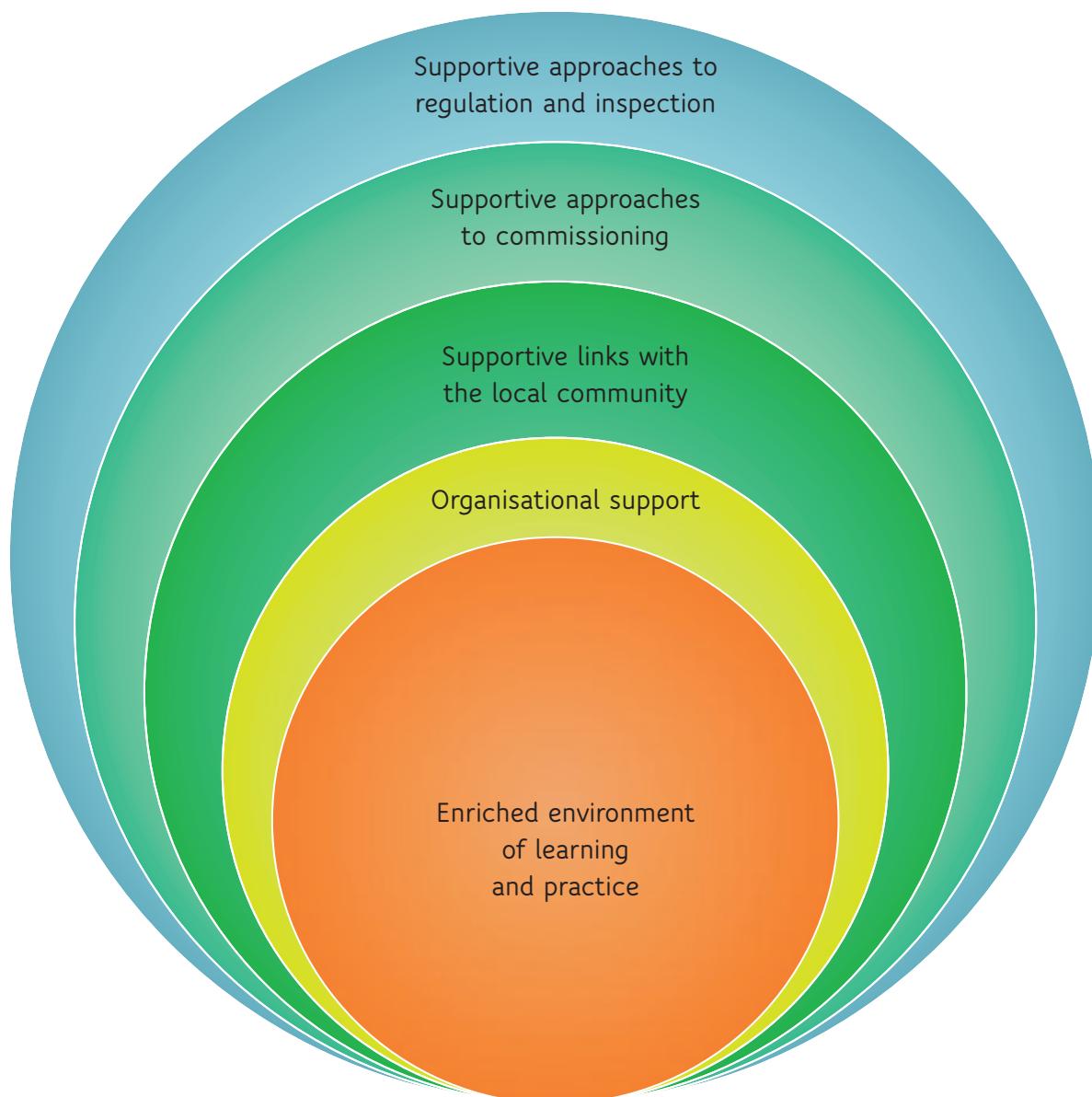
- A whole system approach to supporting the development of an 'enriched environment of learning and practice'
- Good leadership within organisations
- Robust and meaningful quality assurance
- An effective approach to individual and collective learning and development
- Learning and development topics and learning outcomes for influencers

3.1 A whole system approach to supporting the development of an 'enriched environment of learning and practice'

'Enriched environments of learning and practice' (Nolan et al, 2006) cannot exist in isolation, and are very much dependent on support from other stakeholders including organisational management, the local community, commissioners, regulators and inspectors, as illustrated in the diagram on the next page. Without these circles of support, effective learning and good work at the frontline will be impeded or impoverished in some way.

For example:

- Inflexible time and task care and support plans may stop frontline home care staff from being able to respond to the needs of the moment (Patmore and McNulty, 2005).
- Poorly designed and ineffective paperwork imposed on care homes by commissioners and regulators, can impact on the amount of time staff can spend more meaningfully with residents (Warmington et al, 2014).



It is beyond the scope of this framework to go into detail regarding supportive approaches to commissioning and regulation, details of which can be found in recent legislation and guidance. However, it is important to acknowledge the crucial role that these activities have on the ability of individuals and organisations to develop and practice good work.

3.2 Good leadership within organisations

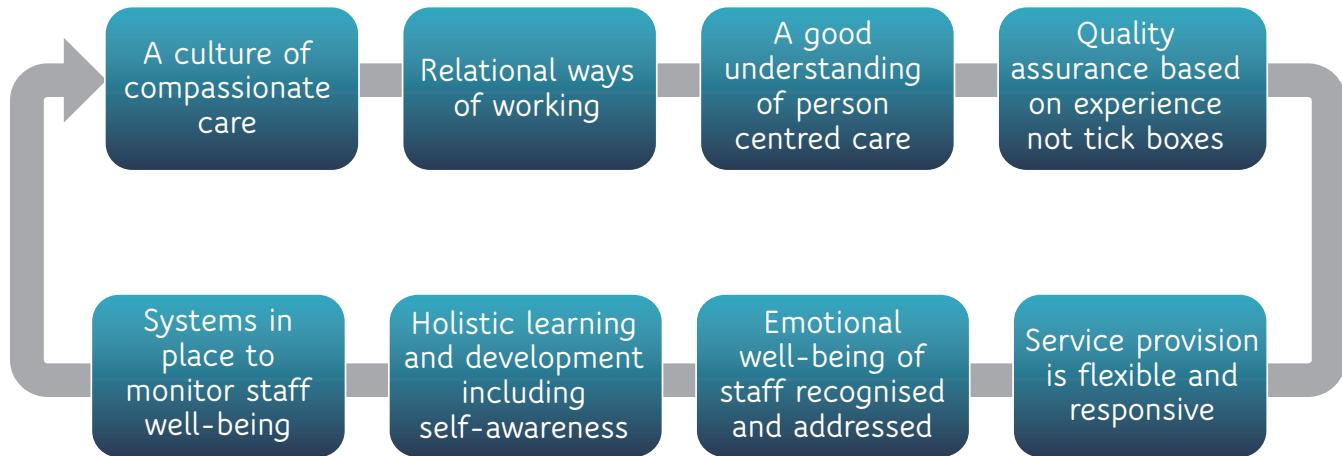
'Instead of trying to come up with a vision and make innovation happen themselves, a leader of innovation creates a place – a context, an environment – where people are willing and able to do the hard work that innovative problem solving requires. One of the leaders we studied neatly summed this up by repeating a line he had heard from a Chief Executive Officer he admired. 'My job' he said, 'is to set the stage, not perform on it' (Hill et al, 2014).

There are many definitions of what makes a good leader and this thinking has developed over time. Some of the earliest thinking outlined the notion of the heroic leader, the person who would swoop-in to save the day; the hero who comes to the rescue. This then developed through other theories including trait and behaviourist theories, situational leadership, contingency theory and on to transactional and transformational leadership. Much has been written about this including references in reviews from a range of business schools across the UK and wider. This also links to reviews of performance management and development systems that seek to improve the performance of managers and hence, organisations. Some of these reviews found that the concept of organisations having a shared narrative around identity and purpose, including clarity about 'who we are' and 'what we value' were central in determining impact. This very much relates to the promotion of co-productive approaches referred to elsewhere in this framework:

'A number of competing and inter-related dynamics were uncovered that influence the extent to which performance management systems facilitate appropriate and desirable forms of behaviour in organisations and the extent to which these are supported and reinforced through leadership development. The most significant of these influences was seen to be one of identity and the impact that these systems can have on a sense of shared 'social identity' and purpose. By way of conclusion we argue that the narrative function of corporate leadership systems in expressing 'who we are' and 'what we value' is equally, if not more, important in determining their impact (positive or negative) than their corrective or developmental capacity per se.' (Bolden et al, 2008).

Sheard (2009) reflects this thinking in suggesting a move away from a 'clinical' service model based on impersonal, task-based care, towards a more responsive and humane 'congruent' service model:

Adapted from a diagram copyright © David Sheard and reproduced with permission.



Practice Guidance for Social Care Managers (Care Council for Wales, 2015) makes a number of observations about the pivotal role that managers have and this includes the following guidance:

'You should do all that you can to actively promote an open, fair and learning culture in the workplace. You should create an environment where others regularly have the opportunity to share good practice, raise concerns, contribute ideas, be creative and innovative, consider the latest research findings and to engage in decision making as part of a team. You should respect, value and acknowledge the roles, contributions and expertise of others. You should promote the sharing of information and resources. You should find ways to celebrate good performance and success'.

Guidance within health services states that:

'The Evidence base where health service staff report they are well-led and have high levels of satisfaction with their immediate supervisors, patients report that they, in turn, are treated with respect, care and compassion. Overall, the data suggest that when health care staff feel their work climate is positive and supportive, as evidenced by coherent, integrated and supportive people management practices, there are low and declining levels of patient mortality. These associations are consistent across all the domains of health care - acute, mental health, primary care and ambulance. Engagement also appears to be higher in health care organisations where leaders create a positive climate for staff so they feel involved and have the emotional capacity to care for others'. (Kings Fund, 2015)



Bringing all this together paints a picture of a leader who embraces the co-productive principles outlined elsewhere in this framework and extends this thinking further. What emerges is someone who is true to their values and vision (i.e. being congruent). This is then underpinned by a true valuing of all people at all levels, including at an emotional and relational level. Much of this resonates with the work of Carl Roger's views about human development (Rogers, 1961) which includes the following significant learning:

- 'In my relationships with persons I have found that it does not help, in the long run, to act as though I were something that I am not'. This is all about congruence, or, as many in management now refer to it – authenticity.
- 'I have found it enriching to open channels whereby others can communicate their feelings, their private perceptual worlds, to me'. This supports the view elsewhere in this chapter and elsewhere about relating to people on an emotional level.
- 'I have found it highly rewarding when I can accept another person'. This relates to one of Rogers' most well-known concepts of 'unconditional positive regard'.

This may seem all rather fuzzy to those brought up in traditional management thinking, however, as can be seen by the research referenced in the Kings Fund document, this type of management can bring about tangible benefits for those who use the service and others. Everyone benefits from an enriched environment where people are truly valued in all roles within a trusting environment. This goes beyond just the service provider and extends to other health and social care providers, commissioners and regulators. Even though there will undoubtedly be continued pressure on all organisations in terms of resources, this type of working is not resource dependant. What is required are leaders and other influencers who can embrace the concepts outlined in this framework and inspire others to do so too.

3.3: Robust and meaningful quality assurance

Quality assurance and improvement processes are central to ensuring individuals receive the best support possible. They ensure that things are working as they should be and there is a continual process of self-reflection. Inspectorates in Wales are increasingly putting more focus on this area in order that organisations that provide services have these processes in place.

Part of any quality assurance system need to be clear about what quality looks like. This why Wales, like other countries, focuses on outcomes for the users of the service. The NHS in Wales also describes the triple aim of:

- Providing the highest possible quality care and excellent experience
- Improving health outcomes and helping reduce inequalities
- Getting high value from all our services

In the spirit of this framework, quality assurance processes need to value and embrace the views of the individual and/or the people who know them best as far as possible. These processes ideally need to involve people in reflecting on what is working well and what needs to be improved, as well as the tick-box approach to ensure things have been done. Essentially this involves asking the question, 'what have we learned from this?'

Traditional approaches to quality assurance often focus most on identifying what the problems are in order to fix them. This often misses out on the gold dust of what is working well and why. When the focus is continually on what is not working, and inevitably whose fault it was, this can lead to a blame culture which does little to engage people in wanting to improve. Focusing on what is working and celebrating pockets of success can do the opposite, leading to people want to make improvements and take an active part in this process.

Whilst this focus on what works is important, this is not to say leaders and managers should not be identifying problems and resolving them as soon as they are able. This is critical in many areas including safeguarding issues or anything that may have an immediate consequence for people's safety or welfare.

There are many ways to involve people, including those outside of the paid workforce, in this process of quality improvement. Whilst questionnaires and surveys have their place, there is growing evidence regarding the use of narrative stories in quality assurance. Techniques such as Experience Based Co-Design (Bate and Robert 2007, Kings Fund) capture the experience of people in health and social care services in the form of stories about the highs and lows of their experiences of care and support. These stories are then shared with staff in group discussions, which can become the foundation stones for quality improvement. The 'Magic Moments' storytelling work in care homes in Wales (Andrews et al, 2015) has also proved to be successful in recognising and developing quality care.

Quality assurance also includes the best use of medicines for people with dementia, which requires close multi-disciplinary team working and medicines monitoring (NICE, 2015).

3.4 An effective approach to individual and collective learning and development

Individual learning

Individual learning for front line staff and managers within health and social care organisations takes place through formal, non-formal and informal routes.

Formal routes centre on recognised accredited programmes at various levels. These result in learners attaining broad based qualifications such as Diplomas or Degrees that prepare them for their area of specialism. These formal qualifications provide the knowledge and skills for a range of work roles and act as a gateway to professional registration. After this, individuals are expected to maintain and develop their levels of competence through further and on-going training. Further training can be accredited or not.

Non-formal routes take place in a semi-structured way through involvement in meetings, supervision, individualised action learning, coaching and mentoring. Although these routes do not result in a formal degree or diploma, non-formal education can often be highly enriching and engaging as it builds an individual's skills and capacities based on their areas of interest and passion. There is also a middle ground of accredited informal learning.

Informal learning is usually incidental with no set programme, curriculum or formal recognition. For example, it might be based on a random piece of advice from a colleague, observation of how others work, skills learned by doing an activity over and over. This type of working can be very powerful because it is potentially occurring all the time. Whilst this form of learning can contribute to the development of good contextualised practice, there is also a danger of learning bad practice, which needs to be recognised and addressed.

Finally, when reflection and learning only takes place within an organisation or service, it often misses opportunities to open up that individual or organisation to the outside world of experience. Therefore, it can reinforce or maintain low levels of individual and organisational absorptive capacity. This is why learning opportunities should always include elements of wider reflection with other stakeholders including people with dementia and carers.

Collective learning

Whilst individualised learning has its place, there is growing evidence to suggest that learning and development are most effective when addressed collectively, especially when it involves a range of different stakeholders with different perspectives, for example through techniques such as Appreciative Inquiry (Cooperider et al, 2003), Communities of Practice (Wenger, 2002), Caring Conversations (Dewar and Nolan 2013), Communities of Enquiry (Lipman, 2003) and Collaborative Action Learning (Barr and Dailly, 2008).

Such techniques not only support learning, but also the *unlearning* of ideas and ways of working that are potentially unhelpful, through a process of listening to and learning from others.

Developing Evidence-Enriched Practice (DEEP) is an appreciative and collective approach to improving health and social services involving people who use services, carers, frontline staff, organisational managers, and researchers. It was developed and tested in Wales and Scotland, in partnership with the Joseph Rowntree Foundation during 2014/15 (Andrews et al, 2015). This approach to learning and development is very much in the spirit of the *Social Services and Well-being (Wales) Act 2014* with a strong emphasis on the co-creation of knowledge and practice, drawing on a wide range of evidence from people who use services, carers, frontline staff, managers and researchers in service and workforce development.

Whilst not being prescriptive about techniques, the DEEP approach suggests that there are five key elements that must all be addressed in collaborative learning and development as outlined below:

Element 1: Valuing and empowering all of the people involved in the project – senior managers must support participants to be creative and able to experiment with ideas. Trusting relationships need to be developed between everyone involved, so people can be honest and feel safe. People need to feel appreciated and their successes (even in little things) celebrated.

Element 2: Valuing and using a range of evidence – it is important to consider ‘what matters’ to everyone involved, which means that four main types of evidence needed to be considered – research, the views and experiences of people who use services and carers, the expertise of frontline staff and organisational knowledge including policy.

Element 3: Preparing and sharing evidence, so that it is interesting and relevant – evidence needs to be shared in meaningful and engaging ways, for example through short research summaries, stories, pictures, poetry or even songs that engage with participant’s emotions as well as their intellects. Sometimes evidence can also be summed up in provocative statements, which get people thinking.

Element 4: Facilitating the exploration and use of evidence – this is perhaps the most important and complicated thing. Well-structured approaches to helping people think and talk together, enables them to be better listeners and more open to learning. As a result, they come up with collective ideas and decisions and everyone feels that their contributions are welcomed. Different bits of evidence can be weaved-in to discussions as they became relevant over time.

Element 5: Recognising and addressing national and local organisational circumstances and obstacles – it is important to consider and tackle things that can get in the way of success. These include well-meaning national and local rules and regulations which do not always fit well with contextual decision making and what participants feel are the most important things in promoting well-being.

The following diagram is a helpful way of summing-up the five elements of Developing Evidence-Enriched Practice:



Further details of the Developing Evidence-Enriched Practice (DEEP) project can be found at:
www.jrf.org.uk/publications/developing-evidence-enriched-practice-health-and-social-care-older-people

A range of DEEP resources and associated learning and development techniques can be found at:
<http://deep-resources.chrismog.co.uk>

3.5: Learning and development topics for Influencers

The Influencer

The following list of learning and development topics and impact statements build on those outlined within the Informed and Skilled sections. They are areas that are particularly critical for Influencers to focus on and be competent in. It should also be noted that there may be a number of different people who are able to take on this role. Impact statements have been referenced in this section on the basis that Influencers have a pivotal role in shaping how services for people with dementia perform and develop. The impact statements link to the National Outcomes Framework in terms of how the influencer can tangibly improve the lives of people with dementia, family carers and other significant people.

LEARNING AND DEVELOPMENT	
SUMMARY	TANGIBLE OUTCOMES Influencers ensure that:
Influencers need to be aware of key initiatives, policies, research and other information that informs others how services could or should develop. They use this information to shape systems of support in order that they best meet individual's needs in creative and individual ways.	<ul style="list-style-type: none"> ■ Plans and strategies are informed by the latest legislation, guidance, research and other relevant information ■ People receive support that is informed by the latest guidance and thinking in terms of quality service provision and other systems of support
Services and support systems are developed by a whole range of organisations and people over time. Very often these are fragmented. The people who provide them and use them are not always aware of the wider range of resources available to them. Influencers need to be able to have as much information as possible about these services and communicate this as effectively as possible.	<ul style="list-style-type: none"> ■ Everyone is clear about what services and supports are available ■ People who could benefit from services are able to access information about them as easily as possible. This includes having information about what is available, when and where ■ People accessing information about services and systems of support are provided with accessible and consistent points of contact, ideally with named individuals

LEARNING AND DEVELOPMENT

SUMMARY	TANGIBLE OUTCOMES Influencers ensure that:
<p>Services are more effective when people work together in a planned and coordinated way. Collaborative working is dependent on good and effective relationships, underpinned by good communication and trust. When this happens scarce resources can be used to maximum benefit, avoiding duplication and gaps in service. This links to effective service mapping – i.e. knowing what resources are available and how and where they are provided.</p>	<ul style="list-style-type: none"> ■ People within organisations and services have relationships that are built on mutual respect, trust and effective communication ■ Services are provided in such a way that they complement each other; offering the most effective support to users whilst also being efficient with their resources ■ Organisations continually review their working relationships in order to ensure they are maximising their potential to work collaboratively
<p>The establishment and development of a culture that reflects the ethics and values outlined in this framework and other recognised guidance is central to the role of the Influencer. Influencers need to ensure that these ethics and values can be seen and felt across all functions of the organisation – i.e. that there is congruence between what they and others say and what they do. This also links to the concept of authenticity, i.e. people being genuine and real. These things often cannot be taught through traditional training. This means that other processes such as effective recruitment, supervision, 360-degree appraisal, role modelling and creative approaches to personal and group development need to be explored.</p>	<ul style="list-style-type: none"> ■ The rights of individuals are always protected and promoted and people are able to recognise this for themselves and for others ■ Individuals are treated with unconditional positive regard ■ People are open and honest in their communication with others wherever possible and this is done in constructive ways that value the other person ■ People reflect on their own behaviour and recognise their strengths and areas for development ■ People are able to identify when they are wrong and feel confident to admit this to others ■ Everyone feels valued and that they matter, that they have a part to play and can contribute as well as receive support ■ People are able to express their views and ideas in an open honest way, confident that they will be listened to ■ People's views and ideas are fully valued and used, where these ideas will contribute to the positive development of services

LEARNING AND DEVELOPMENT

SUMMARY	TANGIBLE OUTCOMES Influencers ensure that:
<p>Influencers should promote co-productive approaches in order that everyone, who wishes to, has an involvement in and ownership of the services provided. This is one of the first opportunities to cultivate Engagement. This goes beyond traditional models of partnership working. Wherever possible and appropriate, strength based approaches should be considered in order to build on the best of what is already there. Approaches such as Appreciative Inquiry have been used successfully in Wales and elsewhere to do this (Rowett, 2015).</p>	<ul style="list-style-type: none"> ■ All key stakeholders, including people with dementia and carers, are offered the opportunity to be actively involved in creating ideas and plans for new and existing services in order that they best meet the needs and aspirations of those people who use them now and in the future ■ Everyone involved in service development has a shared ownership of plans and actions
<p>People providing services need to fully consider the cultural background and language needs and preferences of people with dementia and carers. This forms an intrinsic part of who they are and informs how support should and could be provided.</p>	<ul style="list-style-type: none"> ■ Wherever possible individuals are able to communicate in their first language; this is particularly important in relation to the Welsh language ■ Individual's cultural background is fully considered during the process of person-centred planning to inform how services and support can be organised and delivered
<p>Delivery involves ensuring people receive the right support, in the right way, by the right people at the right time. This element of timeliness has been a particular focus of health services (Morrow et al, 2014). All this support is underpinned by the skilled people on a day to day basis, being valued and empowered to work towards the outcomes defined within this document.</p>	<ul style="list-style-type: none"> ■ Everyone who has an interest and 'stake' in the delivery of services and systems of support is clear about what part they can play ■ People with dementia and carers are involved in the design and delivery of services (e.g. planning, recruitment and quality assurance) ■ Carers and other significant people in the life of the individual feel well supported in order that they can give their best ■ Paid staff feel valued and well supported through quality training and development ■ Staff and others providing direct support are competent to deliver excellent care and support

LEARNING AND DEVELOPMENT

SUMMARY	TANGIBLE OUTCOMES Influencers ensure that:
<p>Influencers are in a prime position to consider and support the implementation of new ways of working that may not have been considered before. This may involve adapting current practice or developing completely new approaches. Whilst policies, procedures and paperwork are important in order to provide a clear framework for people to work within, Influencers are in a position to ensure that these do not stifle innovation (Warmington et al, 2014). This is often a delicate path to tread, ensuring agreed policies, procedures and recording are adhered to, whilst also ensuring these do not limit individual's quality of life unduly. In some cases, this may result in a review of these policies and procedures in light of new learning.</p>	<ul style="list-style-type: none"> ■ People are encouraged and enabled to contribute to new ways of thinking that result in tangible improvement ■ Individuals and other significant people in their lives benefit from services and systems of support that are constantly adapting to their needs and preferences in creative ways ■ Service delivery is not unduly stifled by systems and processes that act against the best outcomes for individuals and other people being supported (e.g. family carers)
<p style="text-align: center;">Quality assurance and improvement</p> <p>Ensuring services stay on track and improve where required is a critical part of the Influencer role. Services also need to have an open and self-reflective culture underpinned by positive intent (i.e. a genuine wish for improvement), which allows for people to be honest and learn from their mistakes as well as their successes.</p> <p>Quality assurance is something that should be owned by and not imposed on the workforce. There should be a focus on improving, not proving; and the lived experience of people who use services and carers should be the main focus of attention, which is often best captured through stories of their experience. Associated paperwork must be proportionate and helpful, not burdensome.</p> <p>Influencers should maximise opportunities to reflect on what they do and this should lead to action. Processes such as Action Learning (Barr and Dailly, 2008).</p> <p>All of the above will ensure that the well-being of individuals is promoted and safeguarded. When feedback is received, either in a formal or informal way, appropriate action then needs to take place.</p>	<ul style="list-style-type: none"> ■ People feel part of a self-reflective culture where they are able to take quality time to review what they are doing and how they are doing it ■ People feel confident to say what they think about services and systems of support ■ People feel ownership of, and responsibility for, quality assurance whoever they are and whatever their role is ■ Focus given to what is working (and why) as well as areas for improvement ■ Everyone's views and opinions are valued ■ People are given feedback about how their ideas and views are taken forwards, or if they are not, why not

LEARNING AND DEVELOPMENT

SUMMARY

TANGIBLE OUTCOMES Influencers ensure that:

Complaints and whistle-blowing

Effective quality assurance systems should enable people to reflect in order to improve services in a pro-active way. However, sometimes services and support systems will fail. When they do, those responsible should react as quickly as possible, in an open and honest way, to respond and rectify identified issues. They should also seek to continually reflect on these failures, seeing them as a unique and valuable learning opportunity. Where systemic issues are identified as part of a complaint, longer term focus should be given to review ways in which these can be addressed. In general, these reviews should avoid attributing blame and seek ways to engage people in open and honest dialogue that builds on best practice.

- Everyone feels confident and able to express their concerns and complaints in an appropriate manner
- Employees fully understand their rights and responsibilities under the law in relation to whistle-blowing
- People who express their complaints and concerns are supported to do so where required or requested
- People who make complaints are fully aware of their rights under the appropriate policies and guidelines
- Where complaints identify shortfalls these are rectified as soon as possible and, where appropriate, everyone is informed what changes have occurred
- Key stakeholders are involved in reviewing systemic issues and this builds on people's personal experiences of best practice

Safeguarding

Keeping people safe is one of the most important things we can do, but this needs to be carried out in a considered manner that ensures individual rights are not compromised unduly. Risk assessments need to always balance the need to protect people with their right to have a good quality of life.

- Individuals are kept and feel safe without their quality of life being unduly compromised
- People understand relevant legislation and local guidance in relation to safeguarding



A closing thought regarding people with dementia

*'So, come out, friends, and dance,
Compose and sing;
Insist on feeling still and tasting still
The great wonder of the world.
Let's show all men that we are still alive'*

Gwyn Thomas, former National Poet for Wales
(quoted in the introduction to the *Strategy for Older People in Wales 2008 - 2013*)

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The photographs have been reproduced with the kind permission of Cathy Greenblat. They are taken from her inspirational book '*Love, Loss and Laughter: Seeing Alzheimer's Differently*' (<http://www.lovelossandlaughter.com/>) These photographs resonate with and complement the principles and learning and development topics in this Framework.

Appendix 1: Resources

1.1 Suggested reading (listed in alphabetical order of authors)

Title, Author & Date	Summary
Dementia: The One-Stop Guide: Practical advice for families, professionals, and people living with dementia and Alzheimer's Disease June Andrews (2015)	This book provides detailed and practical information about what makes a positive difference to people living with dementia including 10 helpful hints.
Broadening the Dementia Debate: Towards Social Citizenship (Ageing and the Lifecourse Series) Ruth Bartlett and Deborah O'Connor (2010)	An edited collection of chapters written by a range of authors, which take a life-course and rights-based approach to exploring and advancing current thinking around dementia.
A Dignified Life, Revised and Expanded: The Best Friends Approach to Alzheimer's Care: A Guide for Care Partners Virginia Bell and David Troxell (2012)	An encouraging and practical approach to supporting people living with dementia. The authors' philosophy of care underpins the approach used by Home Instead homecare agency.
Person-Centred Dementia Care, Second Edition: Making Services Better with the VIPS Framework Dawn Brooker and Isabelle Latham (2015)	A clear and concise outline of what 'person-centred care' really means. The book also introduces the VIPS quality assurance framework to help nurture and evidence person-centred care in practice.
■ Who Will I Be When I Die? ■ Nothing About Us Without Us Christine Bryden (2012 – 2015)	Two books which provide an honest and optimistic biographical account of making sense of life and the importance of being at the heart of decision making written by someone living with dementia.
The Validation Breakthrough Naomi Feil (2012)	The books sets out the principles and practice of validation, which helps people with dementia, staff and carers to stay 'connected' even in the later phase of dementia, when communication can be difficult.
Love, Loss and Laughter: Seeing Alzheimer's Differently Cathy Greenblat (2012)	A beautiful collection of thought provoking photographs and commentary that challenge the typical presentation of people with dementia.
■ Communication and the Care of People with Dementia ■ Dementia Positive ■ Playfulness and Dementia John Killick and Kate Allen (2001 – 2013)	A series of practical books that explore creativity and dementia and the importance and value of 'play' and other forms of communication in helping people to connect with one another and have fun together, whether living with dementia or not.

Title, Author & Date	Summary
Dementia Reconsidered: The Person Comes First Tom Kitwood (1997)	This classic book is by one of the founding fathers of person-centred dementia care. It introduces the concept of 'personhood' in dementia care and how to maintain, rather than undermine it.
Where Memories Go: Why Dementia Changes Everything Sally Magnusson (2015)	A thoughtful and deeply human biographical account of the experience of caring for relatives with dementia written by a carer and broadcaster.
Enriched Care Planning for People with Dementia: A Good Practice Guide for Delivering Person-centred Care (Bradford Dementia Group Good Practice Guides) Hazel May, Paul Edwards and Dawn Brooker (2009)	Detailed and thorough guidance on assessment and support planning with people living with dementia including end of life care.
Risk Decision-Making: Working with risk and implementing positive risk-taking. Steve Morgan (2013)	A practical guide on positive risk-taking and how to apply it in reality. The book includes a number of easy to use checklists to support reflective thinking and practice development.
Dementia Beyond Drugs: Changing the Culture of Care G.Allen Power (2010)	Visionary and practical advice by a Geriatrician which highlights the shortcomings of the biomedical approach to supporting people with dementia and provides an alternative illustrated with case studies.
Living Better With Dementia Shibley Rahman (2015)	A comprehensive guide to some of the latest thinking about how best to support people living with dementia addressing medical, psychological and social needs.
Feeling Matter Most series: <ul style="list-style-type: none">▪ Being: an approach to life and dementia▪ Enabling: quality of life an evaluation approach▪ Inspiring: leadership matters in dementia care▪ Nurturing: emotions at work in dementia care▪ Growing: training that works in dementia care▪ Achieving: real outcomes in dementia care homes▪ Loving: the essence of being a butterfly in dementia care David Sheard and Sally Knockier (2007 - 2015)	A series of books which provide a wealth of principles and practical advice on how to support a meaningful life not only for people living with dementia but also those who support them. This includes the 'Butterfly Household Model' to create moments of human connection, observational audit of care settings and approaches to organisational development which include nurturing the emotional well-being of staff.
And Still the Music Plays: Stories of People with Dementia Graham Stokes (2010)	Stories set at home, in care homes and in hospitals which illustrate how everyone living with dementia is unique and how we must therefore think deeply about each person individually.

Title, Author & Date	Summary
<ul style="list-style-type: none"> ■ Telling Tales About Dementia: Experiences of Caring ■ People with Dementia Speak Out <p>Lucy Whitman (2009 - 2015)</p>	<p>These two books are a celebration of people living, loving, learning, changing and growing with dementia through a collection of first-person accounts from people living with dementia and the people who support them.</p>
<p>Risk Assessment and Management for Living Well with Dementia</p> <p>Heather Wilkinson and Charlotte Clarke (2011)</p>	<p>This book outlines some key issues in risk assessment and introduces the concept of 'silent harms', which can result as a result of inappropriate risk-aversion.</p>
<p>Involving Families in Care Homes: A Relationship-Centred Approach to Dementia Care (Bradford Dementia Group)</p> <p>Bob Woods, Diane Seddon and John Keady (2007)</p>	<p>Provides a practical introduction to 'relationship-centred care' and the importance of supporting and involving families of people living with dementia.</p>
<p>I'm Still Here: Creating a Better Life for a Loved One Living with Dementia</p> <p>John Zeisel (2011)</p>	<p>This book illustrates with examples how it is possible to connect with people living with dementia by engaging abilities which do not diminish over time, such as music, art, facial expressions and touch.</p>
<p>Chocolate Rain</p> <p>Sarah Zoutewelle-Morris (2011)</p>	<p>A practical introduction to meaningful craft activities involving people with dementia.</p>

1.2 Some relevant Welsh organisations that can provide information and support

Title of organisation	Summary	Contact
Age Cymru	A national charity focused on older people, that provides information, advice and services in Wales and hosts My Home Life Cymru	www.ageuk.org.uk/cymru 029 2043 1555
Ageing Well in Wales	A national partnership that promotes Dementia Friendly Communities and other well-being themes in Wales	www.ageingwellinwales.com/ en/home 029 2044 5030
Alzheimer's Society	A national charity focused on dementia that provides information, advice and services in Wales	www.alzheimers.org.uk/ 0300 222 1122
Alzheimer's Society - Talking Point	An on-line forum for people with dementia and carers	forum.alzheimers.org.uk/ index.php?_ga=1.12025459.6194 91125.1455889536
Alzheimer's Society - Dementia Friends	A wide-scale initiative to change people's perceptions of dementia. It aims to transform the way the nation thinks and acts about dementia	www.dementiafriends.org.uk
Brecon Dementia Friendly Community	A dementia friendly community based in Brecon, Powys	www.dementiafriendlybrecon.org.uk 01874 676617 (Rhiannon Davies, Chair of the Group)
Care Council for Wales	The social care workforce regulator in Wales, working to ensure that the people of Wales can count on social services being provided by a professional, skilled and confident workforce. Their website provides access to a wide range of resources	www.ccwales.org.uk 0300 30 33 444
Centre for Ageing and Dementia Research (CADR)	A research organisation in Wales with a focus on older people and dementia	www.cadr.cymru/en 01792 295099
Citizens Advice Bureau	A national charity providing a wide range of advice to citizens in Wales	www.citizensadvice.org.uk/wales 03444 77 20 20

Title of organisation	Summary	Contact
Carers Wales	A national charity providing help and advice to carers in Wales	www.carersuk.org/wales/about-us 029 2081 1370
Carers Trust	A national charity providing help, advice and services to carers in Wales	www.carers.org/wales 0292 009 0087
Contact the Elderly	A national charity hosting Sunday tea parties and other activities for older people in Wales	www.contact-the-elderly.org.uk 0800 716543
Co-production Wales	A social enterprise promoting the role of co-production in public services in Wales	allinthistogetherwales.wordpress.com
Dementia Service Development Centre Wales	A national research and practice development organisation, that publish the magazine 'Signpost'	dsdc.bangor.ac.uk 01248 383719
Dementia Engagement and Empowerment Project	A national peer network for people with dementia with groups in Wales	dementiavoices.org.uk 01392 420076
DEWIS	A national on-line source of information about how to improve well-being in Wales	www.dewis.wales
Live Music Now	A national charity promoting live music in health and social care services in Wales	www.livemusicnow.org.uk/wales 02920 554040
Older People's Commissioner for Wales (OPC)	The OPC is an independent voice and champion for older people across Wales, providing help and support	www.olderpowlwales.com/en/Home.aspx 08442 640670
Person Centred Support	A charity that provides short breaks and befriending for people with dementia in North Wales	www.psspeople.com 0151 702 5555

Title of organisation	Summary	Contact
Public Health Wales	A national NHS organisation providing information, advice and support regarding healthy living	www.publichealthwales.wales.nhs.uk 029 2022 7744
Re-Live	A charity that promotes theatre and creative arts involving people with dementia and training in Wales	www.re-live.org.uk
Social Services Improvement Agency	A service improvement agency based within the Welsh Local Government Association. They have produced a wide range of helpful resources, which are available from their website	www.ssiacymrw.org.uk 029 2046 8685
Wales Dementia Helpline	A national helpline proving emotional support to all people affected by dementia	www.callhelpline.org.uk/ dementia-helpline.asp 0808 808 2235

1.3 Some other UK organisations that can provide information and support

Title of organisation	Summary	Contact
Circles Network	A UK-wide voluntary organisation focused on building inclusive communities on the foundations of justice, advocacy, empowerment and friendships.	www.circlesnetwork.org.uk/ home.asp?slevel=0z&parent_id=1 01788 816 671
Debenham Project	A community led support service for people with dementia and carers in Suffolk	www.the-debenham-project.org.uk 01728 862003
Dementia Care Matters	A training and development organisation with a focus on service and workforce development in care homes	www.dementiacarematters.com 01273 242335
Dementia Services Development Centre Stirling	A Scottish University based organisation providing dementia information, education and design advice	dementia.stir.ac.uk 01786 467740
Dementia Adventure	An organisation which promotes and provides opportunities for people with dementia to access the natural world	www.dementiaadventure.co.uk 01245 237548
DementiaUK	A charity promoting and providing relationship and family centred dementia information and support	www.dementiauk.org 020 7697 4160
Home Instead	A homecare provider agency that specialises in supporting people with dementia and carers	www.homeinstead.co.uk/Index.do 01925 730273
Innovations in Dementia	A community interest company, working nationally with people with dementia, partner organisations and professionals to promote well-being	www.innovationsindementia.org.uk 01392 420076
Joseph Rowntree Foundation	An independent organisation working to inspire social change through research, policy and practice with many on-line research-based resources	www.jrf.org.uk 01904 629 241
Journal of Dementia Care	A dementia journal committed to improving the quality of care provided for people with dementia, by keeping readers informed on a variety of topics	www.journalofdementiacare.co.uk 01371 851802

Title of organisation	Summary	Contact
Life Story Network	A community interest company which aims to educate, empower and enable people in the effective use of life story work	www.lifestorynetwork.org.uk 0151 237 2669
Liveability	A national Christian disability and community engagement charity, tackling barriers in society to make community liveable	www.livability.org.uk 020 7452 2000
Mental Health Foundation	A national charity providing support and research for good mental health, including people with dementia	www.mentalhealth.org.uk 020 7803 1100
My Home Life	A UK-wide initiative that promotes quality of life and delivers positive change in care homes for older people	myhomelife.org.uk
National Activity Providers Association (NAPA)	A national charity and membership organisation for all those interested in increasing activity opportunities for older people in care settings	www.napa-activities.com 0207 078 9375
Shared Care Scotland	A Scottish organisation aimed at improving the quality choice and availability of short breaks with on-line resources	www.sharedcarescotland.org.uk 01383 622462
Silverline	A free confidential helpline providing information, friendship and advice to older people, open 24 hours a day, every day of the year	www.thesilverline.org.uk 0800 470 8090
Social Care Institute for Excellence (SCIE) Dementia Gateway	On-line information and resources, including videos, e-learning material and downloads, for care workers, people living with dementia, carers and families	www.scie.org.uk/dementia
UK Men's Sheds Association	A UK-wide association of men's sheds, which provide meaningful occupation and friendship for men	menssheds.org.uk/#

1.4 Some free web-based learning and development resources under specific learning and development themes

Resource	Summary	Access/link
Well-being L&D theme: Rights and entitlements		
Declaration of Rights for Older People in Wales	This simple but profound policy document outlines six key rights, which are illustrated in everyday language	http://gov.wales/docs/dhss/publications/140716olderen.pdf
Care about Rights? training pack	A thorough and free training resource including film scenarios to support the exploration and promotion of human rights within care services	http://www.scottishhumanrights.com/careaboutrights/introduction
Dementia, rights, and the social model of disability	An outline of dementia in terms of the social model of disability, which suggests that 'problems' result not just from the clinical effects of dementia, but also from a variety of disabling barriers – physical, social and institutional	https://www.mentalhealth.org.uk/publications/dementia-rights-and-social-model-disability
Well-being L&D theme: Physical and mental health needs		
Clinical differences among the four common dementia syndromes	An 'open access' journal articles which provides a clear and concise description of four common types of dementia. You will need to register with Medscape to read – this is free	http://www.medscape.com/viewarticle/564627
Joining up	An Action On Hearing Loss report outlining why people with hearing loss or deafness would benefit from an integrated response to long-term conditions	https://www.actiononhearingloss.org.uk/joiningup.aspx
Joining up	Action on Hearing Loss have also produced a report showing how more joined up services can improve the quality of life experienced by people with dementia and hearing loss	https://www.actiononhearingloss.org.uk/news-and-events/all-regions/news/people-with-dementia-and-hearing-loss-failed-by-lack-of-jointed-up-health-and-social-care-services.aspx
JRF programme 'A Better Life'	A five year programme of research and development regarding what constitutes 'a better life' for older people with high support needs, including those with dementia. The website hosts a range of learning resources including research summaries, poems and songs	http://betterlife.jrf.org.uk/index.html

Resource	Summary	Access/link
Well-being L&D theme: Physical and mental health needs		
Jack and Jill	A short drama about the impact of dementia on families, based on key messages from research	https://vimeo.com/149265276
Barbara – the whole story	A film created by nurses and Guys and St Thomas' Hospital, London to raise awareness of the lived experience and needs of people with dementia	https://www.youtube.com/watch?v=DtA2sMAjU_Y
Call to Action: Dementia Words Matter	"Words are very powerful – they can build you up or put you down. When you are speaking about dementia remember this." Agnes Houston, person with dementia. This guide and video clip reflect on this	http://www.dementiaaction.org.uk/dementiawords
A New Life	A thought provoking song about living with dementia using words spoken by people with dementia	https://www.youtube.com/watch?v=KdadD6eSFQ4&feature=youtu.be
Dementia and Sensory Challenges	A user friendly guide to the sensory challenges (e.g. vision, hearing) associated with dementia, which are not always recognised and addressed due to only focusing on memory loss	http://www.ageingwellinwales.com/Libraries/Documents/Dementia-and-Sensory-Challenges.pdf
Nursing Toolkit	The toolkit contains good practice recommendations and tools to help all NHS services make practical, easy-to-implement, cost-effective changes that are proven to empower staff and improve patient experience.	https://www.actiononhearingloss.org.uk/supporting-you/gp-support/nursing-toolkit.aspx
Recognising Hearing Loss	This accessible video may be helpful for staff in recognising people with hearing loss and some of the links with dementia	https://www.youtube.com/watch?v=vARQ0lx558U
Well-being L&D theme: Safeguarding		
'Nothing Ventured, Nothing Gained' Risk guidance for people with dementia	It is a challenge to tread the line between being overprotective while respecting individual freedoms. This guidance provides a very helpful discourse about the issues at stake, presenting a framework for managing risk in a positive and constructive way by enabling and supporting people with dementia and carers	https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215960/dh_121493.pdf
How Can Positive Risk Taking Help Build Dementia Friendly Communities?	A short report which outlines the key features of positive risk-taking and how these can be applied in the promotion of dementia friendly services and communities	https://www.jrf.org.uk/report/how-can-positive-risk-taking-help-build-dementia-friendly-communities

Resource	Summary	Access/link
Well-being L&D theme: Meaningful living		
Living well in care homes	A free and comprehensive training pack developed by the British Association of Occupational Therapists regarding the development of activities in care homes	https://www.cot.co.uk/living-well-care-homes
People's Collection Wales	<p>A national database of pictures, songs, poems and stories about life in Wales, which can be used as a stimulus for reminiscence activities as well as learning and development. Examples include:</p> <ul style="list-style-type: none"> ▪ 'The Memoires of Strang the Strong: Georgie Muscles' - an anti-bullying book for children written by a man with dementia who still wants to make a contribution to the well-being of others ▪ 'Singing with Betti and Friends' - a collection of songs about and sung by a person with dementia who leads and inspires others to join in with her singing in a day service 	http://www.peoplescollection.wales http://www.peoplescollection.wales/items/443985 http://www.peoplescollection.wales/node/443934
A Celebration of Woodland	A short film about people with dementia engaging with the outdoor environment	https://www.youtube.com/watch?v=JLY_HbPMkEs
The Smile Within	A moving short Australian film about a comedian who uses comedy and playfulness to 'reignite the spark of life' in people with dementia and the people who support them	https://www.youtube.com/watch?v=Qi7I4LbxwG8
Well-being L&D theme: Meaningful relationships		
What do you see?	A 'found' poem that is written from the perspective of an older person, which calls for others to see and connect with the person behind the diagnosis	https://www.youtube.com/watch?v=oIye9fGz2IQ
Gladys Wilson and Naomi Feil - validating a person with advanced dementia	A short film illustrating the power of the validation technique for people experiencing advanced dementia developed by Naomi Feil, an Occupational Therapist	https://www.youtube.com/watch?v=CrZXz10FcVM
Love, Loss and Laughter musical photostory	A musical photostory featuring photographs of people with dementia engaging in meaningful activities and relationships to challenge the negative stereotype of 'suffering with dementia'	https://www.youtube.com/watch?v=c_utcMTOFzw
The Last Taboo	A comprehensive guide regarding dementia, sexual intimacy and sexual behaviour in care homes	http://www.ilcuk.org.uk/index.php/publications/publication_details/the_last_taboo_a_guide_to_dementia_sexuality_intimacy_and_sexualBehaviour

Resource	Summary	Access/link
Well-being L&D theme: Community inclusion and contribution		
Dementia Engagement and Empowerment Project (DEEP)	This project actively promotes people with dementia to contribute and take a lead on the issues that are important to them. The resources webpage is particularly useful in providing a range of guidance and ideas on how to do this	http://dementiavoices.org.uk/resources/
Dementia without Walls	A website sharing many inspiring resources: images, videos, stories, blogs, audio diaries, reports and toolkits. The voices and views of people with dementia themselves will resound through every page	http://dementiawithoutwalls.org.uk
Well-being L&D theme: Social and economic well-being		
Home from Home	An emotionally powerful film resource illustrating the importance of language, culture, family networks for people with dementia moving into care homes	http://www.re-live.org.uk/home-from-home/
Well-being L&D theme: Physical environment		
Design Resource Centre, Stirling University	The Dementia Services Development Centre in Stirling University provides a wealth of information on the design of dementia-friendly environments including a list of books, downloads and links	http://dementia.stir.ac.uk/information/design-resource-centre
Well-being L&D theme: Leadership and collaborative approaches service and workforce development		
The Senses Framework	A framework that can be used to support the development of 'enriched environments of care and learning' through ensuring older people, carers and staff all experience a sense of security, continuity, belonging, purpose, achievement and significance	http://shura.shu.ac.uk/280/1/PDF_Senses_Framework_Report.pdf
Why Good Leaders Make you Feel Safe	A short talk by Simon Sinek about the features of a good leader and the importance of focusing on the 'why' rather than just the 'what' we do in work	https://www.ted.com/talks/simon_sinek_why_good_leaders_make_you_feel_safe?language=en
Practical Wisdom	A short talk by Barry Schwartz that explains the danger of task based job descriptions, rules and incentives. He suggests that 'best practice' is only achieved through the development of virtue and providing a working environment that supports creative and humane practice in response to the needs of the moment	https://www.ted.com/talks/barry_schwartz_on_our_loss_of_wisdom?language=en#t-37494

Resource	Summary	Access/link
Well-being L&D theme: Leadership and collaborative approaches service and workforce development (continued)		
Developing Evidence-Enriched Practice approach	A collaborative approach to learning and development that brings together people who use services, carers, staff, managers and researchers to explore and use a range of evidence in service and workforce development. The resources website provides examples of 'evidence' and techniques that can be used to explore and use them	https://www.jrf.org.uk/report/developing-evidence-enriched-practice-health-and-social-care-older-people http://deep-resources.chrismog.co.uk/
My Home Life	A national movement established to create a world where all care homes for older people are great places to live, die, visit and work. The two websites listed provide links to a wealth of learning and development resources	http://myhomelife.org.uk/news-and-media/resources/ http://www.myhomelifedvd.org.uk/
Caring Conversations	A dialogue-based approach to appreciative and caring conversations focused on service and workforce development in health and social care	http://myhomelife.uws.ac.uk/scotland/caring-conversations/
Appreciative Inquiry	A strengths-based approach to organisational development that can be used in a wide variety of settings	http://www.academiawales.org.uk/Content.aspx?SitePageContentID=3266&SitePageID=332
Community of Enquiry	A reliable and tested technique to facilitate meaningful and democratic dialogue regarding conceptual or 'wicked issues' where many different voices need to be heard	https://www.jrf.org.uk/report/promoting-intergenerational-understanding-through-community-philosophy
Learning Evaluation and Planning (LEAP)	A simple outcome-focused approach to action learning and development and associated project management	http://www.planandevaluate.com
Experience Based Co-Design	An approach to capturing and using the experiences of people in story form and using them for quality assurance and development	http://www.kingsfund.org.uk/projects/ebcd

Resource	Summary	Access/link
Well-being L&D theme: Supportive approaches to commissioning, regulation and inspection		
John Kennedy's Care Homes Inquiry	A very readable review of key issues in the commissioning, delivery and regulation of care homes including some important insights and recommendations for commissioners and regulators	https://www.jrf.org.uk/report/john-kennedys-care-home-inquiry
Fulfilled Lives, Supportive Communities Commissioning Framework and Guidance	Statutory guidance on commissioning for social care. 'When it works well it contributes to significantly improving people's lives. When it doesn't it makes their lives a misery because services do not reflect need'	http://prp.gov.wales/planners/social/strategicframework/wgpolicyguidance/flscguidance/
Care fit for VIPS	Provides a simple framework of four key principles that define person-centred care. Each of the four principles are allocated six key indicators, which can be used to stimulate meaningful dialogue between commissioners providers and regulators around quality assurance	http://www.carefitforvips.co.uk/

Appendix 2: Additional messages, prioritised learning outcomes and links for the NHS workforce

Scope for the NHS in Wales

The Good Work: Dementia Learning and Development Framework for Wales will support NHS services with developing and delivering an appropriate and consistent approach to dementia education and personal development for all employees. This guidance is applicable across the whole workforce irrespective of the employee role, service, area of work, Agenda for Change (A4C) banding or professional group.

NHS Wales embraces the spirit of the Framework, recognising that the health care workforce bring a diverse life experience to the workplace. **Informed, skilled and influential** NHS staff hold a rich resource and are well placed for enhancing human experience, be this through direct role interactions in care or spontaneously arising and not directly connected to working in dementia care settings.

Preparing and developing workforce skills, whether at undergraduate or postgraduate, for professional roles, front line services or leaders in the NHS is complex. A curriculum not only involves commissioning role specific knowledge, baseline, technical or specialist skills, but also assists staff to make links from training into practice circumstance, to develop confidence, to challenge hierarchical role traditions, and to bridge concepts of psychological engagement, of culture, illness, lifestyle and illness across health care.

NHS Wales staff need to be as equally confident and skilled at making appropriate adjustments in care as they are skilled to deliver care in the first place, whenever the circumstance requires this. More often than not it is the individualised interpersonal manner, adjustment and personal flexibility which is the most important attribute of a leader, a teacher, a clinician or any individual staff member. Collectively, a flexible and compassionate workforce creates an organisation which is capable of creating learning, good relationships and a dementia friendly climate.

Interpersonal and organisational awareness and adjustment are the enactment of **wise practice in the NHS**. Delivering observable personal and human interventions that are experienced as supportive to a person living with a dementia are equally experienced as supportive for NHS staff and assist staff to achieve personally determined and service **excellence**.

Professional development frameworks and skills development frameworks involve diverse methods of study and methods of application of knowledge to practice. Within all of the professional frameworks and codes of practice the novice to expert development is achieved by stages of study, assessment, annual appraisal, supervision, reflection and feedback about observations of professional practice. Therefore NHS Wales has professional frameworks from which to develop best practice development in education, training and workforce skills based education. This guidance seeks to link the professional development pathways under the three broad categories of; **Informed**, **Skilled** and **Influencer**, and the understanding that each category should include people with a dementia, carers, families and the staff and other people involved in acts of care and support.

The following sections describe and give examples of the knowledge and skill set for each group of staff in the NHS and signposts to the learning resources.

Who?	Content and outcomes
Category: Informed	
<p>All health staff including those who do not deliver direct care services. This includes:</p> <ul style="list-style-type: none"> ■ Porters ■ Pharmacy ■ Domestic ■ Catering ■ GP surgery ■ Receptionists ■ Dentists ■ Opticians 	<p>All health staff will understand what dementia is, how it affects a person living with a dementia and those around them, and how to provide appropriate support through a clear understanding of:</p> <ul style="list-style-type: none"> ■ The core principles of the Framework as set out in Chapter 1. ■ The learning and development topics for Informed people as set out in Section 2.3 of this Framework, which are built upon the Alzheimer's Society's Dementia Friends public education initiative in Wales. ■ The learning resources contained in the dementia on line programme for NHS staff. <p>The learning and development topics and associated learning outcomes for Informed people will be core learning and a key part of induction for all health staff.</p> <p>The following specific learning and development topics should be prioritised:</p> <ul style="list-style-type: none"> ■ Achieving well-being ■ Meaningful relationships ■ Person-centred approaches ■ Understanding behaviour in dementia ■ Statutory safeguarding procedures ■ Recognising signs and indicators of abuse ■ The Mental Capacity Act 2005 ■ The Mental Health Act 1982 and 2007 ■ Deprivation of Liberty Safeguards ■ Understanding of unconditional positive regard ■ Personal communication and interpersonal skills

Who?	Content and outcomes
Category: Skilled	
<p>Health staff with roles and contact with people with dementia as follows:</p> <ul style="list-style-type: none"> ■ Providing direct care (Informed, with some detailed knowledge and skills appropriate to role). ■ Delivering specialist dementia services (informed, with enhanced knowledge appropriate to role). 	<p>Medical, nursing and allied health professional staff who provide direct care to people such as:</p> <ul style="list-style-type: none"> ■ Primary care staff (to include ambulance staff, GPs, Community pharmacists etc) ■ Emergency Department staff ■ Medical assessment units ■ Medical and surgical wards ■ Older Persons Psychiatric Liaison and rapid assessment interface discharge services ■ Care home staff ■ Intermediate Care Services and staff with specialist roles ■ Community Mental Health Teams ■ Memory assessment service ■ Mental health units <p>will prioritise the following learning and development topics:</p> <ul style="list-style-type: none"> ■ to deliver person-centred care plans; ■ to understand the importance of medicines management and pharmacology in dementia, including monitoring the effects of medications; ■ to ensure that physical health care needs are assessed and met, supporting the person with dementia to maintain for themselves good physical health and well-being including nutrition, oral health, continence, and personal hygiene; ■ to understand the ethical issues when working alongside a person living with dementia and their carer; ■ to understand positive behavioural and care approaches and their importance in meeting an individual's expressed needs which may lead to behaviours that challenge; ■ to assess for and implement appropriate reasonable service based improvements; ■ to ensure where possible that all care reflects evidence and research based approaches to dementia care; ■ to understand the implications of managing services where people with dementia access them; ■ to work in collaboration with the person living with dementia and their carer to develop, deliver and assess a care plan so that it is a truly person-centred approach that ensures continuity of care as appropriate. Including the persons values and personal preferences; ■ to understand the complexity and issues involved in caring for people with dementia at the end of their life, which should include an appreciation of the needs of carers/families during this difficult time; ■ to be able to recognise the signs and symptoms of cognitive impairment and refer on to appropriate services in a timely manner; ■ appreciate the impact of acute and chronic physical or psychological condition upon the person with dementia and their families/carers; ■ understand how environmental factors can impact upon the signs and symptoms of dementia; ■ appreciate the impact that a diagnosis of dementia can have upon a person, their family and/or carers.

Who?	Content and outcomes
Category: Skilled (continued)	
<p>Health staff with roles and contact with people with dementia as follows:</p> <ul style="list-style-type: none"> ■ Providing direct care (Informed, with some detailed knowledge and skills appropriate to role). ■ Delivering specialist dementia services (informed, with enhanced knowledge appropriate to role). 	<p>Staff will be able to make a differential judgement between people who have temporary cognitive impairment due to their health and circumstance and those who have dementia and to understand the pathway for referrals to appropriate services.</p> <p>Staff will be able to recognise cognitive impairment in people and to understand how to escalate concerns over someone's cognitive state.</p> <p>Staff who deliver specialist dementia services and have regular and intensive contact with people with dementia such as:</p> <ul style="list-style-type: none"> ■ District nurses ■ Care home staff ■ Older Persons Psychiatric Liaison and rapid assessment interface discharge <p>Older persons wards in general hospitals will prioritise the following enhanced learning and development topics:</p> <ul style="list-style-type: none"> ■ to understand the specific elements of creating a dementia friendly environment; ■ to work effectively to ensure people with their families and carers are central to the care process; ■ to develop individualised, informed, negotiated and meaningful person-centred care plans; ■ to understand and apply the principles of positive behavioural support; ■ to understand and be able to identify, design and implement service improvement changes; ■ to conduct screening tool cognitive assessments to identify need of referral to memory clinic services. <p>Staff who deliver specialist dementia services such as:</p> <ul style="list-style-type: none"> ■ Psychiatrists ■ Nurses ■ Therapists ■ Community teams ■ Nurse/Therapy consultants and advanced practitioners (AP's) ■ Care managers/ coordinators ■ Liaison professionals <p>Will prioritise the following enhanced learning and development topics:</p> <ul style="list-style-type: none"> ■ in depth knowledge on the process and pathway involved in the recognition screening and referral pathway for diagnosing dementia; ■ to understand specialist memory assessment methods and the application of memory assessment testing in clinical practice; ■ to assess and manage medicine regimes and, where specifically trained to do so, undertake prescribing monitoring and review; ■ to be able to assess and recognise the need for therapeutic intervention and refer to appropriate support services; ■ to undertake care management and coordination of care for people with complex and multiple needs;

Who?	Content and outcomes
Category: Influencer	
Health staff who are in a management, leadership or strategic roles	As outlined in Section 3.5 of the Framework.

Professional development frameworks and links

It is recognised that the Good Work: Dementia Learning and Development Framework for Wales will enable organisations to:

- have a consistent understanding of what good dementia care, support and empowerment looks like;
- guide the focus and aims of dementia education and training delivery through key learning and development outcomes;
- ensure the educational relevance of dementia training;
- improve the quality and consistency of education, training, practice and service development.

The Framework aligns with national and professional guidance which organisations will need to consider when implementing their local dementia learning and development programmes.

The NHS Knowledge and Skills Framework (the NHS KSF) defines and describes the knowledge and skills which NHS staff need to apply in their work in order to deliver quality services. It provides a single, consistent, comprehensive and explicit framework on which to base review and development for all staff.

www.nhsemployers.org/SimplifiedKSF

Profession	Guidance
Nursing	<ul style="list-style-type: none"> ▪ Aligning Nursing Skills Guidelines ▪ Principles for Rotation within Wales ▪ Core Principles for Preceptorship ▪ Mentorship Arrangements across Wales ▪ Aligning Nursing Skills - All Wales NHS Nursing Skill Set for Dementia and Cognitive Impairment ▪ Revalidation <p>http://www.weds.wales.nhs.uk/sitesplus/documents/1076/Aligning%20Nursing%20Skills%20-%20All%20Wales%20NHS%20Nursing%20Skill%20Set%20for%20Dementia%20and%20Cognitive%20Impairment.pdf</p> <ul style="list-style-type: none"> ▪ Dementia and Learning Disabilities https://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1763 https://rcnrevalidation.files.wordpress.com/2015/05/a-framework-to-support-revalidation.pdf

Profession	Guidance
Medical	<p>Dementia training is covered at several different points in medical training:</p> <ol style="list-style-type: none"> 1) In undergraduate medical curriculum at several different points but will vary from medical school to medical school. 2) Cognitive impairment and Dementia is then covered again in the National Foundation Programme Curriculum. 3) For Psychiatry training it is then covered through the Royal College of Psychiatrists curricula - Core Curriculum for Core Trainee Doctors, and Old Age Specialty Curriculum for Specialist Trainee doctors.
Allied Health Professionals	<p>Occupational Therapy: Training in regards to the occupational impact of cognitive impairments including diagnosis such as Dementia in relation to performance in a person's daily life and activities is covered at different stages and levels within Professional Development. These include:</p> <ul style="list-style-type: none"> ▪ Undergraduate training. ▪ Post-graduate training – this may encompass further training on standardised assessments and treatment modalities such as the Cognitive Disabilities toolkit, the Model of Human Occupation, and the Canadian Model of Occupational Therapy. <p>Physiotherapy: http://www.csp.org.uk/news/2013/04/03/first-social-care-standard-focuses-dementia and http://www.csp.org.uk/professional-union/practice/evidence-base/physiotherapy-works/dementia-care</p> <p>Speech and Language: RCSLT position paper – speech and language therapy provision for people with dementia (2014) RCSLT resource manual for commissioning and planning services for SLCN (2009, literature synthesis updated 2014) RCSLT clinical guidelines – Dementia (2005). The RCSLT is preparing new Clinical Guidelines for Dementia which will eventually supersede both the RCSLT clinical guidelines (2005) and the RCSLT resource manual (2009).</p> <p>Guidelines: NICE Clinical Guideline CG42 – Supporting people with dementia and their carers in health and social care (2006) (England, Wales, Northern Ireland)</p> <p>Dieticians: https://www.bda.uk.com/professional/iap/dementia_kf_sheet</p>

Profession	Guidance
Dentistry	<p>Undergraduate training of dental teams, dental students, dental therapists, dental hygienists, dental nurses and clinical technicians. Cardiff Dental School (CDS) curriculum includes Older Person Symposium where dementia training is addressed.</p> <p>Postgraduate training organised by Wales Dental Deanery. Dental teams are encouraged to become Dementia Friends and have Dementia Champion training.</p> <p>Videos - 'The Appointment' and 'Barbara's Story'.</p> <p>Postgraduate courses that heighten awareness of dementia, a 'how to' treatment plan for people with dementia, Dementia Friendly dental premises, to be aware of memory clinic referral care pathways where all newly diagnosed people with dementia must have regular ongoing preventive dental care by the dental team and long term treatment planning, recognise when to refer for more specialist dental care with Special Care Dentists in CDS etc.</p> <p>Health Boards – in house dementia training for Community and Hospital Dental Services.</p> <p>Dental Organisations courses – British Society of Gerontology www.britishgerontology.org</p> <p>British Dental Association https://www.bda.org</p> <p>British Society of Disability and Oral Health www.bsdh.org</p>